

# Accommodating care

Transplant caregiving and the  
melding of health care with home life  
in the United States

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## Abstract

In this article, I explore how medical care responsibilities in the United States are shifting away from formal clinical contexts and into the home. Using organ transplant-related care as an illustrative example of this larger phenomenon, I trace the incorporation of health care into the home using three cases from ethnographic fieldwork near a major transplant center in the midwestern United States. Here, patients and loved ones transform their dwellings, lives, and relationships to attend to the demands of transplant medicine. Bringing together literature on hospitality, caregiving, houses and homes, and place and space in health care, I offer ‘accommodating care’ as a framework for understanding the materializing practices of home-based transplant care. This approach suggests avenues toward studying larger questions about the distinctiveness and overlap of medicine and home life.

## Keywords

informal family caregiving, home, clinic, US health care, organ transplantation

## Bringing the hospital home

During a brief phone conversation with Marvin<sup>1</sup> early one morning to confirm our plans to meet, he reminded me to ‘go ahead and ring the doorbell’ when I arrived, but then to just let myself in. Having been discharged from the hospital just days prior, after being readmitted for a persistent infection related to the liver transplant he had received over four months ago, he still moved about with some difficulty. His wife would not be available to answer the door, since she had already returned to working during the day; Marvin’s income from his disability insurance was not enough to cover the regular household expenses each month. So, after ringing the doorbell, I paused only to listen for a ‘Come on in’ from the upper floor of the couple’s split-level house. I climbed the half-flight of stairs from the entryway to their living room, where I was greeted by a man with a straight mouth but kind eyes who looked older and frailer than his actual age of late-fifties. He was seated in a large reclining chair surrounded by an IV pole and several five-gallon-sized white plastic bags that quite literally were overflowing with medical supplies: tubing, syringes, wound-dressing materials, medication vials, and bottles of pills. Slightly off to one side was a walker, which he used for trips to the bathroom or kitchen. On the other side, also within arm’s reach, was an end table on which a cordless telephone, two remote controls, and a glass of water were neatly arranged.

On the dining room table behind Marvin was a row of slightly wilted floral bouquets, green plants in foil-wrapped pots, and half-deflated shiny Mylar ‘Get Well Soon’ balloons slowly swooping and swaying in the ceiling fan’s breeze. This expression of well wishes from family and friends created a backdrop that likewise framed this area of the house, as though 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-health care company supplying the remainder of the medical equipment, it all intermingled with the furnishings and arrangement of his living room to create a place where ‘clinic’ met ‘home’ in both form and function.

Social scientists paying close attention to organ transplantation have documented the unease that can surround this collection of practices, using descriptors like ‘tyrannous’ (Fox and Swazey 2002 [1974]) and ‘strange’ (Sharp 2006). Manderson and Smith-Morris (2010, 21, 37) point out that global economic relations and biotechnological capabilities – rather than the ‘natural course’ of disease – increasingly shape the temporality and severity of health problems, including organ failure. The adoption of particular medical interventions likewise

<sup>1</sup> The names of all persons and places are pseudonyms.

depends on the extent to which they fit into local contexts, as evidenced by the rejection of organ procurement from ‘brain-dead’ individuals in Japan (see Lock 2002). In the United States, owing to the confluence of particular normative values with technological and economic capacities, popular imaginings tend toward a comparatively sanguine outlook on transplantation.

Widespread assumptions hold that, for recipients, a grafted organ brings a rapid return to life without illness, despite the reality that the road to, through, and beyond transplantation is long and riddled with uncertainty. Patients seeking care in major US healthcare settings undergo long and arduous pre-transplant screening, therapies, and treatments; regular dialysis (if in renal failure); and indefinite post-transplant monitoring and immunosuppression. It follows that transplant-related experiences and demands steadily make their way into the broader context of daily living, where ordinary home and family life must in some manner continue on for transplant hopefuls, recipients, and those close to them. The long-term, life-prolonging capabilities of transplant medicine in fact rely heavily on the very ability of patients and loved ones to accommodate complex treatment and maintenance regimens over time by incorporating them into their daily lives. Life-in-the-balance must be brought into life-as-usual.

With an eye toward understanding how participants in an ethnographic study in the midwestern United States managed to integrate these domains, I draw attention to some of the ways in which health care dovetails with home life. Rather than focusing on the more unique, and sensational, aspects of transplantation, I explore it here as a window onto the larger, and growing, interweaving of biomedicine and contemporary daily life in the United States. Employing the conceptual trope of ‘accommodating care’, I describe how some recipients and their families ‘make room’: to house the material artifacts of intervention-intensive health care, to cosset various types of high-tech biomedical machinery, and to live with (and within) the moral and political economic realities of illness, surgical recovery, and longer-term post-transplant needs. Using ethnographic observations and interview data, I shed light on the creative uses of home space and innovative caring practices employed by patients and loved ones as they attend, as hosts, to the evolving demands of transplant care over time. Such a perspective, I suggest, opens up fruitful questions about ongoing shifts in health care as it moves between hospitals and homes. It likewise brings longstanding theoretical perspectives into dialogue with innovative forays into anthropologies of care and hospitality, furthering our efforts to examine human relations in such juxtaposed moral contexts.

## From home to hospital . . . to home

Houses and homes have accommodated human journeys through cycles of illness (along with birth, life, and death) across historical and ethnographic contexts. Indeed, until well into the twentieth century, most care in the United States was provided in homes by female kin, neighbors, and domestic workers, many of whom developed skillful expertise and authority regarding matters of health, as Abel (2000) describes. But with new developments in biological sciences and other facets of what Starr (1984) calls a ‘tilt toward technology’, health matters came to be absorbed under an increasingly medicalized ‘gaze’ (Foucault 1973 [1963]). By the early twentieth century, many forms of health-related care were rapidly moving out of the hands of women in the home, and into the hands of professional clinicians trained and practicing in formal clinical, biomedical spaces (Abel 2000; also see Starr 1984, 348).

Further changes in recent decades, however, are spurring a return – or at least a partial return – of health care back into US homes. The rise of highly cost-conscious managed care, neoliberal efforts to reduce state-financed health care spending (particularly in the US federal Medicare and state Medicaid programs), and an amplified market-centric concern with profit throughout the health care and insurance industries now coalesce to curtail expensive hospital stays substantially. Even patients who undergo intensive and highly technical medical procedures today spend only a fraction of their time in formal clinical settings (Casida 2005; Cartier 2003; Levine 1999; Williams 2002). This transformation has its parallels elsewhere as well, situated as it is within the wider frame of neoliberal-style global capitalism. Exley and Allen (2007), for example, document a similar ‘(re)domestication’ of care in the United Kingdom.

Organ transplantation and related biomedical interventions are no exception. Refinements in medical equipment, surgical procedures, and drug therapies – in concert with political-economic factors – now make it possible for much transplant-related care to take place outside the hospital, in private homes (see Eilers et al. 2005; Guberman et al. 2005; and Glazer 1990). Patients’ needs and the technologies that can accompany them require family caregivers, and often even patients themselves, to quickly learn skills and tasks that professional nursing staff might previously have performed (Cartier 2003; Casida 2005; Mattingly, Grøn, and Meinert 2011). This form of ‘responsibilization’ (see for example Rose 2007, 4) comes with rather high stakes. As Abel (2000, 257) notes, now ‘patients arrive home sicker as well as quicker’. Further, while ‘nineteenth-century women struggled to retain jurisdiction over skilled medical care . . . caregivers today complain about being entrusted

with responsibilities that far exceed their capabilities' (Abel 2000, 258).<sup>2</sup> These observations provoke us to ask how persons who are bound together in webs of care manage these mergers, particularly in light of the effects of neoliberalism in households constrained by inadequate incomes, a market-based health care system, and a sparse social safety net. They also point us toward inquiring into the ways in which households and more formal clinical domains intersect and interact.

Others have likewise begun to explore these articulations. Examining care for injured soldiers under the US Army's Non-Medical Attendant program, Wool and Messinger (2012, 27) argue that, as family members assume care responsibilities, 'the care of kin [can be subjected to] the logic of the clinic'. Guberman et al. (2005), on the other hand, point to vast ecological differences between homes and hospitals. Notably, at home, unlike the hospital, professional support is not necessarily available at the push of a call button. Mattingly, Grøn, and Meinert (2011) characterize the movement of chronic illness care from the clinic to the home as a 'borderland practice'. In contexts as diverse as Uganda, Denmark, and the United States, they demonstrate, 'homework regimes emerge as creative and unstable activities the forms of which are substantially shaped by the continual local reinvention in home and community spaces' (Mattingly, Grøn, and Meinert 2011, 352). My own findings similarly highlight the imaginative practices and material innovations that emerge in the course of daily living, as 'home life' intermingles with 'health care', and as kin assume responsibilities once reserved for clinicians.

## Accommodating care as a materializing practice

Transplant hopefuls and recipients, together with their loved ones, make accommodations in order to manage the demands of transplant-related care and to secure the desired outcomes of the procedure. These accommodations, which I suggest might be conceptualized together as 'accommodating care', are materializing practices: they encompass both the things people do to sustain each other throughout the transplant process, and the substantive forms such caring practices give rise to. As such, 'accommodating care' is both the means for managing this movement of high-tech health care into the home, as well as a spatial manifestation of the inventive ways in which patients and loved ones make room for, adjust to, and house

<sup>2</sup> While care work today continues to be largely performed by women, men are increasingly conscripted into caregiving roles (for example, Kramer and Thompson 2002). A thorough examination of gender and caregiving, however, is beyond the scope of this article.

medical care over time. Such a perspective has both theoretical and methodological implications, and brings together studies of care, space and place, ‘the house’, and hospitality.

This framework resonates with Arthur Kleinman’s (2012) call for closer anthropological attention to care and caregiving. It leans, as well, on expansive notions of care to include both ‘caring about’ and ‘caring for’ (see Glen 2000). Fisher and Tronto (1991, cited in Tronto 1993, 103), understand care as multidirectional and social (rather than individual or dyadic), potentially ongoing, and inclusive of ‘everything we do to maintain, contain, and repair our “world” so that we can live in it as well as possible’. This ‘world’, further, is composed of all the interwoven components of a ‘complex, life-sustaining web’ (Fisher and Tronto cited in Tronto 1993, 103). Using this lens, we see the mutual dependence of patients and caregivers, who likewise are beholden to others in a web of reciprocal relations. Acts of accommodating care are carried out among interrelated persons operating within a ‘logic of care’, as described by Mol (2008, 62). Further, caregivers with myriad obligations cannot always be immediately available, and often must find proxies for their care. Patients must at times care for themselves. An expansive notion of care, I suggest, can open up our analytical framework to also include material objects and spatial arrangements as among the ‘agents’ of care.

My analysis is also informed by recent work on place and space in contemporary health care, including on the emplacement of health care (for example Kaufman 2003), and the ‘place-worlds’ (Casey 2003, 2245) in which health care today variously is carried out. Williams (2002) looks to the ‘therapeutic landscape’ (following, for example, Gesler 1992) as a springboard for investigating the shift to home-based informal medical care and the implications of what she calls the ‘changing geographies of care’. Describing ‘the spatial manifestation of care’, Milligan (2003, 462) suggests that, as patients’ health care needs increase, rooms within homes are transformed by increasingly ubiquitous medical equipment and practices, such that the meaning and experience of home can change. By comparison, Hodgetts and colleagues (2011, 360) examine the ‘emplacement’ of medications in domestic spaces in New Zealand, documenting how the placement and consumption of medications in the home ‘weaves together person, place and material objects’ in a way that constitutes the home as a space for care.

Focusing on the material evidence of accommodation also resonates methodologically with the work of ethnologists who look to houses and homes for a glimpse into some of the symbolic, material, and practical ways in which people negotiate the inconsistencies and contradictions in social life, especially in contexts marked by significant social upheaval. For example, Carsten (1995), expanding from Levi-Strauss’s work on ‘the house’, shows us that houses are capable of revealing at once the harmony, tensions, and changes in the social relations that are enacted within them. This is particularly relevant in the case of home-based

transplant care among loved ones, intimately tied to one another through moral relations that could at once be tender and frustrated, steady and teetering.

In his classic analysis of the Kabyle house, Bourdieu (2002 [1977], 90) suggests that the relations between human action and the object world, what he called ‘the dialectic of objectification and embodiment’, can best be grasped via ‘the space of the house’, so long as we not forget that our world is ‘read with the body’. While recognizing that the body has rightfully figured prominently in anthropological analyses of transplantation<sup>3</sup> (see, for example, Scheper-Hughes 2002; Cohen 2002; Sharp 2000, 2006; Lock 2002), by examining the home, too, as an emergent cultural form where material, meaning, and practice coalesce, I offer here a ‘cross-fertilization’ of ideas (Sharp 2000, 289, 314–315). And by tracing those facets of transplantation that extend beyond the procedure itself, and into everyday home life, I hope to foster continued dialogue between transplant scholarship and other anthropological areas of inquiry.

Further, ‘accommodation’ evokes notions of ‘hospitality’, a domain that for some time has received scant attention in anthropology, yet, as Candea and da Col (2012, S15) argue, is poised to serve as a ‘theoretical elevator’ in the field. Like the gift in Mauss’s (1967 [1925]) classic analysis, hospitality and hostility can run in the same vein (Candea and da Col 2012, citing Derrida 2000), entailing dual possibilities of mutuality and parasitism, generosity and exploitation. While guests are in some manner at the mercy of their host, hosting, too, can be risky: both share mutual liabilities and vulnerabilities, as Shryock (see, for example, 2004) describes in his work among Balga Bedouin in Jordan. Guest, host, and the materialities of the house come together necessarily and with consequence. Hospitality can affirm, consolidate, and solidify relations, and it can also transform both host and guest, as Selwyn (2000) argues. Notably, acts of hospitality are mediated through carefully prepared food, drink, and spaces. Citing Orter’s *Sherpas through Their Rituals* (1987) Candea and da Col (2012, S9) argue that, when enacted through substances, hospitality ‘does not merely *elicit* cooperative responses, but *coerces* them’ (emphasis in original). As an analytical paradigm, hospitality is applicable across a broad range of contexts, even extending to non-human beings as diverse as Lao ancestral ghosts, welcomed via the organizing of a party, and malarial parasites that make hosts of both humans and mosquitos (Ladwig 2012 and Wagner 2012, discussed in Candea and da Col 2012).

These studies inspire fruitful analyses of transplant caregiving in the home: through careful uses of home spaces and furnishings, and by enacting clinical care in substantive ways,

<sup>3</sup> This work builds upon foundational insights and ongoing careful attention to the body in medical anthropology (see, for example, Scheper-Hughes and Lock 1987; Taylor 2005).

patients and caregivers effectively serve as ‘host’ to US biomedical health care. By incorporating this collective entity into their home life, transplant recipients and their families enact an implicit hope that transplant medicine will sustain life and health, so that their private worlds (returning to Fisher and Tronto 1991) might be repaired. Yet, alongside the thrust of cost-savings measures in market-based health care that propel such large-scale relocations of clinical care to homes, the ties that bind medicine to home life also compel accommodation by patients and loved ones.

## Methods and sample

For a total of twenty-four months between 2007 and 2010, I conducted ethnographic fieldwork near a major transplant center, in a US midwestern city I call Metrotown.<sup>4</sup> This was part of a larger endeavor to learn about the intermingling of transplantation with kinship beliefs and practices, particularly among patients and caregivers. In private homes, inpatient and outpatient clinical spaces, patient education cubbies, and conference rooms, I sought the perspectives of a total of one hundred people: adult transplant patients, their caregivers and other loved ones, and clinical professionals. I came to know the participants in this study at all stages of the transplant process. Some had just begun the series of appointments and clinical evaluations required before transplant surgery; others had already been placed on one or more transplant waiting lists; and still others had received a transplant days, weeks, months, or, in a few cases, years ago. Attuned to the fact that conversations about transplantation inevitably would broach sensitive issues, I looked to qualitative research on sensitive topics (for example, Corbin and Morse 2003), and qualitative methodologists in social work (for example, Padgett 1998) for methodological guidance.

With written, informed consent, I interacted with participants in semi-structured and open-ended interviews (the vast majority were conducted face-to-face,<sup>5</sup> and recorded with participants’ permission<sup>6</sup>), but I also regularly engaged in informal conversations and participant observation in clinical, home, and public settings, keeping detailed ethnographic

<sup>4</sup> I have described these methods elsewhere as well (Heinemann 2011, 2014).

<sup>5</sup> In rare instances, participants preferred telephone interviews.

<sup>6</sup> I took detailed handwritten notes during interviews with the few participants preferring not to be audio-recorded.



fieldnotes throughout.<sup>7</sup> I compiled and analyzed the data I collected using the qualitative data analysis software program QSR NVivo, which allowed me to search, group, code, and analyze for themes, patterns, and comparisons. Several of the people I met during fieldwork, through the sorts of hospitality on which many ethnographic insights are so dependent (see Candea and da Col 2012), ushered me toward more holistic and deeply personal perspectives on home and family life. Participants graciously welcomed me into their homes and lives, sharing food, drink, photos, and long conversations, during periods of convalescence and times of celebration alike. In this article, I discuss three illustrative cases from the larger body of data I gathered during home visits.

Owing both to logistical circumstances and the composition of the transplant center's patient population, I spoke most often with those involved in kidney transplants, followed by liver, blood-forming stem-cell, pancreas, and small-bowel transplants. There are relevant differences between these procedures and the illnesses with which they are associated, as I have discussed elsewhere (Heinemann 2011, 2014). The dissimilarities between kidney transplantation and blood-forming stem-cell transplantation, for example, are not trivial. Still, common ground across transplant types promised that analyzing them together might prove productive. For instance, and especially germane to this article, each involves the use of intensive medical procedures, followed relatively soon after by outpatient, generally home-based recovery, long-term reliance on a post-transplant pharmaceutical regimen, and watchful vigilance against rejection, infection, and other complications.

This approach yielded data on a diverse array of perspectives, enabled detection of patterns that spanned transplant types, and helped situate transplantation in relation to broader sociocultural phenomena in health care, caregiving, and other domains. Further, it enabled a comparative understanding of the transplant experience over time, ebbing and flowing between more acute health crises, and the careful long-term post-transplant balance of immunosuppression, health maintenance, and striving for a return to 'the normal', elusive as it may be (see, for example, Maynard 2006, 2010; Metzl and Kirkland 2010). The ethnographic cases I discuss here illuminate different temporal vantage points along the transplant process. Each also involves a different transplant type and surrounding circumstances. Together, though, they offer illustrations of patients and loved ones – here, married couples<sup>8</sup> – making accommodations for the complexities of transplant-related care in the context of home and family life.

<sup>7</sup> This research study received IRB approval from the University of Michigan, as well as the IRB board at the transplant center, which remains unidentified to maintain confidentiality.

<sup>8</sup> Spouses and domestic partners were most often the primary caregivers to patients in this study.

## Housing health care, augmenting obligations

People approach transplantation not only with the hope of living longer, but also with the desire to fulfill their obligations to others, which they may not be able to do in a state of grave illness (Heinemann 2014). Transplantation becomes a possible route out of the clutches of acute illness episodes, clinic visits, hospital stays, and sometimes precipitous decline, all of which ripple throughout larger webs of relations. But even following a successful transplant, daily life and its materialities, like car keys, kitchen tables, and steps up to a bedroom, can become juxtaposed against still more home medical supplies and ongoing curtailed mobility. My opening story of Marvin illustrates this tension.

As we talked during my first visit, Marvin spoke with nostalgia about growing up in this very same city, eventually weaving in his experiences with polycystic kidney disease, an earlier kidney transplant, and now his more recent liver transplant. With his children no longer living at home and his wife working full time, I asked how he and his family had been able to manage all of his health needs, especially in the early days after a hospitalization. Marvin explained that he actually performed much of his own care, routinely changing the dressings on the wounds he could reach; setting up and taking his medications, including those administered intravenously; and self-monitoring for any signs of infection. Moving slowly and with the assistance of a walker, he warmed his lunches in the nearby kitchen and used the bathroom as he needed.

These practices of self-care in fact are rather common, particularly when a primary informal caregiver, like Marvin's wife, has to maintain paid employment outside the home, whether for income, medical insurance, or both. Self-care also becomes routine when a patient's main caregiver does not live in the same house, as was often the case for recipients who had no spouse or domestic partner. Transplant patients are discharged from the hospital well before they have fully recovered. The post-discharge needs tend to be so great that the complete absence of caregiving support can be considered a contraindication for transplant altogether. It is beyond the scope of this article to more fully explore exclusion from transplant, and in fact there is a relative dearth of empirical literature on this topic,<sup>9</sup> particularly regarding the role of care. From my own observations, though, I can report that participants – often with the support of transplant social workers, nurses, and other clinicians – regularly put notable

<sup>9</sup> Although see, for example, Wolfe (2006) for a discussion of racial, socioeconomic, and other disparities in transplantation in the United States, and OPTN/SRTR Annual Reports ([http://www.srtr.org/annual\\_reports/](http://www.srtr.org/annual_reports/) and [http://srtr.transplant.hrsa.gov/annual\\_reports/2012/](http://srtr.transplant.hrsa.gov/annual_reports/2012/)) for documentation of extant differences across demographic categories among transplant recipients.

effort into piecing together adequate care arrangements. Adult children, friends, neighbors, and even coworkers might be conscripted into this role.

In Marvin's case, a layered team had been assembled. Augmenting periodic visits from a home health care nurse and Marvin's self-administered care, his brother and sister-in-law who lived a block away often helped with a wound on one area of his body that Marvin himself could not reach. His wife regularly checked in via phone during her workday, and he enjoyed calls and visits from other family and friends. Without this support, Marvin noted, his medical team 'wouldn't hesitate to tell you, "Well, you're going into a home"'. These stakes were recounted often by participants, who generally did prefer home-based care over clinic and hospital-based care, and decidedly over longer-term care in a nursing home. Marvin's experience, in fact, would be familiar to many in recovery from intensive biomedical procedures or struggling with ongoing illness or injury. Under several caregiving arrangements, patients might spend long stretches alone, especially after an initial settling-in period and as primary caregivers' other obligations come to the fore. Marvin and his wife were able to partially address this reality by widening the network of those who could periodically check on him.

But the gaps in this arrangement were also accommodated through the strategic use and placement of objects in the home. For instance, Marvin's chair had become a home health hub. It was particularly suited to adjust to his changing needs throughout the day: to sit up, lean forward or backward, elevate his feet, or sleep, with most of his essential objects carefully arranged to surround it. Martin quipped, 'I pretty much have everything I need here'. For changing his wound dressing, he needed only reach into a nearby bag for the supplies. To take his pills, Marvin had a glass of water ready and waiting. When he needed to get to the kitchen or bathroom, he could swing his walker around in front of him, and use it to stand and walk. Rather than a hospital call button, Martin had a fully charged cordless phone, ready if he should need immediate help. The chair itself had been placed close to the kitchen while still remaining with the living room area. This further enabled the accommodation of Marvin's needs, while still allowing the chair itself to retain its semblance as a quotidian household fixture.

Others repurposed the medical supplies themselves to meet additional health-related needs. One wife in another married couple used home peritoneal dialysis while she waited for a kidney transplant. This daily procedure required the use and storage of dozens of sizeable boxes of dialysate fluid each month. Since she had also begun to have greater difficulty sitting down on and getting up from the toilet, she and her husband decided to keep the dialysate boxes stacked and stored on each side of the fixture. In this manner, the boxes could readily be used as arm rests and leverage points, serving as makeshift assistive devices

for her purposes. Medical care could thus be reconciled with 'life as usual' through the emplacement of medical supplies in a way that blends the two categories.

Yet not all of this study's participants were so accepting of medical incursions into domestic space. Another couple, Bernard and Arlene, described the difficulties they faced as they watched their home being given over to store the materials necessary for Bernard's automated home peritoneal dialysis regimen. The need to store so many boxes added significantly to the strains brought by the nightly procedure itself. Arlene complained, 'Almost every room in the house is just dedicated to some sort of medical something. ... As I say, "Boxes, boxes, boxes!" It's a little problem but it becomes big after awhile'. As material and space are repurposed, a home's inhabitants may well alter their ways of going about day-to-day activities in relation to each other. The following case example offers further insight into how relations of caring practice become inscribed by ongoing efforts to accommodate multiple, diverse, and changing health needs over time. It suggests that, in the terrain of daily life, people who are beholden to one another must negotiate what needs to be done, and by whom, tracing amorphous boundaries in the face of dissonant circumstances.

## Accommodating multiple needs

Sitting together in the living room of their small house, located in a smaller neighboring city adjacent to Metrotown, Mary and Rob recounted how Mary came to need a liver, pancreas, and small-bowel transplant. Framed photos lined the walls, including school portraits of their children from each of their first marriages. Mary's extensive collection of cow and angel figurines filled the nearby shelves and TV console. Mary, in her early forties, had been transferred to the transplant center from a nonaffiliated hospital after a surgical error set in motion a cascading series of blunders that eventually destroyed these vital organs. The error had been made during a procedure intended to remove two cysts from her abdomen. Even beyond the destruction of her three organs and the transplant itself, Mary's health had been profoundly compromised by multiple complications over the past months.

Evidence of the couple's attempts to manage this massive influx of health care needs permeated their dwelling. Rob, in his early fifties, sat in a brown reclining chair, separated from Mary's by an end table that held papers, a cordless telephone, and a large plastic pill box – four rows by seven columns of individual compartments, each for a distinct time per day of the week. This grid-like tray, designed to help manage complex daily medication regimens, was an ever-present fixture for nearly every transplant patient I met during fieldwork. Sitting among these items were two insulated beverage holders, one a large plastic jug with a straw and handle that enabled Mary to use it even though her hands were

contracted tightly shut. This complication had developed during one of her many hospitalizations over the past several months. A cane, presently inadequate to meet Mary's ambulatory needs, sat propped against the sofa on the far side of the room. More telling, within reach of Mary's recliner was her walker. Her feet, too, had recently clenched into a 'dropped' position, and she'd had greater trouble walking since her most recent hospitalization. They'd not, however, had to reinstall the temporary wheelchair ramp some friends had helped to build during Mary's initial hospitalization. Hidden out of view were multiple boxes of medical supplies, which were stacked and stored in the couple's bedroom. This transformation of the bedroom space was common in many of the homes I visited, and noteworthy especially because bedrooms in recent decades have come to symbolize an ideal of leisure and 'escape' for members of the US middle class (Arnold et al. 2012). For Mary and Rob, it accompanied a palpable shift in their marital relationship.

Many of the boxes in the bedroom contained necessities for Mary's ileostomy bag changes, which had become a prominent part of everyday living. Small-bowel transplant recipients typically are given a stoma, which is a surgically created opening in the abdomen where waste is routed from the lower small intestine outside the body into a plastic pouch, or bag. This allows time to monitor the transplanted bowel before it is reconnected to the large bowel in a later surgical procedure. These ileostomy bag changes were among Rob's multiple responsibilities as Mary's main caregiver. They were extremely painful for Mary, whose skin had become highly sensitive to the placement and removal of the tape used to hold the bag in place. Keenly attuned to this, Rob poured extraordinary amounts of time, thought, and effort into performing them in such a way that they could be repeated as infrequently as possible. Rob returned several times to this topic during one conversation. His descriptions underscored the fact that they were something over which he carefully strategized and struggled, something he 'tinkered' with (Mol et al. 2010). He said, '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. ... I work on it, I try something different. I lay in bed and I think about it'.

Rob contrasted his own way of performing ileostomy bag changes to that of the inpatient nurses:

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 interjects: '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 continued, '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 attributed the difference to a matter of professional convention and institutional constraint: 'I'm not doubting the nurses. ... You're pretty much trained to do that. And that's good to some extent, but it's also not, to some extent'. I asked: 'Because it takes a little extra time?' He nodded, and replied, 'And they don't have that extra time'.

This lack of time is situated within the larger context of US health care, where professional efficiency responds to cost-conscious industry standards in nurse-to-patient ratios. The differences Mol (2008) describes between a 'logic of care' and a 'logic of choice' likewise apply here. In a 'logic of choice', patients are consumers and health care is a transaction; in a 'logic of care', care is a process of interaction, 'an open-ended process' in which persons '[t]ry, adjust, try again' (Mol 2008, 22). The comparison of Rob's care versus that of the nursing staff places care by clinicians and care by kin in separate moral domains. Yet, in the home, these domains must in some way come together.

Rob in fact had become so adept at accommodating Mary's clinical needs that one conversation with the couple continued virtually uninterrupted as a loud beeping sound suddenly emanated from a machine that was removing drainage from one of Mary's particularly stubborn wounds. Without pause, Rob rose from his chair and proceeded to change the battery pack and reset the device. Just minutes after, the interwoven threads of life as usual came to the fore when Mary's teenaged daughter called to ask permission to go to a friend's house after school. Rob agreed to pick her up later.

The performance of clinical care in the home by those who are closest to transplant patients has the potential to infuse relationships with profoundly complex tensions and contrasting sentiments. In straddling multiple domains while simultaneously attending to the needs of the household and the demands of transplant-related care, which routinely far precedes the transplant itself, loved ones like Rob slip back and forth between personal and professional, family member and health care worker:

Rob: 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. ... Like today 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 –

Rob: And I'm sorry but I just, and then I [have to convince] her to take her medicine and [I] do her bag changes and that makes her hurt. ... And I don't know how this is just gonna work out.

The significance of Rob's obligations, and the extent to which the family was working to reconcile Mary's clinical needs with daily life at home, had entwined themselves into the couple's marital relationship. The ileostomy bag itself, and Rob's dealings with it, posed a barrier to intimacy, with Mary plainly noting, 'There's no intimacy. There can't be'. Specifically, the couple's concessions to medical demands, while entailing very close bodily work, had supplanted sexual intimacy 'and all the playfulness that goes around that', as Rob remarked. The couple's home – including their bedroom, now arranged to house elements of the clinic – likewise offered material-spatial confirmation that their relationship had been recast from husband-and-wife to nurse-and-patient. But Rob's care also had to be accommodating to Mary's continued recovery, requiring a constant fine-tuning in his skill, knowledge, and technique. As Rob explained, '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. ... The more flexible she gets, the harder it is to keep it tight'. Transplant-related care needs thus can fluctuate substantially, demanding ongoing improvisation and creativity to appropriately attend to the changes brought by increasing temporal distance from the transplant itself. Over time, clinical needs often do recede, but they never fully disappear, as the final example below demonstrates.

## A health haven through lingering peril

I met Barry at the Transplant Olympics Team booth at the 2008 Solid Organ Transplant Reunion, hosted by the transplant center at a local hotel conference center. Now in his sixties, Barry had received a heart transplant fourteen years ago. When he heard about the research I was conducting, he invited me to his home where I could also meet his wife, Angela. Some days later, the couple ushered me through their cozy living room and over to their wooden dining room table. On this evening of our first interview, there were none of the pieces of medical equipment or get-well-soon cards and balloons that might mark their home as a 'hospitalized' space. Even Barry's pill organizer had been tucked out of sight. However, the couple together continued to use the spaces of their home in particular ways to accommodate Barry's ongoing medical care needs. For example, the immunosuppressant medications Barry takes to prevent his body from rejecting his transplanted heart make him highly susceptible to contracting common contagious illnesses, and protection from germs is a priority. The ordinary cold might be an uncomfortable inconvenience to most, but it put Barry at risk of serious health complications. Angela spoke about the fear that accompanies the vigilance:

The panic will never leave. And I mean, we are fourteen 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? ... And 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.

Angela includes herself, as Barry's caregiver, among those who might expose him to the dangers of contagion: 'You have to take care of yourself. 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?' Taking care of oneself as a caregiver in fact has a double valence for Angela. She has long held paid employment, but also conducts other activities outside of the house, including leading the children's choir in their church. She finds these practices offer periodic refuge from her position as an ever-attentive sentinel for Barry's health concerns, even fourteen years after his transplant. But while this is one of her ways of taking care of herself, Angela also notes that her activities outside of the home expose her to potential contagions, particularly from children with 'all of their little runny noses', as she put it. Maintaining her own well-being through stress-relieving activities simultaneously made it difficult to always avoid becoming sick (and contagious). Angela's needs in this sense could become pitted against Barry's. When I asked what happens if she does 'catch' something, Angela emphasized, 'You *have* to stay away from each other! You literally do because you know, I'm fearful that I'll give him something'.

During times when Angela might be contagious, each lives in a separate area of the house, with Angela in an extra bedroom and Barry sleeping on the couch in their media room – what has come to be 'his' room – in the basement. Fixing and eating his meals there, too, Barry can safely wait out Angela's communicable state. The couple thus had arranged the spaces within their home to serve as a backup quarantining system, each using particular areas of the house while carefully avoiding others. A precarious balance is managed in the imagination, creation, and maintenance of physical delineations. In this manner, the house offers protection, itself becoming a means for Angela to reconcile her role as Barry's wife and caregiver, with her equally important needs outside of these capacities. Further, the house materializes their life as a couple who, even several years after transplant, share perilous clinical demands that never truly leave. Maintaining a perpetually separable house makes practicable Angela's desire to seek haven from caregiving duties, while simultaneously serving as a health haven for Barry. It enables the couple to accommodate the risks to Barry's health posed by their household's necessary connection to the outside world, and to accommodate their need for daily life to carry on, even in the face of ongoing overlaps in medicine and home life.



## Discussion: Concerns, constraints, and transformations

In her observations about what she calls the ‘place switching’ of health care, Cartier (2003, 2296) writes: ‘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’. The expansion of home-based medical care by kin (and others) comes at a time when there is little structural support for households already subject to the interactive effects of illness and other inequalities (see, for example, Marmot and Wilkinson 1999). Weaknesses in the US social safety net become especially pronounced for those who have fewer resources to begin with, let alone for those who do not have family or other loved ones on whom they can rely.<sup>10</sup> The same dominant political economic frameworks, within which patients and those close to them shoulder ever-greater responsibility for continuing medical care in private spaces and among kin, likewise keep many households in a perpetually vulnerable state. Under a system that tethers health coverage to private employer-provided insurance, even with some expansions in state-subsidized coverage through the Patient Protection and Affordable Care Act, lay caregivers today face pressures to reconcile the competing pull of both paid and unpaid responsibilities. Throughout fieldwork, I met several transplant patients and caregivers who faced such overlapping ‘arenas of constraint’, defined by Inhorn (2003, 16) as ‘various structural, social-cultural, ideological, and practical obstacles and apprehensions’.

More than a century ago, Durkheim (1995 [1912], 210n6) noted that social ideals are revealed through the constraints we experience, and he 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). Does the shifting of medical care responsibilities to patients and families coalesce at a level of moral authority? More specifically, does accommodating this movement, despite the challenges and paucity of state-sponsored resources for doing so, resonate with deeply held, if culturally specific, normative moral convictions about where, how, and by whom health needs are met? Borneman (1997), for one, argues that giving care and being cared for are essential components of relatedness, which encompasses, as McKinley (2001) observes, a world of unavoidable moral obligations. Yet, as Buch (2013) demonstrates, moral obligations in care are not confined only to unpaid care among kin, neighbors, and friends – they hold sway in paid care as well. Intimacies and economies, local moral relations and global neoliberal logics co-inhabit spaces of care. Brown (2013) documents this in Brazil, where ‘Third Age’ groups, which receive small

<sup>10</sup> Although an in-depth exploration is beyond the scope of this article, I can report that such instances were very rare, but did exist.

amounts of city-level funding, enable aging women not only to maintain their own well-being but also to care for others, particularly older kin. In a context of otherwise absent public-sector support, women's culturally mediated orientations to take care of loved ones are undergirded in ways that support the state's interest in managing its liabilities amidst an aging population. How do we grapple with trade-offs between the improvements to well-being that accompany moral orientations toward care, and the risks for exploitation they can pose?<sup>11</sup>

Here, I revisit the frame of hospitality, particularly Selwyn's (2000, 9) observation that acts of hospitality can either 'consolidate the recognition that hosts and guests already share the same moral universe' or 'enable the construction of a moral universe to which both host and guest agree to belong'. To what extent do home and clinic become integrated and 'blended' in the course of the hospital-to-home shift in medical care? Or do they remain distinct, as 'guest' and 'host' – more visitor than affine – in the experienced, lived realities of patients and carers? Many participants awaiting a transplant articulated their hopes that it would offer a route away from the material, affective, logistical, and temporal 'space' in their lives presently occupied by dealings with grave illness and organ failure. To invite these outcomes, the customs of the clinic must be learned. Lay caregivers become well versed in clinical knowledge and skills, developing keen abilities to tend to clinical needs, monitor medical technologies, administer medications, and change ostomy bags. The home, its structure, and its contents all become material tools that can be fashioned to facilitate the incorporation of clinical realities. They serve as the means for accommodating care in forms both immediate and obvious, as in Marvin's 'health hub', and forms more subtle and latent, as in Barry's 'health haven'. Guest, host, and house (Shryock 2004) come together.

But homes in the United States are not formal clinics. While they constitute rather different moral universes in several senses, accommodating care enables the creation of one universe in which both can belong. Specifically, informal caregivers often translate clinical training into practices that conform to the moral obligations of kinship and home life. They wake in the middle of the night, listening for technical glitches in medical machinery; they 'wreck their brains', figuring out how to make daily regimens less painful for their loved one. Lay caregivers also necessarily remain attentive to their own and the household's other needs, for example, to care for children, to work outside the home for income or insurance, or to gain respite.

<sup>11</sup> I thank an anonymous reviewer for their help with this section.

For all of their creativity, resilience, and innovation, the responsibilities of transplant-related home care can and do place formidable strain on people and relationships. When household members fall into a double bind of competing obligations, working spouses might accommodate long absences through particular arrangements of home spaces (like moving recliner chairs closer to bathrooms) and placements of objects (like medical supplies and home medical equipment). These practices materialize as by-proxy physical manifestations of care. Yet domestic spaces like marital bedrooms are not easily made the moral equivalent of hospital storage rooms. They tend to constitute different ‘ethical locations’ (Stonington 2012). They might be given over to these purposes in the name of medical necessity, but the ‘pull of the normal’ (Maynard 2006; cf. Crowley-Matoka 2005) remains. Like a guest who oversteps the boundaries of their welcome, this usurpation of intimate space by medical supplies can be a particular source of tension. Resonating with observations of hospitality across diverse ethnographic contexts, hosting is infused with vulnerabilities. For Angela, even fourteen years post-transplant, ‘normalcy’ is inextricable from panic, as illness still seems just around the corner.

Even as ‘home’ and ‘clinic’ might comprise distinct moral universes, patients and caregivers see little alternative but to find ways to reconcile them. Accommodating care might indeed be interpreted as disciplined conduct, in the Foucauldian sense – capillaries through which neoliberal interests can extend. To be sure, nearly every time I remarked on the challenges they seemed to be facing, patients and caregivers indexed a sentiment of ‘you do what you’ve got to do’ and ‘you just take it as it comes’. It was difficult for patients and those surrounding them to imagine things playing out in any other way. But a full account must also return to the agencies and desires of patients and caregivers. Operating within a ‘logic of care’, they fulfil moral duties through thoroughly practical activities, with sometimes elusive results, but with the aim ‘of crafting more bearable ways of living with, or in reality’ (Mol 2008, 46). Participants much prefer the comforts of home – recalling Marvin and his recliner, surrounded as it may be by bags of bandages, medications, and tubing – to a hospital bed. And, even within the couple’s frustrations, Rob’s care stood in contrast to the ‘detached professionalism’ the couple identified among their clinicians.

With its high level of interventions and its heavy reliance on care in domestic spaces, in spite of all of its unique qualities, transplantation also represents a much wider context of US health care. The scenarios I have described here would be familiar to persons who have undergone other intensive biomedical procedures, or who are struggling with ongoing chronic illness. Even more broadly, these cases raise critical questions about the intertwining of neoliberal logics and intimate moral relations, underscoring the need for earnest attention to the stakes and consequences of hosting what can quickly become a very demanding ‘guest’. The sets of contradictions revealed and resolved through accommodating care spur

us to consider how we might recognize the favorable qualities of care by loved ones in the home, without relinquishing critique of the political economies among its underpinnings.

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