Research Article

Organ Transplant Recipients' Experiences of Physical Activity: Health, Self-Care, and Transliminality

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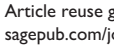

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Abstract

Physical activity (PA) is an important lifestyle component of long-term health management for organ transplant recipients, yet little is known about recipients' experiences of PA. The purpose of this study was to shed light on this experience and to investigate the possible implications of PA in the context of what is a complex patient journey. Phenomenological analysis was used to examine interviews with 13 organ transplant recipients who had taken part in sporting opportunities posttransplantation. Findings illuminate how participants' experiences of PA were commonly shaped by the transliminal nature of being an organ transplant recipient as well as a sense of duty to enact health, self-care, and donor-directed gratitude. This analysis underlines the potential role of PA in supporting organ transplant recipients' attempts to live well following transplantation and makes novel connections between PA and our existing knowledge about challenges related to identity, survivorship, obligation, and patient empowerment.

Keywords

organ transplantation; physical activity; exercise; self-management; health; phenomenology; qualitative; interviews; international

Introduction

Solid-organ transplantation is a cost-effective medical treatment for patients with end-stage organ failure (World Health Organization, 2019). Around 135,000 transplantations are carried out annually worldwide, offering life-saving or significant health-enhancing treatment for patients with kidney, liver, heart, lungs, pancreas, or small bowel diseases (Global Observatory on Donation and Transplantation, 2019). It is important to note that the sustained increase in frequency of transplantations in recent decades (Scientific Registry of Transplant Recipients, 2017) has produced an increasing population of recipients for whom illness is not necessarily resolved through transplantation but instead has shifted to alternative or additional concerns associated with living with a transplanted organ (Neuberger et al., 2017; Painter et al., 2001). These include concerns such as being dependent on lifelong immunosuppressive drug regimen that have associated side effects (Moini et al., 2015), being at risk of multiple morbidities (Stoumpos et al., 2015), having an increased risk of experiencing mental ill health (Copeland et al., 2013; Hames et al., 2016), and potentially requiring further transplantations in future (Graves & Fine, 2016).

Supporting the long-term health and well-being of this growing population is an important area of medical research and practice (Mathur et al., 2014). As Iwashyna (2010) points out, long-term health and well-being are defining medical challenges of the 21st century because "we can now save many patients' lives . . . but we need to broaden our sense of our mission to include understanding, caring for, and improving, the lives of those many patients who survive critical illness" (p. 205). Indeed, as an extension of this point, we are inclined to agree with Shildrick et al. (2018), who recognize that the emotional experiences of recipients and their abilities to rebuild personally worthwhile lives after surviving critical illness are seldom paid enough attention. With long-term health in mind, there is growing attention given to the self-management role of patients themselves through optimizing lifestyle factors as well as adhering to immunosuppressive drug regimen (Been-Dahmen et al., 2018; van Hoof et al., 2018). As Bittermann (2019) notes, health care

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practitioners "must not only provide high-quality, evidence-based *medical* care but also empower recipients with the *self-care* tools for long-term post-transplant success" (p. 666).

Within this area of interest, physical activity (PA) has received some research attention to inform clinical guidelines and patient recommendations (Bellizzi et al., 2014; Mosconi et al., 2014; T. O'Brien & Hathaway, 2016). Indeed, recent reviews are supportive of the ambition to improve transplant recipients' engagement with PA (L. Anderson et al., 2017; Takahashi et al., 2018), and an interest in the role of PA has motivated various national and international initiatives, including *Refit for Life!* (World Transplant Games Federation, 2019), and sport-focused events such as the World Transplant Games and its national-level equivalents (e.g., The British Transplant Games in the United Kingdom).[1] Research has long suggested that transplant recipients can participate in PA to a similar degree to general populations, albeit with some level of precaution (P. Griffin, 1998; Kjaer et al., 1999) and that PA has the potential to improve health outcomes (Didsbury et al., 2013; Heiwe & Jacobson, 2011). Furthermore, in support of the claim that PA could be a useful tool for clinic teams working with patients (Slapak, 2005), several quantitative studies have found positive associations between PA, quality of life, and various psychological outcomes (see Cicognani et al., 2015; McGee & Horgan, 1996; Oguchi et al., 2019; Painter et al., 2001; Wray & Lunnon-Wood, 2008), cohering with Mazzoni's (2014) conclusion that the benefits of PA "go beyond its impact on physical health to involve psychological and social components of quality of life" (p. 2231).

Despite the recognition that PA can yield health and well-being benefits, observational studies have reported that the majority of transplant recipients do not meet the general recommended PA guidelines (Clark et al., 2012; Dontje et al., 2014), suggesting that there is a need to better understand organ transplant recipients' experiences of engaging with PA. Sánchez et al.'s (2007) survey helped inform van Adrichem et al.'s (2016) qualitative study, which revealed several commonly reported barriers (e.g., physical limitations, insufficient energy level, fear, and comorbidities) and facilitators, for example, coping, consequences of (in)activity, routine/habit, goals/goal priority, and responsibility for the transplanted organ, to PA. In addition, Johnson et al. (2013) analyzed questionnaire data from participants at one World Transplant Games event, and concluded that perceived competence, enjoyment, and health were critical psychological factors in the experience of PA that ultimately led to a sense of psychological well-being for participants.

Although these studies are a useful starting point for understanding organ transplant recipients' experience of PA, the knowledge base remains partial and there is much scope for further research. In particular, we are interested in putting qualitative research approaches to use as well as investigating previously unexplored connections with the wider literature concerning the general nature of organ transplant recipients' lived experiences.

Living With an Organ Transplant

To make a contribution to the literature investigating PA for transplant recipients, we drew inspiration from several studies that both shed light on aspects of the transplant recipient experience and offer potential points of connection to PA. For example, the topic of identity has been frequently raised in the patient experience literature, which may have associated implications for understanding PA. Taking an in-depth, qualitative approach, Aujoulat et al. (2014) paid attention to overcoming the trauma of survival, and highlighted how patients are required to integrate their illness experience into their identity. For Svenaeus (2012), identity and selfhood are tied to the transplantation process for several reasons including forms of embodied alienation that come about through reflecting on the origins of the new organ that recipients now bear in their own bodies. Similar notions of identity were relevant in Ouellette et al.'s (2009) study, which utilized the concept of "psychosocial transition" to explain how organ failure can be "part of the ongoing process of adjustment to illness," in that, it "requires that the patients, to a certain extent, change their assumptive world to preserve a good level of psychological functioning" (p. 1137).

However, Bogue Kerr et al. (2018) suggest that the language of "transition" does not adequately capture the illness experience of transplant recipients due to the inherent paradoxes involved with transplantation including being between the binaries of sickness/health, self/other, and life/death. As such, they explore the notion of "liminality" as a way of describing the experience of living in an in-between state of being. Crowley-Matoka (2005) describes liminality as "a state through which individuals must pass as they exit the normal structure of society to re-enter it again in a new social role" (p. 827). Extending this idea, Bogue Kerr et al. (2018, p. 568) propose the term "transliminal self" and suggest that "the transliminal self never completely emerges from its rites of passage and is never completely healed." Indeed, their attention to phenomenological forms of understanding led them to conclude that

> When the normative experience of a person's body is altered, so too is every aspect of that person and who they are in the world. Transplantation offers a new and different, forever liminal, life; it transforms the sick person into a liminal person and, in so doing, leaves them to navigate the

> continuous ebb and flow of the transplant experience. (p. 569)

Issues of identity, transition, and transliminality raise important questions for understanding the experience of PA because engaging (and not engaging) in PA is so often tied up with our understanding of the body and the self, issues that are intimately bound up with health and illness in general and organ transplantation in particular. Applied to a broad range of topics, the intimate relationship between the body and self has been studied through the use of psychological concepts such as physical self-perception (Taylor & Fox, 2005) as well as sociological concepts of physical capital (Bourdieu, 1977; Shilling, 1991) and phenomenological accounts of sensory lived-body experiences (Allen-Collinson, 2009). Given that both illness and PA are necessarily embodied experiences within which the self can be understood and constituted, it makes sense to utilize scholarship on embodiment to meet the aims of this study.

More recent literature has highlighted the unique aspect of the transplant recipient experience related to recipients' complex emotional and moral relationship to their donor—whether living or deceased. G. M. O'Brien et al. (2014) demonstrate that the meanings associated with the trope of organ donation as a "gift" raise the issue of whether the recipient feels deserving and worthy, which ultimately influences their feelings of gratitude. Indeed, although the notion of the "gift" can serve to limit the commodification and hence dehumanization of organs, debates have existed for some time about the inescapable sense of debt that is imposed on recipients as a result of the transplantation process (Sharp, 2006; Sque & Payne, 1994). Sothern and Dickinson (2011) point out that organ transplant recipients must bear witness to the "gift" of their transplant and that the burden for reciprocity inevitably falls heavily on the recipient. Indeed, Shaw and Webb (2015) extend these debates and illustrate how gifts can be understood positively by some but not others. They highlight those recipients who are unproblematically conscious of their obligations to look after the organ and show gratitude, as well as others for whom it can be part of "obscuring and romanticizing the complexities of transplantation processes" (p. 600). Furthermore, Ummel and Achille (2016) show how the meaning of receiving an organ is dependent on the relationship between recipient and donor, with some donors being family relatives and others being nondirective ("altruistic") donors. They noted that donations from family relatives are perhaps easier to understand as it is seen as an extension of already existing reciprocal understandings of kinship. In contrast,

> in the context of a casual relationship, the obligation to give back was more present for the recipient, especially because the donor was unwilling to accept any kind of gratitude, which made it particularly difficult for the recipient to integrate and make sense of his donor's gesture. (p. 201)

These findings are important to consider when attempting to understand transplant recipients' engagement with lifestyle self-management behaviors such as PA. For general populations, PA is already encoded with neoliberal health discourses that moralize and responsibilize a range of lifestyle behaviors (Crawshaw, 2012; Gard, 2011). Within the context of receiving such a significant "gift," which can be accompanied with a sense of gratitude, obligation, and worthiness, it is vital to ask critical questions about how engaging with PA might magnify, avert, mediate, or extend such moralized health imperatives.

Further to these issues, Wise's (2002) phenomenological study with pediatric patients makes the point that transplant recipients "strive for normalcy" in their ordinary, everyday lives in spite of extraordinary illness experiences. Participants in their study "focused on events in their lives that supported the premise of being 'normal'" including concerns related to leisure time and lifestyle. A point of connection here would be to explore the role of PA in recipients' desires to gain a sense of normalcy—whether defined in relation to others or oneself prior to illness—through the perception of PA as something that is part of being "normal."

In the context of these psychological, embodied, moral, and social complexities that are known to be associated with being an organ transplant recipient, this study set out to explore recipients' experiences of being physically active. In doing so, we aimed to extend the previous literature investigating PA for transplant recipients to both understand how to support transplant recipients to be physically active as recipients attempt to live well with their illness and to investigate the role that PA might have on recipients' illness experience more broadly.

The Study

Participants

This study was conducted with an international cohort of 13 adult transplant recipients who had experience of PA posttransplantation. Having gained ethical approval from the Research Ethics Approval Committee for Health at the University of Bath, participants were invited to take part through a recruitment campaign, which involved posting invitations to relevant groups on social media platforms, contacting national transplant sport organizations, and by face-to-face and written invitations during the World Transplant Games event in 2017. Sampling was guided by an intention to achieve sufficient diversity

in terms of gender, age, nationality, and transplant type to assist in highlighting aspects of the recipients' experiences that were common—or indeed unique—among individuals. Due to the limitations of the research team, however, only English-speaking participants were included. No other inclusion or exclusions criteria were applied.

The recruitment process resulted in a participant sample of seven females and six males, aged between 24 and 55 years, from England, Australia, Northern Ireland, Wales, New Zealand, and South Africa, and having received either a kidney, liver, heart, or lung transplant. Although diversity across these characteristics provided us with some reassurance that different voices were being heard, we also acknowledge that the sample size was too small to draw meaningful inferences about the extent to which variations in participants' experiences were related to their gender, age, nationality, or transplant type. As such, our findings ought to be read with this in mind. To protect anonymity, participants' names have been removed in the presentation of data, and quotes have not been linked to identifying characteristics other than noting particular participants' transplanted organ where it was relevant to the experience being discussed.

Data Collection

After providing written informed consent, all participants took part in a semi-structured interview lasting between 32 and 68 minutes (average 45 minutes). Participants residing in the United Kingdom (where the researchers were based) were interviewed face-to-face and participants outside of the United Kingdom were interviewed by telephone (Skype). Although we acknowledge that there are potential differences between interviewing in different ways, we observed no obvious differences between the transcripts of telephone interviews compared with face-to-face interviews, and felt that data from both were successful in helping to gain new insights into the experiences of transplant recipients. The interview guide included questions designed to allow participants to speak broadly about their experiences, such as the following: Tell me about your illness and transplant journey; What do you do to manage your health as a transplant recipient? What has engaging in PA been like since your transplant? Tell me about the people you have met through participating in sport.

Data Analysis

Interviews were audio recorded, transcribed verbatim, and then analyzed separately by the first and second authors, Gareth Wiltshire and Nicola Clarke. Broadly in line with the guidance for making sense of qualitative data offered by Braun and Clarke (2019), both researchers engaged in an in-depth reading of the transcripts with the aim of producing intelligible labels and descriptions that would fairly represent separate and coherent patterns of meaning in the data. Early stages of this iterative process resulted in a range of concepts being recorded in both researchers' personal analysis documents such as relationality, accepting, and confronting illness and mortality, embodying narratives of survivorship, temporality, death, and identity. Wiltshire and Clarke held a collaborative analysis meeting to reconcile points of difference and arrived at three overarching themes: *capabilities, duties of self-care*, and *social engagement*. At this stage, a summary of findings was shared with study participants to enhance our confidence that we had not misunderstood or misrepresented participants' experiences as they themselves understood them.

To facilitate further reflection upon our emerging ideas about organ transplant recipients' experiences of PA, the combined analysis was shared with the third and fourth authors—Cassandra Phoenix and Carl Bescoby—who were asked to challenge the claims and offer new insights where possible. The reflection that followed led to an agreement among the research team that the first two overarching themes (*capabilities* and *duties of self-care*) warranted deeper interrogation by reconceptualizing the thematized data drawing on phenomenological analysis. In recognizing that different analytic approaches may be more suited to some aspects of lived experiences than others, it was decided that the third overarching theme—*social engagement*—would be omitted from the phenomenological analysis (and, therefore, the present research article). Our primary reason for separating the analysis in this way was that the data captured relating to social engagement, in our view, did not resonate with the phenomenological lifeworld conceptual framework with the same strength as the first two themes did. A secondary benefit of this analytic distinction was that we could narrow the scope of our analysis to focus our attention on the more closely related lines of inquiry that existed in the first two themes and also offer a more nuanced discussion about them in the eventual presentation of findings. Thus, our engagement with phenomenology can be described as incremental as the study progressed and matured. That is, our research approach shifted from being phenomenologically informed at the beginning of the inquiry to a position whereby phenomenology was central to the final analysis and presentation of this article.

In reconceptualizing the *capabilities* and *duties of self-care* themes, we hoped to realize the potential of phenomenological analysis to move beyond detailed first-person accounts of experience (although these are necessary) and toward a comprehensive understanding of how phenomena present themselves to consciousness in ways that

are lived but not always apparent, noticed, or reflected upon (Giorgi, 2012). That is, our analytic focus became phenomenological in our appreciation of how our participants "perceived something before learning and incorporating knowledge introduced by others" (Bogue Kerr et al., 2018, p. 563). As Merleau-Ponty (1945/2012) noted about phenomenology,

> although it is a transcendental philosophy that suspends the affirmations of the natural attitude in order to understand them, it is also a philosophy for which the world is always "already there" prior to reflection—like an inalienable presence—and whose entire effort is to rediscover this naïve contact with the world in order to finally raise it to a philosophical status. (p. xx)

Proceeding from this grounding, our analysis was operationalized by a commitment to a phenomenological "attitude." As Finlay (2009) succinctly explains,

> phenomenological research is phenomenological when it involves both rich description of the lifeworld or lived experience, and where the researcher has adopted a special, open phenomenological attitude which, at least initially, refrains from importing external frameworks and sets aside judgements about the realness of the phenomenon. (p. 8)

This commitment has also been described as "a radical and disciplined way of seeing with fresh, curious eyes" (Finlay, 2014, p. 122) and an approach that retains "wonder and openness" to the world (Finley, 2008, p. 1). Although this attitude inescapably involved paying attention to "what it is like" to engage in PA as a transplant recipient, it also went beyond experience as such and beyond the perceptions constructed psychologically by participants. As such, not only did this focus help to examine PA from different perspectives to challenge "common-sense" and "personal" presuppositions (Allen-Collinson, 2017), it also functioned to direct our attention to examining *how* PA presented itself to the organ transplant recipients in the study.

Beyond adopting this attitude, we attempted to think with the lifeworld heuristic framework derived from the phenomenological traditions that follow Husserl, Heidegger, Sartre, and Merleau-Ponty (Ashworth, 2003). Although features of the lifeworld such as temporality, relationality, and intentionality were threaded into our reading of participants' experiences, Merleau-Ponty's (1945/2012) emphasis on the body as our "point of view upon the world" (p. 73) had particular resonance for us. Svenaeus (2001) brings attention to this in the context of the phenomenology of health and illness not least because the physiology of the body "afflicts and sets limits to the different ways we are able to experience and interpret our being-in-the-world" (p. 87). Being astutely aware of this, our interrogation of the data was attuned to the significance of the body, as has been the case in numerous other studies taking a phenomenological approach (see Bogue Kerr et al., 2018; Cormier et al., 2017; Mauthner et al., 2015; G. M. O'Brien et al., 2014; Svenaeus, 2012). Seeing the body as prereflective and permanently present, Merleau-Ponty suggests that it is the intentional relationship between a person's embodied consciousness (situated in a particular space and time) and the world that allows us to create meaning. Foregrounding this notion enabled a focus on how meaning related to PA experiences was constructed between a transplant recipient and their world, rather than as a cognitive process or behavioral response.

Findings

PA, Capability, and the Transliminal Self

The first theme in our analysis unpacks how participants' experiences of PA were a part of the embodied experiences from which their transliminal self was understood. Existential concerns were made possible by the participants' personal histories of illness, which highlighted the phenomenological differences between being healthy and ill. For example, during secondary school, a participant with a lung transplant began to experience the extent of his illness as his cystic fibrosis symptoms developed in a way that seriously affected his ability to function independently, requiring daily therapy and a reduction in PA. By placing limitations on his PA, these symptoms brought feelings of frustration. He said, "everything I sort of did [before being ill], I couldn't do it. And I found that really hard to deal with. There was quite a lot of frustration with that." Similarly, another participant remembered losing energy as his kidney function deteriorated; "just getting out of breath going upstairs and that sort of stuff . . . I noticed that everything, sort of, tailed off." Highlighting how fatigue is a common experience for those with kidney disease, a different kidney recipient spoke about similar feelings of fatigue in her everyday life:

> There was no such thing as exercise or going to the gym anymore. It was out of the question. If I could get a few hours of work that would have been enough for me for the day. That would have wiped me out, you know.

This limited ability to engage with PA during illness prior to transplantation was an important context for participants, providing a necessary structure to the meaning of illness. Against this backdrop, the temporal nature of participants' health was revealed as patients began their recovery following transplantation. One of our participants experienced a poor level of fitness

when going to the gym for the first time following his kidney transplant, which affected his expectations of PA in future. He said,

> I still remember the first time I went back to the gym, I did just 15 minutes on the bike—no great pace or anything like that—but being in floods of sweat and feeling absolutely awful and thinking, "wow this is going to be quite a long road back fitness. It will be quite hard work."

This initial encounter with PA posttransplant provided an embodied experience from which he would need to ground his evaluation of his present limitations as well as his future expectations. For one of the liver transplant recipients, their understanding of recovery was couched in terms that reflected the need to be patient and to understand the slowness of physical progress; "I would just take two weeks at a time. Every two weeks I was starting to feel better and better." As participants started to "feel better," they usually described building toward more challenging and ambitious physical activities while realizing their new capabilities. As one example,

> I remember when I first got home after the transplant I walked to the end of the street and back—and that's probably 100m or something—and I timed it and it took probably 15 minutes or something stupid, you know. It was a real effort. With the walking, I started going to the end of the street and back, and then down the block . . . the Transplant Games was in September and that probably got me walking more and more adventurously.

For all the participants in our study, to varying degrees, this "adventurous" exploration of new physical capabilities was meaningfully associated with what might be referred to as a complex renegotiation of self-identity, understood through ongoing corporeal experiences of oneself as "living-in-the-world" (Mauthner et al., 2015, p. 582). For one of the participants who took part in the Transplant Games, the competitive aspect of sport represented a return to his younger, healthier, more competitive self; "Me being able to establish myself with some competitiveness again that I had when I was like 16, stuff like that has been a really positive thing." Especially in cases where participants had experienced long-term illness (e.g., cystic fibrosis, end-stage kidney disease), our analysis suggests that PA was an opportunity to shift the position of one's self-identity from its association with an ill, abnormal, and deficient body to a healthy body capable of physical performance. Despite such experiences, shifts in self-identity for transplant recipients remained always liminal and never fully accomplished. As highlighted elsewhere in the literature (Bogue Kerr et al., 2018), the reality of a complete restoration being out of reach invites paradox, juxtaposition, and requires that transplant recipients continue to navigate the spaces in between opposing experiences.

For other participants, PA was related to their sense of transliminality not through forming an association with a prior, healthier self, but through exploring a future self and discovering new illness-related limitations. This idea was probably best exemplified when a participant said, "I wanted to see what I could do. I wanted to see what was achievable post-transplant—what this, kind of, 'new me' could do." Using the term "new me," this participant highlights that transplantation represents a (soft) demarcation between an identifiable prior self and his present/future self. Concurrent with existing research highlighting the potential disruption to identity following transplantation (Mauthner et al., 2015), we see our data as an example of transplant recipients emerging from historical experiences of illness and actively seeking out tangible opportunities to realize physical limitations, from which they can refine their understanding of their transliminal, transplanted body-self.

Similarly, a lung transplant recipient talked positively about playing golf after his transplant, but later took up running competitively to "show off his new lungs." He said,

> I felt that golf is good but I wanted to show off my new lungs. I just felt like, playing golf—I can play golf—but wouldn't it be amazing to do something where it's sort of a little bit more cardio-vascular.

As part of this exploration of new capabilities, it was interesting that the lived-body sensation of pain during excessive physical exertion in sport was welcome by one of the participants in the context of his experiences of kidney disease prior to transplantation. As he described,

> Lots of people ask me what my favourite of my different sprint events are, sort of 1, 2, and 400 [meters]. And in a funny way, I often say 400 in some ways because you actually feel so, like you're getting killed so hard going around the 400 that it makes you feel alive. Like, it's the sort of thing—you couldn't feel that sort of experience of the lactic and everything like that building up doing 400 if you were unwell. You don't have that opportunity.

For him, this unpleasant sensation ("getting killed") was evaluated positively because it was part of a host of experiences that would have been out of reach for him during his illness before transplantation.

Exploring new capabilities and limitations was not always an easy process, as has been noted in PA research in other populations (e.g., M. Griffin, 2017). One participant in particular explained how he was conscious of the capabilities of his lungs, but he has learnt to understand

his particular limitations as a lung transplant recipient engaging with PA:

> I get really out of breath. I mean, very rarely, I get a kind of panic as you sort of catch your breath. But then as soon as the body has settled down, I'm sort of okay. So, I do know my limits I think.

In contrast, a heart transplant recipient who had a transplant at age 12 after a sudden cardiac event did not report the same sense of "panic" or consciousness about her transplant during vigorous PA, something that she attributes to the fact that she cannot recall any long-term illness or trauma. Hinting at the particularities that heart transplant recipients can experience in relation to PA, she explained,

> I've never experienced being ill with that side of it. I have just had my heart replaced and just carried on. Whereas, like, people who are ill are more panicked about it, that scary process. Whereas my heart's been, like—it was fine, it was gone, new one in, carry on.

This short narrative not only appears to underplay the disruption caused by transplantation but also demonstrates how social comparisons with others whose transplant experiences involved long-term illness and "being scared" allow her to make sense of her own position in the liminal space, distancing herself from those "who are ill" in the process.

Lived-body experiences can also be seen as familiar ways that PA presented itself to participants, which were then evaluated in the context of historical experiences and future expectations. During these experiences, and the ensuing reflection on them, the self was constituted as participants attend to their physical capabilities and benchmark their health against them. This intentional relationship appeared to sometimes highlight transplant recipients' health, and other times remind them of illness or limitations. An example of this was also observed in the following comments:

> I would walk that [route] a lot in the lead-up. I got slower and slower, but that is something I held onto; a walk to the pier with the dog. So that was the next sort of milestone, to get to the pier and back. And then after that, it was like the time got faster. So that was how it was. Certainly, it felt like a real achievement.

For this participant, walking to the pier and back with the dog was a meaningful part of her everyday life before falling ill and through her deteriorating health, and hence became important in her recovery. As a necessarily embodied activity, walking provided a way of noticing and recognizing both becoming ill (getting slower) and becoming healthy again, serving as a benchmark from which a sense of achievement could be measured against. For a different participant, a similar sense of accomplishment was associated with PA. She said,

> It gives you a sense of accomplishment as well. You can still accomplish stuff that normal people do and sometimes even better. You are not disabled . . . And I think physical activity, any type of physical activity—if you go and throw Frisbee on the beach—you are still capable of using your body in ways that you could have before.

Here, this participant's understanding suggests that the reference points for the perception of accomplishment, and its associated impact on her body–self, are to "normal people" (i.e., healthy populations), "disabled" people, and your body from "before" (i.e., prior self). Again, these points of reference provide the structure from which she understands and constructs her accomplishments and capabilities.

PA as Health, Self-Care, and Duty

Connected to the first set of findings were the deeply held meanings of PA related to organ health, self-care, and donor-directed gratitude. That is, as a health-enhancing practice, PA allowed patients to proactively serve their interests (or projects; Ashworth, 2003) in maintaining good long-term health, as well as enact and embody moral obligations toward their donor. One of the liver transplant recipients in our study described that self-care was important to her because "you weren't born with this organ so you can't assume it's just going to be there and work there and be fine. You need to take extra special care of it." Here, self-care was framed as pertinent because of an awareness of the precariousness and fragility of the foreign, transplanted organ. Presumably, organs that you are "born with" do not elicit the same concerns. Consistently, participants revealed that they were cognizant of the health consequences of alcohol consumption and diet, but PA was similarly meaningful to their every day, behavioral sense of self-care. This sense was also captured in the way another participant spoke about fitness and running:

> I do think I am—most of the time—very conscious of trying to look after myself and keeping the best possible health. And fit, you know, fitness. And even jokingly about the five miles [a reference to an earlier comment], I will actually go out and run later because it just makes me feel better about doing it—and healthy. Keeping fit is good. Whereas before I was never active or involved in any sport—before I was ill.

Not only does this help evidence our claim that PA presents as a meaningful way of structuring health and

self-care for participants but also that the enactment of PA provided participants with a sense that they were *doing* good. This embodied experience of *doing* health seemed to be meaningful in as much as it constituted participants' feeling like they were taking a proactive role in their self-management and gaining control over their future health. Speaking of this, a kidney transplant recipient said, "I don't want to let the disease take over my life. I want to take control over it, and just not let it take over me." Through this simple yet powerful articulation, it is clear that the desire to resist submitting to illness provides fertile ground for PA to be placed meaningfully as an act of resistance. Indeed, we see this as echoing a finding from Shaw's (2015) research with kidney patients, whereby the ethic of self-care included "not letting your illness become you" (p. 240). For another participant, this notion was similarly powerful but more related to being able to contribute to one's health, if not being able to take control of it. In this lengthy extract, one of the liver transplant recipients narrates an important moment following his diagnosis of being told by the nurse that he has "a job to do":

> She just came up, got very close to me, and put her hand on my arm and she said to me, "the problem now belongs to Mr Jameson [surgeon] and his team. But you have a role that you have to play, and you are part of the team as well. Your role is to stay positive and keep healthy as best you can. The problem now belongs to Mr Jameson [surgeon]. He will take ownership of it. He will fix it." And that really just grabbed me. I've got a job to do. Just stay positive. Okay. And that was an amazing moment because the way she told me, when she said "I don't want you to worry about it, I want you to focus on what I have just told you, and that is you must stay positive through thick and thin you must stay positive. That is your role. That is your job. And Mr Jameson [surgeon] and his team will look after the rest." And that really sort of made me go "oh I've got a job to do." And as I came out from the surgery it made me think as I walked away, "that is what I have to do, I have to stay positive and I have to stay healthy." And by healthy, I mean good nutrition, exercise, no alcohol of course. So you know, staying healthy and staying positive. So yeah, and that was definitely a defining moment and I will never forget that.

The significance of this moment for the participant suggests that actively enacting health—perhaps somewhat independently of actual health status—is meaningful in the lives of transplant recipients.

In conjunction with notions of PA as enacting health and self-care, our analysis also illustrated that moral, ethical obligations structured the meaning of PA for participants. Numerous examples of participants feeling a sense of duty and gratitude toward their donor and donor families were identified in the interviews. One participant said,

> I think where you have to sort of start reflecting back is on the fact that somebody has donated those organs and because of that person you are alive so you sort of owe it to them a bit to put it one way.

The use of the word "owe" acknowledges a sense of debt and was used in the same way elsewhere in our data:

> I owe my life to somebody else . . . you always feel that you owe somebody something. Okay, say even with the food I eat, I'm conscious of keeping healthy. Somebody has died for me, that somebody has given me a chance.

For this participant, the sense of debt magnified her desire to engage in self-care and—perhaps more importantly—to abstain from particularly unhealthy practices. Speaking of abstaining from excessive alcohol consumption, she said, "in my eyes, someone had to die for me to get a liver and that's really important. I think it's respectful." Indeed, another participant expressed that she gets annoyed at herself whenever she "overindulges" or does not look after herself as best as she feels possible. She noted, "I feel like, 'oh come on, you've got this [new organ] here and this is the way you are treating your body?!'" Interestingly, the understanding of living with and being connected to one's donor manifested in motivation when exercising for one participant:

> Every day, even now like when I'm out cycling and I am doing a big hill climb and I'm struggling, all I have to do is think about, you know—it could be the end of my physical limits—but if I think about my donor, the next thing I find another 10%.

Such insights bring PA in line with the wider literature related to experiencing transplantation in which acts of duty are carried out by recipients, even though the sense of duty is inadequately met (Poole et al., 2011).

Related to the understanding of the transplanted organ being something deserving of respect and gratitude was the way in which some participants externalized their transplanted organ. Thus, our analysis suggests that when intentionally directed toward their transplanted organ as an "object," participants often understood PA as a way of working on that object. The following example from an interview with a liver transplant recipient was particularly revealing in this regard:

> I'm always conscious that I've got somebody's organ in me and they always say "oh that's ridiculous," but I am. I always give it a little tap—because I know it's a girl—like "are you okay in there?" "Have I been good to you today?" "Have I eaten the right food for you today?" You know, I have a little conversation. I know it's mad.

This participant was playful in this description, recognizing the seeming absurdity of the practices while also speaking as if it made perfect sense to her. In this way, her conversation was with an externalized entity, but not merely a mechanical object; it had a gender and it belonged to somebody so was deserving of respect. This is not dissimilar to how Mauthner et al. (2015) describe recipients' sense of interconnectedness with their donor, often vividly imagining their personal characteristics. Similarly, another participant in our study created distance between what he understood as his "self" and his material body. Here, the organ was more of a "thing" that he is "trying to keep going":

> You can think of it as part of you all you want but ultimately this is something that I am trying to keep going as long as possible. Then again, I perhaps don't think of myself—in a weird way—I kind of think of myself as I'm up here [gestures to head] and these are just bits that I control [gestures to body]. You know? It's an odd way of thinking about it.

Although similar sentiments were expressed by several participants, it is important to point out that some participants (or perhaps all participants in less obvious ways) also understood their transplanted organ in an altogether more holistic way. The following comment points to a sense of accepting transplanted organs as part of one's own body more broadly:

> I've accepted it so quickly . . . Because with this extra kidney I can feel now my head hurts, and my fingers are cold. So it's not just the kidney it is the whole body. Because it affects my whole body, I need to think of it has a whole body because the whole thing would have never been there without this one kidney.

This perspective contrasts somewhat with the externalized and objectified meaning of the transplanted organ in other accounts. In these ways, it is possible to draw connections between taking part in PA as a way of caring for the self, and dutifully caring for an organ and, in a sense, caring for their donor.

Discussion

These findings contribute to the literature in several ways. First, we extend previous research that highlights the importance of identity and the self to the experience of being an organ transplant recipient. Previous research notes that the nature of organ donation often leaves the recipient with questions about who they themselves are (Mauthner et al., 2015). Indeed, Ouellette et al. (2009) demonstrate that resistance and acceptance are part of this process and Aujoulat et al. (2014) illustrate that recipients learn to integrate illness into their identity. This idea of emerging identity management ties closely with Cormier et al.'s (2017) "new transplanted self" as well as various accounts of "liminality" and "transliminality," whereby patients can feel in between the two opposing subject positions of "healthy" and "ill" (Bogue Kerr et al., 2018).

We extend this by showing how PA is involved in this process throughout the patient journey. Specifically, PA was important to our participants because it provided visceral, powerful, lived-body experiences that were capable of meaningfully highlighting physical capabilities and limitations—experiences that allow recipients to make sense of their own position in the liminal space. These were talked about by participants before their transplant at their most ill phase, in the short term following their transplant, and throughout their recovery and rehabilitation. As such, PA was meaningfully related to exploring physical capabilities (e.g., doing exercise to "show off my new lungs"), testing out physical limits (e.g., doing exercise to "see what this 'new me' could do"), and recapturing prior capabilities (e.g., "being able to establish myself with some competitiveness again"). In cases where participants were able to attain good levels of PA, this meant that taking part in PA was associated with a sense of normality because PA was a tangible way of benchmarking against one's experiences before illness.

Linked to how experiences of PA may contribute to transplant recipients' sense of self is the notion of survivorship as part of their transliminal experience. Within organ transplant research, Aujoulat et al. (2014) address survivorship by noting that part of the patient experience is about coming to terms with the trauma of survival. Some of the participants in their study dealt with an awareness about how close they came to death, which resulted in "emotional distress that had undermined their motivation to self-care" (p. 362). However, in their study—as with ours—some participants were able to successfully integrate this awareness into a functional long-term management framework, usually framed in terms of gratitude for being alive and the carrying out of moral, ethical duties toward their donor. Similarly, Amerena and Wallace (2009) suggest that it is important for patients to develop an adaptive attitude to "making the most of a second chance at life." In the same way, our analysis suggests that PA played a part in this success through the meaning-making processes associated with accomplishment, satisfaction, and reflection (e.g., "It was a real celebration. Look at this, I have made it. I'm alive and I can do 3k").

What we find particularly interesting in this regard is in exploring how and why PA elicits a seemingly special quality for the participants in this study in terms of learning to deal with survival in their transliminal experience.

Here, it may be helpful to draw on Frank's (2003, p. 251) work on survivorship as a "craft." He notes,

> The body has to be trained to do the craft; however initially talented the person might be, becoming a craftsperson requires apprenticeship and ongoing training . . . Body and mind work together as the craft is pursued, and the craft shapes body and mind together. Survivors, as I use the word, are self-conscious craftworkers of their lives and of the worlds these lives touch.

That is, it is possible that physical activities can constitute part of this ongoing training of learning the craft of survival—a process in which the body and mind work together in accomplishing. Furthermore, connections can be made between learning the craft of survival and Shaw's (2015) empirical work highlighting how confronting serious illness can provide an opportunity to rise to the challenge of living. In this work, it was found that the realization that time is limited gave one of her participants "a renewed sense of responsibility for her own life and a determination to live fully" (p. 240).

In addition to contributing to the literature on identity and survivorship, our findings align with research demonstrating the significance of recipients' relationship with their donor and their donated organ. Importantly, Ummel and Achille (2016) report that many recipients find it difficult to fully accept the generosity of donation. This is particularly challenging where there are ambiguities around donors' reasons for donating, which results in "difficulties making sense of the experience for the recipient, who could not imagine reciprocity in this context" (p. 201). Similarly, Kang and Stenfors-Hayes (2016) raise the issue that manifests from this understanding as a "moral burden to live well" having received an organ, a point echoed in Aujoulat et al.'s (2014) "feelings of obligation." Indeed, G. M. O'Brien et al. (2014) found that even the language used to describe the process (either "gift" or "donation") had an impact on recipients' emotional relationship with their donor.

This study extends this body of work to incorporate the role that PA can play in shaping recipients' relationship with their donor and their donated organ. Grounded in the understanding that PA is both a part of self-care and meaningfully related to making the most of one's survival, our participants saw PA as a way of demonstrating gratitude and fulfilling what they saw as an obligation (e.g., "someone had to die for me to get a liver and that's really important" and "you owe it them a bit"). That is, if transplant recipients are having difficulty dealing with a sense of duty and obligation, PA may help alleviate these feelings by helping to fulfill such duties and obligations. However, this does raise concerns over the magnification of moralized discourses around PA, implying that PA is an obligation rather than an opportunity for enjoyment, leisure, building friendships, or other reasons, which are altogether less responsibilizing.

Finally, the findings of this study align with and extend research investigating self-care and patient empowerment. Principles such as patient empowerment, shared decision-making, and patient centeredness have become embedded within health care service delivery in recent years (R. M. Anderson & Funnell, 2010; National Institute for Health and Care Excellence, 2019), principles that account for patients' individual backgrounds and their emotional, spiritual, and relational needs (Castro et al., 2016). In agreement with Aujoulat et al. (2014), our findings suggest that building a sense of empowerment is crucial, perhaps as a way for reclaiming a sense of control in a time of uncertainty. In parallel with notions of responsibilization, empowerment is not unproblematic, in that, it can too easily be wrapped up in pervasive neoliberal ideas associated with "healthism" (Crawford, 1980) that tend to simplify contextual complexities and propagate an image of the individual patient as the principal architect of their health-related successes and failures. Nevertheless, we hope that our study brings PA into this conversation, not only as a behavior that has biomedical benefits but also as a practice that leaves patients with a sense that they are engaging with and proactively contributing to their health on their own terms.

Conclusion and Implications

Before drawing conclusions from this research, some important limitations are worth noting. Most significantly, we are aware that recruiting organ transplant recipients primarily through organizations associated with transplant sport and through the World Transplant Games event is likely to exclude people who have had problematic or ambivalent experiences of PA. As a result, it is possible that our findings overemphasize the significance of PA, and we urge caution to be taken not to assume that these findings will be generalizable to all organ transplant recipients, especially those with little or no experience of PA or sport before illness. Future studies are needed to explore the prevalence of the experiences presented in this study across the organ transplant recipient population as well as to consider in what contexts and circumstances these outcomes tend to manifest.

Similarly, as we have alluded to in the findings, there may be important variations in the experience of PA between recipients that were not explored in this study. Whereas several issues appear to be relevant to recipients regardless of transplanted organ, it could also be the case that special attention is needed to understand the particular corporeal experiences of, for example, being out of breath during PA as a lung transplant recipient, having a high heart rate during PA as a heart transplant recipient, or being

perpetually aware of dehydration after PA as a kidney transplant recipient. Similarly, future studies could give greater attention to recruiting participants based on the length of time since receiving their transplant and, relatedly, older adult recipients—a demographic that is underrepresented in this study despite making up a high proportion of the transplant recipient population. Exploring the experiences of older adults and those who may have had their transplant for a greater number of years might reveal new insights into how PA is experienced.

Notwithstanding these limitations, the analysis provided in this study offers new insights into organ transplant recipients' experience of engaging with PA. Taken together, these findings show for the first time how PA can be important for organ transplant recipients' sense of being, shaping health expectations for the future, and self-understanding in the present. Although more research is needed to develop concrete, practical recommendations for interventionist policies and initiatives, we would point to some key implications of this study to be in keeping with organ transplant recipients' lived experiences of PA. We suggest that support offered about PA should be sensitive to the impact that PA can have on the following: how recipients position themselves in between health and illness, recipients' ongoing learning about survivorship, shaping recipients' relationship with their donor and their transplanted organ, and recipients' sense of empowerment and control in a time of uncertainty. Although we recommend that caution should be applied when encouraging recipients to engage with PA, we remain optimistic about the potentially beneficial role that PA can play in supporting illness management following transplantation.

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Note

1. The World Transplant Games is a competitive sporting event held biennially where all competitors are organ transplant recipients. One of the goals of the events is to "highlight the importance of physical activity and healthy lifestyle in the long-term management and well-being of transplant recipients" (World Transplant Games Federation, 2019).

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