

**Transplanting Kinship:
Transplantation, Kin Relatedness, and Daily Home Life in the U.S. Midwest**

by

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To Chris, Oscar, and Graham

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Chapter 1:

Introduction

“My wife has a lot of problems, and I take care of her and she takes care of me, but I don’t want her to have to work so hard. That’s why it’s so important that I get better. This is our last and best hope.”

- Mr. S, who has end-stage renal disease and diabetes, on the morning of his clinical evaluation for a kidney and pancreas transplant

“[My daughter] knows that mommy is trying to get better and that the doctors are trying to fix mommy, so that I can be here a lot longer for her. Because that's my main goal in life now is to raise my daughter and to watch her graduate, get married and have her first child. That's what I want. I want to be able to see all that. I'm hoping that this will be the thing that I need to do all that. [...] Granted, I know that I'm going to be on medication for the rest of my life, because my body is going to try to fight the foreign ... parts that are not, that they're not used to, but...I don't care about that. I'll do it ...because she's so important to me.”

- Emily, prospective kidney and pancreas transplant patient and mother of a toddler

“I don’t know, it might be because I’m a light sleeper and the [home peritoneal dialysis] machine is not silent. Well, Bernard is closer to the machine than I am and he can sleep through anything and I’ll hear the machine going and then I’m lying there listening, and it kind of makes it hard because it’s interfering with my sleep. And what can I say? It’s not anything he’s doing. And if I go to another room to sleep, he’ll never hear the machine when there’s a problem because it’s a very sophisticated machine and if something’s not quite right it gives a signal. Well I’ve laid there sometimes listening to him not waking up and wondering, ‘When is he gonna hear this machine?’ So if I was in another room he wouldn’t

hear it and I don't know...I guess eventually it would work itself out...but that worries me. ... So the whole process is just very draining.”

- Arlene, whose husband is on dialysis and pursuing a kidney transplant.

“I asked her a long time ago, well before she ever had her transplant, I said, are we ever gonna get past a nurse-patient relationship again and be a husband and wife? You know, we don't know, and it could be a long, long time before we will. And that's something that, in a long-time situation like this is, um, I don't think we were aware of it. I wasn't warned about it...And I don't think about it a lot now [but] it does cross my mind, and when it does. It's like, 'Wow, how will things be in the future?'”

- Rob, husband and informal caregiver to his wife, Mary, who had a liver, small bowel and pancreas transplant

“It's just been amazing, where on one level, one day you're just friends to carpool and the boys play together. Or they're on the same baseball team. The next thing you know, they're taking them in for weeks at a time, shuttling them around wherever they need to go. It's just... overwhelming...”

- Jane, whose three children stayed with other families during one of her long hospitalizations for cancer treatment prior to a blood-forming stem cell transplant

“I think my future's pretty well figured out. But I've been seeing this thing on TV that really bothers me. All these people that have no health insurance and no thought of how it's gonna happen and a lot of people are gonna be dropping off and dying because they just can't see doctors. There should be no reason for it. [...] Let's do what we need to do here for these folks and everybody's got some kind of coverage...”

- Zoe, single mother of four children, liver recipient

From the start of this dissertation effort, I set out to examine the interaction of transplantation (both solid organ and blood-forming stem cell transplantation), an increasingly common biomedical practice, with the daily lives of adult transplant recipients and their kin. Looking to round out the picture, I also entered into the field with the intention of better understanding the lives and attitudes of transplant staff and medical professionals. Further, I felt it was important to pay special attention to the

social justice issues that present significant challenges to those who seek transplantation in the hope of living a longer or better life. My initial central guiding question was, “How is the practice of organ transplantation affecting kin relations in the United States?” But after many months of ethnographic fieldwork among transplant candidates and recipients, their closest kin and other loved ones, as well as the social workers, nurses, physicians, and other clinical professionals who work directly with them, and after several more months of reflection and writing, I also was taken by questions about how kinship relationships and ideologies can in turn help to shape the transplant process. This dissertation, then, marks an attempt to address a slightly more complex and informed series of queries: How are the lives and experiences of direct participants in transplantation shaped by the intermingling of kin relatedness and everyday home life – built within a milieu of social moral obligations – as well as healthcare policy and practice in the U.S.? How do shared (and sometimes contested) ideas about what kin *ought* to do or be for one another inform the on-the-ground realities of transplantation in the U.S.? What makes transplantation – as it currently is practiced – possible in the U.S. for some, and exceedingly difficult to access for others?

BACKGROUND AND OVERVIEW

My study considered theoretical developments in kinship studies, science and technology studies, medical anthropology, and social work literature. I focused on three untested assumptions, that:

- 1) transplantation, as a biotechnological practice, is both founded upon *and* affecting everyday cultural norms in the U.S.
- 2) kin relations, cultivated in the home through moral obligations, including those surrounding caregiving, comprise a major conduit for the intermingling of transplantation with everyday home life in the U.S., and
- 3) the arenas of constraint created by various forms of social stratification in the U.S. (which may involve socioeconomic and other disparities including lack of adequate insurance coverage for medical costs; employment, housing and transportation constraints; and other facets of U.S. health care policy) can

reverberate throughout kin groups and can figure prominently in the interaction between transplantation and human relatedness.

While I collected dissertation data during a total of 24 non-consecutive months of qualitative ethnographic fieldwork from 2007 to 2010, the inspiration for this endeavor took root during my master's level social work training, during which I had completed a year-long internship in hospital social work on that Adult Physical Medicine and Rehab Unit at the University of Michigan Health System, where I came to know the occasional transplant patient who needed physical rehabilitation prior to being discharged from the hospital after a transplant. Typically, these were patients who had experienced long hospital stays with multiple complications.¹ It was here that I first began to pay attention to the interactions of patients and their informal caregivers, and began to wonder about what their lives and relationships would be like once they left the hospital. During this time, I also received brief training in the Liver Transplant Clinic at the University of Michigan Health System, and my interest in the interactions of transplantation and daily life eventually led to a decision to conduct preliminary field research in this arena. In that initial context, and under the guidance of a dedicated and knowledgeable liver transplant social worker, I had the opportunity to gain insights about the many challenges which transplant patients and their loved ones face.

These same challenges, it turned out, were not unique to the site of my preliminary fieldwork. Given that U.S. health policies and cost-cutting efforts have led to shorter hospital stays, most post-transplant recovery now takes place outside the hospital, so that the home space also becomes a biomedical sphere. The amount of pre-transplant preparation and post-hospital care required by recent transplant recipients necessitates the presence of social support – usually from a dedicated caregiver or care network. Those who provide care often are patients' spouses, parents, siblings, or others who fall into “traditional” American categories of kinship. At the same time, due to various constraints (e.g., emotional tensions or socioeconomic disparities), such networks of social support can become strained. There also are instances in which patients cannot or do not rely on natal, marital, or adoptive relatives to provide this level of care (see Frey et

¹ Certainly not all transplant patients had experienced such complicated or difficult hospitalizations.

al. 2002). While these scenarios, in which it is difficult to secure a reliable care partner, tended to be rare in my extended field observations, they did exist, and they shed light on some of the areas most in need of attention by social workers and other agents of social change.

These components all coalesced at the central site of this study, to which I refer as the “Transplant Center” throughout this dissertation, except when I mean to describe the larger health system or medial campus of which the Transplant Center is a part. In those instances, I use the term “Health System.” Located in the largest metropolitan area (with a population of over 800,000) of a state which is sometimes classified as part of the “Great Plains” and other times as part of the “Midwest,” the clinical home of this fieldwork included the region’s largest Transplant Program. 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, and clinical professionals. The Transplant Center, and the Health System of which it was a part, served as the hub of my research, and there I interacted with people in outpatient transplant and dialysis clinics, inpatient hospital rooms, and patient education and conference rooms. But two annual walk-a-thon events held for organ and tissue donor awareness, and two Annual Solid Organ Transplant Reunions, all organized and sponsored by the Transplant Center, also served as important settings for participant observation. Moreover, 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.

In order to gain as complex and broad a perspective on transplantation as I possibly could, I chose not to limit my sample to any one particular type of transplant. Because of a combination of logistical circumstances and the composition of the Transplant Center’s patient population, I spoke 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, of course; for example, kidney transplantation generally is medically more straightforward and has a higher success rate than, say 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 transplantation, or 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 (as opposed to allogeneic transplantation, which involves the use of a *donor's* blood-forming stem cells).

The differences between types of transplant are not trivial, and need to be kept in mind throughout the reading of this dissertation. 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. Moreover, such a broad swath in my sampling allowed me to find patterns that tend to transcend the particular types of transplantation, and that can be associated with transplantation as a part of larger socio-cultural trends associated with high-tech biomedical practice in the U.S.

Transplant Care in Homes, Hospitals, and Hotels

Those preparing for and recovering from their transplants encounter a range of possible spaces in which they might engage with transplant-related care, and patients' health status heavily influences where they stay. The most common setting for the pre-transplant period is a person's private home, with periodic outpatient trips for clinical

evaluations or treatment at physicians' clinics or dialysis centers. But this time often is punctuated by emergency room visits and relatively brief inpatient hospital stays for acute episodes precipitated by declining health, or longer or even indefinite stays when a patient's condition has become so severe that the immediate future can only bring either transplantation or death (Chapple 2010 and Kaufman 2005 give extensive discussions of death and dying in contemporary U.S. hospital settings). Those who are too sick to remain home but do not otherwise qualify for inpatient care, often stay in skilled nursing facilities for longer or shorter periods of time. This scenario also can be the case for those who do not have adequate informal care support that might otherwise enable them to continue living at home even as their health declines. While most of the persons I got to know lived within driving distance of the Transplant Center, a few transplant candidates had come from farther away, and depending on circumstances, some found themselves needing to live in temporary housing – whether in short-term rentals or hotels – so that they could get to the Transplant Center quickly enough, once an organ did become available.

Following a complication-free transplant, patients who live within driving distance often are discharged directly to their private homes after a relatively brief inpatient stay (for example, many kidney transplant patients with whom I spoke were back home within 10 days after their surgeries). Others – particularly those who lived farther away – went from the hospital to temporary housing in the local area until their health improved further and their outpatient visit requirements eased up. Depending upon their medical and financial circumstances, these patients might stay in the Health System's on-site hotel, in another local hotel, or in a local apartment where they could obtain a short-term lease. Those who qualified financially also had the option to stay at a large house, located a few blocks away from the Health System, which had been donated to the Transplant Center by a wealthy local family for the purpose of housing this patient population. This house was a large mansion which had been renovated, its numerous rooms professionally decorated and designed to become private bedroom and bathroom spaces for patients and their care partners. Patients who were too sick to go home (or who unexpectedly found themselves totally lacking in appropriate informal care support), but whose insurance would no longer pay for inpatient care, could be discharged to

skilled nursing facilities. But this last scenario was not common in my observations, and none of the patients with whom I spoke had spent extended periods of time in nursing facilities post-transplant.

Among the options the Transplant Center presented to some of its inpatients was a “Cooperative Care” model for post-transplant care. At the time I conducted my fieldwork, this option was considered especially appropriate for those who were undergoing a blood-forming stem cell transplant, or others who could anticipate an extended inpatient stay, post-transplant. In this model, lay caregivers – called “care partners” – receive training and begin to perform acute medical care duties while the recipient is still an inpatient, immediately following the procedure. Rather than recovering in a conventional hospital room on a traditional inpatient hospital unit, Cooperative Care patients, along with their care partners, stay in home-like suites in a building within the Health System that also houses the hospital’s on-site hotel. Here, the elements of biomedical spheres and home spheres had been blended by design (though this did not always play out as intended in practice, nor in experience, as we shall see in Chapter 5).

In fact, however, all of these spaces became contexts in which care partners assumed some of the responsibilities of being medical care providers, in addition to the other dimensions of their relationship to the patient. In this and in other ways which will be made clearer throughout this dissertation, patients and care partners often experienced a blending of home and medical spaces during the pre- and post-transplant period, sometimes in unexpected ways. To wit, this study was founded on the hunch that transplant recipients and those who care for them, through their involvement in transplantation on a daily basis and their dealings with the constraints they face, are drawn into a blended biomedical-home sphere of obligations, where kin relations can be cultivated, intensified, or otherwise changed. A great deal of ethnographic evidence collected during fieldwork suggests that this does indeed turn out to be the case. But the picture, of course, is complex, and as I alluded to at the outset, the evidence suggests that transplantation, home life, and kin relations can be mutually constitutive.

Situating This Study, In Brief

This dissertation research is unique because it specifically examines transplantation – as part of a general increase in the use of high-tech biomedicine – in relation to everyday understandings and behavior surrounding kin relatedness in the U.S., with particular focus on the factors of the home and home life, health policy, and constraints due to socio-cultural stratification in the U.S. From the outset, it was designed to utilize ethnographic data collection in a variety of forms and settings, in order to explore the realms of 1) kin relations and home-based post-transplant care, 2) arenas of constraint experienced by recipients and those who care for them, and 3) the intermingling of science and technology (particularly biomedicine) with daily life. Following recent kinship studies theory, participants did not need to be related by blood, marriage, or adoption in order to be considered “kin” for the purposes of this study. At a time when alternative forms of relatedness have been the topics of ongoing heated debate (e.g., same-sex marriage and family-making via new reproductive technologies), studies such as this are crucial in order to better understand both a) the contexts in which kin relations are created, solidified, called into question, or changed, and b) the power of widely shared (and contested) assumptions about who kin are and what they ought to do for one another, to shape the uptake of large-scale phenomena like transplantation. Further, the empirical findings of this study are intended to be of use in the creation and improvement of health policy in the U.S., and it is hoped that they will have the potential to improve transplant patient care and outcomes, as well as to improve the lives of those who care for transplant recipients.

THEORETICAL FRAMEWORK AND LITERATURE REVIEW

Kinship and Organ Transplantation: Connection, Relatedness, and the Home

The study of kinship, a longtime mainstay of anthropology, has shifted over time. Not long ago, Schneider’s (e.g. 1984) critiques of kinship studies – that they were based on ethnocentric assumptions about biological bases of kinship – led many to shy away from kinship theory (Holy 1996). Others have offered similar critiques (see, e.g.,

Borneman 1997; Haraway 1997). Avoiding such theoretical pitfalls, recent kinship studies treat kin relations less as a given, and more as the product of beliefs, values, and practices. For example, Carsten (2000a:34) argues that relatedness can be composed of various overlapping components, including substance, feeding, living together, procreation, and emotion, that have the capacity to generate new experiences of being related. Elsewhere, Carsten (2000b:700) adds that investments of time in kin relationships, even when those relationships are fraught with tension, may be more important than biogenetic relatedness. Rapp (1987) urges anthropologists to consider the politicization of kinship in the U.S. and elsewhere, and to analyze kinship as the product of innovation in the face of cultural, political, and other transitions. Weston's (1991, 1995) research with lesbian and gay families also supports the notion that conceptualizations of kinship should not be limited to genealogical relatedness (also see Yanagisako & Collier 1987).

Franklin & McKinnon (2001:20) argue that kinship offers a means to analyze local forms and embodiments of boundary crossings and boundary enforcements. Yet even though transplantation is an excellent example of boundary-crossing, there are fewer ethnographic studies concerned explicitly with transplantation in the context of kinship (as noted by, e.g., Finkler 2000:236n63) than one might expect. Those who have taken kinship into account in transplantation have primarily focused on the donor (and donor family) - recipient relationship. Some have commented on the ways in which the transfer of organs between living relatives can intensify or otherwise change their relationships (see, e.g., Fox and Swazey 1978 [1974], 1992:39,40; Lock 2002:334; Jackson 2002:339; and Kaufman, Russ and Shim 2006). Scholars also have examined the potential creation of kin-like connections between deceased donors and donor families, and organ recipients (see, e.g., Fox and Swazey 1992:36; Haddow 2005; Sharp 2001, 2006; Waldby 2002:251). By comparison, Bird-David (2004) advocates looking at transplantation *not only* as a transfer of organs from one skin-bounded body to another, but as a productive process through which relationality is created and re-defined.

One construct that has been useful for understanding how kin relations are created is "the house." Though Lévi-Strauss introduced his notions of "house" and "house societies" (1982:174; 1987:152) to the anthropological literature, his concepts have been

critiqued and re-worked by others (several of these works are reviewed in Gillespie 2000b). For example, Carsten and Hugh-Jones (1995) have called for broadened understanding of the house, arguing that it is a spatial locus of social identity and interaction as much as it is a product of the daily mundane practices of the people who live in and around it over time. As Carsten notes, the structure of a house “reflects in a complex way the social relations that are enacted within it” (1995a:124); houses are capable of revealing not only the harmony, but also the tension, conflict, contradictions, and changes that inhere in those social relations (1995a:127-128). Exley and Allen (2007), focusing more directly on the home as a site of end-of-life care, similarly emphasize the need to conceptualize the home as a social and emotional space. Gillespie suggests that the concept of the house challenges previous ideas about the nature of kinship: assumptions that a group of people share a residence over time because they are kin (Evans-Pritchard 1960 [1951]:178) can be “turned on their head” (Gillespie 2000a:7), making it equally plausible instead that people consider themselves kin because they share a residence over time. Houses and homes became important in this study not only as a setting for data gathering, but also as an analytical tool, useful for conceptualizing the multiple spaces in which transplantation is accomplished in the moral context of everyday relatedness.

Kinship as a Moral Philosophy

This study builds upon recent kinship theory, which rejects the idea that kin relations are restricted to those created through “blood” or marriage, yet it also takes into account Holy’s (1996:168) caution against equating the concept of relatedness with just any kind of social relationship. As a result, this research also incorporates McKinley’s reasoning that kinship is a moral philosophy (1981:360), and therefore the study of kinship is a study of local values and morally binding obligations between persons, in spite of potential conflicts of interest (2001:133,151). Underpinning the ideas put forth here also are insights taken from Emile Durkheim, who emphasized that kinship is *social* (Durkheim 1898). In his *Elementary Forms of Religious Life*, Durkheim (1912) described the bonds of kinship among members of clans bearing the same totemic name within Australian tribal groups:

This kinship does not arise from the fact that they have well-defined relations of common blood [...] if we say they regard one another as being of the same family, it is because they acknowledge reciprocal obligations identical to those that have been incumbent on kin in all ages: obligations of help, vengeance, not marrying one another, and so forth” (Durkheim 1995 [1912]:100).

Durkheim worked to understand the continuation of human sociality even in the face of major change, upheaval, and disagreement, and focused a great deal of attention on public morality as an outgrowth of social life. He saw morality as key to the sustained bonding of individuals together into a social 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” (1984 [1893]: 331). One position of this dissertation is that persons engaging with the transplant enterprise are also engaging with the moral obligations of kinship. Therefore, organ and tissue transfer in the U.S. offers examples of public morality at work, even as it exists as a contested domain where scarce resources limit access, inequalities abound, and the stakes involve nothing short of death itself. As I hope to make clear throughout, patients often do not enter into transplantation simply in order to live longer; in fact, their journey often is fraught with serious doubt, fear, and reluctance. Rather, the pursuit of a transplant can be borne largely out of a sense that it offers their best (or only) hope for fulfilling their obligations to loved ones.

Kinship and Caregiving

A major moral obligation to be explored in this dissertation is that of caregiving. Borneman (1997) has argued that caring and being cared for are essential components in the study of relatedness. Kinship and caregiving have received attention in gerontology studies (e.g., Gubrium 1991; Stone, Cafferate and Sangl 1987; Pinquart and Sörensen 2007), and with regard to gender (e.g., Abel 2000; Pinquart and Sörensen 2006). But much less is known about the particular caregiving and social support obligations involved in transplantation. Throughout this dissertation, the primary focus is on unpaid informal caregiving arrangements, though the perspectives of professional clinical care

providers (including social workers, nurses, dietitians, psychologists, and physicians) also will be taken into account. Indeed, the vast majority of informal caregiving in the U.S. is performed by people who consider themselves related to one another (“Caregiving in the U.S.,” National Alliance for Caregiving and AARP 2009).

Importantly, this study also took inspiration from scholars whose work advises an expanded notion of care that better accounts for its many manifestations (e.g., Kleinman 2009; Kohn and McKechnie 1999; Olesen 1989) and multidirectional nature (e.g., Burack-Weiss 1995; Klaitz 2009; Myaskovsky et al. 2005; Perry et al. 1998; Siston et al. 2001; and Wendell 1996). This fostered insights about the multiple ways – both hidden and obvious – in which persons engage in reciprocal webs of care throughout the transplant process. Thus, the terms “caregiver” and “care partner” (often used interchangeably throughout this dissertation) are given a broad definition. I generally use them to refer to the person on whom transplant candidates and recipients rely for help with anything from feeding, bathing, dressing, wound care, and the administration of medications, to transportation, coordination of paperwork, and communication with the medical team, to emotional and motivational support. But, as Chapters 3 and 4 will illustrate, the very distinctions between “patient” and “caregiver” can erode as we more closely examine the moral obligations among kin throughout the transplant process. Nevertheless, in order to maintain as much clarity as possible for the reader, and to honor the terminology generally used at my field site, I have not altogether abandoned the terms “patient” and “caregiver” in my writing.

Arenas of Constraint and Social Justice Concerns in Transplantation

Although the total number of transplanted organs decreased by 2.5% from 28,291 in 2006 to 27,578 in 2007 (2008 OPTN/ SRTR Annual Report: Transplant Data 1998-2007), and then another 1.1% to 27,281 in 2008 (2009 OPTN/SRTR Annual Report: Transplant Data 1999-2008), in 2007, 183,222 persons were living with a functioning transplanted organ, which marks a 56.6% increase since 1999 (2009 OPTN/SRTR Annual Report: Transplant Data 1999-2008). Overall, as the medical risks of receiving a transplanted organ have declined, transplantation has become more common now than in decades past (cf Fox 1996:259-260). The demand for transplantable organs consistently

outweighs any increases in supply, creating an ongoing organ shortage. The total number of patients on waiting lists (both active status and inactive status) grew 3.8% from 96,874 in 2007 to 100,597 in 2008 (2009 OPTN/SRTR Annual Report: Transplant Data 1999-2008). This increase largely can be attributed to the growth in the number of persons waiting for a kidney transplant, which increased 6.3% to 76,089 in 2008 (interestingly, the number of persons on waiting lists for all other types of solid organ transplants decreased or remained the same, except for heart transplants (which increased 2.8% to 2,711) (2009 OPTN/ SRTR Annual Report: Transplant Data 1999-2008).

In some cases, as with kidney transplantation, patients can continue living for some time without use of the affected organ but transplantation offers a better quality of life (Arthur 2004; Klassen et al 2002; Wiebe 2004; but note that Monroe & Raiz 2005; Joralemon and Fuginaga 1997 question the conceptualization of post-transplant “quality of life”). But in most other cases, patients will die without a timely transplant. Organ shortages are accompanied by constraints faced by those who directly experience transplantation. Following Inhorn’s theoretical construct, these “arenas of constraint” can include “various structural, social-cultural, ideological, and practical obstacles and apprehensions” (Inhorn 2003: 16) that prevent or preclude patients and families from benefiting from transplant technology.

A rich body of medical anthropological and sociological literature has developed around the issues of exchanging limited supplies of tissues and organs –conceptualized as gifts, commodities, or both – between donors and recipients. One of the often-evoked critiques of transplantation is that it sets up an “inherently unreciprocal” relationship between the donor (or the donor’s family) and the recipient (Fox and Swazey 1992:40). Basing their analysis on the obligations of gift-giving outlined by Mauss (1967 [1925]), Fox and Swazey describe this relationship as “the tyranny of the gift” (1978 [1974]:383). Much also has been written about the objectification and fetishization (see Marx 1978a,b [1867]) of donors’ bodies and body parts (e.g., Fox and Swazey 1992:206, 207; Sharp 1995, 2000, 2001, 2006; Hogle 1996; Lock 2002:194; Murray 1996). Medical anthropologists have documented the commodification and sale of organs in a global, unjust and mostly underground market in which poor people supply their own organs to wealthy patients (Cohen 1999, 2002; Scheper-Hughes 2002a,b; and Sanal 2004). But

others note that, although extremes and excesses have been documented, gifts and commodities are not always mutually exclusive (Anderson 2000; Sharp 2000:291-292, drawing upon Appadurai 1986; Frow 1997; Laidlaw 2000). Nor is the commodification of humans unique to organ transplantation (e.g., Copeman 2005, Titmuss 1997 [1970]; Zelizer 1985). Much of this literature focuses on the donor-recipient relationship itself, emphasizing the donor and donor kin. But comparatively little ethnographic work has focused on the daily experiences of recipients and those who care for them.

Usually, a patient must follow a lengthy and difficult road to transplant (e.g., Brown et al. 2006). Waiting list and organ distribution policies and procedures differ by type of organ or tissue and by transplant center, as well as from one cultural context to another, with policies reflecting local beliefs and values (Browning & Thomas 2001; Ubel & Loewenstein 1996; Marshall 1992; and Schmidt & Han Lim 2004). But regardless of the type of organ or tissue, the wait time for a transplant can be lengthened by circumstances over which a patient has little control, such as changes in health status, financial or other socioeconomic disparities, insurance status, inadequate housing (since much of the recovery will take place in the home), or a change or loss of family support (see, e.g., the University of Michigan Transplant Center Website). Each of these factors can be closely linked to the others. For example, connections between illness and socioeconomic inequalities have been well-explored (see, e.g., Farmer 2005; and Marmot & Wilkinson 1999).

Further, the difficulties associated with receiving a transplant can exacerbate already existing hardships (which may have contributed to the need for a transplant in the first place) as well as create new ones (e.g., Crowley-Matoka 2005; Frazier, Davis-Ali and Dahl 1995; Jones and Egan 2000; Perry et al. 1998; Raiz, Davies and Ferguson 2003). Certain challenges unique to transplantation may include the emotional toll of receiving a donated organ or tissue from a deceased donor, the difficulties of recovering from major surgery under home-based care, and the need to take expensive immunosuppressants and other post-transplant medications for the rest of a patient's life, some of which are not fully covered by health insurance (Jones and Egan 2000; Kasiske, et al. 2000). In fact, many transplant recipients find it difficult to return to work post-transplant not only because their health concerns can make full time employment

difficult, but also because they risk losing their official disability status, and thus their medical coverage and a reliable source of income (Raiz 1997; also see Paris et al., 1997). Thus, rather than putting recipients back on equal footing, transplantation may in some cases actually work to maintain or even widen social, economic, and other disparities.

U.S. health policy, which currently favors employment-based insurance, plays a direct role in patients' ability to weather the costs of transplantation and post-transplant medication, or, as in the case of cardiac transplant, it can determine a patient's ability even to become a transplant candidate in the first place (e.g., King, et al. 2005). Simultaneously, trends in private and public funding for health care have played a role in shortening hospital stays, shifting the onus to patients and those close to them to meet the requirements of post-transplant care (Levine 1999; Cartier 2003). Yet, under an employment-based insurance system, those would-be informal caregivers often are a patients' source of health insurance, and must find ways to both maintain full-time employment (as well as the other demands of daily life, such as childcare, housekeeping, organized activities, etc.) *and* cover the responsibilities associated with a largely home-based recovery. Persons who have no spouse, no partner, and no nearby potential or willing informal caregivers can be left in a particularly difficult predicament.

The Home-Hospital-Home Shift: A Brief Overview of Social History and Political Economy

The early discharge of patients from hospitals must be understood in the context of both policy and social history. Abel's (2000) compilation and analysis of the diaries, letters, and narratives of women caregivers, as well as public health accounts, spanning the decades of 1850 to 1940 reveal that care of the sick had long taken place in the home, by women. Though this role was not uniformly welcomed by all women across the lines of class and social race, through women's experiences of care, they also developed a level of expertise and authority regarding matters of health, life, and death. Women not only could consider themselves, but also were considered by others, to be skilled healers and practitioners. But toward the later period which Abel examines, medical care began shifting out of the hands of women performing care in the home, and into the hands of professional physicians and into hospitals.

Starr (1984) notes that later, in light of the U.S.'s newfound prosperity and emergence as a major military and economic world power after World War II, new scientific developments came to be recognized as a national asset worthy of continued public investment. The medical workforce, for example, increased dramatically from 1.2 million in 1950 to 3.9 million in 1970 (Starr 1984:335-336). There was a "tilt toward technology" in both attitude and policy, and funding for the construction of new hospitals was made more readily available, beginning with the 1946 Hospital Survey and Construction Act (Starr 1984:348). It was during this time, also, that employer-provided insurance came to be offered as a fringe benefit, expanding coverage for medical care to more working class families (1984:373)

But these trends were subsequently followed by yet another shift in medical care back into the domestic realm, at least partially. Cartier (2003) argues that the two major arms of publically-financed health insurance in the U.S. since their creation in 1965 – Medicare (the federal entitlement program which provides care for the elderly, disabled, and end-stage-renal disease patients, regardless of income) and Medicaid (the federal-state partnership program that provides care for persons with low or no income) – have been key players in the hospital-to-home shift. Starr (1984) notes that, as it was first conceived, few cost controls were built into the Medicare program. Fee-for-service payments to providers (in which physicians are paid according to what and how many billable services they provide), along with a system that reimbursed hospitals on the basis of their costs, dis-incentivized efforts to control costs (i.e., the more services provided, supplies used, tests run, and therapies administered, the greater the reimbursement payment and the more money could be made). These circumstances led to precipitous rises in health care costs overall (Starr 1984:384-385). Though costs had already been increasing prior to 1965, up until that time, the problem was viewed as one to be borne by individuals and families (Starr 1984:384). But under Medicare and Medicaid, the government's share of the costs increased and that, coupled with a new, more conservative political climate which favored a more curtailed level of government taxing and spending, as well as market approaches to social issues and reprivatization (Starr 1984:417), led to additional reforms.

Cartier (2003) describes the subsequent changes: The 1980s saw the implementation in hospitals of the “diagnosis-related group” (DRG) in 1983, and the Medicare “prospective payment system” (PPS) in 1984. The DRG approach was considered a hospital management tool for controlling costs; it divided diagnosable illnesses into categories, to which standardized lengths of hospital stay could be attached. Through DRG’s, then, hospitals are reimbursed according to the standard length of stay associated with a patient’s primary diagnosis. Coupled with this, under the PPS, Medicare pays hospitals a flat rate per case, regardless of the actual full cost of a patient’s hospitalization; outpatient services are not held to the same PPS payment restrictions on inpatient services. In the wake of these developments, hospital lengths of stay decreased, and in response, home health care agencies, medical equipment dealers, and urgent care centers all grew to meet the new needs of patients. (Cartier 2003:2295-2296)

Cartier summarizes:

Three general problems of the DRGs—under-treatment, avoidance of patients whose DRGs do not account for their illness, and the availability of care in other institutional settings, especially nursing homes—all coalesce to move patients out of hospitals more quickly. [...] The PPS incentives, which shorten the length of stay, can force a shift of subacute care services from hospitals to nursing facilities and the home. (Cartier 2003:2296)

The rise of managed care in the following decade placed additional pressure on hospitals and providers to reduce costs and shift responsibilities to unpaid carers. As Abel notes:

The pace of dehospitalization accelerated during the 1990s as managed care grew. Patients arrive home sicker as well as quicker, increasing the intensity of services family members must deliver. (Abel 2000:257)

Some of the recent trends shaping the place and experience of care in the U.S. extend beyond the direct influence of U.S. healthcare financing policy, and the shift in emphasis from hospitals back to homes as the site of medical care is not unique to the U.S. In the UK, for example, Exley and Allen note (citing Stacey 2006):

60 years on since the inception of the National Health Service, when the delivery of care became firmly focused on the hospital, the UK caring division of labour—between ‘professional’ and ‘lay’ carer—is currently undergoing a process of (re)domestication in which functions are being redistributed back to family members and/or significant others...and/or social care providers. (Exley and Allen 2007:2)

Cartier also points to the importance of large social historical factors, which have included changes in the gendered division of labor in the paid work force (including health care professions). During the later decades of the twentieth century, the U.S. and other countries like the UK enacted political-economic changes which included “a diminished role of the public sector, deregulation of markets, increased privatization, and flexible organization of production, hiring, and management systems” (Cartier 2003:2292). Concurrent with these trends was a massive influx of women into the labor force, and though women’s wages rose, discriminatory wages in the U.S. kept in place gender disparities in income, and women’s increased household income contributions generally did not make up for declines in men’s wages. One result, notes Cartier, is that “we are witnessing decreased household security at the same time that the state has rolled back social services” (2003:2293). One of the intents of this dissertation, then, is to more fully examine the complex interactions between various arenas of constraint, U.S. health policy, and recipients’ kin relations and home life in the context of transplantation.

A Note on Disparities

Importantly, transplantation as a whole is plagued by disparities in access for different demographic groups. While refinements in surgical techniques, improvements in medication, and changing socio-cultural notions about age limitations on the use of high-tech medical interventions has opened up transplantation to older populations (Kauffman, Russ and Shim 2006), other disparities remain entrenched. The 2009 OPTN/SRTR Annual Report indicates that, in 2008, the overall percentage of transplant recipients (for all types of organs) who were men was 62.8%, compared to 37.2% who were women. The characteristics of all those on waiting lists fairly closely resembles this, with women transplant waiting list candidates comprising a slightly higher percentage (41.5%) than recipients (the remaining 58.5% of those on waiting lists were men). Greater disparities emerge, though, when looking at differences by race and ethnicity. The largest percentages of transplant recipients are white (60.9%), followed by those who are African American (19.6%), Hispanic/Latino (13.4%), and Asian (4.9%). There are notable differences between recipients and those who are on transplant waiting

lists (and large disparities remain). For example, the percentage of waiting list patients who are white is smaller (46.4%) and the percentage who are African American is larger (29.0%), followed by 16.8% Hispanic/Latino and 6.6% Asian, compared to recipients. (2009 OPTN/SRTR Annual Report, Tables 1.4 and 1.10)

Eggers (1995) measured differences in access to kidney transplantation according to the race of the patient with end-stage renal disease (ESRD), and found that, whether he looked at the time from kidney failure to transplant, time from renal failure to getting on the transplant waiting list, or time from getting on the wait list to time of transplantation, African Americans with ESRD had worse access to kidney transplantation than white, Asian, or Native American patients with ESRD. Further, as the severity of organ shortages increased between 1988 and 1991, the transplant wait times for African Americans with ESRD increased more than for any other racial group (Eggers 1995). O'Hare, Johansen and Rodriguez (2006) found that racial disparities in transplantation were even more pronounced in rural than in urban areas, with transplant rates being lowest among African American ESRD patients who live in small rural areas.

It would be misguided to assume that transplant disparities stem from conscious decision-making about the allocation of organs. I can say with certainty that the transplant professionals I met and spoke with all showed tremendous personal dedication to serving their patients in the best manner they can, regardless of demographic characteristics. Notably, researchers have pointed to larger persistent structural inequalities that contribute to disparities (Gordon 2001; Wolfe 2003). Others, too, have documented correlations between lifetime experiences of discrimination and achieving "wait list" status as a transplant candidate (Klassen et al. 2002; also see Arthur 2004).

One construct that offers a framework for better understanding disparities is referred to in medical anthropology as "intersectionality." Developed in the late 1990s, the idea behind intersectionality is that social attributes such as race, gender, class, age, and ability status do not exist as truly separate "categories" but rather must be understood with full regard to how each social aspect intersects with and interacts with the others. Understanding what it means to be "African American" or "female" or "employed" or "disabled" in the context of transplantation (or in any other context) is not simply a matter of looking at these factors as checked boxes or separate variables in a study.

Instead, the concept of intersectionality holds that a person experiences the *interrelationship* of these axes in the social-cultural context of their daily life. As Mullings (1997:6) has noted, “It is important to make the point that race, class, and gender are not additive categories; rather, they are interlocking, interactive, and above all relational ones.”

This dissertation does not focus directly on demographic disparities in transplantation, nor was it designed specifically to do so. Rather, I attempted to elucidate some of the challenges (as well as resources) that patients and their loved ones encounter throughout the transplant process, and to place them within the larger context of their daily lived experiences. While I made efforts to achieve as diverse a sample as possible for data collection, white and middle class participants largely outnumber those from other demographic groups. My sample does reflect the makeup of the patient populations to which I had access, and wherever possible, I try to balance the perspectives of those who enjoyed greater privilege with those of persons belonging to groups which had been subjected to oppression for generations. At the same time, it sheds light on some of the important arenas of constraint within which patients and their kin navigate the transplant process.

Science, Technology, and Medicine in Everyday Life

Anthropological theory and ethnographic methods have intersected with studies in science, technology, and medicine for some time now (e.g., Latour and Woolgar 1979; Woolgar 1991; Pickering 1992; Franklin 1995). This intersection has proven to be very fruitful in the field of medical anthropology, giving rise to literatures concerned especially with knowledge and power (e.g., the edited volume by Lindenbaum and Lock 1993; Vaughan 1991), and with the implications of metaphorical and literal connections between the human body and non-human entities and technologies (see e.g., Downey et al. 1995, the edited volume by Davis-Floyd and Dumit 1998, and others who draw upon Haraway’s 1985 notion of “the cyborg”; as well as Rapp 2000, and Martin 1999 [1990], 1994). Others also have written about the deep connections between local beliefs and values, and scientific knowledge and practice (see, e.g., Nader 1996:269 and Shapin 1994).

Anthropologists who have specifically examined transplantation with a science and technology studies lens have engaged with these bodies of literature (i.e., literatures concerned with knowledge, power, values and practices, and of connections between humans and non-humans, in science and technology studies). For example, Hogle (1995, 1996) compared the surgical practices employed in organ procurement in the U.S. and post-unification Germany, showing that technoscientific practices performed on human bodies exist within and reflect local cultural values. In cross-cultural comparisons of North America and Japan, Lock (1996, 1997, 2000, 2002) studied how “standard” definitions of death have changed in light of confluences between life support technologies and organ shortages. Others, too, have argued that conceptual delineations – for example, between self and other, nature and culture (Jackson 2002), and moral and immoral (Lundin 2002) – are sometimes re-drawn in light of transplant technologies. Sharp (2000, 2001, 2006) examined the role of medical technology in the commodification of organ donors’ bodies and organs. Das (2000) explored the various rhetorical, legal, ideological, and discursive threads that come together to create the social contexts within which transplant technology exists. And Simpson (2004) wrote about the strategic employment of Theravada Buddhist values surrounding charitable giving to encourage organ and tissue donation in Sri Lanka.

Franklin (2001:6) urges us to consider the new kinds of connections, as well as the cultural values and ways of life that are at stake in light of those connections, that are brought about by biotechnologies. New types of connections and their implications for kinship have already figured prominently in studies of new reproductive technologies (e.g., Simpson 2001; Edwards et al. 1999; Carsten 2004; Kahn 2000; Ragoné 1994), but have not yet been explored in-depth in research about transplantation (though Sharp 2001, 2006 does include some discussion of kinship in her work).

This dissertation is concerned with understanding the interplay of transplantation with kinship in the U.S. It is based on the idea that recent developments in biotechnologies such as transplantation are fundamentally interconnected with local “commonsense” cultural values, some of the most basic of which are notions of what constitutes family, kinship, and relatedness. For example, refinements in surgical procedures and drug therapies associated with transplantation, which are themselves the

products of changes and innovations in biomedical science and technology, have made feasible the very idea that post-transplant recovery could take place largely under the care of lay persons (Eilers et al. 2005; Guberman et al., 2005; also see Glazer 1990). On the other hand, consideration also is being given to the idea that cultural values surrounding kinship also can shape transplantation. Widely held beliefs about the duty of kin to care for one another lend themselves to the placement of post-transplant care in the hands of kin, rather in, say, the domain of the wider community. Some researchers have focused on the new roles that family members must assume once they become caregivers (e.g., Peterson 1985; Mishel and Murdaugh 1987). With this study, I sought to further understand the nature and mechanisms of the interconnections between techno-scientific innovations and local concepts of relatedness, particularly regarding how the daily life relations between recipients and their caregivers might be affected through their experiences with transplant.

In sum, this research was designed to employ a “cross fertilization” of ideas (Sharp 2000:289,314-315) in order to better understand additional, under-explored mechanisms by which transplantation has become both significant and commonplace in the U.S. Following the lead of recent kinship scholars, it analyzed kin relations in a broader sense, not confined to categories of biogenetic relatedness. While relationality had received some consideration regarding donor-recipient relationships, relatedness among recipients and those who care for them had yet to be thoroughly investigated. This research endeavored to trace arenas of constraint through to post-transplant life, with an eye toward U.S. health policy, in order to better understand the interconnections between inequities and the transplant experience of recipients and those who care for them. It sought to understand what kinship values are at stake and are drawn upon, as well as how they might be changed, in the transplant process. As its major focal point, this study examined the care obligations between recipients and those they consider to be kin, as a mechanism for the interweaving of transplantation with daily life, especially daily home life. More generally, this study was concerned with understanding how technoscientific medical practices such as transplantation enter into the interconnections and interactions of everyday life.

RESEARCH HYPOTHESES AND OBJECTIVES

This research initially was designed to explore one primary, and two accompanying sub-hypotheses regarding transplantation and kinship in the U.S., presented here in both their alternative and null forms.

PRIMARY HYPOTHESIS—Kinship and Home-Based Care: (H₁) It was hypothesized that post-transplant care in the home would transform relations between transplant recipients and those close to them. (H₀) In contrast, home-based post-transplant care might have had little bearing on relations among this study population.

Sub-Hypothesis 1—Arenas of Constraint: (H₁) It was hypothesized that transplant recipients and their caregivers face formidable arenas of constraint throughout the transplant experience that can reverberate throughout kin groups, which may involve socioeconomic and other disparities including lack of adequate insurance coverage, housing constraints, and other facets of U.S. health care policy. (H₀) In contrast, transplantation might have been a fairly straightforward process for transplant patients and their caregivers.

Sub-Hypothesis 2—Organ Transplantation and Everyday Life: (H₁) It was hypothesized that home-based kinship (or kin-like) practices among transplant recipients and their caregivers comprise a major conduit for the intermingling of transplantation with everyday life in the U.S. (H₀) In contrast, these practices might have played little or no role in the interweaving of transplantation with daily life.

In order to examine these hypotheses, my original intentions were to collect ethnographic data to meet the following research objectives:

Objective 1: To determine possible differences and similarities in the experiences of transplantation among recipients and caregivers who are related by blood, marriage, or adoption, versus recipients and caregivers who are not related by blood, marriage, or adoption. (As I will explain further below, in the discussion of my sampling techniques, this objective could not be fully realized, given the relative scarcity of patients and caregivers who were *not* related by blood, marriage, or adoption.)

Objective 2: To determine the effects of home-based post-transplant caregiving on the relations between recipients and those who care for them, and to determine whether and how kin relations can be cultivated through the practice of home-based post-transplant caregiving.

Objective 3: To determine perspectives about the role of the home as a site of providing biomedical care in the U.S.

Objective 4: To determine the specific constraints faced by transplant patients and their kin and caregivers from pre-transplant to post-transplant.

Objective 5: To determine the role of U.S. health care policy in the constraints experienced throughout the transplant process.

Objective 6: To determine attitudes about the various types of recipient-caregiver relations both among this study population, and among medical professionals who work in transplantation.

Objective 7: To determine transplant patients' and their caregivers' daily experiences of and attitudes toward transplant-related science, practice, and technology, including screening and diagnostic tests, surgical procedures, recovery regimens, drug therapies, dietary restrictions, etc.

Not all of these objectives were possible to achieve, given the inevitable various limitations and unexpected detours I occasionally encountered during data collection (these will be described below). All the same, this dissertation incorporates analyses of a broad range of data that resulted from an earnest effort to carry out this research, as designed, as carefully and fastidiously as possible.

RESEARCH DESIGN

This study also was developed in response to explicit calls for ethnographic inquiry into transplant patients' lives in the context of kinship (see e.g., Finkler 2000; Joralemon & Fujinaga 1997; Koenig & Hogle 1995), as well as a relative lack of holistic qualitative research on this particular topic within social work literature that could help to inform future social work scholarship and practice at both micro- and macro- levels. Qualitative methodologies like ethnography are increasingly used in health services

research (Skirton 2001:313). 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 2000).

Research Site and Study Population

After completing a preliminary study among organ transplant candidates and recipients and their family members at another transplant center's liver transplant clinic and hospital unit from September–December 2005, I underwent a search of U.S. transplant centers as potential dissertation field sites.

Metrotown and Surrounding Area

Upon this search, I determined that the proposed study would take place in a Midwestern state, with a medium-sized city (which I refer to as “Metrotown” throughout this dissertation) as its focal point. This city is considered a major center for organ transplantation because of its Transplant Center, which became my primary institutional affiliation. The Transplant Center's service area includes both urban and rural locales: although the Metrotown metropolitan area had a population of nearly 839,000 in 2009, and more than 1.2 million people live within a 60-minute drive of Metrotown itself, the Midwestern state in which it is located has a rather low overall population density. Surrounding the metro area are a series of small towns and rural farmland, on which primarily corn, soybeans, and cattle are grown.

Before they were displaced by white settlers after the Louisiana Purchase, various Plains-dwelling Native American groups had prospered in the area. Metrotown itself is located on a major river, across from a smaller city in a neighboring state. Although Metrotown today overshadows its smaller counterpart economically and in population, its sister city predates Metrotown and in the past had far greater influence. Metrotown's location along the river, along with its historically powerful position along the transcontinental railroad, enabled a rapid development of industry from the mid-nineteenth century, including one of the nation's largest cattle stockyards. Agricultural trade and other related offshoots played a major role in the early economic, political, and

socio-cultural development of the city. For example, the city became home to a major meatpacking industry that attracted first immigrants, mainly from Europe, and then African American migrants from the South. African Americans were first resented as strikebreakers, because they were hired by meatpacking companies in large numbers for this purpose in 1917. But by the 1930s, African Americans became integral in progressive labor unions, and gained political power as the unions worked not only on labor rights issues, but also to end segregation in restaurants and stores. These gains were lost, however, as the meatpacking industry restructured and shed massive numbers of jobs in the middle part of the twentieth century. Although Metrotown remained the sight of considerable efforts in civil rights movements, poverty, racial tensions, and redlining all coalesced to create a form of residential segregation by social race and ethnicity (and concomitant inequalities in schools, housing, and access to amenities and services) that persists to this day.

Currently, the financial, trade, transportation, utility, and information industries form the largest sources of employment in Metrotown. In surrounding areas, small family farms are giving way to large industrial agriculture and livestock operations. As these surrounding rural areas lose family farms and other small business, and experience accompanying changes in employment opportunities, many of the small towns have noticed an outmigration of their populations to more urban areas like Metrotown. At the same time, several towns have been kept alive or even undergone a revitalization as a result of an influx of Latino/Hispanic workers who have responded to greater demands for low-wage labor in industrial agriculture and meat-packing and other similar industries. While these demographic changes arguably have spelled the economic redemption of towns that otherwise might not have survived, white residents in some towns have not welcomed their new neighbors. During the time of my fieldwork, for instance, one city passed an ordinance prohibiting businesses and landlords from hiring or renting to persons lacking documentation of their legal residence in the U.S.

Metrotown itself continues to undergo demographic changes that reflect national trends, with African Americans comprising the largest minority population and the Latino/Hispanic population increasing significantly in recent years. Though it boasts an unemployment rate that consistently is lower than national averages, the city also is

notably segregated along lines of social race and ethnicity, with its wealthiest neighborhoods tending to be predominantly white and its poorest neighborhoods tending to be predominantly African American and Latino/ Hispanic. (“Metrotown’s” Minority Economic Development Council).

The Transplant Center, Cooperative Care, and Non-Hospital Settings

The Transplant Center which served as my primary institutional affiliation is among the most prominent components of the Health System to which it belongs. The Health System, known also for its oncology, cardiac, neurology, and women’s health programs, served as the teaching hospital for a university medical school in Metrotown. The Transplant Center itself specializes in solid organ (e.g., kidney, pancreas, liver, small bowel, and heart transplants) and bone marrow and blood-forming stem-cell transplants. This particular Transplant Center initially was chosen as an especially appropriate site for this study because it was among the only transplant centers to employ a “Cooperative Care” model in the treatment of some of its transplant recipients.

Based on an acute inpatient program first developed at New York University Medical Center in 1979 (Greico et al. 1990), the Cooperative Care model focuses on the use of family and friends to meet the patients’ care needs during hospitalization. These family and friends receive training to become “care partners” who are considered part of the healthcare team (Schmit-Pokorny et al. 2003). Care partners are responsible not only for monitoring and assisting with activities of daily living, but also for performing tasks such as taking vital signs like temperature, blood pressure and pulse, drawing blood and administering medications via an intravenous line, and alerting the professional medical team if there is a change in the patient’s condition. These are acute care skills that traditionally are provided by medical professionals (Eilers et al. 2005). During hospitalization in Cooperative Care, patients and their care partners stay in a home-like setting that has been designed to more closely resemble a private furnished apartment suite than a conventional hospital room. Cooperative Care not only touts the propensity to reduce health care costs (Schmit-Pokorny et al. 2003), but also to more closely approximate the setting within which the majority of post-transplant recovery will take

place, for the purpose of easing the transition from hospital to actual home (McLane et al. 2003).

I must note, however, that while I originally intended to speak with a greater number of patients and caregivers who utilized Cooperative Care, I came to find that this route was only infrequently taken by solid organ transplant recipients, with blood-forming stem cell transplant recipients comprising the bulk of the Cooperative Care population. Since I also wanted to gather a strong showing of data from among solid organ transplant patients, many of my findings concerning life outside the hospital are derived from non-Cooperative Care settings, including patients' own homes and the Baxter House (described above).

Studying transplantation within each of these contexts helped to answer questions about how the home (or home-like setting), as a site of biomedical care, might affect notions of kinship in the context of transplantation. Because this study was designed to collect data with regard to patients' lives outside of the hospital, it enabled comparisons between the clinical setting and the everyday home setting. Further, this study was designed to identify the constraints patients and their kin face due to incongruities between the requirements and resources of the clinical setting, versus those of daily home-life outside the clinic.

Site Matters:

Although a large proportion of the people who participated in this study lived within a two-hour radius of the Transplant Center, geographical location alone was not the only factor that determined the patient population of the Center. The Center's reputation for success in their transplants, comparatively shorter waitlist times, and an attentive, hardworking staff (among whom the norm was an interpersonal style which one of the participants in my study referred to as "Midwestern nice"), also created a draw from other geographical regions of the U.S.

One older African American couple, Bernard and Arlene, had come all the way from a state on the West Coast, and remarked on what brought them to the Transplant Center in the first place. They compared their first, negative experiences with the health system in their home state with the experiences they had at the site of this research:

Bernard: *We knew through going to my doctor and all, that I was losing the use of the kidneys. Every time I went we would get a different reading of how much I had left, and the nephrologist recommended because of how much I had left, the percentage of kidney use I had left, he wanted me to get on the transplant list up here at (a health system on the West Coast of the United States) because it's such a long list and such a long wait. And that was in September of 2005, so I did that and after I was on the list, I thought about it, and it was horrible the way we were shuffled through [at that health system]. It was like being part of cattle, a livestock yard. There was not as much care or concern, or something just wasn't there.*

Arlene: *We had to be there at quarter to seven in morning because we were gonna have et cetera and et cetera, and we were there and no one shows up! with this group of people around! until about 50 minutes later or an hour, and then they were rushing us! Well, here's six people getting shuffled from room to room. [...] It was just awful because as Bernard said, being shuffled like cattle. ... And then you're waiting and waiting, and then after the tour and lectures then they needed to take blood and they needed 15 vials and we had to wait about 2 hours or so before they could draw his blood. And he was exhausted and of course I was livid. But what can you do? And finally they got the blood and then they validated our parking, but we were there so long we had to pay, even with validation we had to pay something like twenty dollars or something to park! The whole thing was just dreadful! Now, twenty-something dollars to park wasn't going to kill us, but to me it was like, wow, we had to come an hour early, and then we sit and wait for hours for a blood test, and then we find out it's all for nothing because there's not any conceivable possibility of getting it [the transplant] here, because he'll time-out age-wise before he gets on a list. And so everyone, you know they weren't paid enough. Some had attitudes of superiority. Some were very nice but it was almost like a waste of time and it was very, just sort of a letdown like from the beginning, a let down for me, waiting an hour after being told you must be here at this time. And never was there an apology, we're so sorry, so I just... And then we went to the Transplant Center and it was like a whole different, totally different. [...]*

Bernard: *It was after this experience that we started looking, I said there's got to be something. We went to [the website] 'unos.com' and it gives you all the different places and time on the list and also rates everybody as to successful surgeries and the whole bit. A lot of the midwestern states stood out – [names three of them] – with successful operations/procedures, and how many transplants they do, and length of waiting list. I started looking into it and I hit upon the Transplant Center and I applied. I called and talked to them and there's the transplant folks and they sent me all the information and I did what they told me to do and sent it back and they gave me a schedule and we made that schedule.*

That's not to say that all patients and caregivers were uniformly delighted with the medical care they received, and I occasionally heard complaints and critiques (some of which I will include in my analyses). As this dissertation will make clear, I was most interested in the dimensions of everyday life and home spaces, and used data about hospital life largely for comparative purposes. Further, this study was in no way designed to be an evaluation of the Transplant Center or its staff. But I can report that, in my qualitative observations, participants' praise for their medical care through the Transplant Center far outweighed their criticisms.

Initial and Revised Comparisons, Sampling, and Recruitment Techniques

As I already have mentioned, I originally intended to compare: a) the experiences of recipients and their caregivers who are related by blood, marriage, or adoption, compared to the experiences of those who are not related in these ways, and b) the “home-like” setting of the Cooperative Care unit, versus the space of participants' actual homes. However, the on-the-ground realities of fieldwork soon revealed that the initial major areas of comparison needed to be revised, for two reasons: 1) I found that it is rather rare for those not related by blood, marriage, or adoption (with the exception of medical personnel) to provide the bulk of transplant care, and 2) use of the Cooperative Care unit tended to be limited to blood and marrow stem cell transplant patients. Other transplant patients' initial recovery period tended to take place in the traditional hospital setting, with them usually being discharged either directly to home or to an outpatient

hotel that is physically connected to the hospital, in the same building which houses the Cooperative Care unit. Others are discharged to a place I refer to as “The Baxter House,” which had been dedicated specifically for use by recovering transplant patients and their care partners.

While these original comparisons will be made throughout the dissertation to extent that they are possible, it was not possible to base the bulk of this project on them as initially conceived. But challenges in fieldwork often give way to unexpected opportunities and new understandings. Instead, then, I found I was able to gain important insights by broadening my initial view of post-transplant care to take into consideration the *multiple* forms of “care” (often referred to in social work literature as “social support” [e.g., Cetingok, Hathaway, and Winsett 2007, drawing upon Heller and Swindle 1983]) that bolster a patient’s recovery. Additionally, this dissertation includes a closer examination of the various non-Cooperative Care, outpatient settings to which many patients are discharged than I otherwise thought would be possible. Also, given institutional norms and the warm reception my research enjoyed at the field site, it became feasible to follow persons at all stages of the transplant process, and even some patients through the process from pre- to post-transplant. Thus, comparisons over longer periods of time also proved to be a fruitful supplement to the original major areas of comparison.

Because this study aimed to achieve a holistic, primarily qualitative understanding of how kinship norms interact with transplant care, it employed non-probability sampling techniques, including both purposive sampling (Luborsky and Rubinstein 1995:104) and key informant sampling methods, which helped to provide data from multiple perspectives. Key informants were selected based upon their availability and willingness to provide more in-depth information about their personal lives, over a longer period of time and in more informal settings than the single interview (Luborsky and Rubinstein 1995:104; Padgett 1998:53).

Purposive sampling was used for the collection of interview data, and involved recruitment of three sub-populations: 1) patients who are affiliated with The Health System and Transplant Center, whether as transplant candidates or as transplant

recipients, 2) patients' family and friends, particularly care partners, and 3) The Health System and Transplant Center staff and medical personnel. Recruitment took place via two channels: a) by myself in clinical settings; and b) via the Transplant Social Workers and Nurses, whom I asked to help identify and refer patients who were able and willing to agree to an interview for this study.

I initially expected that medical social workers would play the most prominent role in recruitment because of their traditional professional role as liaison between the patient's everyday life circumstances and their life in the clinical setting. However, the institutional structure of this field site lent itself to working most closely with nursing staff for recruitment. Specifically, the Clinical Nurse Coordinators comprise the "hub" of patient care. While the permission of the head physician was necessary for establishing a presence in any one of the transplant programs, it was the nurses who tended to be in the best position to help with recruiting patients.

During recruitment, I provided detailed information about the study and obtained full written informed consent prior to each interview. I worked with members of the kidney and pancreas, liver and small bowel, and blood and marrow stem cell transplant programs to develop recruitment scenarios that were tailored to the local structure and norms of each individual program:

Kidney/Pancreas Transplant: The kidney and pancreas transplant team held a clinic in the Transplant Center one morning every week, in which patients were evaluated for transplant. Upon the suggestion of the Program Director and the Program Manager, I met with patients in-between their appointments with clinical personnel to tell them about my study. For those who expressed interest in participating, I scheduled times to meet with participants later, in the Transplant Center, elsewhere on the Health System campus, in their homes, or other locations of their choice, to obtain formal written consent and to conduct an interview. Several of these meetings took place pre-transplant, with participants often inviting me to follow-up with them periodically throughout the transplant process, and at times, through to post-transplant. It was from this transplant

program that I recruited the largest number of participants in my study, and it also was here that I had the greatest opportunity to make my sample as diverse as possible.

The following excerpt from my fieldnotes following one recruitment scenario during a transplant clinic morning is fairly illustrative:

In the clinic that day, there were to be nine patients altogether. Two were there on post-transplant consult; two were there as potential living donors, and five of them were there to be evaluated as potential transplant candidates (on this particular day, seven patients were men and two were women, but the gender mix could vary widely from one week to the next). Of the five potential transplant candidates, two would need to leave by a certain time to go to dialysis, so I ruled them out. One of the remaining three was only scheduled to see a couple of the clinicians, and then would leave immediately, so I ruled him out as well. Two patients remained, both of whom were to see the near-full panoply of nurse coordinators, nephrologists, pharmacy counselors, financial counselors, psychologists, surgeons, social workers, etc. Other than what they could gather by looking at the patients' charts, the nurse coordinators knew little about either of them, only that one was in his 20's and the other was in his 40s or 50s. On the dry-erase board on one wall of the staff room, the nurses added "student" next to the list of clinicians scheduled to see each of these three patients. Then, when the first patient was in-between appointments and no other clinician was available at the moment to see them, one of the nurse coordinators let me know that I could go into the exam room and talk with the patient (and any accompanying caregiver or other loved one) about my study.

Liver and Small Bowel Transplant: Upon the suggestion of the liver/small bowel transplant Program Manager, transplant nurses approached liver transplant inpatients and their caregivers during their hospital stay to introduce this study. The nurse coordinators then relayed the names and contact information of persons who expressed interest, and I then followed up directly with these potential participants for recruitment and written informed consent. Depending upon the wishes and health conditions of participants, I met with them for interviews in the inpatient setting, in one of the patient education/consultation rooms in the Transplant Center, and in participants' homes.

Blood/Marrow Stem Cell Transplant: Upon the suggestion of this program's Nurse Manager and the Director of Oncology Services, I obtained written, informed consent from patients and caregivers when they were at The Transplant Center for their pre-transplant work-up appointments. The nurse coordinators and staff assistants contacted me to let me know when a patient was coming in, and let me know when the patient's appointment schedule would permit my seeing them to explain my study, invite their participation, and obtain written informed consent. When time allowed, I conducted a brief pre-transplant interview at this time. Then, with the participant's permission, and when it was possible, I followed up with participants for a post-transplant interview at a time when participants felt they had had a chance to get settled at Cooperative Care or had become outpatients, once they had begun to regain their strength and had a well-established care routine.

As originally designed, the target sample size for interviews was approximately 20 each among patients and their caregivers who are related by blood, marriage, or adoption (for a total of 40 interviews), and for comparison, 20 each among patients and their caregivers who are not related in those ways but are "kin-like" (for another total of 40 interviews). However, as noted earlier, it was not possible to identify 20 patients and 20 caregivers who were not related by blood, marriage, or adoption. Thus, sampling was weighted heavily toward those related via "traditional" kinship categories. With the additional interviews I conducted among staff and clinical personnel, I was able to meet my original total target sample size of 100 interviews.

The Actual Sample

My sample of participants ultimately had the following characteristics:

- Participants in this study ranged in age from their early twenties to their mid-seventies.
- Overall, 58 participants were women, and 42 participants were men

- 6 were African American (3 men and 3 women); 4 were Latino (1 man and 3 women); 90 were non-Latino white (38 men and 52 women)²
- 13 were clinicians or staff members of the Transplant Center; 48 were patients (transplant candidates and/or recipients), and 39 were caregivers, other family members, friends, or other loved ones. Among this last group, 22 participants were spouses/partners; 6 in the caregiver sample also were being evaluated to become living donors, or had already become a donor. I did not specifically seek out living donors, and spoke only to those who also could safely be considered a member of a patient’s care support network. These six included:
 - A father donating a kidney to his son
 - A sister donating her kidney to her brother
 - A man donating a kidney to his wife’s sister’s husband
 - An uncle donating a kidney to his nephew
 - A woman donating marrow stem cells to her sister
 - A wife donating a kidney to her husband
- One participant was the mother of a deceased donor, with whom the recipient had established contact. While I had not set out to talk with deceased donor families, I was invited by the recipient (who had become a key informant in my study, and who I had the privilege of getting to know very well) and was welcomed by the donor’s mother to get together with them during one of their periodic visits, during which I had the opportunity to witness (this is the best way I can describe the arrangement) their connections. The recipient and the donor’s mother came to develop a remarkably close relationship which both participants referred to as kinship in the most literal sense. More will be said about this in Chapter 7: “Revealing and Reframing Relatedness Through Transplantation.”
- Among the patients with whom I spoke (candidates and recipients), the breakdown by type of transplant was as follows:

² Though these are presented as a list of categories, below, I offer a more complex reading of the category of “race” overall.

- 18 kidney only; 3 kidney-and-pancreas; 3 kidney-and-liver; 1 kidney, with a subsequent corneal transplant (due to complications from long-term use of transplant-related medications)
- 10 blood-forming stem cell
- 5 liver only
- 3 small bowel-only
- 1 liver, small bowel, and pancreas
- 1 pancreas-only
- 1 heart-only
- 1 islet cell-only
- All but four of the patient and caregiver participants were related to their patient/care partner by blood, marriage, or adoption. In 3 cases, the main care partner was a close friend; in one case, a friend had committed to serve as the main care partner, but then backed out at the last minute and the patient essentially had to proceed through the transplant without a dedicated care partner. In this instance, I spoke with the patient only, and never met the friend.
- Although participants were recruited from the clinical context of the Transplant Center and the hospital with which it was affiliated, the study's sample ultimately was fairly geographically diverse. A total of 39 participants were from the larger metropolitan area of Metrotown, and 5 were from small cities located one to two hours away. Another 14 were from small rural towns and 6 were from farms and other rural areas within an approximately two-hour radius of Metrotown; and 8 were from small rural towns and 4 from farms and rural areas approximately two to eight hours away. The remaining 24 had come to Metrotown from locations more than eight hours away; and the places these individuals called home ranged from major U.S. cities to small, little-known towns and rural areas.

A note on sample characteristics and diversity

While I am confident that my sample is diverse in age and social class, and allows the perspectives of both women and men to be represented at similar calibers, the same cannot be said regarding social race or ethnicity. The number of white patients,

caregivers, and clinicians with whom I spoke is notably larger than the numbers for African Americans and Latinos, and the voices of other peoples of color are absent from my sample. I can say that I made every effort to recruit as diverse a sample as possible, and I noticed on average no greater acceptance or reluctance toward participating in my study among one demographic group than another. Though most people were more than willing to participate when I approached them, I also was turned down by white, African American, and Latino patients for reasons including a lack of time, lack of interest, and feeling too ill or uncertain about one's health status to participate. My sample is overall reflective of the patient population to which I had access. The disproportionate sampling of white participants is probably owing to a couple of overlapping circumstances. One is likely the fact that, in the service area of the Transplant Center, white persons comprised the largest racial and ethnic demographic. Another is the nationwide persistence of disparities in access to transplantation, discussed earlier.

The categories of social race and ethnicity gain their significance from socio-cultural, historical, and political-economic factors, and as such, their meanings are multifaceted, complex, overlapping, and interactive. Earl Lewis has offered important insights regarding this. Using the concept of "multipositionality," Lewis notes,

[R]ace is but one part of the self, and race is always relational...black Americans have lived in variegated communities, where class, color, religious, and other differences mattered. (1995:783) [...]

Class, color, religion, and gender amount to a partial list of the forces that situated black life in a series of overlapping diasporas. (1995:786)

Furthermore, Lewis advocates that we pay attention to "how spatial and temporal factors lead historical actors to foreground or background constitutive aspects of themselves" and that we "[c]onsider as well that relational differentials in power maximize the likelihood that certain forms of the self dominate at certain times" (1995:783).

I tried to ask about race and ethnicity in a way that allowed participants to say more about their identity than to simply check a box on a form. This turned out to be a welcomed method of gathering this category of demographic information. One couple, Bernard and Arlene, whom I interviewed together, summarized their perspectives in a way that was both succinct and elegant:

Laura: *What racial or ethnic group do you identify with?*

Bernard: *That's interesting...I'm kind of um, I guess the term African American possibly would be the right way...*

Laura: *Is that a question you find hard to answer when you have to check a box?*

Bernard: *Every time I go over it I have trouble looking at it and go, "Hhmmm, what do I put down here?"*

Laura: *And Mrs. W, how about you?*

Arlene: *African American, and I don't really have a problem with what box to check, only because I only put what the world receives you to be.*

Although I met and spoke with 100 participants in total, not all of them will be described individually in the pages of this dissertation. While I have attempted to include quotes and fieldnotes regarding a wide array of perspectives, I also found it necessary to present the voices and experiences of some participants in greater detail than others. In doing so, I sacrificed any hope of presenting quantitatively generalizable findings. However, I feel I also gained the ability to offer ethnographically rich insights on issues that impacted the lives – to greater and lesser degrees – of those persons I came to know through fieldwork. In this way, I hope to have made a worthwhile contribution.

Research Methodology and Data Collection

This research was designed to employ a variety of ethnographic data collection methods:

Semistructured Interviews: In order to gather data on topics that remained consistent from one participant to the next, this study relied in part on formal, in-depth, semistructured interviews. Slightly different interview schedules were created for each of the study's sub-populations so that appropriate questions were asked among each group. (These interview schedules are appended at the end of this dissertation.) However, all interviews followed a common set of domains designed to gather data directly related to the study's overall objectives. Before I began interviewing study participants, I presented the interview schedule to medical personnel who work closely with transplant patients, to seek feedback on its appropriateness and wording. Interviews generally were conducted

face-to-face, at locations of participants' choice. However, I also accommodated requests for telephone interviews, which some participants preferred because they did not have time during their stay in Metrotown to meet with me, and lived more than 2-3 hours away from the Health System, but still wanted to participate in this research. Three participants preferred that I give them a list of my interview questions, so that they could think about them and then write out their answers to send to me. While I much preferred the face-to-face interaction, and encouraged this whenever possible, I did allow these alternative forms of communication, in order to accommodate participants as much as possible. With verbal and written permission, I audio-recorded interviews for later transcription. In the few cases in which a participant said they were not comfortable with being tape-recorded, I instead only took detailed hand-written notes of the interview.

Unstructured Interviews. In order to also encourage participants to define and expound on issues relevant to their own experiences of transplantation, all participants also were asked to take part in an audio-taped, unstructured interview. These almost always were conducted at the same time and setting as the semi-structured interviews. These were a crucial part of this research, as open-ended interviews are particularly well-suited for dealing with more sensitive topics (see, e.g., Corbin and Morse 2003) that are likely to surround transplantation (such as experiences with and witnessing the suffering of others with chronic illness, the possibility of death, arenas of constraint, care demands, etc.). Both semi-structured and unstructured interview designs have been widely supported as integral tools in qualitative research (see, e.g., Kvale 1996; Padgett 1998; Shaw and Gould 2001; and Spradley 1979).

Genealogical Interviews: Although the topic of kin relations figured prominently in the semi-structured and unstructured interviews, a subset of key informants were selected from among patients and their caregivers for more in-depth genealogical interviews, which also were audio recorded. I had planned to ask several key informants to help me construct kinship diagrams, using a combination of techniques described in Parkin (1997), and McGoldrick, Gerson, and Shellenberger (1999)³. While this method

³ Please note that this second reference offers excellent methods for including biographical information about significant life circumstances and events in kinship charts (or, "genograms"); it is directed at a clinical social work audience but it is important to note that I made it clear in all instances that I was not acting in a clinical capacity.

did provide some empirical data as a measure of how patient-caregiver groups conceptualize their relatedness to each other and to others in their kin networks, it tended not to feel like a “natural” way of interacting with participants, and I used it only very sparingly, in favor of more conversational and everyday participatory interactions with the people with whom I spent time during this research.

Life History Interviews: Key informants also were asked to participate in unstructured, audio-taped life history interviews that occurred over longer periods of time. They were asked to tell their life stories, beginning in childhood and proceeding into adulthood. Life history interviews were chosen as a method for their value in gathering data about historical shifts in understandings of kinship across generations (Plummer 2001:395). In those cases where patients have had multiple transplants over a number of years, these interviews helped to understand changes in transplantation and health policy over time. Transplant patients also were asked to incorporate their experiences with illness and transplantation into the story of their lives. I had intended that the kinship diagrams generated in genealogical interviews would be used to help direct these interviews, but found that key informants needed very little formal prompting of this sort to share their life stories. Thus, these life history interviews tended more often to simply become a part of ongoing conversations and interactions with key informants over the period of this research. These interviews generated interview data that was rich with “illness narratives” (Kleinman 1988; Good 1994; Kirmayer, Mattingly and Garro 2000) surrounding patients’ dealings with illness and transplantation that personalized their accounts of the social and medical aspects of transplantation throughout this dissertation. In addition to audio-recording, detailed notes were taken as these interview data were gathered.

I gave all interview participants a \$10 thank-you gift card to their choice of a local grocery store chain, a national discount department store retail chain, or The Health System’s Cafeteria system. This was meant to be a small gesture of gratitude, and it fit well in the ethnographic contexts within which I was working. In order to avoid the risk that this small amount of money might influence persons’ decisions about whether or not to participate, I did not draw attention to this as an incentive. In most instances, this offer

was an unexpected and happy surprise to participants, and tended to be a source of “small talk” as they spontaneously discussed their three choices.

Participant Observation and Fieldnotes: This study also relied heavily on participant observation and the recording of fieldnotes (Emerson, Fretz and Shaw 2001; Geertz 1973). Participant observation entailed taking part in the daily settings and lives of members of the study population, outlined above. It was carried out via two avenues, in which I: 1) worked to become a familiar presence among the medical staff and personnel at The Health System and Transplant Center, in order to gain an understanding of the ebbs and flows of daily clinical life; and 2) worked to build rapport among key informants and, at their invitation, regularly visited them in their homes to interact with them on a less formal basis. At the end of a field experience, I took detailed notes about everything from the physical setting, the time of day and season of the year, social interactions, and thoughts and emotions. Depending upon the circumstances, I scribbled notes by hand, keyed them into a laptop computer, or spoke into an audio-recorder for later transcription.

In addition to daily participant observation in clinical and home settings, I also participated in:

- Annual walk-a-thon events in 2008 and 2009, organized by The Health System and Transplant Center to promote organ tissue donor awareness
- The 2008 and 2009 Organ Transplant Reunion, an annual event which includes speakers, educational sessions, children’s activities, group pictures, and breakfast and lunch for adult and pediatric solid organ transplant recipients, donors, and donor families

One section from my fieldnotes lends insights into the realities of fieldwork in this setting and among this target community, as well as some of the ways in which interviews and participant observation tended to supported data collection in complementary ways...

My sample is diverse in terms of health status, social class, education, and rural-versus-urban, and I’ve become more mindful and skillful at customizing interviews according to

context, as well as my positionality, etc. For example, I've been finding it necessary to custom tailor the interviews to how much energy or time the person has; whether we're meeting at their home, during a clinic visit, or while they're an inpatient. I also have found it important to adjust my style according to the person I'm talking with (Is this an elderly farmer or a middle-aged urban academic? Is this person pre-transplant and on dialysis? Are they 3 years post-transplant and feeling great? Or is this person one week post-transplant and still in pain?) Also, in the cases where both a patient and their care partner agree to be interviewed, they usually want to be interviewed together at the same time (this may be for a number of reasons, but surely important among them are the fact that participants often lead logistically busy lives, and often also had other appointments to attend). At first I was trying to encourage that we meet separately, but lately I've been finding it helpful in some ways to talk with folks together. It adds another dimension because I can see how patients and caregivers interact with each other, and they often tend to negotiate with each other about their different perspectives of/versions of their story.

Visual Documentation: Additionally, in some cases and always with permission, I took digital photographs to record visual data about physical surroundings (especially those spaces participants identified as their “home,” however they chose to define it) and social interactions among participants. These visual data generated rich ethnographic evidence that I could use to corroborate or qualify interview data throughout data collection. There also were instances in which key informants chose to share certain of their own photographs with me, to help explain to me about their lives and experiences. I include a select few of my own photographs in Chapter 6 on “Revealing and Reframing Relatedness.”

Policy Review: Because this study was concerned with how health policy in the U.S. affects the daily experiences of transplantation among recipients and their caregivers, I also conducted an ongoing review of health policy. This review was to examine current and past health policy trends, alongside transplant-related trends and issues such as the costs related to healthcare, lengths of hospital stay and provisions for caregiving and other health resources, in order to understand how policy and daily life

may be related. This was accomplished through the use of library and internet search engines and databases, local and national news stories, and as well as patterns and trends found in interview data.

Data Collection Management and Analysis

This study employed ethnographic approaches to data management and analysis throughout its duration. Fieldnotes, interview notes, and digital photographs were compiled and entered regularly into a laptop computer. All tape-recorded interviews were transcribed and saved electronically. All data was loaded onto the software program QSR NVivo 8, which was suitable for storing, managing, coding, and indexing multiple forms of qualitative data 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 the research questions and hypotheses, which in turn were related to the larger theoretical issues, discussed previously. Comparisons were made regarding the transplant and caregiving experiences of participants in clinical settings versus the actual home, and pre- and post-transplant, wherever possible. The arenas of constraint and the daily practices and experiences were also analyzed for each transplant group (though, in general, the focus of this dissertation is on common themes across transplant groups). The attitudes of medical personnel also were analyzed.

Privacy and Confidentiality

I took a number of measures to ensure that I was both 1) maintaining the privacy and confidentiality of persons I met and spoke with over the course of this research, as well as 2) presenting an accurate account of what participants were telling me in interviews and what I was observing as an ethnographer. All of the names (of persons, institutions, cities, etc.) that I use throughout this dissertation are pseudonyms. In some cases, I have altered small details regarding participants that would further help to obscure identities without changing the accuracy of the ethnographic data I have recorded and drawn upon here. For example, if I were to describe the car a participant drove, I might say the car was red, when it in reality was another color—such a description would help to hide the person's identity without altering my analyses. During the

written, informed consent process, I made clear my role as a researcher (explaining in plain terms, for example, that I was a social work and anthropology graduate student conducting research for my doctoral dissertation on this particular topic; that while I had social work training, I was neither a member of the transplant team, nor was I there to provide clinical social work services; and that participation in this research would have no bearing on any of the decisions to be made by the transplant team). I also emphasized that participants could decline to answer any question I asked them, and that they could end the interview at any time. I provided participants with several ways to contact me, and stressed that if they ever decided that they'd rather *not* have me quote something they'd said in an interview, or if they'd rather I *not* write about any particular part of our conversation or interaction, I'd honor their wishes (whether they decided this immediately following an interview or weeks afterward). As an additional layer of protection, in those instances during interviews where a topic arose that seemed potentially difficult to discuss, I would ask if the participant felt alright talking about it or if we should move on to another question or even end the interview. In all of these cases, participants preferred to continue with the discussion and the interview. There were a few instances in which a person wanted to participate my study, but seemed to prefer not to go into detailed answers to my interview questions, or seemed to be a bit more guarded in our interactions, and I generally have used data from these interactions only to inform my overall analyses without drawing explicitly upon these as illustrative cases in my writing.

In fact, though, participants overwhelmingly were eager to share their stories, experiences, and perspectives with me. Some even told me they'd be happy to have me use their real names in my writing (in each of these instances, I thanked them but explained that I would need to use pseudonyms in any case). Several indicated to me that it was nice to be given the time and space to tell their story, to have someone *want* to better understand their lives. Many expressed their hope that others [including other patients and caregivers, as well as clinicians and other decision-makers] might benefit and learn from hearing about their experiences.

Entering the Field

In many respects, I entered the field twice: once before and once after a period of maternity leave following the birth of my husband's and my first child. The first entry took place in September and the first two weeks of October of 2007, when I began with a series of meetings with those clinicians who held gatekeeping positions and could advise me on how best to go about recruitment. This also was a time during which I was asked to obtain institutional credentials to interact with patients at the Health System and Transplant Center. Toward this end, I was required to identify a home department within the Health System (through consultation with the credentialing office and with the Social Work department, we decided to settle on "Allied Health Professional"), fill out an application, provide my immunization records, be tested to ensure that I was not a carrier of tuberculosis, and take a urine drug screening test. I also was required to familiarize myself with the information included in an orientation packet (from employee parking policies to workplace conflict resolution to the system of codes used in the hospital setting, so that, for example, I could identify Code Red versus Code Blue announcements), and to take a written exam to demonstrate that I indeed, had understood the information. The process was nearly as lengthy, laborious, and time-intensive as had been the process to obtain Institutional Review Board approval at two different institutions (my home university and that of the Health System University), as well as approval through the Health System University's Nursing Review Committee, and the Health System University's Scientific Review Committee. However, the credentialing process also provided an opportunity to better understand the institutional norms of the Health System and some of the officially-sanctioned expectations of staff at all levels.

After completing a long checklist of credentialing requirements, the weeks passed and I finally received a letter indicating that I had been approved. The next step was to obtain my photo identification badge, which felt to me like a major accomplishment (though my enthusiasm did not register with the seemingly-bored person whose job it was to ask their patrons to turn their back to a plain blue background, stand at the masking-tape line on the floor, and look at the camera). I came to develop mixed feelings about this badge, however, as my fieldwork progressed. It became an outward sign that I did, indeed, "belong" in clinics, inpatient units, and other gatherings of transplant clinical

professionals. But at the same time, I often troubled over what that badge might mean to patients and their caregivers, and took great pains to make clear to them that I was not actually a member of the medical team; that their participation had no bearing on the decisions of the medical team; that, while I had my Master's in Social Work, I was not there to evaluate them as a social worker, nor to provide social work services; and that I was a graduate student at an institution located several hours away (and not at the Health System or one of the other local universities).

As the following excerpts from my fieldnotes illustrate, in many respects, I eventually came to be treated as a member of the medical team, and found myself being very aware and ever-mindful of the fine line ethnographers often walk between insider and outsider status.

Notes from the field, July 2008....

I'm beginning to feel I'm actually a member of the staff here. I'm being given actual appointments to meet with allogeneic stem cell transplant patients, where I'm appearing on patients' schedules and being given reservations in one of the four Patient Education Rooms (named by colors, even though each room has the same beige shade of paint on the walls) for private discussions about my study with potential participants. Today, I was scheduled to see a patient in the "Red Room." Donning my photo identification/credentials badge hanging around my neck from a lanyard, a few minutes before our scheduled appointment, I walked over to the Patient Care Center, the stem cell transplant clinic (separate from the solid organ transplant clinic), gave my name, and asked if the patient had checked in yet. The receptionist typed a search into the computer, found my name there, confirmed that the Red Room had been reserved for my appointment, and told me the patient likely would be checking in down one level at the front desk outside the Solid Organ Transplant Clinic. This also is the front desk for the Health System's on-site hotel, where people from out of town can stay during their hospital or clinic visit. At the front desk, the staff members wear uniforms very similar to those worn by front desk workers at any given hotel chain. When I asked one of the front desk workers whether the patient I was to see had checked in yet, she pointed me in the direction of the clinic area and said I should ask the nurses there. One clinic nurse who

had seemed to make a special effort to be friendly toward me (she herself was a traveler nurse) was among the nurses in the room where I asked; she said the patient hadn't checked in yet, but that I could wait in the "Physician's Room", which also made me feel like a part of the staff there. Another nurse invited me to use one of the several computers that line the room while I waited. During clinics, these computers tend to be in high demand, with clinical personnel of every profession whizzing into the room in-between appointments, sitting down at a station, and checking patients' electronic medical records to get test results, H & P (history and physical) information, or to look back on their own or others' previous documentation and charting. When I walked back to this room, the door was closed, and I entered the room and had just sat down at a computer when a nurse opened the door and let me know that the patient had arrived. She started to hand me a sheet of paper, but not quite understanding the cues, I didn't knowingly take the paper, which prompted her to say "Oh, you don't need the billing sheet?" I explained that I was a graduate student here to do my dissertation research, and that I wasn't performing any billable services. I followed her back up to the front desk, where she pointed out the patient and I thanked the nurse, paused at the desk to pump a dollop of Purell hand sanitizer on my hands (as local custom mandates), and walked over to introduce myself to the patient. Our handshake was delayed slightly by the fact that I needed to keep rubbing and waving my hands to make the alcohol gel evaporate, but the patient was very understanding, and introduced me to his son as well, who was accompanying him during his clinic visit. I re-explained briefly who I was and what I was doing here, reiterating that I was not here to evaluate him as part of the medical team, and proceeded to lead him back up the stairs to the Red Room for a more detailed conversation about my research and to go through the full written informed consent process.

During the time I was working to gain my official credentials, I met with Nurse Program Managers and the heads of the Social Work program, the kidney/pancreas transplant program, the liver/small bowel transplant program, and the bone marrow/stem cell transplant program to introduce (and in some cases, to re-introduce) myself, explain my research, answer questions, obtain permission to recruit patients from their respective

programs, and work with them to determine how best to recruit patients and caregivers, without being intrusive and without interrupting the flow of daily clinical routines. In all cases, I was warmly welcomed.

Once I had my credentials, I began to make arrangements to job-shadow some of the Transplant Social Workers. Since the Health System was a teaching institution and part of a university system, patients who sought their medical care there were accustomed to being asked permission to allow others (usually students) to observe their clinical interactions, and generally did not take issue with my being there, especially after my research project and my status as a graduate student was explained. My first engagements with patients and their loved ones, then, came in the form of observing the sorts of interactions the medical social workers had with their clients on a daily basis. It quickly became clear that social workers perform their duties in all areas of the Health System and Transplant Center. They not only held scheduled appointments with patients and loved ones in clinic areas, inpatient areas, and the Social Work Department offices, but also did impromptu follow-ups and answered questions as they bumped into clients and colleagues in the hallways, waiting areas, coffee stands, commons areas, and cafeterias (or, on nearly any occasion of the chance encounters that take place between people in institutional settings like a hospital environment).

Re-Entering the Field in the Contexts of Parenthood, Childcare, Wellness, and Illness

By the time I had full institutional permission to begin my fieldwork, I was in the final weeks of my first pregnancy. I did not get far in the job shadowing portion of my research before I gave birth to our son, and did not resume fieldwork until January of 2008, when I entered the field a second time. While having children in the field is not uncommon among anthropologists (see the edited volume by Cassell 1987), our situation was somewhat unique, given the nature of my field site and the needs of the people with whom I was working. Many first-time parents of young children who rely on the U.S. daycare system will attest to the fact that the first months (sometimes even year or more) of daycare can tend to be marked by an exposure to contagious illnesses that exceeds what one has become used to as an adult who is not often around young children. An

infant would not have been welcomed in a professional clinical setting, and in order to obtain and pay for our family's health insurance coverage, my husband also worked full-time throughout my fieldwork and was not available for daytime childcare. Thus, conducting full-time fieldwork was only possible with the use of daycare. At the same time, our son was exposed to many more contagions at daycare than he otherwise would have been, and not only did he have a nearly uninterrupted series of colds, ear infections, fevers, and other illnesses, but my husband and I also were exposed to and became ill with several of these viruses as well. Aside from frequently needing to stay home to care for our son when he was ill, there also were a number of times when I had to call participants to reschedule our plans to meet. This is because most of the people with whom I worked were either on immunosuppressants (and therefore were especially vulnerable to even the mildest cold), or they were waiting for their transplant, or they spent their days in direct contact with patients in these positions. As will be discussed in Chapter 2, a patient might be passed over if they were fighting a cold or other infection at the time they were called for a transplant. Believing that I had an ethical obligation to avoid the risk of exposing patients to any illnesses, I took great caution to not come into contact with participants if I felt even the slightest sniffles approaching. And for days after I had felt well again following an illness, I still wore a mask if I entered into clinical areas where immunocompromised patients might frequent.

The role of wellness and illness also worked in the other direction. I had made it a practice to call just prior to a meeting I had scheduled with any participant, to confirm our plans and to make sure the person was still feeling up to it. It happened a number of times that the person turned out to not be feeling well that day, or had not slept well the night before, or had been called in to the clinic unexpectedly for a test or procedure, or in cases where persons were inpatients, had been discharged a day early.

CONNECTING TO THE BIGGER PICTURE

This dissertation research is expected (and hoped) to make contributions to several bodies of theoretical literature, including: 1) kinship studies, 2) science and technology studies, and 3) medical anthropology. Marshall (1992:54) has noted that, in anthropology, medical dilemmas and their resolution are considered to be inextricably

bound to broad cultural circumstances that influence health and illness behavior. Thus, the discipline is particularly well-suited to shed light on the complexities such as those surrounding transplantation in the context of kinship, as well as their implications for everyday life. This interdisciplinary project also is intended to augment an empirical knowledge base upon which practical social work action can be built toward addressing social justice concerns related to transplantation specifically (e.g., Giles 2004) and high-tech health care in general. Giles (2004), for example, has noted the importance of establishing a foundation for social work practice guidelines (in this case, for renal social work) that is based on empirical evidence, to make clear the value and effectiveness of the profession in health care.

Social workers already play a key and direct role at all stages of the transplant process. They often are involved in approaching grieving families to ask if they wish to donate the organs of their dying loved one (Geva and Weinman 1995). They also carry out multiple interventions designed to help prepare patients for transplant, and remain available to recipients and those close to them for long periods post-transplant. As members of interdisciplinary medical teams, social workers often conduct psychosocial evaluations of potential transplant candidates. When used with an eye toward social justice, such evaluations can help to address potential barriers to transplant (e.g., Fisher 2006; Giles 2004). Social work services also take the form of support and education groups that can improve patients' coping skills (as found by Suszycki 1988); stress reduction programs that can help prepare patients for the challenges of transplantation (as found by Gier et al. 1988); and interventions directed at "high risk" patients who were smokers, abused alcohol, had personality or affective disorders, or have poor social support (as found by Tazelaar et al 1992). Zilberfein et al. (2001:101) have also noted the benefits of (and greater need for) post-transplant social work involvement, underscoring the value of a "continuity of care model." Wolfe (2003, 2006) has argued that nephrology social workers are particularly well-situated to work at micro-practice levels to decrease racial disparities in transplantation that appear on a macro-level (also see Arthur 2004).

However, social workers' (and practicing medical anthropologists') presence at all levels of the transplant enterprise could be both increased and improved. Wolfe

(2003, 2006), for example, asserts that because of their ethical and professional position, social workers should develop interventions to ensure that persons of all racial and ethnic backgrounds receive adequate and accurate information, encouragement, and emotional support with regard to considering kidney transplantation as a treatment option for end-stage renal disease. In general terms, Brown (1988) argued over two decades ago that social workers need to stay abreast of medical technological developments (including those related to transplantation) and play a more active role in shaping decisions about how those technologies will get taken up and utilized in health care settings. This remains an issue today. Although social workers usually are included on transplant teams, even rather recent studies have noted instances where their presence and services are lacking. A study by Jones and Egan (2000), for instance, was conducted in a liver transplant program that had no social work services available at the time. In a narrative about her own experiences as a bone marrow donor to her ill sister, Berzoff (1999), too, exposes the significant psychosocial problems that tend to go unaddressed when a transplant team lacks a social worker and when its members focus only on the biomedical aspects of the procedure, to the detriment of patient care.

As Dhooper (1989, 1990, 1994) has argued, social workers have an ethical and professional obligation to work at the individual, institutional/organizational, and policy and societal levels to ensure equality in access to organ transplantation. Because social workers are trained in and practice at each of these levels, they also are uniquely situated to inform and shape the continuously evolving transplant enterprise in all of its arenas, from procurement to post-transplant.

I have conducted this research during a time of remarkable changes and advancements in medicine and biotechnologies. Thus, by focusing on the ways in which one such biotechnology – organ and tissue transplantation – articulates with everyday life via kin relations and home-based post-transplant care, this research, I hope, will deepen our understanding not only of the theoretical implications, but also of the practical implications for those who experience these technologies. Emily Martin (1995:271) has speculated that it is a certain security of position in social hierarchies that allows greater comfort and ease with the types of boundary-crossings (e.g., between self and other, illness and health, life and death, etc.) involved in newer biotechnologies such as organ

transplantation. But this study examines not only the assets that make using biotechnologies easier, but also the constraints that make using such biotechnologies more difficult. Thus, the specific focus of this project potentially will be of greatest practical importance in the health policy arena. It is intended to afford a nuanced understanding of these areas of constraint, which can steer policy decision-making toward better meeting the needs of transplant patients, as well as others with serious, long-term illness.

In sum, empirical data from this study, about how recipients and their caregivers cope with the everyday demands of transplantation, therefore is intended to be useful to anthropologists and social workers alike. Ideally, these research findings can be used to make inroads to 1) improve outcomes for transplant patients, 2) create and bolster relevant forms of support for those who care for transplant patients, and 3) enable medical professionals to better understand and treat their patient population. While all parts of this dissertation should set the stage to accomplish these goals, its structure has been organized so that Chapter 2 will provide a good sense of what is entailed (logistically, emotionally, theoretically, and structurally) in the time leading up to a transplant, while Chapters 3, 4, 5, and 6 will focus heavily on ethnological and theoretical insights, and Chapters 7 and 8 will offer a particular effort toward addressing the more policy- and practice-oriented insights of this study.

Chapter 2

Preparing to “House” a Transplant

While this dissertation is primarily concerned with matters of relatedness and home life, it also keeps intact the notion that the clinical and sociocultural successes of transplantation hinge on creating and maintaining particular bodily states. This has been well-documented, for example, by Margaret Lock in the case of brain death and cadaveric donors whose bodies must artificially be kept alive until organ procurement can take place. This chapter will add to the conversation by exploring how transplant candidates and recipients work together with their caregivers and other loved ones, in multiple settings, to create and maintain certain bodily states required for transplantation. Its analyses are based on field observations that those pursuing a transplant must commit to ensuring that their bodies become and remain an ideal environment, or in a sense, the ideal “house,” for a grafted organ. Pre-transplant, this can entail undergoing meticulous clinical screenings, taking medications, losing weight, avoiding contagions, refraining from substance use, achieving dental hygiene, having surgeries for other health issues, and faithfully maintaining a dialysis regimen. These pre-transplant requirements serve to decrease the risks associated with the transplant surgery itself. They in some ways might be likened to the rites of passage described by van Gennep (1960 [1909]), in that they resemble observances and procedures aimed toward ushering an individual through critical and potentially dangerous transitions and transformations of the transplant journey.

From another perspective, they also act as a screen for medical compliance, which can be taken by clinicians to be a predictor of long-term success or failure of the transplant. Patients considered to be good candidates for transplant, then, are those who are most able to demonstrate compliance through a commitment to embodying the

biomedical norms, beliefs, and practices of transplantation. Quite literally, medical compliance is screened for via laboratory and clinical examinations of bodily states that can only be created through embodying particular, prescribed biomedical practices. Verbal reports of health behaviors, while not discounted entirely, tend to be given less weight as evidence of a patient's health status, or that a person is indeed following prescribed regimens. Thus, the process of preparing for a transplant is in some respects "housed" in clinical and bureaucratic arenas where the actual screening procedures are carried out.

On the other hand, this chapter also argues that the embodiment of biomedical values, practices, and states-of-being takes place over time largely in the context of everyday home life and among kin, and that clinical assessments of the body's preparedness to house a gift of life are *interrelated* with the state of the home and everyday home life in the moral context of kin relationships. These issues also can be mediated by the gendered, political economic, and other intersecting dimensions of houses, home life, and caregiving, which often can follow patterns along key demographic variables (such as age, race, ethnicity, class, gender, ability status, etc.). By tracing some of the connections between the hospital, clinic, and other institutions, as well as clinical professionals, on the one hand, and home life, family life, and informal caregiving on the other hand, this chapter also will foreshadow some of the issues that will be addressed more explicitly in subsequent chapters.

In short, this chapter will offer an account of the pre-transplant preparations that participants in this study had to make. It will frame these preparations in terms of two linked ideas: 1) In a very literal sense, patients considered to be good candidates for transplant are those who are most able to demonstrate compliance through a commitment to embodying the biomedical norms, beliefs, and practices of transplantation. 2) Clinical assessments of the body's preparedness to house a gift of life are *interrelated* with the state of the home and everyday home life in the moral context of kin relationships. While these ideas will be fleshed out sequentially, first with a discussion of matters of the body, and then with a discussion of matters of the house, I hope to make clear their interconnections throughout this chapter.

Demonstrating Bodily Compliance Through Techniques, Technology, and Testimony

Like many transplant programs, the Transplant Center where I conducted my fieldwork has a policy of considering a history of consistent non-compliance to be an exclusionary factor for transplantation. This non-compliance can be regarding medical treatments, medications, or other behaviors that the transplant team feels would affect the patient's ability to care for themselves and their new organ, post-transplant. While many who pursue transplantation do so despite having serious doubts, fears, and reluctance about the procedure (I will more fully develop this idea in Chapter 3 of this dissertation), if a patient has opted to pursue a transplant, they have embarked on a path toward a particular aim, by particular means.

As the ethnographic data presented in this chapter will illustrate, patients are expected to achieve and maintain a bodily state that is amenable to transplantation. Taking cues from Asad (1997), who urged a re-balancing of attention to problems about the formation of the body (which he argues have been largely underplayed) as being interrelated with problems about its representation (which have received greater attention), one component of this chapter's overall position is that a transplant patient's demonstration of medical compliance and achievement of proper bodily states are accomplished through the adoption of particular "techniques of the body," in the Maussian sense. Recognizing that humans differ cross-culturally in their bodily dispositions and practices, in his 1935 work on the subject, Mauss described the human body as humanity's "first and most natural technical object and also technical means" (1979 [1935]:104). He commented on the social nature of bodily practices and dispositions (or, *habitus*), noting that "The constant adaptation to a physical, mechanical or chemical aim...is pursued in a series of assembled actions, and assembled for the individual not by himself alone but by all his education by the whole society to which he belongs, in the place he occupies in it" (1979 [1935]:105). As such, he argued that body techniques are learned through a sort of education, what Mauss calls "prestigious imitation," where authority and social status provide impetus for the acquisition of certain body techniques and not others. He asserted that, in order for a body technique to be transmitted and take hold, it must be grounded in tradition. Jackson (1980), building on

the work by Mauss, as well as Bourdieu (1977 [1972]), has taken an ecological perspective on the habitus, noting that ideas and habits reinforce each other in ways that persist so long as the environment in which they're grounded remains stable.

Few patients or loved ones expressed outright disapproval of the biomedicalized ideals to which they were asked to adhere, and this suggests an already-existing acceptance of these ideals in the U.S. In fact, several examples presented themselves over the course of fieldwork, in which participants who had come far enough along in the transplant process to be included in this study demonstrated already a receptiveness to the practices which would be required to achieve a bodily state hospitable to a transplanted organ. For instance, in clinical encounters I witnessed, it occasionally was apparent that patients felt that they were being evaluated for more than their kidney functioning and blood type, and that what they conveyed at these appointments would be used to determine whether and when they would be admitted to a transplant waiting list. During my efforts to find time in-between clinical appointments to talk with participants, if a physician or other clinician would come to the examination room for their evaluation, I observed that a “knock-knock” on the door would often prompt patients and their care partners to sit up straighter, ready to demonstrate attentiveness and compliance to whomever walked into the room. Patients and care partners at times would work as a team in this regard. In one instance, when the clinical psychologist asked a patient if he smoked, he said that he had quit two weeks ago. His wife asked worriedly, “Is that O.K. or does that hurt his chances to get on the [waiting] list?” She went on to describe the ample family support her husband had in avoiding a return to smoking.

Persons generally responded to these expectations by willingly internalizing medically prescribed behavior modifications and practicing careful self-monitoring. In some cases, people went to great lengths to comply, and to demonstrate their compliance. Some comparison might be made to Petryna's (2002) work in post-Soviet, post-Chernobyl Ukraine, which illustrates how illness and suffering are produced under circumstances in which access to medical, economic, and other social benefits is conditional on the ability of persons to demonstrate their biologically-based suffering in institutionally-recognized/legitimated forms. Petryna emphasizes the intertwining of human lives with the political economy and governance of the state, the limits of

scientific knowledge, and the management of disaster [for comparative case studies in other ethnographic contexts see Das (1995) on the 1985 industrial chemical disaster in Bhopal, India; and Briggs and Mantini-Briggs (2003) on the 1992-1993 cholera epidemic in eastern Venezuela]. Petryna employs the term “biological citizenship” to frame this tethering of certain types of bodily or biological suffering to access to state protections (in the case of transplantation, persons seek access not to state protections but to organs and medical treatments).

Petryna’s concept of biological citizenship (cf Rose 2001; and Rose and Novas 2005) is an extension of Rabinow’s 1992 concept of “biosociality.” Rabinow developed this concept out of his work in the U.S. and France, as a way to understand a “truly new type of auto-production” (1999 [1992]:411) that he predicts will emerge in light of the Human Genome Initiative. Rabinow argues that sociality will become increasingly based on new types of biological identity, and that people will group themselves around their common genetically-based risk-factors and mobilize around ways to escape their genetic destinies. Biological citizenship and biosociality are further extensions of Foucault’s notion of bio-power, which refers to the use, beginning in eighteenth-century France, of “explicit calculations” and “knowledge-power” to render people more predictable and governable through focusing on matters of the body, health, and life (1978 [1976]:143-145). Foucault linked the rise and prominence of biomedicine to its resonance with already-existing discourses and socio-cultural forms (1973 [1963]) and described historical vectors (such as changing discourses about sex, and technologies like the panoptic schema) by which bodies and populations became disciplined, and, eventually self-regulating entities (1977 [1975], 1978 [1976])

Yet transplant patients’ self-regulation and adoption of body techniques are not seamless, uniform, or complete. The process of creating ideal conditions for a transplant can be subject to the widely varying daily lived realities of patients and those close to them, and patients often do not or cannot accept all medical injunctions exactly as they are given. Clinicians are aware that not all medical orders are followed, so while patients are asked about their adherence to medical orders, clinical and laboratory-based measures are considered the indisputable indicators of whether a particular patient is taking their medication, losing weight, avoiding street drugs, or dialyzing as prescribed. In other

words, a major way in which medical compliance is screened for in transplant medicine is via an assessment of bodily states, so that patient's bodies are afforded more credibility than the verbal accounts of patients themselves.

An apt comparison can be made to a case described by Shapin (1994). Using an example from the Royal Society in seventeenth-century England, in his chapter, "Knowing About People and Knowing About Things," Shapin (1994) details the handling of a discrepancy in testimonies about the natural world. The discrepancy stemmed from the reports of divers, who said they felt no discomfort from pressure even when diving in very deep waters. These accounts ran counter to Robert Boyle's theories concerning water pressure, which predicted that deeply submerged bodies would indeed be pressed upon by the surrounding water. Boyle resolved this discrepancy by turning to a surgeon who worked with divers specializing in retrieving treasure from Spanish shipwrecks. This surgeon described how divers who went very deep often experienced tremendous pressure of water pressing on their bodies, with significant effects on their ears and eyes and which sometimes caused them to spit blood. To Boyle, "If vulgar divers' bodies spoke more truthfully than their tongues, then it might be possible securely to establish the reality of pressure effects by relying not upon the testimony of persons but upon the testimony of things" (Shapin 1994:263). Boyle also turned to the testimony of other gentlemen with ties to the Royal Society, to find cases in which bottles that had been submerged off ships into deep waters had been crushed or broken. Within the seventeenth century Royal Society, credibility stemmed from social standing, so that divers' own reports could be given less weight than the reports of surgeons who tended to their bodies, or even than pewter and glass bottles. Divers were afforded no moral grounds for credibility; they were people who labored for a living and could not be considered to speak without ulterior motives for material gain, and furthermore could not be vouched for by other upstanding members of the Royal Society.

"...they need to feel comfortable that I'm going to be a good candidate..."

One example from my fieldwork brings into focus the comparison to Shapin's descriptions of verbal versus bodily testimony, and situates it within the complex interplay of screening, compliance, and credibility in transplantation. Cameron, a white

man in his early twenties who had known since the age of twelve that he one day would need a kidney transplant, expressed a great deal of frustration to me as we sat and talked at his the dining room table in his mother's split-level house, where he spends his time when he's not staying with his fiancé. The source of his frustration was that he had been delayed in moving forward with a transplant because the transplant team was concerned about his past history of using marijuana, and had required him to attend special counseling sessions in order to ensure that he would no longer use the drug. On the one hand, he linked the beginnings of his marijuana use to a time in high school when his grades began to slip, he began to feel depressed and, as he put it, "...[I] kind of got this attitude, live life like it's your last and just have fun while you can." On the other hand, he also had considered his marijuana use to be something that actually enabled him to better follow an exercise regimen – a set of body techniques that also is valued within the medical community – which had kept him feeling strong and healthy prior to the final stages of his renal decline. In any case, Cameron understood well the stakes that were involved now, and he hasn't used the drug for some time. Still, his personal assurances were not sufficient.

They [the transplant team] were concerned about the past marijuana use...that was their concern. So that's another reason why they want me to do the counseling. ...Because if I used marijuana in the future with the anti-rejection drugs, I guess they counter-act each other and the anti-rejection drugs are no longer useful. And so that can kill my kidney too. So there is really, there is a, a huge emphasis on me never smoking marijuana again, which I understand that. I don't, I don't want to affect, or, I don't want to hurt my health or the new kidney at all.

I asked Cameron how the transplant team found out about the past marijuana use, recalling that, during clinical evaluations, patients are asked verbally if they use drugs or drink alcohol in any quantities. Cameron pointed out that his marijuana use had shown up on his lab work, since drug testing is routinely included in any lab work performed

otherwise to gauge, for example, the level of creatinine⁴ in his blood, which is an indicator of kidney function. His medical team had warned him long ago that he would need to be marijuana-free for at least six months before they would approve him for transplant, but at that time, Cameron still felt well and assumed that his kidneys would continue to function for some time yet. But in the end, his renal failure happened rather suddenly, and, as Cameron put it, he “didn’t really have time to quit.”

...They’d known about it from just the labs, the lab work. They do drug testing every time they draw a lab. [...] They told me, you know you’re gonna, you can’t still be smoking pot when, you know, we need six months of clean UA’s before we can do the transplant. So I was still smoking pot, up until dialysis, because... you know,...it was part of the thing. It kind of helped me exercise I guess because I didn’t have any strength. I didn’t want to exercise, so it was kind of like I’d reward myself for exercising kind of a thing and yeah, I just kept smoking for too long, and it crept up on me. Kidneys failed before I knew it. So [I] didn’t really have time to quit before the transplant. I just, I ignored the request until it was too late...

Cameron expressed his aggravation that the transplant team has focused so heavily on his past marijuana use, and that it was proving to be the primary roadblock on his road to transplantation. But not only was his own verbal testimony insufficient, even a basic form of bodily testimony in itself would not do. Though he had met the minimum six months of “clear UA’s” (urinary analyses), he now was being required to complete counseling –in essence to garner additional “vouching for” by a clinical professional – before he could be approved for the procedure (akin to the credentialing criteria required for passage of those unknown to Robert Boyle into the experimental spaces of the seventeenth-century Royal Society, as outlined by Shapin [1999:488]). Cameron feels he otherwise would be able to proceed quickly through the process, especially since his mother is a willing and medically compatible living donor.

Cameron: ...It’s been seven months since I started dialysis, since I last smoked marijuana. Yeah, that’s, that’s been the main thing. My mom’s been tested, uh, tested for compatibility [to become a living donor]. She’s done her workup, everything, and we

⁴ Creatinine is a waste product, produced in the normal day-to-day metabolism of muscles. Well-functioning kidneys remove all of the creatinine from the blood, so when creatinine blood levels are elevated, it can indicate decreased renal function.

match. So we're ready, we're ready to move on. It's just, they want me to do the counseling now. And they need to feel comfortable that I'm going to be a good candidate for years and years after the transplant before they want to do it.

Laura: *And what do you make of that, the holding off on the transplant for now?*

Cameron: *I understand, I understand why. So I understand the idea behind it. However in my case, you know...*[expressing his confidence that he will not return to marijuana use].

In some regards, drug testing might be likened to the “panoptic shema,” which Foucault suggested becomes the surveillance mechanism of choice “[w]hen one is dealing with a multiplicity of individuals on whom a task or a particular form of behaviour must be imposed” (1977 [1975]: 205). Yet Cameron knew that his medical team had long been aware of his marijuana use, and that they were screening him for drug use with every lab draw. He continued smoking marijuana not so much as an act of resistance, but because he felt it enabled him to maintain another bodily technique (his exercise regimen) which also maintained his health. It seemed appropriate within the larger picture of Cameron’s lived experience of finding ways to deal with his renal decline. He did not, in fact, internalize and adopt the requisite drug-free behavior until the stakes changed unexpectedly and he found himself fully and squarely in the world of transplant, where policies regarding organ allocation required that he fall in line with expectations before he could be granted access to the procedure.

It is important to note that, from the perspective of clinicians, the purpose of pre-transplant requirements is not to curtail access to transplantation, but rather to ensure that patients are fully informed, consenting individuals⁵ who will not only be good stewards of a scarce resource (transplanted organs) but also are as likely as possible to benefit from a risky procedure. One physician explained that the “Selection Conferences,” in which the transplant team as a group makes decisions about individual patients’ readiness or not for placement on a waiting list, would be more aptly called “Safety Conferences.” If the team decides a person is not a good candidate for a transplant, it usually is because, in the transplant team’s collective opinion, the patient would be likely to live longer *without* a

⁵ The notion of “informed consent” deserves its own sustained analysis, but is beyond the purview of this dissertation.

transplant. Yet patients often do not or cannot accept all medical injunctions exactly as they are given, and the process of creating ideal conditions for a transplant can be subject to the widely varying daily realities and perspectives of patients and those close to them. Thus, when clinicians present patients with biomedical ideals that do not readily map onto context-specific daily realities, it can place patients and those close to them in situations in which they must decide whether and how to adhere to the regimen prescribed by clinicians, in the face of contradictory values that hold sway in other domains of daily life.

To wit, beyond the physiology of preparing the body to undergo surgery, accept the grafted organ(s), and to avoid infections or future rejection episodes, the creation of the ideal bodily environment for a transplant relies upon social practices within multiple, interrelated contexts. To model this, the remainder of this chapter will draw on the notion of “the house,” not only as a meaningful physical structure in which pre-transplant preparations take place, but also as a conceptual tool. This section, then, situates pre-transplant bodily preparations within the context of home life and the efforts of those seeking a transplant to create an orderly “home” (in several senses of the term) that is ready to “house” a transplanted organ that, it is hoped, will enjoy an indefinite stay.

Connections between bodies and houses have been described, for example by Bourdieu, who observed interlinkages between an embodied system of dispositions (the habitus) and the objectified, material spaces of the house (such as the Kabyle house) (Bourdieu 1977 [1972]: 82-95). (Also see the preceding discussion of Mauss (1979 [1935]).) This chapter likewise will aim to offer a glimpse into some of the ways in which bodies and houses can be intertwined, with real-world implications for persons suffering from serious illness, as well as those closest to them. It is true that the process of preparing for a transplant in many respects takes place in clinical and bureaucratic arenas where the actual medical evaluations and other screening procedures are carried out. But just as importantly, the process also takes place largely in the home and among kin, where the expectations and flow of daily life outside the clinic do not always mesh well with clinical values, norms and requirements. In other words, the various “houses” of transplantation are not always in harmony.

The House

Pointing to what he called the “*chronotope*, (literally ‘time space’)” Bakhtin (1981:84) informs us that, in 19th century fictional works, houses often were used to incorporate time with space in the structure of a narrative. Similarly relying on movement through various “houses,” the structure of this section of the chapter offers one way to connect the separate but related spaces of transplantation with a sense of transition over time, on the journey toward a transplant. Since this chapter directly concerns the transformations of persons into “good candidates for transplantation,” it also is at one level a documentation of a type of rite of passage. Thus, it also takes cues from van Gennep (1960 [1909]:188), who highlighted the significance of houses in “the passage from one social and magico-religious position to another.” Specifically, van Gennep described rites of passage not only in symbolic terms, but in spatial terms, too, pointing, for example, to the rites associated with moving from house to house or from one part of a house to another.

The house-centered orientation of this chapter also is inspired by kinship literature about houses that grew out of some of Claude Lévi-Strauss’ (1982, 1987) later writings on house societies. Focusing on diverse contexts that were widely separated by time and place, in which houses were pivotal in social organization, and drawing upon comparisons between European and Kwakiutl houses (1982), and later on houses in Indonesian, Papua New Guinean, African, and other societies (1987), Lévi-Strauss found in houses the capacity to incorporate different elements of social life that otherwise seemed to be contradictory and incompatible. For instance, drawing upon data from Boas, Lévi-Strauss uses the example of the Kwakiutl house (while making comparisons to houses in Medieval Europe) to argue that, “In societies with ‘houses,’ and as opposed to what anthropologists observe elsewhere, the principles of exogamy and endogamy are not mutually exclusive...As was seen in connection with the Kwakiutl, the exogamous marriage is used to capture titles, the endogamous marriage is used to prevent their leaving the house once they have been acquired”⁶ (1982:183). And further, Lévi-Strauss

⁶ “Exogamy” is marriage outside of one’s own social group and “endogamy” is marriage within one’s own social group. At the time of Lévi-Strauss’ writing this, the anthropological study of kinship focused

observed, both among the Kwakiutl and medieval European societies, descent was considered patrilineal (lines of relation by descent flowed through men, not women), and yet a grandson could become the heir of his maternal grandfather (reminiscent of matrilineal descent). And so, “the father, as wife-taker, sees in his son a privileged member of his lineage, just as the maternal grandfather, as wife-giver, sees in his grandson a full member of his own. It is at the intersection of these antithetical perspectives that the house is situated, and perhaps is formed” (1982:186). Thus, Lévi-Strauss argues:

On all levels of social life, from the family to the state, the house is therefore an institutional creation that permits compounding forces which, everywhere else, seem only destined to mutual exclusion because of their contradictory bends. Patrilineal descent and matrilineal descent, filiation and residence, hypergamy and hypogamy, close marriage and distant marriage, heredity and election: all these notions, which usually allow anthropologists to distinguish the various known types of society, are reunited in the house, as if, in the last analysis the spirit (in the eighteenth-century sense) of this institution expressed an effort to transcend, in all spheres of collective life, theoretically incompatible principles. By putting, so to speak, ‘two in one,’ the house accomplishes a sort of inside-out topological reversal, it replaces an internal duality with an external unity. (1982:184).

Lévi-Strauss’ writings on the house, however, were relatively scant, and his assertions have been critiqued by others, for example, for relying heavily on too narrow a definition of “houses” and “house societies” (see Carsten and Hugh-Jones 1995; Gillespie 2000b). Yet, rather than being dismissed, Lévi-Strauss’ seminal work on houses has remained a useful analytical focus for scholars seeking to go beyond static conceptualizations of kinship. Some of his ideas have been revised and re-worked, for example, by Carsten and Hugh-Jones (1995), who call for a broadened understanding of the house, arguing that it is a spatial locus of social identity and interaction as much as it is a product of the daily mundane practices of the people who live in and around it over time. Drawing from her time spent living in a house with a Malay family in Pulau Langkawi, Carsten notes that houses in Langkawi (and, by extension, homes) are capable of revealing not only the harmony, but also the tension, conflict, contradictions, and

heavily on categorizing societies according to their kinship practices and delineations, with exogamous groups being considered typologically different than endogamous groups.

changes that inhere in the social relations that are enacted within it (1995:124, 127-128). Elsewhere, Carsten provides a perspective that differs from the “oppositions” and their resolution in houses about which Lévi-Strauss had written, and finds in her own work that “opposing principles” are actually fluid, malleable, and transformable in Langkawi houses (Carsten 1995a:127-128). She also (1995b:224, 236-237, and throughout) suggests that it makes no sense to separate blood, food, kinship, and personhood into biological and social categories. Likewise, Gillespie notes that “a house-centered approach demonstrates the impossibility of maintaining traditional taxonomic distinctions” (2000b:42).

Though he does not cite Lévi-Strauss’ writings on houses and house societies, Beidelman’s discussions of the house as a form of “moral space” likewise offer useful insights. From his work among the Kaguru of Eastern Africa, Beidelman (1986: 49) found that, “Kaguru, like people in all societies, order space into different spheres which convey a moral focus for acts and things associated with them.” Further, he argues that houses offer a framework for understanding complex and ambiguous processes (such as sexual reproduction and nurturance) that bring together material culture, biology, and morality:

Houses and settlements provide stages on which Kaguru assert basic ideas and values about themselves and their society. The house provides a useful point of departure for considering the implications of relations between persons and things, those relations that constitute the supposed trivia of everyday life. The deepest forms of Kaguru moral metaphor are embedded in such quotidian affairs. (Beidelman 1986: 65)

Lévi-Strauss intuited that houses, in many respects, were themselves moral persons. In a re-examination of the work of Alfred Kroeber and Robert Spott, Kroeber’s indigenous collaborator, on the Yurok of California, Lévi-Strauss observed that houses were not only the key institutions that supported Yurok society, but also were subjects, jural entities, “each bearing a descriptive name inspired by the location, the topography of the area, the decoration of the façade, the ceremonial function—the name from which is derived that of the one or several owners,” (1982:172-173). From Kroeber and Spott’s accounts, Lévi-Strauss retells the story of the negotiations between two houses when a girl decided to return, with her daughter, to her native town some time after her husband

had died. In this story, though the girl's people returned to her former husband's house all of the bride payment that had been made for her, the husband's house would only accept part of the payment; if they had accepted the full payment return, the widow's daughter would have been unpaid for as if she had no father (the fact that some of the bride payment was left unreturned maintained the daughter's relatedness to her father's house) (Lévi-Strauss 1982:173). Lévi-Strauss points out that, "In this case...it is not the individuals or the families that act, it is the houses, which are the only subjects of rights and duties" (Lévi-Strauss 1982:173).⁷ That is not to say that houses, in the way we are using the concept here, are ascribed personhood or hold the exact same meanings, rights, and obligations as those in, say, early twentieth-century Yurok society. But this does orient us toward the ways in which the various houses I will describe below and throughout this dissertation also can "act" in many ways as social agents that can bestow rights and demand obligations of the inhabitants, and whose architectural, geographical and topographical attributes, spatial layout, objects within (from furniture and "knickknacks" to pictures and wall hangings) are interwoven with all aspects of people's daily lives.

Houses themselves can offer a glimpse into some of the symbolic, material, and practical ways in which persons negotiate the inconsistencies and contradictions in social life—especially in contexts that are marked by significant social change and upheaval. They also can help to frame our understandings of how various social entities (sometimes appearing at once as physical structures and as malleable, subjective, moral person-like conglomerates) can organize social processes. By conceptualizing the various realms of pre-transplant preparations as "houses" (the house of the clinic, the bodily house, the domestic house, and the financial house), then, the aim is to better understand how multiple, sometimes seemingly incompatible domains – clinical, private, bodily, and others – interconnect throughout the transplant enterprise and correspond with persons' experiences of the journey to transplantation. In the end, our focus will shift more toward

⁷ In this story, though the girl's people returned to her former husband's house all of the bride payment that had been made for her, the husband's house would only accept part of the payment; if they had accepted the full payment return, the widow's daughter would have been unpaid for as if she had no father (the fact that some of the bride payment was left unreturned maintained the daughter's relatedness to her father's house) (Lévi-Strauss 1982:173).

the moral social relations of patients and caregivers as being key to the integration of all of these houses.

The Clinical House

One of the major interfaces between home and medical arenas, where transplant clinicians work to get a sense of how well-suited a patient may or may not be for transplant, is the outpatient clinic at the Transplant Center. On renal and pancreas transplant clinic days, patients and any accompanying family members, friends, or other significant others typically arrive at the front desk around 8:30 a.m. From there, they are led to one of eight exam rooms which line a series of hallways forming three sides of a square. Shortly after entering the exam room, and often with little more time than it takes to sling a jacket over the back of a chair and set down a purse or notebook, patients and loved ones begin a marathon of back-to-back appointments with nurse transplant coordinators, social workers, nephrologists, psychologists, surgeons, dieticians, and financial counselors. Patients usually remain in their street clothes (rather than being asked to put on a gown), and except for certain evaluations, tend to remain sitting in one of the few chairs lining the room, rather than on the examination table.

By the time patients arrive at the Transplant Clinic on any given morning, however, they likely have donned gowns and sat on exam tables several times before, and already have begun to navigate a route toward transplantation. Most patients will have had an ongoing relationship with one or more doctors, given the fact that many had long been dealing with chronic health problems prior to beginning the actual transplant process. It is the patient's regular doctor who refers them for evaluation by the transplant team. As one patient put it, *"we knew through going to my doctor and all, that I was losing the use of the kidneys. Every time I went, we would get a different reading of how much I had left, and the nephrologist recommended, because of how much I had left, the percentage of kidney use I had left, he wanted me to get on the transplant list."* There were some cases in which a sudden acute medical episode or traumatic event caused a person to go from having few or no health issues to needing a transplant. This was the case for Mary, for whom a series of medical errors, during what had been expected to be

an uneventful surgical procedure at another institution, led her to need a multi-organ transplant (her story will be told more fully in other parts of this dissertation). Another patient, too, suddenly needed a small bowel transplant following the internal injuries he sustained in a serious motorcycle crash, and was too ill to take a very active role in preparing for or otherwise discussing and weighing the pro's and con's of the emotional, social, and logistical aspects of undergoing the procedure. On the whole, though, whether the time period is extended or abbreviated, those who pursue a transplant find that they must accomplish several levels of preparation simultaneously in order to be as ready as possible (and to outwardly demonstrate that they indeed are ready) to receive this type of medical intervention. In other words, patients and their loved ones must simultaneously keep several houses (both literally and metaphorically) before and throughout their transplant experience.

While I did talk with and get to know patients who were seeking or had already received more medically intensive types of transplant (such as small bowel, liver, and heart), by sheer numbers, kidney transplant patients and caregivers comprised the largest portion of my sample. Depending upon one's relative perspective, this group had the unique good fortune (or disappointing caveat) that they could live on dialysis for months, even years, while waiting for a kidney transplant.

In Mr. S's last appointment of the morning, his transplant nurse coordinator explained how the kidney waiting list works. "If a kidney becomes available, we will call you first to find out if you are healthy or not." She went on to explain that, if he was fighting a bad cold, for example, that wouldn't be the best time to get a transplant. Patients who are waiting for a heart, liver or lung have to be at their sickest before they get called for a transplant, because at that point, nothing else medically can be done for them. But with kidneys, the nurse coordinator explained, it's different. If a patient gets too sick, at some point they might be taken off the waiting list until they are well again.

For those who knew that their kidney function was declining or was likely to cease (e.g., those who knew they had polycystic kidney disease⁸, or those whose diabetes was causing damage to the kidneys), the ideal would be to have everything in order, including a living donor if one was available, in time to have a transplant before one ever had to go on dialysis. This ideal does not always play out in reality, however (as Maynard (2006) likewise has noted in his work on the pre-transplant considerations and dilemmas among cystic fibrosis patients regarding a prospective lung transplant), and the following offers one example in which the “clinical house” as it interacts with the bodily house, can create uncertainty, disruption, and suffering.

Clinical Disruptions Create Shaky Foundations: *“It Could Be Six Months From Now; It Could Be Ten Years...”*

In the case of Cameron (introduced earlier in this chapter), although the preparation for transplant had been long, his complete loss of kidney function was actually very sudden, and caught him off guard. As we shall see, the new interplay of clinical certainties and uncertainties about his bodily house shook the very foundations upon which he was building his life from a young age, and created a great deal of suffering for him. The timing of his transplant had been an unknown for Cameron since he was twelve years old. When he was just entering junior high school, Cameron had to take a sports physical in order to play football and basketball. The routine urine test detected excess protein, and Cameron was sent to a nephrologist, who ordered a kidney biopsy and eventually diagnosed him with a form of nephropathy: Cameron’s immune system was attacking his kidneys. This knowledge placed the young man in a position of needing to consider existential questions that typically are beyond the maturity level and scope of a twelve-year-old. By the time I met him, Cameron had grown very tired of not knowing his fate, and looked to the transplant as a way to put uncertainties behind him, start a new chapter, and begin again to build a new life.

⁸ Polycystic kidney disease (PKD) is an inherited genetic condition which can cause numerous large cysts to grow in the kidneys, enlarging them and changing their structure and often limiting or altogether ceasing their ability to function and filter wastes from the body (NKUDIC 2011).

Cameron: And then right from the start, when I was young and I found out about the disease, it was like my whole mindset changed. From then on, it was no longer about being young and worrying about kid problems and kid stuff. Automatically, I was thinking about just the bigger picture. I was thinking about things completely beyond a 12 year old. I was worried about dying and finding love and starting a family and yeah, it just completely changed the way I thought about life [...] From a young age, I was just worried about how I was gonna live and how I was gonna deal with this kidney disease... I mean at the beginning they thought it could be a year from now when you need a transplant. It could be two years. Luckily it lasted 10 years. So I was fortunate to not need a transplant for a long time, which was unpredictable, so...

Laura: So even at that time, they told you someday you're going to need a transplant.

Cameron: Yeah, they said it could be six months from now, it could be ten years or eight years, ten years from now. And we just never knew, so it was kind of play it by ear and hope for the best. Yeah, I was fortunate to live for 10 years with the disease before I needed a transplant. And so I had 10 years to kind of mentally prepare for it, so when the time finally came, I was ready. I'm just, I'm ready now. It's something I want to get over and get past, just start a new chapter in my life 'cause I've been kind of, I've been waiting for this transplant since I was 12.

I asked Cameron how he came to know that his kidneys were actually failing and that his transplant would be imminent, and he noted that he hadn't noticed any symptoms that he could pinpoint, other than that he had begun to get a bit weak. This happened about six months before his doctors informed him that his kidneys had ceased to function at all. Cameron had long kept himself on a rigorous exercise regimen, as a way of keeping himself healthy and in an effort to help keep his kidneys functioning as long as possible. He combated his new level of fatigue with increasing his exercise. As he put it,

I'd wake up in the morning, the first thing I'd do was jog a couple miles. And then, I would just exercise to kind of give me strength. And you know, just give me endurance to make it through the day. And that lasted for probably a good five or six months and I was starting to feel pretty good actually. I went on vacation and when I came back I had a doctor visit. They did lab work to test, see where my kidneys were at, and that week

after the doctor visit..., I knew something was wrong, I couldn't put my finger on it but I just felt like, like I was dying, actually. Just,... I felt weak and um, not sick but, I just felt like something was wrong. [It's]hard to explain. But I got a call from the doctor and he said, 'Uh, your kidneys are gone. They're all the way gone. You gotta start dialysis tomorrow, and we gotta put the catheter in tomorrow. It's...an emergency, we can't wait anymore.' So it was just out of the blue when that hit me, because he had always told me, 'We want to avoid dialysis at all costs. We want to time it so that, you know, we want you to keep your kidneys for as long as possible. But we also want to have the transplant before you need dialysis.' So there is this kind of a balance of where they wanted it to happen. And we just, it happened too fast. We weren't able to catch it in time. So I had to start dialysis.

Preparing The Bodily House: Dialysis as Transitional Housing

For Cameron and many patients with renal failure, the process of actively seeking a transplant also coincided with the commencement of a dialysis regimen. If, like Cameron, a person has known for some time that a transplant could very well be in their future, dialysis – even more than the transplant surgery itself – might be likened to the most dangerous, liminal state of a rite of passage, the aim of which is to arrive eventually into post-transplant life.⁹ Still, dialysis is very much considered a transitional, non-permanent state in which persons must undergo various forms of bodily and behavioral remodeling in order to survive until a kidney transplant becomes available. As many patients whom I met pointed out, dialysis actually had the potential to be filled with peril and risk. Thus, I point to it here as a sort of transitional structure, a “house” in which persons seeking a transplant would rather not dwell for any lengthy period of time.

I pause here to note that, because of the very nature of the guiding questions of this research and the study design itself, I spoke with persons who *had* decided to pursue a transplant. But not all persons on dialysis take this route, and scholars have pointed to a number of factors that likely come into play among persons who do not choose to seek

⁹ At the same time, the very open-ended and uncertain nature of post-transplant life itself limits somewhat the applicability of the rite of passage comparison, since, despite the hopes and promises of transplantation heavily popularized in the U.S. public imagination, one can never truly escape a state of liminality.

out a transplant. Gordon (2001), for example, conducted a study which included persons who chose not to seek out transplant, and suggested that access to information about transplantation from members of one's social peers might influence patients' decisions about whether to pursue kidney transplantation or remain on dialysis. For example, due to the social nature of dialysis, patients who attend the same center get to know each other well, and when a patient returns to dialysis after unsuccessful transplantation, it can reinforce other dialysis patients' perceptions that the procedure does not work (Gordon 2001:983). However, Gordon (2001) argues convincingly that such decisions are complex and involve multiple, interrelated factors that can include, but also extend beyond racism. For example, ethnomedical beliefs about the integrity of the body, not wanting to get "cut on" for a transplant, concerns about taking many medications, beliefs about the nature of illness and healing (and about the unnaturalness of transplantation), ideas that one's own health is good and that dialysis is working well, and notions about the risks involved in transplantation all were found to play a role in many patients' decisions (Gordon 2001). Other scholars have focused on additional factors, including cumulative experiences of discrimination among disadvantaged populations (Klassen et al. 2002); racial and ethnic differences in social network characteristics that create disparities in access to information about transplantation (Arthur 2004); and disparities in dissemination of information, encouragement, and emotional support from clinicians regarding transplantation as a treatment option (Wolfe 2003).

Emily's Golden Arm

But among those who *do* pursue kidney transplantation, dialysis, too, often becomes a significant part of their journey (and one which they may revisit again if their grafted organ ever ceases to function). If a patient opts for hemodialysis (as opposed to peritoneal dialysis, which will be described later in this chapter), one of the preparations he or she must make is to have a surgery in order to create an access point under the skin, usually in the arm (the thigh is another potential access point site). This will become the site into which two large (12-gauge) needles will be inserted each time the patient goes for a dialysis appointment, allowing blood to flow out of the body through one needle, then pumped through a machine where the blood is cleansed of toxins and extra fluid by a

dialyzer (a function which the diseased kidneys are no longer able to perform), and then back into the body through the second needle. An access site usually is created through the surgical attachment of an artery to a vein (this is called a fistula), but also can be created by inserting a soft tube (called a graft) to link an artery on one end, to a vein on the other.

Emily, who is in her early thirties, is of Mexican American descent, and had a toddler-aged daughter at the time we first met, told me of the time she was diagnosed with kidney failure and was asked to begin thinking about her arm in a new way, as a structural portal for dialysis that must be protected and preserved.

[The doctor] came into the hospital room, and I knew that it was bad, because he basically told me....he came and he looked at my arms, and he's like, 'Which arm do you use?' and I go, 'My right one'. And so he looked at my left one and he was like, 'Okay, from now on, this is your golden arm. You're not going to let anything happen to it. You're going to take good care of it now; be sure that nobody sticks anything [into it]. You can't have your blood pressure taken on it. Nothing like that.' And that's when I found out that he was going to put the access there. So he said, 'Treat this arm like gold. Don't lay on it. Don't do any heavy lifting with it...'

The arm at which an access is created becomes a person's "golden arm" because there are a limited number of places on the human body which are suitable for creating an access. If one site is "lost" to infection, or the fistula or graft becomes damaged due to trauma of some sort (this can occur even through the improper placement of dialysis needles), then another access must be created. Emily's kidney failure had been so severe by the time she was given a diagnosis that she had to begin dialysis using a temporary access through a port which had been placed under her skin and connected to a large vein in her chest. When a port like this is used, it is meant to be a temporary access, to be used only until the graft or fistula has healed. It is a smaller opening for blood to flow through and therefore the effectiveness of dialysis can be reduced (less blood flows through the machine and therefore it is cleansed less thoroughly). Further, as Emily pointed out to me, it leaves a person quite vulnerable to infection, and great care has to be

taken to keep the area clean and dry. But Emily's experiences proved to be complicated, and she needed to keep her port, even after she'd had an access site placed in her arm:

Emily: *They [the dialysis technicians] were having the hardest time trying to access my arm so that they could use it for dialysis. They were having to use my port for the longest time, and it was starting to get to be to, 'When am I ever going to get...?' My whole summer came and went and I didn't ever get to go swimming because of this and I didn't get to take my daughter, for that matter, to the swimming pool either because of that.*

Laura: *Because you have to keep water away from it?*

Emily: *Right, I can't submerge, because this [moving her shirt collar and pointing to the tubing at her port site] leads to my heart. So any infection could be really deadly. So you know, I have to restrict all kinds of activities that I've [wanted] to do this summer.*

For those seeking a kidney transplant, dialysis itself can feel like a roadblock – temporary housing that is difficult to move out of – on a journey which most patients hope to make in a unidirectional and timely manner. While many patients in this study viewed dialysis merely as an inconvenience, a number of them also experienced very serious health problems related to it. Emily had pointed out the constant threat that her port posed to her health, and was frustrated that her dialysis needs continued to include use of this dangerous passageway. Cameron, too, found himself facing life-threatening complications associated with his dialysis. These complications involved his heart, which was particularly frustrating because he had worked so hard for so many years to maintain a healthy heart as a way of keeping his bodily house in the best shape possible.

“I didn't know I could die from dialysis...”

Cameron: *I've had to have heart surgery since dialysis. I've had a healthy heart my whole life, you know? It was caused from my catheter for dialysis. It formed a blood clot in my heart, so it's from complications from dialysis, which are common, I guess. And then I've also had four infections in my line that goes into my heart, so I've had to have it switched back and forth across my chest three times. I'm on my fourth one, I think, so it's, there's just been complications left and right since I started dialysis. And I wasn't ready for that. I didn't know I could die from dialysis. I have to watch my diet: If I drink too much milk or if I eat too much dairy product, there's just, there are certain things, if I*

eat too much of, it can stop my heart instantly. So there's lots, there is just a lot of tension and danger to the dialysis. That's kind of scary you know?

The Bodily House and Incommensurable Demands of Pre-Transplant Life

As Cameron indicates, persons on dialysis also must follow a special diet that is low in phosphorus (which can pull calcium from the bones) and even more importantly, low in potassium (which affects the heartbeat and can prove to be fatal at excessive amounts in the blood). Both of these minerals can accumulate to dangerous levels, not so much because of the dialysis itself but rather because the kidneys no longer remove these substances from the body, and dialysis does so only periodically. These substances are found in foods that usually are considered to be healthful, including many fruits and vegetables. The following is a list of foods that are high in potassium, as reported by the National Institutes of Health:

<u>High-Potassium Foods:</u>		
apricots	kiwi fruit	potatoes
avocados	lima beans	prune juice
bananas	melons	prunes
beets	milk	raisins
Brussels sprouts	nectarines	sardines
cantaloupe	orange juice	spinach
clams	oranges	tomatoes
dates	peanuts	winter squash
figs	pears (fresh)	yogurt

Figure 1: List of High-Potassium Foods. Source: "Eat Right to Feel Right on Hemodialysis," <http://kidney.niddk.nih.gov/Kudiseases/pubs/eatright/index.htm>

And some of the foods that are high in phosphorus likewise are often touted as key components of a healthy diet, and include milk and cheese, dried beans, peas, nuts, and peanut butter. (from "Eat Right to Feel Right on Hemodialysis" <http://kidney.niddk.nih.gov/Kudiseases/pubs/eatright/index.htm>)

Patients – especially those who also are diabetic – might previously have been coached to eat the very foods they now are supposed to avoid, especially fresh fruits and vegetables. Further, the social importance of food complicates the implementation of

these guidelines in a person's daily life. One patient, Mr. S., who had moved to the U.S. from Central America, underscored this point during his appointment with the transplant team's dietician. Answering the dietician's questions about his daily eating habits, he began by listing what he ate for a typical breakfast: "an egg white, a cup of decaf, toast and a couple of pieces of turkey bacon." He went on to describe his noon and evening meals, but then added that his diet varies when he is eating with his Central American relatives. The dietician replied, "You might have to just say, 'I have to watch my potassium,'" and Mr. S chuckled: "My family don't believe in doctors and medicine. They believe that food doesn't affect you in that way – they offer you remedies. They don't have nothing to lose but to take a plane here and chew my butt! If they offer you something, you *take* it and say 'Yes! I'll try that!'" The issue was dropped at this point, and the conversation moved on. No alternatives were discussed other than to break with his family's expectations and follow directly his dietary restrictions. Implicitly, the clinical assumption was that, the biological reality of certain foods being dangerous for patients in renal failure stood on its own, carrying more weight than the socio-cultural realities of kin obligations and sharing food. From there, it fell to Mr. S to figure out how to negotiate these two incommensurable perspectives.

Transplantation brings into focus additional incommensurables as well. For example, those pursuing kidney transplantation must commit to ensuring that their bodies become and remain an ideal environment for a grafted organ, and yet the longer the amount of time spent waiting for transplant, the greater the odds become that a patient will experience declining health related to their renal failure. As Cameron explained, this is no small matter, as his health is related to everything else he experiences on a day-to-day basis.

Cameron: I wasn't sure if I could make it six months, the way things were going, the way I was in and out of the hospital. It's just been a bit frightening that there are more complications, when it started with just kidney problems. And now there's heart problems and all of my other organs are under stress from the dialysis and I feel, I just feel much worse than I used to. I'm used to being confident and just feeling good physically. So to go from that to the way I feel now is just depressing mainly, but it also, it affects just how I...everything starts with my health. If I feel good then I can do other

things and just, it flows into everything else, the way I feel emotionally and how I view life and just how I approach my day. You know, it just starts with feeling good, health-wise.

Transplant Screenings as Bodily “Home” Improvement?

Over the course of my fieldwork, I often would get in touch with the patients and family members whom I’d previously met, sometimes to schedule or confirm a follow-up interview and at other times just to re-connect and stay in contact with those who had invited me to do so. Patients who previously had been “certain” that they very soon would be waitlisted often expressed to me their disappointment that they recently had been told by a member of the transplant team (usually it was the Nurse Coordinator who would relay the information) that the results of a lab test necessitated their return to the transplant center for follow-up testing or for a procedure.

If we extend the likening of pre-transplant preparations to getting the bodily house in order, such preparations might be compared to a remodeling project in which the homeowner has very little input into the design or work plan. Patients are considered to be responsible for following through with medical orders, and coordinating whatever procedures are prescribed. But much like a U.S. homeowner who must undergo an overhaul in their housing structure in order to comply with local ordinances, transplant patients have very little control over the “codes” to which they must adhere. Cameron, for example, was particularly dismayed at the degree to which things were “out of his hands” during his pre-transplant time:

You know, just there’s not so much I can do. A lot of this is out of my hands now. As far as the dialysis and the health stuff. And that’s hard too because there’s nothing I can do right now. Once I get my transplant, I can take my pills every day and there’s stuff I can do to help out my health and to help out my body and my kidneys. But right now most of it’s out of my hands. That’s another hard thing to accept. [...] It’s like, you know you’re going to need a transplant someday. And there’s so many things that you can’t really do to affect your health. There’s genetics or you have health problems and the only things you can really do is exercise and eat right. And so that’s what I did as much as I could,

and now it's like even that, even that's not good enough now. So ... there's just not a lot you can do, except just keep faith and hope for the best.

One common requirement was to have a thorough dental exam and ensure that any necessary dental work was completed before a patient could join the transplant waiting list. This is because any untreated dental problems could be a potential source of infections, to which patients would become especially prone in the days and weeks immediately following their transplant, when they would be on especially high doses of immunosuppressant drug therapies. It happened more than once that a participant needed to reschedule a time we had planned to meet because he or she was still in pain from having a tooth pulled, having a root canal, or having other major dental work performed.

During one of several conversations Emily and I had, for example, she described to me some of the preparations she'd had to make over the past months in order to be added to the waiting lists for both a kidney and a pancreas transplant. At the time of this particular conversation, she was fairly certain that she'd completed the final requirement set by the transplant team, which was to have six teeth removed (all toward the back of her mouth). The bottom teeth were broken and Emily had been told they needed to be pulled out. She was unsure, but guessed that, because the bottom teeth were gone, they had needed to remove the top teeth as well. Emily's main intention was to take care of what she needed to do, and she was less concerned about the reasoning behind the requirements. Regarding her teeth, she said, "It doesn't make sense to me, but I guess that's what they [have to do]... I'm like, whatever! I just want to get on with it."

Additionally, patients very often disliked the aesthetics of the structural changes they were required to undergo. Like a person given the choice of only two or three unpopular colors available for their home's exterior, Emily, who often dressed in youthful and trendy clothing also had to resign herself to the fact that she would need to begin wearing orthopedic shoes designed especially for preventing and treating pressure sores and ulcers that she had begun experiencing as a result of complications from her diabetes. During one conversation, she shook her head as she described the "diabetic shoes" for which she'd had to be specially fitted by a podiatrist, lamenting the fact that

the shoes were available in only the blandest of styles, and her color choices were limited to black, white, brown, or beige.

Other requirements were for more intensive procedures. For example, when I spoke with Mrs. S. several weeks after I'd first met her and her husband, she told me that Mr. S. had recently been back to the hospital for a series of tests to see if he would need to have stents put in place to open up any blockages to his heart. In fact, it was common for patients to be asked to undergo a cardiac catheterization procedure, in which a very thin tube is inserted into a major blood vessel through an intravenous access point (usually in the person's groin, arm, or neck), and threaded into the heart. Using this procedure, the physical condition of a patient's heart can be assessed and, depending upon the presence and extent of heart disease, the need for treatments or interventions can be determined. These can be as non-invasive as pharmaceutical therapies, or as invasive as surgical interventions, for example, to open up or bypass blocked coronary arteries. Or, if a patient's heart likely could not withstand a transplant surgery, this can be detected as well.

There were a few instances in which patients directly attributed an improvement in their overall health to the pre-transplant testing they'd been required to undergo. Bernard and Arlene, the older African American couple (he in his late sixties and she in her early seventies) from the West Coast region of the U.S. who were introduced in Chapter 1, offered one example of this. After their first trip to the Transplant Center, they had been sent home with instructions to get treatment for a vascular problem, of which Bernard had not previously been aware, and which had been detected during his pre-transplant evaluation process. But far from being disgruntled at having to endure a delay in moving forward with the transplant process (and being required to make yet another long trip before he could hope to qualify for a transplant), Bernard felt appreciative and remarked that, even before he actually had a transplant, his health had been improved through the process. He explained:

See here's the thing: I had these problems and if I was still here [in my home state] waiting to be evaluated for the transplant list I'd have these problems that are still building up and they're still working on me. Basically I got to [the Transplant Center], I'm healthier now because of what I found through the evaluation! [...] And so basically

my vascularic is in great shape now. Whatever was bothering me before is no longer there.

The Domestic House

Because most kidney transplant candidates and recipients actually spend the majority of their pre-transplant waiting time and post-transplant recovery outside of the hospital setting, preparations of the bodily home take place primarily in the context of everyday home life and among kin. Home life, then, can affect one's ability to comply with medical requirements, and the state of the home has the potential literally to translate into a clinical recognition of the body's preparedness to house a gift of life. We turn our focus now to an exploration of the domestic home, as a site for the intermingling of clinical realities (the clinical house) with daily life, so that the clinic becomes a sort of houseguest, and as a site where the adoption of prescribed body techniques occurs.

Home Peritoneal Dialysis: The Clinic as a Demanding Houseguest

While many patients in need of dialysis go to a hemodialysis center several times a week, there are other options available to patients whose kidneys do not function. Bernard, for example (introduced earlier) had opted to use a home peritoneal dialysis system. As we shall see, while this form of home-based dialysis comes with its advantages, it also necessitates a major commitment to creating and maintaining a very clinical space in the home environment, so that, in a sense, the clinic becomes transposed into the domestic house.

Home peritoneal dialysis uses the peritoneal membrane – that is, the membrane tissue that lines the abdominal cavity which includes the stomach, liver, and intestines – to act as the filtering agent. Before one can begin this form of dialysis, a catheter must be inserted via an outpatient surgery (it often is placed somewhere near the navel) and given time to heal. Then, once a person has healed and is ready to begin, a solution of salts and glucose called dialysate is transferred into the abdominal cavity by this catheter. Wastes and extra fluid continuously filter through the peritoneal membrane into the solution, and then periodically the solution which now contains the wastes and fluids is removed from

the abdominal cavity via the same catheter. No blood leaves the body during this procedure. There are two types of peritoneal dialysis: continuous ambulatory peritoneal dialysis (CAPD) and automated peritoneal dialysis (APD). CAPD cleans the blood continuously because the patient keeps the dialysate fluid in their peritoneal cavity at all times, typically exchanging used fluid with new fluid four times a day, by connecting the catheter to a solution bag and tubing. Those who use APD (also called Continuous Cycling Peritoneal Dialysis, or CCPD) typically leave dialysate fluid in their abdominal cavity during the day, and then use a cycler machine to perform their exchanges while they sleep at night. (See, e.g., “Dialysis” on the National Kidney Foundation website, <http://www.kidney.org/atoz/content/dialysisinfo.cfm>.)

In order to do home peritoneal dialysis using either system, a person has to have enough storage space in their home to keep several boxes of the salts-and-glucose dialysate solution on hand at any given time. They also have to be able to maintain a meticulously sanitary environment in the spaces where they plan to access their catheter and connect it to the tubing in order to perform their exchanges. Further, they have to harbor constant vigilance against infection at the bodily access site. There also is a risk associated with peritoneal dialysis of developing peritonitis, an infection of the peritoneal membrane itself.

While managing the requirements of dialysis can be a difficult, time-intensive and labor-intensive feat for both patients and their loved ones, it might be thought of as both a literal and metaphoric form of training for the demands of post-transplant life. Depending upon where a person’s experiences might fall on the spectrum of how well or not one can tolerate dialysis (for example, whether or not a patient feels exhaustion, cramping, and/or nausea during or after dialysis, or whether a patient has easy access to transportation and/or logistical support for the dialysis regimen), or how much the demands of a dialysis regimen ripple out to those in supportive, caregiver roles, post-transplant life might seem more or less difficult, as compared to dialysis.

The following excerpts from an interview with Arlene and Bernard lend insight into the daily personal experiences that can accompany peritoneal dialysis using the Automated Peritoneal Dialysis System. We had begun to discuss some of the ways in which a transplant might change each of their lives:

Bernard: *Oh, [it will be] greatly improved. For one thing, I do dialysis every day. Every evening, I hook up to a machine. So it would change our lives quite a bit. We'd be able to travel more... I'd be able to do more things that I'm kind of restricted at this point. So it would really, greatly improve our lives.*

Before Bernard began needing to use dialysis, the couple – enjoying being in their sixties and seventies – had grown accustomed to a vibrant social schedule. But Bernard's dialysis schedule now makes it difficult to participate. It is notable that the reasons they cite have less to do with inconveniences to themselves, and more to do with inconveniences to their friends: “We have to back out of things because we can't do it and there's no way we'll go and ruin everyone else's fun because of holding back or whatever,” explained Arlene. Because Bernard has to be connected to a machine for 10 hours every night, it is important that he begin early enough in the evening because, Bernard said, “If I don't hook up by a certain time, then it's going to carry me over in the morning and I'm gonna be late getting up.” Thus, when they do entertain friends or family, Arlene noted, “We have to kick everyone out early enough to where he's not connecting at 12 midnight or 2 in the morning.”

Certainly in the case of Bernard and Arlene, a significant re-orientation to the spaces of the home and the meanings of those home spaces was required well before the transplant itself would become a reality. For example, the bedroom where Bernard performs his exchanges has become off-limits to anyone but him and his wife, because this space must be kept as sanitary as possible.

Bernard: *If people come in [while I am hooking up to my dialysis machine], they have to wear a mask. It has to be sanitary in a sense because I can't afford to end up with peritonitis.*

Arlene: *And the dialysis machine has been in our bedroom upstairs and that way, well, naturally very few people would even venture up the stairs and then we're always wiping stuff down with a bleach solution as we were told, just to keep germs [out], because now Bernard did get peritonitis one time and it was kind of horrifying to see how it got, it just took, the catheter had touched his own t-shirt and he got peritonitis--not my t-shirt or anything, just his own. So you can see how you've got to keep people away, and*

everybody coughing and sneezing, it's like, 'Back off, don't get too close to him.' So with some of the grandchildren we always tell them, 'If you've got the sniffles, don't go near Grandpa!'

Arlene said this last part with a chuckle, but her tone grew more serious as she described how the bedroom is not simply a place for them to sleep. The presence of the machine has turned the bedroom into a space where she feels she must monitor germs, the dialysis technology, and her husband's health status.

I don't know, it might be because I'm a light sleeper and the machine is not silent. Well, Bernard is closer to the machine than I am and he can sleep through anything and I'll hear the machine going and then I'm lying there listening, and it kind of makes it hard because it's interfering with my sleep. And what can I say? It's not anything he's doing. And if I go to another room to sleep, he'll never hear the machine when there's a problem because it's a very sophisticated machine and if something's not quite right it gives a signal. Well I've laid there sometimes listening to him not waking up and wondering, 'When is he gonna hear this machine?' So if I was in another room he wouldn't hear it and I don't know...I guess eventually it would work itself out...but that worries me. Because he would understand if I went and slept by myself but it's just not, I don't know. So the whole process is just very draining. And yet the idea of going to hemodialysis, you have to go 3 times a week, get up, get dressed, I think that's worse. Because when he first was on dialysis he had to do hemo for a bit and I had to take him and pick him up, and it was ugly. It just was not good. He's out of the house for 3 hours what, 3 times a week? What in the world can you ever plan to do? Nothing.

The couple also has had to refigure the use and meaning of their home because they now must devote notable amounts of space to storing the many boxes of solution Bernard has to use each week for his exchanges.

Arlene: I don't know if you're familiar with the amount of solution that goes with the home dialysis, but every month we get about 35 boxes and so I always say [to the delivery person] 'Leave them there.' But then we have to bring the boxes down and put them, you know, it's just a daily thing and it hogs up... Almost every room in the house is just

dedicated to some sort of medical something... When they bring the solution in they have to, see we're on the second and third level. They have to use an automatic dolly because they have to bring them up and then sometimes it's raining and the dolly is dripping oil. I just feel like it would be a blessing to not have to live with these boxes and to have our carpet look like it's clean again. And see, this is a 3 year thing; it's been about 3 years he's been on it. It can kind of get to you. [...] And of course the delivery people, they're very nice people, but as I say, boxes, boxes, boxes! It's a little problem but it becomes big after awhile.

The medical risks of dialysis (serious infections, risks to heart health, etc.) should not be discounted. But some of the reasons patients prefer a transplant over dialysis have much to do with the fact that dialysis can hinder the ability to go about life-as-usual. The complications of renal failure and dialysis can significantly hinder a person's ability to fulfill their social and kinship obligations to others, and in many ways, and under some circumstances, can create a kind of slow social death (Biehl 2005) over time. For persons like Bernard and Arlene, their changed uses and meanings of their home spaces (needing to be home by a certain time for dialysis at night; needing to curtail entertaining of guests for similar reasons; and occasionally needing to keep grandchildren and other potential sources of infection at a distance) are direct accomplices. In one instance, a participant and her husband told me that they had tried hard to make the most out of an otherwise bad situation. She had suffered terribly from the complications of renal failure, and had become physically very weak as her weeks on home peritoneal dialysis wore on. But the couple laughed as they described how the husband stacked the boxes of solution strategically in the bathroom so that the wife could use them as a ledge on which to lean as she sat down and got up off the toilet. Still, many patients and their caregivers are willing to put up with the challenges, inconveniences, and risks of dialysis only under the expectation that these undesirables will be temporary, though necessary, steps to take on a path toward transplantation.

Aligning the Home With Clinical Needs

From a medical standpoint, the physical home environment is of greater concern for some types of transplant than for others. One transplant social worker explained that

heart transplant candidates, for example, are more often required to make structural changes to their home environment than are kidney transplant candidates:

I ask things like, 'Are you doing any remodeling to your house? Like are you taking down any drywall? Does your house have mold or any of those kinds of things?' Kidney transplant doesn't ask those questions because [...] it doesn't seem to really impact if they have mold or if they have drywall dust or any of those kinds of things that do complicate heart transplant. It doesn't seem to impact kidney transplant, so there's a difference there. A person that has a heart transplant, they might be on a left ventricle assistive device where it requires a grounded outlet, like a 3 pronged outlet.... Well, some of these places, maybe the house was built in 1902. So then you have the issue of ok well they started out with, you know, oil lamps and then they switched from oil lamps to using electricity, and so it's like oh well they didn't have 3 pronged outlets when they put all this stuff in there. So naturally it's not 3 pronged. So we run into those issues when we're trying to ... get them to be a viable candidate [for transplant].

With kidney transplant, there also tend to be fewer long-term limitations, for example, with going up and down stairs. The potential need for intervention will depend on any other health concerns that the transplant candidate might have. A social worker might more closely assess a patient's physical home environment if they use a wheeled walker, or have hip problems, or if their mobility is otherwise limited because of diabetic neuropathy. In some of these cases, the social worker will try to problem-solve with the patient to see if something can be changed so that, for example, they can move their bedroom from the second to the first level of a home, or move from a third floor apartment to a first floor unit. "But most of the time," the social worker noted, it's just the garden variety, everything is fine, and we just move right along ... Kidney transplant, most of the time there aren't any issues going up and down the stairs."

Thus, the home environment can tend to be less of a concern for some types of transplant than for others. As we have seen, though, for patients and caregivers like Bernard and Arlene, the matter is more complex, even for those whose physical home layout would be relatively unimportant from a health care provider's perspective. For instance, a few months after I had first met Emily, she called me to ask if we could reschedule one of the follow-up conversations we had planned. They had discovered that

the apartment in which she and her daughter, mother, and brother all lived had a serious mold problem, and they would be moving that week into a new apartment because they were worried that the mold would pose a danger to her once she received a transplant and was on immunosuppressant medications. Other circumstances can also necessitate moving into an altogether different domestic home for the sake of transplantation, as we shall see below.

Solving the Distance Dilemma: Bringing the Home Closer to the Hospital

In the example of Bernard and Arlene above, the circumstances of home peritoneal dialysis as a part of pre-transplant preparation necessitated that the clinic be brought into the home. In other instances, especially among those seeking transplant procedures that were not available near their home locations, the reverse was also true: persons found themselves needing to bring their home closer to the clinic. Patients often come to the Transplant Center from other parts of the state, the region, and the nation. Clinical personnel also cited instances in which patients had come from across the globe to receive their care at the Transplant Center. Such long-distance travel for treatment appeared to be an outgrowth of two main factors: for some of the most specialized procedures, the Transplant Center was among very few places where such treatments were available; for other procedures (like kidney transplants), the Transplant Center had an exceptionally good reputation for quality of care, a shorter waiting time until transplant, and high transplant success rates (these were among the reasons cited by Bernard and Arlene, above). Cross-border travel for medical care has been documented by medical anthropologists in the case of transplantation (Scheper-Hughes 2002b:45), and for other medical procedures like IVF among Muslims in the Middle East (Inhorn 2003; Inhorn and Patrizio 2009, who propose the term “reproductive exile” in place of “medical tourism,” to better reflect the legal and other constraints under which persons travel in the search for access to reproductive care), and assisted reproductive technologies (ART’s) in Thailand and the Czech Republic (Whittaker and Spier 2010), as well as fetal cell transplants in China (Song 2010, preferring to use the term “biotech pilgrimage” to reflect the intersections of faith, meaning, and political economy in travel for access to bio-technologies). At the Transplant Center, patients and their loved ones

frequently had to make choices about where they would stay in Metrotown, often for an extended period of time, during the transplant and in the early days of recovery. In some cases, patients anticipating a very long waiting, treatment, and/or recovery time found it necessary (or at least their best option) to actually move themselves and their families to Metrotown.

Jane: "...on top of being sick..."

I first met Jane in a Transplant Center treatment clinic room, where patients would typically go for treatments and therapies associated with their transplant regimens. Jane was there on this particular day to get an infusion of medication, one of many procedures she would have to undergo prior to a blood-forming stem cell transplant for which her sister was to be her donor. Jane was in her forties, married, and a mother of three children: one just out of high school, one just beginning high school, and one in elementary school. Jane's husband's career had long been with the military, with Jane working primarily in the non-profit sector, in arts education. Jane had been diagnosed with leukemia, for which the most promising treatment biomedicine could offer would involve a stem cell transplant. During our interview, there were several instances in which a nurse or technician would come into the room in order to check one of the machines which was helping to administer the intravenous medication to Jane, or to check on Jane's status, or to collect some bit of information needed for documentation. This included periodically removing one of the multi-colored stickers lining a paper bracelet Jane had to wear during the procedure. Almost without prompting, Jane held her wrist out each time, so that the clinician could more easily find the appropriate sticker as needed. She later joked to me that she wasn't sure of their purpose, but in her extensive experience as a patient, most of the stickers tended to go unused. Instead, she told me, "most of them come off, like when you're sleeping, you find them on your blanket the next morning."

The stickers, of course, were among the less consequential aspects of her present life. A much more significant part of her daily life was the fact that until recently, Jane had been receiving her care in one state while her husband and children had been living in another state, several hours away if one traveled by car....

Jane: *We just moved down here [a few weeks ago]. [...] Moves are difficult anyway. You don't want to leave your friends, the kids don't want to leave their friends. Fortunately, the military packed us. So we had that to not worry about, although we had to sell a house. We had to find a place here to buy on top of that. There was a six-week separation when I was here in the hospital and my family was in [the northern U.S. state where we had been living]. And meanwhile we're trying to figure out how we're going to move down here. Once I got back to [the town where we had been living], I was there for a couple of weeks with the chemo treatment and then in the hospital for a week and then back down here. So the move was a challenge, but we just took it one day at a time. What else can you do? And you know, we're here. We still have boxes to unpack and that's just an ongoing process. And on top of being sick, having the kids worrying about their mom, moving, trying to get my husband's orders down here, it was a big, big challenge. But you just do it.*

Jane's explanation underscores the extent to which transplantation can impact not only individual patients, but their kin and family life as well. Jane and her family were willing and able to find a way to make the move happen. But for those who were less certain about the feasibility or desirability of a move to Metrotown, other solutions to the dilemma of distance had to be sought out. For instance, Bernard and Arlene lived in the West Coast region of the United States, and they were in the process of making decisions about how they might best prepare to quickly come to the Transplant Center when and if a transplantable and matching kidney became available. One option would be to charter a small airplane (this did not sound good to Arlene, who said she would be reluctant to fly such a distance in a small aircraft). Another option would be to work with one or more airline companies to arrange in advance a guarantee that the couple could board the first available flight should they get "the call" from the Transplant Center. The kidney transplant social worker at the Transplant Center had given them information about this option. Yet another possibility the couple was considering would entail carefully monitoring Bernard's status on the transplant waiting list, and then moving to a temporary residence near the Transplant Center when they thought that he might more likely be called within the coming months. But this would have been difficult, given the

actual uncertainty of the timing for when a matching cadaveric kidney might become available. As Bernard put it, “I’ll do whatever I need to do.” But neither he nor Arlene were certain what approach would be best, and they each indicated that they would defer to the transplant team for guidance regarding what should be done.

Trying to Keep The Financial House Intact

The financial aspects of transplantation (including the procedure itself, the necessary preparations associated with it, and the recovery process and post-transplant life) do not often make it into popular public imaginings of transplantation. One exception perhaps is recent news coverage of Arizona’s decision to end state Medicaid coverage for certain transplant procedures (Lacey 2010a,b). Even then, public dialogue centers much more on issues of payment for the transplant itself, with little mention of the other costs that even the best of insurance policies will not pay for. For example, each of Bernard and Arlene’s contingency plans (and Jane’s interstate move, for that matter) involved expenses that would not be covered by insurance. Though they reported feeling that they currently had enough income to meet their needs, Bernard and Arlene each expressed concern over the costs that would be associated with the logistics they were considering. Likely because they currently had adequate means, Arlene noted, *“We’ve given up on any financial aid. We didn’t think that would happen, but our first trip to Metroland, Bernard called the different kidney foundations and [...]unfortunately after [hurricane] Katrina they told him they’re sorry, they have no money, they have so many people that they’re taking care of. The ironic thing is, a short time afterwards, we started getting solicitations from them for a donation!”*

Thus, even for those who have an ability to pay (as determined by financial aid formulas designed to calculate “need”), the costs of transplantation are formidable and can portend a decline in socioeconomic positioning for those in the middle-class, and can spell disaster for the working poor. Insurance status itself also can play a major role in patients’ and their loved ones’ ability to weather the financial burdens of transplantation. In this way, several houses (clinical, bodily, domestic, and financial) are joined together in a way that can have various outcomes. In some instances, lack of ability to pay for

transplantation can be considered an exclusionary factor, and the entire structure can come crashing down for a patient and his loved ones. But if all goes well, and with a great deal of effort and good fortune, the seemingly insurmountable financial obstacles can be handled, albeit imperfectly, bit by bit. Financial counselors, like other key professionals on interdisciplinary transplant teams, are charged with both screening potential transplant patients *and* with advising them on how to become and remain viable candidates.

One of Mr. S's consultations during his transplant clinic evaluation day was with a pharmaceutical financial counselor, who presented him with a long list of medications, highlighted in blue, which he likely would be taking by the time he leaves the hospital after the inpatient portion of his post-transplant recovery. "Twenty *more*?" asked Mr. S after counting them up, and the counselor pointed out that, with the transplant, he no longer would be on some of the medications that he takes now. These are the standard medications that nearly everyone goes home on, she explained. Mr. S continued, asking, "Now comes one question, and I'm probably jumping the gun here, but I want to go back to work. Is the insurance company going to say they won't cover the meds because it's a pre-existing condition?" The financial counselor said he would need to check with his employer, and Mrs. S added, "But if the new company has over 500 people, they can't do pre-existing conditions, right?" Leaving it at that, the counselor continued on with instructions that his Medicare plan would cover only the medications that he will take for the rest of his life, and that some of these prescriptions will be for vitamins and supplements, which no insurance is likely to cover. For those medications that aren't covered by insurance, Mr. S could apply to medication assistance programs, and would likely qualify because of his financial status. I noticed that Mr. S began to look confused and worried, and his wife, likely noticing the same, turned to the counselor to say, "I do it – don't worry – I do the medicine," as if to indicate to both the counselor and her husband that she would be on top of all this, and it all would be taken care of. The counselor went on to tell the couple that they should start saving up now for two weeks worth of immunosuppressants, because it takes about two weeks to get everything set up with insurance. The couple likely will be billed for \$1,400 upon transplantation. The

counselor ended by assuring them that she would also meet with them again at the time of the transplant so they could review all of this information at that time.

The pharmaceutical transplant counselor dealt only with the matter of medications, which says a great deal about the central importance and formidable costs of immunosuppressants and other post-transplant medications. Later in their series of clinic appointments, however, the couple also met with the financial counselor who handles all other matters regarding the transplant. She was able to answer the couple's many questions about their eligibility for Medicaid in light of their current income. Notably, though Mr. S received disability income only, and Mrs. S received disability plus a small income through a part-time job under a program for disabled persons, the counselor pointed out that their income was above the cutoff point. They would only qualify for Medicaid via a "spend-down," in which they would be required to pay for medical care out-of-pocket until they reached a certain threshold, at which time the state would pick up the rest of their medical costs. Overall, it was clear from this consultation that, just as the medical team was there to advise Mr. S on some of the techniques by which he would need to get and keep his bodily house in order, the financial counselors were there to coach him toward getting his financial "house" in order as well. But as we have seen throughout this chapter, doing so would entail a certain level of demonstrable compliance, which would only take place in the context of daily home life and in relation to the persons who also are most likely to serve as informal caregivers.

Caregivers As Keepers Of Several Houses

In the study "Caregiving in the U.S.," conducted by the National Alliance for Caregiving and AARP (2004), caregivers are defined as persons who are 18 years of age or older, and who perform one or more activities of daily living (ADLs) – such as eating, bathing, getting into or out of bed or a chair, and using the toilet – or instrumental activities of daily living (IADLs) – which include those activities related to living independently, such as shopping, preparing meals, managing finances, housekeeping, and using a telephone – for someone else who is 18 years of age or older ("Caregiving in the U.S.," National Alliance for Caregiving and AARP 2004). These forms of assistance can be provided by either a paid professional (such as a Certified Nursing Assistant), or by

someone who is not paid a wage for their assistance. The 2009 “Caregiving in the U.S.” study estimated that 21.2% of the adult U.S. population provides informal, or unpaid care to other adult friends or relatives (another 5.6% cares for both adult and child care recipients); 18.9% of adults in the U.S. provide unpaid care to someone aged 50 or older and 4.6% care for someone aged 18-49. The vast majority of caregivers (86%) are caring for a relative, as opposed to the 14% who are caring for someone outside the family. (“Caregiving in the U.S.,” National Alliance for Caregiving and AARP 2009)

In transplantation, informal caregivers, from the beginning, can be key to a patient’s ability to successfully coordinate the multiple houses involved in the journey. In addition to being a source of emotional support, they can be a tremendous source of logistical support. Caregivers not only drive patients to and from appointments, but they often help to coordinate paperwork and can be integral to the management of the large amounts of verbal information that flow back and forth between patients and the transplant team. They do this by helping patients to answer clinician’s questions, and remembering which questions to ask clinicians (and furthermore, caregivers help to keep track of the answers).

Although the amount and types of care required can vary by the type of transplant, even kidney transplant patients must be able to identify at least one person who will be there for post-transplant care. Because the default caregiver is so often the person with whom a patient shares a home, the presence and quality of the relationship with this person can greatly affect how a patient fares in the process. For example, a patient in need of a liver transplant due to cirrhosis precipitated by long term alcohol abuse is considered to be of greater risk if their would-be caregiver also suffers from alcoholism. Other risks come to the fore if the patient and caregiver are in a relationship riddled with domestic violence (none of the care arrangements I observed fit these descriptions, but clinicians easily were able to recall instances that did). While I did encounter a few examples of persons who had little to no informal care support, these instances were rare, first because of my study design (which focused on patient-caregiver relationships), and second because identifying some form of informal care support is generally considered among the prerequisites of transplantation. This is one area in which social workers often play a pivotal role through interpersonal practice

interventions designed to help patients identify potential care partners and maintain ties with them. One transplant social worker explained that, in some instances where a patient has no “default” caregiver, the difficulty is not so much in finding someone in that patient’s life to provide care support, but rather to convince the patient that he or she will, indeed, need assistance through the process.

It depends. It depends on the individual. Some people are a little bit more private and they don't feel the, they don't feel the urge, feel the need to do that and so they feel like well, I've always been independent, I've always taken care of myself and so why would I need to really reach out? Even though we're trying to educate them, and they're trying to go through this process themselves, we're trying to let them know that, yes, you do take yourself to and from dialysis, and you are independent. We're not trying to take that away from you, except from the standpoint, we have to point out that you can't drive for a month [after the transplant surgery]. So now who's going to drive you? ...Or you can't lift anything over 10 pounds, which, a gallon of milk is like 8 pounds, 2 ounces. So it's like, who's gonna ... do your laundry? Who's gonna take the laundry downstairs?... So we try to role play with them to try to help them figure those things out.

He went on to point out, though, that lack of caregiver support is an area where notable differences can emerge between the various types of transplantation.

*...For kidney transplant you can be on dialysis for years and years and years. Heart transplant, it can be kind of quick. We've had a couple of them that, you need to have a transplant right away, and you have to go, go, go. And you have to turn your life from being independent, taking care of yourself, to dependent and you're... having somebody else helping you to and from the bathroom. So you go from one extreme to the other [...]
Sometimes it's easier to reach out when you have time on your hands...*

[...]

Kidney transplant is different because aftercare is a little bit simpler...from the standpoint of, ok, you can't drive for a period of time, you can't lift anything over 10 pounds for a period of time. Heart transplant, you might have a left ventricle assistive device, or you might have, you know, a device that you have to keep track of or tabs on and make sure that it doesn't fail because if it does fail then you're dead. You know, so

there's a lot of, there's a big difference, big difference there. So I think the simplicity of the kidney transplant and what's needed or necessary makes it easier for maybe people to say oh yeah, I'll help you out, or yeah, I can take you to and from your appointments. Sometimes the complexity is the real deal breaker and that's what we're running into with heart transplants with certain people because they don't feel comfortable with learning this new-fangled device and, "Gosh darn it if I have to learn this and do all this other stuff and if I mess up you're dead, I don't know if I want to take on that responsibility."

These dilemmas are not solely those of persons who have no spouse, lover, or other close, supportive person in their lives. In talking further with this social worker, I learned that he had worked with one married couple in which the spouse was very reluctant to accept the tremendous responsibility for care of a left ventricle assistive device (LVAD). Further, I also met unmarried persons during fieldwork who received very attentive and supportive care from adult children, and even friends and neighbors, who did not live with the patient but spent large amounts of time caring for them. So it would not be accurate to say that a care partnership can only be effective if patients and caregivers live under the same roof, nor that sharing a domestic space guarantees that a transplant patient's spouse or domestic partner will be able or willing to offer the necessary types and amounts of care. At the same time, spouses and domestic partners most often did become the default caregivers during the transplant process.

Gender and Caregiving

While it has been well-documented in caregiving literature that women outnumber men who assume the roles and responsibilities of informal caregiving in general (the 2009 National Alliance for Caregiving and AARP study found that 66% of unpaid caregivers in the U.S. are women), the demographics of who provides care to transplant candidates and recipients in the U.S. seems not to be well-documented at this time. Although the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients (OPTN/SRTR) tracks and maintains multiple data and detailed records of the characteristics of organ donors, transplant candidates, and

recipients, it does not report data about the characteristics of transplant caregivers. However, a small amount of research (e.g., Peterson 1985; Casida 2005) has focused solely on women caregivers of transplant patients, and lends some worthy insights into gender and caregiving, particularly regarding the challenges women can face as caregivers.

For example, in an older study involving 19 wives of home hemodialysis patients, Peterson (1985)¹⁰ found that the previous family structure and family roles of the wives and husbands were directly related to the impact of the illness on the informal caregiver. For those wives whose roles were not significantly disrupted by having to become a home caregiver (i.e., because they previously had devoted all of their time to family life, did not previously work outside the home, or who did not give up all activities outside the home upon becoming a caregiver), the illness' impact on the caregiver was more directly related to the family's financial status and the husband's adjustment to the illness (Peterson 1985:30). For wives who previously had maintained a dual orientation towards both family and career, the impact of their husband's illness and care needs was more directly related to the extent to which the wives had to take on additional responsibilities for which they felt they had insufficient time (Peterson 1985:25-26). Along these same lines, Mishel and Murdaugh (1987) found that transplant caregiving frequently entailed assuming the roles and responsibilities that the patient had once occupied.

Ginsburg (1998[1989]) has argued that gendered norms surrounding "nurturance" carry with them "moral authority" (147). In other words, assumptions around gender in the U.S. have it that women not only are natural nurturers, but that they *ought to* nurture (or, by extension, provide care). Canning et al. (1996) have commented (in their U.S.-based study among heart transplant patients and family caregivers), "caregiving is a role that is both expected of and more likely to be adopted by women in our culture" (1996:606). In Casida's (2005) qualitative study among wives of heart transplant patients, some of whom had to learn how to help their husbands manage a left-ventricle assistive device (LVAD)¹¹, the caregivers all reported feeling overwhelmed by their new

¹⁰ Although Peterson's study was not focused on transplantation, it is relevant because kidney transplant patients very often have to undergo dialysis while they wait for a donor organ to become available.

¹¹ In order for heart transplant candidates to survive the waiting period, they often must be implanted with a mechanical heart assistance device (e.g., a left ventricular assist device, or, LVAD). In this case, a primary

caregiving role and fearful of carrying the responsibility for their husband's life, yet they also reported acceptance of this role because of social expectations (Casida 2005:148). On the other hand, in a meta-analysis of 229 studies on gender differences in the psychological and physical health, stressors, and social resources of informal caregivers to older adults (not transplant recipients), Pinguart and Sörensen (2006) found there to be smaller gender differences among younger caregivers and in more recent studies, suggesting the importance of considering the effects of social historical changes over time.

In any case, the scenarios I observed in my fieldwork produced examples of patients and caregivers alternately upholding and disassembling gendered norms. Overall, decision-making about transplant caregiving arrangements had the potential to be a morally-charged area, as well as one that could become morally ambiguous. Members of a patient's web of kin often worked to make caregiving arrangements that simultaneously met practical needs, yet also upheld larger expectations about who should care for whom. But the examples I encountered did not always map neatly onto the contours of larger-scale statistical descriptions of unpaid caregiving in the U.S. (which are shaped heavily by trends in caring for the aging).

Among the participants in my own non-random, non-representative, qualitative study, I can report that 24 (61.5%) of the 39 informal caregivers I interviewed were women; among the men, 8 were either spouses or non-married partners of the patient (spouses, regardless of gender, seemed to be the "default" caregivers—of the 39 caregivers with whom I spoke, 22 were spouses). There also, however, were patient-caregiver dyads in which I interviewed the patient but not the caregiver, and in at least two such instances, the care partners were men. But since the focus of this research was not so much on the quantifiable, but rather the qualitative, I can only safely note that participants offered examples that in some instances upheld received notions about gender and caregiving, and in other instances flew in the face of convention.

For instance, in one spousal pair, Rob was an extremely attentive and dedicated caregiver to his wife, Mary, as will become more apparent with further elaboration

informal caregiver is necessary in order to help manage the LVAD and monitor the patient, as well as provide the other forms of support that will help to keep the patient alive as they wait for a donor heart to become available (Casida 2005).

throughout this dissertation. Possessing a deep, slow voice (which also gives away his southern upbringing), a love of Nascar, vocational training as an electrician, and other conventional markers of masculinity among white males in the context of the U.S. Midwest, Rob also was aware of the traditionally gendered nature of caregiving. He commented with some disdain on the fact that other men, particularly those in Mary's family, seemed to look down on him for taking on these duties so willingly, capably, and completely:

[There's] a lot of testosterone. For some reason, men just... I have a difficult time. [...] I just am not going to play their little contest. 'Oh I've got a story that's better than your story.' Or, 'I can do this better than you can do that.' I don't, I don't play that game. [It] is a lot of just testosterone. [...] It's not manly to do that [the type of care he provides for Mary], and I'm sure they feel that way because of what I'm doing, [but] you do it. You've got to do it.

Notably, Mary's mother and very close, long-time (and kin-like) female friend provided respite care about once a week for Rob, who still worked one day a week at a local grocery store during the period of Mary's most intensive caregiving needs. This, in fact, was also true for others in this study. For instance, while one patient's husband was her primary caregiver throughout her health decline and eventual liver transplant, all of her backup sources of care were women, particularly her sisters. On the other hand, while the primary caregiver for another patient – Marvin, a man of European descent in his late fifties who had received both a liver and a kidney transplant) – was his wife, his backup sources of care mainly consisted of men, including a neighbor, a close friend, and his sons (he did also list a sister among his backup sources of care). Marvin's wife worked full-time during the day, and was not always able to take off on short notice for some of the smaller matters with which Marvin might need assistance during the day. Finally, though common, it certainly was not *always* the case that male patients had female care partners. For instance, Calvin was a blood-forming stem cell transplant patient who utilized Cooperative Care, a setting in which some of the most intensive caregiving is required. His wife had passed away some years ago, and his son was his primary care partner, with a male cousin serving as a temporary back-up partway through his recovery.

Participants often reported that their arrangements were based on a foundation of mutual certainty, cited frequently among participants, that ‘I would do anything for them and I know they’d do anything for me.’ Yet caregiving provisions also were bound by circumstances that could profoundly alter the types and amounts of support from those “expected caregivers,” in light of the complicated and overlapping arenas of constraint (Inhorn 2003) in their daily lives. More will be said of this in subsequent chapters.

I also will note here that, while this chapter leaves the actual categories of “patient” and “caregiver” rather intact, my field observations indicate that there are important limitations to such a dichotomous conceptualization of these categories. This will be examined in greater detail in the following two chapters, but the final section, below, will begin to offer some inroads into the perspective that “caregiving” and “patient” status can go both ways in the morally charged realm of kinship obligations and expectations.

The “Need” For A Transplant As Embodied Historical Kin Relations (or, Troubled Relations and Former Lives)

Thus far, this chapter has described the purposeful preparations that persons make in order to seek and receive a transplant. Patients and their loved ones, as we have seen, find they must simultaneously maintain several “houses” (from the domicile itself to the bodily house, as well as several interlocking clinical, logistical and financial houses), in order to practice a demonstrable commitment to embodying the necessary biomedical norms, beliefs, and practices that will qualify them for the procedure. But it also is important to emphasize that patients’ trajectories do not begin and end with their direct dealings with the world of transplant, or that the intermingling of home life with medical care can be parsed from the larger historical narratives of patients’ moral lives. Most of the formal interviews I conducted during fieldwork included space for participants to tell the story of how they or their loved one came to need a transplant. At times, these narratives outlined in bold some of the ways in which morally-constituted kin relationships, obligations and sentiment, intertwine with bodily states in ways that lead persons to eventually “become” transplant patients, via paths that are alternately characterized by paradox, tragedy, moral ambiguity, irony, and redemption.

This section takes analytical cues from moral philosophers Taylor (1989) and Murdoch (1998a, 1998b). Both have underlined the connections between morality and narratives, and their work encompasses questions concerning what constitutes “the good.” Both also emphasize the *plurality* of possible understandings of what is good and valuable in the world.

From Taylor’s (1989) perspective, “moral thinking” consists of three axes: “a sense of respect for and obligations to others, ... our understandings of what makes a full life, [and] the range of notions concerned with dignity, [that is,] our sense of ourselves as commanding (attitudinal) respect” (1989:15). He uses a spatial metaphor to describe an “essential link” between identity and an orientation in “moral space,” suggesting that,

To know who you are is to be oriented in moral space, a space in which questions arise about what is good or bad, what is worth doing and what not, what has meaning and importance for you and what is trivial and secondary. (Taylor 1989:28)

This orientation in moral space is not set as a given, however, and is shaped as an artifact of history (personal and macro-social). A key insight is Taylor’s notion that we develop our moral orientations in *relation to others* over time (e.g., from childhood through adulthood), in a “common space” that is constructed out of various uses of language:

So I can only learn what anger, love, anxiety, the aspiration to wholeness, etc. are through my and others’ experiences of these being objects for *us*, in some common space [...] Even as the most independent adult, there are moments when I cannot clarify what I feel until I talk about it with certain special partner(s), who know me, or have wisdom, or with whom I have an affinity. [...] I am a self only in relation to certain interlocutors: in one way in relation to those conversation partners who were essential to my achieving self-definition; in another in relation to those who are now crucial to my continuing grasp of language of self-understanding—and, of course, these classes may overlap. [...] The full definition of someone’s identity thus usually involves not only his stand on moral and spiritual matters but also some reference to a defining community. (Taylor 1989:35-36)

Murdoch argues against the notion of morality as based on “universal rules,” suggesting that it is “necessary to think of morality not solely as choice and fact-specifying argument, but as differences between sets of concepts – where an exclusive emphasis on choice and argument would be itself one conceptual attitude among others”

(1998a:92). To illustrate this, she points to “the importance of parables and stories as moral guides” (1998a:90):

Certain parables or stories undoubtedly owe their power to the fact that they incarnate a moral truth which is paradoxical, infinitely suggestive and open to continual reinterpretations... Such stories provide, precisely through their concreteness and consequent ambiguity, sources of moral inspiration which highly specific roles could not give. (Murdoch 1998a:91)

Patients and their loved ones often described the “need” for a transplant as arising in the personal historical narrative context of obligations to others, former homes (which, as spatial loci of interpersonal relations in which patients developed their moral orientations over time, also might rightly be likened to “moral spaces” in the sense discussed by Taylor (1989); also see Beidelman’s (1986) discussion of “moral space” among the Kaguru, described above), and the troubled relations they’ve endured. By doing so, they created images of themselves as whole persons with a past that had everything to do with their current medical status, yet also encompassed much more than their immediate dealings with transplantation. Below, I will include one example of a “personal fable,” using Murdoch’s phrase (1998a:84) – which illustrates some of the magnitude, complexity, and power of moral kinship obligations, as they are carried out in the context of home life. This story as told by Grace, a small bowel transplant patient, and her loving husband and dedicated care partner, Kevin, poignantly underscores the ambivalent side of kin relations (Peletz 2001), demonstrating how various kin relations can be both destructive and redemptive. It invokes the contours of shared and contested moral imaginings concerning the obligations of kinship, playing on ambiguities and dilemmas surrounding moral commitments in a manner comparable to the East African Kaguru tales analyzed by Beidelman (1980).

It involves different persons in their own ways pursuing what they interpret to be good or valuable (as heavily dependent on context), yet ultimately creating an environment of toxicity and illness. The story also sheds light on the capacity of morally-constituted kin relations to alternately invoke the destruction of illness and the redemption of healing. Social expectations and injustices along the lines of gender, social race and ethnicity, and class also will come to the fore as factors which intersect,

with multiplicative effects (Mullings 1997) on interpersonal agonies. Gendered practices, especially, are inextricably linked with love in this moral narrative, with the absence of love comprising a key element and source of Grace's suffering. This brings to mind Ginsburg's (1998 [1989]) exploration of the notion of nurturance in the "procreation stories" she documented in "pro-choice narratives" and "pro-life narratives" among abortion activists. Grace's story, though not one of political activism like those analyzed by Ginsburg, highlights the tension between gendered norms and her own experiences surrounding "the moral authority of nurturance," (Ginsburg 1998 [1989]:147) commonly shared within the larger cultural and social context (1998 [1989]:138-139).

Finally, in addition to this being an analysis of a moral narrative, Grace's story also represents an act of remembering the interweaving of body and home life in the space of the domicile over time. In his work on memory and remembering, inspired by the work of phenomenologist Merleau-Ponty, Casey (1987) argues that memory and place are intimately related, and that this relationship is realized through both the lived body and through material things. He writes,

The body and things both lend a distinctive density to their immediate surroundings; and as the body is central for the experiencing and remembering subject who pivots around (and with) it, so things are pivotal points in a given place, constellating it by their presence. (Casey 1987:205)

Casey notes that the ancient Greeks developed a method for remembering in which one would form mental images of the items one wished to remember, and then "store" those items around an imagined house or other easily recalled place, so that the order of the house would aid one in recalling the order of the items to be remembered (1987:182-183). In comparable fashion, Casey suggests, "*houses hold memories*" (1987:211, emphasis in original). As we will see, Grace's narrative brings us to the spaces of her childhood home and her living memories within those spaces. And as it consists largely in memories of an unhappy past which she has embodied, with serious consequences, it also is worth paying attention to the house – particularly its spaces and things contained within – that she recalls in her answer to my query about how she came to need a transplant. I begin here with some of my fieldnotes from a later visit I'd had with the couple, in order to sketch out some of the backdrop for Grace's moral narrative.

Grace: “...*there was no love...*”

It had been some time since our last visit, but there finally came a day when I was able to stop by to see Grace again in her hospital room. Her husband, Kevin, was there too. In fact, when I first walked in the room, I only saw Kevin, seated near the privacy curtain, and thought he was there alone. We talked for a bit and I explained that I had been staying away from the hospital for awhile because I'd been fighting a cold. He said they were now going to relist Grace for a second small bowel transplant because the first one had failed. As we were talking, I heard someone speak from the far side of the room, and as I looked past the half-drawn curtain, there was Grace, sitting in the chair by the window, illuminated by the gray-white light of the wintery day, with the hospital tray pulled over to her. She was drawing something on a piece of paper with colored pencils, and when I asked if I could see what she was drawing, she said, “Well, it's not very good, it's not my best.” It turned out to be an exquisite drawing of [her granddaughter's] name, embellished with flowers and other colorful details. Grace said she was drawing a card to send to her granddaughter, and trying to encourage her granddaughter to write back.

I asked if she was still having a lot of pain and she said it wasn't as bad as before, but was still a nagging persistent lower level of pain. Kevin told me she'd gone in for surgery over Thanksgiving; they had to open her up and do a “wash-out” (which literally entails the washing out of a person's internal body cavity and organs) because she was full of infection, and that had helped some. Now they're just planning to stay here and wait for the next transplant to come. I asked if there was anything at all that they needed from “the outside” (outside of the hospital) and Kevin said no, they had everything they needed, but that he still had my number and they'd call if they needed something. He said that there's a Dollar General store a few blocks away and on the nice day we'd had recently, he was able to go there for some toiletries for himself, and he smiled and said he got Grace that set of colored pencils and a coloring book there. After talking for a little while longer, I began to leave, and then Kevin did stop me and said he did have a question: did I have any experience with using an online video phone? He'd like to get cameras for his kids for Christmas so they could keep in touch that way. I offered to lend

him my video phone camera to try it out, but he declined, saying that he'd done all the research, and just was wondering whether it worked or not.

...

The first time I met Grace and Kevin in person, they shared with me one of the most moving narratives I encountered during this research. Borrowing again from Taylor (1989), throughout our conversations together, it became clear that Kevin and Grace shared common moral space. By playing a crucial role in her continuing grasp of languages of self understanding, Kevin was a key member of Grace's "web of interlocution" (Taylor 1989:36). Each in their early fifties, and aside from the time they had spent at the Transplant Center, they had lived their entire lives residing in a U.S. Gulf Coast state. They celebrated their 35th wedding anniversary in the same month I'd come to know them in 2008. Any of the 13 children in Grace's large Catholic family of origin who wanted to get married was required to do so on Thanksgiving, she explained, because her parents reasoned that they would be fixing a large meal anyway. A wedding feast would be less burdensome at this time because it would involve simply preparing a bit more food than they otherwise already would have prepared.

In fact, both Grace and Kevin made it clear that there had been no love shown to Grace by her parents, who prioritized work, austerity, and pragmatism far more than affection among Grace and the older siblings in her family. Grace was among this older group of children, but in contrast to her other older siblings, Grace had been a child who spoke her mind. Though she also tried very hard to win her parents' approval, she often was in trouble with them. Punishment, Grace recalled, could include anything, up to pulling her hair and "throwing my head up against the brick wall."

As she explained it, at first "life seemed pretty cool, except Mom kept bringing kids home." It came to a point where the family converted even their dining room into a bedroom, and each older child was put in charge of one or more younger children as a designated keeper and bedmate.

There was a lot a lot of pressure on me to make sure that these kids were bathed and fed, lined up after the tub, put them on the couch in their little tighty whities and their little t-shirts. And they didn't breathe until we got 'em their dinner. And then they ate, and we

would eat what would be left over, what was there, what the little ones didn't eat. But my parents a lot of times would get up in the night and my dad would cook them steak and it would just infuriate me because I thought, we get to smell, but we don't get to taste it. It was a strange, um, very difficult upbringing. All the housework on Saturdays would have to be done. We had wood floors; we'd scrape and wax them every weekend, with the hopes that you would get to be the one lucky enough to get your name pulled to go with Mom shopping, on her Saturday shopping trips. But not me because I ain't the good one.

Grace remembered a steady influx of babies as her “Mom kept bringing kids home.” Simultaneously as the family grew, the spatial use of the house, the things within it (like the couch), the daily and weekly bodily and sensory rhythms of feeding, bathing, and housekeeping, and the roles and relations of family members all became distorted from what Grace had been used to (and from U.S. mainstream white middle-class norms). One can visualize along with Grace the lining-up of her younger siblings, freshly bathed, “in their little tighty whities and their little t-shirts.” And as she described the scraping of the wood floors of their house, she conveyed the bodily labor that this weekly chore would entail. As things changed, Grace and her older siblings would eat last, being allowed only what was left after others had had their fill, and she came to be allowed to *smell* but not *taste* the steak her dad would cook at night (rather than during regular meal times, when the exclusion of the older children would have been even more conspicuous). This home environment became an incubator of toxicity that one day would severely compromise Grace's health. Grace and Kevin explained,

Grace: Basically, I was raised with a lot of stress. And ulcers. And it's impacted my whole life.

Kevin: That was the main cause. She had ulcers that just couldn't heal.

Grace: [There were drugs available but] my insurance wouldn't pay for it, and we couldn't afford it.

Kevin: They were experimental at the time.

Grace: And had I had that, I probably wouldn't have lost my stomach to the ulcers. They would have been able to heal. But the main ulcer wouldn't heal, and I kept bleeding out

and they'd find me different places, you know, passed out. And I know my body really well, and I knew something was going on. But when I'd have loss of blood, I couldn't tell, because I was dizzy all the time and tired anyway, so I didn't know if that was a sign or if it would pass. And people would find me and bring me to the hospital.

Both Grace and Kevin link the fact that Grace needed a small bowel transplant directly to her kin relationships and early family life. While they mention that their financial instability and poor health insurance denied them access to drugs that could have offered medical healing to Grace, they point more to a sort of “moral etiology” (as compared with a “political etiology,” as described by Hamdy 2008) for explaining Grace’s health problems.

Kevin: Basically, in a nutshell, her mom was not a mom. She was a queen bee. And she ran the hive, and everybody catered to her, including dad. And everybody was at her beckoned call. I can speak this because I've been in the family long enough and I know all the particulars. And it just worked out that way, just the way the family were brought up. Everybody was raised that way. Three generations, they had 3 generations of kids. They had the oldest ones, they had the middle ones, and they had the babies. When we got married, Grace's bedmate was an 18 month old boy. Grace was having to raise that child. When we left home, it was the next sister in line to take care of him. So it was, both of us came from dysfunctional families so to speak, in a sense. Where there was no love on her end, there was love on my end, but there was alcohol addiction on my end, and it was [abused by] mom and dad. And there was abuse on their side, but it was child abuse. They were abusing the children.

Grace: Just mental, you know, 'You can't do it right,' slap you around, that you'd go to jail for now.

Both Grace and Kevin share a unified perspective on the origins of Grace’s illness, citing abuses by Grace’s parents. Playing a major role was a mother who was not a mom but instead a dictatorial “queen bee,” who broke gendered codes of nurturance (Ginsburg 1998[1989]), offering no love and using the older children to fulfill the duties

of housework and childrearing (see, too, for example, Hochschild (1983) on the significance of “parental love” and “emotion work” in daily family life). Grace’s father provided for the material needs of only some family members, to the exclusion of others, which represented not only a breach of gendered moral expectations and obligations, but also a failure to honor Grace’s (and her siblings’) dignity. Kevin sites his own family’s dysfunction (although, he notes, at least his family environment had provided the basic necessity of love), and the lengths of time he has been in Grace’s family, as the basis for his own credibility in sharing these perspectives. Kevin continues, drawing connections between Grace’s upbringing and her own personality and parenting in her adult life:

Kevin: And it was too much put on a young person, the responsibilities that the parents should have been responsible for, not a child raising a child. And Grace being a typical, wanting to please everybody, stuff like that. That's where all of these ulcers come in. That, in a nutshell, is her character, and she wanting to please everybody and this and that. And with A-typical personality, just going and going. Throughout her life. She was always, if it wasn't our kids, it was another child or something like that, always a mothering figure. Good and bad, you know, good and bad, to worry about everything. And she did worry about everything. It was a big problem for her family. So like in the late 90s when all this came about, when she had numerous operations, she had 14 abdominal surgeries, so she's lost...her first operation was in '99, and it's just been going on and on and on. But we've learned a lot ...She lost her stomach, couldn't eat.

Here, Kevin touches upon the “good and bad” of Grace’s own character and personality, for which he at once ascribes personal ownership to Grace and links to the environment of her upbringing. Grace, as “a mothering figure,” had much to offer her own family of procreation, but the other side of the same coin – Grace’s “A-typical personality,” extreme ambition, and tendency to worry – was also a “big problem” for her family. Here we see an expression of ambivalence toward the ways in which Grace practiced kinship (see Peletz 2001). The couple described together some examples of how these two sides became manifest in daily life: Grace built a successful wedding photography business, which provided much-needed income for the family, yet would

often take it upon herself to also carry an “emergency bag” of supplies so that there would be everything from safety pins and tissues to an extra bouquet and rings on hand to cover up the inevitable wedding-day omissions and mishaps. She would often sew by hand beautiful and elaborate outfits for her children, but would rip out the seams and start all over if she detected a flaw in her craftsmanship. Almost as a direct counter to her own upbringing, Grace was very loving toward her children and grandchildren, but her health problems eventually prevented her from being able to fully enjoy her family life.

In addition to gender, social race and ethnicity (in the context of the U.S. South), and language also were interrelated factors in the unfolding of the moral narrative surrounding the eventual transplant. Grace’s parents expressed their disappointment even in her choice of Kevin as a partner and husband. Kevin noted, *“this was in the early 70’s. I was a drummer [in a band]. I spoke my own mind, I was free-spirited and I was not going to be controlled and I wasn’t told what to do and I had my own mind.”* Kevin’s family all could speak French, which meant that French was spoken in the home, placing his family lower in social ranking, in Grace’s parents’ view. Moreover, Grace explained, Kevin’s mother “was Spanish,” and *[She] could probably pass for African American. And they [my parents] found out what she looked like and immediately started calling him ‘mulot’ which means ‘half black,’ and all those things were just really hard to swallow. You try to keep your pride and your dignity and respect for your parents and not to rock the boat, but it wasn’t getting any better.*

Grace’s parents exerted even more pressure on the young couple when they had their first child, a daughter, who had a food allergy which caused her to lose weight as an infant. In an ironic twist, Grace’s parents, who themselves had withheld nurturance not only of emotion but also of food when she was a child, accused Grace of not nurturing her own infant.

My family thought that we were starving her and so they tried to take her away from us. And so one stormy night, he [Kevin] came home and I was in my fetal position on the floor in the dark holding my baby, saying ‘You gotta get me outta here. I’m having a nervous breakdown.’ Just too much stress.

And so the couple moved away to another city in the same state, where they made their

lives and had only minimal contact with Grace's parents for several years. In fact, it was not until Grace's condition became so severe and she began to need a long series of surgical procedures which left her with no stomach and a small bowel that no longer functioned, that her parents finally came forward and made an effort to reconcile, albeit in their own way and far too late.

Kevin had remained a stable force in Grace's life, and had cared for her through the depths of serious turmoil and illness. By breaking with her parents' assumptions, formed in the context of gender codes that would allow a man to leave his wife under these circumstances, Kevin also shattered some of the other bigoted images they had formed of him, based on matters of social race and ethnicity and language. Kevin described the gist of the conversation Grace's parents had with him during one of Grace's hospitalizations, *"They were very sorry, were very thankful that I'd stayed with her and taken care of her, that they were wrong about me. But it took them too many years to realize it. I forgave them a long time ago because they were just, I don't know the proper word, they just missed the mark on trying to raise their kids better. That lifestyle was unknown to me. The queen bee was the queen bee and that's how it was until she passed 2 years ago. She died while Grace was here, in January of '06.*

Grace then added that, after her parents apologized to Kevin at the local hospital, once Grace had been admitted to the transplant waiting list, her parents came over to their house to visit. This time, they acknowledged that they realized that he had not been able to work for some time. Grace said, *"They finally realized, if he was with me, he was not working. So they came and gave us some money so that when we took the phone call [that a transplantable small bowel had become available] we had some money. And that day they gave us a thousand dollars. And that was the first time in their life they ever said that they loved me."* At this point in our conversation, Grace had to pause for a brief moment as the emotions welled up. *"But it was too late."*

Kevin continued for her, *"Yep, it was just too late. They were not emotional type people. They didn't show their love or anything like that. It was too disciplined of an atmosphere at the house, with no love shown or anything."*

Grace: *They didn't know how.*

Kevin: *Yeah, they weren't taught how. That's where I'm going with the generational*

[difference explanation].

Grace: *They wouldn't talk about it. They would laugh about it: they were 14 and 15 when they got married. It took them almost 2 months to consummate their marriage and they were just very young, and they had no idea, you know, of what parenting or whatever...*

Grace's parents' first-ever expression of love to her was accompanied by their giving the couple a sum of money. The money was of practical help in the logistical preparations for Grace's hoped-for transplant, but this gesture more importantly signified a realization – even if incomplete – of the tremendous challenges the couple had been tackling. Yet, while the parents' expression of love was indeed a monumental moment in Grace's life and was a source of deep emotionality for her, it came too late, long after it could have made a real difference.

At this point, it is worth returning to Murdoch's and Taylor's observations that morality consists not in a set of universal rules or series of choices, but rather has more to do with, in Murdoch's words, moral "vision" (1998a:82) or "moral attitudes which emphasize the inexhaustible detail of the world, the endlessness of the task of understanding, the importance of not assuming that one has got individuals and situations 'taped,' the connection of knowledge with love and of spiritual insight with apprehension of the unique" (Murdoch 1998a:87). Like Taylor (1989), Murdoch shared insights on the relevance of relations and attachment in moral matters:

And when we try perfectly to love what is imperfect our love goes to its object *via* the Good to be thus purified and made unselfish and just. [...] [L]ove is the general name of the quality of attachment and it is capable of infinite degradation and is the source of our greatest errors; but when it is even partially refined it is the energy and passion of the soul in its search for Good, the force that joins us to Good and joins us to the world through Good. (Murdoch 1998b:384)

One of the remarkable aspects of Grace's story was the level of forgiveness both she and Kevin had for Grace's parents. Both of them pointed to generational differences as a powerfully exculpating circumstance. In doing so, they remove some of the personalized blame from the picture, and link Grace's own suffering to her parents' historical narrative, which included marriage at a very young age and a lack of guidance

about how to parent (or more importantly, how to *love*). Grace and Kevin would argue that Grace's parents were not inherently bad persons, and their dispositions were not borne out of conscious choices to be a certain way. Rather, Grace and Kevin place Grace's own suffering within a set of overlapping, interlinked spheres of context and narrative. It thus becomes less a matter of personal narrative and more one of *interpersonal* narrative. In Grace and Kevin's moral narrative, the ambivalent connection between love and relatedness is key to the total breakdown, and then tenuous reconstruction of "the good."

Here, transplantation also plays a relevant role (though, importantly, it is not the leading figure). It becomes both a consequence of relations gone awry and a source of redemption. It not only serves here as a potentially life-saving procedure, but also as a precipitate of reconciliation and increased (though very imperfect) mutual understanding. Grace's dealings with transplantation, quite literally, emerge out of the moral obligations of kinship, *and* become a means by which persons can practice shared values about what kin ought to do and who kin ought to be in relation to one another. This will become a major theme of the next chapter.

Conclusions

This chapter has covered a great deal of empirical and analytical ground, all of which has explored the practices, obligations, and events that lead up to transplantation. We began with an examination of the notion that, in order to gain access to transplantation, patients must embody the norms, beliefs, and practices prescribed by medical practitioners. The path toward this embodiment usually also requires that patients be able to demonstrate compliance with medical regimens. Those seeking a transplant rarely show outright resistance to "doctors' orders," as these regimens very often resonate closely with moral attitudes and values surrounding health that already exist in the world outside transplantation, and in which patients often have long participated even before their first clinical evaluation. At the same time, the majority of pre-transplant preparation takes place outside of clinical spaces: in the home and among kin or other important figures with whom a patient shares reciprocal relations. The

medical requirements for transplantation often do not map well onto the everyday lived realities for patients and their loved ones.

In order to pursue some of the incommensurables involved in preparing one's body to "house" – or, to be a good "home" – for a grafted organ, I then turned my efforts toward better understanding some of the on-the-ground aspects of pre-transplant daily life. I made heavy use of the concept of the house (inspired by kinship studies literature), and did so by exploring the multiple "houses" (bodily, clinical, domestic, financial, and moral) between which patients and their caregivers together navigate in their pursuit of a transplant. Caregivers, to be sure, often were crucial to the linking of these multiple houses, which becomes necessary if one is to hope for a smooth passage through the transplant process.

Last, I ended this chapter with an in-depth examination of one narrative, in which the various houses of transplantation mattered, but which placed the relevance of home life in "pre-transplant preparations" in a different light. While the earlier portions of this chapter explored preparations in terms of the *pursuit* of a transplant, this final section described Grace's development of an eventual need for a transplant. Both perspectives highlight the deep connections between "the bodily house" and home life in relation with kin (as mediated by factors such as gender, social race and ethnicity, etc.), but the latter perspective underscores the relevance of the *moral* aspects of kinship obligations as being integral to persons' participation in the transplant endeavor. These themes, to be sure, will continue to resurface throughout this ethnography of transplantation.

Chapter 3

Local Moralities, Kinship Obligations, and Reciprocal Webs of Care, Part 1: Patients-As-Caregivers

“I Take Care of Her and She Takes Care of Me”

On one Thursday morning, after checking in with the nurse coordinators, I was referred to a patient who had just arrived and was getting settled in Exam Room A. Walking down the hall, I passed other rooms – some doors open a crack and others closed shut – where patients and their family members sat, verifying information in their charts, and having their first appointments of what would certainly come to feel like a whirlwind pre-noon clinic schedule. As I approached one of the windowless doors, I knocked and waited for an answer. The response came via a muffled voice that I could barely hear through the heavy wooden door and, following a slight pause, I tentatively turned the handle and slowly began to push the door open. Finding a couple there inside, I followed through and let myself into the room. A man with short black hair and a long beard was seated, wearing olive green jeans, a green soccer jersey shirt, and tennis shoes speckled with tiny flecks of white paint. He sat, resting his hands and chin on a brown wooden cane. Though only in his late 40’s, he could have been mistaken for approaching retirement age. A woman with blonde hair, piled high in a ponytail, was sitting next to him with her head tilted down, not for the purpose of studying the bright pink shoes on her feet, but for the purpose of resting her eyes.

“Mr. S?” I asked. As I entered the room, the woman woke from her doze and immediately began to explain, apologetically, “I had to take Benadryl because I had an allergic reaction last night, and it’s really knocked me out.” Mr. S. added, “My wife started swelling up after she ate an egg roll, and we had to spend most of the night in the

emergency room, so we're both a little tired." The couple became visibly more relaxed when I assured them that I wasn't there to evaluate them as part of the medical team, but rather was doing social research on transplantation and people's relationships with one another, and wanted to ask their permission to spend some time talking with them in order to better understand the transplant process from patients' and caregivers' perspectives. After I explained the details about my study, the couple welcomed me to spend the morning with them. Without prompting, Mr. S. offered, "I want to have a transplant so that I can go back to work. My wife has a lot of problems and I take care of her and she takes care of me, but I don't want her to have to work so hard. That's why it's so important that I get better. This is our last and best hope."

Mr. and Mrs. S each literally had been both a patient and a caregiver within a 24-hour period. As I observed their interactions with clinicians who were both evaluating and disseminating information throughout the morning, it was clear that the couple had perfected a delicate dance familiar to so many of those I met through fieldwork. At certain points, Mr. S took the lead in answering clinicians' questions and asking them his own, while at other times his wife stepped in and led the couple's side of the high-stakes conversation. This dance had become second-nature to them, since the designation of "patient" and "caregiver" at any given moment was entirely dependent upon the immediate context so that, in everyday life outside of clinical settings, where people care for each other according to shifting needs, the bounds between these categories could become faded and obscured.

Similarly blended were the motivations for entering the transplant process in the first place. Over the course of fieldwork, it was the rare patient who boiled down their reasons for seeking a transplant to a desire to live at any cost. Rather than uncritically accepting this biotechnological solution to their serious health problems, many patients actually regarded it with significant doubts, fears, and overall ambivalence.¹² Although my study initially was designed with a clear distinction between patients as care-receivers, and loved ones as care-givers, it quickly became apparent that patients enter

¹² Although, as I argued in the previous chapter, there was very little overt critique of the biomedicalized ideals to which prospective transplant candidates are asked to adhere once they have begun the pre-transplant process in earnest, I nevertheless observed ambivalence about pursuing transplantation in the first place.

into the transplant process as persons on whom *others* (especially kin) rely heavily as well – that patients are themselves, in fact, also caregivers to others. In some cases, transplantation is viewed as a way to overcome struggles with failing health and to retain or regain a capacity to care for others (especially children and aging parents). In other cases, transplantation presented itself as a way to decrease the burden on others created by the person’s illness. Overall, though, *loved ones rely on transplant patients*, and most transplant patients are deeply sensitive to this, so that the very pursuit of a transplant can become an act of care in itself. Moreover, patients’ understandings of their obligations to others (and kin often cultivate that awareness by reminding each other of their obligations) orient a patient toward their treatment options in particular ways. “Deciding” to pursue transplantation, then, is not simply an “obvious choice,” but rather the *moral* thing to do, given one’s awareness of the world of relations beyond themselves. In this sense, this chapter builds upon the insights of Murdoch (1998a,b) and Taylor (1989), laid out in the last section of the previous chapter.

This chapter and the next will explicitly examine local and interpersonal webs of informal care and reciprocity in transplantation. Drawing from case examples, in this chapter I intend to make the argument that: 1) patients are not passive recipients of care, and can also be caregivers to others; 2) in light of this, local moral sensibilities about how persons ought to care for their kin play a major role in persons’ decisions to pursue transplantation, in spite of its significant drawbacks, and 3) therefore, existing notions of kinship and moral obligation may do as much to shape and perpetuate biomedical health care realities as the other way around.

Expanding Notions of Care: Reciprocal, Hidden, and Basic

There already exists a substantial and growing body of scholarship on caregiving in fields such as social work, nursing, and gerontology studies. These bodies of literature tend to focus on caregiving for elders and for persons with chronic and terminal illnesses from which recovery is dubious (as noted by King and Koop 1999), and have helped to elucidate the more readily quantifiable aspects of caregiving. Anthropology’s disciplinary orientation to understanding human behavior in holistic, comparative, ethnographic, and *relational* context offers notable potential to produce additional rich

insights into care. In recognition of this, during his plenary session at the 2009 Meeting of the Society for Medical Anthropology, Arthur Kleinman called on anthropologists to give greater attention to issues of caregiving. Indicating the potential significance of the topic of caregiving for anthropology, he had written earlier, “Caregiving is, at the existential core, a primary quality of what it means to be human” (Kleinman 2007:593). That the fairly recent, November 2009 issue of *Anthropology News* included elder care among its topics of focus, likely points to the beginnings of a new emphasis on the subject.

Frederick Klaitz (2009) also recently published a compelling account of sentiment, religious faith, and the intersubjective nature of care within the Baitshopi Apostolic church in Botswana, where AIDS has wreaked havoc on kin and other social networks. Klaitz highlights the reciprocal nature of care in what he calls a “crisis of caregiving,” as “familial obligations to provide for the sick and disabled have become increasingly burdensome as resources have dwindled and wage earners have passed away” (Klaitz 2009:17). Running counter to the prescriptions offered by the Botswana state and other official AIDS prevention programs created by international Pentecostal churches, which stress individual responsibility for the prevention of HIV-infection, Baitshopi church members use both caring practices and speech about love, faith, and care in order to “give love” to persons dying of AIDS, to console the bereaved, and ultimately, to *sustain relationships of care* (Klaitz 2009).

The arguments of this chapter are rooted in an expanded conceptualization of care, and further advocate for such an expansion. This is not the first-ever attempt to broaden the notion of “caregiving” (see, e.g., Kohn and McKechnie 1999), but rather is an effort to make an additional contribution to a more holistic socio-cultural understanding of the myriad facets of care. In a recent commentary in the online “Project Syndicate” (project-syndicate.org), in which he criticized western biomedical training for disabling the capacity for medical students and other clinical professionals to give humane care, Kleinman (2009: Paragraph 1) called caregiving “a practice of acknowledgement, empathic imagination, witnessing, responsibility, solidarity, and the most concrete forms of assistance.” Caregiving takes place in the course of carrying out the most mundane, basic aspects of daily life that are aimed toward the well-being of

another. It can be as subtle as an effort made to shelter loved ones from fear or inconvenience. While the labels “patient” and “caregiver” do appear throughout this chapter (and dissertation), the intent here is to shed light on the way persons, even when they are at their most vulnerable, still manage to express and practice care toward others.

Caring relations very often overlap with kin relations, and family ties, whether amiable or fraught with tension, are enormously important throughout the transplant process. The mutual obligations of kinship remain fundamental to the success or failure of transplantation, as one’s likelihood of surviving with a viable graft hinges on the care and support of those surrounding the patient. Indeed, a complete lack of at least one designated and reliable caregiver can be considered a contraindication for transplant, and can prevent a patient from being admitted to a transplant waiting list. Underscoring the importance of a relational perspective on care, the data presented here show that transplant patients’ kin obligations and responsibilities as caregivers to others *also* play an important role in the transplant process.

There are scholarly predecessors whose work likewise has challenged the notion that caregivers, on the one side, provide care that flows in one direction to patients on the other side. For example, Klaitz (2009) finds that those caring for others who are sick and dying of AIDS in Botswana very often themselves also suffer from the disease.¹³ Myaskovsky and colleagues (2005) have argued that persons who deal with health issues (in their study, lung transplantation in the United States) do so within reciprocal, interpersonal relationships, where the line between patient and caregiver can become blurred, and where the actions of one can deeply impact the well-being of the other (also see Siston et al. 2001; and Perry et al. 1998). Similarly, Burack-Weiss (1995) has argued that the labels of “patient” and “caregiver” may be overly reductive, defining each participant in terms of his or her role, and clouding a more accurate and nuanced understanding of each as being part of a mutable, reciprocal relationship (1995:393). And Wendell (1996), too, drawing from a feminist perspective on disability, has emphasized the reciprocity of care and interdependence. She notes that relationships can simultaneously be reciprocal and unequal, with one person giving more care or having

¹³ Likewise, the following chapter on “Caregivers As Patients” will describe findings in my own fieldwork where caregivers are themselves in need of medical care.

more responsibility than another, yet still involve moral obligations on both sides (1996:150).

While I make the case here that patients also are caregivers to others, this by and large was not an emic perspective among those whom I met through fieldwork. Informal care can have a tendency to remain hidden in its many diverse forms (Olesen 1989), and often is not recognized as “caregiving,” even by those who are providing the care. At the Transplant Center, no patient’s pre-listing evaluation was complete until they could identify one or more persons in their life who would be there to support them through the process, and the people with whom I spent my time during fieldwork were used to being categorized and referred to as either a patient or a caregiver (“care partner” was the official term in use). During one conversation with Janet, a white woman in her fifties who received her third kidney transplant during the course of my fieldwork, I mentioned that I had become interested in the idea that patients also care for others, and cited her relationship with her elderly mother as an example of this. She replied, “I don’t really see what I do for my mother as ‘caregiving’.” I pointed out all of the types of assistance that Janet provides every day, from offering companionship, to coordinating her mother’s medical appointments, to providing a place for her mother to live (in Janet’s own house); but Janet, for the most part, remained unconvinced.

Social Moral Processes and Medicine, Science, and Technology

Although the cases presented below are brief sketches concerning the lives of individuals and small kin groups (families), the intent is to convey that persons who pursue transplantation are answering to the larger requirements of living within shared moral norms and obligations (and in doing so, they are also enacting and reinforcing their relatedness). Throughout this chapter are illustrations that these requirements are not rightly considered matters of individual “choice.” This corresponds with some of the insights of Taylor and Murdoch, outlined in the previous chapter, as well as Durkheim, who focused much attention on public morality as an outgrowth of social life, and saw morality as that which bonds 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” (1984 [1893]: 331).

Various areas of scholarship concerning moral relations and the social aspects of biomedicine, science, and medical technologies also help to inform the arguments put forth here. Again turning to the work of Arthur Kleinman, as a medical anthropologist and physician he has commented extensively on the connections between morality and medicine. Using the concept of “local moral worlds,” Kleinman (e.g., 1988; 1999) describes the idea that social relations (including kinship) are the locus within which humans live their values in an everyday sense. Morality is the product of humans asserting, negotiating, revising, and otherwise enacting their values surrounding what is at stake, what really matters (Kleinman 2006), and what any given situation calls for, in their daily interactions with others. Thus, “...moral experience is about the local processes (collective, interpersonal, subjective) that realize (enact) values in ordinary living” (Kleinman 1999:71).

Likewise informed by the notions of moral and ethical negotiations, medical anthropologists Kaufman, Russ, and Shim (2006) have posited that one of the consequences of new biomedical technologies like transplantation becoming more and more commonplace, is that values surrounding care and obligations toward others can get re-worked and re-framed. Their 2006 work focused specifically on living kidney donation and transplantation for older persons in the U.S., and the authors describe a “diffuse ethical field” that has developed as such clinical practices become routine. Kaufman and colleagues argue that this ethical field is “...located throughout the social fabric and characterized by the difficulty, sometimes the perceived impossibility, of saying no—even in late life—to life-extending interventions” (2006:82). The authors illustrate it as being characterized by three features: 1) the treatment choices that transplant patients, families, and clinicians face are not really choices at all; 2) the availability of treatments like transplantation bring forth certain hopes and expectations for a cure, for a return to better health, and for a better life; and 3) (which grows out of the first 2 features): the very nature of caregiving and love has changed so that expressions of care, affection, and value are tied to clinical acts (2006:82-83). Within this ethical field, “Love is actualized often through the commitment to a longer life and

by doing things to prolong life” (Kaufman, Russ and Shim 2006:83). The authors posit that such an ethical field is shaped by mutually-influential factors which include cultural understandings of kinship.

Others also have written about the deep connections between local beliefs and values, and scientific knowledge and practice, with an emphasis instead on the ways in which values can influence scientific knowledge and practice. Well before the advent of medical anthropology and science studies as we know them today, Durkheim, for example, commented that science derives its influence from collective opinion, which itself is a source of moral authority, writing, “All the scientific demonstrations in the world would have no influence if a people had no faith in science” (1995 [1912]:210). More recently, Nader (1996) documented the remarks of nuclear and alternative energy physicists and engineers in the U.S. and Europe, whom she had asked to respond to an article she had written in 1981 (cited in Nader 1996). The article had focused on the influences of politics, economics, ideology, faith, and other socio-cultural, subjective factors, in the generation of scientific knowledge. The physicists’ and engineers’ responses generally validated Nader’s argument in the 1981 article that the production of energy science is permeated by machismo, professional blindness, the strategic use of statistics to portray findings in a particular way, group-think, censorship, and ideology. She writes, “Malinowski found magic, science, and religion demarcated among the Trobrianders; among energy experts we find reason and desire intermingled (Nader 1996:273).

Like Nader, Shapin (1994) also makes the case that scientific knowledge and practice are shaped by beliefs and values. Drawing upon evidence from seventeenth-century England and the Royal Society, Shapin (1994) describes how the credibility of accounts of the natural world stemmed primarily from the moral and social standing of the person giving the testimony. Credible accounts were those from the likes of Robert Boyle and others, who were considered according to the moral standards of those already within the Society to be above selfish motives, who were not bound by material needs or

desires, or who could be “vouched-for” by other Society members¹⁴. Thus, the already-existing local values of the Royal Society elites shaped the very forms of knowledge the Society produced.

Shapin’s historical perspective offers the important insight that even seemingly-new knowledges and practices, in that they are social phenomena, have their roots in something that came before. Writing about the sites of experimentation in seventeenth-century England and the Royal Society, Shapin finds that, while publicists for early laboratory spaces tried to portray them as truly novel, “it is evident that the social relations and patterns of discourse obtaining within the rooms of the Royal Society were rearrangements and revaluations of existing models,” such as the House of Commons and even more so, the public rooms of the gentleman’s private house (Shapin 1999 [1988]:491). In these spaces, once again, “Roughly speaking, the distribution of credibility followed the contours of English society” (Shapin 1999 [1988]: 481). Indeed, Shapin asserts, “no type of building, no type of society is wholly new” (Shapin 1999 [1988]:491).

Likewise, even seemingly “new” knowledge and technologies such as those associated with transplantation must be taken in context. One of the original goals of my research had been to better understand how technoscientific medical practices such as transplantation enter into the interconnections and interactions of everyday life. But my findings suggest that such a unidirectional perspective would be incomplete. Instead, it is every bit as important to examine how the taken-for-granted aspects of daily living enter into high-tech biomedical practice.

Transplantation is Not the Easy Path...

Transplantation is neither an easy nor a quick route to follow (e.g., Brown et al. 2006). Chapter 2 more thoroughly described the onerous challenges associated with the procedure, but a brief recap will be provided here to contextualize the ethnographic evidence that will be presented below. In order to be “waitlisted” and to receive a transplant, patients (usually with support from loved ones) also must be able to negotiate

¹⁴ This also relates back to Cameron needing to be “vouched for” by a counselor before the medical team would consider him to be truly drug-free and ready to be eligible for a transplant, as documented in Chapter 2.

several different domains – which I conceptualized as “houses” – and incorporate them in a way that demonstrates to the transplant team that the person is what they would consider to be a good candidate for the procedure. The wait time for a transplant can be lengthened even by circumstances over which a patient has little control, such as changes in health status, a loss of insurance coverage, inadequate housing (since much of the recovery will take place in the home, on an outpatient basis), or a change or loss of family support. Each of these factors can be closely linked to the others, and connections between illness and socioeconomic and other inequalities have been well-documented (see, e.g., Farmer 2005; and Marmot & Wilkinson 1999; for transplant-specific studies, see Klassen et al. 2002; and Arthur 2004). Thus, the road to transplantation is not an easy one.

Further, the difficulties associated with receiving a transplant also can exacerbate already existing hardships (which may have contributed to the need for a transplant in the first place) as well as create new ones (e.g., Crowley-Matoka 2005; Frazier, Davis-Ali and Dahl 1995; Jones and Egan 2000; Perry et al. 1998; Raiz, Davies and Ferguson 2003). Serious medical complications can arise before, during, and following the procedure, and recipients must perpetually take expensive immunosuppressants and other post-transplant medications, many of which have undesirable side-effects, and often are not fully covered by health insurance (Jones and Egan 2000; Kasiske, et al. 2000). Further, cost-cutting efforts have led to shorter hospital stays, shifting the onus to patients and those close to them to meet the requirements of post-transplant care (Levine 1999; Cartier 2003). (More will be said on this in subsequent chapters.) Many of the patients I met through fieldwork alluded to how hard it can be to accept so much help from others. There is very little that a candidate or recipient can do to feel they are appropriately or adequately reciprocating the outpouring of social, emotional, and material support that can often accompany transplantation. This can be especially so when this support is received from persons with whom one shares ties too loose to be considered kinship, yet too close to be sanitized by distance or anonymity, as was the case for participants from small towns or who had worked in particularly supportive employment environments. For instance, Hank, in his mid-sixties and a proud citizen of a small rural town, had a difficult time describing to me through

tears, the benefit picnic which the community had held to raise money for the out-of-pocket costs associated with his liver transplant. Thus, while treatment choices surrounding transplant may in some cases not really be choices at all, as Kaufman, Russ, and Shim (2006) have noted, those who do pursue transplantation can simultaneously harbor significant ambivalence about the process.

For the Sake of Others: Transplantation as a Caring Act

As the following will illustrate, patients' pursuit of transplantation can grow out of moral processes which center on already-existing and negotiated understandings about their obligations to others, especially toward those they consider to be kin. Various and overlapping aspects of care are highlighted. But across all examples, misgivings about the drawbacks of transplant are set aside as patients live their values as kin and caregivers to others.

Prospective transplant candidates like Mr. S. from the introductory vignette do not get far in their transplant journey without learning about the major risks involved in the procedure. I watched as both his and his wife's faces dropped temporarily as the surgeon began to lay out all of the complications that can occur as a result of a transplant. But Mr. S. seemed to quickly let go of the risks as he embraced the potential benefits each time they would come up. The pieces of information that seemed to cause both him and his wife the greatest concern had to do with the periodic mention by various clinicians that it was possible that Mr. S. might not qualify for transplant, or that there could be no guarantee that a donor match would be found in a timely manner. But even these hypothetical obstacles were quickly rejected as Mr. S. emphasized several times how urgently he needed to get healthy and regain employment so that his wife could find some respite from work and from worry.

“Not Being Able to Function As a Mom or a Wife”

Betsy, a nurse practitioner in her late-thirties, mother of a son and two daughters, and married to her husband for 14 years, described her perspectives on transplant in a manner which highlighted the complexities surrounding whether or not patients feel they have a “choice” about transplantation. She had undergone a pancreatic

islet cell transplant. In this procedure, islets (those cells that produce insulin) are removed from the pancreas of a deceased organ donor using special enzymes (sometimes, the pancreases of two donors are required in order to harvest enough cells), and then transplanted via a catheter into the liver of the recipient through the liver's portal vein ("Pancreatic Islet Cell Transplantation," NDIC, <http://diabetes.niddk.nih.gov/dm/pubs/pancreaticislet/>), where they can begin to make insulin in the recipient. Betsy has additional perspective because she recently had joined a clinical team at the Transplant Center where she would work directly with transplant candidates and recipients. Upon her suggestion, we met for an interview at a coffee shop/diner that was located approximately halfway between both of our addresses in town. At the time, she had about two weeks left of her recent medical leave from work. She had taken this leave in order to recover from her now second post-transplant surgery that she'd had to undergo to correct serious complications following the actual transplant itself.

Betsy had been telling me the story of how she came to need a transplant. She had become severely ill with acute pancreatitis, which had begun during her second pregnancy and progressively worsened over the subsequent years. She eventually was unable to eat anything at all and had to get her nutrition via total parenteral nutrition (or, TPN)¹⁵, which can itself cause serious complications over the long term, including major liver damage. I asked Betsy to tell me about when the option of transplantation first came up. Her comments highlighted the way in which informed "choice" about whether to pursue transplantation is dissolved by the larger moral issues of being able to fulfill one's caregiving roles. Ostensible choice gives way to the intense hope that is embraced by those who see transplant as their only chance for being able to "function," as Betsy puts it, in relation to one's kin in ways that answer to the moral authority of convention. Here, the conventions involve being a mother who can show love to her children in particular ways, being a wife who has divided labor with her husband along dominant middle-class gendered lines, and being a reliable employee.

¹⁵ Patients who receive total parenteral nutrition (TPN) receive all of their daily nutritional requirements via a concentrated solution that is given intravenously, rather than through the gastrointestinal tract.

***Betsy:** I can't honestly say looking back right now that I would do it again. But at the time I didn't have a choice because I was in the hospital and strung out on narcotics [for the pain], and not being able to function as a mom or a wife, or to work, and so at the time it was like, 'Yes, do it because anything's better than this.' Looking back now, I say that [I wouldn't do it again] now, forgetting how sick I was. [...] You know I thought I'd have the surgery and get those islet cells and wake up and everything would be fine and [it didn't go that way]. So it was frustrating to go through it all and not feel any better. [...] And I think for a lot of people who get a transplant, because you're so sick beforehand, and they tell you all this stuff, but you're selectively listening to what you're actually hearing. They certainly told me all the things that could happen and that could go wrong, and they all did [go wrong].*

I asked Betsy to say more about what she meant by “not being able to function as a mom or a wife.” She explained that, until her husband recently took a new job which affords him “nine-to-five” workdays, he had been in the auto sales business for several years, which required him to work long days and odd hours. Although Betsy’s husband adeptly and without hesitation took on new roles during her illness, Betsy had been used to their former gendered division of labor and kin responsibilities. As she put it, it was “usually not that way; our relationship is the other way around,” and she was used to taking care of most of the everyday management of their middle-class home life and child-rearing duties. That Betsy juxtaposes her ability “to function as a mom or a wife, or to work” with being “in the hospital and strung out on narcotics” further points to the moral status of the particular ways she felt a mother or wife *ought* to act, function, and care for her loved ones.

She recalled,

It had come to a point where I was either in bed or on the couch on TPN 24 hours a day and missing, not school stuff like conferences and stuff, but like going to eat lunch with them [the kids], and even just getting up to do reading [with them] at night because I was so exhausted. So they were reading to themselves, and those kinds of things that I had been doing, I completely lost out on those things that you totally take for granted until

you can't do them anymore. I mean going to the park, taking them to the zoo, and stuff like that.

Betsy's concern had been that her illness prevented her from being able to participate not so much in the official duties of parenthood – for example, going to parent-teacher conferences – but in the small everyday “taken for granted” caring acts like reading to her children at night, which for her defined motherhood and family life. This notion of what everyday life is supposed to look like, and the hope that transplant can offer toward gaining (or regaining) normalcy, was also cited by others as a compelling reason to pursue transplant, as the following will illustrate.

“So that I can be here a lot longer for her...”

At 5:25 on a cool Saturday morning in late September, I watch a raccoon climb out of the parking lot dumpster and disappear into the thinning bushes nearby. Just a minute later, Emily, in her mid-thirties, emerges from her apartment building and shuffles over to my car idling beneath a glaring street lamp that daylight won't subdue for nearly another two hours. She has welcomed me to accompany her to dialysis this morning, and when we arrive at the dialysis center, we walk through one set of sliding doors, then have to wait for someone to “buzz” us in before we can walk through the next set of sliding doors. From there we walk over to one side of a room where Emily enacts a well-rehearsed ritual of bodily practices. She steps onto a scale, and then uses other machines to take her own temperature and blood pressure, which she self-records on a form that she will hand to the dialysis technician once she sits down at the station that's been assigned to her for this particular day and time. It will be almost 5 hours later when Emily will be disconnected from the dialysis machine, will have a white plastic pressure clamp placed on her arm until the dialysis needle site has adequately clotted, and Emily will get back up out of the chair, and weigh herself again, checking to see how much fluid the machine was able to remove from her body this time. When we step back out of the windowless dialysis center, blinking at the now bright and cloudless sky, it feels like we've just passed through a time warp, and I drive her directly back home so that she can rest for the remainder of the day.

This is Emily's routine three times per week. It not only keeps her alive and in good enough health to wait for a transplant, but her faithful attendance at these appointments also signals to the transplant team that Emily is compliant with her regimen, consistent, reliable, and a good candidate for transplant (this theme was explored more fully in Chapter 2). And yet, exhausted from dialysis, she will be unable to do as much as she'd like with her young 2-year old daughter on a warm autumn Saturday afternoon, and will rely on her mother and brother to care for the little girl while Emily sleeps. Normally, it would be the same mother or brother who would drive her to and from her appointments – her husband joined the military for the much-needed health insurance and income (Emily had not yet been approved for long-term disability status) and he currently is stationed overseas. She and her daughter now live with her family of origin, and though Emily is well aware of the effort they put into keeping her as healthy as possible while she waits for a kidney and pancreas transplant, her greatest motivation and hopes center on her daughter. For Emily, pursuing a transplant is not so much a choice, but rather is the only way to save both herself and her toddler from a world of doctors, dialysis, hospital stays, and an uncertain future.

The following two excerpts are from one of a number of interviews and less formal conversations I had with Emily. This particular interview had taken place before the day I accompanied her to dialysis, described above. At this point in the conversation, Emily had begun telling me about the fact that her low blood sugar episodes had become both more frequent and more frightening for everyone involved. One recent incident had happened during a visit from her maternal grandmother, and her maternal aunt's nine-year-old daughter, both up from Dallas. Emily is the nine-year old's godmother, and had been very directly involved in her life while Emily was still living in Texas. Emily expressed embarrassment about her relatives having to witness the effects of her blood sugar suddenly dropping, but clearly indicated that her greatest concern is for her daughter.

Emily: [My goddaughter] is really attached to me, and you know, I love her to death. She's my sweet little girl. [...] She was here a few weeks ago with my grandmother.

Unfortunately, they had to sit through one of my episodes. I don't have the awareness that my blood sugar is dropping, but when it happens, not only does it happen quickly, but then I get stubborn about it. And I keep telling everybody, "You're the ones that are crazy. I'm fine. I'm normal," and the entire time I'm like falling asleep. [...]. My mom, this is how she looks at it, she's like, "Emily you are going to go on a trip and you're never going to come back; that trip is a one-way trip to not coming back, because if you go into that coma, there's a good chance you don't come out of it." And my not having awareness...is pretty scary to my daughter. It kills me to see what it does to her and how it really affects her because, it's like she distances herself from me, she doesn't want to be near me. She just wants to be cuddled by my mom, and then it takes her from a few hours to almost a day or two before she warms up to me again because she's just so scared of what it was that just happened.

Laura: *So what does happen?*

Emily: *They have to call the paramedics to get me out of it, because sometimes I won't even wake up. And so the paramedics will come give me a shot of something to get me out of it. They ask me if I want to go to the emergency room. Usually I say no and then, other than that, I just sit here and have to look at everyone's face of disappointment and being upset and scared, because it's scary. I mean, I'm not living it on their side, so I'm not seeing what they're seeing. But it's also scary on my end. I just really feel for my daughter. I hate what it does to her. That's why I'm just so anxious to get on this transplant list. I want to get this over and done with.*

Emily almost certainly has been told by members of the transplant team that it is possible that recovery from the surgery could take quite some time, and could be disrupted by post-transplant complications (this information is included in all pre-listing evaluations as part of the verbal and written informed consent process). However, Emily's expectation is that, once she gets admitted to the transplant list, she soon will be able to "get this over and done with." Emily's imaginings of immediate results needs to be considered in light of her understanding of the urgency of the matter. She laments that her daughter has witnessed too much, that the toddler worries a lot, has nightmares, often asks if Emily is okay, and that she can sense when Emily's blood sugars are dropping.

This is a clear example of illness being an interpersonal, interrelational experience, with effects that go well beyond the individual to permeate kin groups at multigenerational levels. It also illustrates that the lived values of kinship are thoroughly enmeshed with the moral processes of working out what is to be done about illness. A transplant, for Emily, represents the hope not simply of a return to health for her own sake, but rather the hope of removing the trauma and suffering that her illness inflicts on those she loves. At another point in the interview, Emily told me about her dietary regimen, medications, dialysis and other tests and procedures – including major dental work – that she had undergone in an effort to get put on the transplant waiting list. She also explained that it has been difficult, but she does it because she wants to “be there” for her daughter, and she finds it very important that her daughter grow up with a mother.

Emily views transplantation as a promise of a longer life, as a way literally for her young daughter to continue to have a mother. But farther along in our conversation, Emily reveals that “being there” for her daughter means something beyond mere existence, and rather carries with it a moral status that entails prescriptions for *how* a mother should be there for her young child.

Emily: *I want her to have a normal mommy, [...] a mom that can run and play with her, that can do things that I can't do with her all the time right now. Right now, pretty much all I can do is, I can give her a lot of love and affection, but she needs a lot of physical play time and sometimes I just don't have the strength to do it. And that really hurts me to know that I can't do that for her. [...] I just want her to have a normal..., I don't want her life to be surrounded by hospitals all the time. [...] She's too little to be worried. She should be carefree and playing and everything, you know?*

Laura: *Have you told her that you are going to try to get a transplant?*

Emily: *I told her; she knows why I am going to the doctor. She knows that mommy is trying to get better and that the doctors are trying to fix mommy, so that I can be here a lot longer for her. Because that's my main goal in life now is to raise my daughter and to watch her graduate, get married and have her first child. That's what I want. I want to be able to see all that. I'm hoping that this will be the thing that I need to do all that. I know that they said that with a pancreas transplant, that would take the diabetes away. So that's why I'm praying to get both [a kidney and a pancreas]. [...] Granted, I know*

that I'm going to be on medication for the rest of my life, because my body is going to try to fight the foreign ... parts that are not, that they're not used to, but...I don't care about that. I'll do it ...because she's so important to me.

Emily focuses on her strong desire to bring her own mothering capabilities more in line with what she calls being a “normal mom,” who is able to do the sorts of things a mother *should* do with and for her daughter. While her brother and mother willingly and capably fill in where Emily cannot, Emily rejects this as an acceptable long-term scenario. Uncles and grandmothers, in Emily’s local moral context, are technically capable of performing parenting duties, but they cannot provide the moral equivalent of “mothering.” She acknowledges that the transplant will come with new challenges, but they are eclipsed by Emily’s great hope that the transplant will “fix” her and allow not only herself, but also her daughter, to be freed from the confines, complications, and implications of kidney failure and unmanageable diabetes. To not opt for a transplant would be to fall short of fulfilling her responsibilities as a mother.

The Social Weight of Transplantation as a “Restraint” to “Centrifugal Tendencies”

The examples presented thus far highlight instances in which patients themselves push toward transplant out of a sense that the procedure will enable them to better fulfill their duties and roles as caregivers to others. As we have seen, the obligations of care can include particular practices, as well as the provision of protection from worries, fears, and even the inconveniences of serious illness. The feelings of being out of line with their obligations toward others as a result of their ill health, expressed by Mr. S, Betsy, and Emily, speak to broader social and cultural understandings about the moral expectations for mothers, fathers, husbands, wives, grandmothers, uncles, etc.

Durkheim offered several insights on the nature of obligation in social life. He noted, for example that, “[b]ecause we fulfill this or that domestic or social function we are caught up in a network of obligations from which we have no right to disengage ourselves (Durkheim 1984[1893]: 173). Seen in this light, we might say that none of the persons I observed in my fieldwork (since they all were pursuing transplantation) found it to be within their rights to eschew the procedure, even if they had reservations about it

(this will be explored further below). In his later work, *Suicide*, Durkheim approached the tensions between individual desires and the collective forces of society:

...each of us has a double impulse. We are drawn in a social direction and tend to follow the inclinations of our own natures. So the rest of society weighs upon us as a restraint to our centrifugal tendencies and we for our part share in this weight upon others for the purpose of neutralizing theirs. We ourselves undergo the pressure we help to exert upon others.
(Durkheim 1951 [1897]:319)

Not only are obligations in social life beyond a matter of individual choice, he argued, but something to which we tend to adhere “*irrespective of any utilitarian calculation of helpful or harmful results*” (Durkheim 1995 [1912]:209, emphasis in original). Further,

...the hold society has over consciousness owes far less to the prerogative its physical superiority gives it than to the moral authority with which it is invested. We defer to society’s orders not simply because it is equipped to overcome our resistance but, first and foremost, because it is the object of genuine respect. (Durkheim 1995 [1912]:209)

Indeed, the persons I have described thus far in this chapter seemed to revere the kinship obligations they cited. This is not to say that there is no room for resistance or leeway for people to act against the grain, so to speak. Certainly not all people with the kinds of health problems that transplantation is able to address *always* pursue the procedure (see, e.g., Gordon 2001). But I also encountered instances in which people pursued transplantation, even though they may not fully have *wanted* to do so. Kinship carries with it not only obligations, but rights as well. Notably, I met persons during fieldwork who probably would not have sought a transplant, if it had not been for others laying claim to the rights associated with kinship and reminding patients of their obligations. The following sketches, then, will round out the ethnographic picture, underscoring the notion that the moral obligations of kinship are social in nature, are shared and reciprocal, and are continuously worked out and reinforced in relation to those *surrounding* potential transplant candidates as well. While the first vignettes included persons who did not give real consideration to paths other than a transplant, the following cases highlight instances in which patients initially resist transplantation, but then are challenged, even reproached, by others for stepping out of bounds not only of what is expected of them, but what is needed of them.

“I really didn’t think I needed it, but everyone convinced me I did...”

I first met Blaine, in his mid-thirties, on the solid organ transplant unit. He was coming to the end of the relatively short portion of his post- pancreas transplant recovery that would take place in the hospital. Shortly after I introduced myself to him, a young woman who was Blaine’s nurse came in and handed to him one of the small plastic cups full of pills that punctuate daily life as an inpatient. He expertly swallowed them all at once with a few sips from the straw of his oversized plastic water jug, bearing the hospital name and logo, which was a standard issue to all inpatients. Upon becoming an outpatient in the next couple of days, these tiny pill cups would quickly be replaced by the 7-column by 4-row “pill tray” (an example appears below) present in most transplant patients’ private living spaces.



Figure 2: Weekly pill organizer tray.

Although he currently lived in a small city in a sparsely populated area of the state, Blaine would spend the remainder of his recovery time in the house in which he’d grown up, located in an even smaller town in another very rural area of the state, under the care of his mother. He would recover there because his wife of ten years struggled with an ongoing addiction to prescription drugs and he and his parents feared that his wife might begin stealing and taking his pain medication.

In a later phone conversation that we had, Blaine told me about the encouragement he’d felt from his family to go ahead with the transplant, even though in his words, *“I probably wouldn’t have went through the surgery [without] my mom pushing me because I just didn’t really think I needed it a whole lot, but everyone kind of*

convinced me I did so....” One major reason for Blaine’s hesitation was his concern that he would not be able to make the payments for his modular home and pay his other bills if he’d have to miss so much work while recovering. Though he had worked in the sheet metal department for a local construction company, he now relied on Medicaid and Medicare for his health insurance. As Blaine explained about his insurance providers, “they don’t cover everything all the time.” He doubted, for example, that his home health care expenses would be covered. On top of the financial hardships, Blaine had been concerned about whether the surgery would even succeed and have the intended effect of alleviating his wildly fluctuating diabetic blood sugars. He told me he’d become diabetic at age 9 as a rare complication of chickenpox, and like many who are considered to be candidates for a pancreas transplant, Blaine’s blood sugars were not well controlled by even the most careful monitoring and treatment. His low blood sugar episodes were comparable to Emily’s, described above. As Blaine explained, his family “...*really pushed ... for it [the transplant] because they hated the low blood sugars. They really had to take care of me a lot because I was having a lot of [them]. [...] I'd pass out sometimes and they'd have to call the EMTs...I wasn't interested in it [getting a transplant] at all really and my mom and my dad kind of persuaded me to go through with it...*”

Blaine had adopted his wife’s daughter, now in her early teens, when she was 3 years old. He had helped to raise her from 6 months old, and currently is her primary caregiver, as his wife’s drug use hinders her own ability to parent. Thus, between needing to remain healthy for his daughter who relies on him for her daily needs, and being told by other family members that the low blood sugar episodes were becoming too difficult for them to handle, in spite of his initial hesitation, Blaine’s decision about whether to undergo a transplant was inseparable from his obligations to members of his kin group. In the local moral world (to borrow Kleinman’s term) of his immediate and surrounding circumstances, opting for a procedure that would come with notable risks, even with no guarantee of a successful outcome, was the responsible and caring action to take.

The final vignette of this chapter offers another illustration of the Durkheimian “restraint to our centrifugal tendencies” at work in transplantation. Here, a patient would rather give in to her illness than undergo the agony of further medical treatment, but her loved ones act as a counter to her own wishes and firmly nudge her back in line with her moral obligations to her family.

“Your family needs you!”

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 devout Catholic in her later fifties, 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 10-20% to about 50%. Just four years earlier, she had been diagnosed with – and had beaten – breast cancer. Annette recounted how her friend, her husband, and her sisters all worked to convince her that she had to attempt the chemotherapy and transplant, because she was needed here, in *this* life.

Her sister, Lynn, summed it up well during a long and poignant conversation at her kitchen table:

I felt it was really important that we rally around her and pull her through this because she really had no desire to do it. And that upset me more than anything, that she just wanted to let this be the end, ‘I’m done.’ And even when she was in the hospital and I was up there with her, one day she said to me when she was really in the depths of it, she said “I just want, just tell them to just let me go. I want to be done.” And I said, “But you’re not done and if I have to drag you through this I’m going to drag you through this! Your family needs you!” Her daughter had just had a baby and was living at home. There were a lot of things going on and I said, “Annette you just cannot leave them hanging. She needs you a lot right now.” And we had that conversation more than once when I was up there with her.

No one, of course, would have physically forced Annette to undergo a transplant, but the procedure nevertheless was the compulsory path to take as a mother, a wife, and as a sister. While Annette was ready to accept death, her family members were not. Despite

Annette's own wishes or desires, her family, Lynn pointed out, *needed* her – Annette was *obligated* to live, or at least to try to do so.

Additional examples abound, spanning age groups, gender, race and ethnicity, rural and urban contexts, and class. This research found that adult children care for aging parents who cannot live independently; fiancés want to be well enough to follow through on their wedding plans; husbands care for wives with dementia and other health problems; grandparents hope to live long enough to teach their grandchildren what it means to be a farmer. Transplant patients are by no means a homogeneous group. But with very few exceptions, those whom I met in the course of fieldwork could be said to provide care to others in some form or another. Loved ones *rely on* transplant patients, and most transplant patients are very conscious of this, even as they grapple with the challenges and problems that come with undergoing transplant.

Moral Imperatives and the Shape of Biomedicine

Barbara Koenig (1988) has written about the “technological imperative” in biomedicine— that is, the emphasis on using the latest technologies less because they are effective and more because they are there. She argues that, in contemporary biomedicine, the technological imperative tends to translate into a *moral* imperative to provide new, increasingly high-tech therapies as the “standard of care.” The evidence presented in this chapter suggests that this “moral imperative” is deeply enmeshed with the kin obligations that persons carry out in their daily lives.

Biomedical solutions neither exist independently of the larger social context, nor should they be considered a sort of prime mover. I submit that the increased reliance on transplantation has as much to do with persons viewing it as their most viable way of putting into practice a powerful set of morals about their obligations to others, as it has to do with new breakthroughs in biomedical technologies. I do not dispute that biomedicine is a powerful shaper of “the normal” (e.g., Lock 2002). Undoubtedly, it is a major component of the context of our times. I also do not dismiss the notion that already-existing bio- [and other] technologies can change our expectations about illness, health, birth, life, and death (e.g., Lock 1997). Further, there is ample empirical evidence that

biomedical practices can influence local understandings of kin relatedness (e.g., Thompson 2001, and also see Chapter 7 of this dissertation). All the same, biomedicine and other forms of technology should not be assigned agency that they do not have. My own findings thus support the reciprocal notion that existing moral notions of, for example, what a “normal mommy” should do (or be) for her young child, can in turn increase the likelihood that a procedure like transplantation can come to be taken as something that is practically beyond a matter of choice. In other words, moral obligations such as those which inhere in kin relatedness can augment the “moral authority” (to return to Durkheim’s insights) of biomedical approaches like transplantation. This phenomenon, in turn, might be influential in fueling demand for transplant-related goods and services, and in further supporting “new” developments in biomedicine.

Conclusions

To conclude what I have tried to demonstrate here, everyday lived moralities concerning kinship and other obligations articulate with biomedicine in ways that have meaningful consequences regarding the uptake of biomedical practices like transplantation. Patients are members of complex and reciprocal webs of care and obligation. Though the particulars of individual case examples can differ significantly, the product of patients enacting their values surrounding kinship and obligation in the context of interpersonal (and collective) processes is that transplantation becomes *the right and caring thing to do for one’s family and loved ones*. Organ and tissue transplantation can be more holistically understood as a social phenomenon and as a moral exchange in light of the evidence presented here, that transplant candidates and recipients are neither uncritical or passive consumers of biomedicine, nor purely self-interested persons who seek simply to live at any cost, but rather are simultaneously caregivers with significant moral and kinship obligations – which they can fulfill only by remaining alive and [more] well for the foreseeable future. Even if they personally are reluctant to pursue transplant, patients’ kin and loved ones can be quick to enforce the social moral code that holds them equally responsible as caregivers. Overall, when faced with the problem of incapacitating illness, patients who otherwise are unable to fulfill

their caring roles and expectations instead come to express and practice their care by turning to the particular solutions offered by biotechnologically-intensive medicine, despite the formidable risks and challenges.

Chapter 4:

Local Moralities, Kinship Obligations, and Reciprocal Webs of Care, Part 2: **Caregivers-As-Patients**

This chapter will pick up on a point that was introduced at the very beginning of the previous chapter, in which Mr. S remarked that “my wife has a lot of health problems, and I take care of her and she takes care of me.” Here, I intend to make the case that the health of supportive persons in a transplant candidate or recipient’s kin or social network (caregivers) is so intricately interconnected with the transplant endeavor that caregivers themselves can also be (or can become) patients through the transplant process. This case will be supported by carrying over two major threads from the previous chapter. The first is the notion that, under the circumstances of and local moral obligations in transplantation, the boundaries can fade between the categories of “patient” and “caregiver.” The previous chapter argued that patients are not passive recipients of care, but rather actively serve as caregivers to others who rely heavily on them. This is true in a literal way, in the sense that transplant patients often are the main care providers for their young children or an aging parent, or a spouse who also suffers from serious health problems. But just as importantly, the very pursuit of a transplant can be an act of care in itself, borne out of an obligation to remain alive and available to be there, and to care for, others. This chapter will in turn examine some of the ways in which those surrounding transplant candidates and recipients – caregivers – can in fact simultaneously be patients during the transplant process.

The second thread which links this chapter to the previous one has to do with continuing to work upon a broadened notion of care and here, “caregiver.” Olesen has argued that greater attention needs to be paid to informal or “hidden” care in its many diverse forms, provided by both women and men, who should be conceptualized not only

as providing care but also as producing health (1989: 5). This theme was outlined in the previous chapter, where I argued that care can take several forms—some subtle and some overt. Here again I will describe instances in which kin willingly make tremendous sacrifices for one another, in which short-term health and well-being are given up in exchange for the prospect of health, well-being, and life in the longer-term (Olesen's notion of "producing health" is quite germane here). It should be noted that important exceptions exist: not all carers consider their giving care to be a burdensome act (also see Casida 2005 and Schultz and Sherwood 2008), and not all relatives are willing to make these types of sacrifices for one another, as will be illustrated elsewhere in this dissertation.

Here, we will explore three contexts in which caregivers can simultaneously also be patients during the transplant process. The first we will examine occurs when the person who is the main source of support for a transplant recipient also deals directly with matters of their own health status throughout the process. The second and third involve living organ donation. While I initially did not expect to meet persons who concurrently served as direct informal caregivers *and* sought to become living organ donors to the person seeking a transplant, over the course of fieldwork I did indeed encounter such scenarios. I also met family members who previously had not shared an emotionally close relationship with the transplant candidate, but nevertheless offered to become living donors, and in performing this particular caring act, simultaneously became both patients and caregivers (not only in the sense that giving an organ is an act of care, but also in the sense that they became an important part of the recipient's web of support).

One important distinction between this chapter and the previous one is that, in my observations, there appeared to be greater moral certainty surrounding the ways in which patients are caregivers to others. Even though some of the persons I described may have come to transplantation with some reluctance, there was little doubt – on their part, or on the part of their loved ones – about the idea that kin *ought* at least to try to continue living in order to be there for one another. But the instances I will describe below shed light on living donation as a moral field that is much more ambiguous and in need of careful negotiation by all parties involved. In other words, the idea that patients are also

caregivers throughout the transplant process seems to exist on much firmer moral ground than does the idea that caregivers can also be patients in transplantation.

A unifying theme, however, is that for all three types of scenarios to be explored in this chapter, to varying degrees and in different ways, the health of a transplant candidate's kin became intertwined with the transplant endeavor to the extent that they ought not to be considered caregivers only, but patients as well.

Who Is The Patient Here? Caregivers' Health In The Context of Informal Transplant Care

While caregivers' health in particular was not a major focus of this study, the issue arose often enough over the course of my fieldwork to warrant attention. A fair amount of research has focused on the toll that transplant-related caregiving responsibilities can take on the carer's mental health, well-being, and sense of quality of life (Peterson 1985¹⁶; Wicks et al. 1998; Siston et al. 2001; Canning et al. 1996; Dew et al. 2004; Burker et al. 2005), some of which highlights the burdensome aspects of caregiving. For example, in a study of psychosocial adjustment and distress among 40 bone marrow transplant patients and 39 of their primary caregivers, Siston and colleagues found that caregivers reported similar or greater levels of distress when compared to patients (Siston et al. 2001: 1186). The researchers speculated that this had to do with the changing role and additional responsibilities that caregivers find they must take on in the interest of helping their partners through the transplant process (Siston et al. 2001). And in a 2004 study, Dew et al. focused on the prevalence and timing of onset of *clinically diagnosable psychiatric disorders* in a representative sample of 190 caregivers to heart transplant recipients throughout the first 3 years post-transplant. They noted that the cumulative rates of disorders among the study population were higher than the rates found among the transplant recipients for whom they were caring (as reported in previous studies by Stukas et al. 1999 and Dew et al. 2001, cited in Dew et al. 2004). The authors had expected that transplant caregiving might be different than other forms of chronic illness caregiving because transplantation is expected to *improve* patients' health (cf King

¹⁶ Although Peterson's study was not focused on transplantation, but rather on dialysis, it is relevant because kidney transplant patients very often have to undergo dialysis while they wait for a donor organ to become available.

and Koop 1999), while other types of chronic illness are so often marked by steady declines in patients' health. But by the end of the study, the cumulative rates of disorders among the study population were similar to or greater than those found in other studies of (non-transplant) family caregivers.

Less common in empirical literature on transplant caregiving is an explicit focus on the interrelationship between transplant caregiving responsibilities and transplant caregivers' *physical* health. Probably coming closest was a study of 83 primary family caregivers to heart transplant recipients, conducted by Canning and colleagues (1996), which detected a relationship between physical health and mental health in transplant caregiving. But again the focus was particularly on psychological distress. The authors concluded that psychosocial factors such as employment status, personal resources, and social support, as well as caregivers' physical health, were associated with long-term effects on post-transplant psychological distress among caregivers. However, in the absence of research specifically having to do with transplant caregiving, comparisons can be made to research regarding the relationship between physical health and other types of informal caregiving. One study by King and Koop (1999) among a non-randomized sample of 120 cardiac surgery patients (60 men and 60 women) in Alberta, Canada, found that 30% of their caregivers reported having a significant health problem of their own. Research on the relationship between physical health and caregiving also has received some attention in aging studies literature, (e.g., Pinquart and Sörensen 2003, 2006, 2007; Schultz et al. 1995; Vitaliano, Zhang, and Scanlan 2003). In a meta-analysis of 176 studies on caregiver physical health, Pinquart and Sörensen (2007) found the following factors to be related to worse physical health among caregivers to older adults: severity of care recipient behavior problems and cognitive impairments, length of time spent in the caregiver role, co-residence with the care recipient, being a non-spousal caregiver, higher caregiver burden and depression, higher age, lower socioeconomic status, and lower levels of informal support (2007:131). In another meta-analysis of 23 studies comparing the physical health of informal caregivers to dementia patients with that of non-caregivers, Vitaliano, Scanlan and Zhang (2003) found that caregivers had a 23% higher level of stress hormones and a 15% lower level of antibody responses (both considered physiological indicators of health risks) than did non-caregivers. Two meta-

analyses that examined both physical and psychological health together found greater evidence supporting the negative associations between psychological health and caregiving, compared to evidence supporting negative associations between physical health and caregiving (Pinquart and Sörensen 2003; Schultz et al. 1995; also see Schultz and Sherwood 2008). Nevertheless, much of this research upholds the idea that mental and physical health are interrelated, as reflected in an introductory remark by Schultz and Sherwood (2008), who noted: “The associations between physical and psychological health and being an informal caregiver are well established.”

Over the course of my own field research, I took no formal objective measures of caregiver mental health, quality of life, or well-being. I did find evidence that transplant caregiving can be a tremendous responsibility, and I met many caregivers who (usually willingly and without complaint) sacrificed a great deal in order to provide practical and emotional support to their loved ones in need of a transplant. Quite often, perhaps because transplantation can tend to be such a physiologically-focused domain, caregivers told me about their various physical health problems that had already existed well before their loved one came to need a transplant. Overall, the data and insights I offer below have to do with the ways in which caregivers’ physical health is *intertwined with* their provision of support throughout transplant process.

Decline in Health, Decline in Employment, Better Position to Care? Caregivers Who Are Patients

Members of one kin network whom I came to know in this research (Annette, a blood-forming stem cell transplant recipient; her husband; and two of her sisters all became participants) spelled out the interlinkages between the health of one caregiver – Roberta – and her *availability* over the course of the transplant to care for Annette. Before I elaborate on this point in particular, I will take a brief detour to offer a more thorough description of Annette’s reciprocal web of care. This temporary “long road” approach offers some emic critique of assumptions that caregiving is inherently burdensome (and thus a detriment to one’s health). Annette and her siblings were noteworthy in their mutual consideration of care to be a reciprocal *investment* in each other’s health.

“Annette’s Balcony Club”

Annette, who also appeared in the previous chapter, had a large extended family with many siblings and their spouses and children living in the same city. Not only were the members of Annette’s family (both her family of origin¹⁷ and her family of procreation¹⁸) living in relatively close proximity to each other, but they also were emotionally and socially close. Annette said she talked on the phone with each of her siblings at least once a week, and with some of them daily. When I asked Annette who helped her most through her transplant, she had a long list of individuals who were there for her. She had help from several of her family members, from a few of her very close friends, and from members of her church. This fits with the “hierarchical-compensatory model” of care, proposed by Cantor (1979), in light of her findings from a study among 1,552 elder inner-city residents of New York City that residents turned first to family members, then to friends and neighbors, when they needed informal care assistance or support.

As a tangible reminder of the support with which she was surrounded throughout her illness, Annette still has two sweatshirts that her family had custom-printed for her: one for each set of cancer treatments she has been through. Annette herself and her siblings all have a strong Catholic identity, and the first sweatshirt has “Annette’s Prayer Team” written on it, along with the names of family and friends. The second one has a family picture on it, with “Annette’s Balcony Club” written on it, inspired by a Christian literature book that Annette and her sisters had read by Joyce Landorf Heatherley (1984) called *Balcony People*, which is about the persons in one’s life who support you and “cheer you on.” She still wears them occasionally, especially on those days when she doesn’t feel well or is more tired than usual.

Indeed, Annette considers the care she received from her family members to be a reciprocal engagement among team members—not “tit for tat” so much as a mutual *investment* in each other’s health and well-being. She put it eloquently:

I did a focus panel at the Transplant Center about transplant and treatment. They asked everyone around the table if they felt cancer had been a burden to their family. I said,

¹⁷ This would include her parents and siblings.

¹⁸ This would include her spouse or partner and their children.

“No, it brought us closer together.” Like my sister taking me to treatments, that was her investment in getting me well. They are investing in returning me to health; I don’t consider that as a burden. [...] I was the only one of ten people who said I don’t feel I’m a burden.

While most of the participants I met through fieldwork were part of mutually supportive kin networks, Annette enjoyed exceptional support, where multiple persons not only met her needs, but anticipated them in advance and went well beyond doing just the minimum they could do to help. For example, during the week she began her treatments the first time, her refrigerator and stove both broke down, so Annette’s sisters and brothers all pooled money together and her sister Roberta took her to the local furniture and appliance store to pick out new ones, all without Annette or her family asking or even expressing a wish for her siblings to do so.

This tradition of family members helping one another preceded Annette’s struggles with illness. A sister had died of breast cancer and a brother had died of lung cancer before Annette had received her own initial diagnosis, and the siblings had come together to support them as well. Lynn in particular was involved in the process with their two siblings who had died. She had taken both the sister and the brother into her home so that she could care for them there as they fought and lost their battles with cancer. (The fact that a sister and a brother both had already died of cancer was significant in Annette’s family strongly encouraging her to accept the stem cell transplant treatment for her own cancer, even though she herself was hesitant, as we saw in the last chapter.)

Annette’s husband also had been a major source of support. Ever since she had sustained a head injury in a serious car accident – well before she needed a bone marrow stem cell transplant to treat her lymphoma – he already had taken over much of the everyday domestic labor like doing the laundry, which previously had fallen more to Annette (and had followed the gendered divisions of labor with which many white middle-class women in Annette’s age range were familiar). But, she said, since her husband also works full time, he would have had to take unpaid time off from his job in

order to take her to her many medical appointments, or to stay with her in the daytime during her hospitalizations.

One of Annette's sisters, Roberta, has multiple sclerosis and had just newly taken disability retirement from the county's Primary Health Care Department, shortly before Annette had learned of her diagnosis. In the job from which she'd just retired, Roberta had worked in medical billing at the county health level, and thus had extensive knowledge and expertise to offer Annette in dealing with the complicated tangle of her medical bills. This tangle involved Medicare, private health insurance, physicians' bills, hospital bills, and medication costs, so Roberta's willing assistance in this arena alleviated a great deal of stress and worry about the financial aspects of Annette's treatment (more will be said of this in the discussion of U.S. health policy in Chapter 7).

But just as important, Roberta no longer had to report daily to a place of employment. Though her disability prevented her from being able to climb the several steps up to Annette's house (and thus she could not offer help in Annette's home), Roberta still could drive. Therefore, with her now relatively open and flexible schedule, as well as her access to a car and ability to drive, Roberta was able to take Annette to all of her outpatient appointments. Annette told me that she and her sister were already very close, and became even closer throughout their experiences together and the fact that Roberta had become very attuned to Annette's needs. Annette put it this way:

I was always more comfortable with Roberta there. It just worked. She knew when I was really fearful or tired. We had a prayer we said every time I started a treatment.

And when it came time for Annette to be hospitalized for the actual transplant, Roberta was able to spend every day with her sister while she was there. Annette suggested that I should talk with Roberta as well, and took the lead in introducing us to each other via email. Roberta said she would be happy to meet with me, so we made arrangements for an interview. In the following, I give an extended description of Roberta's home environment, and the setting of our interview. Even though Roberta was a caregiver, much of the context I present here closely resembles the contexts of other invited visits I made to the homes of transplant candidates and recipients. This is relevant because it suggests that Roberta might have been attuned to Annette's needs because she herself had become oriented toward some of the potential challenges posed by health issues. In any

case, it highlights how shared experiences of the up's and down's of illness, which also can materialize in the home environment and home life, might provide another level at which convergences can take place between the status of "patient" versus that of "caregiver."

At Home With Roberta

When I parked my car in front of the garage attached to her ranch-style, one-level house, and walked up the two steps to the front door, Roberta was already standing in the doorway with her walker. Like her sister, Annette, Roberta was warm and almost instantly familiar. She said hello and asked me if, on my way in, I could grab a small box that the postal delivery person had left on her door step. She asked where I'd like to talk—in the kitchen or the living room—and I said I was happy to go wherever would be easiest for her. She said the living room was probably easiest, so I took the couch and she sat in a lifting recliner chair, situated opposite the couch, then reached into a pouch on the front of her walker containing a cordless telephone, remote control, and other things she liked to keep at hand. She took out the remote and pointed it at her stereo to turn off the classical music which had filled the room. After going through the written informed consent process, Roberta told me that she first would like to let her two large dogs in, one by one, and that she'd waited to do so because she knew they would think I was there to see them and would be very excited at first. Once they get used to you, she told me, they'll settle down. True to her predictions, after some initial exuberance, each dog soon decided simply to lay or sit nearby. Roberta asked me if I wanted something to drink, offering water, juice, or anything else I might like. I agreed to some water, and she sent me to the kitchen with instructions to take a glass from the cupboard located – as it is in so many other households in the Midwest – above and to just to the side of the sink, and then to fill my glass at a small station which held a large inverted jug of water, and at its front, a blue tap for cold water and a white tap for water kept at room temperature.

"It was good for all of us..."

We eventually got down to talking about her role as Annette's caregiver. I asked her how much time she had spent in the hospital with her sister, and Roberta replied:

Everyday. I got there at 8am and stayed until her husband got off work, sometime between 3 and 5, and he'd stay until our other sister [Lynn, introduced in the previous chapter] got there at night. And then Lynn would spend the night with her. [Annette's husband] would go in in the morning before he went to work, and stay 'til I got there at 8. So someone was with her at all times.

She added, "We didn't want her [to be] alone, ever." Their sister Lynn slept on a cot in Annette's room every night, and got dressed every morning and went from the hospital to the elementary school where she worked as a Teacher's Assistant. She would wait to leave until Annette's husband arrived at 6:30 or 7:00am. On the days when he would arrive earlier than that, Lynn would be able to drive home from the hospital to shower and change her clothes there before work. Annette's husband then stayed until Roberta arrived at 8:00am, and then returned to the hospital after his workday to relieve Roberta, staying until Lynn arrived for the night, and the routine would begin again. Roberta recounted, "...and of course she thanked us a thousand times, but ... it was good, it was good for all of us."

It was not long at all before Roberta made it clear that she and Annette have helped *each other* out as each has needed the other's assistance and support through the different health problems each of them has encountered over the years. When I asked how Annette's cancer and transplant affected her daily life, Roberta spoke to the reciprocal nature of their emotional and practical support toward each other:

I've always been glad to be alive and I know that everything is a blessing. I really believe that. Every day is a blessing and I think that's part of it and what this stem cell [transplant] has done. It's taken Annette... knowing what she knows now if she had to do it again she would. It's just completely changed her life. Well, then that to me changes my life too. Because I broke my hip. She was there for me. She comes over, you know, she lives as far north as I live south [in the city] and gas prices, she'll still drive and take me to the doctor, take me to the grocery store. She'll take me anywhere I wanna go and do anything I need. And she's met so many people I think and touched so many people's lives and she'll say, "Ok guys, you've got a lot more people out there to touch." And that's what I think people need to do. I think we get a calling to do that.

And indeed, Annette has “given back,” or offered her own efforts toward the well-being of others beyond her kin network. She now regularly volunteers her time to “Look Good, Feel Better,” a nationwide program in which volunteers teach beauty tips and techniques to cancer patients to help them counteract some of the appearance-altering side-effects of cancer treatments.

As described earlier, rather than feeling guilty or ashamed for having to accept so much care from her family, as other transplant candidates and recipients sometimes described their own feelings about needing help, Annette considered her family’s care to be an investment in her health. In turn (but not so much in return), Annette now drives her sister Roberta to her appointments and errands, and stays with her during her hospitalizations. This parallels Olesen’s argument, mentioned above, that greater attention ought to be given to the ways in which informal, hidden, and diverse forms of care actually produce health.

This description of Annette’s web of care illustrates an instance in which a caregiver’s own status as a patient actually enabled her to be there with and for her loved one through the transplant process. In her struggles with significant health issues of her own, Roberta also held a refined sense of understanding and empathy, and could offer well-informed support for her sister. The picture can be complex, however, and can involve ambivalent perspectives and emotions. In another case – that of Mary, a small bowel, liver and pancreas transplant recipient, and Rob, her husband and primary caregiver – the transplant caregiver was at once grateful to be able to provide support *and* in a state of suffering brought on by the very health conditions that had better positioned him to be able to care for his wife.

“...as my vision decreases, as the way I see it, the importance of my jobs that I’ve had have also decreased”

Although Rob has been Mary’s primary caregiver throughout her small bowel, liver, and pancreas transplant journey, he endured ailments of his own. For example, Rob suffered from a painful back injury, for which he needed to take medication, and which limited his ability to work full-time. Many years before, he also had developed severe

glaucoma, which was the initial cause of his decline in employment status. I learned this when I asked him to tell me about the kind of paid work he's done over the years.

I've done all of kinds of different jobs. I mean, I started working when I was 12. I've done all kinds of different jobs. I graduated high school. I have a diploma in electronics. I did work in electronics for...probably 10 or 12 years. I have severe glaucoma. My vision is decreasing; as my vision decreases, as the way I see it, the importance of my jobs that I've had have also decreased. Now...one day a week they let me [work at] the same [grocery] store she [Mary] works¹⁹ at, as a cashier. That's just to cover insurance. Before that I was doing maintenance over at [a local food processing plant], and before that was electronics.

It is evident as Rob describes his changes in employment that he would rather be working in electronics than as a supermarket cashier. And the difference in pay between these two lines of work is significant and affects the family's ability to cover their monthly bills. At the same time, his employment status (which is linked to his health status) also has allowed him the flexibility in his schedule to be at Mary's side through all of her health struggles. This seemed to mitigate, at least temporarily, some of Rob's dismay at not being able to work the kinds of jobs he would prefer. And as we shall see in the following chapter, Rob had mixed feelings about Mary's health slowly improving and her care needs decreasing over time, since it would also mean that he could become less useful to her and *still* be unable to work his preferred type of paid employment.

A Well-Practiced Team

Another feature of the caregiving relationship between Roberta and Annette was that they each seemed to work with the other, at once recognizing each other's strengths and limitations, and alternately "taking the lead" as their respective needs evolved over time. Likewise, Mr. and Mrs. S exemplified a patient and care partner acting in concert as a well-practiced team. Mr. S pointed out very early in our acquaintance, during their morning of back-to-back appointments with the transplant team, that his wife also had "a

¹⁹ At the time of our conversation, Mary was not working because of her health status. However, her employer had assured her that she could return to work there if she ever felt up to it. Such assurances about future employment actually were quite rare among the participants I met in this study.

lot of health concerns,” and the two of them took care of one another. At the time, however, Mr. S was in poorer health and had begun to have greater care needs than Mrs. S, whose health needs prevented her from being able to work full time, but did not require regular assistance. Further, as mentioned in Chapter 2, Mrs. S had taken over the primary responsibilities for coordinating her husband’s numerous prescriptions. At the same time, each partner was very involved in the various consultations they had over the course of the morning. Even with regard to Mr. S’s medications, the couple’s team approach to their separate but shared health concerns was evident as they discussed and compared the different prescriptions that each was on for their various conditions, during their visit with the pharmacy financial counselor, even though the counselor was there only to discuss Mr. S’s current and future medication regimen as it pertained to his potential transplant.

Further, both Mr. and Mrs. S had been approved to receive disability benefits due to their respective health issues, and were able to have a very sophisticated conversation with the transplant financial counselor about how their household finances and each persons’ health insurance might be impacted by the changes (in health status, in medication needs, and in ability to work) that would come with a transplant. It was evident that both partners saw the transplant, despite the challenges that were certain to accompany it, as an investment in Mr. S’s health which, if it improved enough, would allow him to return to work and attain a better income for both of their well-being.

All of the cases I have described thus far have offered illustrations that caregivers very often literally *are also patients* during their journey with loved ones through the transplant process. This already-existing patient status opens up new connecting points at which transplant patients’ health and well-being can become interwoven with the health and well-being of the persons comprising their reciprocal webs of care. The second half of this chapter offers an examination of “caregivers-as-patients” from a slightly different perspective—that of living organ donation, in which caregivers, in fact, *become* patients as they accompany their loved one through the process.

Giving Care Through “Gifts of Life”: Caregivers Who Become Patients

A broadened notion of care allows us to examine care in its most subtle and hidden forms; it also enables us to conceptualize scenarios that might otherwise not at all be categorized as “caregiving.” In the case of transplantation, this can include living organ or stem cell donation. In many instances, kin make notable sacrifices to help transplant candidates and recipients through the process. Living donation, though, is perhaps among the most extreme investments in another person’s health that can be made.

I encountered instances in which parents became the living kidney donor to an adult child, as well as scenarios in which adult children donated to a parent, or had themselves tested to see if they could donate. Contrary to my initial assumptions as I entered into this research, primary informal caregivers occasionally *do* also in fact become living organ donors to their loved ones. Spouses, so often the “default” caregiver, also could be the first in line to be tested for donor-recipient compatibility. Notably, despite her many health concerns, even Mrs. S inquired about the possibility of her becoming a living kidney donor to her husband.

An Overview of Living Donation

A potential recipient may wait years for an organ from a deceased donor to become available, but their wait time can be significantly reduced in cases where a willing living donor can be identified. The first instance of living organ donation was also one of the earliest successful kidney transplants, performed in 1954 by Dr. Joseph E. Murray and his colleagues at Peter Bent Brigham Hospital (now Brigham and Women’s Hospital) in Boston, Massachusetts, where he successfully transplanted a kidney from Ronald Herrick into his twin brother, Richard Herrick (Lock 2002). But living donation did not comprise the majority of transplants for long, and in the following years, more organs soon came from deceased or brain-dead donors (see Lock 2002). On the other hand, according to the 2009 OPTN/SRTR Annual Report while transplanted organs from deceased donors still outnumber those from living donors, living donation has comprised a substantial proportion of transplants over the past decade, and in 2008, 6,216 of all

transplanted organs came from living donors (as compared to 21,065 of all organs transplanted from a total of 7,984 deceased donors).

The vast majority of organs donated from living persons are kidneys; in 2008, nearly 96% of organs from a living donor were kidney, while only 250 (4%) were livers (or rather, a portion thereof, since living liver donation is only possible because the donor can regenerate the portion of a liver removed for transplant). These two organs comprised the only type of living donations in 2008, compared to 2007, during which six living donor transplants were of lungs and one was of a portion of intestine (there were no living donations of a pancreas or heart that year, even though such procedures had been performed in small numbers in the past.²⁰ (2008 OPTN/SRTR Annual Report)

Among kidney transplants in 2008, 5,966 were from living donors, and 10,551 were from deceased donors (Axelrod, et al. 2010). The number of living donor transplants peaked in 2004 (at 7,004 transplants) and declined 10% by 2008 (2009 OPTN/SRTR), but there have been medical efforts to increase those numbers, for example, through the use of less invasive laparoscopic methods for procurement, and with improved immunosuppression methods, and the increased use of A-B-O blood-type incompatible living donation.

At the time of my fieldwork, the Transplant Center also was participating in a nationwide initiative in renal transplant known as “paired donor exchange” or “donor swapping,” which is designed to augment living donation and increase patients’ opportunities to receive a kidney. In some cases, a transplant candidate may have someone in their life who is willing to donate a kidney, but they are not a compatible “match” for transplant. When a second, also incompatible donor-recipient pair is found, and when Donor 1 is a match for Patient 2 and Donor 2 is a match for Patient 1, the two pairs can choose to “swap” kidneys so that both patients can receive a transplant from a living donor.²¹ Figure 3, below, illustrates this process:

²⁰ A “living heart transplant” can technically take place during a domino-style procedure during which a cadaveric heart and lungs together are transplanted into a lung transplant recipient, whose otherwise healthy heart is then transplanted into a heart transplant recipient. This is performed only very rarely, and only in instances in which it is determined that the transplant is more likely to be successful if the cadaveric heart and lungs remain connected together.

²¹ Only one of the kidney recipients I came to know in study – Janet – had actually participated in a paired donor exchange. In this arrangement, her cousin had become a living donor to another patient, and in turn, Janet received a kidney from that patient’s incompatible donor. While this phenomenon carries with it

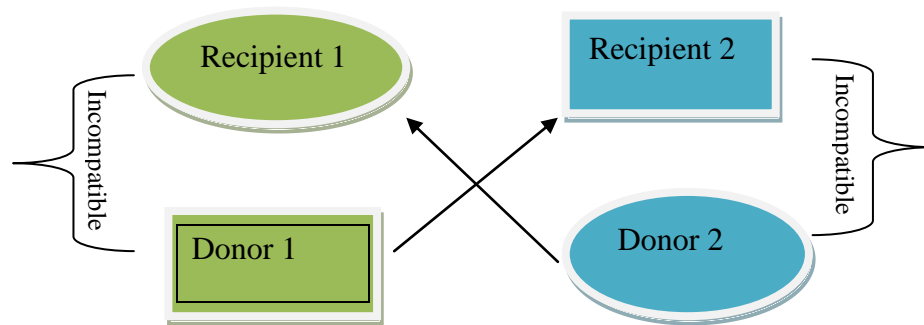


Figure 3: Paired Donor Exchange

With living kidney donation as an option, patients find they must consider whether or not they wish to pursue this as a possible avenue toward a transplant. Having a living donor certainly is not a prerequisite for a transplant. But candidates do learn early-on in the process that those who receive organs from living donors not only tend to have a shorter wait until their transplant, but often also have better outcomes than those who receive a kidney from a cadaver (Axelrod, et al. 2010). So as part of the initial evaluation process, those seeking a transplant are asked whether they have anyone in their life who may be willing to consider a living donation. I had not set out to do a study on living donation, but it eventually became clear that living donors also can be caregivers, and the practice is undeniably bound up with the matters of kinship, moral obligation, and care with which my research *was* directly concerned.

The Call to Give: Moral Ambiguities in Asking and Receiving

After a long morning of back-to-back evaluation appointments with members of the kidney-pancreas transplant team, Mr. and Mrs. S invited me to join them for lunch in

some of the same potential for the creation of relatedness among people who otherwise would be strangers, such connections are hindered in a similar manner to the potential connection between transplant recipients and deceased donor kin. Likewise, this is meant to be an anonymous exchange, where actual donor-recipient pairs do not learn each other's identities. I was given anecdotes from other participants who reported hearing of instances in which families overheard each other talking in waiting areas or patients discovered each other as they awoke from anesthesia in post-surgical recovery rooms, but Janet and her cousin never learned who their exchange partners were, and Janet did not express an interest in making an effort to find out this information.

the Transplant Center cafeteria. We fanned out to the different food stations to make our selections – choosing from the offerings of salads, a pizza and pasta bar, freshly grilled meat or vegetarian fare, or one of the entrées of the day – and then to the checkout lanes, which were busy during this noon rush. The lane I had chosen took longer to get through than theirs had, so that they found a table and sat down before I did. As I walked up to their table, I noticed that Mrs. S was talking on her cell phone. Mr. S told me that his wife had wanted to call their son right away to let him know that the financial counselor said that any living donor would be covered under Mr. S’s Medicare insurance. Serving now as both an information hub and an advocate for her husband, Mrs. S hoped to spread the news quickly to the rest of their family, thinking that others might be more willing to be tested for compatibility if they knew they wouldn’t have to shoulder the medical costs themselves.

The subject of asking someone to be a living donor frequently came up in my conversations with kidney transplant candidates, as it has for other ethnographers similarly interested in these matters. Focusing on what they called the “ethical field of kidney transplant,” Kaufman, Russ and Shim noted,

The recipients and prospective recipients we spoke with articulated a broad range of ethical opinion about the need and urgency to ask for and accept an organ, the obligation not to ask and not to take, and the responsibility either to wait years for a cadaver donor or to quickly solicit one’s own potential living donors. (Kaufman, Russ and Shim 2006:87)

I likewise found diversity among the participants with whom I spoke, though a unifying thread was that “asking” occupied a rather charged and morally ambiguous position among this group. One man said he would never consider accepting a living donation, even if someone had offered. I also observed instances in which patients very freely asked others to consider donating, although this, too, seemed to be less common. In some cases, as with Mrs. S, a spouse or care partner would put out the word on the patient’s behalf. A number of those in need of a transplant felt strongly that they never could *ask* another person to put themselves through the surgery, and would only consider living donation if someone freely and willingly approached *them* with the offer. One father and adult daughter whom I met had a great deal of perspective on the matter of “asking” and living donation, noting their struggles with the thought of someone else

electing to have a surgery – in essence, to become a patient – in order to save or improve another’s life.

“...sad and grateful at the same time”

When I first met Hank, a white man in his mid-sixties, he, his wife, and his adult daughter were sitting in an exam room, waiting for his next appointment to begin at the kidney transplant clinic. I had a chance to get to know him and his daughter Eliza better, though, during a conversation around Hank’s kitchen table on a mid-spring afternoon, surrounded by the smell of home-cooked roast beef that would later become the family’s Sunday dinner. Hank had been born and raised on a farm in the Midwest, and now lived with his wife in a small town not far from where he grew up, where they raised their three children, two of whom also now live in the same town and one just a short distance away. He had worked for many years in auto repair and auto parts sales, until the late nineties, when he and his wife bought a small garbage and yard waste service in their small town, which they still own and operate today. His wife now drives the truck full time; his son performs repairs; and he fills in where he can and as his health allows, filling requests for extra pick-ups and helping elsewhere as needed. Because of their garbage service, because of how long they have lived there, and because of their “the more the merrier” approach to their daily life and special occasions (like 4th of July picnics and camping trips that they regularly make open to others who might want to join them), the family is deeply rooted and well-networked within their small community. As Eliza explained, the town has around 4000 residents and her dad probably knows 90% of them. His familiarity within the community goes hand-in-hand with the tremendous amount of support he has felt throughout his dealings with serious health concerns.

Hank had needed a liver transplant in the early nineties because of a degenerative liver disease. He then had to have heart surgery in 2000, and now, almost 17 years after his liver transplant, he was in need of a kidney transplant. His kidney failure actually was precipitated by years of taking his immunosuppressant medication, combined with his heart medication and his diabetes. As he was beginning the kidney transplant evaluation process, the medical team found he had another heart blockage, and as he put it, true to the medical team’s predictions, the heart catheter procedure (and the dyes used in the

process) caused his kidneys to stop working altogether, and he now was on dialysis.

Eliza explained that, at their initial kidney transplant evaluation, they were asked to watch a video that explained the transplant process, including the clinical methods for determining donor-recipient compatibility. She found out that her father has blood type “O,” which differs from her own. Because his blood type is so common, there will be more people on his waiting list than on waiting lists for other blood types, which would increase his wait time for a cadaveric kidney. She added with a hopeful note that the doctor said that their difference in blood types would not necessarily exclude her as a potential living donor because they now look at an array of markers, and that she hadn’t even been tested yet for compatibility. Nevertheless, despite Eliza’s wishes, she likely would not be as strong a candidate to become a living donor as someone who shared the same blood type. But as she and Hank went on to recount the offers they’ve already had from others to be tested for compatibility, they described some of the features of this moral landscape. Here, ambiguity grows more intense as one moves beyond the more easily recognizable moral space of relations based on blood, marriage, or adoption, and out to the space of friendship and neighborliness.

Other boundaries come to light as the topics of “asking” and being inappropriately *made* to feel obligated come up. Notably, Eliza stands in wonderment – sad and grateful at the same time – at the capacity for generosity from people who are not blood relatives: *We also have had, you know whether or not it pans out to be anything or not, we’ve had a couple of friends that have already mentioned that they are ‘O’ positive and that they would be willing to get tested. And you know, we don’t know. We’re not sure how we feel about that yet. But I guess the way I felt about it, I was just unbelievably, it just kind of almost made me sad and grateful at the same time that somebody would even offer that’s not even an immediate blood relative. I just, to me that’s amazing, that a friend of your fa- you know, and I think it kind of speaks highly of my dad. Because I think if you know people would just be willing to say, ‘Well I’d get tested,’ that is kind of neat to me that people would do that.*

And Hank added that he felt *...pretty much the same. I wouldn’t ask anybody; I would never ask anybody to do that. I couldn’t. But I found it pretty remarkable that somebody would say, ‘Well hell, I’d give you a kidney.’ (Laura: This might be a dumb question, but*

why wouldn't you ask?) Well, I just wouldn't want anybody to... I think if I had to ask they would kind of feel like, 'Well geez, I guess I probably should. I know the guy, I've known him all my life and all this....' and I don't want people to think that, I guess.

I asked Eliza whether she felt like she might be in a position to ask people, on her father's behalf. She pointed to some of the instances in which people would ask about her father's health and her initial reaction to the outpouring of support she witnessed: *... and initially I sort of felt guilty when they would offer because I was like, 'Gosh, I hope they don't think that I'm saying this because I want them to be like, Hey you should donate because I might not be able to!' So then I kind of felt guilty. But then I thought, I shouldn't feel guilty because surely they wouldn't offer if they didn't want to. And again it doesn't necessarily mean that just because they're offering that they would be able to. And I just started thinking how wonderful it was that we had such great friends that would even offer. But I think that if it were me and I were having to be in that situation, I think I kind of understand how Dad would feel. Because I think initially you're scared, but yet you also, you don't ever want to impose on somebody else, and you know that that person [the potential living donor] is going to have to go through a surgery and my thought on that is, it's completely an elective surgery. It's not like you have to have this or you're gonna die. You're just doing it and there are risks involved, I mean no matter what, anytime you have a surgery, anytime you go under anesthesia. I don't think there would be very many people that would feel comfortable saying 'Hey! I really need your kidney. Could you get tested? It's sort of a selfish act almost, I think, because you sort of feel like, it's sort of like you're saying, 'My life is more important than yours.'*

Here, Eliza gets at the complexity of empathy (for her father, for potential donors), or, the “unself-ing” involved in the moral pursuit of the good, to borrow Murdoch's term (1998b:3639,376). Eliza has arrived at this perspective by way of their previous dealings with transplantation, pointing out that they have thought very deeply about organ donation, for the very fact that her father received a liver from a deceased donor. This has given Hank nearly seventeen years of life that he might not otherwise have had. Her dad's receiving the transplant affected every single person in his family, as well as his

friends and every single person that he knew; at the same time, it also affected every single person in his deceased donor's family. And for that very same reason—in a sense, this deep understanding of the ripple-effect of living and dying—she thinks it would be hard to ask someone to give you an organ, because "...if something were to happen to that person then it would be hard for you to deal with."

But between the friends who have come forth, and with Eliza as a potential back-up candidate (despite the fact that her blood type does not match her father's), Hank is in the fortunate position of *not having to ask*. She directly ties her father's friends' willingness to donate, to his propensity to "give you the shirt off his back."

I mean truly, I'm speaking for my dad and for me, just because of the way I see him with his friends, and he's the kind of person that would do pretty much anything for everybody. He'd give you the shirt off his back. And to have somebody do something like that for you I think is just a testament that, again, you've lived your life right. Because if somebody's willing to do something like that for you, you've obviously done something or treated somebody in a certain way or they wouldn't even offer, because that's a pretty big sacrifice to do for somebody.

In a very literal sense, Eliza conceptualizes this wealth of willing donors as a testament to the kind of person her father is, and the kind of life he has lived. And so, in the absence of well-established conventions surrounding the kinds of giving and receiving involved in living donation, Eliza turned to the more well-worn path of attributing their good fortune (i.e., an abundance of potential willing donors) to the merit and character of her father.

"Maybe some families have that. I just don't have that in my family..."

On the other hand, certainly not all transplant candidates who would benefit from a living donation are able to pursue this as an option – especially in light of constraints surrounding the act of "asking" – due to circumstances well beyond the moral fiber of their individual personality. Simply not everyone is surrounded by a cohort of willing donors. For example, during one conversation with William, an African American kidney transplant recipient in his late forties, I asked him whether there is anyone in his life who might become a living donor to him. The first time I met him was in the solid

organ outpatient clinic, where he was just beginning the evaluation process for what would become his third kidney transplant (he'd had the first at age 17 and the second in his early thirties—both were cadaveric transplants). He later welcomed me into his home, located in a diverse neighborhood that would have been considered by many of the city's citizens to be situated just between the unofficial, de facto borderlines that have in effect separated “white” and “Black” in Metrotown for decades. His neatly kept home was on the second floor of one of the apartment buildings lining his block. Just as William's urban surroundings stood in sharp contrast to Hank's picket-fence, nearly all white, small-town neighborhood, William's reply differed markedly from Hank and Eliza's account of their experiences with prospective living donors.

I don't have anybody that I... my family has never said anything about that, and I've never asked them. [...] Maybe some families have that. I just don't have that in my family. [...] So once again, I have to kind of look at my life and say, Ok, if it's a matter of life or death, where am I at? Is there somebody that's gonna step forward? And if there's not, then what do I do? I have to step up. I would love it if there was. But I don't foresee that. And because I've had two transplants before, my family just thinks that 'Oh, well, if the kidney's not there you know, he'll get another one.' I don't think they know the history and how long they last and the benefits [of a living donor].

William has a half-sister who is 6 years older than him, but she struggles with drug addiction and the two of them have not spoken since their mother died five years ago; they have never been emotionally close. His father lives in the U.S. Southeast, and they too do not have a solid relationship, though they do talk occasionally. He does have one aunt to whom he is very close, and who helped him seek out a therapist at a time when he was struggling with anger and a series of failed romantic relationships. Otherwise, although he has a large extended family on both his mother's and father's sides, many of whom live in the area and are aware of William's health issues and transplants, he does not have a supportive or emotionally close relationship with most of them. If he was given a third transplant, that kidney, like the first two, would have to come from a deceased donor. William accepts this as simply the way things are, and spoke several times about how fortunate he feels to even have been given two transplants

in his life, that a third would be “the sprinkles on the icing of the cake,” far beyond anything he ever had expected. Still, William acknowledges a difference between the people in his kin and close social network, versus stories he’s heard of people coming forward in other transplant candidates’ lives.

I had a cousin that I grew up with; we’re about 10 months [apart]. And he actually said to me one time, he said, “Oh, I’d donate a kidney to you, but my wife would freak out,” and I’m thinking, “Well you didn’t have to tell me that. You could have just kept that to yourself. I mean, do I feel better because you would?” And so, I’ve always known that, there hasn’t been anybody in my family who would do anything like that, not anything close to... You hear these stories about people who do these incredibly generous acts for people, but I don’t know if I know anybody like that.

Like William, others who commented about their abundance or lack of living donors, often pointed to characteristics of their kinship and social networks. However, one aspect that tended to go unevaluated in an explicit way by participants were larger constraining factors like some of the political-economic and other social inequalities and longstanding histories involving privilege and oppression. For example, researchers have documented that, in the U.S., African Americans can tend to be less willing than whites to become organ donors (e.g., Boulware et al. 2002a,b; Mocan and Tekin 2007), owing at least in part to a mistrust in hospitals and a health care system in which Black patients historically have experienced mistreatment. These patterns can play out in comparative contexts as well. For example, Shaw (2010) advocated that we must consider the greater reluctance among Maori than non-Maori citizens in New Zealand to donate organs, “in the context of inequalities, the long-term effects of colonization on Maori health outcomes and disaffection toward a culturally unsafe health care system” (2010:143). Taking a phenomenological approach to the issue, Shaw suggests that decision-making surrounding donation “emerges from conceptual schemas, inculcated social practices and memories of prior historical experiences; and these structures of meaning influence people’s perceptions of what is going on in deliberation with others in the here-and-now” (2010:143).

While Shaw’s approach is insightful, it also is worth examining some of the “here-and-now” aspects that likewise shape the “structures of meaning” surrounding

living donation. Toward this end, I would add from my own observations that having a plethora of donors reflects not simply one's closeness of personal connections to others (though this often was the focus of participants' explanations), but rather various levels of capacity for this very particular form of "giving." Having good-enough health and adequate order in one's life to be able to coordinate the logistics and medical regimen of preparing for and undergoing the donation procedure are just two important factors. Also, donors must have the ability to pay for the out-of-pocket expenses not covered by insurance. Although a transplant recipient's insurance typically will cover the medical costs associated with living donation, the non-medical costs such as time away from work, added childcare expenses, and travel costs like transportation and outpatient housing, generally must be paid for privately.

"...and how you repay them, I don't know..."

Thus, the medical risks and the potential social and political-economic constraints associated with living donation add to its morally ambiguous status. And its vague and variable position can leave recipients especially prone to the discomforts of not knowing quite what an appropriate form of reciprocation might look like. As our conversation turned to the matter of how living donation might play out *interpersonally*, I asked Hank and Eliza whether they thought their relationship with a person who donated would be changed, and the two of them responded together:

Hank: Well, I think it would make that bond of friendship much tighter, knowing that they gave you the gift of life. That's a pretty precious gift. So yeah, I'm sure it would give you a different...

Eliza: I don't think you could ever look at that person the same again.

Hank: And how you repay them, I don't know how.

Eliza: And I don't think you'd ever, you would always know that they did that for you. It would just be so special.

This difficulty with ever being able to reciprocate the gift of a donated organ has been the subject of social analysis by Fox and Swazey (1978 [1974]:383), and Hank and Eliza were not alone in expressing this sentiment, nor in their prediction that living donation would surely change the donor's and recipient's relationship with one another in some

way. But among the six living donors I with whom I spoke, I observed a tendency to downplay their act, in a way heading off the potentially “tyrannous” aspects of a donated organ (Fox and Swazey 1978 [1974]:383), preferring instead (at least as they reported in interviews with me)²² to emphasize their hopes and expectations to return to “normal life” as soon as possible after the procedure. Further, although five of the six actual and prospective living donors I met had learned of the need and offered themselves up for the donation, one had been directly asked. This suggests that “asking” is not in all cases unheard-of, and the gift of a donated organ need not at all times be considered to have “tyrannous” qualities.

Secular Donations: “*He asked if I would be interested and I said sure...*”

Stanley, in his early sixties and of Western European descent, had been directly asked by his nephew, who needed a transplant, to consider being tested for compatibility. Stanley had been born and raised in the eastern U.S., and through a combination of chance and conscious decision-making ended up in the Midwest after his military service, where he became a nurse. He conceptualized his upcoming living kidney donation to his nephew primarily in very practical kinds of terms (though he still had a sense of it being “meant to be” in some way). Compared to Hank’s friends, whose offer to donate a kidney stem at least in part out of the quality of their relationship to Hank, Stanley said he had not previously had a particularly close relationship to his nephew. Further, he didn’t anticipate that their relationship would change significantly for having gone through the process together. He was not taken aback by having been asked. Rather, he pointed out that he was considered to be a good physiological match to his nephew, and that he happened to be the only member of the extended family who lived in the same state as his nephew. Plus, he noted, they all (the extended family) had known for some time that his nephew “would need a new kidney someday,” so he had already anticipated getting tested when the time came.

It wasn’t a surprise that he’d need a transplant. It was just a matter of time. Sometime this summer he called and we met and talked, and he indicated that his kidney function

²² Since living donation was not a major focus of this study, I gathered rather scarce amounts of data from true participant observation among this group, and rely more heavily on interview data.

was at, I think he said 19% or something. And his doctor indicated that we should probably begin the process and not have to wait 'til the last minute and then have to find a donor; he should begin the process and get on a transplant list He asked if I would be interested and I said sure. And we began the process. And I figured, my feeling was, if it was meant to be, it was meant to be... (Laura: Was that a hard conversation to have with your nephew?) No, not at all. Because again, it wasn't a surprise. We knew it eventually would come to that.

Though there were others who were willing to become donors to his nephew, and who had been determined to be compatible, the typical protocol is that only one person moves forward through the process at a time.

The testing is expensive and you don't want to be doing everybody. You just need one. ...and those then who are compatible, the decision had to be made of which one should move on. Since I live in [the same state] and everybody else family-wise is [on the east coast], I opted to move on.

Stanley actually had expected *not* to make it all the way through the evaluation process before being dropped as a potential donor. He found, though, that he not only was compatible with his nephew (which was the first step in the process), but also was surprised that he passed the cardiac physical exams. "I must be in better shape than I thought I was," he mused. He pointed out, "If at any point it doesn't work out and they feel you're not physically able to, or you decide you don't want to, then they go to the next person and take them through the steps." But, after completing and passing several more medical tests, and moving through the numerous steps, Stanley found that he was indeed poised to become his nephew's living kidney donor.

While I argue that living donation can be conceptualized as a form of caregiving and support of the transplant candidate, Stanley, it should be noted, did not himself consider his willingness to become a living donor to be an act of care.

We weren't that close to begin with. (Laura: Have you noticed anything different about your relationship now?) Not really. We exchanged Christmas cards at Christmas, but no, we didn't spend a lot of time together. So it's not really gonna change anything. No, we really don't do a lot of communicating.

Rather, Stanley framed his donation of a kidney as something that needed to be done, and for him, it simply happened to work out that he was positioned to be a living donor. He was aware of the significance of the surgery, both for the recipient and for himself, particularly the medical and physiological significance, perhaps owing to his training as a nurse. He did seem to have a sense of wonder about this being “meant to be.” But he did not contextualize his act as being life-altering in the long term. Rather, he fully expected to return to work and life as usual very soon after the transplant.

Sacred Relations: *“I gotta say...it’s a higher power”*

In contrast to the kind of call Stanley had received from his nephew, another living kidney donor whom I spoke with felt very strongly that his donation to a brother-in-law was a most sacred connection, facilitated through a calling by “a higher power” to come forward with his offer.

As Jerald and his wife, Alice, sat together and read one of the email updates Alice’s sister had sent out to family and friends to report that her husband’s kidney function had declined to the point that he would need to pursue a kidney transplant, a powerful sense came over Jerald. An auto mechanic with his own business who had just entered into his sixties, and who had been born and raised in the rural northern Midwest, Jerald had been married to his wife (in her late-fifties) for 34 years. They both are Lutherans for whom faith is woven into the very fabric of their 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, and to hear Jerald tell it, the worry was palpable in the email. Alice’s sister had also included 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 said he immediately noted the blood type “in black letters” and went on: “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 said, “I gulped” when Jerald said he thought he could be the donor, “but he said it with such determination,” and she

now fully supports his decision. Jerald explained his immediate sense about the donation as one would 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."

Notably, the influence of a higher power afforded Jerald certainty and moral footing.

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 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.

At the same time, both he and Alice also had a sense of the *uncertainty* that the potential recipient and his wife might very well feel.

Obscuring Living Donors' Patient Status

The type of giving relationship that can accompany living donation has the potential to be both intensely charged and morally ambiguous. At the Transplant Center, clinicians work very hard to keep in place powerful protections for potential living donors. Members of the transplant team take very seriously their responsibility to screen for even the slightest sign that a donor might be proceeding with the process against their wishes. And I found the Nurse Coordinator who works with all living donors to be exceptionally caring and perceptive. She shared with me anecdotes about some of the creative ways she and other members of the team had helped living donor candidates who had changed their mind – for any reason – excuse themselves from moving forward, in a manner which saved face for both the donor and recipient. The specific reasons for

excluding someone as a living donor are not shared with potential recipients, which leaves always available the option to say that so-and-so has been excluded as a potential donor because they were found not to “fit criteria” (even if the only criteria they no longer fit is *willingness* to be a donor). But the full panoply of policies and protections for donors cannot completely solidify the moral ground of living donation, and in the end, donors and recipients find their own ways of resolving the ambiguity of this particular type of giving relationship (sometimes to greater and sometimes to lesser degrees). I observed instances in which living donors actively worked to protect the recipient from feeling that their needs have placed a burden on the donor. One way in which they accomplished this was to avoid disclosing the full details of their patient status to recipients. Through the lens of an expanded notion of care, these efforts can rightly be considered a form of caregiving.

Jerald and Alice, for example, described some of the ways in which they tried to shield Alice’s sister and brother-in-law from feeling any shame, guilt, or even false hope throughout the process. They did this out of care and concern, by actively and purposefully obscuring Jerald’s patient status. For example, as Jerald now had to undergo various procedures in order to physically prepare for the donation, Alice talked to her *other* sister about her concerns, and avoided mentioning her concerns to the sister whose husband was to become the recipient. Jerald has been surprised at how tremendously supportive others have been, and there is a tendency for people to hold Jerald up as a hero. But Alice noted that they would rather not have this touting as a hero, in part out of safeguarding their brother-in-law from any potential shame or other unwanted attention. And from the beginning of this journey, Jerald did not even tell his brother-in-law about coming forward as a donor until he found out for certain that the two were medically considered a good match for transplant. When he did in fact call him to tell him, the two engaged in a moral negotiation in which they could begin to work out the ambiguities of their respective positions.

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 says, “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.

Here, Jerald did not emphasize the sacred spiritual aspects of his donation to his brother-in-law, and instead placed the impetus for the decision squarely and solely on himself (“I just made up my own mind, this is what I was gonna do”). This might indicate that, while his religious experience afforded *Jerald* the conviction to proceed, he recognized that it might not have put his brother-in-law at ease as much as would the idea that Jerald had made up his *own* mind about the matter.

While his brother-in-law did ultimately 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 couple was making to the Transplant Center as part of the donor evaluation and preparation, Jerald and Alice stayed at the home of Alice's sister and her husband. This offered another opportunity for each of them to disentangle some more of the moral vagueness of living donation and of someone offering care to another by volunteering to become a patient. Jerald and Alice had planned to go straight to the Transplant Center, and then to stop at the other couple's house on their way back up north, but their brother-in-law called and insisted on them staying at his and his wife's home on their way, and then they would drive Jerald and Alice the remaining hour and a half distance to the Transplant Center.

Alice noted that being together at her sister's and brother-in-law's home and talking, the four of them together, was an incredibly important part of the process. The recipient couple had a chance to express to Jerald and Alice their concerns about Jerald's health, and about how they were going to manage finances while Jerald was still recovering and unable to work. They were able to ask Jerald whether he was *sure* about this, since he is a grandfather (a kinship category that carries with it additional rights and responsibilities), and wanted to know what the couple's three adult children really thought about it all (again in deference to closer kinship ties than the ones the two brothers-in-law shared). As Alice explained, it was so important to physically be present there with each other in order to *fully* communicate about the matter, and with the complete spectrum of body language and voice inflection available to them, the laughter, tears, and emotion of it all “just poured out,” allowing each of them to move forward with

less doubt and hesitation. Jerald told me that he and his brother-in-law had had a good relationship prior to this, but that moving through this journey together has strengthened their bond (or, as he put it, “it’s brought us closer together”).

The moral status accorded to living donation as a whole, and to living donors and recipients in particular, is relational and changes over time and from one local moral context to the next. For instance, Jerald feels that his relationship to his brother-in-law has become emotionally closer, while Stanley does not anticipate that his relationship with his nephew will change in any substantial way. Jerald himself invested much more significance in his donation than did Stanley. That is not to say that Stanley has no sense of wonder about how he came to be the donor, noting that he felt “if it was meant to be, it was meant to be,” but Jerald considers his decision to donate to be part of a sacred religious experience. And yet, I also observed some hesitance among living donors to allow the experience to alter things in a permanent way, as if yearning to maintain some of the stability of a more familiar moral field.

Alice noted that the pamphlets she has read about organ donation say that right now, Jerald is in the spotlight, but that after the transplant, he will likely fade to the background as their brother-in-law comes to the fore as a recipient. For now, they will continue to wait for everything to fall into place so that they can go ahead with the procedure. Once Jerald gets through the physical healing post-surgery, Alice is not sure that a whole lot else will change; the couple will still center their lives around their grandchildren, they’ll still get phone calls from family members, and they’ll still help with Jerald’s aging parents. Much like Stanley, the couple expects that day-to-day life will go on post-transplant, much as it had before.

“I didn’t want her to know that I was worried...”

Another very clear example of this was offered by Robin, a white woman in her mid-thirties who, when I met her, had just performed the very act of donating blood-forming stem cells to her sister, Jane (who was introduced in Chapter 2—she is white and in her mid-forties). These cells later would be transplanted into her sister as part of the treatment for Jane’s life-threatening leukemia. Jane and her family had just moved from a northern U.S. state to a suburb of Metrotown in order to be closer to the Transplant

Center where she would be receiving her cancer treatment. Robin, a self-described non-denominational Christian, considered religion to be a major part of her life. She lived in a small, middle-class suburban community in the “Bible Belt” of the Southeastern U.S. with her husband, two five-year old daughters, and teenaged step-son, but had traveled to the Transplant Center to become Jane’s living donor. I met and spoke with Robin on a very cold January afternoon, while she was undergoing the final stages of the donation process, known as apheresis.

On the day I met with Robin, she was sitting in a large reclining chair, in a room filled with machines and monitors – mostly the same shade of beige as the surrounding walls. Filtering through the space were sounds from the beeps and blips of the equipment, intermingled with the sound of daytime television, which could be viewed on one of the screens mounted on the walls of the room. She had just made the actual stem-cell donation. Earlier, she had received the last injection in a five-day series of medication that increased the stem cell development in her bones, causing the stem cells to spill out into her blood. Twelve units of her blood were taken out of one arm and circulated through an apheresis machine, which removed the stem cells from her blood, with the remaining blood being returned to Robin via the catheter in her other arm. And now, the “harvest” complete, the catheters had been removed and she was resting. Robin’s stem cells would then be stored until they would be transplanted into Robin’s sister, Jane. This would take place after an intensive round of chemotherapy would have destroyed Jane’s own blood-producing stem cells; Robin’s stem cells would be given to Jane through a central line with the idea that, after 2 to 3 weeks, they would find their way to Jane’s bone marrow and begin producing new, healthy blood cells. Jane’s other sibling, a brother, also had been tested for compatibility, but did not match Jane’s tissue type as well as Robin did.

Robin explained that she of course was more than happy and willing to donate the necessary component of her sister’s life-saving treatment. But even though the procedure had not required surgery or general anesthesia, it also had not been a painless, straightforward, or effortless process. Even on the day I met with her, Robin needed to take a break twice from our interview because she was overcome by waves of nausea

(although I offered each time to end the interview, Robin said she would prefer to finish it, but that she just would need a few minutes). Logistically, it had been stressful for Robin and her husband to arrange for her travel and coverage of her responsibilities at home, such as school pick-up and drop-off for their children. Robin, who worked part time and has a more predictable schedule than her husband, had assumed many of these aspects of child care. Her husband is a state trooper who works a variety of shifts, none of them the 8am to 5pm of so many working parents in the U.S. He had decided to take leave from work during the time she would be away from home, but never before had he been the sole caretaker for such an extended period for their three children.

In a tone reminiscent of Alice's, who also tried to shield her sister from concerns over Jerald's well-being as a donor, Robin explained that she tried not to convey her worries to her sister Jane, who was to become the recipient of her donated blood-forming stem cells.

There were a lot of stresses on my part but I didn't want to let Jane know that I was stressed, because she had her own stress going on. I didn't want her to know that I was worried about how I was gonna get my plane ticket or who was gonna care for my kids because she was fighting cancer. So I didn't want her to worry about me, so I didn't want to tell her. So whenever I talked to her [on the phone], I tried to just be positive and like I had it all under control. And then I would vent to other people.

Previously, however, Jane would have been one of the main people Robin would have talked with about things that were on her mind. The two of them had long been very close, and talked regularly on the phone, usually three times per week. Jane, too, had considered Robin a confidante. The two of them have much in common, with their oldest children being close in age and with both sisters working for non-profit organizations. Robin noted that each of them tended to refrain from talking too much about Jane's cancer or Robin's donation, trying instead to focus on the "normal," everyday aspects of their lives, even though it was difficult for each of them to avoid the subject.

And so, to not talk about the normal stuff that was stressing me was hard. And to try not to talk about her cancer was hard. Because she was used to talking to me about the small stuff and she didn't want to talk to me about the big stuff. Because that was her one relief,

was just to talk about which kid broke their cell phone. Or who took a test and got a C. So that stuff helped her maintain normalcy. So we purposely didn't talk much about the stressful stuff.

These efforts to “maintain normalcy” become a crucial component of preserving ties to the more familiar moral ground of the way things were before living donation and transplant entered into the picture. Robin also expressed a strong desire to not allow the transplant process to change anything about her and her sister’s relationship together, and described her discomfort with creating the weight of added obligation for Jane. Again like Alice and Jerald, Robin tried to avoid being portrayed as a hero.

I think you probably downplay what you're going through because I don't want the praise for it, I don't want the big “thank you's” for it, I don't want her to feel obligated to me for it. So I've kind of downplayed with her my role in it. She'll come in and introduce me as the donor or whatever and I try not to make a big deal about it just because I don't want her to always think she owes me something, or that I'm any more special than me as the sister before, you know? So I don't want to say that our relationship's changed a whole lot.

At the same time, Robin had experienced “nearly every symptom they listed on the page” of potential side effects and risks associated with being a stem cell donor. This included a great deal of physical pain – particularly, a significant amount of pain in her bones – throughout the actual donation process. Further, on top of the physiological risks and side effects, it had been much more emotionally difficult to be away from her home, children, and husband than Robin had anticipated. Yet out of care and concern for Jane and Jane’s family, Robin continued to try to shelter them from the knowledge that she was suffering through the process. This was especially difficult because during her time here, she had been staying with them in their home.

And you know when you feel bad, it's hard enough when you're sick being at home, but I'm away from my family and my environment, staying at somebody else's house, away

from my husband and kids and I'm trying to hide that I'm in pain. So I would retreat to my niece's room and they would think I was just going to bed early. And I had to call my husband and say, 'Look I'm in really bad pain, but I can't tell anybody because I don't want them to worry about me.' Because I'm doing this for her; I'm doing this regardless of how bad I feel. [...]

I think everybody underestimated the homesickness of it, what it would be like to be in pain and homesick at the same time. I don't think anybody...I haven't really shared that with anyone because I don't think they'll...there really is no way to understand how it felt, how it was, going through pain and sickness like today and being homesick.

Being away from the familiarity of her own home space, and physically disconnected from the comfort of her own husband and children, added to both the physical and the emotional discomfort of Robin's experience. As this aspect of the donation process had been unexpected and underestimated by everyone, there were no conventional "rites" associated with this uncertain passage, and Robin hoped to return home and get back into her regular life.

At the same token I hope I can go home and go back to normal. I don't want this praise for this, I don't want people to say "Oh what a good thing you're doing for your sister." I would have done it for a stranger, you know? First of all, how could you say no if you were a match for a stranger, never mind your own family member? So I guess other people kind of put you up on a pedestal, "Oh what a wonderful thing you're doing." And again, I don't want that. I just, it's extraordinary for me and it's extraordinary for her, but I don't want it to inhibit the normalcy of life. Because it wasn't about what I did. It's just something that had to be done. [...]

You just keep thinking, it's short term, and then you'll be back home, back to normal life. You'll feel better and it's for a good cause. And I'm looking at the bag of blood, thinking, "Ok, that's my sister's cure. That's what I came to do."

Here, Robin recognizes that this experience is "extraordinary" for both her and her sister, yet also wants to control its potential to spill over into other relations and aspects of her

life. She re-emphasizes her longing to return to “the normalcy of life” that, she hoped, would not be markedly altered by the morally uncharted territory of her journey. And once again, Robin also works to diffuse any potential added obligation for her sister by downplaying the donation as a gift to Jane in particular, instead insisting that it was just something that “had to be done,” even if it had been a stranger who had been in need. In doing so, she further normalizes the act as conforming to well-established conventions that are as tangible as the bag of blood hanging next to her.

Conclusion

In many cases, the health of those closest to a transplant candidate or recipient can become implicated and intertwined with the transplant endeavor, so that caregivers indeed can also become patients. By offering specific examples of this phenomenon, this chapter has more fully developed the larger notion that the categories of “patients” and “caregivers” are not fixed, with care flowing in only one direction. Both patients and caregivers rely upon and care for each other in ways that sustain and are sustained by transplantation in the U.S. This chapter also offers yet another dimension to the overall assertion in this dissertation that transplantation resonates deeply within interpersonal webs of kinship, reciprocal care, and mutual moral obligation.

Living organ donation and informal caregiving, in spite of its difficulties, are sacrifices that the persons described in this chapter make for one another – sometimes out of love and fondness (though not in all cases), but firmly out of a sense for what must be done. The mutual sacrifices that persons make for one another were of interest to Durkheim, who wrote extensively about the cohesive forces of social life. In his 1893 *Division of Labor in Society*, he argued that such acts of sacrifice and moral obligation were the very foundation upon which every society exists:

Thus altruism is not destined to become, as Spencer would wish, a kind of pleasant ornament of our social life, but one that will always be its fundamental basis. How indeed could we ever do without it? Men cannot live together without agreeing, and consequently without making mutual sacrifices, joining themselves to one another in a strong and enduring fashion. Every society is a moral society. In certain respects this feature is even more pronounced in organized societies. Because no individual is sufficient unto himself, it is from society that he receives all that is needful, just as it is for society that he labours. Thus there is formed a

very strong feeling of the state of dependence in which he finds himself...Such sentiments are of a kind not only to inspire those daily sacrifices that ensure the regular development of everyday social life but even on occasion acts of utter renunciation and unbounded abnegation. (Durkheim 1984[1893]: 173)

While the practice of transplantation in the U.S. has notable distinctive characteristics, it resonates closely with some of the already-existing ideologies of those who seek out and most directly experience transplantation. For example, as I argued in the previous chapter, patients turn to transplant in order to continue to “be there” for their loved ones. In turn, as this chapter describes, those surrounding persons in need of a transplant often are there for potential recipients, either alongside their own struggles with illness, or by the very fact that they’ve willingly become patients themselves, as living organ and tissue donors. At the same time, while the moral kinship obligations underpinning the notion that “transplant patients are also caregivers to dependent others” are rather widely shared and comprehensible, the donation of an organ – even as an act of care – appears to exist on much less stable moral ground. As persons come forward and offer to become patients in this manner, both donors and recipients must find ways to work out the local terms and meanings of the exchange, resembling in some ways what Rayna Rapp (2000) has called “moral pioneering” (in reference to women’s use of amniocentesis in the U.S.). As we saw, for example, with living donor participants’ expressions of hope that life post-transplant will return to normal, persons often approach these uncharted moral waters only with a steady eye toward more familiar moral ground.

This chapter also has posited that, in both living donation and in more quotidian forms of transplant caregiving, the health of both patients and caregivers can become intertwined at multiple levels. Our understanding of the moral landscape for this interweaving must also take into account the context of social injustice. For example, both living and cadaveric transplantation have been the subject of intense critique for its propensity to commodify persons and body parts on a global scale. Also important is the perspective that a profit-driven framework for health care in the United States has created a biomedical system which requires the service of informal caregivers without providing adequate structural support for such responsibilities, and which prioritizes life-saving

high-tech procedures like transplantation over life-sustaining, quality health care that is accessible to all.

As William (whom we met in this chapter) reminds us, not every person is part of a kin network where extensive daily caregiving, let alone living organ donation, are feasible or realistic. While participants often attributed the presence or absence of willing donors, for example, to the type of person one is, the type of family one has, or the kind of life one has led, important larger constraints can powerfully influence the richness of support (whether in lay caregiving or in living donors) that a transplant patient will have. The following chapter will continue to address the resources and constraints among transplant candidates, recipients, and the persons closest to them, by turning to focus more directly on transplant-related care in daily home life throughout the transplant process.

Chapter 5:

Transformations: Home Life and High-Tech Health Care

The day-to-day recovery and health maintenance work in private spaces, linked to clinical spaces by the nature of their use throughout the transplant process, constitute a great deal more of the transplant experience than what usually receives public attention. Popular images of transplantation often focus on one of two extremes. Transplant recipients often are portrayed either as critically ill hospital inpatients (whether waiting and hoping that an organ will become available in time, or immediately post-surgery in intensive care), or they are held up as fully and immediately cured persons who have received a miraculous “gift of life” (television advertisements and Donate Life websites commonly feature images of transplant recipients of various ages smiling, playing sports, hugging their partner, pushing a child on a swing, etc.). Transplantation, to be sure, is a major life event for patients and their loved ones, but fieldwork also has brought to light profound ways in which members of this group incorporated the significant and complex “up’s,” “down’s,” and “in-between’s” of the transplant process into the larger context of their everyday lives.

With an eye toward how participants manage to integrate the many incommensurable aspects of transplantation, this chapter gives attention to homelife and the everyday dimensions of recovery and care associated with this high-tech medical practice. In this way, it will return to some of the threads introduced in Chapter 2, particularly regarding the intermingling of clinical and domestic spaces. Such a vantage point also brings to light the shifting of major medical care responsibilities to patients and their loved ones outside of the hospital and into the private home. I have argued elsewhere in this dissertation (especially in Chapter 3) that already-existing moral obligations among kin can shape biomedicine. The evidence presented here points to

how the demands of post-transplant care can in turn alter kin relationships – by turning “home life” into “health care” and “kin” into “clinicians.” This does not negate the earlier argument, but instead underscores the idea that this transition is neither complete nor unidirectional. In fact, this chapter also will offer evidence that the current practice of biomedicine in the home (within the context of the obligations of kinship and home life) can actually alter the practice of biomedicine in the hospital as well. A key point, therefore, is that the spheres of home care and hospital care can remain both distinct *and* interactive. Far from being relevant only at a theoretical level, I propose that the insights of this chapter are crucial from an applied perspective, as they can shed light on a number of social justice and service concerns (which will be examined at greater length in subsequent chapters).

Bringing Home the Hospital

During a brief phone conversation with Marvin earlier in the morning to confirm our plans to meet for an interview, he had reminded me to go ahead and ring the doorbell upon arrival, but then to let myself in. Having been discharged from the hospital just days ago, after being readmitted for a persistent infection related to the liver transplant he had received over 4 months ago, he still moved about with some difficulty. His wife had returned to working during the day to supplement the income Marvin receives from his disability insurance, so she wouldn't be available to answer the door either. So after ringing the doorbell, I paused only to listen for a, “Come on in!” from the upper floor of his split-level house. I climbed the stairs from the entryway to Marvin's living room, where I was greeted by a man with a straight mouth but smiling eyes who looked older and frailer than he probably otherwise would, seated in a Lay-Z-Boy recliner chair surrounded by an IV pole and several 5-gallon-sized white plastic bags that were overflowing with medical supplies: tubing, syringes, wound dressing materials, medication vials, and pills. On the dining room table behind him, almost imperceptibly wilted floral bouquets, plants, and half-mast shiny mylar “Get Well Soon” balloons from family and friends created a backdrop which framed this area of the house, indicating that a number of the basic elements of Marvin's hospital room had been packed up and taken home with him on his day of discharge. With a home care company supplying the

remainder of the medical equipment, it all blended with the furnishings and spatial arrangement of his living room to create a space that melded hospital with home in both form and function.

Like Marvin, many patients who undergo intensive and highly technical medical care spend only a fraction of their recovery time in traditional inpatient settings. Refinements in medical equipment, surgical procedures, and drug therapies, which are themselves the products of changes and innovations in biomedical science and technology, have made feasible the very idea that post-transplant recovery could take place outside the hospital setting, largely under the care of lay persons (see Eilers et al. 2005; Guberman et al., 2005; and Glazer 1990). Some patients, including Marvin, even perform many of their own transplant-related cares (like changing the dressings on accessible wounds, taking medications, etc.) when the primary informal caregiver has to maintain paid employment outside the home for the income, for the medical insurance, or both. Further, the emphasis in current U.S. health policy on private, commercial, employer-provided medical insurance has contributed to cost-cutting arrangements and health care financial restructuring, which also has led to decreased lengths of hospital stays in recent years. The net result of this confluence of trends has been a shifting of the weight of post-transplant care to patients and those close to them (Levine 2003; Cartier 2003; Williams 2002).

Homes and Hospitals

As I have argued in previous chapters, recent trends and practices in high-tech health care also take shape within the context of longstanding local cultural values surrounding kinship and relatedness. A look at the intermingling of contemporary western biomedicine with the home and home life, further, provides a fruitful way to approach the kinds of maintenance work, innovations, renegotiations, and contexts that can both reinforce and rework kin relationships. This orientation is inspired by kinship literature about houses that grew out of some of Claude Lévi-Strauss' (1982, 1987) later writings on house societies. This literature was discussed in Chapter 2; here again, we will rely on the theoretical perspective that houses are capable of incorporating the seemingly incommensurable. Carsten (1995a) and Gillespie (2000b) remind us that a

house-centered approach can help us to conceptualize the actual fluidity of categories; we will extend this to our attempt to understand not only the transformability of houses and clinics, but also the malleability of kin relationships, in post-transplant life. And following Carsten's (1995a) view, houses are capable of revealing at once the harmony, the tensions, and the changes in the social relations that are enacted within them. Our focus here on home spaces and daily home life, then, will afford a better view of the experiences and perspectives of recipients and the kin who help them most, post-transplant. Further, Casey's (1987) emphasis on the place, space, and materiality of memory also prompts us to pay attention to the ways in which participants' homes changed over time as they worked to meet the demands of post-transplant living.

Other scholars have specifically looked to the home as a locus of medical care. In a study which focused on the home as a sight for high-tech health care in Québec, Guberman et al. (2005) conceptualize the home as a complex environment that combines physical, psychological, and social aspects to comprise a multidimensional ecological space that contrasts with the hospital in several ways. Factors such as the size, layout, condition, cleanliness and climate (physical aspects) of a home; patients' assumptions that being home should entail a return to a sense of normalcy (psychological aspects); and the stability or instability, presence or absence of substance abuse, addictions, mental illness, abuse, violence or neglect, and financial status (social aspects) of a home (Guberman et al. 2005: 266-268) all can shape the place and space of post-transplant home-based care. Guberman and colleagues (2005) question the transferring of high-tech medical care to the family and to the home, where, unlike the hospital, professional support is *not* necessarily available at the push of a call button. I observed persons exhibiting great adeptness and expertise in handling tasks that otherwise would be performed by clinical professionals in a hospital setting. And support from a member of the Transplant Team was always available via telephone. But the physical separation of homes and hospitals in many ways left patients and caregivers vulnerable to potential sudden crises like bleeding, infections, or respiratory problems.

Historically and comparatively, though, the house is not at all an unusual setting for humans to journey through the cycles of life, illness, and death. For example, on the island of Gawa, Nancy Munn found that "[t]he Gawan house is the bounded arena of

social space within which the most intimate care and protection of the person takes place. It also is the locus of transitions into life and death” (1986:34). And as outlined in the Introduction, the large-scale removal of care from the home to the hospital and other formal, clinical, biomedical spaces took place relatively recently. In the nineteenth century, for example, care was provided largely under the expertise and experienced authority of women kin and neighbors (Abel 2000). At the turn of the century and on into the twentieth century, particular developments in the biological and medical sciences and technologies (e.g., germ theory), the concomitant growth of biomedical power and professional authority, and the rise of the health care industry weakened significantly the autonomy of lay women caregivers (Abel 2000).

But the shift from hospital-based care back to home-based care is occurring under very different circumstances. The trends documented by Abel (2000) are not being altogether reversed. For example, a general recognition of lay experience and the value of interpersonal sensitivity to a patient’s needs are not uniformly replacing the authority of biomedical knowledge and expertise. As Allen (2000, 2001) has pointed out, although family members are becoming more and more involved in caring work, they are not afforded equal involvement in health care decision making. Changes in the gendered division of paid labor (in which a vastly greater proportion of women now work outside the home) create new pressures for lay carers who often find they must accommodate the competing demands of both paid and unpaid responsibilities. In my own field observations, men, too, could be conscripted into lay caregiving roles. Complicated and expensive medical technologies accompany patients to their homes upon discharge, requiring family caregivers to quickly learn skills and tasks that otherwise would only be performed by nursing staff in hospitals. As Abel puts it, “Nineteenth-century women struggled to retain jurisdiction over skilled medical care, but caregivers today complain about being entrusted with responsibilities that far exceed their capabilities” (2000:258).

Over the course of fieldwork, I found that the present return of care to the home is occurring within a context in which elements of home life on the one hand, and high-tech health care on the other, increasingly are blended together. This seemed to be taking place despite the contemporary constraints posed by the need for and demands of paid employment, geographical distance between kin (many participants’ parents, siblings,

and children lived far away), and competing demands of daily life. Under these circumstances, both homes and kin relationships can be transformed and redefined.

Redefining Home, Redefining Relationships

Milligan (2003:456) has written about the importance of the interrelationship between people and place in health care, what she calls “the spatial manifestation of care.” The boundaries between formal and informal caregiving, in both formal and informal spaces, can become increasingly blurred as patients and caregivers progress through the illness experience (Milligan 2003). As patients’ care needs increase, rooms in home spaces are transformed by increasingly ubiquitous medical equipment and practices, and

...this blurring of public and private space can mark a change in the meaning and experience of home where carers and cared-for experience an increased dis-location from the home space. Domestic space begins to take on characteristics of non-place as it becomes a site of transience and movement—the home-space becomes a place of work as living rooms take on features of the hospital ward and health professionals and care-workers move in and out, governed by time constraints and a lack of shared identity (thus understanding) with the cared-for. (Milligan 2003:462)

In the opening vignette, particular areas of Marvin’s home space had taken on characteristics of a clinical space. For every piece of furniture, porcelain figurine, and framed family picture in his and his wife’s living and dining room, there was a bag of tubing and syringes, a box of medication, an IV pole, or a sterile bandage pack. Though he had just returned home from the hospital a few days before I spoke with him, other examples below will show that the interconnections between home spaces, clinical spaces, and the other domains of daily transplant living can continue to affect kin relations and family life long after infections have cleared and surgical scars have begun to fade. A grounded theory study by Mishel and Murdaugh (1987) found that heart transplant patients and their partners enter into a negotiation stage after the recipient returns home following transplant and as they begin to settle back into everyday life. The most dangerous time following transplant is the first six weeks, because the threat of rejection is greatest at this time. This also is a period during which doses of immunosuppressive medications are fine-tuned. But in the final stage of a process

Mishel and Murdaugh (1987) termed “redesigning the dream,” (i.e., the dream of what heart transplantation is able to offer) heart transplant recipients and their partners learn that their definition of “normal life” can no longer include absolute certainty, predictability or stability because even with a successful heart transplant, life could be cut short at any time. Patients and their partners then enter into a dynamic and interactive process of negotiation with each other about their future life that involves a re-establishment or re-evaluation of each person’s power, meaning, and role in life (Mishel and Murdaugh 1987:336). This negotiation process entails balancing the patient’s vulnerability against the partner’s needs, can be marked by conflict, can continue into the long term and can take many different forms according to the different changes and circumstances that arise to which patient-partner dyads must adapt (Mishel and Murdaugh 1987:336).

Notably, this final process of needing to revise “the dream” of transplantation’s promised offerings of rejuvenation and normalcy is precipitated by the return to home. It is here that the expectations of what daily life *should* look like (crystallized by the presence of quotidian things around the home like checkbooks, recliners, pantry staples, car keys, kitchen tables, tools on one’s workbench, steps up to a bedroom, etc.) all can seem most at odds with the way things now *are*, given one’s state of health (likewise now crystallized by home medical supplies and curtailed mobility). Home spaces take on new meaning, just as a home’s inhabitants take on new ways of going about their day-to-day in relation to one another. The following provides another example from my own fieldwork of this renegotiated partnership – in the context of larger webs of relations – being expressed in the creative use of home spaces.

A Health Haven

I met Barry, a white male of European descent in his sixties, at the Transplant Olympics Team booth at the 2008 Solid Organ Transplant Reunion, hosted by the Transplant Center at a local hotel conference center. As I approached the table, Barry asked me a question commonly heard in any space – clinical or otherwise – where transplant patients gather, “So what do you have?” I explained that I was not a transplant patient or caregiver, but that I was a graduate student studying the social aspects of the

procedure. Upon hearing more about my research, Barry graciously welcomed me to visit him and his wife, Angela, a woman in her late fifties who describes herself as Mexican-American, at their home for an interview. Barry's heart transplant took place fourteen years ago, and there were none of the medical equipment or "get well soon" cards and balloons delineating their home as a conspicuous biomedicalized (or "hospitalized") space. However, I learned that Barry and his wife have modified the very way they use their home space in order to accommodate the fact that the immunosuppressant medications Barry takes to prevent his body from rejecting his transplanted heart makes him extremely susceptible to contracting common contagious illnesses and experiencing serious complications from them. While sitting together with the couple for an interview at their dining room table, Angela talked about the level of vigilance that must always be kept against Barry coming into contact with contagions. Other persons, including Angela herself, are to "stay away" from Barry if they have even the mildest symptoms of a cold. Just as the awareness, even "panic" is always in place, so the spatial arrangement of the couple's home allows them to be ever-prepared to handle the potential introduction of germs into their haven.

Angela: People cannot come to my house if they have a cold, I mean they cannot come because he is too susceptible. [...] The panic will never leave. [...] And I mean, we are 14 years out. It doesn't leave! It doesn't leave you! You know, and when he gets a cold, I panic. Is he going to be okay? [...] You have to take care of yourself [as a caregiver]. I know they tell you a thousand times, but you really have to take care of yourself, because if you get sick, how can you help them? And when you are sick, stay away from them. (Laura: And now what happens if you get sick?) You have to stay away from each other. You literally do because you know, I'm fearful that I'll give him something.

Barry: 'Cause see, right now we've got one extra bedroom. We've got the bedroom upstairs and then my room, my whole TV room is in the basement, and you'll notice we don't have a TV up here. We got a big screen down in the media room downstairs.

Laura: And so you can just be kind of in separate areas of the house?

Both: Yeah, yeah

Barry: Yeah, and we've got a couch that I can sleep on downstairs.

Angela: *And you know, again you know, everybody, anybody that knows us knows, you do not come over to our house if you have any, the sniffles, sneezes, and we've had people have to call and say, "I really apologize, I cannot come over because I have a cold." And I understand, I say, "Bless you, thank you for not coming!" Because it's just too dangerous for him.*

Milligan (2003) points out that 1) the home can imbue its residents with the power to exclude unwanted persons from their home space, 2) the home serves as a private haven, and 3) the home serves as an embodiment of identity and self-expression (2003:461). Angela and Barry speak of their home as a space which they can fortify against contagious illnesses and the people who may be carrying them – including Angela herself, who, despite her best efforts, can at any time become an unwitting carrier of dangerous germs. In order to release the stresses she feels in her responsibility to watch over Barry (even 14 years after his transplant), Angela works and conducts activities outside of the house, including leading the children's choir in their church. While she cites this as one of her ways of taking care of herself, she also notes that it sometimes presents a risk to Barry's health because of her exposure to children with all of their "little runny noses" (in Angela's words). And so they have arranged the space within their home to act as a backup quarantining system so that during times when Angela might be contagious, through the maintenance of physical barriers, they can prevent her spreading common but dangerous illnesses to Barry.

Here, then, seemingly contrasting principles, qualities, and functions are brought together and made workable through the couples' innovative uses of their home. The house, as a protective barrier, becomes a means for Angela to balance her role as Barry's wife and caregiver, against a very real need to also work outside the home and do other activities that she enjoys. It functions as an environment which mitigates against the risks associated with the interconnections between the home (as both a place for everyday living and for clinical maintenance of a health condition) and the outside world which includes an extended web of social relations (as both a refuge from caregiving duties and a source of potentially dangerous germs contracted from others).

Relocations and Relationships

Patients and their loved ones can sometimes find that they must not only redefine their living space, but relocate it altogether for the sake of the transplant. This idea was introduced in Chapter 2, with Bernard and Arlene contemplating a move and Jane and her family actually having moved, in order to be closer to the Transplant Center. Here, I will present another example of relocation, which carries with it a potential re-arrangement of the ways in which kin relate to one another.

“I tell them, ‘Hey, you know the Transplant Center is there’...”

Edward, in his early seventies and Tamara, in her early forties, are an African American couple who met at their church and had been married for just over a year at the time I met them. They lived in a small community located about 90 minutes from the Transplant Center. Edward has polycystic kidney disease, which is causing his kidneys to fail. After I first met the couple in the outpatient clinic at the Transplant Center, I continued to have a number of in-person and telephone conversations with them together as a couple (and with Tamara on the phone) as they were trying to qualify for her to become his living kidney donor. Tamara also had assumed the tremendous responsibility of handling all of the paperwork and communication with the transplant team. These administrative duties constituted a nearly full-time occupation as she coordinated appointments, organized documents, filled out forms, and integrated medical orders into the couple’s daily lives. This included not only filling Edward’s prescriptions and making sure he took the correct ones at the correct times, but also maintaining her own diet and exercise regimen, as they had been told that Tamara would only meet medical criteria to become a living donor if she would be able to lose a significant amount of weight.

The couple invited me to their home one afternoon, which was located in a residential area of their small city, filled with winding streets and a park nearby that was temporarily flooded from recent snowmelt and spring rains. As we sat together on their plush living room couch and chairs, they expressed to me their relief that they had the means for Tamara to quit her job, allowing her enough time to manage it all. They also had converted an entire room in the basement of their one-story house to become a

workout room, where Tamara could use and store an exercise ball, resistance bands, floor mats, and weights, and could work out to exercise videos. In a literal sense, they had adjusted their home space and their lifestyles for the sake of the prospective transplant (as a reciprocal “investment” in each other’s health, much as in the previous chapter, where Annette’s family had invested in her health; and which enabled Tamara to adopt the necessary body techniques that would make her a better qualified “house” from which to transfer a donated organ, which resonates with threads from Chapter 2).

Tamara seemed to fully and willingly embrace her roles, and expressed a great deal of motivation for the transplant, even as it necessitated tremendous sacrifices on her part, beyond the donation of a kidney. This is because, as Tamara explained to me, they likely would be moving soon, to a townhouse that Edward had found advertised in the newspaper. It was located in a new subdivision, over an hour away from their current home, but just 15 minutes away from the transplant center, and would allow them to live closer to where Edward would be getting his follow-up transplant care for the indefinite future. This decision, though practical in many ways, was objectionable to Edward’s longtime friends and neighbors. He had developed this extended web of relations over the many years he had lived in this particular neighborhood and had been a member of his church and work communities. As this social network long pre-dated the couple’s partnership, there were assumptions that Tamara as a new relation, rather than the demands of transplantation, was the impetus for Edward’s leaving. Tamara explained, *There might be someone saying, “I don’t want Edward going to Metrotown.” You know, I tell them “Hey, you know the Transplant Center is there.” And there might be some statements in there, “Well, she took him away from us.” No I did not! You know, I did what I had to do, and his input is in it also. You’re talking, uprooting someone who has been here, he’s been here longer than I have, since ‘74, but I’ve only been here 17 years, and to uproot him and move him is not because we’re trying to get away from any, you know, distractions. But it is, the need is there, we have to consider doing this. And sometimes those are not popular decisions. Oh my!*

Tamara emphasized that living with a transplant is a commitment so great that they both feel it justifies the move, but she also explained that their new home would

have neither the size nor the custom-built character of their current house. In a sense, the couple would be redefining their home as a satellite clinic. Far from being a straightforward matter, this involved making adjustments to their relationships with others and their relationship with their living space, and by extension, some key expressions of their identity. Although Tamara could sense the disapproval of members of the community who feel she is taking Edward away from them, she herself would be sacrificing a great deal with this move as well. In addition to the cookie-cutter quality of the new townhouse, it also would be located in a retirement community. This is significant because Tamara is only in her early forties.

What's more, later in the interview, Tamara explained that their relocation also would be away from her twelve-year-old son, who would move in with his father in order to stay in their current community and avoid having to attend a new school. When asked if this will be difficult for her, Tamara acknowledged that it will be. But she then fell back on a phrase that could be called the mantra of most participants in this study who are dealing with hardship: "you just do what you have to do." This language of pragmatism seemed to be shorthand when words to convey the incommensurabilities of transplantation were in short supply. It also pointed to a common orientation toward tangible *action*, and *doing* what must be done when faced with matters of life and death. Specifically here, Tamara's conclusion is understandable in light of the fact that Edward (and Tamara, if she becomes his living donor) would be discharged from the hospital long before having fully recovered from the surgery. They must anticipate possible emergencies if post-transplant complications should arise, and in any case, would have to make multiple follow-up trips as outpatients to the transplant center, thus warranting the relocation. But in redefining "home," Tamara also would be redefining fundamental aspects of her relationship with her son (including the amount of time they will be able to spend together, and the fact that they no longer will share in-person each other's day-to-day lived experiences as readily as when they shared living space full-time). This carried with it the potential to alter the family's functioning in significant ways.

The case described above also corroborates the findings of other researchers (e.g., Mishel and Murdaugh 1987 and Dew et al.2004). For example, Dew and colleagues (2004) commented on the role changes that the families of transplant candidates often

experience during this time, and likewise pointed to the need for moving closer to the hospital in case an organ should become available and/or in order to attend frequent medical appointments. Some patients' families relocate with them, and some remain in their original location; either scenario can present formidable hardships with regard to daily living, family relationships, and caregiving, and such challenges do not disappear following a successful transplant.

Home or Hospital? Practitioner or Partner? Blended Boundaries Through and Through

One way to conceptualize informal caregiving is as a blended position, in which lay caregivers become responsible for bridging the two realms of hospital and home. Informal caregivers often have to begin early in the transplant process to straddle two roles, becoming simultaneously part personal and part professional, part family member and part health care worker, so that hospital and home remain at once connected and yet distinct.

An excerpt from Casida (2005) demonstrates the extent to which lay caregivers of transplant patients can be asked or expected to take on responsibilities with which they otherwise would have remained completely unfamiliar, and that until very recently had been confined to the domain of professional and/or hospital based medical practice.

It is a standard practice in many heart transplant/mechanical heart programs in the United States to designate a patient's family member as a caregiver for a patient with an LVAD [(left ventricular assistive device)] who is waiting at home for a heart transplant. The designated caregiver is expected to be available to the patient 24 hours a day and to perform specific tasks and take on responsibilities related to the care of the patient. Extensive education and training of patients and their family members/caregivers is usually provided by an LVAD coordinator. The education and training include performance of basic nursing procedures such as care of the LVAD exit site/wound, observation for signs and symptoms of infection, monitoring the functionality of the LVAD, and responding to alarms and emergency situations. (Casida 2005:146)

This excerpt concerns heart transplantation, but while the specifics of care can vary by type of transplant, the fact that lay persons become home-based high-tech biomedical caregivers holds true across all types of transplant. One striking example was Betsy's

mention (she was introduced in Chapter 3) that, in the earliest days of her post-pancreatic islet cell transplant recovery at home, every member of her family, including her three school-aged children, had to learn vital aspects of Betsy's care needs. Betsy noted:

When we first did the transplant, I was on very tight blood sugar control, hoping that would help them [the islet cells] heal and not stress it too much. It had a tendency to drop my sugar really, really low. So we taught our kids how to test mom's blood sugar, how to use the glucometer, and made sure they knew how to call 911. I get really slurred speech and they can tell.

While Betsy explained that each of her three consecutive transplant-related surgeries has been increasingly troubling for her children, she did not elaborate on whether or how this particular set of circumstances might impact their family life. What we can infer, though, is that Betsy's home became as a satellite clinic (in which clinical, domestic, and bodily houses converge and overlap), and family members became trained clinicians. This was crystallized, for example, in the glucometer and her children's knowledge and use of it; this new, mixed domain for the day-to-day enactment of social relations could very understandably be troubling for Betsy, her husband, and her children. But at the same time, it became a necessary arrangement in light of the stakes involved. Others whom I met likewise offered evidence that the performance of clinical cares in the home by those who are closest to transplant patients has the potential to infuse relationships with profoundly complex, and sometimes contrasting sentiments.

Nurse and Patient or Husband and Wife?

In my first tape-recorded interview with a married couple I came to know very well over the course of my fieldwork (I have mentioned them in Chapters 2 and 4 thus far), Mary, in her early forties, and her husband Rob, in his early fifties, recounted how an unrelated surgical error with serious medical complications eventually made a liver and small bowel transplant necessary in order to save Mary's life. For that first interview, we sat together in the living room of their house, the walls of which were lined with family pictures and the school pictures of Mary's two daughters (one in high school and another in junior high) from a previous marriage, to whom Rob is a very dedicated stepfather, and of Rob's daughter from a previous marriage, who had died a few short

years ago from complications of an illness that also had caused kidney failure. I later learned that Rob's first wife had died of cancer, and that he had tended to both his wife and his daughter in their last days, which afforded him a very close perspective on caregiving and loss, and very certainly shaped his orientation toward caring for Mary. He explained to me that the difference was that, with his first wife and daughter, he knew that death would be imminent and that there was really nothing he could do to "screw up," whereas for Mary, he feared that her well-being and potential to get better were much more in his hands. In other words, the stakes were even higher in transplantation because the aim was to eventually restore life and health; Rob feared that, as a caregiver, he could "screw up" those chances if he did something wrong or failed to solve a transplant-related dilemma.

These family pictures were held in frames along the walls and propped up amongst a figurine collection of cows and angels lining the shelves of their entertainment center. The room also was furnished with a computer desk and chair, a sofa, and two recliners separated by an end table which held papers, beverages, and their cordless telephone. One of the beverage holders was a large plastic jug with a handle and straw, enabling Mary to hold it independently, since her hands had been left contracted shut as a complication of some of the pain medication she had needed to take during her hospitalization. Intermingled with all of this were Mary's walker (which she needed to use not only due to post-surgery weakness, but also because the same medication which had caused her hands to contract shut also caused her feet to contract into a dropped position), her 4-row-by-7-column plastic pill box, and multiple boxes of medical supplies now stacked in their bedroom. From the outside, the only hint of this blended hospital-home environment was a wheelchair ramp up to the back door, hardly noticeable when one came and went out the front.

As we sat and talked together, Rob in his chair and Mary in hers, and I in the computer chair facing them (this eventually would become the comfortable seating arrangement for nearly every conversation we would have), it became very clear that the abrupt shift from being a healthy, vibrant woman who enjoyed working hard and playing sports, to suddenly becoming gravely ill, caused Mary tremendous emotional pain. Her

eyes filled with tears as Rob explained how medical challenges have impacted their lives as a couple and as a family, and what it has been like to be Mary's primary caregiver.

Rob: *It's turned the whole family upside down. It's changed our relationship. [...] Put it that way, I won't say that it's better or worse, but it's definitely changed our relationship. (Mary: There's no intimacy. There can't be.) I asked her a long time ago, well before she ever had her transplant, I said, are we ever gonna get past a nurse-patient relationship again and be a husband and wife? You know, we don't know, and it could be a long, long time before we will. And that's something that, in a long-time situation like this is, um, I don't think we were aware of it. I wasn't warned about it. (Mary: I don't think people necessarily see that coming.) And I don't think about it a lot now [but] it does cross my mind, and when it does. It's like, 'Wow, how will things be in the future?' I mean, there are signs that I know of, like today I, this [ostomy] bag is kicking my ass and I don't know, I've tried everything I can, and I blew up. I'm sure she's mad at me about it (Mary: I'm not) and I'm sorry but I just, and then I [have to convince] her to take her medicine and [I] do her [ostomy] bag changes and that makes her hurt [because I have to pull the tape from her skin to change the bag]. [...] And I don't know how this is just gonna work out. [...] I would trade places with her in a heartbeat if it would get her there. But if she does get back to 100% normal, she won't need me, and that's a fear, regardless. Even if it is stressful and no matter how stressful it is, it's still good to be needed. [...] As far as our marital relationship, I don't think [it has changed,] in my eyes. Me personally, it hasn't really, other than the sex portion of it. Um, and all the playfulness that goes around that, the flirting that goes around that, that's all pretty much gone now. Other than that, I don't think it's been a change in our relationship, the way, it hasn't affected the way I feel about her, I still feel the same about her now as I did before. If that makes any sense...*

Patient-partner negotiations that take place in a home setting can be infused with tension and contradictions for both parties. Rob both wished for Mary's full recovery, and yet expressed fear over the prospect of no longer being needed. He willingly took on the challenge of managing Mary's ostomy bag and the bodily waste it collects, and yet

lamented the loss of sexual intimacy. This made even more significant the fact that the couple's bedroom served as storage space for the myriad boxes of medical supplies Mary required for her daily care. Rob reported that their experiences with transplantation have "turned the whole family upside down," and at the same time insisted that their relationship had not been changed.

In fact, this third claim – that transplantation has *not* changed the patient-caregiver relationship – was echoed again and again throughout this study's interviews. Much as the "do what you've got to do" mantra became shorthand for reconciling competing necessities through action, the insistence that "I don't think it's been a change in our relationship" serves as shorthand for reconciling the challenges of maintaining a sense of stability and perhaps even reinforcement in participants' most intimate relationships in spite of the fact that the circumstances of transplantation can "turn the whole family upside down." This, too, is a form of doing what must be done, even when things don't make sense in the ways that they used to. It marks an attempt to carry out normalcy in the face of the harsh realities of dealing with the types of extraordinary situations transplant patients and their informal caregivers encounter together. And yet, there also is indication that, consistent with the literature on kinship and the home outlined earlier, changes in the social use of home spaces actually can and do create new terms upon which patients and their loved ones must renegotiate their relationships.

Transformations Are Not Unidirectional

The move to home-based high-tech biomedical care is made possible in part through the training, by clinicians, of lay persons to develop the knowledge and skills necessary to do the job. But, as in the case of Mary and Rob, there are indications that biomedicine, as practiced by lay persons, can in turn become shaped to conform to the moral bonds of relatedness and commitment. This transformation is neither uniform nor complete, and the following does not negate an assertion I made at the beginning of this chapter, that lay experience is generally not [yet] given the same authority as biomedical expertise even as care is shifted from hospitals once again back to homes. But it does qualify this assertion, and serves as a reminder to pay attention to the *interactive* transformations that can take place as clinical and domestic domains blend together.

Specifically, in the following excerpt from the same conversation as above, we see that Rob and others in Mary's network of lay care providers – even Mary herself – came to be very knowledgeable and capable in their ability to perform procedures like ostomy bag changes and wound care, so that they themselves were positioned to effectively troubleshoot equipment problems, and even to train others. Importantly, this knowledge and capability developed out of a very sensitive, personal, and *caring* form of caregiving.

Laura: *How did your mom and [your close friend (to whom Mary had been very close since childhood)] learn some of the different kinds of cares?*

Mary: *Everyone had to be trained by the nurse, except [my friend] wasn't trained – Rob trained [her]. But my sister and my mom were both trained how to do it. And they all helped [her] and I knew how to do [...] it because I was sitting and watching them every day, so I could walk somebody through it. You know, actually, that's what I have to do is my ostomy bag when I go in the hospital, because the nurses don't know so I have to walk them through it.*

Laura: *So you're actually teaching people how to go along...*

Rob: *When she went through for her transplant – her ostomy is located in a tough place – they were changing it out every two to three hours. (Mary: It was bad.) I said, if you need me in here to do this, I can. She would lay there and just cry. There was a certain amount of, I guess you would call it detached professionalism, that they don't care if she's hurting. I do. ...*

Mary: *Well, it's just a matter of taking time. They would just rip the bag off where Rob would use his one finger, and then go another finger, and another finger, and another finger...*

Rob: *Not just that, but it's a matter of like—we're having some tough times right now with the bag. It's just driving me up a tree, and I can't get the bag on and I know it's because she's getting better, her flexibility is getting better [...]. The more flexible she gets, the harder it is to keep it tight. And I'm racking my brains trying to figure it out, and I'm so frustrated with myself because right now I'm only getting the bag to last a day. And I just can't stand it. It's like it's kicking my ass, and I don't like it. I just can't,*

I'm not smart enough to figure it out. I work on it, I try something different. I lay in bed and I think about it, but I do care if it's hurting and I do care how long the bag lasts. And like I said, I'm not doubting the nurses. I never, I've always just called it a detached professionalism. You're pretty much trained to do that. And that's good to some extent, but it's also not, to some extent. (Laura: because it takes a little extra time?) [Rob nodding] And they don't have that extra time.

Mary: When I was on [the transplant recovery unit], one of the nurses, I just fell in love with her and we just sat and talked a lot. Well, bag changes [a loud beeping starts coming from the wound-vac machine; Mary checks the battery pack sitting next to her chair] – it's a low battery. (Rob: I'll charge it) [Rob gets up to work on the machine] Yeah, um, while she was doing the bag changes, the bag changes would take four or five, sometimes six hours, I mean, they were long.

Rob: And then they would leak and they would have to turn around and start all over.

Mary: ...peel it off and start back all over. They literally, literally got a Ziploc bag and cut it up and put it over my stomach. And that one would last a day. They were in there every day, pulling tape off my stomach every day. They finally had to put me on a Fentanyl sucker. I was on Dilaudid, I was on Vicodin, a little Fentanyl sucker, and what else was I on for pain? I was on three or four different kinds of medicine and none of it would take the pain, or even touch that. And now when they put the tape on me it makes little red marks. You can touch my stomach and it leaves little red marks because it is so sensitive now, because of what they've done, what they were doing, a bag change almost every day there.

Similar to many informal caregivers I met through fieldwork, Rob demonstrated a very strong commitment to providing the best care possible to Mary, literally lying awake at night to strategize about how to overcome difficulties presented by medical equipment (here, the ostomy bag) and alleviate some of his wife's suffering. This dedication of time, patient effort, careful consideration and creative innovation, in Mary and Rob's experience, stands in contrast to all but one nurse in particular. Mary remembered this nurse, who would take the time to "sit and talk a lot," as an exception to the norm they encountered during their hospital stay. Significantly, it was under this nurse's care that

they were able to find at least a slightly more workable solution, through the use of a less biomedically conventional, more low-tech material, that could be found in most U.S. homes – the resealable plastic (“Ziploc”) bag.

Mary and Rob demonstrate the point that greater involvement of informal caregivers need not entail a one-way movement of biomedical care, expertise, and technology from the hospital/professional clinical domain to the home/informal caregiver domain. Rather, the fields are relational, intermingling, and multi-directional. Further, they can interact in important ways so that each realm of health care can be shaped by the other. A study by Jones and Egan (2000) likewise supports the idea that the “hospital to home” shift should not be thought of in uni-directional terms. Their research offers evidence that informal transplant care is not confined to non-clinical, community settings, but often takes place right in the hospital at the time of transplant. In their qualitative longitudinal study in a mid-southern U.S. city, Jones and Egan (2000) focused on the experiences of 20 liver transplant recipients. A frequent theme in patient interviews was that their formal health care (both inpatient and outpatient) was affected by significant understaffing of clinical professionals. To summarize their findings regarding how crucial it became for family members to perform caregiving responsibilities right in the hospital, Jones and Egan write:

In every case, family members made up for the deficit. It was not unusual for a family member to be present in the recipient’s hospital room on a 24-hour basis following transplantation surgery. They often maintained this schedule for the duration of the recipient’s inpatient treatment. Without exceptions, recipients were emphatic about the importance of the care provided by family members to their successful recovery. In many cases, family members assumed nursing responsibilities such as emptying bedpans and changing dressings. (Jones and Egan 2000:77)

Similarly, Rob and Mary found themselves knowing *better* how to perform some of Mary’s most important cares than did most of the clinicians, and were ready to take their own “home grown” brand of biomedical care with them into the hospital. Rob at one point even asked the nurses if they “need me in here to do this” during Mary’s painful ostomy bag changes. At the time of this particular interview, Mary still had to walk clinical professionals through the procedure whenever she was hospitalized. Indeed, lay caregivers can develop knowledge, skills, and expertise which are equally

effective, yet distinct from those of most clinical professionals. Rather than being characterized by what Rob calls “a detached professionalism,” Rob’s expertise grows out of a very time-intensive, personalized, and *attached* form of care that has been cultivated in the home, where persons often try their very best to bring together the moral obligations of kinship (to love, to care, to “be there” for one another) with the clinical demands of transplantation.

Redefining Hospital Spaces

Notably, a recent trend in the highly competitive hospital care market is to renovate hospital rooms to feel more home-like. As I outlined briefly in the Introduction, this new level of competitiveness owes at least in part to new pressures created by the DRG system and the Medicare Prospective Payment System implemented in the 1980s, as well as managed care in the 1990s. Caplan (1989) adds that, from the early 1970s, “Profits were being squeezed through increased wage demands (in part to pay for rising out-of-pocket expenditures for medical care) and by steadily rising employer contributions to pay for workers’ health benefits;” what emerged was a corporatization of medical services (Caplan 1989:1145). One indicator of this corporatization is the ubiquitous advertising of home-like birthing suites in television, billboard, radio, and print advertisements. This move to make hospitals feel more home-like is not unique to the U.S. Exley and Allen (2007), for example, point to a comparable development in the UK in home-birthing and palliative care suites. The health system of which the Transplant Center is a part likewise has taken part in this trend, and at the time I conducted my fieldwork, the Transplant Center employed a “Cooperative Care” model in the treatment of some of its transplant recipients (especially those receiving blood-forming stem cell transplants). During inpatient hospitalization under Cooperative Care, patients and their care partners stay together in a setting intended to more closely resemble a private, furnished apartment suite than a conventional hospital room. In a reflection of the realities of shortened hospital stays, these types of spaces are promoted in part for the idea that they more closely resemble the setting within which the majority of post-transplant recovery will take place, and thus have the potential to ease the transition from hospital to actual home (McLane et al. 2003).

A great many resources have been put toward bringing “the home” (or, more accurately, certain elements of the home) into the hospital via spatial and material design. The Cooperative Care rooms I visited tended to have a small living area with a loveseat sofa for lounging, and a small kitchenette with a modest amount of cupboard storage space, a small refrigerator, and a microwave oven, all separated from the sleeping area by a see-through glass door (allowing for a sound barrier between the two areas, for example, while a patient rests, but not obscuring the care partner’s watchful eye). Just off to the side of the living space was a private bathroom, to be shared by a patient and his or her care partner(s). In the rooms also were light wood-grain-colored dressers and closets; shelves housing televisions, VCR’s and DVD players; as well as a small table and chairs. The table and chairs tended to be placed at the far end of the sleeping area, near a window which allowed the daylight to shine in on the two double beds found in a typical room. As I explain more fully elsewhere in this dissertation, in practice, Cooperative Care rooms at The Transplant Center were more often used by bone marrow stem cell transplant patients (who usually are required to remain inpatients for very long periods of time following their transplant) than by solid organ transplant patients. Although the designer’s intention was to make this space “home-like,” among those with whom I spoke who had stayed or were staying in Cooperative Care, the general consensus was that the space felt more like “a nice hotel room” than an actual home.

Regardless of which hospital unit they stayed on, I asked most participants who had spent a great deal of time as inpatients whether the hospital ever began to feel like home to them. The responses were somewhat varied. Some participants who had spent especially long and frequent periods of time as an inpatient would jokingly refer to the hospital as their “home away from home.” Others listed some of the ways in which they and their loved ones tried to make their hospital rooms feel more home-like (e.g., by decorating for holidays, bringing in pictures of their loved ones and children’s or grandchildren’s drawings, bringing favorite blankets or comfortable clothes, etc.), but still maintained the distinction. And still other participants emphatically insisted that the home and the hospital were two very different places for them, and that the hospital absolutely did not *ever* become “home” to them. Across the board, though, most of those with whom I spoke about their hospital stays emphasized their eagerness to get back to

their actual home, often missing their favorite chair, their own bed, their own kitchen, and their own or their partner's cooking. This offers yet another reminder that, while the realms of home and hospital can blend in important and profound ways, the two domains also retain distinct qualities, characteristics, and significance.

Conclusion: Transformations, Constraints, and Concerns

This chapter has explored a phenomenon in which high-tech biomedical care is transferred to the home, where patients and those close to them rearrange their spaces, lives, and relationships to accommodate the demands of transplant. Field and interview data collected in the course of this study revealed many compelling examples of patients and their loved ones being extraordinarily innovative in light of the challenges, constraints, and transitions they encounter throughout the process of transplantation. Through innovation and the efforts of loved ones to “do what must be done” while trying to maintain a sense of the way things once were (before illness, before transplantation, and before kin relations began to take on some of the qualities of a “nurse-patient” relationship), biomedicine is being taken up, re-worked, and transformed into a different form of biomedical practice than what initially made its way into the home.

There have been efforts on the part of hospital administrations and their clinicians and other staff, through the design of new hospital spaces, to bring elements of the home into the hospital. While part of the impetus for this trend is to create more appealing and pleasant spaces (a necessity in the competitive, commercial, corporatized hospital market), at the Transplant Center, it also is touted as a way to provide a simulation of the environment in which most of the transplant recovery will take place. Indeed, the practice of biomedicine is being shaped by the political-economic (i.e., U.S. health care policy) reality that it now does and must be able to take place in the context of everyday home life, which includes cooking, sleeping, spending time together, and sometimes attending school or working in paid employment. But the two domains still remain at times incommensurable in the experienced, lived, realities of patients and carers. Many of those with whom I spoke about the matter indicated that a hospital environment that is modeled after a home space is aesthetically pleasing and rather appreciated. But while

the *care* of home travels fairly readily in the lay home caregiver, the *sense* of home appears not to transfer as easily.

Likewise, not all aspects of the hospital can be packed up and brought home on the day of discharge. Patients and their care partners usually are eager to return home. Once there, visiting nurses and CNA's often do come to the house on a regular basis, and patients and their caregivers are free to call their transplant nurse coordinators with questions or concerns whenever they wish. All the same, the responsibilities of transplant-related home care can and do place formidable demands and constraints on people and relationships, and there sometimes are inadequate resources available to support those who find themselves struggling. Weaknesses in the safety net of this system are especially pronounced for those who have fewer resources to begin with, as well as for those who do not have family or other loved ones on whom they can rely for round-the-clock care (specific examples from fieldwork will be described in the following chapter).

In many cases it became clear that patients and caregivers often do face significant "arenas of constraint," defined by Inhorn (2003:16) as "various structural, social-cultural, ideological, and practical obstacles and apprehensions." Durkheim, in his *Elementary Forms of Religious Life*, noted that social ideals are revealed through the constraints we experience, and drew a direct connection between the two, calling constraints "the visible, tangible expression of an underlying, inner fact that is wholly ideal: *moral authority*" (emphasis in original; 1995[1912]: n.6, 210). Despite being required to shoulder the risks of providing a bulk of transplant-related cares, the majority of participants in this study incorporated them into their daily lives with little or no protest and tried their best to accommodate the new arrangements as more or less part of the natural order of things. Indeed, it was difficult for patients and those surrounding them to see things as playing out in any other way. To be sure, nearly every time I remarked on the challenges they seemed to be facing, patients and lay caregivers were quick to verbalize a "do what you've got to do" and "just take it as it comes" sentiment. This underscores the moral authority of widely accepted notions about binding obligations among kin to provide care even under difficult circumstances.

It also can facilitate the shaping of high-tech biomedical care into a novel home-based enterprise.

While many lay care providers are both capable and willing, the trend is deserving of critique. “Self-care” in itself is not inherently unacceptable – indeed, Mary and Rob, and many of the other participants in my fieldwork noted that their family members gave better and more personalized care than the clinical staff were able to give. Yet there are many injustices growing out of things as they currently stand. With the considerable potential for complications, infections, and rejection, especially in the first days and weeks after transplant, even the most innovative lay care partner can quickly find himself encountering problems beyond his capacity. In her 2003 analysis of what she calls the “place switching of health care services” in the U.S., Cartier points out that, “The overall economic result of shortening the length of stay in hospital is that the health management and economic risks of subacute and daily life care are shifted to patients and families, who are typically neither professionally equipped nor trained to meet subacute care needs” (Cartier 2003:2296). The same economic restructuring trends that push for earlier discharge, are also having the effect of asking patients and those close to them to shoulder more and more responsibility for continuing medical care in private spaces at the individual level.

In addition, since medical coverage in the U.S. is so closely tied to employment, patients’ families find themselves in a double-bind of competing obligations. Either at least one family member must continue to work full-time outside the home in order to keep medical coverage and income (Emily’s husband, for instance, had joined the military in order to secure health care benefits for his wife and daughter, as I discussed in Chapter 3), or else they cut back to part-time status or less in order to provide care to their ill or recovering family member, and risk losing the family’s primary means to pay for the significant and perennial costs associated with transplant (such as follow-up care and anti-rejection medications). Thus, the increased care needs of early-discharged patients and the movement of their care to spaces outside the hospital can present an even greater challenge to families and home life. This and similar concerns will be taken up more thoroughly in Chapter 7, which will focus on public social and health policy conundrums related to these very issues.

But before we turn our view specifically to some of the policy matters raised in this dissertation, our focus will remain for one more chapter on kinship and relatedness. At the beginning of the present chapter, I offered evidence that kin relations can become altered through the transplant process (even as they in turn can also work to shape the practice of transplantation, as the two domains interact). The following chapter will document and analyze of some of the additional ways in which relations can become revealed and reframed over time through transplantation.

Chapter 6:

Revealing and Reframing Relatedness Through Transplantation

The practice of transplantation, as we have seen, has implications that extend well beyond the transfer of organs and tissues between bodies. Certainly, at stake are the deeply moral matters of life and death. Within such high-stakes contexts, kinship relatedness (another deeply moral social matter) can simultaneously be revealed, reframed, and reworked. Here, we will return once again to the theoretical frameworks provided by scholarship on kin relatedness, which emphasizes the social nature of kinship. Building upon earlier analyses, this chapter will describe in greater depth some of the complex ways in which the transplant process effectively reordered relatedness among transplant candidates and recipients, their caregivers and other loved ones, donors and donor families, and clinical personnel. Through their involvement in various aspects of transplantation (including pursuing a transplant, directly caring for or otherwise supporting a transplant patient, or becoming an organ donor or donor family), members of these groups participate in reciprocal webs of care and moral commitment upon which hinge the very clinical and socio-cultural²³ feasibility of transplantation. Notably, this chapter highlights evidence that transplantation as it is practiced in the U.S. often defies commonly held ideals about the self-sufficiency and boundedness of the American family, even as patients, their loved ones, and clinicians draw upon dominant mainstream kinship ideologies throughout the transplant process. I will approach these notions via two angles, and as such, this chapter is divided into two parts.

Part I will present evidence that another party – the deceased organ donor and donor kin – is another significant member of a transplant recipient’s web of relations.

²³ An example of socio-cultural feasibility would be the fairly widespread acceptance despite the potential discomfort with the notions of brain death or harvesting organs from human bodies.

Whether or not that party is acknowledged by recipients, and whether or not that party offers acknowledgment in turn, I argue that the *potential* for connection is there, and thus can open up transplant participants to new, extended networks of kin. In light of this, participants' understandings of their relations can be revealed, reframed, reinforced, or some combination of all of these. Like more conventionally recognized forms of kinship this connection can be emotionally close or distant, highly charged or rather neutral, amiable or fraught with tensions. The evidence I present will be drawn heavily from conversations and other interactions with Mary and Rob (the small bowel, liver, and pancreas recipient and her husband, who appear throughout this dissertation), as well as from my participant observations at Transplant Reunions.

Part II will present evidence, more in keeping with the rest of this dissertation, from my observations concerning the kinship ties among transplant candidates and recipients and those who care for them. Here, I will argue that relatedness can become revealed and reframed as persons share, for example, the intense and extraordinary experiences of transplantation. Up until now, though I have tried to keep an eye toward more extended webs of relations, my focus has been on patients and their primary informal caregivers. In Part II, I will broaden this view in order to account for the clinicians, fellow patients on hospital units, fellow residents of temporary housing for long-term outpatients, and friends and neighbors to whom patients must turn for help—all of whom can become very important members of patients' and caregivers' webs of relations. I will conceptualize these cases largely in terms of the kinds of solidarity and social cohesion that can bring persons together in the context of transplantation. In addition to acknowledging Rabinow's ideas about biosociality, I also will borrow more again from Durkheim's insights, some of which I have outlined earlier in this dissertation. At the same time, I also came to know persons who did not enjoy a socially cohesive experience with transplantation, and I will present their perspectives as well. Finally, I will examine some of the ways in which birth and death – likewise crucial aspects of kinship and relatedness – also can come to the fore in person's dealings with transplantation.

Overall, by foregrounding social relations rather than body parts, this chapter will add to ongoing anthropological discussions about kinship and relatedness, as well as transplantation and other manifestations of high-stakes, high-tech biomedicine.

PART I:
REVEALING AND REFRAMING RELATEDNESS VIA TIES BETWEEN
DONORS/DONOR-KIN AND RECIPIENTS

One subject that has received some attention by scholars is the connection – or potential for connection – between donors and/or the kin of deceased donors and transplant recipients (Bird-David 2004; Forsberg, Backman and Möller 2000; Fox and Swazey 1992; Haddow 2005; Waldby 2002, to name just a few). The central focus of this dissertation has not been on donor-recipient relations, but rather on the relations between patients and caregivers. However, the importance of these aspects of transplantation cannot, of course, be ignored. Even though I did not set out to look specifically at the issue, the matter of the relationship between transplant recipients and the kin of deceased donors came to the fore periodically – and in the case of Mary and Rob, in a very major way – during the course of my fieldwork.

A New Life Celebration

During a brief telephone call I'd made to Mary to schedule a follow-up interview, she sounded much more full of energy and enthusiasm than she had the first time I met her some months ago. She let me know right away that she would be glad to meet with me, but this would not be possible until later because this week is "crazy" for her, as she was having a New Life Celebration the coming Sunday. Unsure of what a New Life Celebration exactly was, I asked whether they've had a birth in the family. Mary said no, this was a party they were having to celebrate the one year anniversary of her "new life." I paused another moment and she clarified: "that's when I received my transplant." She

said the Transplant Center nurses had told her about other patients' New Life Celebrations, and that it was a nice way to mark such a milestone (the nurses all had insisted, 'You've *got* to have a new life party!'). Hers was to be a party for all of the nurses and therapists and for everyone who had been so good to her and helped her along the way. The event would be held open-house style (meaning guests could come and go freely), from 4-7pm at her house, and they would have sandwiches and cake.

Mary was especially excited to share that, since the last time we'd last spoken, she had received a letter from the donor family; it was from the donor's mother. In this letter, Mary found out that the donor was a woman; she learned the donor's first name; and she learned that the donor had enjoyed riding horses. Mary was so happy to get this letter, and plans to display her letter to the donor family, and the donor family's letter back to her, on a table at the party for everyone to read. "You really should come to the party, Laura." I said I definitely would be there, and expressed my gratitude to have been invited.

"It's My Birthday!"

Mary's collection of cow and angel statuettes, prints, and figurines greeted guests at the door on the summer afternoon of her open house celebration. Most prominent, as one approached the front door, were a statuette of a cow nearly a foot tall, sitting reclined next to the door, and a stylized picture of an angel hanging on the door itself, featuring the phrase, "I Believe." Mary was positively radiant, bridging with ease her two roles as both host and guest of honor at her New Life Celebration. She no longer needed to use her walker to get around, and for mobility relied only on a set of braces that supported her shins and ankles. Her hands were no longer contracted shut, as they had been when I'd first met her (this complication had been an unfortunate side effect of one of the pain medications she'd been given during her hospitalization for the complicated series of medical events that had led up to her need for a transplant in the first place), and she was able to use them a great deal more than had been the case some months ago. It seemed that everyone at the party was in good spirits, equal parts celebratory and relaxed, and overall, at ease. Mary, Rob, and Mary's two daughters all were wearing "Donate Life" t-shirts; Mary also sported a large pink lapel ribbon with "IT'S MY BIRTHDAY!"

splashed across the front in bold letters, as well as a metal lapel pin in the shape of the green loop of ribbon which symbolizes and advocates for organ and tissue donation awareness.

Spread across the kitchen counter, buffet style, were slices of cheese, ham, and turkey to be paired with buns for sandwiches; baked beans; potato salad and macaroni salad; and bowls of red, orange, and blue gelatin salads. On and around the kitchen table were sweet tea, unsweetened iced tea, and lemonade, and a decorated cake that had been made by one of Mary's friends. Next to the cake was a copy of the letter that Mary had written to the donor family, as well as the handwritten reply Mary had received back from the donor's mother, both of them displayed in frames.

Family members, friends, nurses, physical and occupational therapists, and others who had helped Mary through the transplant and recovery process in one way or another, all mixed and mingled; many already knew one another, but those who hadn't yet met struck up conversations seemingly without hesitation. Mary introduced me to her mother, and she and I had an opportunity to talk about the significance of this celebration, that just a year ago they were all very uncertain whether Mary would survive, and whether a hoped-for transplant would even become a reality. She shared with me how concerned they all had been for Mary, and we chatted for some time until she was called away by someone asking where they might find more silverware. The two extremes – needing to contemplate the death of one's daughter as a very real, near-term possibility, and needing to replenish the plastic silverware (and maybe the cold cuts or jello-salad as well) on a party buffet table – seemed on the surface to be completely at odds. And yet, these same juxtapositions, as I have tried to show elsewhere as well, tend to permeate the lives of transplant patients and their loved ones.

A group of Mary's former co-workers from a local grocery store also were in attendance, and they joked with Mary a great deal about some of the pranks they used to pull on each other when she worked there. One had brought a hat in the shape of Mickey Mouse ears, which had come to serve as the equivalent of a "dunce hat" at their place of work, and which Mary had once been fond of making people wear when there was occasion to do so. The mood temporarily turned more solemn, though, when one former co-worker told the story of when she brought flowers to the hospital during a visit with

Mary. Furrowing her brow, Mary asked if she had been awake when the co-worker had visited, and the co-worker said yes, they even had sat and talked for a little while. Mary shed tears as she explained that she didn't have a memory of that incident, there being so many things that she couldn't remember from that period of time, when she was still in very serious condition, and even during the earlier stages of her recovery.

Two of the visiting nurses who had worked most with Mary and Rob were there, and had brought their own children with them. Likewise, the physical and occupational therapists who had guided much of Mary's ongoing physical rehabilitation regimen also were there, and they too had brought their children. The atmosphere overall made attendees feel free to blend in conversation circles and seating arrangements both inside and outside of the house. Before long, I was asked to hold an infant while a new mother ate and visited with others, and at another point I pitched in as several others had, to help clear tables of used paper plates and cups.

During one trip back into the kitchen with a handful of used plastic cups, I stopped to take a closer look at the letters that Mary and the donor's mother had exchanged. Mary happened to walk by and I had a chance to ask her more about them. Actually, she said, her sister-in-law (her brother's wife) had been the one who typed up her letter. Mary, the sister-in-law, and Rob all had sat down together one day to talk about what Mary would like to say in such a letter, and then her sister-in-law went ahead and wrote it on Mary's behalf. "She just has such a wonderful way of putting things into words," Mary explained. During a later visit, some weeks after the New Life Celebration, Mary pressed a copy of the letter into my hands, and with her permission, it appears below. [It also had featured the names of Mary, Rob, and her two daughters, but I have erased them here to maintain confidentiality.]

Dear Donor Family:

For the past three months, I have often thought about what I would say to the people who, in a time of grief and despair, could think of others and donate a loved one's organs. I am very sorry for your loss. Now that I find out I can write to you to express my gratitude, it is difficult to find the words to adequately express my feelings. "Thank you" just doesn't seem quite enough, but your generosity in giving a part of your loved one to me is a wonderful deed.

I received a liver, pancreas and small bowel. I want to let you know what a difference your kindness has made in my life. I am a married 41 year old mother of two wonderful teenage girls and have an incredible husband who has gone above and beyond the vows he had taken 10 years ago. Your gift to my life will enable me to watch my girls play sports and see them graduate high school. Our family is looking forward to the day when we can travel and take vacations again. Never in my dreams would I have thought my life would have become what it is today. The transplants are doing wonderfully, and I am growing stronger and healthier every day . . . thanks to your unselfish kindness.

In closing, I would like again to extend my thanks and condolences and hope that one day you will be able to open up a line of communication with me and my family. Thank you for entrusting me with a living legacy from your loved one. I will always treasure this gift and I will always keep your family in my thoughts and prayers.

Figure 4: Letter from Mary to Donor Family.

The donor's mother had replied with a handwritten note on a partial sheet of 3-hole punched lined notebook paper, which Mary had mounted onto a purple backing and framed:

"I have started writing this letter so many times and I am not sure I can do it now. So just let me say I pray that you are doing well. My Claire would be very happy about this. She was a very beautiful girl and she loved riding horses. Maybe I can write more next time.

Her Mother, Lois²⁴"

²⁴ "Lois" and "Claire" are pseudonyms, like all the names of participants which appear in this dissertation.

Per a common policy of anonymity, each of their written exchanges had been screened for identifiers and relayed by their state's respective Donate Life organizations. Mary said she already had written to her donor's mother a second time, to ask whether she would be willing to open up direct lines of communication that would not need to involve their local Donate Life organizations. She still was waiting to hear back from them.



Figure 5: First Letters between Mary and Lois, Framed and Displayed in Mary's House.

New Life, New Relations

Just a few weeks after the New Life Celebration, Mary called me at my home, very excited to share with me that she finally had heard back from her organ donor's mother, in response to her second letter. Mary told me she literally shook as she opened the letter, which provided the donor mother's full name, phone number, and a note that she indeed was willing to communicate directly, and that Mary could call her anytime. Mary called that very evening, and the two women talked for an hour. The donor's mother, Lois, told Mary the story of how her daughter, Mary's donor, had died, and that, by the time Lois had reached the hospital, her daughter Claire was already brain dead (see Lock 2002 for an in-depth examination of "brain death" in organ transplantation). Lois said she learned that there had been four recipients whose lives were saved through the donation of her daughter's organs, but that Mary was the only one of the four to write a

letter. Mary felt shocked that Lois had not heard from others. “It was the least I could do, Laura,” she told me, indicating that, from the beginning, she had felt a moral obligation toward the donor and donor’s kin.

Claire had been the mother of three boys; the oldest was in high school and the other two were twins, both in junior high school. Mary went on to describe all the uncanny similarities the two women had discovered existed between their two families as they talked on the phone, beginning with the fact that Claire’s sons were the same ages as Mary’s two daughters. Lois’s husband (Claire’s stepfather) had the same name as Mary’s husband. When Rob was younger, he had worked as a Youth Baptist Minister, and Lois’s husband was himself a Baptist minister. Lois works in a pharmacy, just as Mary previously had. Both families drive the same make, model, and color of car (they differ by only one or two model years). Mary gave Lois a physical description of herself, and had mentioned that when she dies her hair, she colors it auburn. “Red hair?” Lois had asked to confirm—“my daughter had red hair, almost auburn.” Mary also noted that, “The way Lois described Claire’s hair, it was just like my youngest daughter’s hair.” The connections forged in the similarities between the two kin groups (in names, in family birth chronologies, in material possessions, and even in hair) were as if they had been in place all along, and had become solidified and made visible by the transfer of organs from Lois’s daughter to Mary. Both women cried throughout the conversation, and the tears would begin again each time another point of similarity revealed itself.

When Mary told Lois her own story of how and why she came to need a transplant, Lois’s response was that, “If this hadn’t happened to you, Mary, then we wouldn’t have met.” Lois also had had a son who had died some years ago, and now she had lost her daughter as well. “Now,” she told Mary, “you are my daughter.” In the days and weeks that followed this initial phone call, the two women talked on the phone several times each week. Mary later told me that Lois refers to Mary’s daughters as her granddaughters, and they call her “Grandma” in return; the relationship between the two women has in many ways extended to a relatedness between their two family groups. I asked Mary how she felt about all this, and she summed it up with a mix of certainty and wonderment: “It’s just awesome.” In their first phone call, Lois told Mary that she’d felt a connection with her as soon as she’d received the initial letter. “Do you mind if I

tell you that I love you?” Lois had asked. “No,” Mary replied, “because I feel the same way.”

The relatedness between the two families, then, was mutually acknowledged between Mary and Lois as a bond of love. It would be overstepping the evidence I have available to say that this bond of love is just like the kind of love Lois had for her own children. But it does seem to emerge out of a longing for at least an analog to what was lost in the death of Lois’s daughter – not as a *replacement*, but more as a *likeness*. The two women found evidence of this likeness to be spread throughout their respective kin groups, as points practically ready-made for the blending. Mary had not just lost a loved one to death; her connection to the tragedy was that her own life had been *saved* in its wake. But the circumstances leading up to and including the transplant *had* created tremendous losses and upheaval for Mary – Lois recognized this by pointing out that, “if this hadn’t happened to you, then we wouldn’t have met” – and Mary, too, was open to the new bonds of connection that such a deeply powerful exchange could create. Indeed, Mary had a strong sense not only of the potential for a form of kin relatedness with the donor family, but also of the moral obligations that come along with kinship.

Witnessing Connection

The fact that it was already dark at 6:30pm on a day that earlier had felt almost spring-like was a reminder that we were still deeply entrenched in mid-winter. When I pulled up to the house, Mary’s front door was propped open and only the full-view storm door, to which festive translucent Valentine’s Day clings had been generously applied, separated the warmly lit and welcoming inside from the dark and now very cold outside. As I walked to the door, I could hear the people inside discussing my arrival and I didn’t even have to knock before Mary answered the door and greeted me with a big hug. Standing right behind Mary were a woman and a man, whom I immediately realized must be the donor family. Mary stepped aside and introduced us, first the woman, Lois, who extended her hand with a heavy seriousness that broke when she felt my cold fingers and remarked that they were freezing. “I should have worn my gloves on the drive over,” I agreed. Next, the man who had been standing just behind Lois stepped forward and she introduced him as her husband, Rob. He, too, noted how cold my hands were, and we all

made a brief foray into small talk about the weather. Mary mentioned that her Rob was staying in the bedroom because he wasn't feeling well (much like, as we saw in the previous chapter, Angela kept her distance from Barry any time she might be contagious). Mary offered to take my coat, and as she walked across the room to drape it over the back corner of the sofa, I could see that her mobility had continued to improve over the past months. Looking around the room, I also noticed that a great deal had changed since the last time I had visited Mary and Rob, in the late summer/early fall. Several of the cows and angels had been put away; the television and the computer areas had been swapped; and new curtains hung at the windows. Several new items lined the walls, including new decorative hangings and a framed news article about Mary's and Lois's stories (and that of their newfound connections). Photographs, especially, had been re-grouped, reframed, and switched out with updated and additional family pictures. Turning back to Lois and Rob, I asked them how their visit had been going thus far, and they told me about some of the weather-related travel delays they'd had getting here, that they'd had a very nice visit, but that they also were beginning to feel ready to get back to their home, located in the warmer U.S. south.

The topic shifted quickly, however, to the fact that Mary already had told us all a good deal about each other, and walking back from the sofa, she asked me to explain my project to Lois and Rob, which I did as I took off my shoes and placed them near the entry rug. I told them I was so sorry for the loss of their daughter, and as Rob began right away to tell me about her, Lois walked over to one of Mary's living room rocking recliners and sat down. "That's her right there," Lois said, pointing to a framed 8 x 10 photo sitting on the top of a set of corner shelves that now filled the space where Mary previously had displayed only the two letters. The frame had a red valentine heart tucked in one corner, and a green ribbon comprised of "Perler beads" (the little plastic beads one arranges into a design, which are held together on a grid of small pegs and then fused together with a hot iron). On the shelf below Claire's photo was the framed copy of the typewritten letter which Mary initially had sent to Lois (not knowing at the time the identity of the donor or donor kin). Below that, the framed handwritten response from Lois, which shared a shelf with a ceramic tile plaque that read, "Organ Donors Are Heroes. I think of my hero each day. Be A Hero. Be An Organ Donor." Finally, below

that, an ornamental frame with “FAMILY” written across the bottom held a photo of Mary and Lois, with Mary standing just behind her, hugging Lois’s shoulders.



Figure 5: Corner Shelves in Mary’s House.

As Lois tucked one leg underneath her, she folded her arms across her chest and let out a little shiver. In a way that either a thoughtful host or a dutiful daughter might, Mary immediately got up and found a yellow quilt, and brought it over to Lois, who turned to me and asked, “Is it cold in here?” I said that I wasn’t so cold today as I usually had been all winter. Rob began again to describe Claire to me, offering details such as the fact that she’d loved to ride horses. Lois noted that it had not been an easy decision to donate, as they’d never talked about it in their family before. When the nurse first approached them to ask if they’d like to consider donating their daughter’s organs and tissues, Lois’s first response had been, “No, I don’t think so.” But then the nurse talked with her some more about it, and Lois said she’d like to go home and discuss it with her husband and grandchildren (Claire’s sons). After much deliberation, discussion, and prayer as they watched their daughter on life support, Lois said, she’d eventually decided that Claire’s spirit had already gone to Heaven, and her organs could be of use to someone who needed them.

As the couple went on to describe their experiences to me, Mary sat down at a laptop computer (which had replaced their old desktop computer) on a desk near the front door. Lois and Rob began to tell me about the ties they'd formed with their state's Donate Life foundation, and that they even had agreed to appear in a television advertisement which would feature their story as a means to raise awareness about donation (and ultimately to increase donor rates). Mary turned around to us and said, "Laura, I'm burning you a copy of the commercial right now." Then she played it, and Rob and I stood over Mary's shoulder while Lois watched from the recliner chair.

The advertisement featured segments of Lois and Rob describing what their decision to donate their daughter's organs has meant; the gravity of their emotion and conviction is conveyed through the waver in their voices, the earnest squinting of their eyes, and the gesturing of their hands throughout the short video. The clip opened with soft piano music playing, and the visual of a black screen displaying in white letters the donor's name and date on which she died (the date on which she became brain dead), followed by an image of the same 8x10 photo of Claire which Mary had displayed on her top corner shelf, and Lois beginning, "It took a lot of praying, I mean this just wasn't a spur of the moment decision." Rob explained further, "It has given *life* to someone. We're not talkin' about a wink, or a kiss, or a glass of tea, we're talking about *life*. She has given life to this lady." The screen shifted to text explaining that three of the donor's organs went to Mary, listing the state in which she lived. The couple reappeared on the screen and Rob continued, "When we finally made contact with the recipient, where she finally got through both agencies and we really made contact, not only just through letters and telephone calls, but then when we made personal contact..." Next came an image of a combined family photo which included Lois and her husband sitting in the middle, with Mary standing just behind Lois, and Rob (Mary's husband) standing just behind Rob (Lois's husband), and Mary's two daughters standing one on each side of the group. The screen remained on this image as the voice of Rob continued "They're *family*, man, I mean they're *family*! This lady is alive because of our daughter." Back to the footage of the couple standing and expressing their feelings, Lois said, "The results of this decision that we have made, has been a blessing not only to us, but to others, and like Rob said (and then the screen switched to a photo of Mary and Lois, the same photo Mary had

displayed on her bottom corner shelf). "...Mary is a part of, she's carrying part of my daughter, so that makes her family." And next the screen returned to the photo of the couple's daughter, Mary's donor, followed by a black screen with white lettering: "Donation is a Blessing," and then back to the couple, with Rob nodding as Lois went on, the pain in her voice palpable, "Losing Claire was *tough*, but the decision that we had made and the results of this decision has, I believe, opened doors for other people to make the decision of becoming a donor." Rob added, "And it's filled a void in our life." Lois: "Yes, yes." Last, the screen flashed a grey background with crepuscular ray-like white beams of light rippling across, with "Monday's Miracle," in large black lettering, then underneath appeared the web address, flanked on each side by the state's Donate Life logo on one side and the state's Organ Recovery Association logo on the other side. Last, a woman announced, "*To become an organ donor go to donatelife.org.*"

This video clip covered several themes. On the one hand, the advertisement touts the message that a *decision* to donate a daughter's organs carries with it several benefits, for the donor family, for the recipient, and for others who may be contemplating similar circumstances and in need of a positive model to emulate. On the other hand, a theme emerges concerning what has been given: both part of a daughter, as Lois says, and *life itself*, as Rob points out. And as a transfer of both flesh and life itself, Lois and Rob go on, transplantation has literally created new kinship ties ("they're *family*, man! I mean, they're *family!*"). But the kinship ties thus created – like all kinship ties have the potential to do – also are imbued with certain rights and responsibilities, the moral obligations of relatedness.

That such a relationship can emerge out of this powerful form of exchange is in line with the insights of Mauss, who drew upon ethnographic evidence about gift exchange in multiple contexts and pointed out that gifts embody, personify, and extend the personhood of the giver; they bind us to one another in deeply significant ways: "The gift itself constitutes an irrevocable link" (Mauss 1967 [1925]:58). Yet, while the organs themselves certainly are of tremendous significance, as fleshly socially imbued entities about which Lois and Rob (and Mary and her family) care very deeply, it is notable that not only were organs given, but life itself. Our analysis thus also benefits from Levi-

Strauss' (1969 [1949]) theorizations about the value of exchange itself for its capacity to bind people together. He wrote,

[T]he value of exchange is not simply that of the goods exchanged. Exchange—and consequently the rule of exogamy which expresses it—has in itself a social value. It provides the means of binding men together, and of superimposing upon the natural links of kinship the henceforth artificial links—artificial in the sense that they are removed from chance encounters or the promiscuity of family life—of alliance governed by rule. (Levi-Strauss 1969 [1949]:480)

Lévi-Strauss was writing in reference to marriage, exogamy, and the incest taboo, and the “goods” being exchanged were marriage partners. But his ideas about the binding significance of exchange itself offers a framework for understanding transplantation as another means of binding people together in a way that goes beyond the “natural links of kinship” and expands the potential field of relations to include others who likewise become bound by shared moral obligations.

Carsten (2000b) has examined adoption reunions in Scotland in order to inquire about the contrasts that are made between “biological” connections with birth kin and “social” connections with adoptive kin. The narratives of adult adoptees who had made contact with their birth relatives suggest that such reunions tended to be marked by a lack of solidarity between adoptees and birth parents, and often involved significant pain and upheaval. Such reunions often highlighted the lack of time that had been invested into biological relatedness over the course of a lifetime. Carsten notes, then, that the motivations of adopted people to seek out their birth parents were not unambiguously born out of a search for biological connections. They also, rather, represented efforts to construct “continuities of identity which can link together their past, present, and future” (2000b:700), even if those linkages represented ruptures and gaps in connectedness. Carsten argues, then, that adoption reunions “expose a fiction at the heart of biological relatedness, that biology encapsulates the relation” (2000b:700).

Similarly, Mary's and Lois's experiences of relatedness are neither encapsulated by nor fully accounted for by the biological connection created by transferred organs. Even an analysis focused too heavily on the organs themselves would miss much of the picture. Rather, this new kinship tie emerged out of the giving itself (not just of organs, but of *life*) and out of the similarities that came to light (which were discovered through

Mary's and Lois's efforts to construct "continuities of identity," to use Carsten's (2000b) phrase) that had linked their families together all along). Though Mary and Lois had not previously known each other or had any reason before becoming acquainted to believe themselves to be connected, through the unique and powerful experience of having each played a direct part in organ transfer, they had, in fact, become kin. And from that point, the newly joined families began to ratify their bonds through some of the same rituals and practices of kinship that would be recognizable to most anyone with mainstream U.S. cultural orientations.

Practicing Relatedness

After watching the video together, we talked about what it had been like to take part in the filming of it. I mentioned the family photos and asked about them. "Yeah! We had our family photos taken," said Mary, as she directed my attention to a third wall in the living room, the majority of which was covered by two composite frames featuring an extensive array of the members of Mary's family posing with Lois and Rob in a variety of combinations:



Figure 7: New Family Photos.

One had the full family picture that had been featured in the Donate Life video, surrounded by four smaller pictures: the two Rob's sitting side by side, each turned slightly outward away from the center; Mary, Lois, and Mary's two daughters; Lois alone with Mary's daughters; and Rob (Lois's husband) alone with Mary's two daughters. The bottom frame then contained three pictures: a larger center picture of Lois, Rob, and Mary; and then on each side: one picture with Mary standing behind Rob (Lois's

husband) and hugging his shoulders and the other of Rob (Mary's husband) standing just behind Lois.

When did you have these pictures taken? I asked. They had gone to have them taken the last time Lois and Rob were in town. Mary and Lois talked about the visits they'd had back and forth since they first made contact. Mary and her family had gone down once to visit Lois and Rob at their home in the U.S. South, and Mary was planning to go again sometime in the spring, by herself this time. This was Lois and Rob's second visit to Mary's home, and both women commented on the fact that on this visit, they've felt closer than they ever had before. When they're not in each other's physical presence for a visit, each woman calls the other to talk on the phone once a week, so that they've talked at least twice a week since they first opened up lines of communication; but their relationship had reached a much deeper family connection during this visit. Mary and Lois then reiterated once again the many connections they've discovered to exist between their two families, and they arrived at a shared description of how they have become one family together now. "We went from having three grandsons to having two more granddaughters," noted Lois. Mary's beagle had come over and plopped herself down in between the living room recliners, "and three if you count Susie." Mary agreed and elaborated on how they all share mutual feelings about their bond.

"And I gave Mary my daughter's name," added Lois. A bit uncertain what she had meant by this, I asked about it, and Mary offered, "Yep, I've been baptized—Rob (Lois's husband) baptized me, and my baptismal name is Jolene, which was Claire's middle name." I asked what brought Mary to become baptized – when we first met, she had reported that they believe in God, but don't really consider themselves to belong to any one church or attend regular services. She explained that she simply had come to know the Lord through talking with Lois and Rob over time. She got tears in her eyes as she told me about this. I was somewhat surprised at this adoption of her donor's middle name, but even more so at another occasion later in the evening when Lois actually *used* the new name to refer to Mary. As Mary and Lois were talking about how well Mary's new pastor and Rob had gotten along during the pastor's visit earlier in the week, Mary began scratching her neck and shoulder. Lois said to her, "Now Jolene, you've got to leave that rash alone."

“Have you met Lois’s grandsons yet?” I asked Mary. Yes, she had met two of them; one of them just didn’t quite feel ready to meet Mary when she had been there for a visit the last time a couple of months ago. “But we’ve got all their pictures lined up on our fridge.” Mary then took me through their kitchen, past the long counter to their refrigerator, where pictures of Lois’s grandsons alternated with pictures of Mary’s daughters in order, from oldest to youngest. One of Lois’s grandsons had been of pivotal influence in the very fact that the donor family responded at all to Mary’s initial letter to them. Lois said that she actually had been uncertain whether or not to write back, so she left it up to her grandsons, who ultimately made the decision to open up direct communication.

Further, Lois said, Rob had pointed out at the time that they had to figure that the recipient *must* be an appreciative person, else she would not have written in the first place. As our conversation went on, Rob excused himself to go downstairs, offering Mary, Lois, and me the opportunity to talk further. “We converted our basement into an apartment, too,” noted Mary, “that way, Grandma and Grandpa have their own place to stay when they’re here.” Lois elaborated that, though it got a little cold last night, the basement apartment was very nice, with a bedroom, bathroom, and washer and dryer.

Mary and Lois were by far most instrumental in building the bonds between their families, and Mary later told me about additional trips that the two women had made back and forth to each other’s homes to stay for extended periods of time, without their husbands or children. At the same time, both husbands and Mary’s two daughters seemed quite comfortable with these new connections, evidenced by the casualness with which Lois and Rob were referred to as “Grandma” and “Grandpa” during my subsequent visits with Rob, Lois, and her two daughters. I had no opportunity to directly participate in interactions involving Lois’s grandsons, so have no firsthand observations concerning their comfort with these bonds. Mary did note that at least one of Lois’s grandsons (Claire’s sons) took a bit longer to warm to her, but during one of her visits, she helped the young men do some painting around their grandmother’s house, and Mary felt they all had become much closer over the course of working together.

Haddow (2005) has pointed out that the idea of the deceased ‘living on’ in others can be quite powerful for donor kin, and this phenomenon is evident in some of the ways Lois relates to Mary. Indeed, she has said as much, noting that because part of her daughter now lives in Mary, Mary has become a daughter to her. This also is evident in her practice of calling Mary by her deceased daughter’s middle name. Mary, who sought out the connection initially and deeply treasures the bond, seemed to accept this. She neither cringed nor looked uncomfortable when Lois did so. At the same time, in this case, an assumption that this relationship is built solely on the idea of the deceased living on in others would not be accurate. It should be noted that Lois did *not* repeatedly call Mary “Joleen” throughout the evening, and though this one instance did catch me somewhat off guard, it was quite clear that Lois well recognized Mary’s unique personhood. Mary seemed to have been deeply moved by her baptism, and appeared to be honored to share Claire’s middle name, but did not dwell heavily on the name; it seemed to pose no existential risk to her. The evidence does support the analysis that the two women share a close bond that is based on more than only the use of kinship terms or deceased loved one’s names, and upon which Mary and Lois have begun to build by investing mutual time, effort, and material goods. Despite the fact that it goes against common mainstream U.S. notions that families are independent, autonomous units, and in some ways flies in the face of transplant policies which maintain anonymity between donors and recipients (and their respective kin) as a default, each party welcomed becoming more and more enmeshed over time.

In fact, the two nuclear kin groups actively sought out and enacted various practices of blending with each other. They made regular and extended visits to each other’s homes, even though they lived hundreds of miles apart. They had their family pictures taken together, and proudly displayed them as prominently as family pictures might be displayed in any other household. Mary became baptized into the same faith as Lois and Rob, and at the time of this writing, still shares a bond of active faith with them. A tangible sign of this is that, during my most recent visit to Mary, she gave me one of the wooden crosses that she and Lois had spent time decorating together during Mary’s latest visit to Lois’s home. Mary helped Lois’s grandsons to paint their grandmother’s house, and in doing so, overcame some of the coolness one of them had initially shown

toward Mary. And, recalling the insights of Carsten and Hugh-Jones (1995), who conceptualized the house as a spatial locus of identity and interaction as much as a product of the daily practices of those living in and around it over time, Mary's home very notably had begun to serve as a locus of the family's new identity as part of an intensely shared bond – evidenced by the family pictures, for instance. Likewise, with the remodeling of their basement to become a “second home” for Lois and Rob during their visits, Mary and Rob had altered the actual structure and function of their house to become a tangible product of the particular enactments of kinship in which they were engaged. Just as Mary's body now housed part of Lois's daughter, Mary's domicile now could also house Lois herself.

Not Everyone Makes A Solid Donor-Recipient Connection

It must be said that the connection between Mary's and Lois's kin networks was extraordinary and not the norm among the participants I met and came to know. But it does powerfully illustrate some of the farthest reaches of the potential which transplantation holds for revealing, reframing, and fostering kin relatedness. The bonds shared within Lois's and Mary's combined webs of relations can accurately be described as being filled with great reverence. Generally speaking, donors and donor families *are* revered within the transplant community. At the same time, as Sharp and others have documented, they also can be relegated to the background. Most recipients broached the topic of donation at some point in my conversations with them, whether their organ came from a living or a deceased person, without being asked directly about it. Few of them dwelled on it, however, and cadaveric donation was not often discussed at length.

Certainly not all recipients wish to know their donors, and not all donor families wish to establish contact with the recipients of their loved ones' organs. It is quite rare for donor kin and recipients to develop the kinds of ties shared by Mary and Lois; in fact, this was the only relationship of its kind that I encountered over the course of my own fieldwork. The policies of anonymity which required Mary's and Lois's initial correspondence to be stripped of any names, contact information, or other clear identifiers are built at least in part on a sense in the medical community that donors and recipients should be protected from the potentially overwhelming emotions and

relationships that could arise out of a connection between strangers bound by the unique exchange of organ transfer. Prominent transplant scholars have addressed this topic.

Lock (2002), for example, has pointed out that policies of anonymity have not always been the norm. In the early years of transplantation, medical teams did freely share detailed information about and between donor kin and recipients. For example, the photographs of Louis Washkansky and Denise Ann Darvall, recipient and donor of the world's first heart transplant in 1967, were published side by side (Lock 2002:80). The procedure was performed in South Africa²⁵ but its publicity was widespread, with articles appearing in U.S. media outlets such as the *New York Times*, *Newsweek*, *Time*, *Ebony* and the television program *Face the Nation* (Lock 2002). But by 1969, photographs of donors were no longer publicized, and “donors became cloaked with anonymity as the ambiguity of their condition drew attention” (Lock 2002:86).

Lock suggests that the policy of donor anonymity grew out of the sense that donors' deaths usually were of a violent nature. Most are caused by trauma to the head – whether by gunshot wounds or injuries sustained in accidents – which leaves the solid organs in the rest of the body intact and in transplantable condition. But Fox and Swazey (1992) suggest that the policy of anonymity grew out of a discomfort, on the part of transplant professionals, with the types of interactions that would take place between recipients and their kin and donor kin. Building on their notion of the “tyranny of the gift,” Fox and Swazey (1992) describe a concern among clinicians that if donor kin and recipients are in contact with each other, the donor kin can make demands on the recipient, and can insist that the recipient take proper care of the donated organ, which still in many ways belongs partly to the deceased donor (“How's my loved one's heart? Are you taking good care of it?”). They argue that transplant professionals attempt to avoid fostering a feeling of indebtedness on the part of the recipient or of influence on the part of the donor kin (Fox and Swazey 1992).

Sharp (2001) has argued that transplant professionals have an important stake in preventing connections from being forged between recipients and donor kin. She writes, “Communication and contact between these two lay parties are feared by professionals as

²⁵ Lock notes that the geopolitical setting of this first heart transplant was significant: “Physicians on both sides of the Atlantic recognized that South Africa might be a suitable location because it was known to be less sensitive about ethical issues than either the United States or Great Britain” (2002:80).

potentially emotionally explosive and, ultimately, destructive to the missions associated with organ transfer, since they offer competing views of death and the donor body” (Sharp 2001:114). This entails, then, a close management of the views of death by recipients on the one hand, and by donors on the other. Sharp illustrates that recipients are encouraged to view donated organs as “replaceable mechanical parts in which no attributes of donors can survive” (2001:114). (In my own conversations with patients, when the topic of their donor organ did come up, I found no instances in which recipients had felt that certain attributes of a donor’s persona had been transplanted into them along with the organ, but most recipients also seemed not to have a purely unemotional view of organs as simply “replaceable mechanical parts.”) In contrast, Sharp continues, *donor kin* are encouraged by procurement professionals to see organ donation as a way to ensure that their deceased loved one will continue to live on in others (2001:114). Sharp (2001) suggests that transplant professionals in the U.S. understand the success of the transplant endeavor to hinge at least in large part on the maintenance of these different and competing perceptions of the meanings of death and the status of transplantable organs. Communication between two parties who are expected and encouraged to view the same organs in such different lights could therefore undermine the enterprise; such contacts could be “emotionally explosive” and could ultimately diminish public support. (Sharp 2001)

There is evidence that some restrictions are being relaxed regarding public displays of information about donors. For example, several Donate Life websites provide text and videos containing the names, photographs, and stories of particular donor-recipient pairs (Lois and Rob participated in the making of one such video, as described above). That certainly is not to say, however, that direct donor-recipient relations, when they do exist, are necessarily straightforward or without their tensions. Others whom I met in the course of this research also shared stories of overcoming barriers of anonymity and making connections across the donor-recipient boundary, and such connections were not of uniform ease, significance, or intensity.

One of the venues in which these stories seemed most poised to arise was at the Annual Organ Transplant Reunion, hosted each year by the Transplant Center. At the event, transplant recipients and their loved ones are treated to meals, a keynote speaker,

tours, and educational sessions aimed at providing information about post-transplant health matters. Just as importantly, recipients and their loved ones have an opportunity to meet with the clinicians and fellow patients whom they came to know during their clinic visits and hospitalizations, and to meet new persons with whom they know they will have at least some things in common. In the following, I will describe some of the settings, scenarios, encounters, and interactions I observed and participated in while attending one of two Transplant Reunions during my fieldwork. In doing so, I aim to convey not only additional examples of donor-recipient relations (and how the topic can come to the fore when recipients and loved ones gather), but also examples of some of the ways in which transplant patients and loved ones can forge connections with other patients and loved ones through bonds of shared experiences and understandings. Thus, this account of the Transplant Reunion will bridge Part 1 and Part 2 of this chapter.

Transplant Reunions and Collections of Coincidence

Mary, Rob, and one of their two daughters happened to arrive at the same time as I did at the Welcome Reception Dinner on the first day of the Solid Organ Transplant Reunion. I noticed they all three were wearing white “Donate Life” t-shirts with the message, “To the world, you may be one person, but to one person, you could be the world,” written on the back. We all walked together to the newly constructed building on the medical campus where the dinner and keynote speaker event was to be held, pausing while Rob helped Mary negotiate the steps, and then to fill out name tags near the ballroom entrance at a small table staffed by some of the Transplant Clinic nurses, who we all recognized immediately despite the fact that they were wearing dress clothes instead of their clinic scrubs.

I followed Mary’s family to the buffet line, which included an array of food including a vegetable platter with ranch dip, flatbread rolls (including turkey and spinach-vegetarian options), apricot/orange glazed chicken pieces, barbeque glazed chicken pieces, asparagus wrapped in filo pastry, a fruit tray with dip, and a tray of dessert bars, brownies, and cookies. As we moved through the line, Rob filled two plates: one for Mary, who told him what she’d like; and one for himself. The couple invited me to sit with them and after we chose a table near the end of the buffet line, Mary’s daughter and

I went over to the drink stand, where we could choose from iced tea, coffee, water, or red punch, all served from ornate beverage fountains (the coffee from a percolator). When we sat back down with drinks for the table, Mary began talking about how much she has been looking forward to this. The previous year, she had been unable to attend because she was in the hospital. The evening's event included staff-led tours of the rest of this, the newest building on the medical campus. Mary and Rob knew the nurse who was leading the tour that lined up right by our table, because she had worked with the couple during Mary's hospitalization for her transplant, and the three of them joked together that the nurses would be able to recall patients better if they were all wearing hospital gowns. Just as I was about to join the tour, I spotted Barry and Angela sitting at another table across the room and excused myself to go sit and talk with them for awhile.

While Barry, Angela, and I were talking, another couple sat down at our table across from us and began to eat quietly by themselves. At some point, however, Angela asked from across the table which one of them had had the transplant? The woman smiled and said she was glad to know that you couldn't tell just by looking at them. As we all sat and talked, the two couples discovered multiple parallels in their lives. Barry was a heart recipient whose primary informal caregiver had been his wife, Angela, and the wife in the other couple had been a liver recipient and her husband had been her primary informal caregiver. The four of them swapped stories about what it's like to experience the mood swings and other side-effects of the steroids commonly used in the anti-rejection arsenal (as well as what it's like to try to *care for* someone who is on steroids and experiencing these mood swings). This led to discussions of the other medications each recipient currently was taking, or had been on in the past. After a brief pause in the conversation, Angela asked where the other couple was from, and after each couple shared more information with the other, they were led to the realization that they had mutual friends. After exploring those ties and recounting what each had heard lately from the mutual friends, the conversation then turned to each family's story of waiting for the transplant – how long they'd had to wait and what it had been like to receive the call – which eventually led to each couple sharing the story of how they'd met the respective donor families.

The newspaper played a role in both cases (and other participants likewise mentioned the newspaper – both news stories and obituaries – as a source to which they had turned for information on the possible identities of donors or recipients). Barry and Angela were featured in an article about Barry’s transplant in the local newspaper, and someone from the donor family happened to see it and reached out to contact them. For the other couple at our table, a member of their family saw an article in a newspaper about a person who had died and become an organ donor around the same time of her liver transplant, and upon learning this, the recipient couple made the effort to get in touch with the donor family. Though there were many similarities in the two couple’s stories, there was one point where their experiences had been very different. After meeting the donor family, Barry and Angela felt that there had been no real connection; it had felt more like just a “meet-and-greet.” The other couple, however, had immediately felt a deep connection, and have continued to stay in touch with the donor family over the years.

Current transplant policy also maintains anonymity between donors and recipients in cases of living donation through matched-pair donor exchange. But since all four parties are undergoing surgery at the same time, there is potential for persons to “discover” each other. In one case, a wife who was not a match for her husband, donated her kidney in a donor exchange in which the matched pair was a father and daughter, with the daughter being the donor and father being the recipient. The wife who donated her kidney on behalf of (but not directly to) her husband reported that the four of them met each other en route to the operating room and realized their connection because they had heard each other’s conversations. The matched pairs, however, did not opt to stay in touch in this case.

Perhaps capturing well the current status of donor-recipient relations was one of the final events of the same year’s Solid Organ Transplant Reunion: the group photos. In them, patients were grouped by ages: pediatric transplant patients and “Teens in Transplant” comprised two groups, regardless of what type of transplant they had received, and the adults were further sub-divided by the type of transplant they had received. Then, the final group photo was reserved for donors and donor families.

Waiting for this last call was a couple, sitting at a table just off to the side of the staging area, looking around, perhaps to see if anyone else might be waiting for the same photo. No one else stepped forward, however, when the photographer announced this category, and the few others who remained in the conference ballroom at this point had sectioned themselves off into a smattering of tables or stood in small circles of conversations and farewells, and seemed not to notice the lone couple posing for a particularly close camera shot.

This observation needs to be contextualized: the Transplant Reunion is geared more toward solid organ recipients and their loved ones than toward donors and donor kin, so it is not completely incongruous that donors would have less prominence in that venue. The Transplant Center also holds annually an Organ and Tissue Donor Awareness walk-a-thon event (participants can run, bike, or skate as well), in which the families of deceased donors attend in greater numbers. I participated in two such events during my fieldwork, and saw entire teams walking together, all wearing t-shirts with the photo, name, dates of birth and death, and other bits of information about their loved one who had died and become a donor. But this event is not solely designed as a memorial to donors or in support of donor families, and also shares its purpose as a fundraiser to promote awareness of (and participation in) organ and tissue donation. Thus, while donors and donor kin are indeed revered within the transplant community, as I noted earlier, they also do not seem to enjoy as visibly prominent a position. While the potential is tremendous for there to be the kinds of connections, borne out of this very powerful form of giving, that were experienced by Mary and Lois and the liver recipient couple who sat across from Barry, Angela and I, they are not inevitable in light of the policies and structures that are held in place as a continued divider between donors and recipients.

PART II:
REVEALING AND REFRAMING RELATEDNESS VIA WEBS OF CARE

The first half of this chapter gave attention to the kinds of relatedness that transplantation can potentially foster between donor kin and recipients in the transfer of human organs. However, the main focus of this fieldwork was on the kinship ties among patients and those who care for them, and rich data regarding this lends further insight into the driving questions about the intertwining of organ transplantation and kinship in the U.S. The remainder of this chapter will examine additional ways in which relationships can become revealed and reframed through the experience and on-the-ground realities of transplantation. As we shall see, the opportunities for developing and re-shaping bonds of relatedness can be many and varied.

For example, the logistical realities of receiving medical care in a Transplant Center that may be located hundreds of miles away from one's home can change patients' (and their lay care partners') child-rearing practices, and parents might find they must become creative with relatedness patterns in order to meet their children's needs. The medical realities of transplantation may spell the end of a person's reproductive capabilities, thus changing kinship structures that would be shaped otherwise through procreation. Intense bonds can develop between patients who have shared similar experiences in common with each other, which others in their lives perhaps can hardly relate to. Further, through the experience of spending difficult and vulnerable times together, patients and clinicians, too can sometimes develop unexpected connections that grow well beyond professional duties to care. Ultimately, a unifying thread that brings each of these diverse examples together is that each has the potential to expose and extinguish persistent dominant ideologies that families are bounded, independent units. This is especially relevant if we take seriously the notion summed up by Durkheim, in his *Division of Labor in Society*, that "any ideal is stayed upon nothing if its roots aren't grounded in reality" (1984 [1893]:xxvii), or Jackson (1980), building on the work by Mauss and later, Bourdieu, who asserted that ideas and habits reinforce each other in ways that persist only so long as the environment in which they're grounded remains stable.

Solidarity and Knowing What Someone Else is Going Through

In his 1912 *Elementary Forms of Religious Life*, Durkheim used the term “effervescence” to describe the intense emotion, energy, and enthusiasm that can arise among participants in social gatherings. He specifically cited ethnographic accounts of the periodic brief large gatherings among Australian aboriginal clans, (Durkheim 1995 [1912]:211-214), but also pointed to the Crusades and the French Revolution as longer-term examples of “general effervescence.” In such settings, people might be moved to do things or feel things they otherwise would not, outside of this type of social gathering (also see Shilling and Mellor 1998). Drawing from the Australian example, Durkheim noted:

The very act of congregating is an exceptionally powerful stimulant. Once the individuals are gathered together, a sort of electricity is generated from their closeness and quickly launches them to an extraordinary height of exaltation. Every emotion expressed resonates without interference in consciousnesses that are wide open to external impressions, each one echoing the others. (Durkheim 1995 [1912]:217-218)

The “openness” and enthusiasm among participants at the Annual Solid Organ Transplant Reunions might serve as an example of this phenomenon (though it is very muted, of course, in comparison to the Australian clan gatherings, Crusades, and French Revolution). As we saw just above, the Transplant Reunion created opportunities for Barry and Angela to share and compare their stories with another couple who also had gone through the transplant process together. Such scenarios are common: at each of the two reunions I attended, it was evident that patients and their loved ones tend to be very open to meeting and engaging with other patients and loved ones. Even total strangers who otherwise might have had little in common displayed an openness toward connection and sharing experiences, swapping stories, and exchanging information about strategies for daily living (e.g., dealing with the side effects of medications, taking practical steps to avoid contagions while still participating in social activities, etc.) at the transplant reunion.

Durkheim also implied that this “stimulating action of society” can arise out of a “moral harmony” that participants might feel in relation to one another (1995[1912]:213). In the conversation between Barry and Angela and the couple across the table, they

talked about the difficulties of caring for someone who is on steroids. Both Barry and the recipient from the other couple talked about the waves of rage that could come over them unexpectedly, which they both felt as a real emotion, yet knew on some level that it was a side-effect of their medication. And Angela and the husband caregiver from the other couple talked about how hard it was to simultaneously witness the person you love go through these mood swings, avoid reacting to them by keeping in mind the fact that “it’s the medication talking,” and continue to carry out their caregiving responsibilities (like making sure the recipient *does* take all of their medications, even if the recipient is angry about having to do so). At the core of these discussions, in my interpretation, was an assessment of how each person *ought* to be and act, in the face of such difficult circumstances. And the fact that each couple understood where the other was coming from because they themselves had had comparable experiences, placed them in a sort of “moral harmony” with one another, creating a level of solidarity that they could not necessarily share with others who had never actually been through it. One product of the Solid Organ Transplant Reunion, then, was also the creation of an atmosphere where people could share solidarity in their common bond of transplantation.

A number of people who participated in my research also attended the reunion each year, touting it as a way to re-connect with both patients and clinical staff with whom they had bonded over the course of their dealings with transplantation. When one woman I had met earlier in my research spotted me across the room at the Reunion lunch, she waved to get my attention and beckoned me over to her table, where she introduced me to three other recipients and their partners. She explained that they all had been on the Solid Organ Transplant Unit floor together. Having received their transplants within just days of each other, all had come to know one another very well during their stay, and had encouraged each other during their early days of recovery. While they kept in touch via phone and email, they looked forward to the reunion each year, knowing that it would be a time when they could reconnect in person.

Chance Encounters and Common Ground

Transplant reunions are certainly not the only opportunity transplant participants have for finding and connecting with one another. For example, Betsy (whom I

introduced in an earlier chapter; she was in her late thirties and a mother of three children, and married to her husband for nearly 15 years) told me the story of a little girl whom she happened to meet, who'd also had an islet cell transplant at the Transplant Center: "We met them [the little girl and her parents] on a plane ride home from Las Vegas; they sat in front of us the whole time and I overheard them talking about islet cells and I poked my head around and said, 'Are you talking about islet cells?'" The little girl at that time was on her way to back to the Transplant Center to also get a small bowel transplant, as the islet cell transplant had been for her only part of her full course of treatment. They had not been able to get a "Life Flight" (a medical transport by air) for the trip, and thus had to take a regular passenger airline flight. Betsy noted that, since their first meeting, she has developed a very close relationship with the little girl and her family. She went on to describe what it had been like getting to know them, how good it had been to find someone else who had had the same rare treatment and thus could relate to each other's experiences and concerns, and said their two families actually were going to go to the local Children's Museum together the coming evening.

In addition to the effervescent openness so evident among those attending Reunions and other, more accidental encounters among persons directly involved in transplantation, there is a clear sense of solidarity rooted in an understanding and appreciation for the unique challenges associated with transplantation. One tool for understanding the sociality among transplant participants might be Rabinow's concept of biosociality, that is, "the likely formation of new group and individual identities and practices arising out of ...new truths" such as those created by genetic testing (Rabinow's particular example) and other forms of new scientific knowledge (Rabinow [1992, abridged 1998] 1999: 413). Indeed, those engaged in transplantation do have "medical specialists, laboratories, narratives, traditions, and a heavy panoply of pastoral keepers to help them experience, share, intervene, and 'understand' their fate," (Rabinow [1992, abridged 1998] 1999: 413), and the annual transplant reunions are direct evidence of this. Thus, such a concept accounts for the drawing together of persons around the locus of their shared experience of transplantation in general. Yet, while transplant patients share much in common, there also is a keen mutual interest in learning and comparing one

another's unique stories, which certainly tend to have common themes, but also exhibit notable diversity.

Further, while useful, the concept of biosociality seems not to account sufficiently for the evidence that transplant patients and loved ones form and reshape various forms of connection and relatedness on a broader scale that goes beyond the locus of clinical knowledge and practice to include not only present daily life, but also interpersonal histories. The medical clinical aspects of transplantation comprise an extremely important facet of life among those I got to know during this research, but must take their place alongside the other extremely important facets of personal and social lifetimes. In the conversation between Angela and Barry, who had had a heart transplant, and the other couple in which the wife had had a liver transplant, each couple seemed to be just as interested in the differences in their experiences as in the similarities. And each wanted to share information about their own daily lives, particularly their family lives, as much as information about their transplants. In addition, while their common medical experiences prompted their initial encounter, the couples delighted even more in the fact that they had friends in common (a separate issue altogether from their transplants). The aims of transplant patients at the gatherings and other encounters I witnessed and heard about from participants, generally seemed to have less to do with organizing to achieve certain political ends, and more to do with offering one another mutual support in various forms (not only practical advice and acquired knowledge, but also listening and emotional support, etc.) – in a strong sense, to foster solidarity.

Durkheim, in *The Division of Labor in Society* ([1893] 1984) famously wrote about different forms of social solidarity, particularly making distinctions between mechanical solidarity (which he associated with smaller-scale societies in which social cohesion produces closely shared beliefs, values and practices) and organic solidarity (which he associated with larger diverse societies in which social cohesion produces greater specialization and the division of labor among persons). But perhaps even more importantly, Durkheim was interested in morality and its association with social cohesion, calling morality “the indispensable minimum, that which is strictly necessary, the daily bread without which societies cannot live” ([1893] 1984:13). Among the participants I got to know who developed intense connections with other patients and

caregivers, there was a shared appreciation of the types of challenges persons encounter throughout the transplant process, and into post-transplant life. This mutual sense of understanding seemed to form a moral code which guided interpersonal interactions in social gatherings like the setting of the reunion, as well as those chance encounters in the larger world, when two transplant patients might happen to discover each other through the course of everyday life.

“I know what you’re going through because I’ve totally been there myself...”

Betsy had worked in the field of nursing for over twenty years. She had struggled through numerous complications since her islet cell transplant, but when I met her, she was nearly ready to return to work, where it happened that she would begin working directly with other transplant patients, in a clinical professional role. When I asked her about her thoughts on going back to work, she said she was worried that the other clinicians might try to “baby” her, that they might act like “mother hens” even though she would not need to be protected in this way. But, she added,

It's great to be able to say to other patients, 'I know what you're going through because I've totally been there myself,' so it's not somebody preaching at you who's never been there; so I'm excited about that because I think it's therapeutic to me and hopefully helpful to others; and I don't plan to broadcast it, 'Hey, look at me, I've been there!' but just look forward to being helpful.

Betsy offers a sophisticated view of an orientation that she knows, through direct experience, will be appropriate at this intersection of moral worlds (those of clinical professionals, who are supposed to be helpful, and those of patients, who will be suffering in various ways). In this way, she will be especially well-situated to care for transplant patients because she herself had once been in their same (or very similar) position. Notably, she anticipated that being in this position could offer reciprocal benefits, being at once therapeutic to her and helpful to others. At the same time, her moral sensibility also allowed her to recognize that, even among this group, there are a diversity of experiences, and will have the sophistication to be able to not be “preachy” or to “broadcast” her former patient status, yet to offer especially insightful assistance to others. This, potentially, could provide additional opportunities for her to form bonds

with others (and as I will describe further below, clinicians and patients do sometimes develop connections that overgrow the limits of a professional-patient relationship).

Current Realities Can Also Call for Shared Living Space: The Baxter House

In developing his concept of biosociality, Rabinow predicted that biosocial groups might redo their home environments in accordance with the demands of their newly discovered genetically based conditions, but did not elaborate greatly on this notion ([1992, abridged 1998] 1999). Relying on other literature about houses, as I have outlined elsewhere, I have analyzed some of the ways in which patients and caregivers *do* modify their home environments in order to accommodate the new realities of transplantation. But the travel required to one of a relatively small number of Centers nationwide that perform specialized transplants can necessitate a redefining of the home environment in other ways as well. Betsy, referring to the little girl and her family whom Betsy had happened to meet on a passenger airline flight, remarked that she couldn't imagine having to leave family and friends behind to go have surgery somewhere else so far away from home. Other participants who lived in relatively close proximity to the Transplant Center gave similar remarks, indicating how heavily they themselves had needed to rely on their extended kin and social networks for material, logistical, and emotional support throughout their transplant and recovery. How do people do it, they would ask, when they're hundreds of miles away from home?

For those who are no longer ill enough to qualify for inpatient status – whether in the hospital or in Cooperative Care – and who cannot afford the nightly rates of the on-site hospital hotel rooms, one available option is to stay in the Baxter House. This once had been the private home of a wealthy family who had been historically prominent in Metrotown, and who donated the house to the Health System for use by transplant patients who were receiving outpatient care through the Transplant Center. It also was to be used by care partners of both outpatients and inpatients whose actual homes were not within easy driving distance of the Center. The intention was to offer a low-cost option for those who cannot commute on a daily basis for the frequent treatment and follow-up required by this patient population.

The Baxter House sits on the corner of two residential streets, a few blocks from the Transplant Center. The distance is walk-able, although there also is a shuttle service to transport patients and their care partners back and forth as needed. The street view of this three-level, 10-bedroom mansion is impressive, but the real grandeur lies within. As guests pass into the secured entrance, they are met with the ambient smell of cinnamon and sandalwood as they step into a beautiful foyer with thick, ornate carpet, original sculpted woodwork, and deep, rich colors on the walls, floors, and furniture. Measures had been taken to preserve the house's historical value. But the house also had been renovated, decorated, and furnished by professional designers when it first was donated to the Health System.

I previously had met with participants for the occasional interview here at the Baxter House (I allowed participants to choose the setting for their interviews, and for some, this was the most comfortable and convenient location). But one day, one of the two staff members who maintains the house gave me a full tour. She took the time to tenderly point out each room's unique features: a hand-painted border here, a particularly beautiful light fixture there, along with especially comfortable chairs in one room, and a private sun balcony in another, where a guest might sit for long hours or even sleep, in one case, to escape a spouse's snoring. Even the bedspreads had been individually chosen to fit with each room's unique theme. My tour guide also furnished each room with stories and memories of various guests who had stayed at the house. In a small offshoot to one hallway was a painting of a dog, jokingly referred to as "our house dog," which was as close to a real dog as could be had in the house, being that a segment of the house's guests are immune-compromised.

To access each of the three floors, we used a combination of steps on different sides of the house, as well as the elevator, which we eventually took from the third floor all the way to the first, where we continued the tour with a walk through an enormous kitchen. Guests have the use of a microwave in the kitchen, and are given space to store food in one refrigerator, and may store medications in a separate refrigerator. There are additional house policies toward the preparation and consumption of food, however. For example, guests are not allowed to cook using the stove or oven (the house manager, a trained chef, uses these appliances on occasion to cook large community meals for all the

guests). Guests also are asked to mark the date on any food they are storing, so that the staff will know whether it has been forgotten or should be discarded. Continental breakfasts are provided every day, and the half-pint cartons of milk, loaves of bread, and other perishable supplies for this meal are kept in neat rows on the shelves of a larger refrigerator, separate from the one used by guests.

Guests are not allowed to have food in their rooms because there had been problems in the past (presumably with spills or food left out to spoil), and instead are asked to use the commons area of the kitchen, which has tables and chairs. Anyone is free to use the large formal dining room table, which is situated beneath a large and ornate metal and glass chandelier comprised of delicate, individual flower stems interwoven together. This also is where everyone eats together when the house manager prepares special large meals (sometimes for holidays, sometimes for birthdays, and sometimes “just because”).

From there, we enter one of the common rooms on the main floor, where there is a television, video players, a writing desk with a computer, and sofas and chairs. Only one of the private rooms has a television in it, and the lack of in-room televisions, combined with the fact that guests must not eat in their rooms, encourages people to use the handful of commons areas, where they can visit and get to know each other, relax, reflect, or read a magazine or a book they’ve borrowed from the sizeable library upstairs.

Our tour concluded near the entryway where it started. Here, there was a “sign-in” table, where there were two guest books in which people had written messages of varying length about themselves, their stories, their thoughts, and their experiences. Next to these books was a photo album, on the cover of which was a young woman’s senior picture, with a placard underneath that said, “In Loving Memory.” The album had been donated by the family of this young woman, as they had stayed at the Baxter House while their daughter received treatment at the Transplant Center. It was to be used for holding pictures taken at the house, and it offered poignant evidence of the attempts at lightheartedness, even by those for whom life might literally be hanging in the balance. For example, one picture had been taken during a Halloween party, and in the lineup of costumed guests, I recognized two of the participants I had gotten to know through fieldwork, Kevin and Grace, donning matching Superman and Superwoman garb –

complete with capes – along with smiles to rival the big “S” printed on the chest of each outfit. This couple had been among the longest-staying guests the house had ever had, although Grace spent the majority of her time in the hospital, and on the few visits I had previously made to the house to meet with other study participants, I’d often had the opportunity to say hello to Kevin as well. It was especially moving to see this picture, since by the time I came to know the couple, Grace was already having difficulties with serious complications from her transplant, and since I also had learned during a recent follow-up phone call to Kevin that Grace had passed away earlier in the year (I will say more about this at the end of this chapter). I recognized guests in other pictures as well, including husband and wife Jerome and Charlotte, and son and mother Craig and Ruby. The four of them, it happened, had gotten to know each other very well during their stay at the Baxter House, even though Jerome had received a liver and Craig was a small bowel recipient, and the two families continued to stay in touch even after returning to their homes in states situated hundreds of miles apart.

While patients and their kin may cycle into and out of the Baxter House over time, many guests’ lengths of stay overlap considerably. In these scenarios, patients and their kin not only share a common bond of having been through transplantation, but also of having shared living space, time together, and often meals as well. This sets up the Baxter House as another type of “house” within which relationships can be developed through the shared experiences (both challenges and successes) of transplantation. These relationships can form between the house guests, as was the case for Jerome and Charlotte with Ruby and Craig. But the house staff also can play an instrumental role, and themselves can become rather significant in guests’ lives during their stay at the Baxter House.

Indeed, both staff members take great care to create as supportive an environment and cohesive a community as possible. Partly to care for the furnishings of the house itself, and partly to care for the guests, the person who showed me around the house sometimes will take suitcases off of beds and put them in guests’ closets for them. She also, though she is not required to do so, often will tidy up guests’ rooms for them, and will put clothes left in the house washing machine (which anyone is free to use as they need) into the dryer, then fold them and put them on the guest’s bed if she knows they are

having a particularly rough time and have had to spend long days at the hospital. The staff members themselves (along with the guest books and photo album) serve as living repositories of the stories and particularly charged periods of patients' and loved ones' lives, carrying with them a record of the goings on over the days, weeks, months, and years. They keep in touch with many of the people who've stayed in the house, often calling to check in on parents, siblings, spouses, and other loved ones, even long after a patient might have died.

The house staff also take it upon themselves to create as inclusive a community as possible. For example, during one of my calls to the house, I was asked whether I knew of any women who spoke Arabic. There was a guest couple, in which the husband spoke both Arabic and English, but the wife, who was the patient, spoke only Arabic. Occasionally, the husband was away from the house and thus unable to translate on his wife's behalf. The only interpreter that had been available through the Health System was a man, and neither the husband nor wife had felt comfortable using the man as an interpreter without the husband present. "We just would like to be able to get to know her a little better," the staff member explained.

Ian, the house manager, explained to me that he and his co-worker take their jobs very seriously and very personally. He lives on-site, in quarters connected to, yet separated off from the main house. He has been the first and only person to fill this particular position, and when he initially began the job he was tasked with making final preparations before the very first Health System guests arrived. Toward this end, he literally slept in each bed, tested out each shower, and tried out all the amenities, making sure that everything was comfortable and in working order. Ian is a trained chef, and holds large Thanksgiving and Christmas dinners each year, as well as the periodic "big breakfast" in the formal dining room. He and his co-worker also host celebrations for Mother's Day, Father's Day, birthdays when they're aware of them (one adult man received his first birthday cake ever during his time at the house), anniversaries, or other significant milestones, some of which had been recorded in the photo album. "We would have even more pictures," Ian told me, "but we can't afford the film and developing costs for all of them." Though the house has an account at the hospital, the paperwork and

logistics make it very difficult to access the money for these types of costs, he explained, so he and his co-worker simply cover a large portion of them out of their own pockets.

He also pointed out that, while the house rules about where and how food can be prepared and consumed might potentially feel overbearing for guests, it also pushes them to meet each other, eat together, and increases the potential for people to be more open toward one another. This is not to say that all guests are uniformly social, nor that everyone seeks a common bond or displays a desire to get to know one another. But aside from the few who truly prefer to keep to themselves, guests routinely seek out both Ian and his co-worker not only for logistical help, but for emotional support. As Ian put it, “We’re their shoulder to cry on and their balloon to celebrate with,” and the environment can sometimes become very family-like.

Other Instances of Clinicians Becoming Family

Although Ian has his own living quarters that are separated from the rest of the Baxter House by a lockable door, he and the guests very literally do share a house. While the same could be said of tenants who all live in a duplex, an apartment or a house that has been converted into rental units, in those cases neighbors may live in close proximity without ever having a conversation or even learning each other’s name. By contrast, under the circumstances and arrangements at the Baxter House, guests often draw the house staff into their daily personal lives and webs of relations. Ian often shares with guests some of the meals which he has prepared; guests know where to find him if they need to during his “off” time; he sometimes is among the first persons outside of the hospital with which patients and family members share news of procedures, test results, and prognoses. His living space is separate, but his life is intertwined, and professional boundaries are continuously renegotiated as patients and those close to them turn to Ian and his co-worker (who lives off-site) for added support, understanding, and empathy.

“It just puts you on a different level than most mere friendships...”

Even clinicians who do not share their private residence with patients and families can find their lives becoming intertwined with those of patients and their family members who have especially long hospital stays (i.e., in certain types of transplantation, especially

blood and marrow stem cell transplantation, or in cases where medical complications prevent a patient from being discharged). In one conversation with Cate, a nurse in her mid-twenties of Eastern European descent who worked with both adult and pediatric blood and marrow stem cell transplant patients, I learned that hospital-based medical professionals, too, find themselves periodically evaluating and negotiating the “professional boundaries.” While clearly defined in the ideal, in reality, the boundaries can be quite blurred. As a nurse, Cate explained, it occasionally happens that one feels a very deep connection to a patient or their family members. In certain rare instances, one almost cannot help but become emotionally involved, to cross “professional boundaries” and to become friends or even a part of the family with some patients and their informal caregivers.

She went on to describe scenarios in which bonds of great significance can develop between medical professionals and patients or family members.

I've heard from patients and families – especially family members after a loved one died – that they feel that the hospital was a second home to them or that the nurses or staff were like a second family to them. It's because of the long time that they've spent in the hospital; it just takes so long sometimes, that they'll spend months in the hospital. Especially if the city they live in is far away, they're totally uprooted from the support system they usually have and so they don't have it here and so we try to...I mean it's not like we can do everything and be there for them all the time or anything but whenever we can as a staff we try to support them and get to know them as a person so that if we can help them in some way, either just letting them vent a little occasionally or whatever it takes.

She added that, in her experience it seems to be more usual for patients and family members to express the feeling that a nurse or other staff member had become like family to them, than it is for a nurse or staff member to experience the same level of relatedness toward the patient or family member. At the same time, she recognizes that, even though she would not consider these types of bonds to be those of kinship, the kinds of moments that she as a nurse has shared with some of her patients and their family members can sometimes carry greater weight even than those moments shared in typical friendships.

In one such instance, Cate took care of a young boy for many months, and came to know his mother and grandmother very well over time:

In really unique situations like with that little boy and his mom and stuff, I would consider them a lot closer than just friends; we've been through so much together, like cried together and stuff like that. It just puts you on a different level than most mere friendships. I don't know if I'd go so far as to say they're my family, but they might say that about me.

One possible exception that Cate noted, though, was the close relationship she had developed with one patient in particular – Annette – who also has been described earlier because she, too, was a participant in this study. Weeks earlier, Annette had told me she thought of Cate as a member of the family, and considered her to be like a niece. Cate told me she considered Annette to be like a grandmother to her. When they first met, Cate was still a nursing student, and was completing her last semester “on the floor,” (i.e., working in an actual clinical setting, in a hospital unit), and Annette had come to the hospital for her cancer treatments and autologous stem cell transplant. Cate explained that Annette witnessed her conversion from being a student to becoming a nurse, and that “She [Annette] just taught me a lot about living and life.” They connect “on a belief level;” both of them share a strong Christian faith and have had several conversations with each other about their deep religious beliefs.

It is important to note that Cate situates Annette as a grandmother, perhaps partly because of their age difference and also perhaps because Cate’s own living grandmother does not fit squarely with dominant U.S. mainstream ideals concerning what a grandmother is or does. She describes the significance of the relationship in this way: *Just to have an older person in my life that can help give me sage advice....I do have a good relationship with my one living Grandma, but she's the type of person who more kind of does their own thing and doesn't get too involved in the lives of her grandkids and I think that's just her nature or personality. And that's ok because we still have a good relationship and stuff but as far as having an older woman in my life like that, Annette is probably more so that way, and I've told her that. [And] she's just a wonderful person. And for that, too, like our relationship as friends and as more like family, more came*

about after she was done with the hospital probably. Because I cared for her in the hospital, I had chances to talk with her a lot and things like that, but it wasn't until I called her [after she had been discharged] to see if she wanted to have coffee and she was open to it and then we started meeting and then we became better friends.

It was when she crossed the professional boundary, Cate went on, that the two women became closer. Additionally, while Cate celebrates the fact that Annette is able to offer sage advice, she also noted ways in which she herself has been able to contribute to the relationship, particularly when Annette was doubtful whether she wanted to go on with the treatment (a point which her sister Lynn also described in Chapter 3).

I've had the chance to just encourage her. She was really not sure she wanted to go through the transplant and everything like that. She knew it would be difficult. And she has done so well and she's gotten to see two of her grandkids growing up that she wouldn't have been able to see.

It is worth pointing out, however, that Cate alternately referred to Annette as “like a grandma to me” at some points and as “a very close friend” at other points in the interview. This suggests that caution should be exercised in calling their relationship one of “kinship,” and as Holy (1996:168) reminds us, it is imprudent to equate the concept of relatedness with just any kind of social relationship. Still, this was a relationship of significance to both Annette and Cate, and thus serves as another example of the potential for transplantation to interact with notions of relatedness. These notions can be quite flexible, simultaneously reifying already existing norms and ideals (about, for example, what a “Grandma” is or ought to be), and reframing how we both reckon and carry out our relations with others (prompting questions such as, is this person a patient, a friend, a relative, or all three?).

Creating Kinship Through Creative Solutions to Complex Dilemmas

The flexibility of kinship is made apparent in other aspects of the transplant experience as well. Rayna Rapp (1987) argued that kinship is a product of innovation in the face of contestations and transitions. When faced, for example, with the constraints of a lack of available support from kin (which can be the product of myriad cultural,

economic, and political factors), transplant participants often become very resourceful and creative as they seek out sources for assistance (the following chapter will address this in the context of social policy). The on-the-ground realities of transplantation, that it *does* place tremendous demands on patients and caregivers alike, whose kinship obligations carry over throughout the transplant process (as we saw in Chapters 3 and 4), and who do not always enjoy tension-free relationships with their kin, can effectively shatter mainstream ideals about the boundedness of the individual or nuclear family.

In one instance, Blaine, introduced in Chapter 3, had become the sole primary caregiver for his adopted daughter, whose birth mother (and Blaine's wife) was struggling with addiction to pain medications. When the time came for Blaine to have a pancreas transplant, he knew that his wife would be unable to reliably care for their daughter while Blaine was in the hospital and recovering at his parents' home several hours away. So for the duration of his transplant and recovery, Blaine decided to place their daughter under the care of a friend and his wife, who also had two children of their own: an eight-year-old and an infant.

I asked Blaine how he selected the person with whom their daughter would stay, and he replied,

I just chose them because they seemed the most reliable and like the people that would get her to school on time and everything for me. And they help her out with her homework and you know, they are just really good people and good parents.

Blaine talks with his daughter every night on the phone, and said she has been doing very well with the arrangement. He also noted that this move understandably has been difficult for his wife to accept, but said, "*We just talked about it after I placed her [our daughter] there and then she kind of could see my point of why I didn't want her to stay with her because she might relapse or something...*"

Blaine told me he considers this friend to be a brother to him, and the two have become even closer as a result of this arrangement.

But tensions and fissures in kin relationships are not the only reasons for needing to arrive at creative solutions to the challenges that come up in the transplant process. Another study participant, Jane, who reported having a very solid relationship with her

husband and children, likewise had to make difficult decisions about who would care for their children while she underwent her medical treatments. Jane, who received a blood-forming stem cell transplant with her sister (Robin) as the donor, was introduced in Chapter 2. Together, Jane and her husband had decided it would be best for the family to move hundreds of miles away from their previous residence to a suburb of Metrotown, since her specialized therapy would necessitate a close and fairly long-term relationship with the Transplant Center. Her husband had a career in the military, and was able to secure a transfer to the military base in this Metrotown suburb, so that he could be there to help care for Jane. But earlier in her battle with cancer, she and her husband had come to the Health System for six weeks of treatment, and they decided it would be best if their three children remained in the community they were living in at that time.

During Jane's first round of treatments, their two sons went to stay with a family who had two boys the same age. The four boys were friends, the families had shared carpooling duties, and the father in the host family had been the wrestling coach to one of Jane's sons. Jane's daughter went to stay with her boss, who is "like a second mother to her," in Jane's words. Jane went on, with a small laugh, "...and her husband is very strict and my daughter is afraid of him. So I figured that would be a good." In both cases, the families offered to take in the children (without Jane having to ask), and she was in awe of these gestures, especially since they had only known them for a couple of years. When I asked her to tell me about her relationship with the families with whom her children have stayed, Jane said, with a wavering voice,

It's just been amazing, where on one level, one day you're just friends to carpool and the boys play together. Or they're on the same baseball team. The next thing you know, they're taking them in for weeks at a time, shuttling them around wherever they need to go. It's just an overwhelming...

This most recent period during which Jane was receiving her treatment at the Transplant Center, she and her husband decided that it again would be best for their sons to remain behind so that they could finish the school year and avoid having to switch to a new school so late in the term. This time, however, her youngest son decided he would like to spend the time with his best friend and his mother, and the mother was very

comfortable with the arrangement so Jane felt that was working out well. The arrangement for her daughter also had been changed from the first time Jane and her husband had been away for Jane's treatments: the decision was made to have her daughter finish her senior year requirements and graduate early so that she could move to the new home nearer the Transplant Center along with Jane and her husband. Jane explained:

...after the six weeks I was here and she was there it was really tough on her, I think, emotionally. And I couldn't see five months of that, nevermind she is...still a teenager, who likes to go out and do whatever. And we had a couple of instances during the six-week time that she really, well she got grounded and it's hard to ground your kids while you're here and [they're] with somebody. Even though you know you trust that adult completely, it's still not ideal. It took some time convincing her, one, that we didn't think that she could handle it emotionally, and [two,] we needed her here with us. So that's the way it panned out, and so that will be a great help to have her here.

This part of Jane's story highlights some of the ways in which core dominant ideologies about the self-sufficiency of the American nuclear family both come to the foreground and break down in the face of transplant. Jane, her husband, and the host families had to find ways to co-parent Jane's children through both support and discipline. Jane, however, did not go so far as to say that the host families were "kin" or "like kin" to them. In fact, she felt these circumstances were not ideal. Thus, here again, restraint is called for in labeling just any close relationship "kinship," and the families that hosted Jane's children for extended periods may offer some analogy, but do not replace Jane's and her husband's parenting. This is evidenced by the fact that it was Jane who grounded her daughter during her first six week round of treatments, not the host family (though the host family was responsible for enforcing this form of discipline). The new arrangement – in which their daughter graduated early in her senior year of high school and moved along with her parents to be closer to the transplant center – not only addressed the dilemma of how to parent a teenager in the midst of family upheaval and uncertainty, but would also more fully incorporate their daughter as a source of help in meeting the extra demands created by illness and this particular form of therapy. So in

another sense, then, this represents a turning inward toward nuclear family members to provide some of the logistical resources Jane's illness and treatment would demand (e.g., help with transportation to and from appointments, help with housework, etc.). In both senses, though, this supports an overall argument of this dissertation that the requirements surrounding transplantation can impact family structures and family dynamics in unique and complex ways that deserve the attention of social scientists and practitioners alike.

Many Faces of Kinship

Other aspects of Jane's story further highlight how transplantation can make existing kin relationships even more complex. Here, we shall see that the moral obligations of "kinship" call for relatives to be both creative and innovative. Family members become living donors, caregivers, conduits for communication, and even movers and housekeepers, and in doing so, can reveal and reframe certain aspects of those relations.

In Chapter 4 we learned that Jane's sister, Robin, had traveled to the Transplant Center from several states away to become Jane's living blood-forming stem cell donor. Robin had experienced many difficulties not only with making arrangements for her husband and own children during her time away, but also with the side-effects of the medications she needed to take for the stem-cell donation, and on top of it all, feeling much more homesick than she ever had anticipated. Robin had remarked that she did not want Jane or Jane's family to know how hard this had been for her, and made efforts to shield them from this knowledge, confiding to her husband over the phone only when she felt she could do so without Jane's family's awareness. But when I asked Jane whether she had noticed anything about her and her sister's relationship as they've gone through the transplant process together, I learned that information can travel through many circuitous routes among kin, and Jane had gained awareness of (and appreciation for) Robin's struggles, despite Robin's best efforts to hide them. Jane noted:

Yeah, we're definitely closer. I consider her to be my life saver. I think she feels the same way. She would do anything for me [voice wavers] and this is the, she's got two five-year-olds at home. So for her to, you know, say "Yes, I'll be your donor." But the reality of it is, she is away from her family for 10 days. She's got to arrange for child

care, her husband is a state trooper so he works shifts. So who is going to take the kids? When is he going to get them to school? She's homesick, you know? She didn't realize that she'd be going through pain with the Neupogen shots and all of that on top of it. And she won't complain; she complained to my mom and my mom told me [small laugh], but you know she won't say anything to me. I think that she knows what she's going through is minimal compared to what I'm going through.

Laura: After your mom relayed that information...

Jane: My sister was like, "How dare you?! You weren't supposed to tell her! That's why I didn't tell her!" [small laugh] And maybe that's another way of my mom dealing with things too, you know? Because she's not here and because she wants to be here, but she can't be because she's going through her own treatment. And every other word out of her mouth is, "When you're ready for me to come too, just let me know."

Their mother, who lived in the eastern U.S., had also been diagnosed with cancer and was undergoing treatment at the same time as Jane. This was significant because their dealings with serious illness not only prevented Jane from being able to spend time with her mother, but also kept her mother from being able to be with Jane in person (despite her offerings to come whenever Jane was ready for her to visit). Jane interpreted her mother's relaying of Robin's true feelings as simply a way for her mother to help out, feel involved, and "deal with things" even if from afar. In essence it was one creative means by which she could remain engaged and make good on her own moral obligation to care, given circumstances that prevented her from more conventional caring arrangements.

Members of Jane's family of origin have made their homes throughout the U.S., and the disruptions, flows, and intervening management of information have been a significant factor in her kin relationships in other instances as well. Jane's parents have been divorced for a number of years. She has essentially no relationship with her step father (but did not say more about this), and she describes her actual father as being generally "self-centered." She told me that, when she called him for the first time about her diagnosis, "he didn't know what to say" and he inappropriately "launched right into, 'Well we're going to see so-and-so for Christmas and now you, and we're gonna go see

your sister after that,” rather than speaking with her directly about the serious information she had just given him. This inappropriate reaction pointed to a moral *disharmony* in their relationship, and a *lack* of effort toward solidarity. For a time, the incident created an even greater rift between them. But Jane went on to say that her stepmother learned of Jane’s disgust and relayed the information to Jane’s father, and the matter eventually got resolved and the two of them now talk more than they ever had before.

“...learning as we go, adapting as we need to...”

Like many transplant recipients, it was not possible for Jane to arrange for round-the-clock care from an informal care partner, so she was not eligible to use the Cooperative Care unit at the Transplant Center. That is not to say, however, that Jane was lacking in care support. In creative ways, as she puts it, everyone “sort of pitches in.” For example, Jane’s brother also came from another region of the U.S. to visit the previous weekend, and helped out with some of the unpacking of moving boxes, which “was such a blessing,” as Jane explained, because her husband was just starting his new job and had little time to spare. Her husband and daughter, too, made adjustments to help out, to make the infeasible work as well as possible:

I don’t have someone to stay with me 24/7. I’d like to be in the Transplant Center apartments [Cooperative Care] or whatever but that just isn’t feasible. I think my husband and I have agreed that he needs to take leave, because with what I’m going through and what he’s going through at work [...] And starting a new job, really, he needs to keep his mind focused on something and he just can’t do both. So, I think he’ll be taking some leave. My daughter’s down here now. She spent two weeks up in [our previous place of residence] after we came down. She graduated early and I’ll rely on her a lot for transportation back and forth with our boys to school. The whole family, too, sort of pitches in.

Jane noted how her loved ones have risen to the challenges they’ve all been faced with. Her daughter has thus transitioned from being a high school senior to also being a

source of logistical help (with transportation, for example). But the real change in her relationships that Jane has noticed most prominently has been that with her husband: *A definite change is with my husband. He is not the caregiver in the sense that he just comes to appointments. He wants to flush the [IV] line. He gives me Neupogen shots, and everything, he wants to do everything that the nurses are doing as much as he can so that's been different.*

Laura: And has that surprised you in any way?

Jane: A little bit because he's usually kind of squeamish, but he sat through watching the bone marrow biopsy the last time I was in the hospital and had one. And I was surprised at that, but he just wanted to be there to hold my hand. And I'm like, 'I don't need you to hold my hand,' and 'I've been to these,' and I'm very independent. And he's a little more, you know, wants to be there to help so I let them. I mean, I'm happy to let him do the line²⁶ and fix the vancomycin²⁷ I have to have at home and he sets it all up [in the portable machine that we put the tubing and medicine through] and stuff like that. And it's kind of surprising, but...he's happy to do that. In fact, he'll say, "Do you need some help?" and I'll say no. And he's right there and he's doing it anyway so yeah that's been really nice.

Laura: Has that changed your relationship on a broader level in any way, because he's now doing some of the things like these more medical-type cares?

Jane: Yeah, yeah. Um my grandparents were married 42 years, and on my grandmother's deathbed she gave me her wedding ring. I took that at the time [to mean] that she believed that we would last just that long so he now says, "You owe me 42 years, so you got to get better. I need you to, you're only 42 years!" (small laugh). So just things like that. Granted, sometimes it's tough. He has a lot to pick up when I'm in the hospital or, [he asks] "How come you're taking another nap?" And he's not a big reader, so he's not read a lot about what caregivers go through, so it's just kind of been, well, learning as we go, adapting as we need to.

²⁶ Intravenous lines need to be periodically cleaned and flushed with sterile solution, for example, to ensure that the full dose of an IV drug is administered, and to prevent infection, clotting, etc.

²⁷ Vancomycin is a medication used to treat inflammation of the intestines that can result from the use of certain antibiotics.

Thus, Jane and her kin offer an example of creativity and innovation in light of incongruencies between the demands of transplant care and the on-the-ground realities of home life and interpersonal kin relations. They found ways for their children to avoid disruptions to their school year by her hospitalizations and their move, by staying with host families for extended periods of time. They found ways to complete a cross-country move, complete with packing and unpacking, in the midst of dealing with life-threatening illness. They found ways to deal with the fact that there would be no one person who could stay with Jane 24 hours a day, with a daughter who graduated early from high school and a husband who took a leave of absence from a new job and overcame “squeamishness” to become a very hands-on source of help with Jane’s medical cares. And they found ways to maintain certain forms of closeness and to open lines of communication, even when barricades had been erected by distance (in the case of her mother), out of protection (in the case of her sister), or out of strained relations (in the case of her father). Jane was keenly aware that her infirmities required a lot of her husband and other members of her kin network. But here we also see an example, in line with those we saw in Chapter 3, of a patient being reminded by others in her life that she carries the reciprocal obligation to “get better” because she’s needed here, in this life (Jane’s husband only half-jokingly tells her that, ‘You owe me 42 years, so you got to get better’). She and her husband (and by extension, the rest of her kin network) cope with these stressors by, in her words, “learning as we go, adapting as we need to” and simultaneously turning inward toward the resources of the nuclear family, while also extending outward in light of the reality that families, indeed, are not bounded, completely independent entities.

Negotiated Relations: “Bringing Us Together?” or “Tearing Us Apart?”

Participants often remarked that they had in many ways become closer to their loved ones as they’ve faced together the challenges posed by transplantation. As I discussed in Chapter 5, this was a common sentiment, even among those who also noted that their dealings with transplantation had also created great upheaval in their families. These seemingly incommensurable sentiments can effectively be incorporated together as patients and their loved ones deal with the challenges of preparations, recovery, and

reciprocal forms of care in the domestic home (and in various other “houses” that become linked in the transplant process). Some participants expressed surprise that they had developed closer relationships with their care partners, as in the case of Calvin and his son who were staying together in the Cooperative Care Unit of the Transplant Center (Cooperative Care rooms were purposefully designed to be “home-like” environments, as I described in greater detail in the Introduction and Chapters 2 and 5).

Calvin, a white male in his late fifties, had undergone a marrow stem cell transplant as part of his treatment for leukemia. Persons who receive this type of treatment are required to be closely followed for 100 days after the transplant. When their home is far away, patients like Calvin might stay in Cooperative Care for this extended period. During this time, they are expected to have a care partner stay with them to monitor closely for signs of complications following the treatment. Calvin’s wife had passed away some years ago, and his adult son, in his thirties, agreed to be Calvin’s primary care partner, with Calvin’s cousin planning to provide additional supportive care periodically during the post-transplant period. Both Calvin and his son lived several hours away from the transplant center. In a pre-transplant interview, Calvin mentioned that he was unsure how well he and his son would get along during their time together in the close proximity of something resembling a shared hotel room (see the earlier descriptions of Cooperative Care). But at a post-transplant follow-up interview, he described with some dry humor how their relationship had evolved after having gone through the experience together and having had to learn how to live in such close quarters.

Calvin: We’ve always had a good relationship. [But during this stay] I’ve been a little bit more, probably a little bit more patient with him than I normally would be as I’m, you know, kind of a, ‘either do it my way or the highway’. And now, if he wants to go out I let him go out.... [he goes on to explain that he hasn’t had a lot of complications that he’s needed his son to help him with]. So yeah, I think I’m a little bit more tolerant with him.

Laura: And what do you attribute that to?

Calvin: Well, I mean I have to be. I mean, if I’m not, he’s going to be pissed off and I’m going to be pissed off. So this way we’re getting along, but I mean, we go out to eat and stuff so it’s, it’s not too bad. We always did have a good relationship, but I was probably

a little hard on him all the time. But I'm just less, less strict with him now, is probably the best word for it.

Although Calvin does not put things in such terms, by living in the same space as his son again for the first time since his son moved out on his own, Calvin has renegotiated his role as a father. As an adult child who lives independently of his father, Calvin's son has long been able to go out without his permission. But Calvin notes that he now is more tolerant of his son, and if he wants to go out he "lets" him go out.

Carsten (2000b:700) has emphasized the investment of time as a constituent of kin relationships. In the case of Calvin and his son, time certainly is an important factor, and adds to our analysis of relatedness in the context of the house. By once again spending their days in close proximity (and spending a great deal of time together), where conflict might not easily dissipate, a temporal bridge is made between the period when his son was a dependent with whom Calvin was once strict, and the time now, when Calvin has to relate to his son as a fellow adult. This new relationship has been negotiated under conditions in which Calvin and his son have shared a living space that is part hospital, part home-away-from-home (which comprises a spatial connection, or bridge, between their daily lives as well). And in the course of renegotiating their relationship's terms, Calvin feels that he and his son developed a new level of closeness.

"There's no one to get mad at..."

Yet as patients and their loved ones negotiate the many uncertainties, anxieties, and stresses of transplantation, close relationships also can sometimes be greatly taxed. Earlier, in Chapter 2, I introduced Cameron, a young man in his twenties who was frustrated because his progression through the kidney transplant process was being slowed in light of his needing to fulfill extra requirements due to a history of marijuana use. He explained that his fiancé, too, was frustrated with the situation. They had put their marriage plans on hold until after Cameron could receive his kidney transplant, for which his mother was to become his living donor. The fact that Cameron already had a willing living donor who was a match made him even more incredulous. Cameron explained that he and his fiancé sometimes find themselves directing irritations toward

each other, even though they both have a sense that the true source of their frustration is the situation they find themselves in, and over which neither has direct control:

Yeah, we talk a lot. Mainly, you know, we're kind of upset that we have to wait for the transplant. So that's what we talk about mostly. Sometimes there is this built up resentment and anger, and sometimes it shows itself where we will fight with each other about it because there's just ... no one else to get mad at really [and] only two people talking about it. So sometimes it can affect our relationship in that way, where we just will be mad and there's no one to get mad at. So we kind of take it out on each other, but it's really, we're angry about the situation.

Thus, the transplant process also can strain relationships, necessitating a continuous re-evaluation of where one stands in relation to others. Cameron recognizes that he and his fiancé “take it out on each other,” even though they’re actually “angry about the situation.” But in other ways, the challenges of transplantation can have the effect of throwing the current (and historical) status of your kin and social network into stark relief, making painfully obvious the way things are, and revealing certain aspects that patients (and those surrounding them) might otherwise never have had to confront.

When It's Hard to Find Somebody Who Cares

I also learned of examples in which patients were left to navigate the transplant process with very *little* or almost no informal care support to speak of. As we've already seen through other examples in this dissertation, because patients often become so ill prior to a transplant, and now are discharged from hospitals to their homes well before they have really healed from a transplant surgery, they are required to identify someone they can rely upon to provide assistance, as a prerequisite to being approved for a transplant. Often, persons turn to their immediate family members (I have already discussed the issue of spouses being “default” caregivers). But cases in which a person has no potential caregiver in their life who is related by blood, marriage, or adoption – the most common categories from which informal caregivers are drawn in the U.S. – can bring forth some of the ambivalences, ambiguities, and discontinuities in the often taken-for-granted aspects (including moral obligations) of kinship. They also can illustrate

some of the ways in which persons create kinship, and in doing so, both revise and uphold some of the assumed characteristics of relatedness in the U.S.

“Yes, she’s a family member – I wouldn’t be doing this if she wasn’t family.”

One caregiver I met, Jacob, was the long-time on-again-off-again boyfriend of a woman who’d had a liver transplant two years ago. Though he’d grown up on a farm, his father died when Jacob was a senior in high school, and his mother decided to hold a farm sale and buy a house in town. Since then, he has lived in various small rural towns located one to two-and-a-half hours outside of Metrotown. Jacob and his girlfriend had met through a mutual friend, and during the summers, when she got laid off from her usual job, she came to work at the same lumberyard as he did. Jacob admired her ability to do the kinds of manual labor that tended to be divided along gender lines, especially in the rural small towns of the region, recounting, “She could run a nail gun as good as any man.” He taught her how to run a forklift, which enabled her to get a better job that she enjoyed for some time, until the plant closed down. She had long been a heavy drinker, Jacob explained, but she drank even more after she lost her job with the plant’s closing. Though he himself drank a fair amount of alcohol too (and explained that he’d received so many DUI’s²⁸ that his driver’s license had been revoked for 15 years), Jacob tried to warn his friend that she was endangering herself.

I said, ‘you gotta slow down ‘cause the liver man is gonna come knocking.’ She would say, ‘I’m ready.’ But when the chips were down, she wasn’t ready.

His friend began to develop some of the symptoms of liver failure. Jacob noted that “she was yellow, and very cold, and didn’t want anyone around her,” although she did contact him to ask him to bring over some electric space heaters, and to move her television into her bedroom. He came to her house one day, and she wasn’t able to answer the door, so he called the paramedics.

Jacob’s friend received a liver transplant two years ago. Though Jacob did not go in to the particulars of this, it is safe to say that his friend would have been required to undergo treatment for alcoholism, and would have had to remain sober for an extended period of time in order to qualify for the transplant waiting list, as this is the policy at this

²⁸ Citations for Driving Under the Influence of alcohol.

field site (and similar policies are in place at transplant centers nationwide). But when I met Jacob, he was at the Transplant Center with his friend because, in his words, “she fell off the wagon.” He had suspected that something was wrong recently because he would call her and would be able to tell over the phone that she had been drinking. She did not want him to come to visit her, but when she stopped answering her phone altogether, he ignored her wishes and went to see her. “She looked really bad,” so he called the paramedics again, who took her to the slightly larger town nearby, where she was promptly sent on to the Transplant Center in Metrotown. But Jacob wanted to emphasize something he felt was a crucial aspect of his friend’s story.

This lies deeper than everyone thinks. Her mom and sister live [on the West Coast] – her sister lives with her mom. I called them the last time she was sick. She’d been in [this state] for 22 years, and I’ve known her for about 18 years, maybe 20 years. They’ve never come out to visit her. The doctor asked me, ‘What do you think is really wrong with her?’ I said, ‘Well, you are the doctor!’ She’s an alone person and got depressed. And the more you get depressed, the more you get depressed. Yes, the plant stopped, but her mom would call, and [my friend] didn’t wanted to be ashamed of where she lived. She didn’t want to be looked down on.

Jacob went on to paint a picture in which he and his hometown connections in the town in which his friend lived had begun to form a family around his friend that was more reliable and supportive than her biological kin had been for some years. In the town nearest to where Jacob had grown up, there was a woman who had long been like a second mother to Jacob. He and her family (including herself, her husband, and their seven children) spent a great deal of time together, “running around town.” Jacob was treated as one of the family: “They would do anything for you, they never lie, they’re good people, and there’s love and trust.” This woman had a saying, “‘We’re all brothers, just from different mother mud.’” Though Jacob had needed to move to a different town for work, she and her family had begun to help out his friend when they could, inviting her to their holiday celebrations, for example. “You just don’t leave a fallen man behind,” Jacob explained.

And now that his friend was sick again, Jacob had begun to make plans to have her come and live with him. Jacob anticipated that some of the logistics could prove to be a challenge. He worried most about her risk of falling. He would have to help her with her medications, he said, though he didn't know very much about them yet. He would need to make sure that she started to eat better because her diet had become very poor. And he would need to get her to and from her appointments, even though he no longer had his license. He was confident that this was the best, indeed, only option. But, he said, he would have to keep her busy (ostensibly so that she would not return to drinking again). This could prove to be an even greater challenge.

She's gonna buck and wanna get out. When someone is in prison 30 years, they get institutionalized and two days before they get out they're scared. Maybe she's sort of institutionalized in her lifestyle and now that it's time to get out, she's scared. She locks herself in, just like a prison. All her life she's been locked up, she's the king of her cell and no one's gonna mess with her there, don't cross the line. She's been in prison 25 years, and now is the release date and the world out there is scaring her and it ain't gonna be that little cell and it ain't gonna be that drinking. When you are in, at first you hate it, and don't know how to live with yourself, and then you get used to it, and then you're afraid.

When I asked him how he thinks he might handle the difficult times, he said he would just try to talk some sense into her and not get angry. "If I get in a fight with someone, all it proves is whether they're a better fighter than me, and I get bloody and the problem is still there." This is the most his friend has ever admitted that she needs help, and he felt that he was that someone who needed to be there for her. When I asked him if he considered his friend to be a family member, Jacob seemed almost indignant at the question. "Yes, she's a family member – I wouldn't be doing this if she wasn't family."

Jacob zooms in on some of the fractures and fissures at the intersections of transplantation and kinship matters. When the doctor asks Jacob what he thinks is really going on with his friend, Jacob's response cuts to the limitations of a lifesaving biomedical treatment like transplantation, which is ill-equipped to address the root of his friend's problems that, as Jacob puts it, "lies deeper than everyone thinks." His

commentary also points to yet another incongruence between the requirements of transplantation (here, that a recipient abstain from alcohol) and the realities of life outside the clinic (in this case, the emotional wounds of a painful family history). In Jacob's assessment, the real problem is his friend's hurt and ambivalence over a mother and a sister who, according to powerful mainstream ideas surrounding the moral obligations of kinship, are *supposed* to care and be involved in her life (this resonates with the "moral etiology" of Grace's need for a small bowel transplant, as I described in Chapter 2).

Jacob also points to some of the ways in which, in the absence of these more expected forms of kin support, he and members of his social network have become family to his friend. This innovative relatedness emerges in part out of his appreciation for the colloquial wisdom of his "second mother," a woman who also had incorporated a young Jacob into her family life: "We're all brothers, just from different mother mud," along with his own moral orientation that "You just don't leave a fallen man behind." This form of relatedness resonates with some of Weston's (1991) insights regarding gay and lesbian families, or, "families we choose," in San Francisco. In her observations, gay and lesbian men and women alternately critiqued and upheld heteronormative ideologies about biogenetically based kinship, as they redefined "family" as being those people you can rely on, who offer both emotional and material support, who share a past, and whose ties are unconditional, resilient even in the face of conflict (Weston 1991).

Jacob anticipated that there would be a great deal of conflict in his and his friend's future together. At the time we spoke, Jacob intended to bring his friend home to live with him once she had been discharged from the hospital, even though they were no longer romantically involved and he had been dating other women. He was going to become a caregiver who not only would ensure that she would avoid falls, get to and from her appointments, and eat better, but also would work to keep her from drinking. Likening her drinking to a prison, and pointing out that she has become "institutionalized" and would be fearful of what life outside the walls of alcoholism would look like, Jacob nevertheless was determined to honor his obligations: "She's gonna buck and wanna get out," he noted, but she is *family* to him. Indeed, he emphasized, "Yes, she's a family member – I wouldn't be doing this if she wasn't family."

Alienation and Connectedness

Though transplantation itself, as a high-tech biomedical intervention, is ill-equipped to address the on-the-ground ambiguities of kin relationships, there nevertheless are very caring, astute clinicians who try to work with patients to assemble adequate care arrangements. I met and spoke with professionals who were very keen to some of the disconnects between official clinical requirements and life outside the hospital. For example, one transplant social worker pointed out that multiple factors can overlap to shape the ease or difficulty with which patients are able to find a care partner, especially when the need for a care partner is immediate and unexpected. A patient's interpersonal style and social habits, their connectedness within their community, the size of their city or town, or proximity of rural neighbors (which all can make one feel more anonymous or less anonymous), as well as the resources to which their loved ones have access, all can be major factors.

Some people are very connected, just in the community, whether it be through the church or through other civic duties or responsibilities that they have, or just, they are friendly, they're friendly individuals and they happen to have a lot of friends or they have a lot of neighbors. I've had a few other people that live in a vast city like Metrotown, and they have nobody. And so they don't go out, they don't do anything, they might have a few, they have a friend at work, you know, they have a child at home, but that's about it. They don't, you know, don't socialize, they don't surround themselves with others. They just kind of go to work and do their thing, and they have to have a heart transplant and they don't have anybody, or their child isn't able to do that because they don't have the resources to provide that level of care.

Thus, the types and amounts of care to which a person has access (or which someone is able to give) are shaped not only by family dynamics or individual personalities, but also by constraints that can be built into the very communities in which they live. These multiple, overlapping, and interactive domains can also include legal definitions and constraints that do not always map well onto the on-the-ground realities of family life and kinship bonds. One nurse with whom I spoke, Cate (mentioned earlier in

this chapter), who worked frequently with blood-forming stem cell transplant patients, described some of the more difficult instances she had encountered in which geographical distance, family tensions, or other forms of interpersonal alienation left patients without adequate or appropriate caregiver support. Bound by laws regarding medical decision-making, next-of-kin, and confidentiality of medical information, nurses are sometimes in closest proximity to these scenarios.

Laura: How do people make decisions about who will step into that caregiver role, if the person has a number of people who could?

Cate: Well, if there's time to plan, we try to look ahead and see that, like I remember one patient in particular who seemed to have no one. He'd kind of alienated himself from his family, whether it was his fault or not, but he just had no one. Never had visitors, never had family, and he lived in Metrotown. It's not like he was from some far-away place. And I think it was a situation where his daughter would have been legally his next of kin, [but] she was far away and we always had to do consents over the phone and stuff like that when he wasn't able to give his own consent. And in that type of situation, you just do the best you can. And you deal with calling, even though they're not really there and you try to explain what's going on and they have to blindly consent and trust that the healthcare team is doing what's needed for the situation, so that's hard. And then there's other situations where ...obviously the person's next of kin is their daughter or son who's oldest, but it's like the youngest one of the family who is always there with their family member, always taking care of them, has the most health knowledge, and they in our opinion would be best to give consent because they really understand what's going on. But it's this person who, it's the older person who is in California who is still holding on to that next of kin status, who wants to be the one making the decision even though they have no idea what is best for their family member. They're so far away from their situation. So in a situation like that, we can't do a whole lot. We can encourage them to think about making that person who's closest to the situation next of kin, but if it's going to cause a huge family rift, there's not much you can do about it and you just try to inform everybody like that older child that, 'This is what's best; why don't you talk to your younger brother about it 'cause this is what we recommend.' But you can't force

them to make a decision.

Clinicians, then, often do what they can to foster appropriate care arrangements. But they are restricted by legal and institutional constraints, professional boundaries, and the limits posed by heavy patient loads and full daily clinical schedules.

I also spoke with patients who directly had found themselves in a situation where, in spite of promises made by others to help them through the transplant, they were left without adequate care support. For example, Marguerite, a white woman in her mid-fifties, whom I came to know through this research, had received a marrow stem cell transplant as part of her cancer treatment some years ago. She recounted to me the fact that she found that she had no family members who were willing or able to provide informal care for her during the transplant process. Her parents both had passed away and her only sibling was a brother to whom she was not particularly close and who, in any case, lived far away and would not have agreed to stay with her during her treatment. She had lived in the area most of her life, and currently resided in a city adjacent to Metrotown, where she enjoyed the support of a few close neighbors but otherwise did not have a major individual presence within the community. Prior to the transplant, Marguerite *thought* she had made arrangements with a friend of hers who had agreed to become her care partner for Cooperative Care. But in the days leading up to her scheduled treatment, when she tried to finalize plans with this friend, the friend backed out of the arrangement, indicating that she wasn't certain that she could be there to provide care, after all. This left Marguerite without a care partner and unable to stay in Cooperative Care. And, even though Marguerite lived in the Metrotown area, with no one to care for her at home, she had to spend the full intensive monitoring period following the blood-forming stem cell transplant as a hospital inpatient. While some persons I met in this research also stayed the full monitoring period as a hospital inpatient, and were comfortable with doing so, Marguerite was the only person I met in such a situation who was completely lacking someone who could serve as a personal advocate, who could help to ask questions of the medical team and remember their answers, who could help to troubleshoot complications, or provide at least sporadic support and encouragement.

In this scenario, a hospital social worker came to fill this role for Marguerite, which offered some amelioration of the dilemma, but because of staffing, workload, and professional boundaries, the social worker could only offer a certain amount of assistance. We have seen at least one instance already in this chapter in which a clinician and a patient (Cate and Annette) developed a kin-like relationship. Indeed, Marguerite and this social worker have stayed in touch over the years. But Marguerite did not feel that her transplant experience was a positive one overall; she did not feel that her needs were adequately or consistently met, and in many ways felt she suffered alone through the difficult emotions as well as medical complications that arose during her treatment.

And last, I met a man at one of the Organ Transplant Reunions whose experiences likewise represent some of the holes that can be present in one's overall web of care. This man described to me how he had become very ill while waiting for his transplant. His wife had divorced him, and his sister was his primary caregiver, but the two of them lived in different residences some miles apart. He had needed to leave his job because of his illness; this was a difficult move for him, he explained, because he was a self-described "people person." During the winter, while he was so sick (but before he needed to be hospitalized), he was unable to "get out of the house" by himself. Yet the weather prevented his sister from being able to pay him a visit every day, let alone to take him on outings (which he craved tremendously). He described the immense feelings of isolation that he endured all that long winter, and though he did manage to survive that period, and had done well with his transplant, he said he wouldn't wish that kind of loneliness upon anyone.

Creative Measures Can Produce Webs of Care Both Weak and Strong

Each of these examples raise questions about the strengths and weaknesses of a health system that relies so heavily on expectations that patients will be cared for by kin or other relations of deepest significance, who must be able to dedicate the time and resources to providing such care, and that it is up to patients to arrange for care support from certain categories of persons. The fact remains, however, that even those who found themselves isolated and without adequate support did not tend to criticize the system. These findings suggests that current health care models tend to be rooted in

rather widely shared assumptions that these relations of reciprocity and giving are universal, natural and bounded in every case, despite ample evidence that this is not really so. In light of these assumptions, which do not always correlate with the on-the-ground realities of personal lives, when lay care support is inadequate, patients tend to suffer. Pre-transplant evaluations and protocols mandating the presence of lay care support can potentially have the two-pronged effect of steering inadequately supported patients away from transplantation (which is problematic in its own right, since this becomes an access issue for already disadvantaged populations), and leaving patients vulnerable to the cracks and fissures of a hastily pieced-together web of care. Little can be done in instances like that experienced by Marguerite, whose friend backed out at the very last minute, or the man I spoke with at the transplant reunion for whom climate and weather limited his sister's ability to tend to his needs.

At the same time, it also is important to be mindful that persons very often become incredibly innovative in constructing webs of care and filling in gaps as needed. Furthermore, more common than examples of patients finding themselves isolated and without care were patients who expressed amazement at just how unexpectedly generous and giving some of the persons even at the far fringes of their social network became upon hearing about the patient's illness and transplant. Jane was particularly eloquent in describing what she had noticed about her relationships with others, whom she previously had considered only acquaintances:

It's sort of surprising those ones that will just come out of the woodwork. I mean, ones that you've just seen in passing, and you just say "hi" and we don't socialize with really but they're the ones who, I have a Caring Bridge site [and] they're the ones to post everyday. And they're the ones who e-mail and send you a care package in the hospital. And the ones that you think are closer or any you maybe socialize with are the ones who maybe are a little more stand-offish. For whatever reason maybe the ailment scares them or they don't know what to say, or they feel helpless or whatever. That was kind of surprising, but just in general. I have had support from people I haven't even met, you know, friends and family members and friends of friends heard about it for whatever reason, made the connection and reached out. It's just amazing. It's overwhelming to

see how much support you have out there and how many people pray for you and they don't even know you, so it's kept my positive thinking going....

Jane's descriptions stand in contrast to those of Marguerite and the man who had felt so isolated as he waited for his transplant. Jane had been surprised at who had become supportive and who had become withdrawn, but overall, expressed amazement at the fact that people she didn't even personally know had "reached out" to her, offering their prayers and encouragement. The fact that Jane's story spread to so many is suggestive of the power that transplantation can have to resonate with emotions, hopes, and fears, especially those surrounding our collective relationship with life and death.

LIFE AND DEATH

Given the stakes involved in transplantation, every aspect of it is permeated by co-existing notions of life and death, which likewise literally shape the structure of kin networks and give particular meaning to kin relationships. Others studying transplantation have noted that the "life" side of transplantation tends to be afforded much greater visibility than the "death" side of it. For example, as Sharp (1995:372) has documented, "birth" and "re-birth" metaphors in transplantation are common, buoyed up, and dominant among recipients and those close to them. I encountered examples of this in my own fieldwork.

Annette's Re-Birth Day

For example, similar to Mary at the beginning of this chapter, who wore a badge declaring "It's My Birthday!" at her New Life Celebration held on the anniversary of her transplant, Annette likewise conceptualized the day of her transplant as a "Re-Birth Day." *Surrounded by her husband, sister Roberta, Roberta's roommate (who had become a member of the family over the years), Annette's daughter, and newborn granddaughter, Annette is sitting up in her hospital bed and holds in her lap a small cake decorated with green and white frosting. She smiles in spite of the fact that she has just completed a grueling round of intensive chemotherapy, and behind her smile, one can detect the exhaustion that has been settled over her for days.*

This description is of picture, which was one of a series of photos that Roberta's roommate had taken that day, labeled "Annette's Re-Birth," and shared with more distant family and friends via an Internet photo site. When they met me, both Roberta and Annette suggested that I should see the photos as well. The rest of the pictures capture the other goings on in the room at the time, and indicate that Annette held this cake as she waited for the blood-forming stem cells (which had been removed, frozen, and stored prior to the chemotherapy) to come up to body temperature in a warmer before the bag containing them was hung from an IV pole and administered intravenously back into Annette. As we sat and looked at the pictures together, Roberta remarked:

She was gonna die and be reborn...that's basically what they do. They kill everything in your body and then put it back in. [...] That's what they do. They basically kill everything in your body and start all over again, and so to me that's what it is. This is a re-birth. So when we took these pictures, you're being reborn...you're getting another chance in life.

This suggests that, even though the emphasis in transplantation may be on life more than on death, patients and their loved ones can have a very keen sense that life and death are not at all times separated, and that one can merge with – and emerge from – the other.

The Presence of Death

Transplant patients face not only illness but a shortened lifespan (i.e., death) without replacement of key organs or tissues. As participants in reciprocal webs of relations, and as persons on whom others depend heavily, patients aim to stave off death as long as possible, sometimes even at great personal sacrifice (as I examined in Chapter 3). Some recipients of cadaveric organs do not freely explore the fact that their organs came from another, deceased, human being, and the transplant enterprise is structured in such a way that recipients are shielded from unwanted relations with persons with whom they literally share ties of bodily substance (Sharp (2001) has thoroughly documented this phenomenon). Others, like Mary, who did receive her organs from a deceased donor, keep themselves very open to that reality, and find meaningful ways to foster the memory of their donor, as well as ways to reckon the new forms of connection that such an exchange can potentially create.

But death in transplantation does not exist solely in the domain of deceased donors and their kin. For instance, Annette, who received an autologous marrow stem-cell transplants, was her own personal source for her transplants. Yet she and her family members were keenly aware of the direct presence of death, even as she was receiving her transplant. Thus, even as transplantation represents a massive collective effort to stave off death, it can never be freed from the difficult realities that life cannot permanently escape death. Over the course of my fieldwork, a few of the persons I met were forced to face the pain of loss through death, despite heroic efforts to maintain life, and among the heartrending stories I encountered, that of Grace and Kevin was especially poignant.

“She was surrounded by family...”

It had been a few months since I’d last seen Grace and Kevin, and I decided to call one day in April to get back in touch with them. Kevin answered the phone with his signature cheerful, kind voice and he immediately remembered who I was. I said I just had been thinking about them and wanted to call and check in to see how they were doing, and he said, “Well, you know Grace passed in January.” This was the first I had heard this, and was very sorry to learn of it. Kevin reminded me that Grace had agreed to the second small bowel transplant that they knew might become necessary at some point since her first transplant was no longer functioning. They weren’t able to take all of her bowel out. She already had no stomach, since it had been removed some time ago, so the transplant team had to leave some of the bowel in so that they’d have something to connect the second transplant to. Grace did get the second transplant, but the drain line was not able to suction enough bile. As Kevin put it, “she had a leak,” and eventually infection spread throughout Grace’s body as she became septic.

Grace died in January. But Kevin said he was able to get the family up there (from their homes in the South up to the Transplant Center in the Midwest): her dad, her older sister whom she was closest to, the children, and the grandchildren. So she was surrounded by family and was alert, Kevin said, and she told them all that God called her name, and a few breaths later, she passed. It was a good death, he said, a beautiful death, and when he goes he hopes his death can be as good as hers. Kevin told me he knows that

he'll be able to join her again someday. And he said it's good to know that she's not suffering and they're not waiting and wondering anymore.

But, he said, it's been difficult for him because she was his main focus for the last ten years of his life, and he's felt a little lost without her. Kevin went back home and "hung out" for about a month, but then did go back to work at the beginning of February. He said he was going to take longer time off, but it was winter there and it just got to be hard for him to be home alone all day. The weather was dreary and it was hard to get out. So he went back to work and that's been going well; he's doing pretty well. The mornings and days are good, and the only time it gets hard for him is in the evenings when he comes home to an empty house.

In spite of all of the technological interventions so common in hospital deaths – an example of what Chapple (2010) has called the "ideology of rescue," Kevin felt that Grace's death had been a good death, even a beautiful one. It was a relief to no longer have to endure the waiting, wondering, and suffering they'd been faced with throughout their transplant journey. Grace took her last breath as she felt a connection with the divine ("God called her name"). Kevin, too, took comfort in their shared Christian faith, which likewise situates life as emerging out of death; it offered him the assurance that they would be together again one day in their lives-after-death. And significantly, at her death, Grace had been surrounded by those she loved (her husband, children, grandchildren, and sister), and by those with whom she had found reconciliation (her father). In this way, Grace's death encapsulated some of the powerful ways in which transplantation, to its very core (at the intersections of life and death), can engage with our understandings of what it means to be related to one another, for better or for worse.

Conclusions

This chapter's final section has focused on the simultaneous infusion of both life and death in transplantation, and serves as a reminder of some of the high stakes involved. Within the context of such stakes, relations and relatedness can become revealed, reframed, and reworked. I began this chapter with an exploration of one particular bond that developed between Mary and her family, and the family of the woman whose vital organs Mary received in a small bowel, liver, and pancreas

transplant. Mary and Lois (the deceased donor's mother) seemed to form a bond of kinship that was meaningful and genuine both to them, and which expanded to a blending of their two kin networks. While the idea of Lois's daughter "living on" in Mary was a powerful one, and indeed, this notion comprised a part of the relationship, I argued that it did not adequately encompass or describe their relationship. The evidence from this case supports less an "organs-based" perspective, and more a perspective that this kinship bond was initially founded upon the giving of life itself, and then built up by the active and sustained material practices of kinship. These practices literally took form in Mary and Rob's house, and in turn fostered further kinship-building processes. For example, Mary and Rob not only prominently displayed photos of their new blended family on their walls, but also created an apartment space for Lois and her husband, which in turn fostered more visiting and more blending. I pointed out that, while it highlighted some of the potential that transplantation holds for creating kinship, this particular level of connection between recipients and donor kin was rather exceptional among those I met in fieldwork. Part of this may be due to policies which maintain anonymity between donors and recipients, but even among those I spoke with who had met their donor families, there was a range of experiences and perspectives regarding their encounters.

In the second half of this chapter, I examined additional ways in which kin relatedness seemed to flex, grow, and change through transplantation. Relying on the notions of social cohesion, solidarity, and understanding what someone else is going through, I analyzed data from observations at the Annual Organ Transplant Reunion, inpatient hospital units, patients' home lives, and housing for long-term outpatients (the Baxter House). In doing so, I noted instances in which the circumstances of transplantation – as a process which demands much from its participants – could bring persons together in ways that likewise held potential for the creation of new relationships and the re-casting of already-existing ones (while also supporting a cautionary stance against calling just any sort of relationship *kinship*). Over the course of long hospital stays, inpatients and loved ones can develop ties with fellow inpatients and loved ones, and these ties can grow and extend for years following the actual transplant. Likewise, as clinical professionals and other staff work closely with patients and family members over long periods of time, close bonds can sometimes result as professional boundaries erode

in a shared space infused with suffering, encouragement, emotion, and care. In the Baxter House, house staff not only become personally involved in the lives of patients and loved ones staying there, but also – through action and through spatial design – purposefully try to cultivate a sense of mutual support and cohesion among the guests. And finally, the example of Jane illustrated that, as patients work to meet the multiple challenges of transplantation, the support they receive can come not only from their immediate kin, but from persons at the farthest fringes of their social networks, and even from persons they've never met. Patients and loved ones often find that they cannot get through the process without the help of others, and, as Jane put it, participants adapt and learn as they go, while “everyone sort of pitches in.” By finding creative ways to address dilemmas, then, patients and those surrounding them also can create new ways of relating to one another.

Thus, one underlying theme of this chapter has been that transplantation can expose some of the mythical qualities of the idea that American families are self-sufficient, bounded, independent units. It can do this even as participants simultaneously rely on and uphold dominant kinship ideologies about what certain categories of kin *ought* to do or be in relation to one another. By engaging deeply with the moral obligations of kin relatedness, transplantation can provide the impetus to redraw some of the terms of those obligations.

I also examined instances in which some of the moral conventions surrounding certain categories of kinship and care were *not* followed (i.e., when it's hard to find someone who cares). In the case of Jacob, we saw an example of tremendous innovation and creative kinship practices, aimed at providing care for his friend. But with Marguerite, for example, we saw that even as persons *do* find creative and innovative ways to address some of the dilemmas presented by a more tattered web of relations, the webs of care they piece together likewise can sometimes be frayed and unreliable. Such instances highlight some of the weaknesses of a high-tech, very demanding procedure like transplantation, as it currently exists in a policy environment which relies heavily on informal, unpaid support from those surrounding patients. The following chapter will, in turn, go on to more fully analyze the intersections of social policy with some of the on-

the-ground realities of daily living for persons who most directly participate in transplantation.

Chapter 7:

A House of Cards: Health Policy Paradoxes

Is your study gonna help reform some of the things that the government's doing wrong? [...] I think [this state] could have put my transplant off for awhile. If I had gotten treatment when I first needed it, I wouldn't have had to be approved for SSI in [the Northwest state], and maybe wouldn't have needed the transplant for a long time.

I think my future's pretty well figured out. But I've been seeing this thing on TV that really bothers me. All these people that have no health insurance and no thought of how it's gonna happen and a lot of people are gonna be dropping off and dying because they just can't see doctors. There should be no reason for it. [...] Let's do what we need to do here for these folks and everybody's got some kind of coverage...

-Zoe, single mother of four children, liver recipient in her mid-forties

This chapter will give more particular attention to the role U.S. health policies can play in the everyday lives of transplant candidates, recipients, and those who care for them. It will examine some of the inconsistencies and gaps in health-related social and public services by drawing connections to on-the-ground realities in the local contexts of patients and caregivers as members of extended networks of kin, neighborhoods, and communities. While some of these issues will have been mentioned in other areas of the dissertation, this chapter will provide a more in-depth and concentrated focus, out of which more concrete implications and policy recommendations can be developed in the final chapter's conclusions.

I will begin this chapter with an ethnographic sketch of one participant, Zoe, whose own and family's lives became entwined with a fragmented network of policy

realities as she became so ill from Hepatitis C and cirrhosis that a liver transplant came to be her only hope for survival. Next, I will examine some of the particular intersections of transplantation with health policy, including a brief history of the development of Medicare's ESRD program. This is in keeping with an underlying premise of this dissertation that a more holistic understanding of transplantation in the U.S must include close attention to the policy matters that create some of the structural conditions for transplant health care service delivery and daily life for candidates, recipients, and those closest to them. I also will include a brief synthesis of some of the historical perspectives on how healthcare has come to be financed in the United States, and why this might be so. The final sections of this chapter will return once again to the current intersections of transplant care with public health policy, in the lives of persons I met through this research, with an eye toward some of the ways in which patients, caregivers, and communities respond to unmet needs in the current moral landscape of transplant-related care.

In their 2006 work, *Poor Families in America's Health Care Crisis*, Angel, Lein, and Henrici argue that:

[A]cademic researchers and public policymakers have not focused sufficiently on the impact of instability and the lack of routines on all aspects of poor families' lives or on the role of poor health and the lack of health care coverage in exacerbating that instability. Ultimately, we see no solution to this major social problem and personal tragedy other than a fully funded, federally mandated, universal system of basic health care coverage. ...[P]iecemeal and partial reforms may be an inevitable first step, but a continuation of the current system that focuses on work solutions and coercive welfare policies will never address the health care coverage problems of the poor.

(Angel, Lein, and Henrici 2006:26-27)

One of the less-examined aspects of transplantation has been the role played by policy, even though it became clear through fieldwork that policy matters greatly in the lives of transplant patients and those closest to them. This chapter therefore marks a modest effort to take up Angel's, Lein's, and Henrici's call to focus more heavily on the intersections of instability, poor health, and lack of health care coverage in the lives of

the nation's most vulnerable. Toward this end, I will begin with an in-depth case study, as told to me by Zoe, a liver transplant recipient.

October, 2008, after 7:30pm

When I first met Zoe, she was in her mid-forties and a single mother of 4 children, 3 of whom currently lived with her. One of the first things I noticed about her (aside from the tattoos covering her arms), was that she seemed to be equal parts soft-hearted and tough-as-nails, simultaneously quick to make a friend and unafraid to call things exactly the way she saw them, unafraid to impart potentially damning information about her life, yet protective of the details. We met during one of the morning outpatient transplant clinic days; it was autumn, and her liver transplant had been in the previous spring. She had been called back to the Transplant Center for some follow-up testing because one of the labs she'd had drawn at her hometown clinic indicated that she needed to be seen by the transplant team (she didn't elaborate further). When we got together again on the evening of the same day we'd first met, we sat and talked in one of the patient education rooms in the Transplant Center. She was staying in the hotel directly connected to the Health System, so she felt this would be a good place to meet.

Over the course of our interview, she told me she didn't really have a job and that her main source of income is Supplemental Security Income (SSI), a federal program for persons with little or no other earnings and who are aged 65 and older, blind, or disabled. But, she said "it's not enough to live on, not at all," and therefore, she supplements her income informally: "[I do] stuff that I get a little money out of." She earned her GED in the nineties, and worked mostly in food services, but she had been forced to quit her job when she was diagnosed with Hepatitis C. Notably, by the time she was diagnosed, she already had become nearly too ill to work, and in any case, did not have access to employer-provided health insurance. Zoe's health care costs now are largely covered through the state's Medicaid program (though, as we shall see, access to this program, too, was a hard-won achievement). She notes,

So I pay \$2 co-pay for prescriptions. Otherwise I'd never be able to make it. I don't know how I'll ever get a real job that takes taxes and stuff because nobody's gonna insure me, you know?

Zoe lives on the second floor of a three-story apartment building. Her apartment is a loft, where space is far from ample; her son's bedroom is in one of the closets. She lives in a small town (populated by "mostly old Swedes," she adds). Her Grandma was a descendent of a Southwest Native American people, but Zoe has not pursued Indian benefits. She grew up in the town in which she currently lives, then moved to a different small town, then another, both in the same rural region of the same state.

She proudly described her four children to me, beginning with her oldest son, who planned to go into the navy in the early summer. Zoe said she feels "it's the best thing he can do because he's guaranteed a future; it's a little scary though..." She added that it might provide him with some needed structure, and will offer both income and retirement benefits. Her next oldest, a young teenaged son, "knows everything; just ask him—he'll tell ya!" She went on, "he's got a girlfriend who wants to text him all the time." Zoe wants him to get a job so that he can learn about money and how to manage it. "He's had a paper route before but I ended up doing half the work for him, so it wasn't really worth it to me. So I come up with jobs for him." She described her third oldest son, who would soon be entering middle school, as doing really well in school; "he has nothing below a C+; he likes to spend all his free time on the computer at school." And finally, her daughter, the youngest and in second grade "always wants to know there will be food wherever she goes; she doesn't like to go anywhere after dark; she likes school. She's late on losing her teeth but is starting to lose her front teeth now." When Zoe described herself, she said, "my friends keep telling me guys like me, but I don't care; my kids are my main focus."

Zoe had been married before but "it wasn't a good thing – he was a drug addict and physically abusive." She is no longer in touch with her ex-husband: "he's festering away someplace in [a small town in a rural part of the state where this study took place]. I wish he'd get better, but we haven't seen him since 2003." Both she and her former husband had used the same drug of choice, methamphetamines; her ex-husband was using when she met him, and their relationship was based largely on their shared drug habits. She told me she ended up using meth for 15-20 years (daily for 15 years).

She'd had her youngest three children with her ex-husband, and these are the three that live at home with her at this time. But, she said, she "got in a bind" when her

oldest child, whom she'd had with a former partner, was 7 years old, and she signed him over to his father rather than allow the state to take him and "[put] him where he knows nobody." He now lives 12 miles away; they talk on the phone every now and again, and she gets to see him regularly. Zoe said she has a very good relationship with her first son's father. He took care of all four of her children (including those who were not biologically his own) when she had her transplant, and she notes, "If I wouldn't have made it, he would have kept them."

When I asked if this had been a possibility, Zoe replied, "It was real close; I had to spend time in a nursing home for awhile." This led us to discuss the MELD (Model for End Stage Liver Disease) scoring system, a key component of liver allocation policy in the U.S. which takes into account a range of variables (based on the results of certain laboratory tests) to assign a numerical value indicating how urgently a patient needs a liver transplant in order to survive. Under this system, transplantable livers go to those individuals on the waiting list who are the most ill and closest to death. Following this rationale, these patients are in the greatest need of a transplant, in comparison to all others on the waiting list. But Zoe felt it didn't make sense that they let people get so sick, but "I guess there aren't enough parts."

In fact, several aspects of Zoe's experiences with illness and her transplant highlighted policies and structures that don't, in fact, make sense when we examine how they impact the daily lives of the persons they ostensibly have been designed to help. Very often, the shortcomings of this nation's system create the most suffering for the most vulnerable. During Zoe's years of methamphetamine use, a friend who gave her all of her tattoos also had Hepatitis C, and the two of them sometimes would get careless with their needles as they injected meth together. She said she also had been a heavy drinker for some years, and suspected that a combination of these behaviors probably led to her contracting Hepatitis C with cirrhosis and eventually needing a liver transplant. But a closer look at Zoe's movement through her illness and transplant process reveal that other structural factors also played a major role in her illness experience, creating crushing obstacles and extreme difficulties. These include health policy paradoxes, which became especially apparent as Zoe struggled quite literally for the survival of both herself and her children.

With the help of her oldest son's father, who took in Zoe and her younger three children when she left her husband, she stopped using methamphetamines and cut herself off from both the people and the lifestyle that had kept her entangled with substance use for so many years ("I basically went to a room and took my boots off and said, 'Don't bother me I'm done!'"). By this time, Zoe already had been able to tell that her health was declining. Yet she was having trouble accessing medical care because she lacked health insurance:

I knew I was sick for several years...but I couldn't get [this state] to [cover my healthcare]. When I filed for SSI in [this state], they said 'Oh you don't really need that...' I went to [a state in the Northwest Region of the U.S.] and got it in 90 days. [This state] has no understanding of what's going on in the world, I guess.

SSI and Medicaid eligibility are in most cases linked; if one qualifies for SSI, one generally also meets the requirements for Medicaid. The state in which Zoe currently lived was among those that use the same rules for determining eligibility for Medicaid as the federal Social Security Administration uses to determine eligibility for SSI. But it does require that persons file a separate application for each program, and it possibly was at this juncture that Zoe's application process broke down. She went on to explain the series of events in greater detail, further highlighting the shortcomings of the fractured system of health care on which so many rely:

I went to a doctor in [a nearby, larger town] because I was tired all time. He said "well you have Hep C," and did a biopsy and found cirrhosis too. So I knew I was sick and that I had to stop working food service because that's what he told me, but nobody told me, "Oh, well, we can treat you." Nobody told me that until I got past the point of being able to be treated. So there's not enough information out there or they're not giving it out to enough people. The information's there but if nobody's ever told you, it doesn't do any good. If they're on that shelf all day long and I don't know it...So I got to the point where there was no hope of treating it. I still got stuck with social services people saying you've got to be on unemployment first [before you can be eligible for other benefits]. And I'm like, "You don't get it - when I go to work, I wear myself out, then I get too tired, then I get sick and then I lose the job. Why are you making me be on unemployment

first? I don't understand it." And they go, "Hep C doesn't stop you from going to work." And I go, "Well, ok, whatever. I guess you know what you're talking about more than I do." I'm just sick and tired, you know? Like I said, it took going to [a state in the U.S. Northwest region] for them to [cover my medical care], and the doctor [there] said, "You're working in a hotel? You're not supposed to be around chemicals! You can make beds if you can handle it."

While in the eyes of those representing the social services system, Zoe appeared *unwilling* to work, she in fact was very willing to work, but simply was unable to meet the specific demands of her particular work environment. Indeed, she was willing to go to great ends in order not only to get care for herself but also to provide for her children. *I went to [the Northwest state] because I was tired of [this state], and I could see things swirling because the job thing. It was like a circle. I used to go out and cut fire wood out of farmers' treelines and stuff, and I'd tell the farmer, I'll clean that up for you if you let me keep the wood and sell it.*

Laura: So you would chop the firewood?

Zoe: Yeah, I knew how to run a chainsaw.

Laura: Even when you were sick?

Zoe: Yeah, you gotta do something to pay them bills.

Since, under the social services-sponsored work program, she was unable to find a job in her own small community (which would have been difficult to do for even the most qualified, educated, healthy, and well-connected), she had been required to start traveling at regular intervals to the next town over to look for work. Indignant at what she saw as the wastefulness of such a regimen, Zoe began to refuse to do this.

They said, "Oh, we gotta cut you off because da-da-da-da," and I say, "Because I don't want to hop in a cab and go to [a larger town several miles away], make you guys dead head two ways, pay for daycare and sit in this stupid little office and get a job over there that I'm gonna have to get toted to?" This is like 60 miles they're talking about every day and I'm going, "This is ridiculous!" Because there was nothing around my area and they said, "We'll take you to [the other town] and you can sit there and go make

applications in [the other town].” Yeah, 60 miles away! And I’ve got no car at this time because my car had blown up. Then I got another broken car that I got cheap and I drove it until the wheels fell off pretty much and traded in the body for a car that worked.

Having been cut off from any consistent source of income, and still unable to secure medical insurance, Zoe decided to pack up her car and her children and move to the Northwest, where a friend of hers had grown up and was returning to his home, and where she had heard there would be better resources available to herself and her children. *And I took [that car] out to [the state in the Northwest]. Took my younger 3 kids and Freddie the poodle. Anything we could fit into that ‘85 Grand Am went with us, and we lived in a tent for awhile. BLM [the federal Bureau of Land Management] has campgrounds all over there for free; [there were] food pantries we could go to all the time. [...] The kids loved it out at the campground - hey we’re camping! I didn’t really think of myself as homeless; we had shelter, we could access food, we had rivers...*

Zoe’s move to the Northwest took place about three years prior to my meeting her. To her understanding, the availability of state-subsidized resources had proven to bring many positive changes: she found a supportive program for parents of divorced children and officially ended her marriage to a man who had been both abusive and a potential undertow back into meth use; she secured SSI and obtained access to health care through the state’s Medicaid program; and at the local Health Services office, she began to be evaluated for a liver transplant.

She had been away for about a year when her father’s death prompted her move back to her home state.

So I packed the kids up and drove back in another car, with a hitch put on it; I got that car from an impound lot for \$300 – it was a good car – and pulled a U-Haul trailer back home.

Once Zoe returned, she was able to maintain the health care coverage she had secured in the Northwest, and continued the transplant evaluation process.

I was on a list from the end of December to the first part of April. The doctors wanted me to go to NA [Narcotics Anonymous], but I didn’t think I needed twelve steps to do what I

wanted to do in the first place, and my primary nor my doctor here [at the Transplant Center] never pushed it. I said, "I'll pee in a cup a couple days of week. Call me at random, I don't care."

Zoe said her time of waiting was very scary and difficult. She tried to continue maintaining a home life for her children, and to cook for them (she expected herself to be able to do so, since much of her previous work had been in food services and she was used to cooking). But she ended up having complications like encephalopathy, common among patients with liver failure, which, as she put it, "makes you looney."

I went to my neighbor's apartment thinking I was at my own place, and they said, "Do you know where you're at?" And I said, "Yeah I'm at home. What are you doing here?" Her neighbors called 911, which brought both an ambulance and the police. It was determined that Zoe had become so sick that she could not remain at home and had to reside in a skilled nursing facility.

She hated this arrangement for a number of reasons. The facility was located 18 miles away from where her children were staying (the boys were staying with her oldest son's father, and her daughter was staying at a friend's house). She also said the conditions were unsanitary, and within 10 days she had to be hospitalized, first back in her home town and then for three weeks at the hospital to which the Transplant Center was connected. She successfully lobbied to be discharged to her home, rather than back to the nursing facility.

But in the meantime, with the intervention of the emergency responders, the child welfare division of the state's social services department had become involved. A case worker visited Zoe's home and determined that her living environment was not fit for her children to come home to. After learning this, during her hospitalization, her mother and brother cleaned the apartment in an effort to present a better case for allowing Zoe's continued physical custody of her children. She recalls with disdain the unfolding of events and the ironies of when and for what reasons she was offered state help (juxtaposed against when and for what reasons she was denied the help she needed):
And then I came to the team meeting. The county attorney declined to press charges [for invading my neighbor's property] because it was a medical issue, and CPS said the

house wasn't livable. But by that time, it was because my mom had come over. I think it was kind of chicken shit of them because they knew I'd already been in the hospital [prior to this] and they weren't willing [at that time] to set me up with some help. It was a medical issue and they were bringing home health over and having them check on me. I sure could have used somebody like a housekeeper or provider kind of person. And then after my transplant they dinked around so long for it [to arrange for some domestic help] that I got somebody that I was gonna get signed up to do it. And they took so long to do that, they decided well you don't need any help now.

Zoe went on to explain how tight her finances now are, relying on the SSI program for income, which is directly linked to her maintenance of Medicaid, and juxtaposed against the expenses associated with her own medical needs and the daily needs of her children. For her post-transplant regimen, she currently has to take 12 drugs daily, for which her monthly co-pay expense is \$25. Alone, \$25 may not seem to be an overwhelming cost, but it takes on new meaning when placed in the context of Zoe's larger circumstances:

My co-pay is \$25 a month. Twenty-five dollars could make a little bit of difference on something, I don't know, like half a tank of gas for my car or a pair of shoes for my kids. So it adds up, you figure \$300 a year on co-pays. As long as I'm drawing a dollar of SSI, I can be on Medicaid. (Laura: And that's what would drop off if your income went up?) Right, I could make \$65 - this is messed up, this is really messed up - I could make \$65 before they start taking, for every \$2 I would make, they would take \$1 of it away. [...] If 75 cents could drop you off [of public assistance], it's just too cut and dry. Right, that 35 cents over might be just because you got an extra 15 minutes this week [at your job] that you won't get the rest of the time. [...]

I'm allowed to make \$65 a month reported income. I can see if they gave a higher amount as supplemental, but it makes no sense. There is no way you can raise kids on \$637, plus their \$364 because their dad doesn't pay child support. He's ordered that he owes me for a couple of years now. That's why I was out cutting firewood; that's why I do the things I do. (Laura: You had a transportation service to come here [today to the Transplant Center for your appointment]?) Yeah, my car won't go out of town because

my car is a piece of crap, and that's another thing. [This state], if you're on an employment program, they will fix your car unless it costs more than the value of it to fix. And then if you work someplace for 30 days, like 30 hours a week, then they will put \$2000 towards a car for you, but on a medical issue, they're willing to pay that transport. I tell you what, the transport costs \$500 every time they send me on it, right? Ok, put \$500 into my car, and don't be buying the transport next time! And they will not help you get a car and get your car repaired if you're not in an employment program. But they'll pay \$500 for that damn [medical] transport.

The paradoxes created at the intersections between public support policies and Zoe's daily lived experiences are myriad. When she applied for income assistance and Medicaid, Zoe was told she first needed to participate in the state's employment program. But had she been able to access more reliable medical care in the first place, she might very well have stayed healthier and been able to maintain full-time employment for a much longer period of time. Had she been given access to help with housekeeping after her first hospitalization, she might have been able to provide a more "fit" environment for her children to live in; procedures for getting this kind of help were put in place only after her transplant, and by then, her health had begun to improve to the point that she no longer required as much help as she had when she was at her most ill.

Under the employment program, the state was willing to pay for car repairs up to the value of one's car, but Zoe's car was worth only a few hundred dollars, and the repairs would have been much more costly. The state would provide \$2000 for a replacement car for persons on public assistance who had worked 30 hours a week for 30 days, but without a reliable car, it was difficult to find such employment. What's more, Zoe could not understand the rationale of being made to arrange for child care and be shuttled to a town 60 miles away, to fill out applications for jobs which she would be too ill to maintain, in any case. And ironically, the state would pay for transport services when transportation was needed for a medical issue – at a cost of \$500 each time, in Zoe's case – but would not apply that \$500 toward a reliable car that Zoe could drive herself.

Though Zoe now receives supplemental income, it is not nearly enough to provide

for the needs of her children. She has the very legitimate fear that, if she lost eligibility for her supplemental income, her eligibility for Medicaid would soon follow. This is untenable. As a single mother with only a GED diploma, it is unlikely that Zoe would be able to find a job in her rural area that would both pay enough to provide for her family's needs and offer employer-provided health benefits. Moreover, under the U.S. system of health insurance as it stood at the time of our interview, with pre-existing conditions restrictions and lifetime benefits limits, Zoe's medical history and current needs left her all but uninsurable on the independent market for health coverage. In light of these circumstances, borne out of a deeply flawed and fragmented social safety net (including what Angel, Lein, and Henrici (2006:53) have called a "tattered health care safety net for poor Americans"), she honors her obligations toward her dependents as best she can, chopping and selling firewood here, and doing other things that "get her a little money" there.

A New Direction?

Notes from the field: Monday, March 22, 2010

The radio alarm clock began this day with a flurry of news stories about the passage of a bill in two subsequent votes by the House of Representatives. With the enactment of health care reform under the 2010 Patient Protection and Affordable Care Act, some important changes will unfold over the coming months and years. The bill should extend health care coverage to more than 30 million uninsured persons in the United States, so that upon the full implementation of this legislation, about 95 percent of U.S. citizens will have health insurance. Within this next week, the Senate is projected to vote on (and likely pass) a set of resolutions made by the House.

Historically in the U.S., health care has been treated not as a basic human right, but largely as a privilege to be accessed through employment. Even retirement health benefits through Medicare can only be accessed if one has met the work requirements. Or, if you fit the criteria for some forms of disability and are unable to work, or if you fall below a very low income level and have dependent children, you might be granted – but certainly not guaranteed – dubious coverage. That the newly expanded coverage under the 2010 Patient Protection and Affordable Care Act is only reserved for U.S. citizens

underscores some of the serious inequalities, weaknesses and concessions that will persist even under this legislation. But that it likely will pass at all marks a notable achievement and a large step toward addressing at least some of the most egregious abuses of the current system

Those who had opposed this legislation predicted that if it passed, there would be grave consequences for individuals and for the nation as a whole. Apocalyptic predictions have been characteristic of those who opposed health care reform from the time this most recent national conversation initially ramped up with town hall meetings the previous summer. But I cannot help but think of the many people with whom I've spoken throughout this study, whose lives would surely have been made less complicated and less stressful if they hadn't needed to worry about being dropped from their insurance policies because they were not well enough to continue working or attending college classes full-time, or because they had exceeded the maximum amount their insurers were contractually obligated to cover (even in cases where it was a series of medical errors which had led to exceedingly costly complications in the first place, as was the experience of Mary and Rob). A number of participants had remarked that they would be uninsurable even if they would eventually become well enough to move off of Social Security Disability and seek full-time employment, and like Zoe, found themselves having to choose the assurance of medical coverage over the stability of a higher income.

The 2010 Patient Protection and Affordable Care Act

According to a document prepared in April 2010 by the U.S. House of Representatives Committees on Ways & Means, Energy & Commerce, and Education & Labor, with the passage in 2010 of the "Patient Protection and Affordable Care Act," by 2014, 32 million currently uninsured Americans will have access to health insurance coverage. This will be accomplished through a variety of avenues: Medicaid programs will be expanded to those earning up to 133% of the federal poverty level (in 2010, this figure is \$29,326.50 in annual income for a family of four in states other than Alaska and Hawaii²⁹); tax incentives will encourage more small businesses to offer health insurance to their employees; and individuals who do not receive health insurance through other

²⁹ <https://www.cms.gov/MedicaidEligibility/downloads/POV10Combo.pdf>

avenues will be required to purchase health insurance privately (or face financial penalties that will increase each year). To offset this last requirement, lower-cost plans will be offered through Health Insurance Exchanges, and tax credits will be issued for those making incomes above the Medicaid thresholds but below 400% of the federal poverty level. Importantly, some of the most reprehensible barriers to accessing health care coverage will be lifted. For example, insurance companies will no longer be allowed to deny coverage for pre-existing conditions, nor to drop persons from their insurance rolls when they become sick, nor to impose lifetime caps on coverage amounts, and will not be allowed to charge higher premiums based on health status, gender, or other factors. Higher premiums can only be charged based on geography, family size, or tobacco use, and the ratio of highest to lowest premiums on providers' different plans cannot exceed 3 to 1. (<http://docs.house.gov/energycommerce/TIMELINE.pdf>)

Further, as The Henry J. Kaiser Family Foundation "Focus on Health Reform" series describes, under the Community Living Assistance Services and Supports national insurance program (referred to as the "CLASS-Act"), individuals will have the voluntary option to purchase insurance which they could use if they became disabled and required long-term care and support. This program would pay out to its beneficiaries a cash benefit that can be used to purchase non-medical services and supports that they could use *either* for institutional care, such as in a nursing home, *or* for home-based, community living (including "home health care, adult day care, assistive technology, home modifications, personal assistance services, respite care, accessible transportation and homemaker services") (The Henry J. Kaiser Family Foundation "Focus on Health Reform" 2010a). Home-based community care also will be supported in a new state Medicaid program, known as the "Community First Choice Option," which will make non-medical services and spending (excluding room and board, assistive technology devices, medical supplies and equipment, home modifications, and vocational rehabilitation) available to individuals making incomes up to 300% of Supplemental Security Income guidelines (which amounted to \$2,022 per month in 2010) (The Henry J. Kaiser Family Foundation "Focus on Health Reform" 2010b).

The Intersections of Transplantation and Healthcare Financing Policy

As my fieldnotes indexed above, several of these changes will directly improve the lives of the patients and their families with whom I spoke during fieldwork – including Zoe. Persons who become sick are at their most vulnerable and in highest need of health insurance coverage, yet the business models of some of the nation’s largest insurance companies counter-intuitively prescribed denials of coverage in these instances. Transplant surgeries themselves are extremely costly, and any subsequent hospitalizations for complications, infections, or rejection episodes can quickly bring patients up to the lifetime cap limits on their private insurance policies. Due to pre-existing conditions clauses on many policies, a loss of insurance coverage (which often accompanies the loss of a job due to a person’s illness limiting their ability to work) can be devastating because the initial illnesses which precipitated the transplant in the first place often prevent patients from being able to find other private insurance. Even those transplant patients who recover fully and become well enough to work again find themselves reluctant to give up, for example, any disability insurance benefits they might have had, knowing that there could be a limited range of employers who carry policies that would accept them. And many expressed to me their worry that, even if they were able to find a private insurance policy that would cover them after their transplant, they would be unable to afford the grossly inflated premiums they, as a “high risk” policyholder, would be required to pay.

The new health care reforms also will improve the lives of transplant patients and their families, since home-based care will likely be better supported. Under the Medicaid “Community First Choice Option,” Zoe may have found it easier to remain in her home (rather than have to go to a nursing home which she felt offered substandard care). Likewise, she might have had easier access to housekeeping services (thus avoiding the deterioration of her home conditions to the point that it was deemed an unfit environment for her children).

In addition, more people likely will receive better and more consistent care earlier in their course of illness and organ failure, and are likely to have access to transplantation (Axelrod, Millman and Abecassis 2010a). Zoe, for example, very likely might have been able to stay healthier, continue working longer, and postpone a liver transplant in the first place if she had received more consistent and reliable care (in which she likely would

have had treatment for her Hepatitis C). Under the reformed system, beginning in 2014, coverage will be extended to millions of currently uninsured individuals. This will be accomplished through new requirements for individuals to carry health insurance or pay progressive fines. Individuals will have a range of options for securing their healthcare coverage, doing so either through their employers (and businesses employing more than 50 employees now will be required to offer health insurance or face fines of \$2000 per full-time worker over 30 employee), by purchasing a policy through state health insurance exchanges, or through their state's Medicaid programs (which will be extended to those whose incomes are below 133% of the federal poverty level).

For years, transplantation has been held up as a classic case of the type of high-tech, high-cost medical intervention that benefits very few but is expected to be included in health financing systems (see, for example, Schuck's 1989 article in the *Journal of Health Politics, Policy and Law*, which is critical of governmental financing for organ transplants). These issues also are the subject of fierce recent debate in states like Arizona, which at the time of this writing has decided to cut certain types of transplantation from among the procedures the state's Medicaid program will finance (Lacey 2010 a,b). Transplantation is a lifelong commitment in which recipients have to take powerful drugs to prevent organ rejection, follow complicated medical regimens, and continue to return for ongoing follow-up medical care. The full costs associated with the procedure and post-transplant regimen would be essentially impossible for all but the very wealthiest private individuals to meet on an out-of-pocket basis. This makes cuts such as those being made in Arizona an enormous social justice concern, since it specifically would prevent the state's poorest individuals from being able to access certain transplants.

“...the day your bill came...”

Even while patients with healthcare coverage generally are not directly exposed to the full financial costs of transplantation, many are well aware of the running totals in their medical care. Eliza, the adult daughter (in her mid-thirties) of Hank (in his sixties) who had received a liver transplant and now was in need of a kidney transplant, discussed the experience of seeing just one portion of the medical bills her father incurred during

his first transplant. Though Hank received various forms of care support from each member of his immediate family, including his wife, his daughter Eliza had become his primary advocate, care coordinator, and caregiver so that the family matriarch and Eliza's brothers (who lived in the same small town) could continue to operate the family's small garbage service business. As a self-employed small business owner, Hank was at the mercy of the private individual insurance market, and did not enjoy the protections (e.g., from pre-existing conditions clauses) offered by large employer group-based coverage. As I spoke with both daughter and father together, our conversation turned to their consideration of the financial costs of transplant, which Eliza also weighed alongside the fact that the transplant allowed her to "have that family member with you that might otherwise not have been." Eliza turned to her father and said,

I remember being at home the day your bill came, like your first bill. And it was in a big yellow manila envelope and it was 48 pages. And it wasn't everything, it was just the initial, like, here's your first bill. And it was 48 pages long! And I just remember thinking, Oh my God. And you know at the time, you had what, a half a million dollar policy? (Hank: 250 thousand. It took all that, plus). And you know it's gone, and here you sat, where you had a major transplant and nobody will even touch you. Nobody wants to insure you. They look at you like, uh, have you ever heard of pre-existing conditions? And so then you sit and you... So it totally it changes everything. It changes your financial, it changes your lifestyle, too, because it gives you a whole new look on life because you appreciate every single day because you have them there. You have that family member with you that might otherwise not have been. But...

Lack of insurance, therefore, currently can rule out the possibility of having a transplant. An inability to pay for the transplant and post-transplant maintenance therapies can be considered by interdisciplinary medical teams to be an excluding factor for individuals who otherwise would qualify for the procedure. This has the effect of barring the uninsured from having access to this type of treatment. In my own professional training experiences as a social work student, and from several observations made during fieldwork, I witnessed the diligent work performed by transplant social workers and their colleagues (especially financial counselors) together in an effort to help

patients and families find and maintain health care coverage. Social workers thus often find themselves on the front lines of battling for more equitable access to the procedure. But, as we shall see, the number of tools available are much greater for renal transplant than for all others (if Zoe had had renal failure instead of liver failure, she likely would not have struggled as much for access to medical care). Only one type, renal transplantation, enjoys automatic coverage under the Medicare End-Stage Renal Disease (ESRD) program. According to Fox and Swazey 1978 [1974]), renal transplant gained this special status as a result of a number of factors, including successful lobbying campaigns, the visibility and growing number of dialysis patients, the relative success of kidney transplantation, and a desire on the part of the federal government to demonstrate support for new life-saving technologies. The following section begins with a fuller description of the events leading to the creation and evolution of the Medicare ESRD program, but ends with a suggestion that this program grew out of a context in which health and health care enjoyed not only a different political status, but also perhaps a different moral status than what currently exists today.

The Medicare ESRD Program – A Brief History of A Major Intersection of Transplantation with Public Health Policy

When the Medicare program was first signed into law in 1965, it did not yet include an “ESRD” component. A nephrologist, once president of the National Kidney Foundation (NKF), and key player in getting Public Law 92-603 passed and signed by a reluctant President Nixon, Dr. George E. Schreiner offers in a 2000 article in the *American Journal of Kidney Diseases* a detailed and personal account of how the Medicare ESRD program developed. In it, like Fox and Swazey (1978[1974]), Schreiner (2000) describes the coming together of several factors involving developments in medical knowledge and technologies, growing awareness of the availability of new and promising forms of treatment, a growing population of persons with ESRD, and political mobilization at local, state, and national levels. Beginning with the first successful dialysis of a human in 1924, and then the creation of an “artificial kidney” (an early prototype of the dialysis machine) in 1946 and further innovations in the following decades, by the 1960s, dialysis had become a promising and life-saving technology.

Yet cost and geographical availability greatly limited access to an unacceptably small portion of those experiencing uremia (the medical term for what legislatively and otherwise came to be called “end stage renal disease.”) As Schreiner notes,

Ferment for national legislation began as soon as it was apparent that state, local, and private programs differed markedly in scope, eligibility, criteria for selection, support for facilities and patients, and for overall expenditures per region, per patient, per family or per taxpayer: however you wanted to manipulate the numbers. [...] Uremic humans were already migrating from state to state and from country to country...shopping for survival. (Schreiner 2000: Paragraph 11)

As media and other public outcry increased, and after the convening of two separate committees of experts in the mid-1960s, the introduction of more than 100 different bills in Congress, several testimonies given before Congress, and strong advocacy associates at the National Kidney Foundation and other advocates, legislative support grew for a national approach to what Schreiner (2000) calls “the ESRD problem.”

Momentum was growing. In a companion article to Schreiner’s, Charles Plante noted that a 1968 planning session of what he called the “Nephrology ‘high command’” in Washington, D.C. had prompted a piecemeal expansion of support for kidney disease care within various federal programs (through the Vocational Rehabilitation Act, the Regional Medical Program Service, the Crippled Children’s Act, the Chronic Disease Control Program, the National Institutes of Health, and the Veterans Administration) (Plante 2000: Paragraph 12). But “[p]aradoxically, it was the inadequacies and inherent unfairness of the amended programs that prompted many legislators to look for alternative solutions” (Plante 2000: Paragraph 13). Schreiner, Plante, and others lobbying for a universal national approach also were very adamant that the solution which passed should not be dependent upon annual appropriations and budget disputes, since persons with ESRD generally cannot live more than a couple of days without regular dialysis treatment. As Schreiner notes,

The thought of returning to Congress every 2 years when procrastination in the budget process was leading to whole agencies being shut down or running on continuing resolutions, was a frightening prospect to us as it would be annually for the patients. (Schreiner 2000: paragraph 25)

To prevent this from happening, they agreed on a tactic to propose an amendment to the Social Security Act that would redefine disability (which had been defined as an inability to work for 6 months) to include uremia (since a disabled ESRD patient would die in 6 months without dialysis or a transplant) (Plante 2000). And in 1972, despite the oppositions of many powerful players, [including then President Nixon, the Secretary of Health, Education, and Welfare (now Health and Human Services), the Director of the National Institutes of Health, the Director of the National Heart Institute and its head of kidney research) (Schreiner 2000: Paragraph 28)] the Medicare end-stage-renal-disease (ESRD) program, Public law 92-603 was enacted, creating universal coverage (for dialysis and/or transplant) for ESRD patients.

The initial commitment was to cover the costs associated with dialysis, but when kidney transplantation came to be viewed as a lower-cost therapy with better long-term results, Medicare coverage was extended to transplants as well (see Schuck 1989). In his companion article to Schreiner's, Plante (2000) notes that the state-by-state National Campaign for a Uniform Anatomical Gift Act was instrumental in the addition of transplantation. He suggests that it increased public awareness of the role and potential benefits of organ transplantation, and in turn translated into support among legislators, effectively securing a place for kidney transplantation as a component of universal coverage for ESRD (Plante 2000).

The Medicare ESRD Program Today

Various other changes have been made to the Medicare ESRD program over subsequent decades to reduce or control costs. For example, in the 1980s, Congress enacted the Medicare Secondary Payer provisions, which mandates that, if a patient already has private insurance, the private insurer must be the primary payer for a 30-month "Coordination Period." At the time I was collecting data for this study, there was a one-time, three-month waiting period to become Medicare-eligible for dialysis therapy. In the meantime, a patient is expected to pay for the costs of their treatment through private insurance, a Medigap (Medicare Supplement Insurance) policy, a state Medicaid program, Veteran's Affairs, or out of pocket, depending upon a patient's individual circumstances. Other state health and kidney programs also can sometimes offer some

assistance. This waiting period is waived if a patient agrees to participate in a home dialysis training program and to do home-based dialysis regularly for the first four months.³⁰ (U.S. Department of Health & Human Services, Centers for Medicare & Medicaid Services: “Medicare Coverage of Kidney Dialysis and Kidney Transplant Services”)

However, while coverage for dialysis requires a three-month wait, there is no waiting period to be eligible under Medicare for transplant therapy, and coverage extends to the last day of the thirty-sixth month after a transplant surgery (and this coverage would be extended in case of the need for a subsequent transplant or if the patient needed to go back on dialysis) (Ehlers 2002:286). As mentioned earlier, patients who are not eligible for Medicare sometimes qualify for Medicaid coverage; however, not all states include organ transplantation as being among the “basic services” they are required to provide (Ehlers 2002:286). And some while some states in the past did cover transplantation under Medicaid, those like Arizona (whose state Medicaid program is titled, “The Arizona Health Care Cost Containment System”), in the face of large budget deficits, are cutting certain types of transplants out of their lists of covered procedures (Lacey 2010a,b).

Commercial and private insurance often do play a role in paying for transplantation.³¹ However, that coverage can be very tenuous if a patient loses his or her job over the course of their illness, and if a spouse does not or cannot provide coverage through an employer-based plan (this may be the case especially if their caregiving responsibilities prevent them from being able to work full-time, or if they themselves are ill, or if their employer simply does not offer health insurance). Under pre-existing conditions clauses (which existed at the time of data collection, but which will be eliminated as that portion of the 2010 Patient Protection and Affordable Care Act goes into effect), transplant patients often found it extremely difficult if not impossible to acquire replacement private insurance if they lost their insurance due to a change in employment status. Losing one’s ability to pay for the expensive immunosuppressive

³⁰ In Chapter II, I described some of the unique challenges to home-based peritoneal dialysis.

³¹ HMOs and managed care organizations have various payment strategies (such as capitation plans that pay providers a set fee per plan member; reimbursement at a global rate; case rate reimbursement; per diem payment, etc.) and requirements (such as precertification requirements) (Ehlers 2002:287-288)

medications, the cost of which can range from \$13,000 to \$25,000 each year (Axelrod, Millman and Abecassis 2010b), and without which the organ or tissue graft will not survive, can threaten the success of the transplant and the life of the patient.

More changes to Medicare and its ESRD program surely will come with the new Health Care Reforms described earlier in this chapter. For example, new provisions have been designed to close the Medicare “donut hole” which currently requires beneficiaries to pay 100% of their annual prescription costs once their total costs have reached \$2251, and until their total reaches \$5100 in costs. Under the new regulations, by 2020 Medicare will pay 75% of generic drug expenses, and will require manufacturers to discount by 50% the costs of brand-name prescriptions while beneficiaries are in the ‘donut hole’ coverage gap. And, given that more patients already will have some form of health insurance, existing wait times for Medicare ESRD coverage likely will be problematic for fewer individuals. (Axelrod, Millman and Abecassis 2010b)

Holding Together a House of Cards

Access is likely to be improved for those needing medical care for non-kidney related organ failure. This would mark a step toward closing a major hole in the existing health care “safety net.” Currently, an uninsured individual who can’t work yet doesn’t qualify for Medicaid *may* be granted access to health coverage through Medicare under the Social Security Disability program. The criteria for this, however, are stringent, and the application process is long and onerous, requiring, among other documentation, a doctor’s written opinion about a patient’s ability (or inability, as the case would be) to work. And there are no guaranteed outcomes; a patient’s application can be denied for any number of reasons, not the least of which could be a simple typographical error. Even if a person is granted “disability” status, they must recertify their status on a regular basis, requiring more paperwork and more risk of losing coverage over small changes in health status or application errors.

Thus, U.S. health care coverage for the sick might be likened to a house of cards; it is fragile, subject to forces over which one has little control, and “holding it together” can require intensive amounts of careful, concentrated attention to managing several unfixed parts. Even for those who enjoy full or even overlapping insurance coverage for

their health care costs, it can be extremely complex, confusing, and difficult to properly and successfully navigate all of the regulations, caveats, and bureaucracy-laden pathways created in the context of such a fragmented system of health care financing as currently exists. Some of the more fortunate patients with whom I spoke cited as a major source of support the help they received from a family member or a close friend in sorting through the myriad of paperwork.

Annette, for example, was lucky enough not only to have full private and Medicare (disability) insurance coverage of her autologous blood-forming stem cell transplant, but also to have a sister, Roberta, who once had worked in medical billing as a career. During our first interview, Annette had spoken of the tremendous relief Roberta provided in this arena, and I followed-up with Roberta in a subsequent interview. Roberta said she herself felt “blessed” that she was able to help:

The one thing I was blessed about was, I also did billing when I worked at the county. So I told Annette, “Do not look at your bills. Do not look at them! What I want you to do with them is, put them in a shoebox. Don’t look at them, don’t even worry about them. It’s all going to be taken care of. And I want you to wait six months, and I mean six months before you even wait to open them and look at those final bills, because by the time Medicare pays what they pay, and your insurance pays what they pay, before you owe the [Transplant Center] or whoever, it’s gonna take ‘em six months at least, and it’s not anything you can worry about.” And it’s really funny: she brought me over a whole shoebox full of bills and I said, “Great, it’s no problem. This is what you owe the [Transplant Center], this is what you owe Dr. Smith, and this is what you owe Dr. ‘So-and-So.’” And she was like, “How did you do that?” And I said, “By the time everybody does their stuff, it’s six months. And if you look at those bills and stress about them and worry about how you’re gonna pay \$250,000 or whatever that hospital bill was, you’re gonna go crazy. So let the insurance companies do their jobs, and then once you start getting those bills that say insurance has paid, you owe, then we’ll go through and make sure that they billed everything.” So, and I tell people that because that’s how long things take. It doesn’t usually take six months but something like that, stem cell and the insurance and the Medicare and all, everything, if you want to send them \$20 every month until this is settled, but I said it really takes a long time. [...] So then we went

through the bills and what she had paid, what she had to pay. And she said, “I don’t know what I would have done if you hadn’t have done this.” But you just have to wait and make sure that they bill everything. And they do, you know, but they bill Medicare, and then they send that to the insurance, and she was in there 30 days, I’ll bet. And you know, every different doctor bills, and yes, it’s all through the [health] center, the medical associates or whatever that is, that is billing her, but that poor girl or guy you know has pages of them! So you just have to make sure that everybody got billed for everything.

Having access to a resident “expert” on medical billing, however, was the exception, and not the norm. Some care partners, like Tamara, who was the wife and full time care partner to her husband Edward as they prepared for her to become his living kidney donor, was able also to devote herself to the time-intensive tasks of managing his insurance paperwork and bills. She noted that she had become very good at taking care of these matters, and was glad to have been able to lift some of these responsibilities from Edward’s shoulders. Most patients and their loved ones, though, simply muddled through the bureaucratic aspects of insurance coverage as best they could. Limited as many of them were, however, by time or by knowledge and expertise on insurance and billing matters, oversights could prove to be costly. Hank and Eliza described their ongoing dealings with insurance and other financial aspects of Hank’s transplant care:

Hank: *I still make payments to the hospital. I’ve spent a lot of money for medicines and all the way through, but we seem to make it somehow.*

Eliza: *Now...he’s [recently] been able to get onto Medicare for disability. And we just recently, we wish we would have known this sooner – a lot of times it’s our own fault because we didn’t research things but a lot of times it’s, insurance is very confusing and they don’t give you a lot of help unless you actually go to somebody that specializes in it – but we just found out that the [Medicare] Part D does cover some of his medicine. So he has been able to get onto that.*

Hank: *Blue Cross Blue Shield just signed me up for a supplementary policy that will help Medicare, that whatever they [Medicare] don’t pay, they’re [the Blue Cross Blue Shield Supplemental Policy] supposed to pick up. It’s kind of expensive, but it’s gonna be less*

than what heart surgery and transplant will be. So we got hooked up with that May 1st, just in time to maybe do [cover] some of this [the medical care and prescriptions they anticipate for his next prospective transplant].

Significantly, while Hank, Eliza, and many others with whom I spoke about these issues might have bemoaned their dealings with insurance matters, persons tended often to consider it their own personal responsibility to properly navigate the system. Eliza was not alone in attributing mistakes that were made (in their case, a failure to realize that they could have gotten coverage for some of Hank's medications through Medicare Part D), to a failure on their part to sufficiently do their research or ask the right questions. And those who were better able to manage the system because of special expertise or extra time to devote to it (such as Annette and Roberta, and Tamara and Edward, above) felt fortunate and blessed to be in this exceptional position. In other words, access to healthcare and adequate coverage for healthcare (and the ability to manage the tenuous nature of that coverage) was very often seen as a problem at the individual, personal level – even by those who were suffering under the current system. For example, Zoe's insights and thoughtful comments about the larger structural obstacles she faced were actually quite exceptional among the participants in this study. Yet, when I asked her directly what she felt had been the main obstacles she has faced throughout her illness and transplant process, even Zoe momentarily turned the conversation back to her own personal level of responsibility:

Laura: *What have been the main obstacles you've experienced along the way?*

Zoe: *None of them seem like obstacles. Things were arranged for my kids. None of it seemed insurmountable. The hardest part (said with a laugh) was letting them get that IV on me!*

All of this stands in marked contrast to the understandings of poor Egyptian dialysis patients, documented by Hamdy (2008), who widely drew larger connections between their own individual struggles and widespread social injustices created in the wake of the failed Egyptian state: toxins in the environment, unreliable services, and substandard medical care for the poor. Taking her cues from patients and their loved ones who rely for their care on state-run dialysis wards, Hamdy points to the “political

etiologies” of illness. She perceptively argues that:

[T]he ways in which people make sense of illness are inevitably political moves that either ignore or speak to power...our views of our bodies and our views of sociopolitical distribution of resources are mutually constitutive. (Hamdy 2008:563)

While this chapter has not focused on patients’ explanations for why they are ill, the comparison to Hamdy’s findings does throw into greater relief the tendency among many of the persons I met to focus on the micro- rather than the macro- etiologies of their own challenges in working within the current structure of health care service and financing in the U.S. And the relative paucity of overt critiques of the *system itself* among study participants suggests that the way things *are* seems practically to be part of the natural order of things, pointing to the hegemony of the system as it currently stands. As the following section describes, however, the persistent state of the U.S. system is the product of historical factors.

Fragmented Network of Health Care Policy – Historical Perspectives and Persistent Problems

In a chapter on the “American Style” of setting health services priorities, Clancy and Danis (2000) characterize the U.S. health system as disjointed, with the population relying on piecemeal health coverage through a combination of public (federal, state, and local governmental) and private (both individual and employer-based) financing. Such a disjointed system, as we already have seen, leaves many people vulnerable to falling through its cracks, and a recent U.S. Census Bureau report (“Income, Poverty, and Health Insurance Coverage in the United States”) indicated that 16.7% of Americans (50.7 million) had no health insurance in 2009. Various scholars have turned to historical analyses in order to understand the roots of such a fragmented system.

For example, in exploring the question of *why* the U.S. still lacks a formal, universal system of health insurance, Quadagno (2005) argues that physicians drew upon their cultural authority and hegemony to mobilize under the American Medical Association (AMA) to defeat some of the earliest efforts to enact comprehensive national

health care coverage (e.g., from the Theodore Roosevelt's efforts beginning in 1912, to Truman's proposals in the late 1940s, and Medicare in the 1960's). Likewise, in their analyses, Posner, Gild, and Winans (1995) and Lotto (1998) support the idea that physicians and those at the top of a longstanding hierarchy among those professionally involved in healthcare have historically leveraged their ability to influence policy-related matters. And, Quadagno asserts, subsequent efforts were consistently blocked by organizations and alliances among various special interest groups, who fought the development of national health care coverage each time the issue came up. Quadagno (2005) argues that four other often-cited reasons for a lack of national health coverage – 1) anti-state values, 2) a weak labor movement, 3) racial politics, which, she notes, leads to disparities in the current employment-based coverage system, and 4) the effect of the American political institutions and the legacies of past policy decisions – can only partially explain why there is no national health insurance. She writes, "...[there is] only one historical constant across every case, namely, that each attempt to guarantee universal coverage has been resisted by powerful special interests who have used every weapon on hand to keep the financing of health services a private endeavor" (Quadagno 2005:205).

Using the comparative example of Canada, which does have national health care coverage, Boychuk (2008) argues that the U.S.'s history of racial politics actually was a key element in explaining the lack of U.S. national health insurance. The defining difference between public health care policy in these otherwise very comparable nation states is that, while "territorial politics of language and region" are prevalent in Canada, racism and the issue of race have permeated American politics (2008:xv). He notes:

The failure to include national health insurance in the New Deal pushed federal health insurance reform into a period where it became deeply entangled with the issue of civil rights. As the federal government became more clearly committed to desegregation after 1945, federal intervention in virtually any policy area could be construed as a potential challenge to the racial status quo, and the specific federal approach to health insurance reform in this period exacerbated these fears. In this context progress on national public health insurance met powerful resistance. (Boychuk, 2008:185)

And though race was less prominent an issue during the national healthcare debate of the Clinton years, Boychuk argues that race politics shaped the interactions between health care reforms, crime control, and welfare reform in the 1990s, asserting,

The intersection between the politics of race and the politics of health reform helps explain why health reform shared company with these two other policy planks, why it proceeded as far as it did, and ultimately, why it failed. (2008:186).

Caplan (1989), too, takes a historical perspective, highlighting trends in the struggle for power among different professional organizations within healthcare to explain the growing tendency toward profit-driven health care. However, using primarily archival evidence and a Marxian theoretical framework, Caplan (1989) argues that the commodification of health care in the U.S. is not new, and rather must be understood in the historical context of successful efforts by physicians (again, via the AMA), hospital administrators, and pharmacists to bring health care out of the domestic, lay realm and into the realm of formal, professional care (cf Abel 2000). What is recent, Caplan asserts, is the degree to which health care has become a *corporatized*, for-profit enterprise. This, ironically, is having the effect of pushing a great deal of health care back into the lay, informal, domestic realm.

Policy and Health Care in the Contexts of Gender, Class, and Race

A study by Silverstein and Parrot (2001) used a random national sample of 1,559 adults who had participated in the AARP's "New Roles on Society Survey on Intergenerational Linkages" to study public attitudes toward public policies designed to provide aid to informal caregivers. The authors (2001:369) found that the women in their study were more supportive than men for such policies, and linked this to the fact that informal caregivers are most often women, and that this group would most stand to benefit from policies designed to aid caregivers. While Silverstein and Parrott (2001) advocate for public policy that offers support for (even as it maintains) the status quo of informal, private in-home caregiving, their conclusions stand in contrast to the ideas put forth in 1985 by Nelson, who strongly advocated for a shift in caregiving responsibilities out of the private household realm and into the realm of collective, community-based

provision of all types of care. Nelson (1985:64) identifies her goals as part of “a feminist strategy to shape state responses to women’s changing economic position in the short term, in a way which does not strengthen traditional gender roles and which lays a basis for further change.” She also argues that current state policies conflate the concept of caring *about* with that of caring *for* someone, the problematic assumption being that emotionally caring about someone must translate naturally into responsibilities for caring for their physical and other needs. Nelson (1985) insists that feminist strategies surrounding caregiving must work to separate these two concepts.

Notably, my own field observations suggest that caring *about* and caring *for* are indeed also merged in dominant mainstream assumptions among patients and caregivers about the moral obligations of kinship. Emotion does seem to play a significant role in this conflation. Further, an expanded notion of care considers the caring-about aspects of care to be *included among* the caring-for aspects of caregiving, so that “caregiving” legitimately encompasses both the most obvious forms of care (i.e., tending to a person’s physical needs), as well as the more hidden forms of care (i.e., trying to shield a loved one from emotional turmoil). However, my field observations *also* indicate that, far from there being a given, “natural” translation of one into the other, this merging takes place over time, through the daily *social practices* of kinship.

In the context of my fieldwork, the most reliable caregiving scenarios indeed seemed to be ones in which the lay care provider (whether male or female) both cared *for* and *about* the transplant patient *and* had the capacity to perform this care (especially regarding their own employment arrangements). But this also is likely interconnected with the policy structure within which patients and caregivers were operating to begin with. Here, then, the reciprocal obligations of kin relations intersect with codified regulations concerning the production and maintenance of health. It also is important to keep in mind the notion, also argued elsewhere in this dissertation, that patients, too, act as caregivers to their loved ones [and likewise both care *for* and *about* those close to them]. For example, one of the reasons Zoe faced challenges in finding someone to care for *her* outside of the hospital was that she herself had long been the person in her kin and social network to whom people would turn when they needed help. She explained: *It was great that people would help out, but it was really, really, really hard to ask them*

because I'm the go-to. I'm the fixer. I'm the one people go to with, "Man, I don't know what I'm gonna do." And then I had to turn around and say the same thing. I was always the one who pulled it out of my butt, you know, and fixed it for everybody else.

Additionally, Zoe relied heavily on both men and women – and was turned down as well by both men and women – as illness, transplant, and her post-transplant needs compelled her to draw upon a network of care support. This came to light when I asked how she knew who she did and didn't feel comfortable approaching for help. Zoe said her mother came with her to the hospital when it was time for her transplant, and stayed with her during her 10 days as an inpatient and six weeks in the Transplant Center hotel as an outpatient. Even though she and her mother had long shared a close relationship, Zoe said their time together restored a lot of the ties between them that had been damaged during her time of heavy methamphetamine use. Zoe's best friend, the daughter of one of her cousins, also called Zoe every day during her transplant and recovery, and was a significant source of support as well. Zoe went to her oldest son's father without hesitation to ask for his help with her children, and he agreed without reservation or stipulation. But she also had approached her brother and his wife for help, mostly to be additional care support for her children ("I just thought my brother would help me because he was my brother"). Much to her shock and disappointment, Zoe told me, her requests for help were denied. She primarily blamed his brother's wife:

The other day, I called her [my brother's wife] because my son was getting out of school and needing a ride to the clinic so he can get his allergy shots. And it was pouring rain, and of course I'm halfway in-between my 'part time job' of coming up here to the auction block [to the Transplant Center], and my son ended up walking home in the rain with no allergy shots. I don't go to my brother's house [anymore] because I don't want to cause drama for him.

All of this certainly does not refute the fact that caregiving duties, indeed, currently are borne disproportionately by individuals, very often women. Furthermore, Zoe's challenges overall support, rather than refute, Nelson's (1985) larger goals to more equitably share the burdens and responsibilities of caring for the sick in our communities.

But these findings do complicate a bit the role of gender in transplant care, and underscore the need to examine other intersecting factors as well. Class, for example, clearly played a *major* role in Zoe's suffering.

Boychuk (2008)'s argument that racial politics have shaped the lack of national health insurance in the U.S. also is worth returning to. His analyses were written prior to the signing into law of the 2010 Patient Protection and Affordable Care Act, but there are elements of his argument that rang true in this latest development as well. As I have noted earlier, several provisions of the new law are certain to improve the lives of many transplant candidates, recipients, and their kin. But the law also has a number of shortcomings, and it will not extend coverage to all persons living in the U.S. One of the largest groups that will continue to be left out of the safety net is the population of undocumented immigrants living and working in this country. The notion that this was not only an explicit and purposeful exclusion, but also a response to deeply entrenched ambivalences toward a category of persons, was crystallized during President Obama's September 2009 address to a joint session of Congress, in which he outlined his proposals regarding health care reform. The President made a point of stating that his proposal would *not* extend insurance coverage to those who were in the country illegally, and Representative Joe Wilson from South Carolina shouted back, "You lie!"

It also marks a reflection of what Hoffman (2006) has referred to as "the historical ambivalence and contradictions of U.S. attitudes and policy toward immigrants," together with "the continuing irrationality of the U.S. health care system, in which spectacular technology and expensive medical miracles flourish alongside the denial of basic health coverage and services to millions" (Hoffman 2006:249). Hoffman was writing specifically about the issues raised in the case of Jesica Santillan, a seventeen-year old undocumented immigrant from Mexico who, as a result of a medical error, was given a heart-lung transplant with organs of the wrong blood type. In her chapter, Hoffman highlights some of the overlaps of "two areas – organ transplantation and immigrant health access – where shortages and scarcity are endemic and are explicitly acknowledged" (Hoffman 2006:25).

Local Responses to Unmet Needs

Policies are not asocial entities, but rather exist in the historical context of local values, assumptions, experiences, and priorities. As I have noted throughout this dissertation, at this particular moment, many of the responsibilities for care – including transplant care – are being transferred back into the hands of patients and members of their informal support network. And as the availability of professional services recedes, patients’ experiences can vary widely, subject even to chance meetings. The following example will illustrate how one woman, an elderly Spanish-speaking patient from Mexico, suffered under a system in which maximizing profits and cutting costs have become core values. Though she enjoyed legal status as an immigrant and had Medicare insurance coverage, she still faced immense barriers to receiving even basic medical care, let alone access to transplant services. I learned of this woman’s story via, Gabriella, one of this study’s participants. Gabriella described to me how she came to know this woman because they both attend the same dialysis center. She began,

It just so happened that the lady that was sitting next to me, I knew she was Hispanic from the get-go, [though I’d] never heard her talk [before]. ... And it just...occurred to me one day, ...One of the nurses came in, and she was trying to tell her something. And I was like, do you want me to translate for you? And they were like, “You speak Spanish?”, and I was like, “Yeah.” And then so I ended up, you know, meeting her like that and she [the woman] was like, “Oh my goodness, you speak Spanish?” and I’m like, “Yep I do.” You know, I told her my whole history, where my family is from, stuff like that, and she was really happy. And just from talking to her, I felt just absolutely, I thought I had a bad case of kidney failure and stuff like that. But she really is not well off at all, because on top of the barrier of the language, no one ever told her, her doctor that she sees, because she doesn’t, because she has Medicare. And because she has to go to the clinic that they tell her to go, is to where, just run by, I think there is one downtown, which I think is a Spanish clinic. I’m not sure what it’s called but they never mentioned to her, not one time, that she had the choice of asking for a transplant, instead of having to go through this for the rest of her life. She didn’t know that. She’s like, “No one ever mentioned that to me. No one tells me these things. My son can only read so much in English and translate to me in English, but other than that...”

Not only that, but the technicians, they don't do what she asks, like she's been trying for the longest time to tell them that "When you tape me back up" – because they have to put gauze on you to stop the bleeding, because they put that heparin in you so that you don't clog while ... the blood is cleaning out [...] So if you don't put the pressure on there the way that you're supposed to and tape it up... you're going to bleed everywhere. And so, when they do it to her, because she's also an elderly lady and her skin is a little bit more delicate, when they tape her up with that paper tape and she pulls it off, not only does she have a hard time trying to pull it off, but it also pulls off her skin. So in order for that not to occur, it's easier for her if ...they fold up the end [of the tape] and add a little so that she can do, slowly doing it inch by inch. So I started telling the technician, "She wants for you to fold the end, if you could please fold the ends for her" and then you know, now she's happy because now she can say "Hey look, this lady's hurting me!" Now I can tell the lady, "Hey, you're hurting her now. You're doing something not right." And so they call on the head nurse to come over and help out and stuff. And you sometimes need it, you know, because a lot of, I've found out myself, is that those technicians, you don't go to school for that, that's on-the-jobsite training. [...]

[And] another thing ... she's also practically blind herself. She can't see anything, so she doesn't even see the TV because she doesn't see anything. And since she doesn't have any help ... getting around either. [I feel] so bad because I don't have a car of my own and I would be like, "I would help you to your appointments," ...because she can't even go to her appointments. And that is the saddest part of it all because she's got really bad glaucoma, and ... you know, like the transportation, she gets free transportation [but] all they do is drop her off at the door. And see, the thing is that she's blind and she doesn't know how to speak English. So for her to go in there and ask what, how do I get to this person? You know, there's no way for her to communicate with anyone.

[And] it's like she's not seeing the right people...The only nephrologist that she sees is..., I think they come like once a month to come talk to you there at the dialysis center and other than that, that's it. And the nephrologist doesn't talk to her because he doesn't

... speak Spanish. And there's no translator there on site. Well except for me, I'm the only one that's been translating for her.

[And] she lives with her son and he barely makes like \$300, a paycheck and then, what she saves for Medicare is just, you know they're struggling and it's like a really sad... After I told her about [the option to try for a transplant], I said you should apply for that so he [her son] finally got the social worker to go over there and fill out the application. She just needs to fill out some of the questions and then ... she needs to give the paperwork to her doctor and the doctor needs to fill out the rest. There's a social worker there at the dialysis center. She's there, from Monday through Friday, and if you need any questions or need any help, she's there to help out, but like I said, ... she [the elderly woman] didn't know [about the social worker]. No one communicates with her, no one tells her anything.

I knew there was another person here that spoke Spanish, ... but they never set them together, which I never understood ... either. So it's like, "Well you guys should just keep her here next to me. And if you have any questions or if she has any questions I can let you know ...but it just doesn't seem right that she can't communicate with you guys." And they get frustrated because she's trying to, you know, she's trying to signal to them what she wants. And they won't listen, you know?

Plus, she's such a Grandma, she is like my, it could be like me saying no to my grandmother and I would never do that. I would help my grandmother to the end.

Notably, the dialysis center which Gabriella and this woman attend is part of a large for-profit franchise network which tries to keep costs low in order to increase monetary gains. The scenarios Gabriella describes highlight some of the ways in which patient care is compromised, for example, when centers are run primarily by poorly trained, poorly paid, overstretched technicians, the availability of trained nursing and social work staff has been stripped to a bare minimum, and translation services are not offered. The result is a very *inhumane* form of medical care, where an elderly woman's

request for even the smallest consideration (i.e., to fold the end of the tape a bit so that when she removes it, her skin doesn't rip) goes ignored.

But these constraints in turn exist in relation to barriers and challenges outside the dialysis center. For example the woman Gabriella has befriended cannot attend all of her appointments (to treat her glaucoma, among other conditions). Her son works full-time and is not generally available to help in this capacity; the household subsists on poverty wages, so she relies on the free transportation service. But the free transportation service she uses drops her off in front of the clinic and does not escort her to the doctor's office, even though she is blind. She cannot ask passersby for directions because of language barriers. And even when she *does* see her healthcare providers, whether at the Spanish-speaking clinic *or* at the dialysis center, she is not presented the option of a transplant. Even though there is a social worker available at the dialysis center, she has had no access to the social worker's services.

This case illustrates a reprehensible breakdown in the delivery of medical services even when a patient *does* have insurance coverage. While Gabriella's entering the picture promises to markedly improve her friend's life, she can only offer limited relief from the constraints this woman faces, and even this partial support only came about due to their fortuitous assignment to dialysis machines that happened to stand side-by-side. Nevertheless, this way of addressing unmet needs through the informal, impromptu outreach of others is in close keeping with the experiences of patients and their extended networks, both today and in the past.

For example, in their discussions of how universal coverage for ESRD came to be, both Schreiner (2000) and Plante (2000) give some of the greatest credit to grassroots organizing and public outcry over the injustice that a life-saving treatment was available but inaccessible to so many because of an inability to pay.

Public awareness of the severity of problems facing patients and their families occurred most vividly in small towns and cities where people tried to help friends and neighbors raise funds for dialysis. In the early years in the 1960s, people had bake and candy sales, collected coupons (Kool cigarettes, Betty Crocker) ran marathons, played bridge, hit golf balls, competed in cookoffs: all to one end, to support someone in need of dialysis. (Schreiner 2000: Paragraph 13)

Similar fundraisers continue to exist today, and during my fieldwork, it was not uncommon for local newspapers and television affiliates to report on some of the events hosted across the region to raise funds for persons who were struggling to meet the costs associated with a much-needed transplant. Bake sales, yard sales, auctions, raffles, dances, and breakfasts, lunches and dinners were just a few of the venues by which families and friends try to raise funds for patients and their loved ones to be able to pay their transplant-related expenses. Churches, too – which in small towns often comprise a major core of the community – frequently are another source of material support for struggling patients. For example, when I asked Blaine to tell me about the community in which he lived, he responded,

Blaine: *Um, well, it's a, I think it's a pretty giving community because they've really given a lot to me since I've been laid up. They've helped me out a lot with their donations and stuff.*

Laura: *Like financial donations?*

Blaine: *Yeah, and they've, a lot of the people at the church had a bake sale, and just a lot of people have been real giving.*

Likewise, Hank and Eliza described a local community fundraiser that Hank's friends had organized on his behalf about a year after his liver transplant:

Hank: *During my liver transplant, three of my good friends got together and got a benefit thing going. It was kind of special. I didn't want them to do it at first but they said, "we're gonna do it. We don't care whether you like it or not." I said "ok." But when it was over, they handed me ten-thousand dollars [sniffling, tears].*

Eliza: *They did. They did a big barbeque pork dinner thing at the park. And they had a bunch of businesses and individuals donate items, and they had raffles. And they had homemade quilts and homemade knives that this guy makes, that he carved out of deer antlers, and just all kinds of stuff that people donated. And the dealership that my dad worked at for years donated a car. They really put together a nice benefit.*

Hank: *Quite a deal. People from small towns pretty much hang together. They come out and open their billfolds and just dug in.*

Eliza: *I think it means a lot more when you know that person and you know the money's*

actually going to that person. Like I always feel guilty because I hear all these stories even in Metrotown, and yet you don't know if you can trust that the money is truly going to that family. But when you know that there's something going on and it's here and you know the people that are doing it, you know that the money is getting back to that family.

These accounts from recent fieldwork, placed alongside Shreiner's comments about the role of grassroots fundraising and the resulting heightened awareness of the plight of dialysis patients, together raise questions about what, if anything, community events like the one described above by Hank and Eliza portend for the future of more equitable coverage for high-cost, high-tech medical care. Like dialysis in the 1960s, transplantation is a life-saving procedure to which there is limited access; in both cases, one of the obstacles to receiving treatment was lack of ability to pay (although unlike dialysis, access to transplantation currently also is limited by the availability of transplantable organs).

Hank noted that "people from small towns pretty much hang together," and this is a sentiment that others had shared with me as well. Yet certainly not all participants from small towns felt comfortable allowing their dealings with transplantation to become community affairs. For instance, recall Jerald, the living kidney donor and his wife, Alice, who favored privacy and preferred not to be in the local spotlight. Some from rural areas reported having only a small network of persons from whom they felt they could draw support (accompanied by some from urban areas, in turn, who cited a wide range of family, friends, and acquaintances who had been very giving). So my data are not suggestive of a neat mapping of urban-rural differences in level of material or social support available.

Eliza's remarks, though perhaps intended to support the implicit urban-rural comparison her father was making, may point more to variations in the moral landscape over space and time. Eliza links one's willingness to open one's wallet for a person needing help with the costs of transplant, to the degree to which potential financial donors actually *know* the patient and his or her family, and can be assured that any money given actually will go directly to the person in need. Personal acquaintance with the patient and family bestows upon them a moral status that outright strangers might not

enjoy, and which makes those in a position to give more sensitive to a moral obligation to do so. It is notable that Gabriella, above, mentioned that her friend was so much like a *Grandmother* to her. She says she would help her own grandmother “to the end,” and so, too, she will help this elderly woman whom she initially came to know simply because they sat beside each other and both spoke Spanish.

Conclusions

Might personal experiences with the shortcomings of U.S. healthcare eventually translate into larger political attitudes toward universal access to health care and better integration of medical care with other social services? At the time of this writing, a federal government-run program guaranteeing universal access to healthcare remains a very contentious political issue, and it is not at all clear, for example, that grassroots fundraising for transplant candidates will broaden support for universal coverage in a manner comparable to the role Schreiner feels such a phenomenon played in moving the nation toward a federal Medicare ESRD program. Passage of the 2010 Patient Protection and Affordable Care Act marks an important step toward reforming some of the most egregious injustices within the system under which the participants in this research had to operate. Yet, even this move relies heavily on the continued use of for-profit, private insurance for health care coverage. For this and other reasons, the new health care reforms certainly will not solve all problems associated with transplantation in the U.S.

For example, even with insurance coverage, Gabriella’s friend had long been denied access to *information about* transplantation, let alone the procedure itself. And the new health care reforms do not offer the promise of a more seamless integration of medical care with social services like translation and transportation. They also will not address all of the present concerns highlighted by this dissertation research, such as the emotional, physical and logistical challenges associated with transplantation, lay caregiving, and home-based recovery (though, to this last point, certain provisions of the new reforms would reduce Medicare payments to hospitals with high rates of readmissions, which could very well discourage premature hospital discharges). And of course, the new law will not abate the tenuous ethical aspects of transplantation at its most fundamental levels (such as the notion of brain death, the fetishization and

commodification of human body parts, and the abuses created by a global underground market for organs), which have been the focus of much anthropological and social scholarship, as outlined in the Introduction and elsewhere in this dissertation.

Many of the critiques of the 2010 law from within the transplant professional community come from those at the “top” of professional hierarchies. For example, Axelrod, Millman and Abecassis (2010a,b) predict that the cost-savings measures required of private insurers, along with the increasing numbers of patients who will bring lower Medicare and Medicaid reimbursement rates, will translate into downward pressure on reimbursement rates for specialized services such as those common in transplantation. They also worry that increased access to transplantation, to the extent that it will not be accompanied by an increased supply of transplantable organs, will result in a flood of new transplant candidates, and create even longer waitlists, increasing waitlist mortality rates, and pressuring practitioners to use marginal organs (2010a). The authors argue that this would result in “a worsening in posttransplant outcomes in an effort to reduce waiting-list mortality and a concomitant rise in transplant costs” (Axelrod, Millman and Abecassis 2010a:2199). Yet it is important to note that transplant waiting lists have been swelling steadily for several years, and likely would continue to do so even without health care reforms. Further, while on balance, health care reforms may not lower overall health care spending in the U.S., even critiques from scholars such as Axelrod, Millman and Abecassis are tempered by admissions that “HCR [Health Care Reform] may not ‘bend the cost curve’ as desired, although it should improve access to health care” (2010b:2204).

Singer and Castro (2004) argued in the Introduction to their edited volume *Unhealthy Health Policy*, that policy can both reflect and serve to reinforce structural inequalities. They also insightfully point out that “health policies are shaped by a number of factors, only one of which (and sometimes the least of which) is concern with public health” (Singer and Castro 2004:xiii). Since many of the 2010 reforms will not take full effect for some years, it remains to be seen what impact the new provisions will have on the everyday lives of transplant candidates, recipients, and those closest to them, as well as the clinical professionals who work directly with this population. One thing is quite certain, however: organ transplantation is deeply intertwined with issues and policies

concerning how healthcare is financed in the U.S., and examinations of these ever-evolving interconnections will be crucial in any holistic discussions of the socio-cultural aspects of transplantation.

Chapter 8:

Conclusion

This dissertation represents an attempt to add to ongoing conversations about transplantation, particularly in socio-cultural and medical anthropology and in social work, by zooming in on the intersections of kin relatedness and daily home life among transplant candidates and recipients, and those who care for them. I have presented findings from my fieldwork in a major Transplant Center in the U.S. Midwest, and in homes and communities in the region surrounding the Center. My analyses pointed to the salience of moral obligations in reciprocal webs of care, cultivated within and reflected in houses and home life. These interwoven domains, I argued, both shape and are shaped by transplant care, which in turn is linked to evolving policies and practices of public health.

I made a series of interrelated arguments from one chapter to the next that roughly traced the contours of what I referred to throughout as “the transplant journey.” This should not be taken to mean that transplantation is a straightforward process in which persons travel unidirectionally from ‘Point A’ to ‘Point B’ and so forth; as I hope to have made clear throughout, the process actually can be fraught with disruptions, re-starts, detours, and impasses. But since I focused my research on persons who ultimately did hope to receive a transplant (i.e., they had in mind a particular destination and were participating in procedures –akin in some ways to what van Gennep (1960 [1909]) referred to as “rites of passage” – designed to get them there), I felt the reference was appropriate.

In order to create a foundation for the rest of the dissertation, I began with an examination of the pre-transplant evaluation and preparation process required in order for patients to be considered by clinicians to be viable candidates for the procedure. I posited

that, by following the preparations recommended by clinicians, patients commit to embodying particular biomedical practices and values. In a sense, the clinical goal is to create bodies that are well-suited to “house” a grafted organ or tissue, in medical terms. But much of the pre-transplant preparation actually takes place in patients’ homes, in the context of home life among kin and others to whom they are close, where clinical prescriptions do not always mesh well with the on-the-ground realities of daily life. In order to pursue these themes, I drew primarily upon the concept of the “house,” and tried to show that, in order to be granted access to transplantation, patients and caregivers must successfully navigate, negotiate and integrate several domains – clinical, bodily, domestic, and financial “houses.” I also pointed out that caregivers can be crucial in the successful integration of these disparate domains, and introduced some of the mediating factors in transplant caregiving, especially including gender. This chapter focused overall on pre-transplant requirements, but ended with a section which also examined pre-transplant life from a slightly different perspective, through an in-depth look at one patient’s (and her husband’s) response to the question, “How did you come to need a transplant?” This analysis in many ways was a “moral etiology” involving kin relationships (as compared to Hamdy’s 2008 concept of the “political etiology”). It brought to light some of the ways in which transplantation can be interwoven with personal moral historical narratives that extend well into the past and connect deeply with domestic houses, home life, and the obligations of kinship. It also underscored the notion that participants’ life narratives do not begin and end with transplantation, and served as a reminder that transplantation – both interpersonal experiences of it and as a phenomenon in itself – must be understood as being highly contextual.

In Chapters 3 and 4, I pointed more explicitly to the importance of reciprocal webs of care and moral obligations toward kin in transplantation, and relied on an expanded notion of “care” (Kleinman 2009; Kohn and McKechnie 1999; Olesen 1989) to include both its more obvious and its more hidden forms. Participants in this study often reported that a transplant was the patients’ main (or perhaps only) hope of fulfilling their obligations to others (e.g., to be a better or more ‘normal’ mother whose health did not interfere with her ability to parent; to continue living so that one could provide ongoing support to a spouse; to be there for one’s grandchildren; etc.). Thus, overall, a major

finding of this study was that the notions of ‘patient’ and ‘caregiver’ need to be examined more critically, and that the boundaries between these categories can be quite fluid. Patients themselves are caregivers to others, and are considered vital members of reciprocal webs of care without whom their kin networks could not effectively function.

Informal transplant caregivers, however, also are patients when they experience health problems of their own over the course of caring for the transplant candidate/recipient. While health issues can develop during their tenure as a caregiver, they also in some cases exist even before they become transplant caregivers. Ironically, this can seemingly place certain persons in a better position to provide informal transplant care. And otherwise physically healthy caregivers can turn into patients when they seek to become living organ donors. I noted that this particular form of patient-caregiver status is especially permeated with moral ambiguities, and participants negotiated the pitfalls of giving and receiving often through engaging in concerted efforts to shield each other from potential shame, discomfort, or stress.

Chapter 5 shifted the focus to some of the ways in which recipients and their loved ones incorporated transplantation into their daily lives and routines. I argued that, in the context of daily life, houses and home life can become blended with the clinical domain, particularly during the transplant recovery process. This chapter paid attention to the ongoing shift of medical care responsibilities – even some of the high-tech aspects of transplant care – out of the hands of clinical professionals and into the hands of lay persons. In effect, for example, the relationships between “husbands and wives” can begin to resemble one of “nurses and patients.” I noted that participants simultaneously worked to hold on to their lives as they once knew them (adhering to a mantra of “nothing’s changed”), even as the way they related to each other could be altered at its very foundations.

I also noted that the transfer of skills, knowledge, and expertise regarding transplant care was not unidirectional, flowing only out from the clinic and into the home. Rather, as patients and loved ones worked to overcome predicaments, and found “home grown” solutions to some of the technical challenges of transplant-related care, these newly specialized skills, knowledge, and expertise became portable and could be transferred back into the clinic as patients and caregivers presented what they’d learned

back to clinical staff (during re-hospitalizations, clinic visits, etc.). Overall, a major argument of this chapter was that domestic and clinical domains could remain at once distinct *and* interactive, and similarly, informal care could simultaneously take the form of clinical expertise *and* personal attachment.

Chapter 6 returned once again to a concentrated focus on the reciprocal webs of care and moral commitment that can be revealed and reframed among persons directly engaged with transplantation. Dividing my analyses into two parts, I first developed an in-depth examination of an exceptional yet illustrative relationship that one of the study's participants, Mary, and her family developed with the kin of her deceased organ donor. This relationship was exceptional in that it was quite rare in my observations to encounter such an intense, close, and mutual bond between recipients and deceased donor kin. Others I met during fieldwork had likewise made contact with their donor families, and had experienced varying degrees and kinds of intensity and emotion in their encounters. But in Mary's case, all parties most directly involved labeled their bond as one of kinship, and not only used conventional kinship terms for one another (grandmother, daughter, family), but also engaged in conventional kinship practices over time (having family photos taken, sharing living space over extended visits to each other's homes, etc.). This relationship was illustrative in that it offered a glimpse into the tremendous *potential* that exists for new forms of kinship to emerge in transplantation, which is characterized not only by the giving and receiving of organs, but the giving and receiving of life itself. While anonymity policies may make it more difficult for donor kin and recipients to connect, the potential for connection persists.

The second half of this chapter likewise took a broader view of social relatedness in transplantation to include those who might be situated farther out in extended webs of social relations: clinicians, fellow patients and caregivers, fellow guests in an outpatient housing setting, friends, neighbors, acquaintances. I pointed out that here, too, there was tremendous potential for new relations to form, particularly as persons found that they shared experiences in common (as persons who had met on hospital units because they had transplants at or around the same time, or had shared communal housing spaces over time in outpatient housing settings like the Baxter House), and likewise could contribute diverse forms of care to each other (as in the give-and-take among clinicians and patients,

and as with informal networks in which “everyone pitches in” in their own way). These findings directly resonate with the Durkheimian notions of solidarity and social cohesion. But I also examined instances in which social and kin relations became decayed and webs of care were tattered, especially in cases where persons in need of a transplant found they could *not* rely on those they had assumed would be there for them.

As a whole, in this chapter I found that, even as persons simultaneously draw upon and prop up dominant conventional ideas about kinship in the U.S., the daily realities of living vis a vis transplantation can very effectively erode notions that the family is a bounded, self-sufficient, independent entity. Further, I elucidated some of the ways in which kin relations could become revealed and reframed in new ways throughout various aspects of the transplant process, while also maintaining a cautionary stance against calling just any form of relatedness “kinship.” Finally, by focusing more heavily on social relations than on the organs themselves, I attempted to demonstrate that both transplantation and kinship are fundamentally deeply engaged in matters of birth (giving life), life, and death, and returned to these themes at the end of this chapter.

The analyses in Chapter 7 centered around the intersections of U.S. health care (and other social) policies with the on-the-ground realities of transplantation. I focused heavily on the experiences of one study participant, Zoe, and on a secondhand account by another participant, Gabriella, in order to illustrate how this nation’s fragmented network of policies, which ostensibly exist to provide a safety net for the most vulnerable, can further exacerbate their suffering. In light of policy shortcomings and breakdowns, individuals, groups, and communities often weave together local moral responses to the unmet needs of patients and their loved ones; however, such responses often emerge out of chance encounters (e.g., between Gabriella and the woman she sits next to at the dialysis center). Thus, they are not a given, are not guaranteed, and do not exist for everyone.

I also recounted some of the historical points of view on why the U.S. has failed for so long to create a national system for universal health care coverage. An historical account of the development of Medicare’s ESRD program offered further perspective on the tremendous gaps that exist in coverage for transplantation (i.e., renal transplant patients are insured, while other transplant patients are not). As a whole, this chapter also

offered insights into how gender, race, and class (and language) can intersect with policy matters in ways that not only exacerbate inequalities and suffering in transplantation, but also erect barriers to even the more basic forms of medical care. Finally, I tried to place these matters within the context of the recent passage of the 2010 Patient Protection and Affordable Care Act, and argued that, while this surely will improve the lives of persons like those I met in the field, it marks only a partial answer to persistent needs, leaving much more work to be done at the intersections of health care (transplantation and otherwise) and daily life.

THEORETICAL IMPLICATIONS

As I have said from the outset, I hope this work will contribute to ongoing theoretical discussions about transplantation, about kin relatedness and family life, and about the social study of medical science and technology. This sustained focus on social relations rather than body parts in transplantation, and on daily life rather than on the procedure itself, has placed these three domains of scholarship in dialogue with one another. Out of this, a number of implications have come to light.

Transplantation Both Shapes and Is Shaped by Kinship Practices

Drawing upon scholarship in kinship studies, as well as the insights from Durkheim, the evidence from my fieldwork in this particular space and time supports the notion that kinship is a social and moral relationship among persons who are beholden to shared ideas about *what kin ought to do and be for one another*. Throughout the transplant process, these moral relationships existed as reciprocal webs of rights and responsibilities to care and be cared-for, and to give and receive (not just organs, but time, effort, concern, even love and attachment). That is not to say that such obligations are always carried out in practice, and I also observed several instances of ambivalence among and toward people who consider themselves to be kin, sometimes with serious consequences for health and well-being.

I found that shared moral orientations also can prompt patients and caregivers alike to turn toward the resources available to them to carry out their duties toward one

another. In this dissertation, I documented instances in which high-tech, high-cost biomedical procedures like transplantation can be counted among the resources available for carrying out the obligations among kin to “be there” for one another. One implication, then, is that kinship ideologies and practices can actively shape biomedical care in notable ways. This finding also addresses Koenig’s (1988) concept of the “technological imperative” in medicine, and suggests expanding it to account for the “moral imperatives” of certain forms of life-saving medical care in the context of kin relatedness.

In turn, I found specific examples of persons whose relationships (e.g., between patients and caregivers, but also between recipients and donors/donor kin, recipients and their extended network of friends and acquaintances, and living donors and their communities) had taken on new meanings over the course of the transplant process. The implication of this is that transplantation does carry with it the potential to shape relatedness, particularly in that it articulates with various channels of social cohesion and solidarity for all those involved – patients, caregivers, clinicians, and others at the far reaches of patients’ webs of relations. And as persons work to meet the challenges they encounter in the face of serious illness and transplantation (and by extension, other forms of high-tech biomedical care), the idea that “families” are bounded units can begin to erode.

Also, as transplantation does involve the giving and receiving of both organs and life itself, it is particularly positioned to be interwoven with notions of kinship, and uniquely poised to create new forms of kinship (such as those that can develop between donors and/or donor kin and recipients). Yet, while the specific genesis of these relations is part of a rather recent phenomenon, I also observed that persons who had become connected through transplantation *also* further developed their relationships (making them more kin-like) by following rather conventional kinship practices – many of which were strongly anchored to the home and home life. The implication of this is not only that transplantation can both shape and be shaped by kin relatedness, but also that, as Charis Thompson has noted in her examination of new reproductive technologies, “technological change and cultural conservatism go hand in hand” (2001:199).

Incommensurability and The “House”

A third major thread that reappeared throughout this dissertation has to do with the seemingly incommensurable aspects that patients and their loved ones encountered throughout their dealings with transplantation: At its core, transplantation involves both life and death. As more and more of the responsibilities for medical care are shifted back out of the hands of clinical staff and into the hands of patients and those close to them, spouses, partners, and even children can start to become clinical practitioners. The dilemmas and transitions that this entails can bring loved ones “closer together,” and yet at the same time, “turn the family upside down.” Under the reciprocal obligations of kinship, as I have emphasized, patients can be caregivers and caregivers can be patients. And when those obligations are not upheld, mothers, fathers, brothers, and sisters can become persons one hardly relates to, while friends and neighbors can become the closest family members one has. Domestic spaces can begin to take on the qualities of clinical spaces (I also observed some, though a bit less, integration of objects from the home being brought into clinical spaces during extended inpatient stays).

I think it is significant that so many of the incommensurables of transplantation come to light during both the pre-transplant and post-transplant recovery periods. It is during these periods that patients spend the bulk of their time in their homes, where day-to-day living must at some point continue on, (though perhaps in an altered way), even in the midst of the turmoil and uncertainty of illness and (sometimes tenuous) recovery. The implication is that a *combined view* of both daily life (as including social practices and moral orientations) *and* “houses” (as material structures and social spaces that incorporate the sometimes contradictory aspects of daily life), can indeed offer a powerful approach to perplexing questions in both anthropology and social work.

Gender and Care:

Kohn and McKechnie (1999:2) assert that “It is very important to look at the way in which ‘care’ and caring practice have been socially constituted and evaluated over the years,” and point out that assumptions about care are challenged across social, cultural, and technological shifts over time and space. The authors give examples of assumptions that have characterized the way care has been conceptualized in the past, but which have

been fruitfully challenged in recent years. One example they raise is the outdated assumption that women are “natural” carers (of children, the ill, the elderly, and the dead), whose caring work was placed firmly in the domestic, private, and “invisible” spheres, and was devalued and assumed to produce no economic gain (1999:3). These assumptions have been thoroughly critiqued in light of feminist deconstructions of ideas about production, femininity, and dichotomous notions of public/private, feminine/masculine, etc. In some instances, transplant caregiving can perpetuate these old assumptions to the extent that it very often is performed by women and takes place increasingly in domestic spaces without financial compensation. On the other hand, informal transplant caregiving also challenges old dichotomies in that it integrates home and hospital, lay and professional, personal and political. Further, since spouses so very often are the default caregivers, men as husbands might more commonly fulfill the caregiving role for wives as transplant patients than men might fulfill caregiving roles, for example, for aging parents. Transplant caregivers are not unchanged in the process, but rather assume new roles and responsibilities. Just as importantly, the relationships between transplant candidates and recipients and those closest to them can be both revealed and reframed for having gone through the process together. As we saw with the examples of Betsy, Rob, and others, even the roles that participants in this study might previously have divided along gender lines were sometimes re-ordered in order to meet the demands of the transplant process and recovery.

Arenas of Constraint:

Transplantation is not, in fact, a straightforward process for transplant patients and their caregivers. Members of these groups indeed faced formidable arenas of constraint (referring again to Inhorn’s (2003) development of the concept) that reverberated throughout kin groups even before transplantation. However, the arenas of constraint faced by members of these groups also had a tendency to come to the foreground even more over the course of the transplant process. These constraints could include physical (feeling fatigue, pain, nausea, etc.); emotional (facing illness, possible death, managing relationships); financial (paying for the transplant, maintaining health care insurance coverage, financing living expenses during transplant and recovery);

identifying a caregiver; maintaining employment; and trying to make logistical arrangements for the transplant (childcare, house-sitting, transportation, paying bills, etc.). In other words, the 'flow' of challenges did not appear to be uni-directional; arenas of constraint (like moral obligations) instead seemed to be interrelated with transplantation in an interactive sense. Thus, already-existing constraints had the potential to impact the transplant process itself, which in turn had the potential to exacerbate constraints, etc.

However, a surprising finding was participants' (both patients and caregivers) tendency to downplay the significance of the structural constraints they faced. This may be related to a strong willingness to endure formidable hardships in order to be given a transplant, and to live with a transplant. It resonates with the notion that transplantation can be considered not simply a hegemonic form of biomedical practice, but also an idea and a promise upon which study participants hung their expectations, hopes, and imaginings of a better and longer life for themselves and those close to them. Interestingly, when asked about constraints they may face, most participants expressed what might be called a mantra, for how often it was recited in interviews: "you just do what you have to do."

IMPLICATIONS AND RECOMMENDATIONS FOR PRACTICE

Considering the formidable constraints associated with transplantation, as outlined above and throughout this dissertation, it is important that social workers play a key role at all stages and levels of the transplant process (Geva and Weinman 1995). And because social workers are trained in and practice at each of these levels, they also are uniquely situated to inform and shape patients' and loved ones' on-the-ground experiences, as well as the larger and continuously evolving transplant enterprise itself.

My research focused on transplant patients and those close to them. It is important to note, however, that many patients choose not to pursue transplantation (e.g., Gordon 2001; Wiebe 2004), and scores of others are not given access to a transplant, even if they want and could benefit from one. Dhooper (1989, 1990, 1994), for example, has argued that social workers have an ethical and professional obligation to work at the individual, institutional/ organizational, and policy and societal levels to ensure equality

in access to organ transplantation. Recent valuable work has been done to document, understand, and reduce racial and other disparities in transplantation (e.g., Arthur 2004; Klassen et al. 2002; and Wiebe 2004). While a focused, in-depth analysis of these types of transplant disparities was beyond the purview of this dissertation, what *can* be said here is that the implications and recommendations I outline below also could have the potential to augment efforts aimed more specifically at ending transplant disparities by race, gender, and other social distinctions.

Social workers are unique among the health care professions in that they are in a position to advocate that biomedical care remain congruent with the larger context of patients' lives outside of clinical settings (Beder 2006:65). Today, as members of interdisciplinary medical teams, social workers conduct psychosocial evaluations of potential transplant candidates, carry out interventions designed to help prepare patients for transplant, and remain available to recipients and those close to them for long periods post-transplant (Zilberfein et al. 2001). I observed social workers steadfastly collaborating with patients to ensure that family and social support networks remain intact, that health care and prescription medication coverage go uninterrupted despite employment disruptions for patients and those close to them, and that the rest of the medical team have a clear and accurate picture of the challenges and resources that surround patients in their everyday lives.

Yet practitioners have an even larger responsibility to shape the very nature of health care. In light of the findings I have presented above, and with an eye toward local moral processes and kinship obligations, I propose that 1) medical social workers working in transplant and other biomedical settings should advocate for a more holistic, web-of-relations – oriented approach to care that better accounts for the full range of “human resources” available to a patient along with the significance or meanings associated with those resources, and 2) social workers and anthropologists are uniquely positioned to influence the present health policy debates, and ought to work to make larger social justice issues a more prominent concern in the local moralities of health care in the U.S.

The Patient-Caregiver Relationship and a Holistic, Web-of-Relations-Oriented Approach to Care

In many ways, the ideas put forth thus far build upon what practicing medical social workers have long known: transplant and other patients do not undergo the journey alone, but instead do so in the context of myriad and complex human relationships. One of the roles social workers often play on interdisciplinary transplant teams is to help patients identify at least one person on whom they will be able to rely for care and support, especially during the post-transplant recovery outside the hospital (Beder 2006). Thus, members of a patients' social network rightfully factor into social workers' assessments and interventions.

Most study participants considered natal/marital/adoptive relatives to be the most obvious, desirable, and 'natural' choice in care partners. [Cases in which kin of this type are unable or unwilling to provide care often are viewed, even by those patients themselves, as cases in which the patients' life story includes tension, tragedy, struggle, hardship, estrangement and/or disillusionment.] Medical professionals recognize the potential for stress and hardship that can arise among patients and those close to them as they encounter the challenges of transplantation, and emphasize the importance of having in place a plan for care support during the post-hospital recovery period. However, in spite of this recognition, while there are clinical staff whose primary duties are to address the needs of post-transplant patients, their focus is mainly on the medical aspects of post-transplant life (and the responsibility lies with individual patients to contact the clinic when needs arise).

It follows, then, that the formal resources available during post-transplant follow-up (as well as pre-transplant preparations) remain somewhat limited with regard to such *non-medical* issues as recipient-caregiver relations. These shortcomings were pointed out to me by participants who expressed that they had not felt adequately prepared for some of the ways in which their relationships would be strained in the process. One resource that is available is the transplant support groups hosted by the transplant center and its clinical social work staff. However, while patients and their loved ones are invited to attend these, the onus remains on individuals to seek out these resources, and one's ability to attend can be limited by structural and logistical factors such as access to

transportation, availability of time, and interest among both patients and caregivers to seek help and support via this particular format.

Under current systems of health care delivery, it is common that "...families are viewed primarily in relation to their help with the management of the patient. There appears to be little interest in the roles and reactions of families of ... patients apart from their ability to provide home care" (Peterson 1985:17, drawing upon the work of De-Nour 1973). Such a view fails to capture the complexities of patients' relationships with others, and professional clinical practices that are based on it will thus be limited in their effectiveness. The challenges that inhere in serious illness tend to reverberate throughout kin networks and extended webs of relations. As Siston et al. (2001:1186-1187) note, "caregivers should not be regarded solely as a patient's support system but rather as individuals who may themselves be in need of additional family, social or other supportive services." Under a reciprocal perspective of patient-caregiver relationships, transplant patients likewise ultimately would benefit from services aimed toward the well-being of the *entire* web of care.

Medical social workers in today's health systems often are restricted to designing interventions that are intended (at least officially) for the benefit of the individual patient. By drawing upon a perspective that patients' lives are deeply intertwined in moral relationships with those around them, social workers can develop and promote a more holistic approach to health care. The proposal here is for practitioners to become leaders in changing current paradigms. Some efforts in this direction have already been made. For example, Saltz and Shaefer (1996) have called for a more dynamic integration of family caregivers into interdisciplinary clinical teams. But such an approach remains problematic if it builds on a dichotomous conceptualization of the categories of "patient as care-recipient" and "family member as care-giver." In those instances in which a patient is unable to identify a caregiver, it is important to assess the possibility that the patient himself or herself is typically the main care provider to *others* in his or her life. Upon exploring the extent to which patients are the keystone members of their kin or other social network, under a holistic, web-of-relations-oriented approach, practitioners can think more creatively about the types of services and/or interventions that might most

effectively serve *both* the patient *and* his or her networks, and ultimately could promote more effective care for all parties.

An approach that focuses on integrating family caregivers into interdisciplinary medical teams also would be problematic if it were founded on an idea that families in the U.S. are bounded, self-sufficient, independent units. As I have pointed out, patients can benefit from the care of persons at the farthest reaches of their webs of relations (recall the examples of Jane and Blaine, both of whom asked friends and acquaintances to care for their children during their hospitalizations and recoveries). Along these same lines, it is crucial for practitioners *not* to approach care arrangements with preconceived or static notions about *who* might be considered “kin.” Indeed, relations by blood, marriage, or adoption sometimes can prove to be among the *least* caring individuals in a patients’ life, while friends, lovers, and neighbors can be among the *most* caring and reliable (recall the example of Jacob’s friend).

Importantly, as outlined in the NASW’s Code of Ethics, the core values of the profession (service, social justice, dignity and worth of the person, importance of human relationships, integrity, and competence) (National Association of Social Workers 1999) all in principle orient social workers toward such an expanded conceptualization of families, kinship, and care. Some of the most formidable obstacles toward carrying out these principles come not at the level of individual practitioners but at the level of institutional constraints (e.g., time, medical billing practices, professional hierarchies, etc.). Yet one can imagine new care models in which social workers are given the staffing, funding and other resources to offer true, tangible support not only to patients, but also to those with whom patients are involved in reciprocal networks of care and obligation.

Health Policy as a Moral Issue

In the 2006 *Handbook of Families and Health*, Wilson noted that “Public policy can alter the ability of...families to fulfill their obligations to dependent members” (2006:273). Outlining a model for family-centered health policy analysis, he posits that the industrialization of medical care (one component of which is the “ever-increasing

pace of technological advancement”) is a major component of medical costs, and thus a significant factor in health policy decisions (2006:286). Since individuals make their health decisions in the context of families, which in turn shape society and determine the effectiveness of public health policies, Wilson argues, scholarly and public debates must not overlook the ways in which such technologies and costs influence the pressures felt by patient-family networks (2006:287).

With regard to the ongoing debates surrounding healthcare reform, social workers and anthropologists have a unique opportunity to continue to offer ideas and fresh approaches that could simultaneously advance patient care *and* improve broader social outcomes. Toward this end, for example, the NASW joined a coalition known as “Health Care for America Now” (as noted by Gorin 2009). The NASW website also includes updated policy statements, proposals, action alerts, and press statements specifically pertaining to health care reform (NASW website <http://www.naswdc.org/advocacy/healthcarereform/default.asp>). It is essential that practitioners who typically address the immediate concerns of individual patients and those close to them keep in sight the larger picture as well—that is, the social, cultural, and political-economic contexts that form the conditions under which individuals encounter the challenges in their everyday lives. Furthermore, it is essential to continue to work toward a stronger “safety net” that more seamlessly weaves together health care policies with other social policies and services. Adequate health insurance is only one strand (albeit a major one); as we saw in the examples of Zoe and Gabriella’s Spanish-speaking friend, access to reliable transportation, child care, language interpretation services, and adequate housing all can play immense roles in health and well-being.

As professional collectors of real-life stories of oppression, social workers (and anthropologists as well, as Sargent (2009) has noted) possess a tremendous capacity to shed light on the injustices and inequalities of the current system. This might be accomplished by publishing not only in academic journals (Gorin 2009 is a recent example), but in forums that reach wider audiences; by speaking not only at conferences and to colleagues, but also in community settings where social workers and anthropologists can contribute directly to the ongoing conversations and debates among the general public. It also should be achieved by empowering patients and others – both

with and without adequate health insurance coverage – to influence more directly the discourses on U.S. health and social policy (see, for example, Chadiha et al. 2004; Gutiérrez et al. 2005).

Social workers and anthropologists can do much to reframe the moral issues in health policy debates. The current emphasis on high-tech medicine, as I have argued here, is rooted at least in part by moral negotiations at the micro level. But we would do well to promote greater access to healthcare as a compelling and overarching moral issue. When the public conversation remains fixed only on *individual* rights, it can easily deteriorate into disinformation and anxieties that more healthcare coverage for those who lack it can only come with a decrease in the quality of coverage enjoyed by those who currently have it. Conversely, a re-orientation of the dialogue toward reciprocal webs of obligations could offer a promising counter-narrative in current debates.

NEXT STEPS: REMAINING QUESTIONS AND FUTURE DIRECTIONS

While this dissertation does offer additional insights into questions surrounding transplantation, it leaves several more unanswered, and further calls to mind new domains for inquiry.

Disparities

Though my research paid close attention to arenas of constraint in transplantation, my focus was overwhelmingly on persons who *did* (or were about to) gain access to transplantation. Thus, important questions remain concerning disparities in access to this and other forms of high-tech, high-cost biomedical care. What specific roles *do* the axes of “intersectionality” (Mullings 1997) and “multipositionality” (Lewis 1995) – including social race and ethnicity, class, gender, sexuality, ability status, and age, but also faith and religious belief, language, history, and geographical and neighborhood location to name just a few – play in shaping who enjoys access to transplantation, versus who does not? Qualitative *and* nuanced quantitative research which sets up direct comparisons between those who are admitted to waiting lists, those who actually receive transplants, and those who are not admitted to waiting lists at all would offer crucial information. Additionally, further direct ethnographic inquiry into daily life among persons suffering

from conditions that *can* lead to transplantation (focused, for example, on the daily management of chronic conditions like diabetes, heart disease, renal failure and dialysis, to name a few) would undoubtedly yield additional valuable insights.

Caregiving

...and Gender

The scenarios I observed in the field alternately upheld and disassembled gendered norms. We might speculate about the reasons why this is so. Perhaps it has to do with changing values surrounding gender and caregiving. Perhaps it has to do with expectations that transplant caregiving will be temporary, so that very long-term-care arrangements (which might fall more toward women) are not considered necessary. Perhaps it has to do with the fact that transplant care often is for patients in younger age ranges, so that women are more likely to have full-time paid employment that prevents them from being able to be full-time informal care providers, and/or so that male spouses are more likely to be well, able-bodied, and able to fill the caregiving role. I have tried to highlight gender as one important facet among many which comprise transplant caregiving as a complex phenomenon. But large-scale research focused more directly on the subject of gender and transplant caregiving would undoubtedly yield additional useful empirical data and greater insights into these matters.

...and (Non-) Kinship

Next, in light of the fact that it was exceedingly difficult in this research to recruit equal numbers of caregivers who were kin versus non-kin, lingering questions about kinship and caregiving come to the fore. Are non-kin the caregivers of last resort in informal care? Would it have been as difficult in other regions and contexts within the U.S. to find transplant patient-caregiver pairs and groups who didn't consider themselves to be kin? How about in other socio-cultural and global contexts? We surely could understand more with further comparative cross-cultural and cross-regional (and historical) work specifically on caring practices in high-tech health care.

...in the LGBTQ Community

In addition, while I spoke with no patients or caregivers who identified themselves to me as lesbian, gay, bi-sexual, transgendered, queer, or questioning their

sexuality, I also had not included this as a specific question in my interview protocols. Research on kinship and caregiving has not been altogether absent in either anthropology (e.g., Borneman 1997; Weston 1991), or in social work (e.g., Fredriksen 1999). Further, empirical data suggests that members of the LGBTQ community do indeed provide a notable portion of informal care in the U.S. For example, in their large study of caregiving responsibilities among gay men and lesbians (N=1,466), Fredriksen (1999) found that 27% were caring for another adult with an illness or disability. Within this group, 61% were caring primarily for friends, 16% were caring for parents, 13% were caring for partners, and 10% were caring for other adult family members. But much more research is needed which pays closer attention to the experiences of members of the LGBTQ community, in order to more fully understand kinship and caregiving in general, and home-based transplant care in particular.

Changes Over Time in Health Policy and Home Life

The movement of so many aspects of medical care back into domestic spaces and into the hands of informal caregivers is part of a larger historical and political-economic moment, and is intricately tied to matters of U.S. social and health care policy, which likewise are undergoing significant changes even at the writing of this dissertation. How will kinship, caring, houses, and home life factor into the implementation of the new health care reforms, especially with increased support for home-based care through the CLASS Act and Medicaid's Community First Choice Option? How will the reforms shape the phenomena I have documented here? Presently, even those gains made with the 2010 Patient Protection and Affordable Care Act – incomplete and imperfect as they may be – are in peril, as efforts are underway to repeal the act altogether (“Statements to the Legislative Branch: NASW Opposes Repeal of the Patient Protection and Affordable Care Act” 01/12/11). Future longitudinal research will be crucial not only to understand the theoretical implications for how policy intermingles with lived experiences, but to anticipate practice strategies that will continue to improve the lives of all persons, especially the most vulnerable.

FINAL THOUGHTS

Much could be realized by making the broader moral issues of health, illness, and care resonate more closely with the local contexts of our daily lives. Medical anthropologists, social workers, and others whose domains of inquiry include illness and suffering understand that socio-cultural values, practices, expectations, processes, institutions, and other conventions, play a profound role in producing human affliction. As I have tried to demonstrate here, everyday moralities concerning kinship and other obligations, as they are lived in the context of home life, articulate with biomedicine in ways that have significant consequences for how health care is both experienced and practiced. While high-tech biomedicine can offer near-miraculous forms of healing, if it causes social suffering (Kleinman, Das, and Lock 1997) in its own right, and moreover cannot be accessible to all (because of cost, because of limited supplies, because of various forms of bias, or for whatever reason), it is crucial that we explore and advocate for alternative paths that might more broadly fulfill our obligations in social solidarity with one another. The capacity to accomplish better health care for all hinges on social workers and practicing anthropologists continuing to work not only at the interpersonal level in health care, but also at the macro, policy levels, where they can ensure that policy changes are informed by social justice concerns. It also will require sustained interdisciplinarity, and concerted, thoughtful integration of empirical research and theoretical insights from both social work and the social sciences.

Appendix 1:
Semi-Structured Interview Protocol Used With Patients

“Transplanting Kinship - Organ Transplantation, Kinship,
and Daily Life in the U.S.”

Semi-Structured Interview Protocol: PATIENTS
Principal Investigator: Laura L. Heinemann, MSW, MA

1. Could you begin by telling me a little bit about yourself? (allow participant to answer in open-ended manner, and then follow-up with prompts as needed)
 - a. *How old are you?*
 - b. *Are there any particular racial or ethnic groups with which you generally identify?*
 - c. *Where do you live?*
 - d. *Where are you from?*
 - e. *Do you have someone in your life that you consider to be your partner (married or otherwise)?*
 - f. *Do you have children? (If “YES”: What are their ages?)*
 - g. *Where do other members of your family live?*
 - h. *What do you do for a living?*
 - i. *Do you currently work?*
 - j. *Does anyone in your household currently work? (Ask only if no household members have paid employment: If neither you nor anyone in your household are working outside the home, what are your sources of income?)*
 - k. *Do you feel you have enough income to meet your/your family’s needs?*
 - l. *How are your medical costs covered? (insurance? out-of-pocket? other?)*
 - m. *Do religion or spirituality play a role in your life? (how so?)*
2. How would you describe the community you live in?
3. Could you tell me about your family? For example, who lives in your household? What are the age(s) of your child(ren)? Who else do you consider to be part of your family?
4. Could you tell me about your home? What does “home” mean to you?

TRANSPLANT/ILLNESS EXPERIENCE

5. Could you tell me about when and how you found out that you were/was going to need a transplant?
6. When you were told that you were going to need a transplant, what did that mean to you? (*Prompt: What was it like? How did you feel about it? What sorts of thoughts did you have about it? Was it unexpected, or did you have a feeling that a transplant would someday be necessary?*)
7. At what stage in the transplant process do you consider yourself to be?
8. How did transplant/has the need for a transplant affected your daily life? What have you had to do differently now?
9. As I understand it, the transplant team places a lot of emphasis on the need to follow medical instructions. Can you tell me about how it's been for you to do everything the doctors, nurses, and other staff members ask you to do? What, so far, has been the most difficult to do?

PATIENT-CAREGIVER RELATIONSHIP QUESTIONS

10. What sorts of things have you noticed about your relationships or interactions with others as you go through the transplant process? (*Prompt: With family? Friends? Co-workers? Neighbors? Others?*)
11. What person or persons have helped you the most through the transplant process so far?
 - a. How would you describe your relationship to this/these person(s)?
12. How were decisions made about who would help you through the transplant process?
 - a. *Was there anyone in particular that you turned to right away? (If so, why did you turn to this person or persons, as opposed to others?)*
 - b. *Did you have to ask or convince someone to help you, or did someone offer right away? Can you tell me about this?*
13. During your hospital stays, what sorts of things did/has (*name of care partner(s)*) do/done?
 - a. How or in what ways did they help out?

- b. Where did they stay while you were in the hospital?
14. What sorts of things does (*name of care partner(s)*) help you with currently?
15. What has it been like to have (*name of caregiver(s)*) help you out in these ways?
16. Have the types of things that you need help with changed over time? In what ways?
17. What sorts of things have you noticed about your relationship with (*name of caregiver(s)*) as you've gone through the transplant process together?
18. What clinical professionals have played the most significant role in the transplant process for you?

QUESTIONS ABOUT HOSPITAL AND HOME SPACES

19. What has it been like to spend time at the hospital?
20. Has/Did your room ever start(ed) to feel like a home to you? Why or why not? (Can you tell me more about this?)
21. Can you tell me what a typical day is like for you right now?

ARENAS OF CONSTRAINT

22. Have you run into any obstacles or experienced any constraints on your way to having a transplant or at any point throughout the process? (*Prompt: Healthcare coverage? Work? Everyday needs? Family needs? Stigma of any kind? Other tangible needs? Other psychosocial needs?*)

If "YES":

- a. What were they?/What happened?
- b. Was it unexpected?
- c. How have you dealt with that?
- d. What sorts of things – if any – have helped you to get back on/stay on track?
23. What would you say are your main concerns for the future, from your perspective now?

GENERAL PERCEPTIONS

24. Before you yourself became so familiar with transplantation through personal experience, what did you know about it and what were your thoughts and opinions about it?

25. And what are your general thoughts about transplantation now? (*Prompts: How has that changed from before? If someone who knew nothing at all about transplantation were to ask you to explain it to them, how would you do this? What would you tell them?*)
26. Before we end this part of the interview, do you have any questions that you would like to ask me?

UNSTRUCTURED PORTION OF INTERVIEW:

Is there anything I've asked you about so far that you'd like to say more about?

Is there anything that you can think of that has been important or significant in your experiences with transplant or daily life that I haven't asked you about?

(The PI will ask questions as appropriate to the direction of the interview from this point forward.)

Thank you so much for your time and for sharing your experiences and perspectives with me.

Appendix 2:
Semi-Structured Interview Protocol Used With Caregivers

“Transplanting Kinship - Organ Transplantation, Kinship,
and Daily Life in the U.S.”

Semi-Structured Interview Protocol: CAREGIVERS
Principal Investigator: Laura L. Heinemann, MSW, MA

1. Could you begin by telling me a little bit about yourself? (allow participant to answer in open-ended manner, and then follow-up with prompts as needed)
 - a. *How old are you?*
 - b. *Are there any particular racial or ethnic groups with which you generally identify?*
 - c. *Where do you live?*
 - d. *Where are you from?*
 - e. *Do you have someone in your life that you consider to be your partner (married or otherwise)?*
 - f. *Do you have children? (If “YES”: What are their ages?)*
 - g. *Where do other members of your family live?*
 - h. *What do you do for a living?*
 - i. *Do you currently work?*
 - j. *Does anyone in your household currently work? (Ask only if no household members have paid employment: If neither you nor anyone in your household are working outside the home, what are your sources of income?)*
 - k. *Do you feel you have enough income to meet your/your family’s needs?*
 - l. *How are your medical costs covered? (insurance? out-of-pocket? other?)*
 - m. *Do religion or spirituality play a role in your life? (how so?)*
2. How would you describe the community you live in?
3. Could you tell me about your family? For example, who lives in your household? What are the age(s) of your child(ren)? Who else do you consider to be part of your family?
4. Can you tell me how you know/are related to *(name of patient)*?

TRANSPLANT/ILLNESS EXPERIENCE

5. Could you tell me about when and how you found out that *(name of patient)* was going to need a transplant?
6. When you were told that *(name of patient)* was going to need a transplant, what did that mean to you? *(Prompt: What was it like? How did you feel about it? What sorts of thoughts did you have about it? Was it unexpected, or did you have a feeling that a transplant would someday be necessary?)*
7. At what stage in the transplant process do you consider *(name of patient)* to be?
8. How did transplant/has the need for a transplant affected your daily life? *(Prompt: How has it changed your life? How has it changed what you do every day? Etc.)*

PATIENT-CAREGIVER RELATIONSHIP QUESTIONS

9. What have you noticed about your relationships with or interactions with others as you go through the transplant process with *(name of patient)*? *(Prompt: With family? Friends? Co-workers? Neighbors? Others?)*
10. Do you have someone that has helped you to help *(name of patient)* through the transplant process?
 - a. How would you describe your relationship to this/these person(s)?
11. Is there anyone else in your life right now that you're also helping out or caring for on a regular basis?
12. How were decisions made about your helping *(name of patient)* through the transplant process?
 - a. *Why are you a caregiver, rather than someone else?*
 - b. *Was it a difficult decision for you to agree to fill this role?*
 - c. *Looking back now, do you feel you had a good idea about what it all would entail?*
13. During *(name of patient)*'s hospital stays, what sorts of things did you do/have you done?
 - a. How or in what ways have you been helping out?
 - b. What sorts of things have you had to learn how to do?
 - c. Where did you stay while you were in the hospital?

14. What sorts of things do you currently help out with?
15. What has it been like to help out in these ways? (*Prompt: Has it been difficult? Can you tell me more about this?*)
16. Have the types of things that you help with changed over time? In what ways?
17. Can you tell me what a typical day is like for you right now?
18. What have you noticed about your relationship with (*name of patient*) as you go through the transplant process together? In what ways?

ARENAS OF CONSTRAINT

19. Have you run into any obstacles or experienced any constraints on (*name of patient*)'s way to having a transplant or at any point throughout the process? (*Prompt: Healthcare coverage? Work? Everyday needs? Family needs? Stigma of any kind? Other tangible needs? Other psychosocial needs?*)
If "YES":
 - a. What were they?/What happened?
 - b. Was it unexpected?
 - c. How have you dealt with that?
 - d. What sorts of things – if any – have helped you to get back on/stay on track?
20. What would you say are your main concerns for the future, from your perspective right now?

GENERAL PERCEPTIONS

21. Before you yourself became so familiar with transplantation through personal experience, what did you know about it and what were your thoughts and opinions about it?
22. And what are your general thoughts about transplantation now? (*Prompts: How has that changed from before? If someone who knew nothing at all about transplantation were to ask you to explain it to them, how would you do this? What would you tell them?*)
23. Before we end this part of the interview, do you have any questions that you would like to ask me?

UNSTRUCTURED PORTION OF INTERVIEW:

Is there anything I've asked you about so far that you'd like to say more about?

Is there anything that you can think of that has been important or significant in your experiences with transplant or daily life that I haven't asked you about?

(The PI will ask questions as appropriate to the direction of the interview from this point forward.)

Thank you so much for your time and for sharing some of your experiences with me.

Appendix 3:
Semi-Structured Interview Protocol Used With Clinical Personnel

“Transplanting Kinship - Organ Transplantation, Kinship,
and Daily Life in the U.S.”

Semi-Structured Interview Protocol: CLINICAL PERSONNEL
Principal Investigator: Laura L. Heinemann, MSW, MA

1. Could you begin by telling me a little bit about yourself?
2. As you know, my study is looking at family and kinship relations among those who have had first-hand experiences with transplantation. Could you tell me about your family?
3. Could you explain to me what your job is at The Health System/Transplant Center?
 - a. *What is your title?*
 - b. *Where do you work?*
 - c. *Do you work full time or part time?*
 - d. *How long have you worked here?*
4. What did you do before you came to work here? (*Prompt: Have you always been a [occupation/title]?*)
5. Could you walk me through what a typical day is like for you at work?
6. In what capacity do you interact with patients?
7. In what capacity do you interact with patients' family members?
8. In what capacity do you interact with patients' caregivers?
9. How common (or not) is it for the patient's caregiver to be someone who is not related to them by blood, marriage, or adoption?
10. How do decisions tend to get made about who will step into the caregiver role for any given patient?

- a. *Is there anyone in particular that patients tend to turn to right away? (If so, why do you think that is so?)*
11. Do you ever see instances in which there is difficulty or tension or any sort of struggle for patients in trying to determine who will help them through the transplant process? *If “YES”:*
- a. *Could you tell me more about this?*
- b. *How do these instances tend to get resolved? (Who or what helps to resolve them, or, on the other hand, may prevent their resolution?)*
12. Are there any general things that you’ve noticed or come to know through experience about the role of the caregiver in helping a patient get through the transplant process?
- a. *Do you find that the way in which the patient and caregiver are related to each other makes a difference?*
13. In your experience, does going through the transplant process in any way change the relationship between the patient and their caregiver(s)?
- a. *In what ways?*
14. Thinking about some of the patients you’ve worked with who seem to get through the transplant process in the most successful and smooth way, is there anything that you’ve noticed about these patients or their circumstances that seems to help them or work particularly well for them?
15. And now, thinking about some of the patients you’ve worked with who really seem to struggle through the transplant process, or who really run into problems or struggles along the way, is there anything that you’ve noticed about these patients or their circumstances that seems to hinder or constrain them, or to really just make things more difficult for them?
16. How big a part does healthcare coverage seem to play in transplantation?
17. In what ways are patients’ lives changed through transplantation? *(Prompt: With regard to family life? Work? Social status? Ability to meet their needs? Etc.)*
18. From what you know and what you’ve seen through your work, what sorts of things do you think often happen in the lives of patients and their caregivers, family, friends, neighbors, etc., once they leave the hospital after a transplant?
19. Has any personal experience with illness affected your own daily life?
20. Have you ever had a personal experience with providing health-related care to a family member?

(If “YES” to EITHER 19 or 20):

- a. Do you think that your own experiences with illness and/or with providing health-related care to one of your own family members in any way affects how you work with patients and their families or friends?
21. How has working in the transplant field affected your life? (*Prompt: How has it changed your life? How has it changed what you do every day or how you think about the world? Etc.*)
22. Has working in the transplant field affected your relationships with others in any ways? (*Prompt: With family? Friends? Co-workers? Neighbors? Others?*)
23. Before you yourself became so familiar with transplantation through professional experience, what did you know about it and what were your thoughts and opinions about it?
24. And what are your general thoughts about transplantation now? (*Prompts: How has that changed from before? If someone who knew nothing at all about transplantation were to ask you to explain it to them, how would you do this? What would you tell them?*)
25. Have you noticed any general trends or changes in transplantation overall since you’ve started working in this field? (*If “YES”: Can you tell me about them, or explain them to me?*)
26. Before we end this part of the interview, do you have any questions that you would like to ask me?

UNSTRUCTURED PORTION OF INTERVIEW:

Is there anything I’ve asked you about so far that you’d like to say more about?

Is there anything that you can think of that has been important or significant in your experiences with transplant or daily life that I haven’t asked you about?

(The PI will ask questions as appropriate to the direction of the interview from this point forward.)

Thank you so much for your time and for sharing some of your experiences with me.

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