



LEEDS
BECKETT
UNIVERSITY

Citation:

Wiltshire, G and Clarke, NJ and Phoenix, C and Bescoby, C (2020) The role of sport-based social networks in the management of long-term health conditions: Insights from the World Transplant Games. *International Review for the Sociology of Sport*. ISSN 1012-6902 DOI: <https://doi.org/10.1177/1012690220979202>

Link to Leeds Beckett Repository record:

<https://eprints.leedsbeckett.ac.uk/id/eprint/7358/>

Document Version:

Article (Accepted Version)

Creative Commons: Attribution-Noncommercial 4.0

The final version of this paper has been published in *International Review for the Sociology of Sport* by SAGE Publications Ltd, All rights reserved. © Gareth Wiltshire, Nicola J Clarke, Cassandra Phoenix, Carl Bescoby, 2020. It is available at: <https://journals.sagepub.com/home/irs>

The aim of the Leeds Beckett Repository is to provide open access to our research, as required by funder policies and permitted by publishers and copyright law.

The Leeds Beckett repository holds a wide range of publications, each of which has been checked for copyright and the relevant embargo period has been applied by the Research Services team.

We operate on a standard take-down policy. If you are the author or publisher of an output and you would like it removed from the repository, please [contact us](#) and we will investigate on a case-by-case basis.

Each thesis in the repository has been cleared where necessary by the author for third party copyright. If you would like a thesis to be removed from the repository or believe there is an issue with copyright, please contact us on openaccess@leedsbeckett.ac.uk and we will investigate on a case-by-case basis.

Title

The role of sport-based social networks in the management of long-term health conditions: insights from the World Transplant Games

Authors

Gareth Wiltshire, School of Sport Exercise and Health Sciences, Loughborough University, UK.*

Nicola Clarke, Carnegie School of Sport, Leeds Beckett University, UK.

Cassandra Phoenix, Department for Sport and Exercise Sciences, Durham University, UK.

Carl Bescoby, Department for Health, University of Bath, UK.

*Corresponding author. John Beckwith Building, Loughborough University, Epinal Way, Loughborough, LE11 3TU. g.wiltshire@lboro.ac.uk. 01509 225449.

Journal

International Review for the Sociology of Sport

The role of sport-based social networks in the self-management of long-term health conditions: insights from the Transplant Games

Abstract

In the context of an increasing clinical need to better support self-management for people living with long-term health conditions (LTHCs) an interest in the role of social networks has emerged. Given that sport participation often provides opportunities for social engagement, a space to explore self-management at the intersection of medical sociology and the sociology of sport has opened up. This article presents findings from an exploratory qualitative study with organ transplant recipients who have participated in Transplant Games events – national and international multi-sport competitions for organ transplant recipients. Our findings illustrate how sport-based social networks serve as resources of health-related knowledge, provide participants with additional affective support and help shape health expectations for the future. Although sport-based social networks were seen as an overwhelmingly positive resource for our participants, it is plausible that harmful unintended consequences could arise for patients with existing self-management issues. As such, it is recommended that people seeking to use sport as a tool to enhance illness self-management should consider the various and powerful ways that social networks can be impactful and anticipate potential consequences accordingly.

Keywords: *sport, social networks, medicine, organ transplantation, self-management*

Introduction

People with long-term health conditions (LTHCs) must engage in ongoing self-management practices in order to reduce the symptoms of their illness, minimize its impact on physical functioning and cope with its complex psychosocial consequences (Gallant, 2003). As an important and growing area of healthcare research and practice, strategies to optimise LTHC self-management have shifted in focus in recent years from a tendency to target individual-level outcomes such as behavioural, educational and cognitive improvements (Pai and McGrady, 2014) and towards a social understanding of self-management. This shift aligns with the succinct idea that people do ‘self-manage’ their conditions, but they do not self-manage *on their own* (Vassilev et al., 2013). This new direction has opened up a space for medical sociology with an emphasis on understanding the role that social networks play in helping patients to live well with their condition (Morris et al., 2016; Vassilev et al., 2019).

Organ transplant recipients are a growing LTHC population who have received a solid organ (e.g. heart, kidney, liver, lung, pancreas) or a stem cell transplant from a living or deceased donor (WHO, 2019). Transplantation is widely referred to as a treatment rather than a cure due to the need to monitor the functioning of the transplanted organ, the potential recurrence of the disease that led to requiring a transplant and the potential for comorbidities resulting from the use of life-long immunosuppressive drug regimen (Neuberger et al., 2017; Stoumpos et al., 2015). Research has shown that problems with self-management for organ transplant recipients exist in relation to non-attendance to clinical appointments (Pankhurst et al., 2020), non-adherence to medication (Cassuto et al., 2016) and incidence of mental ill-health (Corbett et al., 2013) among others. As is the case for the conversation about LTHCs more broadly, advancing a sociological understanding of the phenomenon of self-management may provide important insights into how self-management is accomplished and, therefore, what might be done to better support transplant recipients in practice.

In an attempt to contribute to this area of interest, this article explores how sport may offer new opportunities to develop and mobilise social networks with the potential to support self-management. We bring sport into the conversation here because sport has long been understood as social practice whereby participation encourages – and often necessitates – an engagement with a community of others (Jarvie, 2003). Research continues to build on this assumption with recent studies exploring how social capital can be built through participating in sporting initiatives (Adams et al., 2017), how female football players draw on social networks to make career steps (Rosso and McGrath, 2013) and how collaborative networks are critical to sport-for-all programmes (Dobbels et al., 2019).

On this basis, we suggest a new and fruitful direction to this interest might be explored which connects the otherwise diverse interests of sport, social networks and medical sociology. With our focus on organ transplant recipients in mind, we bring sport into view through exploring the experiences of participants at ‘Transplant Games’ events – such as the World Transplant Games (WTGF, 2019) and national-level equivalents like the British Transplant Games in the UK (TSUK, 2020). These events are multi-sport opportunities to take part in competitive sport against other transplant recipients, often while representing the hospital where participants received their transplant. Transplant Games events are relatively modest in scale, not dissimilar to the early incarnations of disability sport that focused on rehabilitation (Purdue and Howe, 2012), invoking a similar ethos of camaraderie and survivorship attached the Invictus Games for military veterans (Cree and Caddick, 2019) and shares the notion of challenging dominant narratives about sports participation and performance as is the case with the World Masters Games (Dionigi et al., 2013). As such, Transplant Games events represent an excellent opportunity to shed light on the potential of sport to enhance and mobilise social networks that may contribute to the self-management of LTHCs.

In what follows, we present some of the relevant literature upon which the study was grounded before presenting the methods used and the findings themselves. The article then closes with a brief discussion on what we see as the implications of the study for practice and future research.

Sport, illness and the power of social networks

This research project necessarily builds on and contributes to the growing body of work aiming to understand the experience of sport and exercise for people living with illness which has emerged as a significant area of interest in recent years. Often utilising qualitative methodologies, this literature includes the experiences of people taking part in sport and exercise with, for example, asthma (Allen-Collinson, 2014; Owton and Allen-Collinson, 2016), heart disease (Moola et al., 2015; Meredith et al., 2019), epilepsy (Scarfe and Marlow, 2015), multiple sclerosis (Richardson et al., 2019; Horton et al., 2015) and arthritis (Hunt and Papathomas, 2020). No articles, to our knowledge, exist about organ transplant recipients in sport-related journals. Indeed, although numerous studies about Transplant Games events have been published since they began in the 1990s (Cho et al., 2017; Atamañuk et al., 2017; Deliva et al., 2014; Johnson et al., 2013; Wray and Lunnon-Wood, 2008; Griffin, 1998; Slapak, 1997; McGee et al., 1996) they remain unexplored in scholarship related to sport. As such, we hope to introduce a novel medical population into this body of work in the hope of opening up new lines of inquiry and potential areas of overlap.

Furthermore, with an explicit interest in drawing lines of connection between sport, social networks and medical sociology, this present study takes a different direction to much of the existing literature exploring the experience of sport and exercise for people living with illness. That is, the majority of this research tends towards the explication of illness as it

manifests in private, personal, lived-experiences as witnessed by individuals. Rich and nuanced insights have been achieved through drawing heavily on phenomenology (Allen-Collinson, 2014; Owton and Allen-Collinson, 2016; Scarfe and Marlow, 2015), narrative psychology (Hunt and Papathomas, 2020; Richardson et al., 2019) and by centralising emotions (Meredith et al., 2019). These insights are, no doubt, imperative but beyond Moola et al.'s (2015) illumination of how 'shared experiences' are important, a dedicated analysis into the ways in which social and relational aspects of everyday life can shape, constrain and enable lived experience is yet missing.

In taking this direction, this study hopes to extend the existing literature that demonstrates the importance of social networks for the self-management of LTHCs. This research has, in part, emerged in response to dissatisfactions with individual-level contributors to LTHC self-management and towards the notion that everyday self-management is situated in social relationships structured by group membership and often tied to particular social identities and positions (Jones and Williams, 2017). Indeed, this social approach follows the well-established idea that individual health outcomes often derive from the collective resource of social capital (Story and Carpiano, 2017). As such, there is increasing recognition that self-management is not just an individual but a collective process whereby social networks can potentially make a considerable contribution to improving health outcomes for people with LTHCs (Rogers et al., 2011). Social networks play a role in sharing knowledge and accessing resources (Vassilev et al., 2014) and there is significant input from 'weak ties' within these networks – like neighbours, colleagues and acquaintances – not just the more intimate relationships with 'close ties' such as family members or a spouse as is widely assumed (Rogers et al., 2014). This understanding has led to practical initiatives and interventions to enhance social network support (e.g. Welch et al., 2020), but little is known about whether and how sport participation might contribute to such goals.

Methodology

Research focus

The analysis presented here represents a focused component of a wider investigation with the objective of exploring the potential role of sport and exercise in the ongoing challenge of trying to enhance self-management for organ transplant recipients. As sport and exercise could feasibly have a wide range of impacts on self-management, it should be noted that we chose to explore the role of social networks from the outset after having identified it as an area of interest from an initial scoping review of the literature. Because of this interest, references to social experiences were included in participant information sheets and within the interview schedule. As such, one of the key research questions that guided the study from the outset was: how do organ transplant recipients' sport-based social networks contribute to the self-management of their illness? By way of clarification, we take 'sport-based social networks' to mean the array of relationships that our participants have with other individuals that are mobilised through engaging in sport, such as Transplant Games events.

Research context: Transplant Games events

We use 'Transplant Games events' to describe the various sporting events specifically organised for transplant recipients that all of our participants had participated in. The largest of these events is the Summer World Transplant Games which is organised every two years, the most recent of which hosted around 2,500 competitors from over 60 different nations. Transplant Games events also includes national-level competitions as well as organ-specific events such as the European Heart and Lung Transplant Championships. It is relevant to note that these events are accessible and inclusive with most events not requiring an entry standard.

While high quality performances are strived for and achieved, Transplant Games events consistently emphasise an ethos that centres around ‘celebrating the gift of life’, promoting participation for all and raising awareness about organ donation. The schedule of competition includes a range of sports, from athletics, cycling, swimming and football through to bowling, darts and snooker as well as winter sports at the Winter World Transplant Games. Social and cultural activities are often organised – particularly at international events – which means that opportunities to socially engage with other participants are available.

Participants

Thirteen transplant recipients who had experience of participating in Transplant Games events were recruited to take part in this study. After obtaining ethical approval from [University anonymised], participants were recruited by advertising the study on social media platforms, through national Transplant Sport organisations and by face-to-face and written invitations during the World Transplant Games in 2017. As an exploratory study, we were led by a desire to achieve diversity across gender, age, nationality and transplant type. As a result, the participant sample consisted of seven females and six males, aged between 24 and 55, from England, Australia, Northern Ireland, Wales, New Zealand and South Africa, and having received either a kidney, liver, heart or lung transplant. This recruitment strategy helped avoid the error of recruiting a skewed sample of participants based on only one of these characteristics but also placed limits on our ability to make claims about how experiences were diversely shaped by these characteristics, such as the gendered nature of participants’ experiences. In line with this, our approach was to try to reveal some of the commonalities between participants’ experiences and the processes that they were involved in. To maintain anonymity in what is a somewhat small community, gender-neutral pseudonyms and pronouns (them/they) are used in the presentation of data in this article and we have avoided attaching identifying

characteristics (such as transplanted organ, nationality and age) to participant quotations where at all possible.

Data collection

Semi-structured interviews were considered an appropriate method to gain insight into the way in which participants' sport-based social networks contribute to LTHC self-management. Interviews lasted between 32 and 68 minutes (average 45 minutes) and were conducted face-to-face with participants who resided in the UK and by telephone (Skype) with participants outside of the UK. Despite an awareness about the possible differences between conducting interviews in different ways (Irvine et al., 2013) the lead interviewer ([initials]) did not feel that the ultimate findings were affected because differences were mediated through different kinds of interactions during the conversation itself. As an example, the interviewer perceived that telephone participants were more self-conscious about whether they were saying 'too much' or 'too little' with their answers due to not being able to see visual cues from the listening interviewer. The interviewer dealt with this by explaining this tendency at the start of telephone interview as well as using more verbal cues and interjections while listening to participants speak. The interview guide was structured around topics intended to direct the conversation towards the experience of being a transplant recipient in general, the experience of sport and exercise as a transplant recipient and the social impact of engaging in Transplant Games events.

Data analysis

The analysis process began with interview transcripts being read independently by two members of the research team ([initials]). As part of the wider study, the two analysts proceeded in a largely data-driven way broadly in alignment with guidance offered in reflexive thematic

analysis (Braun and Clarke, 2019) while still maintaining boundaries to the analysis as defined by the research objectives and questions. The transcripts were read first for familiarisation and then codes were developed from initial annotations through to more refined themes, each with ‘a central organising concept’. The themes were refined through a collaborative conversation between the two analysts and then further when being shared with two additional researchers ([initials]) who were asked to challenge the claims and offer new insights where appropriate. Following this, a summary of our findings, including examples of interview quotes, were then presented back to study participants for comments. The reason for including this step was not because we thought it would ‘ensure validity’ or confirm that our interpretation was ‘correct’ – as has been thoroughly critiqued elsewhere (Smith and McGannon, 2018) – but rather more straightforwardly to reduce the risk that we had mistaken or misunderstood what participants were trying to communicate (Maxwell, 2012). In practice, we should note that little was gained from the process on this occasion but we maintain that doing so at the very least offered a space for participants to reflect on the research as well as demonstrated a willingness to present a summary of findings back to participants which, in our view, is preferable to not doing so.

This process resulted in three overarching themes (engaging in social networks; physical activity, capability and the transliminal self; physical activity as health, self-care and duty). Owing to their orientation towards phenomenological aspects of taking part in sport and exercise as a transplant recipient, it was decided that the second and third themes warranted further analysis through phenomenological conceptual lenses. This allowed us to think with lifeworld heuristics and lived-body experiences which brought out interesting issues about identity, survivorship, obligation and empowerment (see [anonymised], 2020). The ‘engaging in social networks’ theme was thus developed separately from the phenomenological interrogation in the latter stages of analysis and reporting. We felt that this was justified not only because it allowed us sufficient space to present the rich details that came out of the

interviews, but also because the emerging ideas meaningfully connect with and contribute to a separate literature base making these findings of interest to a different set of researchers in the field. Within the engaging in social networks theme which is the focus of this paper, our interpretation was organised into three domains: (1) shaping knowledge, (2) affective communities and (3) health expectations.

Findings

Shaping knowledge

Our analysis highlighted how sport-based social networks play an important role in the shaping of knowledge about health, illness, treatment and management. In a process similar to what is described by Vassilev et al. (2013), gaining knowledge occurred through engaging in knowledge exchange conversations with sport-based social networks about topics such as medication, dietary advice and bodily changes. Jordan said plainly that Transplant Games events were somewhere to “learn a bit about how to manage your condition” and also that this was “something that I didn’t expect to get from the Transplant Games.” In Jordan’s words, it was an opportunity to,

learn from the greater experience and learn from, maybe, from some of the good things that some people have done and probably some of the mistakes that some people have made.

This idea was also true for Charlie but with the added interest in gaining knowledge from people in the network who enjoyed less problematic transplant recipient journeys. In terms of what exactly people were interested in knowing about, one of the most common areas of interest was medication. As Chris explained,

I’m quite intrigued when I ask people what drugs they’re on, or they tell me what drugs they are on. Because I don’t take hardly any drugs, and I was like “gosh I only take four

pills a day”. And they were saying “I am taking this” and “I am taking that”. And I am thinking, “should I be taking more?” So that has made me query a few things.

While participants in our study did not express an inclination to question their own clinical team, they did feel that gaining knowledge about the treatment that other transplant recipients received put them in a position in which they were informed about the clinical decision making that they were part of. In this way, sport-based networks built through participating in Transplant Games events can be seen as ‘information networks’ which is significant because such networks have been showed to be related to better self-management capabilities (Koetsenruijter et al., 2016). It is relevant, too, to point out that these information networks do not seem to be facilitated specifically by the sport participation aspect of the Transplant Games but rather the various opportunities to spend time with and engage socially with other recipients as part of the event as a whole.

In addition to knowledge exchange about transplant-specific medication, one patient also discussed how they drew on sport-based social networks to discuss the experience of the menopause as a transplant recipient. As they explained,

I have been able to speak to a couple of ladies in my age category from the [national team] to find out things like at our age what can we take what can we not take. ‘How you are dealing with this?’ ‘Has the transplant’ – you know because we are transplanted – ‘is it different or harder?’ So, it’s insightful and valuable information that I can’t get from my own GP because he doesn’t know. He can’t tell me. (Frankie)

The notion that information of this kind was unavailable from conventional medical sources is significant for our interest in the role of sport-based social networks in illness self-management. Indeed, this was also a belief shared by several other participants in this study. For Jack, hearing advice “first-hand” was more about reassurance: “it’s all well and good you reading it or the doctors telling you that you can do it but you’re always going to have your doubts, especially when little things go wrong.” Similarly, for Frankie it was reassuring to hear

this information from people in their network but also a more powerful way of receiving the same information. In Frankie's words:

Yeah, you sort of take it onboard better if it's someone here who has gone through it. And you can be reassured more if it is someone who has maybe been in the same situation as yourself. And it can maybe put your mind at rest if you think how this is happening and this is okay, it's normal.

When probed further on why sharing knowledge between people in the network might be important, one explanation offered was that participants feel more comfortable to ask questions with people within their network than with medical professionals. Jamie said, "I know it's silly, but there's no silly questions. It's all natural." This suggests that sharing knowledge within a social network may be especially important for people who may lack confidence or maturity because of being worried about feeling "silly" but also, perhaps, for patients who feel uncomfortable talking about embarrassing issues and those who feel like they don't want to waste their consultant's time with a "silly" question. This may be an example of the notion that utilising social networks for self-management requires an ability to deal with relationships effectively (Vassilev et al., 2014). Yet, while sharing information like this was seen as a benefit from the perspective of participants in this study, we see some cause for concern about the potential for exchanging harmful information – an issue also raised with regards to low education groups in other research (Koetsenruijter et al., 2016). This opens up interesting and unanswered questions about trust in healthcare professionals, the role of expert patients and the negotiation of treatment concordance between patients and healthcare professionals.

Affective communities

Our analysis also suggests that social networks developed through Transplant Games events can be considered as resources that have an emotional impact on participants. The significance of the Games in this regard is, perhaps, that it provides a ‘meaningful activity’ (James et al., 2020) through which the closeness between network members can be developed. This is perhaps unsurprising given that sociality has been shown to be important in the comparable context of the World Masters Games whereby sports participation in older age is seen as an opportunity for social stimulation and engagement (Dionigi et al., 2013) and involves a sense of connectedness among a ‘unique community’ (Dionigi, 2007). Indeed, similar to how Moola et al. (2015) describe the significance of having a shared understanding with others with the same condition, social networks developed through Transplant Games events were thought of by one participant as like “a wee [little] club” (Frankie), invoking the notion that transplant recipients are ‘insiders’ with connections and common bonds not accessible to others. As Max succinctly put it, “the whole emotional journey of going to the Transplant Games forms this incredible community that you are a part of.”

Differentiation between sport-based social networks and everyday social networks was also noted through the notion that only transplant recipients “understand” what other transplant recipients have been through and that they “get it” in a way that non-transplant recipients do not. One participant was explicit in saying that they valued the emotional support from Transplant Games social networks even more than their family in some respects:

From my point of view, it’s better for me than my own family because we are not that close. I have a lot of brothers and they are all living away. I get more out of it than probably anyone else. I found it invaluable. I love it. I would be lost without the Games, actually. (Frankie)

Similarly, speaking about a friend that they met through the Games, Morgan said that “I talked to him about stuff that I wouldn’t even talk to [my spouse] about. And I only met him through this.” Although it is unclear from our data whether or not the closeness felt between

recipients is somehow assisted or reliant on the sporting context in which recipients meet, we are inclined to suggest that there are particularities about sport that could be significant. These include, for example, the notion of competing together as part of a team and experiencing meaningful successes and failures that are witnessed and shared with others in the network.

On this foundation, our analysis highlights the different ways that people within the sport-based network interact to accomplish the emotional support that they value and that, ultimately, may impact self-management. In this regard, the simple but powerful act of sharing stories appeared to be important to participants in our study. As Max explained, sharing stories was “spiritual” and “overwhelming.” Similarly, for Charlie, sharing stories was part of the “camaraderie” of Transplant Games events and people’s willingness to listen was a way of enacting and accomplishing the sense that “you’re all in it together” invoking a sense of ‘collective efficacy’ (Vassilev et al., 2014). Indeed, Jack valued talking about the side-effects of medication with other transplant recipients because “you can just compare stories and swap stories that you can’t swap with anyone else.” This ‘swapping’ of stories emphasises that these relationships are formed on the basis of reciprocity, which is an important characteristic of networks like this (Rogers et al., 2014). In these ways, it was clear that it was not simply the telling of and listening to stories within a network that was important but telling stories in the knowledge that the listener could empathise with them and that a reciprocal relationship was being formed.

In Jamie’s experiences of talking about illness, conversations with other transplant recipients were far more comfortable. As they noted,

I feel way more comfortable talking about when I went ill. Because the stuff that was happening it’s a bit - if you just tell it to everybody else they would be like ‘oh’ - not recoil or anything but, that they would be like that.

Similarly, for Morgan this meant that conversations about future concerns went differently with people in their sport-based social network than they did with, for example, their spouse. Not only does this type of relationship mean that “nothing is taboo” (Jamie) and that there is even an occasional level of “dark humour” (Alex) about illness and mortality, but also that swapping stories cultivated a sense of normality about illness experiences. That is, despite the knowingness about the extraordinary nature of each others’ stories, sharing stories brought normality to these extraordinary experiences:

People always treat me a little bit with kid gloves at home – “oh you’ve had a transplant”, “you’re such a wonderful person”, “you are an inspiration”. I’m not here, because everybody is the same. My family think I’m the most amazing person in the world, but I don’t think I am at all, you know. I’ve just survived an illness. But here you are not, you’re just normal and I quite like that. Being treated normally, that’s good. (Frankie)

Beyond enabling storytelling and providing a sense of normality, the nature of mutual understanding and “getting it” meant that members of the sport-based network supported each other when experiencing acute illness. Robin talked about how much people would “rally around” and put out messages of support during periods of more immediate serious illness that transplant recipients are at risk of experiencing. Robin said, “we have all been praying and whatever for [team mate] to get a kidney, and it happened just a few weeks ago.” This was backed up by Alex who said, “it’s kind of like a little group that you can just – whenever someone is ill – it’s like you all group together.” Indeed, after witnessing the emotional support that people in the network give each other, there was a sense that participants understood that there was an available resource should it be needed in future.

Health expectations

The third finding that our analysis produced is that sport-based social networks play a role in self-management through shaping health expectations. In this context, we take health expectations to mean the assumptions that participants have about their future health and illness, including their capabilities, limitations and mortality. For many participants, social networks had a hopeful impact on health expectations because people bear witness to the good health of an overwhelming number of transplant recipients taking part in Transplant Games events. As Leslie put it,

It's good to see that thousands of other people are going through the same thing, and successfully. Yeah, that's probably the main thing [...] it gives you hope that you can keep going and keep living for as long possible.

In the context of much uncertainty and fragility about the longevity of transplanted organs, seeing others who have lived with transplants for many years was encouraging, presumably because it enabled participants to imagine their future in similar terms. As Charlie said,

You see some people walking around with organs that are 30 plus years old. A lot of people aren't told the, kind of, length of their organs and stuff like that but as kidney patients we usually are because we tend to have the need for more than one throughout our life. I got told initially, 20 years is probably the average for a live donor – which is, they say it's the *crème de la crème*, you know, from a *living* person. But you get people 30-40 years ago, you know. Coming up to nearly 40 years some of them.

Here, Charlie shows that seeing other transplant recipients “walking around” with transplants far beyond the 20-year duration that they were initially told to expect was particularly encouraging. While the impact described here does not appear to be contextualised in sport and therefore could plausibly be facilitated through non-sport initiatives, it is also possible that the Transplant Games is particularly powerful in this regard because recipients bear witness to each other performing in a range of physically demanding sporting competitions far beyond “walking around”. Similar to Charlie, Jamie described talking to a kidney patient

with a 25-year old transplant as “really reassuring”. As with Charlie, Jamie also picked up on the fact that the particular person in question received a transplant from a deceased donor, suggesting that the 25 years is a low-end expectation. Jamie explained,

When he said ‘25 years’ I thought ‘oh that must have been a good live donor kidney you got there’. Then he was like ‘oh no, it was from a deceased donor’, and I was like ‘wow’ [...]. So yeah, that is really good to know, if you keep on top of it.

Here, we take Jamie’s feeling – that it is “really good to know” that even a kidney from a deceased donor can last 25 years – as a feeling closely related to his hope about the longevity of their own transplanted kidney. As with most feelings of hope, however, we suggest that there may be risks associated with false hope in cases where individual patients have significantly different prognoses to others in their social network. That is, questions may be raised here about the increased emphasis on health expectations being grounded in social comparisons and norms rather than unique medical circumstances. Indeed, similar to how older adults sometimes understand sport as means of ‘resistance’ to aging (Dionigi et al., 2013), it may be the case that transplant recipient understand sport as a means of resistance to future ill-health.

In addition to shaping expectations about the longevity of the transplanted organ, participants also gained an idea about the quality of their future lives from engaging with people in their sport-based network. For Jack, “not only do you get to see what is achievable, it drives you. It motivates you to become better at either a sport or just to become healthier.” Indeed, as a multi-age group competition the Transplant Games events gave Alex hope about the possibility of staying involved in sport as an older adult. Reflecting on talking to and watching a 75-year old team member, Alex said “he’s like a star. I love watching him. He's so positive. If I’m like that when I'm older, I'll be happy.” Implicit in this expectation is not only that they will be alive as an older adult, but also that they will be taking part in sport and doing so with

positivity. Our suggestion is that these hopeful expectations about future health may have a beneficial role to play in quality of life by reducing anxieties experienced in the present.

In contrast to hopeful health expectations, several participants discussed how social networks developed through Transplant Games events led to being concerned about ill-health and death. Reflecting on past team members who have died or are too ill to compete, Robin said that “sometimes that can be upsetting.” For Jordan, interacting with others who talked about recurring serious illness made them concerned about future health:

I guess maybe I have an underlying fear that maybe my liver disease will come back one day. I don't know if there is any truth in that. I'm not expecting in any way that it will but, you know, it gets you sort of thinking about it a bit.

Jordan further went on to say that even though “talking to people is a positive experience” at Transplant Games events, it can also entail more uncomfortable interactions. They said; “you hear ‘oh my kidneys are only functioning at 30%’ or something. And then it's the reminder of ‘I have to be really careful and have got to drink all that water and do all those things’.” For this reason, hearing about the ill-health of others in the network was troubling but it was also described in the interview as “a healthy reminder that it's not all plain sailing.” This appeared to also be the case for Frankie:

We have lost a few, sadly, of our team [...] I don't know if it is directly related to, you know, that the medication... I'm not sure. I don't want to dwell on that too much. I just think we have to deal with everything if and when it arrives. It is like anybody, you know. You just try and look after yourself and be healthy.

Here, Frankie expressed sadness about the death of a fellow team member but didn't want to “dwell on” the harms of long-term immunosuppressive medication – which has been strongly linked to problematic long-term side effects (Moini et al., 2015). In this way, it is understandable that the recognition of mortality is immediately turned to present behaviours of

trying to “look after yourself and be healthy” which we see as relevant to improving LTTC self-management.

Discussion and conclusion

In response to our guiding research question (how do organ transplant recipients’ sport-based social networks contribute to the self-management of their illness?) our study points to three possible answers: (1) by having an impact on participants’ knowledge about health, illness, treatment and management, (2) by serving as a resource with an emotional impact on participants and (3) by having an impact on participants’ health expectations.

While we consider this article to represent a useful exploratory starting point, several cautionary notes should be stated with a view to inform future research and practice. We are most cognizant of the risk to generalisability based on our sampling strategy in which only transplant recipients with positive experiences of engaging with sport-based social networks were likely to have been recruited to the study. That is, it is plausible that there exist transplant recipients who have attended Transplant Games events and have not engaged with social networks in the same way as this study describes, yet the voices of those transplant recipients are omitted from this study. As such, we would urge caution in assuming that future participants who are encouraged to attend Transplant Games events will experience social networks in the way that our participants have. Such assumptions may also rely on the extent to which future competitors already have established social ties to other transplant recipients and hence might be less predisposed to seeking out new connections.

Notwithstanding this limitation, we suggest that these findings contribute to and extend the existing literature in several meaningful ways. For researchers interested in understanding the experience of sport and exercise for people living with illness, this study may be useful in

highlighting similarities and differences between different LTHCs. One clear similarity can be seen between how transplant recipients as well as children with heart disease value relationships with other patients because being with others with similar experiences, at the very least, can reduce the feeling of being “isolated and alone” (Moola et al., 2015, p. 285). While it may be the case that this is particularly important for people living with LTHCs that are uncommon, we see no obvious reason why the three domains described in this study would not be important to people a range of LTHCs and hence could be new areas to explore.

Another contribution of this study might be through offering an expanded view of lived experience which accounts for social and relational aspects of illness. Phenomenological accounts of sport and exercise for people living with illness (e.g. Allen-Collinson, 2014; Owton and Allen-Collinson, 2016; Scarfe and Marlow, 2015) may benefit from incorporating how others ‘show up’ in the lifeworld of agents and serve as an essential structuring component of being. Indeed, we agree with studies that draw heavily on narrative psychology and have revealed how storytelling is intimately tied to illness experience (e.g. Hunt and Papatomas, 2020; Richardson et al., 2019) but would add that the social context of this storytelling – i.e. who is listening to the story – is a context not to be ignored. Similarly, the network of social relations around individuals appears to be critical for researchers interested in the emotion and illness (e.g. Meredith et al., 2019). The key difference in the perspective provided by our attention to social networks is that suggestions for practical implications lean towards strategies to reveal and build informal networks in addition to strategies to enhance emotional intelligence and provide further clinical support. In these ways, our approach has made visible the ways in which illness is a socially situated experience and one, therefore, that may be impacted by changing social networks change over time and differences in social networks between demographic groups.

Finally, we hope that our findings have drawn previously unknown connections between sport and the medical sociology literature interested in social networks for LTHC self-management. Existing research rests on the fundamental idea that the self-management agenda needs to better include social networks of support which often take place outside the provisions available from formal healthcare services, such as from consultants, transplant coordinators and clinic health psychologist (Rogers et al., 2011). The main contribution of this study may be in demonstrating that social networks built in sport settings can help satisfy some of the emotional and social needs that recipients require from their social network at large as well as undertake some of the ‘work’ (Vassilev et al., 2013) that their friends and family might otherwise be required to undertake. However, although our study is supportive of initiatives and charities using sport as a tool to seek broader healthcare goals, several points of concern could be raised for particular patients based on our interviews. These include the potential that engaging in sport-based social networks may, for example, increase the likelihood of experiencing grief in cases when a person in the network has died. Indeed, given the finding that much health-related knowledge and advice is shared among members of the sport-based network, it would be important to investigate whether this led to an empowered sense of ‘mastery’ for patients who learn to feel engaged and autonomous about their illness (Heaton et al., 2016) or, instead, whether this exposes patients to potentially ill-informed and harmful guidance about self-management. Given our interest in the role of social networks, it may also be important to consider whether sport-based social networks increase the emphasis on health expectations being grounded in social comparisons and norms rather than unique circumstances. That said, it is also true that we have found no evidence of harm caused by engaging with sport-based social networks and, as such, our optimism about the potential of sport to contribute to improving LTHC self-management should be emphasised but more research is warranted.

References

- Adams, A., Harris, K., and Lindsey, I. (2017). Examining the capacity of a sport for development programme to create social capital. *Sport in Society*, 437(July), 1–16.
- Allen-Collinson, J., Owton, H. (2014). Take a deep breath: Asthma, sporting embodiment, the senses and ‘auditory work.’ *International Review for the Sociology of Sport*, 49, 592–608.
- Atamañuk, A.N., Ortiz Fragola, J.P., Casonu, M., Lirio, C., Graziano, V., & Cicora, F. (2017). Physical Activity Among Organ Recipients: Data Collected From the Latin American Transplant Games. *Transplant Proceedings*, 49, 354–357.
- Braun, V. & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport Exercise and Health*, 11, 589–597.
- Cassuto, E., Pageaux, G. P., Cantarovich, D., Rostaing, L., Loupy, A., Roche, B., ... & Bourhis, Y. (2016). Adherence to and acceptance of once-daily tacrolimus after kidney and liver transplant: results from OSIRIS, a French observational study. *Transplantation*, 100(10), 2099-2106.
- Cho, W., Kim, H., Park, U., Park, W., Yu, J., Yoon, I., Kim, S. & Ahn, C. (2017). Rehabilitation of Transplant Recipients and Transplant Games. *Journal for the Korean Society of Transplantation*. 6–15.
- Corbett, C., Armstrong, M. J., Parker, R., Webb, K., & Neuberger, J. M. (2013). Mental health disorders and solid-organ transplant recipients. *Transplantation*, 96(7), 593-600.
- Cree, A., & Caddick, N. (2019). Unconquerable heroes: Invictus, redemption, and the cultural politics of narrative. *Journal of War & Culture Studies*, 1-21.
- Deliva, R.D., Patterson, C., So, S., Pellow, V., Miske, S., McLister, C., Manlhiot, C., Pollock-BarZiv, S., Drabble, A. & Dipchand, A.I. (2014). The World Transplant Games: An incentive to improve physical fitness and habitual activity in pediatric solid organ transplant recipients. *Pediatric Transplantation*, 18, 889–895.
- Dionigi, R.A., Horton, S., Baker, J., (2013). Negotiations of the ageing process: Older adults’ stories of sports participation. *Sport, Education and Society*, 18, 370–387.
- Dobbels, L., Voets, J., Marlier, M., De Waegeneer, E. & Willem, A. (2018). Why network structure and coordination matter: A social network analysis of sport for disadvantaged people. *International Review for the Sociology of Sport*, 53, 572–593.
- Gallant, M. P. (2003). The influence of social support on chronic illness self-management: a review and directions for research. *Health Education & Behavior*, 30(2), 170-195.
- Griffin, P. (1998). Exercise and sport after organ transplantation. *British Journal of Sports Medicine*, 32, 194–194.
- Horton, S., MacDonald, D. J., Erickson, K., & Dionigi, R. A. (2015). A qualitative investigation of exercising with MS and the impact on the spousal relationship. *European Review of Aging and Physical Activity*, 12(1), 3.

- Hunt, E.R. & Papathomas, A. (2020). Being physically active through chronic illness: life experiences of people with arthritis. *Qualitative Research in Sport Exercise and Health*, 12, 242–255.
- Irvine, A., Drew, P. & Sainsbury, R. (2013). ‘Am I not answering your questions properly?’ Clarification, adequacy and responsiveness in semi-structured telephone and face-to-face interviews. *Qualitative Research*, 13(1), 87-106.
- James, E., Kennedy, A., Vassilev, I., Ellis, J. & Rogers, A. (2020). Mediating engagement in a social network intervention for people living with a long-term condition: A qualitative study of the role of facilitation. *Health Expectations*, 23, 681–690.
- Jarvie, G. (2003). Communitarianism, sport and social capital. *International Review for the Sociology of Sport*, 38(2), 139–153.
- Johnson, U., Hinic, H., Billström, A. & Gäbel, H. (2013). Transplant Recipients’ Experience of Participation at the World Trans-plant Games in Gothenburg 2011: A Study of Psychological Well-being. *Open Transplantation Journal*, 7, 1–9.
- Jones, I. R. & Williams, G. (2017). Bourdieu, capitals and health. *Sociology of Health & Illness*, 1(39), 3-4.
- Koetsenruijter, J., van Eikelenboom, N., van Lieshout, J., Vassilev, I., Lionis, C., Todorova, E., Portillo, M.C., Foss, C., Serrano Gil, M., Roukova, P., Angelaki, A., Mujika, A., Knutsen, I.R., Rogers, A. & Wensing, M. (2016). Social support and self-management capabilities in diabetes patients: An international observational study. *Patient Education and Counselling*, 99, 638–643.
- McGee, H.M. & Horgan, J.H. (1996). Participation in the Cardiac Transplant Games: Impact on health-related quality of life. *British Journal of Health Psychology*, 1, 245–252.
- Meredith, S.J., Wagstaff, C.R.D. & Dicks, M. (2019). Getting to the heart of the matter: an ethnography of emotions and emotion regulation in cardiac rehabilitation. *Qualitative Research in Sport Exercise and Health*, 11, 364–381.
- Moini, M., Schilsky, M. L. & Tichy, E. M. (2015). Review on immunosuppression in liver transplantation. *World Journal of Hepatology*, 7(10), 1355-1368.
- Moola, F.J., Faulkner, G., White, L. & Kirsh, J. (2015). Kids with special hearts: the experience of children with congenital heart disease at Camp Willowood. *Qualitative Research in Sport Exercise and Health* 7, 271–293.
- Morris, R. L., Kennedy, A. & Sanders, C. (2016). Evolving ‘self’-management: exploring the role of social network typologies on individual long-term condition management. *Health Expectations*, 19(5), 1044-1061.
- Neuberger, J. M., Bechstein, W. O., Kuypers, D. R., Burra, P., Citterio, F., De Geest, S. & Metselaar, H. J. (2017). Practical recommendations for long-term management of modifiable risks in kidney and liver transplant recipients: A guidance report and clinical checklist by the consensus on managing modifiable risk in transplantation (COMMIT) group. *Transplantation*, 101(4S), S1-S56.
- Owton, H. & Allen-Collinson, J. (2016). Conformers, Contesters, Creators: Vignettes of asthma identities and sporting embodiment. *International Review for the Sociology of Sport*, 51, 699–714.

- Pai, A. L. & McGrady, M. (2014). Systematic review and meta-analysis of psychological interventions to promote treatment adherence in children, adolescents, and young adults with chronic illness. *Journal of pediatric psychology*, 39(8), 918-931.
- Pankhurst, T., Evison, F., Mytton, J., Williamson, S., Kerecuk, L. & Lipkin, G. (2020). Young adults have worse kidney transplant outcomes than other age groups. *Nephrology Dialysis Transplantation*, 35(6), 1043–105.
- Purdue, D. E., & Howe, P. D. (2012). Empower, inspire, achieve:(dis) empowerment and the Paralympic Games. *Disability & Society*, 27(7), 903-916.
- Richardson, E. V., Barstow, E.A. & Motl, R.W. (2019). A narrative exploration of the evolving perception of exercise among people with multiple sclerosis. *Qualitative Research in Sport Exercise and Health*, 11, 119–137.
- Rogers, A., Brooks, H., Vassilev, I., Kennedy, A., Blickem, C. & Reeves, D. (2014). Why less may be more: a mixed methods study of the work and relatedness of ‘weak ties’ in supporting long-term condition self-management. *Implementation science*, 9(1), 19.
- Rogers, A., Vassilev, I., Sanders, C., Kirk, S., Chew-Graham, C., Kennedy, A., ... & Kapadia, D. (2011). Social networks, work and network-based resources for the management of long-term conditions: a framework and study protocol for developing self-care support. *Implementation Science*, 6(1), 56.
- Rosso, E.G.F. & McGrath, R. (2013). Beyond recreation: Personal social networks and social capital in the transition of young players from recreational football to formal football clubs. *International Review for the Sociology of Sport*, 48, 453–470.
- Scarfe, S. V. & Marlow, C. (2015). Overcoming the fear: an autoethnographic narrative of running with epilepsy. *Qualitative Research in Sport Exercise and Health*, 7, 688–697.
- Slapak, M. (1997). Organ Donation: Transplant Games, The Wand Successful Methods. *Transplant Proceedings*, 29, 3047–3049.
- Story, W. T. & Carpiano, R. M. (2017). Household social capital and socioeconomic inequalities in child undernutrition in rural India. *Social Science & Medicine*, 181, 112-121.
- Stoumpos, S., Jardine, A. G. & Mark, P. B. (2015). Cardiovascular morbidity and mortality after kidney transplantation. *Transplant International*, 28(1), 10-21.
- Transplant Sport UK (2020) BTG. Retrieved from <https://transplantsport.org.uk/btg/> [Accessed 28th May 2020]
- Vassilev, I., Rogers, A., Blickem, C., Brooks, H., Kapadia, D., Kennedy, A., ... & Reeves, D. (2013). Social networks, the ‘work’ and work force of chronic illness self-management: a survey analysis of personal communities. *PloS one*, 8(4).
- Vassilev, I., Rogers, A., Kennedy, A. & Koetsenruijter, J. (2014). The influence of social networks on self-management support: a metasynthesis. *BMC public health*, 14(1), 719.
- Vassilev, I., Rogers, A., Kennedy, A., Oatley, C. & James, E. (2019). Identifying the processes of change and engagement from using a social network intervention for people with long-term conditions. A qualitative study. *Health Expectations*, 22(2), 173-182.

- Welch, L., Orlando, R., Lin, S.X., Vassilev, I. & Rogers, A. (2020). Findings from a pilot randomised trial of a social network self-management intervention in COPD. *BMC Pulmonary Medicine*, 20, 162.
- World Health Organisation. (2019). *Human organ transplantation*. Retrieved from <https://www.who.int/transplantation/organ/en/> [accessed 24th June 2019]
- World Transplant Games Federation (2019) *Refit for life!*. Retrieved from <https://wtgf.org/refitforlife/> [Accessed 1st August 2019]
- Wray, J. & Lunnon-Wood, T. (2008). Psychological benefits for children and adolescents who have undergone transplantation of the heart from participation in the British Transplant Games. *Cardiology in the Young*, 18, 185–188.