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Integrating paid work and chronic illness in daily life: A space-time approach to understanding the challenges

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ABSTRACT

The upward trend of chronic illness in working age populations calls for better understanding of the difficulties chronically ill people face with workforce participation. Existing research focuses primarily on physical limitations and employer attitudes about chronic illness. Here we use a space-time approach to illuminate the importance of negotiating logistical challenges and embodied rhythms when balancing work and chronic illness. We draw from time geography and rhythmanalysis in analysing interviews from a qualitative case study of 26 individuals living with chronic kidney disease in Australia. Difficulties with paid work arise from: (1) competition for space-time resources by employers and health services; (2) arrhythmias between the body, work and health services; and (3) the absence of workplace rhythms on which to 'hook' health activities. Implications for workplaces and health services design are discussed.

1. Introduction

Globally, populations are living longer, with higher rates of chronic illness, and will be increasingly expected to work until later in life (OECD, 2010). In Australia, one-third of the working age population reports at least one chronic illness (Australian Institute for Health and Welfare, 2009), and this may grow with proposed increases to the retirement age (Commonwealth of Australia, 2014). The implications of such a compositional shift in the health profile of the labour force are problematic, as it is widely acknowledged that people living with chronic illness can find it difficult to obtain and sustain employment (e.g., Edwards and Boxall, 2010; Roessler et al., 2011). Yet, for the individual, paid work can lead to improved health outcomes (Ross and Mirowsky, 1995), financial security (Falk et al., 2013), and social inclusion (Bryngelson, 2009). For nations, greater paid work participation may decrease social and health benefits spending, especially among mature-aged adults (OECD, 2010). It is increasingly important, therefore, to better understand how difficulties participating in paid work arise for people with chronic illness, and the implications therein for labour markets, workplaces, and health services.

This paper contributes to understandings of this problem by examining the roles of both space and time in how individuals with chronic kidney disease (CKD) experience and navigate illness and paid work in daily life. We draw from time geography (Hägerstrand, 1970) in considering how various parts of a person's life (e.g., health care access, paid work) compete for finite spatial and temporal resources. We draw also from rhythmanalysis (Lefebvre, 2004), with its orientation to the sensory experience of the body to also embrace embodied experiences of time and space that may be particularly pertinent to everyday life with chronic illness (e.g., fluctuating energy levels). We aim to see whether and how the interplay of space-time dimensions of illness and paid work make it difficult for a person living with chronic illness to engage in paid work. We use interviews from a qualitative case study of 26 individuals living with CKD in the Australian Capital Territory (ACT) and nearby communities in Australia.

The problem of workforce participation by people with chronic illness has been explored through models of disability. While there is substantial and long-standing overlap between chronic illness and disability scholarship, important divergences between the lived experiences of chronic illness and disability exist, and the way chronic illness fits into various models of disability is still debated (Crooks et al., 2008, p. 884). Nevertheless, individuals with chronic illness and disability do share experiences that are relevant to paid work participation, such as the persistence of impairments over time, restrictions on what people can do and where, and the need

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to adapt and cope with impairments. These similarities have allowed research on chronic illness to draw productively from models of disability. The first of these models, the medical model of disability, emphasizes the effects of the chronically ill body's capacities, states, and needs on the individual's ability to perform employment responsibilities. Research in this area indicates that work adjustments, retraining, and reduced job demands are key to successful labour force participation (e.g., Boot et al., 2013; Chorus et al., 2001). The second is the social (Oliver, 1990) or socio-political (Dyck and Jongbloed, 2000) model of disability, which problematizes society's attitudes towards and expectations of ill or disabled bodies. This model concludes that unsupportive organizational cultures (e.g., Edwards and Boxall, 2010), discrimination (e.g., Roessler et al., 2011), and stigma (e.g., Shier et al., 2009) are key barriers to workforce participation. A third model, the biopsychosocial model, attempts to integrate the medical and social and is used in many contemporary disablement frameworks (Jette, 2006). We were, however, unable to find examples of its application to the problem of paid work participation by people with chronic illness.

Paid work is part of everyday life, and health geographers have provided rich accounts of embodied everyday experiences of people with chronic illness, particularly in understanding the roles of space and place (e.g., Crooks, 2007; Driedger et al., 2004; Dyck, 1995, 2002; Dyck and Jongbloed, 2000; Wilton, 1996). Research in this area has drawn primarily from social models of disability, reflecting a priority for social and cultural understandings of the body (Moss and Dyck, 1999, p. 372). Health geographers have explored changes to individual lifeworlds due to chronic illness, meaning changes to "the taken-for-granted, mundane experiences and activities of everyday life as carried out in particular spatio-temporal settings," (Dyck, 1995, p. 307). An important focus of this research has been on the "places, routes, and paths" people with chronic illness use to live out their lives (Crooks, 2007, p. 578). This body of research has found that the onset of chronic illness can result in altered senses of place, uses of particular spaces, and spatial extents of daily life (Crooks, 2007, p. 579).

While health geographies of chronic illness have explored the roles of space and place in everyday life, the temporal dimension of chronic illness has received far less attention. When time is considered alongside space, it is typically over the long-term, wherein changes occurring in particular places in an individual's life over extended periods of time are explored. For example, Wilton (1996) describes the shifting spatial dimensions of everyday life experienced by men with HIV/AIDS as the disease progresses over time. Driedger et al. (2004) consider how chronic illness frames individuals' senses of themselves as located in 'past, present, and future' temporal settings. While they overlook the diversity of temporalities experienced in everyday life (Adam, 2013; Shove et al., 2009), such studies begin to address the need to pay closer attention to the role of both time and space, as these dimensions play a significant role in regulating the everyday experiences of people with chronic illness (Driedger et al., 2004, p. 134).

Time, as well as space, likely plays an important role in employment experiences of people with chronic illness. Activities related to managing chronic illness cost individuals, on average, at least 2 h per day (Jowsey et al., 2012). Yet, time, including how long people work, how fast and when, is also fundamental to the wage exchange underpinning employment, and power relations are reflected in who can decide the terms of this exchange (Thompson, 1967). Therefore, people with chronic illness may be subject to unique and poorly understood temporal dynamics of negotiating employment that must be considered alongside spatial factors. Indeed, research has shown that time pressure is experienced disproportionately by employees with disabilities (Pagán-Rodríguez, 2013), and can hinder chronic illness management in the workplace (Balfe et al., 2013). Furthermore, working pace (Wilton, 2004), and work hour flexibility (Hall and Wilton, 2011) are key factors in successful workforce participation for disabled workers.

Space-time approaches are especially good at grasping the interaction of various barriers, advantages, and characteristics experienced by individuals as they go about everyday activities (Dijst, 2009). These approaches are designed for "temporally integrated geographies" (Kwan, 2013, p. 2) of human experience and behaviour, in which the complex roles of both time and space are brought to the fore (see May and Thrift, 2001; Schwanen and Kwan, 2012). For example, people often feel stymied by the simple fact that they cannot be in two places at once, and space-time approaches can reveal different kinds of logistical constraints on and affordances to individuals' activities (Hägerstrand, 1970). Moreover, space-time approaches examine the repetitions that shape daily life, nudging or even propelling certain activities forward so they are performed with ease, while stifling others to the point of a daily struggle (Lefebvre, 2004). Despite its relevance and potential, few studies have used a space-time approach to explore the everyday experiences of people with chronic illness. Notable exceptions include Takahashi and colleagues' (2001) analysis of the space-time contexts of service access for individuals with HIV/AIDS in the United States, and Ansell and colleagues' (2011) relational space-time analysis of the impacts of AIDS on young people in southern Africa.

In summary, our aim is to examine the role of space and time in shaping the way individuals with CKD experience and navigate illness and paid work. Below, we elaborate on the spatio-temporal approach used in this study. Our methodological approach is then described, and results are presented and discussed.

2. A spatio-temporal approach to paid work and chronic illness

By using the term 'space-time', we signal our conceptualisation of space and time as inextricably entwined and multidimensional (Schwanen and Kwan, 2012). Space and time are linked in the sense that shifts in one ripple through the other; distances across the globe are effectively shorter as transportation modes become faster, for example. Furthermore, people experience space and time in many different ways, and the multiplicity of this experience must be embraced in order to understand daily life (Adam, 2013; May and Thrift, 2001). For the sake of analysis, we simplify this diversity of space-times into those experienced as logistical resources and those embodied as rhythms.

2.1. Space-time as a resource

The first of these – space-time as a resource – refers to the negotiation of the cultural constructs of clock/calendar time and universal space, both of which are conceived as absolute and external to the individual. Here, time is understood as progressing linearly at a predictable pace, and space takes on Cartesian properties with universal coordinates and distances. But space-time resources shape, and are shaped by, social practice (Shove et al., 2009). For example, most doctors require patients to be present at the office waiting room, whether the doctor is running on time or not. As such, patients 'spend' space-time resources travelling to and accessing health services which, for some working individuals, may have to be 'paid back' to their employer if the visit was during working hours. Experienced this way, space-time is an important logistical resource needed to perform activities, and is finite and often in short supply. All activities have certain appetites for time and space in the absolute sense, and most have ideal locations and times for their performance (Hägerstrand, 1970; Shove et al., 2009).