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Finding joy in poor health: The leisure-scapes of chronic illness

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Abstract

Globally, increasing numbers of people face the challenge of enjoying life while living with long-term illness. Little research addresses leisure participation for people with chronic illness despite its links with mental and physical health and self-rated quality of life. I use a space-time geographical approach to explore experiences with leisure in everyday life for 26 individuals with chronic kidney disease (CKD) in Australia. I examine ways in which the spatial and temporal characteristics of illness management and symptoms shape where, when, and how participants can enjoy leisure, focusing on: 1) logistical conflicts between illness and leisure; 2) rhythmic interferences with the force of habit in skilful leisure performance; and 3) absorbing experiences of encounter with self and place through leisure. Data were collected from 2013 to 2014. Participants kept diaries over two sample days and then participated in semi-structured interviews. Findings show that the voluntary nature of leisure offered participants important benefits in coping with and managing illness over the long-term, including opportunities to experience greater sense of control, an alternative experience of one's body to the 'sick body', and knowledge creation that supports adaptation to the uncertainties of illness trajectories. The ability to engage in meaningful leisure was constrained by the shaping forces of illness symptoms and management on participants' leisure-scapes. Illness treatment regimens should therefore be adapted to better accommodate leisure participation for chronically ill patients, and leisure should be explicitly incorporated into illness management plans negotiated between patients and health practitioners. Finally, greater understanding of the transformative capacity of habit in activities of experimentation and play may have wider-reaching implications for leisure's potential applications in public health. Leisure should be taken seriously as a vehicle for enhancing wellbeing and adaptation to life with long-term illness.

Keywords

Australia; chronic kidney disease; leisure activities; quality of life; wellbeing; time; place; habit

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Introduction

Globally, increasing numbers of people face the challenge of enjoying life while living with long-term illness. Worldwide, chronic illnesses such as cardiovascular disease, chronic obstructive pulmonary disease, and diabetes accounted for over half of premature deaths in 2012 (World Health Organization 2016). For wealthy countries like Australia, the chronic illness burden is borne primarily by ageing populations. Living long-term with illness not only demands managing and coping with shifting symptoms and treatment regimens alongside everyday necessities, such as housekeeping and paying bills, but also presents the challenge of finding experiences and activities that bring joy, fulfilment, and pleasure in what, for many, are a substantial number of years of life spent with poor health.

The pursuit of pleasurable, discretionary activities, referred to here as *leisure activities*, by people with chronic illness has received little attention despite its importance for quality of life and long- and short-term health (Katz 2004, Katz et al. 2009). Indeed, public health researchers have demonstrated a general reluctance to engage seriously with ideas of pleasure (Coveney and Bunton 2003). Within the chronic illness literature, most research about the impact of illness on everyday activities has focused on the ability to perform ‘obligatory’ activities, such as maintaining hygiene and sleep, and, to a lesser extent, ‘committed’ activities, such as paid work and child care, at the expense of ‘discretionary’ activities like hobbies, tourism, or participating in clubs or religious organisations (Katz 2004, 44–45).

It is known that leisure is among the first activities sacrificed after functional abilities decline with illness. Three months post-treatment, cancer survivors report greatest reduction in high physical demand leisure activities (34% reduction) and social activities (16% reduction) (Lyons et al. 2013). Individuals with rheumatoid arthritis report substantial reduction in recreation (e.g., taking walks, gardening, bicycling), hobbies or crafts, traveling or getting around the community, social events, religious activities, and visiting friends or family at home (Katz 2004, 47). Reduction in leisure has been attributed to having limited energy (Lyons et al. 2013), less available time due to illness management (Katz 2004), pain (Ahlstrand et al. 2015), and decreased muscle strength (Marko 2012).

Leisure activities are often key sources of meaning, enjoyment, and sense of purpose. Leisure encompasses a diverse and complex category of activities that is usefully divided into ‘casual’ and ‘serious’ leisure. Casual leisure is an “immediately, intrinsically rewarding, relatively shortlived pleasurable activity requiring little or no special training to enjoy,” as in talking with friends or strolling in a park (Stebbins 2001, 53). Serious leisure, in contrast, “is the steady pursuit of an amateur, hobbyist, or career volunteer activity that captivates its participants with its complexity and many challenges,” (Stebbins 2001, 54). Examples are having a committed volunteer role in an organisation or playing a musical instrument. While casual leisure is often a regenerative response to the strains of everyday life, serious leisure can take on a significant role in how a person constructs their sense of self and builds their social world, offering social rewards, new friends, the feeling of being a part of a group that has accomplished something significant, and a sense of being needed (Stebbins 2001, 54–55).

Loss of valued activities often leads to depressive symptoms (Katz 2004, 48), which can inhibit recovery from surgery (Mutran et al. 1995), increase the risk of physical decline and mortality (Bruce et al. 1994, Covinsky et al. 1999, Penninx et al. 1998, Pulska et al. 1999), and are associated with poor adherence to medication regimens or overmedication (DeVellis 1993, Katon and Sullivan 1990) and poor treatment adherence (Katon and Sullivan 1990). It may also mark a crisis of departure for the individual in how they anticipated their life would unfold (Bury 1982, 171). Inability to perform valued activities, such as leisure, may play a substantial role in how people with chronic illness perceive their health, above and beyond health status, disease symptoms, and general physical functioning (Katz et al. 2009). In short, it is important to better understand chronically ill individuals' experiences with leisure due to the close relationships these activities have with short- and long-term health and perceived quality of life with illness.

Differences between where, when, and how people enjoy leisure can be conceived in terms of diverse "leisure-scapes" (Van der Poel 1997, 178). Van der Poel proposed that leisure-scapes are closely linked to a person's social identity and position, and can differ based on normative restrictions on what is appropriate for a particular context (e.g., the meeting places of sexual subcultures), expectations about social positions and roles (e.g., 'soccer moms'), and the resources individuals can draw from (e.g., finances and social capital) (Van der Poel 1997, 178–179). For example, the leisure-scape of someone with wealth is likely to feature options for privacy, as money can buy access to time and space away from scrutiny.

Health status might also shape a person's leisure-scape in terms of where, when, and how they can enjoy leisure given the unique spatial and temporal characteristics of chronic illness symptoms and management (Jowsey 2015, Crooks 2007). Chronic kidney disease (CKD), a term used to describe loss of kidney function over time, for example, can fundamentally restructure a person's life. Like most chronic illnesses, it is characterised by a general trajectory of physical decline, accompanied by intensifying symptoms, co-morbidity, and an increasingly burdensome treatment regimen (National Institutes of Health 2012). CKD is a growing health concern worldwide (Zhang and Rothenbacher 2008). In Australia, it is increasingly prevalent, estimated at 13.4% of the total population (Green and Ryan 2009, 2). CKD has five progressive stages. End Stage Kidney Disease (ESKD) refers to the final stage of disease. In ESKD, the kidneys are no longer able to remove enough waste and excess fluid to keep the body alive, necessitating either on-going dialysis treatment or a kidney transplant.

In this paper, I apply a qualitative space-time geographical approach (Schwanen and Kwan 2012, Rainham et al. 2010) to explore the spatial and temporal forces shaping the leisure-scapes of 26 individuals with CKD in the Australian Capital Territory and nearby New South Wales communities in order to better understand the apparent tensions between enjoying life and managing chronic illness. I begin by drawing from the literature to describe the spatial and temporal characteristics of chronic illness and the space-time geographical approach used in this analysis. Methods are described. Then, findings from the space-time geographical analysis are presented and discussed.

Space, time, chronic illness, and leisure

Space-time geographical approaches are designed for “temporally integrated geographies” (Kwan 2013, 2) of human experience and behaviour, in which human mobility and the complex roles of time and space are incorporated into analysis (May and Thrift 2001). Health geographers have provided rich accounts of chronically ill individuals’ experiences with space and place (Crooks 2007, Driedger, Crooks and Bennett 2004, Dyck 1995, Dyck and Jongbloed 2000, Wilton 1996, Dyck 2002), highlighting altered senses of place, uses of particular spaces (e.g., modified home routines), and spatial extents of everyday life (Crooks 2007, 579).

Chronic illness experiences are also threaded through with characteristics of temporality (Jowsey 2015), including permanency, permeation, and fluctuation. Chronic illness is permanent, meaning it endures long-term and often forecasts a trajectory of health decline. It typically causes some extent of functional impairment (Australian Institute of Health and Welfare 2015). The management and effects of impairment permeate throughout a person’s life, altering everyday chores, close relationships, and social and work activities (Jeon et al. 2010, 70). Chronic illness also often fluctuates, sometimes widely, in severity and type of symptoms over the long- and short-term. Rheumatoid arthritis disease activity fluctuates from season to season, for example (Iikuni et al. 2007), and the lives of individuals with recurrent cancers are punctuated by unpredictable symptoms that improve, worsen, disappear, and re-emerge (Charmaz 1997).

In short, living with chronic illness often means coping with and managing sometimes unpredictable disruptions to and restrictions on where, when, and how a person can participate in everyday activities. While space and time are experienced in many different ways in everyday life (Adam 2013, May and Thrift 2001), at least three senses of space-time may be particularly relevant to understanding leisure participation with chronic illness: 1) logistical space-time resources needed to perform leisure; 2) everyday rhythms that interact with the repetition of skilful leisure activities; and 3) absorbing experiences of embodied encounter with self and place through leisure.

Logistical space-time resources

As with all activities, participation in leisure requires logistical access to certain amounts of space and time. Conceiving of space and time as finite resources needed to perform activities is helpful for understanding how activities in a person’s life may compete with one another (Rainham et al. 2010). For example, a community choral group needs both a common meeting place and coordinated blocks of time. A person taking medication that makes driving at night unsafe may struggle to find transportation to evening choral rehearsals and therefore drop out of choir. In another example, dialysis patients have expressed feeling ‘tied’ to the machine and that arranging to dialyze while on vacation is stressful and medically risky (Polaschek 2003, 47). Finally, other illness management activities of CKD, such as complying with dietary restrictions, may make a person reluctant to venture beyond familiar environments that support compliance, curbing participation in leisure activities that require travel.

Rhythm and repetition

In addition to logistical space-time resources, leisure activities involving skill require regular repetition to be rewarding and pleasurable (e.g., dance performance or learning a foreign language). Through repetition over time, the force of habit facilitates mastery of a skill, allowing the action to move further and further from consciousness into the unconscious ‘intelligence of the body’. This frees the mind for other pursuits and greater mastery (Sinclair 2011, Ravaissou 2008). An example is a person who learns to juggle and then learns to balance on a unicycle while juggling. Recent geographical work has built an ecological understanding of habit as a “creative and unpredictable process through which bodies and environments mutually evolve and take shape,” (Bissell 2013, 121). An important shift in this conceptualisation of habit is that the narrow focus on the individual as the site of habit is broadened to consider the individual and their environment as an indivisible medium in which habit may thrive (Bissell 2013).

In the absence of favourable conditions for repetition, therefore, the force of habit can become blocked, disrupted, or wane. The concept of rhythm (Lefebvre 2004, Edensor 2010a) aids in understanding the forces that support or undermine repetition. Rhythms circulate in everyday environments and within and between bodies. They are found in, for example, work schedules, the body’s cycles of sleepiness and wakefulness, the ebb and flow of pedestrian crowds, and seasonal fluctuations in consumption of goods and services. Each rhythm is linked to its own place. Within a given place (or body), multiple evolving rhythms abound, playing in harmony or in discord (Lefebvre 2004, 67–68). The corporeal fluctuations common to chronic illness may introduce arrhythmias into the human-environment medium where a habit thrives, disrupting skilful leisure activities. For example, dialysis patients often describe feeling light-headed after dialysis. For a retired patient with morning dialysis, their regular afternoon piano playing may be disrupted by the introduction of a dialysis-day-fatigue-rhythm that peaks in the afternoon. Without regular repetition, the piano player’s experiences of mastery and pleasure will diminish as the skill of piano playing fades from the intelligence of the body.

Embodied encounter with place

Finally, the absorbing experience of embodied encounter with place is an important dimension of leisure. Some leisure activities, such as building a sand castle or going to a music festival, facilitate absorbing, sensual experiences in which the person encounters the world and themselves in new ways. Social and cultural geographers have explored the importance of space and place in leisure (e.g., Crouch 2013, Hall and Page 2014). Space can be understood simply as the background, distance to, container for, or location of leisure (e.g., a National Park) (Crouch 2000, Henderson and Frelke 2000), or as a cultural text that is read and recognised (e.g., an ‘exotic’ landscape in a travel brochure) (Crouch 2000). It can also be understood as an encounter, as the individual engages with, encounters, and grasps the world through a process of embodiment (Crouch 2000, 67). This perspective provides insight into the mutually transforming process occurring in sensory engagement with place through leisure practices (Crouch 2000, 68). For example, in a darkly lit night club, dancing and intoxicated bodies contribute to ‘making’ the clubbing context into which people may voluntarily lose themselves. Alternative narratives of self that contrast with the ‘problem

body', uncertainties, and limitations of chronic illness could arise through voluntarily engaging in transformative experiences of leisure. In short, the unique spatial and temporal characteristics of chronic illness symptoms and management and those of leisure activities likely interact to shape the leisure-scapes of people with chronic illness and the meaning and value they derive from leisure.

Methods

Participant recruitment and ethics approval

Participants were purposively sampled for a range of characteristics that may influence space-time organisation of daily life (e.g., age, gender, disease stage, working status, caregiving responsibilities). They were recruited through Renal Services, The Canberra Hospital in Canberra, Australia. Data were collected May 2013–April 2014. Participants received a card and \$20 AUD supermarket gift certificate as a gesture of gratitude. Ethics approval was obtained from the Australian Capital Territory (ACT) Human Research Ethics Committee (ETHLR.13.018). Pseudonyms were applied to preserve participant anonymity.

Study design and methods

In order to learn about how participants experience the interactions that occur between the space-time characteristics of different parts of everyday life, a multi-method qualitative case study approach was taken. A key advantage of the case study approach is that it “can ‘close in’ on real-life situations and test views directly in relation to phenomena as they unfold in practice,” (Flyvbjerg 2006, 235). Following Schwanen (2006), data were gathered pertaining to participants’ everyday activities, the constraints and affordances experienced in how they can organise what, where, when, and how they perform activities, and rhythms circulating within everyday contexts and the body. Data on participants’ movements between locations and activities performed over two sample days were recorded by participants on paper travel and activity diaries (see McQuoid et al., 2015, supplementary materials). The diaries provided a general picture of the number, types, and temporal demands of activities participants juggle (e.g., chauffeuring children, employment, doctor appointments, volunteering), where these activities are located, and transportation used. At the end of each sample day, participants completed a CKD management inventory of activities related to managing their illness and comorbid conditions, and rated the level of success they felt they had had in performing each activity (see McQuoid et al., 2015, supplementary materials). The inventory was created in consultation with the literature (Green and Ryan 2009, Levin et al. 2008, National Kidney Federation 2012) and a nephrologist within the study context after an unfruitful search for existing inventories.

Initially, only one day was sampled in order to minimize the data collection burden for participants. However, a pilot study of three participants made it clear that variable schedules (i.e., dialysis treatment days versus non-dialysis treatment days) and fluctuating states of the body from day-to-day required a larger sample from each participant. The remaining 23 participants provided two sample days, and those receiving dialysis were asked to sample both a non-dialysis day and a dialysis day. While sampling more than two days would arguably provide a richer understanding of participants’ regular daily activities, interactions

with organisations, and experiences of illness, I chose to minimize the sampling burden for participants, many of whom are juggling many activities and negotiating significant demands of chronic illness, in order to encourage ability and willingness to participate.

Interviews

Participants (n=26) were interviewed by the author on the day following the sample days, or in a few cases, within a few days, as was convenient for the participant. Most interviews lasted 90 to 120 minutes (range: 1–3 h). Participants were asked to select the most convenient and comfortable location, providing it allowed for privacy and minimal noise. Most interviews were conducted in participants' homes, with others occurring in meeting rooms at participants' workplaces or university campuses, dialysis clinics, and one at a cafe.

At the beginning of each interview, the interviewer familiarised herself with the diary and inventory content by reviewing and clarifying what participants had recorded. A semi-structured interview format was undertaken in which the participant was asked to 'lead' the interviewer through the sample days. Interviewees were asked to provide such vivid 'play-by-play' detail of their activities, movements, and experiences that someone could make a movie of their day. Participants spontaneously compared or were asked to compare and contrast the events of those sample days with their 'usual routine.'

Analysis

Interviews were audio recorded and transcribed verbatim. Transcripts were coded by the author using QSR Nvivo10 qualitative data analysis software. Following Saldaña (2012), thematic analysis was undertaken in which repeated readings of the data were followed by grouping content to summarize main emergent themes. Particular attention was given to the spatio-temporal dimensions of everyday activities, bodies, rhythms, routines, and health service contexts.

Findings

When participants discussed finding enjoyment in life, there was often a tension between living life in a way that feels meaningful and enjoyable, on the one hand, and restraining oneself, spending time on, and limiting mobility in managing illness, on the other (see also, for example, Kralik, 2004 on pacing and creating order in everyday life with chronic illness). There is risk in this balancing act, which participants recognised. Bill (age 40, full-time public servant, clinic dialysis), who dialysed throughout his twenties "while everyone else was backpacking and shagging," provided an extreme example. He missed a kidney transplant during his twenties because he went for a rare night out after dialysis to loud bars with friends. When he got home he had 45 missed calls from the hospital, missing the transplant opportunity. While he could have chosen to sit by his phone waiting for a possible transplant phone call, he felt the need to forget about his illness, go out, and feel 'normal' with his friends.

Taking these kinds of risks is important for many participants in order to feel that illness is not controlling their life, and to feel that they are not 'missing out'. As Bill puts it, "You have to *claw* something back for yourself." What that 'something' is varies between people.

For Larry (age 77, pensioner, clinic dialysis) it is having a small beer once a week when he picks his wife up from the bowling club: “I don’t devoid myself of everything, because if I just sat here and had dry biscuits and a drink of water every day, you’d go round the twist [go crazy].” Bill has “hung [his] hat on Coca Cola,” as he put it humorously. The beverage is unadvisable for people on dialysis because of the phosphate content, but he drinks it every day as “a big fuck you to kidney disease,” a defiant gesture against everything the illness has taken from his life. Similarly, before Martin’s (age 43, unemployed, clinic dialysis) kidney transplant failed from cancer treatment, he would go out and drink with friends even though this was medically unadvisable. His sense of conflict is evident in the quote below, as he felt the transplant was a gift of life that should be enjoyed as well as preserved:

My theory was... yes it’s a gift, but you can’t... *not do* anything you want – you can’t look after it and treat it like a precious jewel – yes you *do*. Can’t go out and – and do everything like that. *But*, it’s a gift of *life*. So you gotta go out and *enjoy* life.

Other participants described the importance of serious leisure pursuits (Stebbins 2001) in enjoying life and not feeling ruled or defined by illness (see also Charmaz, 2006). Sandi (age 30, part-time administrative assistant, functioning kidney transplant) talked about how important developing writing as a hobby has been over the years of living with chronic illness. Seeing progress over time in her writing gives her great satisfaction:

To the people who are sick: don’t stop fighting. Find something to keep yourself going. I found writing; I’m really into writing. [...] Distract yourself; pick up hobbies and do it.

In the sections below, I explore how the logistical space-time conflicts between chronic illness and leisure shape the leisure-scapes (Van der Poel 1997) open to participants to enjoy. Specifically, I report on themes concerning the shrunken potential path area available for travel, logistical conflicts with local leisure activities, problems of synchronisation for group leisure, and the need to avoid certain places at certain times to protect the body. Then, I examine participants’ experiences of meaningful encounter with the world and self through leisure (Crouch 2000), and the role of the rhythms of chronic illness in informing these experiences. I discuss themes concerning the experience of loss of skilful leisure, the importance of leisure for coping and adaptation, alternative experiences of the ‘sick body’, and ways in which corporeal rhythms can disrupt skilful leisure performance.

Logistical space-time conflicts

Participant accounts demonstrate that health is a force shaping the terrain of leisure and what can be enjoyed there. The most obvious example is how the spatio-temporal characteristics of chronic illness management shrink the potential path area (see Weber and Kwan 2003) available for travel. Tourism is now a leisure expectation for most people in wealthier countries (Hall and Page 2014). Dialysis limits participants from rewarding themselves with touristic travel and feeling that they have lived a full life. For example, Cathy (age 69, pensioner, home dialysis) described her disappointment after her kidneys failed and she and her partner were unable to travel abroad after a lifetime of saving and working hard.

Bill (age 40, full-time public servant, clinic dialysis) described the trauma of having a kidney transplant but says he would rather go through this again than live on dialysis indefinitely, largely due to his love of travel:

I never ever had any, even the slightest ‘Maybe I could live out my days on dialysis.’ I’m like now, ‘You know, if I get a few things sorted and, I could maybe do that.’ But I *can’t*. ‘Cause there’s too much I want to do. [...] Travel’s the big one.

Participants described contending with space-time constraints on travel derived from variations between different countries’ *carescapes* (Bowlby 2012) in terms of the availability, affordability, and quality of health services. For example, when James (age 66, pensioner, functioning kidney transplant) was told he would need dialysis within six months, he promised his wife a trip to Venice before he had to start treatment. During his following appointment, his specialist told him his window for travel was closing more rapidly than expected, and advised him to “run to either Italy or England because Australia has a healthcare agreement with those two countries” as a contingency plan while abroad. In another example, Bernard (age 40, full-time public servant, clinic dialysis) had to learn how to navigate the particular carescape of the Philippines in order to visit family and feel confident in the quality and availability of medical care should something go wrong while dialysing.

Logistical conflicts between chronic illness management and leisure activities can also arise locally. For example, Cathy (age 69, pensioner, home dialysis) and her partner had to give up many roles in community organisations after the on-set of ESKD due to conflicts with dialysis and medical appointments. After years of prioritising illness over leisure, Cathy, like the other participants, expressed the need to feel that she had some control over her own challenges given that so many were imposed on her by illness:

The last few years I’d had many challenges thrown at me, um, not of my - you know -choosing. And I just felt that it was time for *me* to choose something to challenge myself.

For Cathy, the challenge took the form of applying to become a baking judge in a large rural women’s association. While the exams to become a judge were a worry for Cathy, so were the space-time logistics of juggling dialysis with regional travel to judging events:

[My partner] said, ‘I think that’s a wonderful idea! You make inquiries. You *do* it.’ And I said, ‘Oh, the only thing is they can ask you to go anywhere in the state and so I’d have to make sure and realise it was only a restricted area I could go in.’ He said, ‘That doesn’t matter, I think that’s a brilliant idea.’ [...] And I thought, ‘Now this would be a real challenge.’

Cathy passed the judging exam on her first try, and “went flying out” of the exam room to tell her husband. The organisation has been able to accommodate her restricted potential path area for judging competitions. Still, Cathy is less active in the organisation than she would like and she cannot stay for social gatherings after meetings because she has to get home to start dialysis in the evening.

Leisure is further constrained for participants who work and have heavy space-time demands from chronic illness. Bernard (age 40, full-time public servant, clinic dialysis), for example, spends virtually all his weekday space-time resources on full-time work, dialysis three evenings per week, and cycling on non-dialysis evenings in order to prepare for a transplant. Rarely, he goes for a drink with colleagues, but: “[I]t’s usually just being at home.”

Illness management activities can also complicate the spatial and temporal synchronisation needed for group leisure. Similar to the challenges of synchronising family member space-time paths observed in many contemporary households (Pocock, Skinner and Williams 2012), leisure activities are increasingly difficult to coordinate in space and time between individuals due to increased variation in leisure consumption patterns (Urry 1994, 139) (e.g., not eating communally at fixed times and places). Joan (age 85, pensioner, stage 4) expressed being so fed up with missing an annual reunion of friends in Sydney because of doctor appointments that she decided to skip the medical appointment if they cannot reschedule her, even if it is a risk to her health. In running this risk, she engages in the balancing act of enjoying life and managing illness alluded to by many participants:

[My friends] ring me up every year and I’ll say, ‘Yes I’ll be there. I’d love to go,’ and I’m either in hospital or there’s some appointment I’ve got to keep or something or other. [...] So I’m thinking, yeah maybe I’ll put it forward to January. If I go to hospital they’ll have to see me in there, won’t they, if anything goes wrong?

A final logistical conflict between illness and leisure is the need to avoid certain kinds of places at certain times. For example, James (age 66, pensioner, functioning kidney transplant) has to avoid exposure to the sun due to his greatly heightened risk for skin cancers from transplant immunosuppressant drugs. This restricts outdoor activities, like watching a sports game, walking, or cycling, to shaded areas and evening hours.

Rhythms, habit, and encounter

‘Doing’ leisure cannot simply be understood in terms of how people spend segments of time at particular places. While I have focused thus far on logistical access as key to opening up a person’s leisure-scape, the “sensuousness of practice” (Crouch 2000, 68) fundamental to enjoying oneself through leisure must also be attended to, and with a different perspective on space-time. As found in other studies (Katz 2004), several participants described the loss or diminishment of leisure activities to physical impairment. This loss was especially keenly felt when it was a leisure activity involving a skill the participant had been developing over years. Brian (age 38, sporadically employed, failing kidney transplant) described his love for outdoor adventure sports, a pleasure that will be increasingly difficult to access as his kidney transplant fails. He directly connects what he learns from engaging with the world in this embodied and often risky way to his adaptation to living and coping with years of chronic illness and its uncertainties:

I think it actually – pushing yourself to that sort of point, beyond the pain barrier, that you can actually... actually realise that you can feel in [stutters] – indestructible in a way. [...] You know, I think, like when you’re going for a transplant you do not know what’s going to happen. You go entering the unknown.

So if you did the same rock climb over and over again, that just becomes like walking up a set of stairs. There's no risk, there's no nothing. But if you're taking it to the extreme and you actually realise that, you know, I'm going to be doing a 90 degree overhang, and trying to get over this thing without falling off, and without like, you know, really doing yourself some damage – and you know, that fall for like a 100th of a second, you can feel like you're falling for 20 minutes. [...] So you can work with any sort of situation you're put in. You're pretty sure that you'll do your best and you know your best. And the more you know, as I said, knowledge is a powerful thing. And the more you know, the better your guesses can be. [...] Ya, I'm fightin' [laughs].

Brian's experiences with rock climbing can be understood as encounters with the world through leisure – a way of making new, in-depth knowledge about the world and one's relationship with it (Crouch 2000, 65). For Brian, this knowledge concerns his capacities in relation to his world with chronic illness, and the scary possible events that may unfold as his transplant fails. It is less a cerebral knowledge of facts about the world, or even associated memories and emotions about particular places of leisure. More so, it is the bodily intelligence of habit allowing Brian to adapt to and transform with his body and environment.

Why would someone facing so many challenges and risks to their health constantly pursue the incorporation of “the knife-edge of fear” (Sharpe 2013, 170) into their hobbies? Arguably, Brian becomes more practised in handling fear and uncertainty via the anaesthetising effects of habit through increasingly challenging leisure activities. Voluntary risk-taking, or “edgework” (Lyng 1990), provides Brian with a sense of self-determination and fleeting omnipotence. The experience of feeling fear while doing extreme sports becomes less and less remarkable to him with repetition, helping him to adapt to the shifting terrain of chronic illness and, perhaps, giving him more capacity to enjoy moments of beauty along the way:

You know I went down the coast, swimming with the whales last week. [...] It was absolutely enormous and... the water can go so sort of dead. And then you can just hear the [makes blowing noise] as they come up. And it's just – like a whole, whole wall in front of you. It's just massive. And the way they actually glide and swim is so... serenity. Ya, it's just unbelievable. You also know if you get too close it can be deadly. [...] And when you come back your smile is just beaming. You know, pride. And seeing something that beautiful. But at the same time that dangerous. [...] Hmm, ya. It keeps me here [tears up]. I won't give up. No way.

A tearful sense of awe accompanies Brian's description of immersing himself alongside the ocean's giant inhabitants. Brian's heightened awareness of his mortality due to illness may lead him to perceive parallels of survival and fragility between himself and nature in a way that may be unique to those who have lived through life-threatening illnesses (see also English, Wilson and Keller-Olaman 2008).

The pleasure and aliveness experienced by engaging in leisure also provides an alternative experience of one's body that contrasts with the ‘problem body’ defined by illness. One of

Neal's (age 73, pensioner, clinic dialysis) lasting loves in life has been riding motorcycles. He lit up during the interview in the dialysis clinic while he described riding his motorcycle down a winding, rural road outside Canberra. Neal's encounter with the world through his motorcycle is, as Crouch puts it, of a "time when the awareness of place and its features are encountered 'in the round', as surrounding volume," (Crouch 2000, 68). It is a time of flow (Csikszentmihalyi 2000) in which Neal is deeply engrossed in his body's engagement with the world:

Cotter Road, you've got to drive, you've got to ride it, you're alert and there are kangaroos, and there are emus and there are all kinds of things on the road. You really have to know what you're doing, you really have to stay alert, and it's good. It's not just zombie. [...] I think it's being out in the air, you're not wrapped up in a tin box, you're actually outside, the weather's around you, you can feel what's happening. [...] I think it's more than transport, it's good, and you know, my bike is particularly powerful, so you've got to be very careful what you do. You're involved. I think that's the best word about motorcycling, you are totally involved.

It is not just being engaged with this particular place of leisure that is so stimulating for Neal. He relates with his body in negotiating "the border between ease and resistance" (Sharpe 2013, 171) as he balances the pleasures of mastery and flow with the effort to maintain control of the speeding bike.

Elsewhere, I described how rhythms in participants' everyday contexts can encourage or discourage skilful performance of illness management by interfering with the repetition of these activities in everyday life (McQuoid et al., 2015). Rhythms "folded in and through a permeable body" (Edensor 2010b, 4) also influence participants' abilities to sustain serious leisure in their lives. The transformation of rhythms of the body due to chronic illness can shift the human-environment medium where habit thrives in skilful leisure practices. Neal's rides along Cotter Road are getting much riskier now that his energy levels have started plunging unexpectedly from time to time, a development he attributes to dialysis. The introduction of this new rhythm of weariness dramatically shifts the border between ease and resistance in riding a powerful motorcycle down a winding road home to wildlife and other unpredictable conditions. As Neal pointed out, the motorcycle does not afford him with a way to easily accommodate this new rhythm into his practise. As a result, Neal rides much less frequently and for shorter distances, providing fewer opportunities to experience the pleasures of immersion in appropriated time (Lefebvre 2004) of this activity.

Maintaining serious leisure activities in everyday life with chronic illness can require individuals to adapt to transformations in the "entangling of rhythms that circulate in and outside the body" (Edensor 2010b, 5). Deny (age 72, pensioner, stage 4) has adapted by developing new bodily knowledge and sources of pleasure as illness has dramatically shifted his body's relationship with his environment. In addition to CKD, cardiovascular disease, and near blindness, Deny has chronic obstructive pulmonary disease (COPD) which limits walking to very short distances. Neither he nor his partner can drive, and in the sprawling suburbs of Canberra, as he puts it, "You get handcuffed if you can't drive a car."

Deny has ‘un-handcuffed’ himself to some extent by expanding his potential path area by learning to use a computer. As his vision and mobility have declined, he uses a magnifying program to see screen content. It is an important window of engagement with the world for him now, to read news, visit websites he enjoys, and read emails.

I mainly taught me-self things about it. If you play around with it, it’s like driving a push bike or driving a car. You soon learn if you... make yourself want to.

Discussion

These accounts of leisure in life with CKD contribute to a largely overlooked aspect of everyday life with chronic illness. While most studies have, at least implicitly, de-emphasised the importance of leisure in everyday life with chronic illness in favour of obligatory or committed activities, my findings highlight the distinct meaning and value of leisure to participants as they cope with and manage illness over the long-term (see also Katz 2004, Katz et al. 2009). It is precisely the voluntary – rather than obligatory – nature of leisure that allows it to have such a positive influence on a person’s outlook on and ability to cope with life with chronic illness.

Bill’s statement that, “You have to *claw* something back for yourself,” offers a striking visual metaphor for the feeling of being denied too many valued experiences due to illness. These activities are valuable, not just for granting opportunities to passively experience pleasure, but for being able to voluntarily engage in a challenge and to experience a heightened awareness of oneself in relating with the world (Sharpe 2013). Cathy’s decision to apply to be a baking judge was motivated by her desire to turn the tables on her illness which for too long had been “throwing” her challenges not of her “own choosing”, as she put it. Neal’s experience of being “totally involved” while motorcycling down a winding road provides an alternative experience of his body in contrast with the ‘sick body’ that demands attention and care and limits ability. Finally, leisure offers opportunities for making knowledge (Crouch 2000, 65) that facilitate adaptation to the changes and uncertainties brought on by chronic illness. Brian’s rich descriptions of outdoor rock climbing and ocean swimming are filled with a sense of wonder about himself in relation with the world. In these encounters through leisure, he practices with fear and generates a sense of self-efficacy (Bandura 2010) in being able to “work with any sort of situation you’re put in,” including the fearful experience of entering the unknown as his kidney transplant begins to fail.

A space-time geographical approach offered a novel perspective on how and why leisure is often scaled back or discontinued with the onset of chronic illness. Previous research on chronic illness has identified barriers to leisure, such as limited energy, time demands, pain, and decreased muscle strength (Lyons et al. 2013, Katz 2004, Ahlstrand et al. 2015, Marko 2012). Findings from this study emphasise ways in which the spatial and temporal characteristics of chronic illness symptoms and management can shape the leisure-scape of a person with chronic illness. For these participants, leisure participation was made more difficult by logistical space-time conflicts and difficulty synchronising with the space-time paths of others due to the need to access health services, anticipate possible health

emergencies, and perform treatment regimens, as well as the necessity to avoid certain environments to protect the body.

Also apparent were ways in which unique rhythms of CKD (e.g., fatigue following dialysis) can disrupt the skilful performance of leisure. The notion of the person and their environment as an indivisible medium in which habit may thrive (Bissell 2013) is useful for understanding how a shift or mutation within the body, brain, or environment (e.g., changes in rhythms of the body) can disrupt skilful performance of a valued activity (e.g., riding a motorcycle) and associated experiences of flow (Csikszentmihalyi 2000) and appropriated time (Lefebvre 2004).

Further engagement with the concept of habit (Grosz 2013) could deepen our understanding of the value of places for leisure for those living with chronic illness. Work on therapeutic landscapes (Gesler 1992) has investigated how places can be experienced as healing and health-enhancing. An ecological framing of habit could facilitate greater understanding of ways in which place can support not only healing and recovery from illness (e.g., English, Wilson and Keller-Olaman 2008), but also maintenance of health and wellbeing (e.g., Williams 2002). An example is the transformative experiences had by physically impaired individuals within the spaces of experimentation provided at a rural respite care centre (Conradson 2005, 345). These experiences can be understood as opportunities for generating new embodied knowledge within novel mediums for habit that are offered in thoughtfully designed environments.

My findings also highlight the importance of spaces of playful experimentation, more generally, for individuals to encounter themselves in relation with the world in new ways. Regardless of health status, all people need opportunities to engage in the kind of knowledge-making my participants described in order to develop resilience to life's varying challenges. For instance, Cohen-Cline et al. (2015) propose that green spaces are linked to mental health through the creation of social ties and reduction of mental fatigue, and that physical activity acts as both mediator and confounder in this relationship (p. 524). My study suggests that green spaces may facilitate not only physical activity, relaxation, and socialising, but also experimentation, play, and 'surround sound' sensory engagement, and so provide opportunities for adaptive knowledge-making through leisure. Pitt (2014) has argued for emplacing therapeutic flow experiences by considering how socio-spatial processes influence an individual's ability to become absorbed in an activity. Similarly, my study suggests that creatively planning and developing shared spaces in the built environment may encourage habit's "fundamentally creative capacity" that opens up the possibility for stability in a constantly changing world (Grosz 2013, 219).

The transferability of these findings is limited by several factors. First, the symptoms and management of chronic illness vary between diseases and, therefore, will likely shape a person's leisure-scape in different ways. Second, this study is limited by possible participant selection bias, as the renal patients who contend with the most severe space-time constraints in everyday life were probably less willing or able to volunteer for data collection activities. Therefore, the accounts of space-time conflicts provided here may not sufficiently indicate the extent of the problem for some individuals living with CKD in the study setting. Despite

these limitations, the value of this type of case study is that it can sensitise practitioners and researchers to questions of access to and benefits of leisure that are helpful to ask within their setting or disease context in order to support people with chronic illness in enjoying the benefits of these activities.

Conclusion

Rather than disregarding leisure as a dispensable category of activities in everyday life with chronic illness, leisure should be taken seriously as a vehicle for enhancing wellbeing and adaptation to life with long-term illness. As illness symptoms and management intensify, these voluntary, playful activities can become more difficult for individuals to access as their leisure-scapes are shaped and constrained by the spatial and temporal characteristics of chronic illness. Future work should consider how illness treatment regimens can be adapted to better accommodate leisure for chronically ill patients, as well as ways in which leisure can be explicitly incorporated into illness management plans. Practical limitations on the prioritisation of leisure are to some extent unavoidable in both self-managing illness and providing care for chronically ill patients. However, at minimum, health service providers should frame leisure as a legitimate and beneficial everyday activity for patients.

At the heart of my emphasis on the importance of play, experimentation, and pleasure is an acknowledgement that for people with chronic illness, putting life 'on hold' until good health returns is not an option. There is an imperative to live well *with* illness that must be recognised in the framing of chronic illness management. Even beyond chronically ill populations, a greater understanding of the transformative capacity of habit in activities of experimentation and play may have wide-reaching implications for harnessing leisure's transformative potential for public health.

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Research highlights

- Leisure is a poorly understood aspect of everyday life with chronic illness
- This study highlights its benefits for coping with and adapting to chronic illness
- Spatial and temporal characteristics of illness shape participants' leisure-scapes
- Corporeal rhythms may disrupt repetition and habit in skilful leisure performance
- Leisure should be accommodated for and incorporated into illness management plans