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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.

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## 1. 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

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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 short-lived 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.

## 2. 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 et al., 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.

### 2.1. 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

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