

Living with transplant

Never quite beyond illness

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Abstract

Organ transplantation is often held to epitomize the power and promise of biomedicine. Yet life after transplant does not so clearly mark an ‘after’ to illness, and instead requires close monitoring and treating for organ rejection, graft failure, or the side effects of medication regimens. Such medical domains are counterbalanced, in turn, by relations of kinship, friendship, home and work life. In this Position Piece, I call for attention to the interconnected tensions among these domains, focusing on one illustrative case example: that of Janet, a three-time kidney recipient. By detailing Janet’s lifelong imbrication of daily life with vulnerability and biomedical intervention, I delineate the mismatch between popular imaginings of transplant as ‘cure’ and the realities of living a life that is never quite beyond illness.

Keywords

organ transplant, post-transplant, medicine, complications

Introduction

Organ transplantation serves as one of the ‘crown jewels’ in what historian Emily Abel (2013, 1) has called ‘medicine’s triumphal epic, which emphasizes the sensational advances that have rescued people from death’ (see also Kaufman 2015). It is widely held to allow loved ones – whether deceased organ donors or gravely ill recipients – to ‘live on’. Its curative possibilities epitomize the power and promise of biomedicine.

It follows, then, that transplant-related public discourse in the United States is saturated with powerful, pervasive forms of hope and consolation, revealed through human interest news stories, promotional materials meant to motivate potential organ donors, and advertising of regional health systems' transplant programs. Taken together, almost as a genre, messages around transplant tend to follow a familiar narrative of dramatic transformation: the gravely ill patient becomes a thriving, active individual through high-tech medicine and the generosity of organ donors and their families (Scheper-Hughes 2007; Sharp 2006). Predictably, these messages are accompanied by images of people laughing with family members, returning to work, or walking through a verdant park with a friend or a partner – all thanks to a transplant.

But, optimistic discourses notwithstanding, the lived realities of transplant are far more complicated. They take shape in the persistent tethers between the often counterposed domains of biomedicine and the everyday. One does not merely live a longer life because of transplant; rather, one lives with transplant while also living the ideals and realities of kinship, friendship, occupation, and leisure. The transplant endeavor relies on patients and their loved ones to weave together the myriad strands among these domains. While illness might be periodically obscured in the tangle, it is never truly severed from the experience of living with transplant. Thus, as one does what it takes to raise children, hold employment, care for elder kin, maintain friendships, play, and sustain a household while also taking medicine, managing side effects, monitoring lab values, and undergoing medical procedures, one is living with transplant and never quite beyond illness. In this sense, transplant living engages questions at the heart of this special issue: how do we de-center illness as a privileged category in medical anthropology without losing sight of its continued presence? How do we understand the relationship between biomedicine and the everyday when there is no 'after' to illness?

As I detail throughout this Position Piece, transplant entails much more than the surgical imbrication of bodily tissues. Potential candidates learn quickly that the transplant process demands much: intensive evaluation and arduous pre-transplant procedures, emotional upheaval and moral uncertainties, a lifetime of reliance on expensive and complex medication regimens, and the very real possibility that it will all be in vain. Transplantation appeals not simply to hopes for a longer life, but to the restored possibility of engagement with the day-to-day contexts of kinship, friendship, leisure, and occupation. Patients who might otherwise hesitate nevertheless turn toward transplant out of a sense of obligation to children or grandchildren, aging or infirm parents, or others who rely on them and suffer the ripple effects of their life-threatening illness (Heinemann 2014, 2016; see also Manderson 2011). For recipients, everyday *living*, rather than life itself, becomes the stake.

But transplant recipients and clinicians alike point out that the procedure trades one set of problems for another: the difficulties of dialysis for the side effects of immunosuppressants;

the fears of organ failure for the fears of organ rejection. In best-case scenarios, there is no interruption in a recipient's ability to take their myriad post-transplant medications, side effects are kept to a minimum or sufficiently mitigated with other therapeutics, infection is avoided, rejection kept in check, and a grafted organ maintains its functioning for several years. Yet, it is also possible that the transplant 'fails', the patient experiences post-surgical infection or other complications due to a suppressed immune system, obstacles arise to follow-up care, or that the grafted organ is lost to rejection. In these scenarios, a patient's best hope is to re-qualify – and return to the transplant waiting list (see Manderson 2011). Those recipients who live longer increasingly experience not only the celebrated benefits of transplant medicine, but also its more hidden cumulative detriments. Their lives are sustained by having received a transplant, but they also are constrained. 'Held up' in both senses of the phrase, they live in suspension.

Over time, immunosuppressant medications can increase risks of cancer, osteoporosis, high blood pressure, diabetes, and other complications. If the ideal of a successful transplant is represented as life beyond the reaches of illness – a return to the 'normal' as envisioned by patients and loved ones – then the lived reality of transplantation reveals that normalcy is elusive (Wolf-Meyer 2014; see also Manderson 1999) and is tethered to the chronicities (Estroff 1993; Manderson and Smith-Morris 2010) of enduring medical intervention and monitoring (see Heinemann 2015).

Below, I foreground some of the ways transplant belies the assumed curative potential of high-tech biomedicine by looking closely to the experiences of Janet, a three-time kidney recipient. More specifically, I trace Janet's lifelong imbrication of vulnerability and biomedical intervention with daily living and webs of relations, highlighting the persistent tethers (and their tensions) that in some ways sustain and in other ways suspend Janet over time.

A suspended walk with Janet: Living with transplant in the long term

Janet had been wanting to get out of the house. The weeks of winter had been wearing on her and her living space was already feeling smaller now that her elderly mother had moved in, joining Janet, her adult son, and her two dogs. Tired of feeling cooped up, she called one afternoon to see if I could join her for a matinee. After purchasing tickets and popcorn, we chatted while walking down the theater's long hall. What funny things were my young sons saying these days? How was her mother feeling? How did my husband like his new job?

What did she think of her son's new girlfriend? But as we walked, Janet's breathing became labored and her steps slower. She stopped talking and paused to lean on a railing. Making our way to sit down, I asked whether we needed to get some help. As in, medical help. But,

between breaths, and with an expression that said she meant business, she said no, we're going to see this movie.

I first met Janet – middle class, white, and nearing sixty years of age – in 2008 during one of her appointments in the outpatient solid organ transplant clinic of a major transplant center in the US Midwest. This site was the hub of my ethnographic study, which I conducted during twenty-four non-consecutive months from 2007 to 2010. My fieldwork included ethnographic interviews with transplant hopefuls, candidates, and recipients, as well as their loved ones and clinical professionals. I also gathered data through participant observation in inpatient and outpatient settings, participants' homes, and other community spaces. My guiding questions sought insights into quotidian home life, kinship, care, and caregiving, as patients and loved ones made their way toward, through, and beyond transplantation. For some of my interlocutors, like Janet, biomedicine both permeated the everyday and folded into her fuller life course.

That day at the movies, Janet was over a year out from her third kidney transplant. Congenital glomerulonephritis had caused her kidneys to lose function from the time she was an infant. By age eleven, physicians told her parents the kidney disease was so substantial and progressive that Janet would not live into adulthood. Partially true to prediction, her kidneys ceased functioning when she was nineteen.

But renal transplant, while still rather new, was by that time a viable treatment option even where she lived, in the heart of the American Great Plains. By age twenty, in one of the first transplants performed in the state, Janet became, to borrow from Ronald Maynard (2006, 226), 'a living testimony to failed prognostication'. This kidney, a living donation from her father, fulfilled its intended purpose for about twenty years before Janet needed to return to the transplant waiting list. She received her second transplanted kidney from a deceased organ donor. The third was through a paired kidney exchange, or 'swap': Janet's cousin, whose blood type was incompatible with Janet's, donated her kidney to an anonymous person with whom she matched; this person's incompatible living donor in turn donated a kidney to Janet, who was likewise an anonymous match.

From her first transplant, Janet's release from end-stage renal disease was only ever partial and temporary. She has needed dialysis in the weeks and months prior to each of her subsequent transplants. And beyond kidney disease, she has endured what Lenore Manderson and Narelle Warren (2016) call a 'recursive cascade' of 'multiple chronic conditions', many traced back to her decades-long reliance on anti-rejection, immunosuppressant medication regimens. The compounding side-effects of her post-transplant therapies included: cataracts from age twenty-seven; arthritis precipitated by an immunosuppressant discontinued thirty years ago; a

shoulder replacement due to arthritis; skin cancer, to which she is prone due to her medications; and, ironically, renal damage from the anti-rejection regimen itself.

These multiplicative health matters were accompanied by a formidable stock of pharmacotherapies in Janet's home, stored in a three-tiered plastic stack of drawers on rollers she once wheeled out for me to see. Each drawer was stocked with bottles of pills, liquids, creams, eye drops, and inhalers, measuring caps, organizers, tubes, gauze, scissors, and syringes – all used according to a complex prescribed schedule.

But it would be inaccurate to frame this long list of conditions, and the piling on of medical interventions to address them, as straightforward evidence of Janet's perpetual illness and inescapable patienthood. For one, Janet was as much a caregiver as she was a patient; on the very day we first met, she both received medical care as a patient in the transplant clinic and provided and coordinated care for her mother, who had been hospitalized following a recent fall. Further, health concerns did not, in fact, define her. Though she had recently gone on permanent disability support, she'd previously held a long career as a corporate trust administrator at a large regional bank. She owned a home for much of her adult life, had married then divorced, and adopted and raised a son. She led an active social life and enjoyed crafting decorative wreaths and bowls as a hobby.

Tensions and tethers: Medicine and the everyday

Janet's experiences of living with transplant reveal the tensions and tethers between everyday life and medicine in the long term. Her walk to the movie theater that winter afternoon was slowed and suspended not by reduced kidney function, but rather by a flare-up of chronic obstructive pulmonary disease (COPD), which she attributed to her several years of cigarette smoking. She had taken daily smoke breaks with a friend and co-worker at the bank where she had worked for thirty years. Her career ended a year and a half before her most recent transplant, when she went on permanent disability leave, feeling pressured by her supervisors. The iatrogenic long-term effects of transplant medicine left her with declining eyesight and diminished health overall, and she had begun to make repeated mistakes. Janet explained:

Work had been really bad. Really bad. I had to get out before they kicked me out. [...] I was sick, and my eyes... I was making a lot of mistakes. And my boss said, 'While I understand, we can't have this'. So we got to the point where he said, 'Other people are starting to watch your work'. I've been there thirty some years, and you know, your job's on the line. I called [my doctor] and said, 'I need your written report [...] that I can't work anymore now'. And he did. The following morning, there was a fax there [Janet begins to cry]... And that was a Friday, so I just worked that last day.

Successful transplants enabled Janet to build a career, but the complications of transplant-related medicine also facilitated her career's end. In other words, Janet's work life was sustained but also constrained by decades of transplant living.

Though they no longer socialize at work, and the sociality of smoking no longer plays an immediate role in their bond, Janet's friend and former co-worker remained an ongoing, important node in Janet's web of support. They still get together at a local bar once a week to play what Janet calls 'old lady bowling' on a video game console. It was this same friend who brought Janet to the hospital for her most recent transplant and looked in on Janet in the days following the procedure.

This was critically important because transplant recipients spend little time recovering in hospital before they are discharged. Shorter hospital stays may be made possible by refinements in medical practices, but they are made imperative by health institutions looking to cut costs in a market-based, profit-driven US health care system. In the absence of a more comprehensive public safety net, it falls to individuals to bridge the gaps. Janet's ability to live, work, and develop this close friendship would not have existed without transplant medicine. But given that Janet would be sent home so soon after the surgery, transplantation might have been perilous without the care of her friend.

Thus, friendship, employment, health care policy, and state-of-the-art biomedicine all anchor these interwoven threads comprising Janet's lived experience. To this list, we must also add kinship and family life. Janet had married, but divorced her husband when their son was five years old. Left in a precarious financial situation, she and her son moved to a trailer park, which Janet considered an ideal setting to mother a child because it would allow him several freedoms. Her desire for a particular kind of daily family life also posed risks to her health.

... because then I could take a swing set, and if he screamed and yelled or, you know, was being a kid, there wouldn't be somebody bumping a broom on the ceiling of an apartment. [...] And they had a swimming pool and tennis courts, and a playground area. And the pool was wonderful, of course, but, well, skin cancer... You can tell just right where my swimming suit sits and where my skin was damaged.

Years of immunosuppression can leave transplant recipients more prone to some forms of skin cancer. Janet's pursuit of an idyllic and affordable childhood for her son meant she spent long hours in the sun at the pool and playground. Over time, then, the medication regimen that kept her well enough to raise a child also transformed time outdoors into amplified risks to her health. It also precipitated further medical intervention: to remove the cancerous cells, Janet had to undergo a long and uncomfortable series of chemical skin peels under the close

supervision of a dermatologist. Her skin cancer, then, was a site for the confluence of biomedicine's promise and biomedicine's perils.

Rather than extricating recipients from the tangles of illness, a successful transplant makes ongoing medical oversight nearly inevitable. This supports scholarly observations that the increasing dominance of medical therapies weaves patients and loved ones into 'cycles of surveillance and care' (Wolf-Meyers 2014, 155). But medical surveillance and care are, in practice, also fragmented and partial. They are cross-cut by the practical necessities of everyday life, particularly within the patchwork-style US system where individuals are made privately responsible for financial constraints.

For example, upon approaching her third kidney transplant, Janet's bone marrow ceased making blood cells, and her doctor prescribed injections of Procrit (a brand name for epoetin alfa). Safe use of this medication requires regular monitoring through blood tests. But the costs of frequent office visits add up quickly. This posed a problem for Janet, for whom finances were a persistent worry. To avoid the mounting office visit charges, Janet decided to self-administer the injections:

I was giving myself the injections and getting the lab work done, and the lab report would go to the doctor and they would decide how much to do the next time. It was not working well at all. I wasn't getting my labs necessarily when I was supposed to... When I first started getting the shots and I was getting the lab work done and the report was going to the transplant office, apparently nobody was looking at it, because when I went to see the doctor, which I was only seeing the nephrologist every year, I think, and he looked at [my hemoglobin level] and he said, 'It's twenty-two. You could have a stroke sitting here right now'.

Janet's experiences illustrate the burdens and risks borne by recipients as they live the tensions between countervailing domains. Here, those domains include medically necessary monitoring, the high costs of US health care, and the disjointed system through which it is accessed. She minds the gaps through attempts to self-care, but her attempts are foiled by the very domains she is navigating. She is living with transplant and all that it brings, but also is never quite beyond jeopardy.

Imbrications and continuities

Transplantation relies on imbrications of separate entities: the overlapping of flesh, grafted from one person to another. Even the surgical closing of a wound by overlapping successive layers of tissue is itself an imbrication. And transplantation likewise necessitates the

overlapping of sociocultural domains (homes and hospitals, life and death, illness and healing, biomedicine and daily life) and lives (donors and recipients, patients and caregivers). But the transplant endeavor also depends on those imbrications to eventually become *integrations*. For recipients, tissues fuse, incisions heal, and biomedicine and daily life weave together.

As Janet's experiences demonstrate, this overlaying also comes with iatrogenic realities: the multiple complications that long-term recipients must navigate. Poorly equipped to address sociocultural complexities, transplant medicine instead looks toward more familiar frontiers as it pursues an end to its potentially negative health consequences. This is exemplified by recent experimental attempts to couple bone marrow stem cell transplantation with kidney transplantation to induce 'immunological tolerance' in recipients: transplanting the donor's immune system along with the donor's solid organ would remove the risk of rejection and immunosuppressants would no longer be necessary (Chen et al. 2016). Investigational developments in 3D printing may also be used to 'print' transplantable organs using a patient's own cells, theoretically eliminating the risks of graft rejection along with the perennial shortage in donated organs (Hann et al. 2019). Such futuristic pursuits overlap with enduring ideals of progress and promises of renewal long woven into biotechnological development (Abel 2013, 2). They resonate with other powerful currents in transplant-related discourse, which liken transplants to cures: an end to illness and the beginning of life beyond its reaches.

As Matthew Wolf-Meyer (2014, 155) notes, cures have an 'implicit linear trajectory'; they 'follow a longstanding Western interest in transcendence' and 'offer a final release from woes' (ibid., 146). The transplant endeavor lends itself to public framing as a linear series of 'events': the 'brain death' of an organ donor (see Lock 2002), a very ill individual receiving 'the call' when an organ becomes available, the act of surgery. On their surface, the period 'before transplant' and the period 'after transplant' would seem clearly delineated and distinct. The ethnographic realities I have described here, however, suggest something else. After one receives a grafted organ, one might be better described as 'with-' rather than 'post-' transplant.

Indeed, Janet's experiences bring to light the mismatch between imaginings of transplant as 'cure' and the realities of living with transplant. Instead of manifesting life 'after illness', transplant living comes into being through the rich *interconnections* of kinship, friendship, work, leisure, and home life, and through their persistent tensions with ongoing biomedical intervention – the myriad stakes involved in what Lenore Manderson and Carolyn Smith-Morris (2010, 18) refer to as 'lived experiences of continuity'. No less, transplant living is deeply shaped by the policy and political economic contexts woven throughout. Rather than as a cure, transplantation might be more accurately understood as a recursive arrangement of 'therapies' (again, see Wolf-Meyer 2014, 155), which demand that patients and loved ones successfully manage a lasting tether to medical care. Life after transplant inflects life before

transplant, but does not so easily mark a new beginning as is suggested by the ubiquitous metaphors of rebirth, ‘new life’ or – to underscore the theme of this issue – an ‘after’ to illness.

To conclude, I highlight questions inspired by the focus of this special issue: how do we understand the lifeworld and experiences of Janet, who has followed a thoroughly recognizable path in the American context, and who also has been repeatedly situated in relation to the pursuits of curative biomedicine? What does it mean to be a mother, a daughter, a friend, an employee while simultaneously remaining a patient (an inpatient, an outpatient, a pediatric patient, a surgical patient, a transplant patient, etc.), both enabled and constrained by therapeutic regimes, and never quite beyond illness? How do we account for enduring tethers to biomedicine without slippage toward the biomedical-centrism we are rightly cautioned to challenge (Manderson and Smith-Morris 2010, 6)?

In other words, the orienting questions of this collection push us not merely to ask, ‘What happens after illness?’, but also to wonder, ‘What do we see when we look beyond illness as a privileged category in medical anthropology?’. Indeed, Janet’s experiences seem to insist that illness can hardly be erased, neither empirically nor conceptually. Because illness is always lived in tension with other domains of lived experience, it is best analyzed and theorized within these tensions as well.

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