Time, space, and everyday life with chronic illness:
A qualitative case study of chronic kidney disease in Australia

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**Acknowledgements and dedication**

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Abstract

This thesis investigates experiences of time, alongside space, in negotiating everyday life with chronic illness. In countries like Australia, increasingly large portions of populations spend many years of life living with and managing ill health. This financially burdens nations, challenges health care system design and the traditional patient role, and alters the health profile of the labour pool and available caregivers. On the individual level, chronic illness instigates a fundamental shift in how life is experienced and navigated.

Research on place and health has relied primarily on traditional, Euclidian conceptualisations of space and place. Many health geographers have worked beyond these, providing rich accounts of chronically ill individuals’ everyday experiences with place. The temporal dimension of chronic illness, however, has received far less attention. Time, as well as space, likely plays an important role in how individuals negotiate different parts of everyday life given the long-term, permeating, and fluctuating nature of chronic illness.

I draw from a qualitative case study of 26 individuals living with chronic kidney disease in the Australian Capital Territory and nearby New South Wales communities in Australia. My spatio-temporal geographical approach embraces multiple senses of time and space, and recognises the entangled relationship between the two – conceptualised as space-time. Attention to social practices illuminates how different senses of space-time shape, and are shaped by, everyday activities. The concept of habit reveals how mutual transformation occurs between individuals and their environments over time. Participants recorded travel and activity diaries and an illness management inventory over two sample days. In-depth interviews followed in which participants ‘led’ me through their sample days.

I examine interactions between the spatio-temporal characteristics of four areas of participants’ everyday lives: self-management of chronic illness, paid work, caregiving, and leisure. Findings show that a unique dimension of living with chronic illness is the negotiation of the spatio-temporal characteristics of chronic illness symptoms and their management. These characteristics weave through, and sometimes clash with, those of other pressing areas of everyday life. When logistical or rhythmic incompatibilities arise, everyday activities become more difficult. In conclusion, health status is an important factor shaping spatio-temporal organisation of everyday activities and space-time accessibility, and rhythms circulating within everyday contexts influence the level of effort required to perform everyday activities. Efforts to increase quality of life and social inclusion for individuals with chronic illness should target the reduction of spatio-temporal conflicts within individuals’ everyday lives.
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Publications arising from this thesis

Peer reviewed publications


Manuscripts in preparation

Supporting kidney patient routines: The importance of predictability in health service access (First author).

A space-time ecology of habit: The case of chronic illness self-management (First author).

It was dinner time, bed time, and no family: The space-time conflicts of providing care as a person with chronic illness (First author).

Illness and pleasure: Encounter within the leisure-scapes of chronic illness (First author).

Peer reviewed paper competitions


Conference presentations


McQuoid, J., Theorizing health activity performance: Rhythm, practice and habit, C9-Go8 Health Futures Forum, Shanghai Jiao Tong University, October 2013.


McQuoid, J., Rhythms and habits: Patient self-management of chronic kidney disease in daily life, Gender and Research Workshop, the Australian National University, 8-9 August 2013.

Seminars

McQuoid, J., Integrating paid work and chronic illness in daily life: A space-time approach to understanding the challenges, National Centre for Epidemiology and Population Health Seminar Series, the Australian National University, 5 June 2014.

Conference posters


Chapter 1 - Introduction

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1.1 Everyday life with chronic illness

It is becoming increasingly common for large proportions of populations in countries like Australia to spend many years of life living with and managing ill health. Around the world, non-communicable, chronic illnesses such as depression, cardiovascular disease, chronic obstructive pulmonary disease, and diabetes are increasingly prevalent (World Health Organization, 2008, p. 47). Non-communicable diseases now account for almost half of the global burden of disease and are projected to dominate the global burden of disease by 2030 (World Health Organization, 2008, p. 51). For high-income countries like Australia, non-communicable diseases are of particular concern where the burden is borne by ageing populations who must manage these conditions over the longer-term of their lives. Chronic illnesses, meaning those which are “long-lasting with persistent effects” (Australian Institute of Health and Welfare, 2014, p. 90), are the leading cause of illness, disability and death in Australia, accounting for 90% of all deaths in 2011 (Australian Institute of Health and Welfare, 2014, p. 94). An overwhelming 77% of Australians have a disease or other health problem lasting six months or more (Australian Institute of Health and Welfare, 2008, p. 33). Along with the non-communicable diseases such as those mentioned above, many communicable diseases add to the chronic illness burden. For those for whom access to good treatment and drugs is possible, diseases such as HIV are increasingly understood as chronic rather than acute illnesses due to the extended years of life provided by advances in disease management, medical treatment and pharmaceutical drugs (Schmitt & Stuckey, 2004).
The rising prevalence of chronic illnesses poses a financial and capacity burden to nations in several ways. In Australia, health care expenditures have grown faster than both population and economic growth, from $4,276 per person in 2001-02 to $6,230 in 2011-12 (Australian Institute of Health and Welfare, 2014, p. 47). Chronic illnesses account for approximately $11 billion, or 22.4%, of Australian health care expenditure (Australian Institute of Health and Welfare, 2005).

Chronic illnesses also burden nations by altering the health profile and capacity of the labour force. In Australia, a full 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). This trend in the labour force is problematic given the known difficulties individuals with chronic illnesses have entering into and persisting in the labour market (e.g., Edwards & Boxall, 2010; Roessler, Hennessey, Neath, Rumrill, & Nissen, 2011).

Chronic illnesses are also challenging health care system design and the traditional role of the patient. This is due to the historical orientation of the health care system toward addressing acute rather than chronic illnesses (Holman & Lorig, 2004). The rise of chronic illnesses has rendered the current health care system design ineffective and inefficient for the health care needs of present day Australians. Chronic illnesses are more difficult for the health care system to address and require a more active role by patients in their own care due, in particular, to the gradual onset, multivariate causality, and need to manage chronic illness over the long-term. This contrasts with the case of acute illness in which an abrupt onset, single causality, and return to normal health for the patient with proper treatment is more typical (Holman & Lorig, 2004).

At the individual scale, chronic illness has a particular set of characteristics that it introduces into the lives of those with chronic illness, their loved ones, and caregivers. These include permanency, permeation, fluctuation, and invisibility. Chronic illness is permanent, meaning that it will never be cured, will almost certainly endure over the long-term in a person’s life, and will often forecast a trajectory of decline in the person’s health. For example, different types of multiple sclerosis are defined by patterns of disease relapse and progression occurring over decades of a person’s life (Confavreux, Vukusic, Moreau, & Adeleine, 2000). Chronic illness typically causes some extent of functional impairment or disability (Australian Institute for Health and Welfare, 2015), and the management and effects of this can permeate throughout different aspects of a person’s life, including “time, activities of daily living, family and interpersonal relationships, social and work activities, and finances,” (Jeon et al., 2010, p.
70). Chronic illness often fluctuates, sometimes widely, in terms of severity and type of symptoms over the long and short term. The lives of individuals with recurrent cancers, for example, are marked by “good days and bad days” (Charmaz, 1997, p. 1) of unpredictable symptoms that improve, worsen, disappear, and re-emerge. In another example, rheumatoid arthritis disease activity has been shown to fluctuate with the seasons (Iikuni et al., 2007). Finally, chronic illness often has an element of invisibility, meaning that it is not always apparent to those around them that a person has a chronic illness. Individuals with fibromyalgia report that others often dismiss their symptoms (e.g., pain) due to the lack of outward signs of symptoms or physical deformity (Kool et al., 2010).

The convergence of these characteristics of chronic illness in a person’s life often instigates a fundamental shift in how life is experienced and navigated. For this reason, research efforts are building around what it means to live with a chronic illness in the everyday, how people may live the most fulfilling lives possible with chronic illness, as well as the impacts of chronic illness on the life trajectories of individuals with chronic illness and their caregivers. These topics have most often 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, Dorn, & Wilton, 2008, p. 884). Nevertheless, individuals with chronic illness and disability do share experiences that are relevant to the ways in which everyday life is navigated, such as the persistence of impairments over time, restrictions on what people can do and where, and the need to adapt to 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, emphasises the effects of the chronically ill body’s capacities, states, and needs on the individual’s ability to perform activities in everyday life such as employment. The second is the social (Oliver, 1990) or socio-political (Dyck & Jongbloed, 2000) model of disability, which problematizes society’s attitudes towards and expectations of ill or disabled bodies. A third model, the biopsychosocial model, attempts to integrate the medical and social and is used in many contemporary disablement frameworks (Jette, 2006). The biopsychosocial model draws attention to relationships between “biological, psychological, and social dimensions of illness” (Borrell-Carrió, Suchman, & Epstein, 2004, p. 576).

Understandings of the long-term impact of chronic illness on people’s lives have also been heavily influenced by Bury’s (1982) understanding of chronic illness as a specific kind of
disruptive event in people’s lives: a biographical disruption. This way of framing chronic illness has been used effectively to understand the long-term disruption of chronic illness in how individuals with chronic illness and their caregivers construct their identities and imagine their futures (e.g., Jowsey, 2011).

1.2 Space and place in everyday life with chronic illness

Everyday life with chronic illness has also been explored through a spatial lens. There is a very long tradition of research concerning the relationships between space, place, and health, which has experienced a resurgence of interest since the 1990s (Cummins, Curtis, Diez-Roux, & Macintyre, 2007). This field of research has been criticised for its employment of typically limited conceptualisations of space and place, identified as one of the “weakest theoretical areas of current practice in health and environment research,” (Matthews, 2008, p. 257). However, health geographers have proposed alternative ways of engaging conceptually with place to address these weaknesses (see Andrews, Evans, Dunn, & Masuda, 2012; Andrews, Hall, Evans, & Colls, 2012; Cummins et al., 2007; Kearns, 1993; Kearns & Joseph, 1993; Kearns & Moon, 2002). And, a call has been made for “recognizing that individuals become relationally embedded in multiple health damaging and health promoting environments, across time and space, and at multiple scales,” (Cummins et al., 2007, p. 1835), and for more exploration of “locally entangled life and health care practices beyond the immediate primary care settings” (Kovandžić et al., 2012, p. 537).

Research on place and health in recent decades has been based primarily on a traditional, Euclidian conception of space and place (Cummins et al., 2007, p. 1835). Studies most often conceptualise geographic context in terms of aggregates, proximities, or specific sites. One approach is to understand an individual’s exposure to health related environmental factors via an administratively defined aggregate around their place of residence (e.g., Sacker, Wiggins, & Bartley, 2006) or the place of residence itself (e.g., Corneil et al., 2006). Another is to represent the level of access to healthcare and health resources the individual or community has using proximities of place of residence to health services or health resources (e.g., Kaukinen & Fulcher, 2006; Schuurman, Randall, & Berube, 2011; Wolch et al., 2011). A third is to examine qualities of service provision settings, such as the degree of patient privacy they provide (e.g., Balfe, Brugha, O’Connell, McGee, & O’Donovan, 2010), in relation to health outcomes (see also Curtis, Gesler, Prieb, & Francis, 2009; Egdell, Bond, Brittain, & Jarvis, 2010; Hassink, Elings, Zwekhorst, Van Den Nieuwenhuizen, & Smit, 2010; Kovandžić et al., 2012; Lee, Kearns, & Friesen, 2010). And, finally, qualities of restorative or health enabling
settings such as natural landscapes are also examined in relation to health and wellbeing (e.g., Cattell, Dines, Gesler, & Curtis, 2008; Duff, 2011; Foley, 2011).

These approaches have certain recognised drawbacks. For one, it is understood that residential location and actual lived space do not necessarily correspond and neither does an individual’s definition of their neighbourhood often coincide with administratively defined boundaries used as proxies for ‘neighbourhood’ (Basta, Richmond, & Wiebe, 2010; Matthews, Detwiler, & Burton, 2005; Smith, Gidlow, Davey, & Foster, 2010). This makes it easy to mistake what an individual actually interacts with in everyday life, and “may severely underestimate the total effect of ‘context’, in its myriad of forms and in its multiple locations, on individuals,” (Cummins et al., 2007, p. 1830-1831). Actual lived space includes contexts beyond the neighbourhood like those of work, travel, hobbies, and social activities which should also be considered in assessments of health-related environmental exposure (Basta et al., 2010; Matthews, 2008). Place-based approaches are also criticised for under-appreciating the variation between individuals with different socio-demographic characteristics in what might constitute ‘their environment’, as well as how differences like gender, age and income can create greater or lesser levels of accessibility between individuals residing in the same neighbourhood. For example, older, retired individuals often have more neighbourhood-centred lives as compared to their younger, working counterparts who tend to move about regionally and within various contexts (e.g., home, work, school, etc.) throughout the course of everyday life (Perchoux, Chaix, Cummins, & Kestens, 2013).

Furthermore, conventional measures of accessibility to health resources and services miss the interdependencies between daily activities and temporal constraints of everyday life (Kwan, 1999b; Schwanen & De Jong, 2008). Approaches limited to assessing health accessibility from the perspective of the home address provide only a partial picture given that individuals often juggle and coordinate activities held at various locations throughout the day (Neutens, Schwanen, & Witlox, 2011). Socio-demographic differences in accessibility are linked to variations in time-budgets, transportation options and the like between individuals. These can produce wide differences in one individual’s ability to reach a health resource as compared to another who may very well live next door (Neutens et al., 2011). For example, the design of place-based measures obscures gender differences in space-time accessibility within dual earner households. Because women tend to perform a disproportionate amount of in- and out-of-home domestic and caregiving tasks in addition to paid work, they experience more constraints derived from having to coordinate their activities with those of their family
members. As a consequence they experience less flexibility in organizing activities in everyday life and in where they can go (e.g., Kwan, 1999a; Palm & Pred, 1974).

Finally, while qualitative studies of people’s perceptions and experiences of specific health-related places such as the doctor’s office provide valuable insight into how characteristics of particular places might influence health and health-related behaviour (Cummins et al., 2007, p. 1836), they grasp neither how services and resources integrate into the broader fabric of everyday life activities, nor the experiences individuals have moving through contexts both external and internal to service provision sites.

Relationships between health and context are dynamic, and approaches are required that can grasp this complexity: “[R]esearch in place and health should avoid the false dualism of context and composition by recognising that there is a mutually reinforcing and reciprocal relationship between people and place,” (Cummins et al., 2007, p. 1825). It is debatable how appropriate conventional, place-based accessibility and environmental exposure measures ever were for examining the roles of space and time in health outcomes and behaviours. However, several social and technological developments in recent decades clearly demand more personalised approaches in order to reveal the variety of contexts and activity patterns individuals with different socio-demographic characteristics experience, and how these may produce varying health outcomes. One such development is the increasing heterogeneity and individualisation of schedules and lifestyles appearing in recent decades (Shove, 2009; Southerton, 2009). Also relevant to how we conceive of relationships between health and place are the increasing mobility and dispersion of activities in space and time due to the influence of faster transportation, Information and Communication Technologies (ICTs), and socio-economic shifts such as greater participation of women in paid work (Couclelis, 2009; Cummins et al., 2007; Neutens et al., 2011; Perchoux et al.). Nevertheless, the most common approaches to studying space-time-health relationships still persist in examining time and space separately; lacking ecological validity and becoming increasingly obsolete.

Many health geographers have worked beyond the dominant and limited conceptualisations of space and place, and have provided rich accounts of individuals’ embodied everyday experiences in understanding the relevance of space and place to everyday life with chronic illness (e.g., Crooks, 2007a; Driedger, Crooks, & Bennett, 2004; Dyck, 1995a, 2002; Dyck & 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 & 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, 1995a, 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, 2007a, 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 everyday life (Crooks, 2007a, 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) described the shifting spatial dimensions of everyday life experienced by men with HIV/AIDS as the disease progresses over time. Driedger and colleagues (2004) considered how chronic illness frames individuals’ senses of themselves as located in ‘past, present, and future’ temporal settings. While these accounts do not address the diversity of temporalities experienced in everyday life (Adam, 2013; Shove, Trentmann, & Wilk, 2009a), such studies begin to address the need to pay closer attention to 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).

1.3 Considering time in everyday life with chronic illness

Social theorists are increasingly acknowledging that space and time are inextricably entwined and multidimensional (e.g., Crang, 2005; Harvey, 2009; Lefebvre, 2004; Massey, 2005; May & Thrift, 2001; Parkes & Thrift, 1980; Schwanen & Kwan, 2012). Following this revelation, the incorporation of the role of time, alongside space, in health research offers a richer and more ecologically valid understanding of the relationships of both space and time with health. Indeed, within the field of health research, the idea that both space and time are fundamental to understanding health issues is gaining acceptance. Rainham, McDowell, Krewski, and Sawada (2010) advocate for using individuals’ movements in time and space as the basis for defining the contexts relevant to people’s health. Furthermore, insufficient quantities of time (time scarcity) as well as feelings of being pressed for time (time pressure) have been linked to socially patterned health inequalities (Strazdins et al., 2011; Strazdins, Welsh, Korda, Broom, & Paolucci, 2015). People need to be able to access health services and resources across space in a timely fashion, as exemplified by hospital and clinic catchment area planning efforts (e.g., Schuurman et al., 2011). The importance of healthy living environments in terms of what is present (e.g., fresh produce and green spaces) and what is absent (e.g., fast-food restaurants
and violent crime) on health outcomes such as childhood obesity is also widely researched (e.g., Burdette & Whitaker, 2004).

Time, as well as space, must be recognised as having an important role in how individuals experience the negotiation of different parts of everyday life with chronic illness given the long-term, permeating, and fluctuating nature of chronic illness in individuals' lives. A small but growing body of research has chartered relationships between time and chronic illness experiences (see, for a review, Jowsey, 2015). Chronic illness has been shown to influence how individuals perceive themselves as located in the past, present, or future, which, in turn, impacts on concepts of self (Charmaz, 1997). For example, an initial crisis of symptoms may be experienced as an interruption, rather than a permanent feature in a person's life. In this early experience of chronic illness, the individual may become absorbed in a patient role while waiting for their prior health to return, suspending their past self and putting regular activities 'on hold' to return to after the crisis is over (Charmaz, 1997, p. 11). When symptoms keep returning, chronic illness becomes an insistent intrusion in the person's life that must be given "continued attention, allotted time, and forced accommodation," (Charmaz, 1997, p. 42), pre-empting valued activities associated with past conceptions of self. As such, chronic illness forces people to restructure everyday life in order to accommodate its permanent presence (Charmaz, 1997, p. 170). Bury (1982) famously observed that this kind of establishment of chronic illness in a person's life disrupts their anticipated life-course trajectory, departing from the typical rhythms of childhood, adolescence, adulthood, and old age (Jowsey, 2015). Furthermore, the changes in the states and capacities of the chronically ill body are known to be unpredictable in nature (e.g., Dyck & Jongbloed, 2000), introducing unique, embodied temporal dimensions into everyday life. For example, the corporeal rhythms of chronic illness may cause individuals to worry about and try to anticipate when their body will 'fail' them in being able to perform activities associated with many different parts of life.

The management of chronic illness has its own temporal and spatial characteristics. Time, as experienced through clocks and calendars, features in the heavy temporal demands of managing chronic illness. By one estimate, activities related to managing chronic illness cost individuals, on average, at least two hours per day (Jowsey, Yen, & Paul, 2012). Strazdins and colleagues (2011) stress the underappreciated importance of time as a health resource for health supporting behaviours, such as exercise, which are often part of managing chronic illness. For many, chronic illness forces a temporal restructuring of everyday life: “Intrusive illness takes time – for symptoms, for symptom control and prevention of flare-ups, for handling prior activities more slowly,” (Charmaz, 1997, p. 43). There is a juggling act for many
with chronic illness wishing and able to engage in other activities in everyday life. This juggling involves the process of learning to pace, schedule, and arrange treatment regimens and cope with symptoms along with other activities like “caring for children, being sexual, doing housework, cooking, shopping, and keeping a physically or psychologically stressful job,” (Charmaz, 1997, p. 136).

Temporal as well as spatial dimensions likely influence the employment experiences of people with chronic illness. Time, including how long people work, how fast and when, is 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 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 & Wilton, 2011) are key factors in successful workforce participation for disabled workers. Those able to control the “structuring, scheduling, pacing, and content” of work are more likely able to continue working with chronic illness (Charmaz, 1997, p. 77).

Furthermore, individuals with caregiving roles and families experience particular temporal and spatial dimensions of caregiving that may interact with the temporal and spatial dimensions of chronic illness. Families tend to try to coordinate the movements of family members in time and space through routines and rituals for practical reasons, but also to promote stability and resilience in the family (Fiese et al., 2002). Contemporary accounts of family life describe time pressured lives for caregivers, particularly working mothers (e.g., Daly, 2002). In the spaces and times of caregiving and family “the dominance of co-presence is obvious,” (McKie, Gregory, & Bowlby, 2002, p. 906), creating a constraint that restricts caregivers’ paths in time and space by where and when those dependent upon them need them. The demands of caregiving on a person’s time and physical presence may clash with the considerable temporal ‘costs’ of chronic illness management noted above, and this may exacerbate feelings of time pressure in caregiving. Furthermore, there is a “fluidity of time and space” (McKie et al., 2002, p. 913) in being needed as a caregiver, including “planning, worrying, anticipating, speculating,” (McKie et al., 2002, p. 915) that may interact with the already fluctuating and unpredictable nature of chronic illness. Finally, the notion of spending ‘quality time’ is felt by many contemporary caregivers as a necessary part of giving care in addition to the logistical and practical temporal and spatial aspects of caregiving (e.g.,
Southerton, 2009). This raises questions about how the spatial and temporal characteristics of chronic illness may influence ‘quality time’ with family members.

And, finally, the spaces and times implicated in the pursuit of leisure, recreation, and tourism for people with chronic illness may be examined. Leisure activity participation by people with chronic illness is rarely studied even though these activities are linked to chronically ill individuals’ mental and physical health (Katz, 2004). Difficulties performing these kinds of discretionary activities are most often explained in terms of functional limitations of chronic illness, which can become more or less disabling depending on the type of leisure activity the person wants to perform (e.g., hiking versus talking with friends) (Katz, 2004). The level of difficulty people with chronic illness have in persisting in enjoying leisure activities likely varies depending on the spatial and temporal characteristics of different leisure activities and how these interact with the spatial and temporal characteristics of their illness and its management. Literature on the spaces and times of leisure activities, more generally, has noted a de-synchronisation between leisure activities of individuals, the ways in which individuals use leisure time consumption choices to inform their identity, and the ways in which different individuals are constrained in participating in different leisure activities at different places and times (e.g., Mowl & Towner, 1995; Stalp, 2006; Urry, 1994; Van der Poel, 1997). Furthermore, the ways in which individuals relate with, are transformed by, and transform spaces of leisure has been studied (e.g., Crouch, 2000). Questions of access to the times, spaces, and places of leisure, synchronisation of leisure practices, frequency, physical requirements and embodied encounter with leisure can be examined in relation to the temporal and spatial dimensions of living with and managing chronic illness. These spatial and temporal characteristics of leisure may interact with those of chronic illness, presenting unique challenges to people with chronic illness in enjoying leisure activities.

1.3.1 What space-time geography offers
Space-time geographical 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 & Thrift, 2001; Schwanen & 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 of individuals’ activities (Hägerstrand, 1970). Moreover, space-time approaches examine the repetitions and differences people perceive within themselves and their surroundings over time. Rhythms shape everyday 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). Furthermore, space-time geography’s viewpoint on everyday life taken from the individual’s path through time and space provides an opportunity to foreground corporeality and matter over abstract social theorising (Gren, 2001, p. 216). This offers an avenue through which to explore ongoing processes of transformation between bodies, minds, and environments over time.

Despite their relevance and potential, few studies have used space-time approaches 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. Further inquiry is needed into the importance of health status as a factor shaping where, when, and how individuals perform everyday activities, and, how the temporal and spatial characteristics of other areas of a person’s life impact on experiences of chronic illness management and symptoms.

1.4  A space-time approach to everyday life with chronic illness

1.4.1  The case of chronic kidney disease

This thesis takes a space-time geographical approach to the problem of everyday life negotiation for people with chronic illness. I examine experiences of both space and time – conceptualised as space-time – in a qualitative case study of 26 individuals living with chronic kidney disease (CKD) in the Australian Capital Territory and nearby communities in rural New South Wales in Australia. CKD was chosen for this study due to its similarities with many other 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 term used to describe loss of kidney function over time, for a period of at least three months (National Institutes of Health, 2012). It is a large and growing health concern worldwide (Zhang & Rothenbacher, 2008). For example, seventeen percent (17%) of Americans are in some stage of CKD (Bharakhada et al., 2012), and 14% of males/13% of females in the United Kingdom have some stage of CKD (Roderick, Roth, & Mindell, 2011). In Australia, its increasing prevalence, estimated at 16% of the population (Green & Ryan, 2009, p. 2), represents a threat to quality of life for those living with CKD and their caregivers. It is a substantial contributing and underlying cause of death in Australia, and a strain on the health care system’s resources and capacity (Green & Ryan, 2009).
In the space-time geographical approach developed for this study, I draw from time geography (Hägerstrand, 1970) in considering how various parts of a person’s life – managing chronic illness, paid work, caregiving and family, and leisure, recreation, and tourism – compete for finite spatial and temporal resources. I draw also from rhythm analysis (Lefebvre, 2004), with its orientation to the sensory experience of the body, to embrace embodied experiences of time and space that may be particularly pertinent to everyday life with chronic illness (e.g., fluctuating energy levels). I draw from literature on social practice (Shove, Trentmann, & Wilk, 2009b) in understanding how different senses of space-time are shaped through, and shape, everyday practices of individuals and social institutions. Finally, I understand the habitual nature of everyday life through the tradition of thought on habit that understands habit as open-ended plasticity allowing for mutual transformation between individuals and their environments over time (Grosz, 2013; Ravaission, 2008).

1.4.2 Aim and objectives

This thesis aims to understand experiences of time, alongside space, in negotiating everyday life with chronic illness. In meeting this aim, I satisfy five study objectives:

1) Identify the predominant activities in participants’ lives (e.g., managing chronic illness, working).
2) Describe the spatio-temporal characteristics of everyday activities and of chronic illness (e.g., (in)flexible, fluctuating, (un)predictable, (ir)regular, cyclical, episodic, (in)frequent, (im)mobile).
3) Understand the origins of these spatio-temporal characteristics (e.g., externally/externally imposed, the body, treatments, conventions of social practice, social institutions, individual habits).
4) Observe how spatio-temporal characteristics of activities and chronic illness interact (e.g., arrhythmias, conflicting demands on space-time resources).
5) Understand how participants experience the interaction of these spatio-temporal characteristics.

1.5 Thesis structure

I proceed from this introductory chapter through seven subsequent chapters: Chapter 2 – A Review of Space and Time, Chapter 3 – A Review of Everyday Life with Chronic Illness, Chapter 4 – Methodology, Chapter 5 – Study Setting, Chapter 6 – Findings: A Diary Sketch of Everyday Life, Chapter 7 – Findings: Interacting Space-times of Everyday Life, and Chapter 8 – Discussion and Conclusion. In the following chapter, Chapter 2 – A Review of Space and Time, I bring
together literature on space-time geography, social practice, and habit to develop the space-time approach that informed the design, execution, and analysis of this case study. In Chapter 3 – A Review of Everyday Life with Chronic Illness, I provide background information on chronic kidney disease, and then discuss possible contributions of a space-time approach to understanding four aspects of everyday life negotiation for people with chronic illness: 1) patient self-management of chronic illness; 2) paid work participation; 3) caregiving and family; and 4) leisure, recreation, and tourism.

In Chapter 4 – Methodology, I justify the methodological approach taken in this study, and describe the multiple methods employed and how these complement one another. I describe recruitment and sampling and saturation in the study. I report on the potential ethical issues of the study and strategies taken to mitigate each of these, followed by data collection procedures, and procedure and techniques of analysis. Finally, I report on participant characteristics. A description of relevant characteristics of the study setting, including important features of the health care system, is provided in Chapter 5 – Study Setting.

I present the findings of the space-time analysis in Chapters 6 and 7. First, in Chapter 6 – Findings: A Diary Sketch of Everyday Life, I provide a sketch of participants’ everyday trips, locations, and activities by drawing from the travel and activity diary and illness management inventory data. Next, in Chapter 7 – Findings: Interacting Space-times of Everyday Life, I analyse the four areas of everyday life that emerged as most important to participants. These are: 7.1) Patient self-management of chronic illness, 7.2) Paid work participation, 7.3) Caregiving and family, and 7.4) Leisure, recreation, and tourism. As most existing literature has studied these different parts of chronically ill people’s lives independently of one another, each sub-section begins with a short section outlining the usual approaches taken to understanding how people with chronic illness experience each aspect of everyday life. Then, I present the space-time findings, reflecting on existing approaches. The chapter concludes with a summary of findings.

In Chapter 8 – Discussion and Conclusion, I begin by discussing the contributions of this study to space-time geography and health geography. Subsequently, I discuss contributions to health geographies of chronic illness, along with specific implications of findings for understanding chronic illness experiences in: patient self-management of chronic illness, paid work participation, caregiving and family, and leisure, recreation, and tourism. Then, I consider study limitations. Finally, I conclude the thesis by revisiting the thesis aim, summarising findings, and proposing future lines of work.
Chapter 2 - A Review of Space and Time

2.1 A space-time approach to understanding everyday life with chronic illness

2.1.1 Space-time as a resource
2.1.2 Space-time as rhythm
2.1.3 ‘Doing’ the everyday
2.1.4 Space-time, practice, and habit

In this chapter, I present the space-time geographical approach used in the design, execution, and analysis of this study. I draw primarily from literature on time geography, rhythm analysis, social practice, and habit in formulating my approach.

2.1 A space-time approach to understanding everyday life with chronic illness

By using the term space-time, I signal my conceptualisation of space and time as inextricably entwined and multidimensional; an understanding now shared widely among social geographers and other social theorists (e.g., Crang, 2005; Harvey, 2009; Lefebvre, 2004; Massey, 2005; May & Thrift, 2001; Parkes & Thrift, 1980; Schwanen & Kwan, 2012). Other terms used to express this idea are May and Thrift’s “timespace” (2001) which recognises the diversity of senses of space-time and minimises conceptual separation of the two (May & Thrift, 2001, p. 3). Lefebvre’s analysis of rhythms unites time and space, demonstrating “the interrelation of understandings of space and time in the comprehension of everyday life,” (Elden, 2010, p. vi). Harvey (2009) refers to “space”, “space-time” and “spacetime” in differentiating between the absolute, relative and relational ways in which space and time are experienced, conceived and lived. Adam (1998) discusses “timescapes” of activities and interactions of organisms and matter, emphasising their “rhythmicities, their timings and tempos, their changes and contingencies” (Adam, 1998, p. 11). And, Massey (2005) writes of “time-space” (p. 177-180). My purpose here for using the term space-time rather than other variations is to position this thesis with reference to the body of work known as critical space-time geography (see Schwanen & Kwan, 2012).

The way we conceive of space is greatly influenced by our understandings of the nature of time, and vice versa (Crang, 2005). So, too, are our experiences of different senses of time
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and space influenced by one another; shifts in one ripple through the other. To give a few examples, the universality of the ‘natural’ temporal cycles of day and night is challenged where urban spaces with street lighting and 24 hour service economies have developed. Distances across the globe are effectively shorter as transportation modes become faster. Furthermore, time spent stuck in highway traffic may seem shorter if the destination is a desirable one, just as time spent waiting for a bus may seem longer if there is a great degree of uncertainty as to when or if it will arrive.

People experience and conceive of time and space in many different ways, and the multiplicity of this experience must be embraced in order to understand everyday life (Adam, 2013; Crang, 2005; May & Thrift, 2001). Adam brings our attention to several different senses of time: time frames (e.g., seconds, days, years, eras, epochs); temporality (e.g., process, irreversibility, impermanence); tempo (e.g., pace, intensity/rate of activity); timing (e.g., synchronisation, Kairos); time point (e.g., moment, Now, instant, juncture); time patterns (e.g., rhythmicity, periodicity, cyclicity); time sequence (e.g., series, cause and effect/simultaneity); time extensions (e.g., duration, continuity); past, present and future (e.g., horizons, memory, anticipation) (Adam, 2004, p. 144).

Answers to questions about time and space lie, some argue, not in philosophical questions about the nature of time and space, but in examining human practices and processes (Adam, 2004, 2013; Crang, 2001; Harvey, 2009). The construction of different senses of space and time, or “the means by which a particular sense of time comes into being and moves forward to frame our understandings and actions,” May and Thrift (2001) argue, is intimately wrapped up in four inter-related domains of social practice: 1) timetables and rhythms, referring to rhythms of the seasons, the body, and the tides, for example; 2) systems of social discipline, both secular and religious, as in the use of surveillance in the workplace to impose strict time discipline on workers; 3) human relationships with instruments and devices that are devised to mark or delineate the passage of time and the expanse of space (e.g., a speedometer in a car and highway signs with distances to destinations), or alter our conceptions of and relationships with time and space (e.g., real-time satellite broadcasting of a sporting event across the world); and, finally, 4) various texts which set out “particular understandings of time return to regulate that which we would codify (for example, the Book of Hours)” (p. 3-5).

For the purposes of this study, I focus primarily on two experiences of space-time that are particularly pertinent to everyday life for people with chronic illness. The first is space-time experienced as a logistical resource needed to perform activities. This is brought into focus due
to the ways in which important aspects of everyday life such as paid work and health care access are widely regulated by systems of discipline using clock and calendar time and universal space. The second sense of space-time I bring into focus is the embodied sense of patterned repetition and difference in space-time, or rhythm. The body’s importance is foregrounded due to the inherently corporeal dimension of chronic illness, as exemplified by circadian rhythms, cycles of toxin and water build-up in the blood prior to a dialysis session, patterns of energy decline, rest and rejuvenation, and of blood glucose readings.

2.1.1 **Space-time as a resource**

Space-time as a resource refers to the negotiation 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. Urry (1994) observes that clock time is associated with efficiency and productivity (“time is money”), that the “modern person” is oriented to the future and the passage of clock time while devaluing the past, that clock time is a resource “which is to be organized, regulated and distributed”, that industry, leisure and work are all organised around clock time, “that cultural texts have a narrative structure with a beginning, middle and end; and that long-term historical processes of social improvement are conceivable and realizable,” (p. 133).

Access to space-time resources shapes, and is shaped by, social practice (Shove et al., 2009a). 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, is finite, and is 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., 2009a). Thereby, regular activities consume, compete for, and shape the spatio-temporal contexts of people’s daily lives (Shove et al., 2009a). Time geography provides a set of analytical tools with which to understand the logistical constraints on a person’s access to space-time resources (Hägerstrand, 1970).

2.1.1.1 Classical time geography

Classical time geography is associated with the human ecological tradition of human geography. The fundamental concepts of time geography were developed in the 1960s, ‘70s,
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and ‘80s. Torsten Hägerstrands landmark presidential address in 1969 at the ninth European Congress of the Regional Science Association, “What About People in Regional Science?” stimulated geographers to consider the conditions circumscribing human action by paying attention to the paths and activities of individuals in time and space. Hägerstrand criticized the regional science approaches of the 1960s for being too concerned with the aggregate-level distribution of people and entities in space, treating a population “as a mass of particles, almost freely interchangeable and divisible,” (Hägerstrand, 1970, p. 9) thereby neglecting the connectedness of human activities that take place in time- and space-bound situations (Dijst, 2009). The theoretical model he initially outlined in his presidential address was intended to motivate policy-oriented, quality of life research. It was what he called “a kind of socio-economic web model” (Hägerstrand, 1970, p. 10) which sought to illuminate the “social organization and technology that exist at the micro-level from which the individual tries to handle his situation,” (Hägerstrand, 1970, p. 8) and to relate this micro-level situation to macro-level, aggregate behaviours and outcomes. Later, Pred (1981) and others expanded on this idea, attempting to demonstrate “… how the dialectics of detailed situations that underlie time-geography are relatable to structuration or the dialectics of practice and structure,” (p. 10). As Hägerstrand put it, there was, at the beginning of the 1970s, a ‘twilight zone’ between individual biographies and aggregate population statistics still to be explored.

The time geographical approach takes as its starting point the paths that all materially based entities draw in time and space. The space-time path represents “the uninterrupted sequence of movements and stationary activities undertaken by the individual in space-time,” (Neutens, Schwanen, & Witlox, 2011, p. 27). As such, everything that occupies space is always in ‘movement’ even when physically stationary because of the passage of time. We can think of this in terms of daily paths, yearly paths, life paths, and so forth. These space-time paths – of people, things, and elements – cross each other in what are referred to as stations or bundles (Hägerstrand, 1970). Figure 2.1 illustrates the space-time aquarium, which represents individuals’ paths through time (looking vertically) and across space (looking horizontally), observing how they cross paths and bundle at certain points. The illustration to the left depicts the daily paths of members of a household, who start the day at home together, depart for various activity locations during the day, and return home to sleep. The illustration to the right depicts the daily paths of the children of a particular school, beginning the day at various home locations, joining at the school for the middle of the day, and then parting ways again for home. In another example these paths could have included the passing of a rain cloud or bus, the toy a child takes to school, a virus, or any other number of people and things that may
have created a path within the time frame and area of interest. The space-time aquarium helps to visualize the sequential nature of the activities along each person’s path, the relationships between different paths in terms of timing, spacing, and activity participation, as well as how any given context can be viewed as a coming together of many different space-time paths that relate to each other in different ways.

Figure 2.1 Space-time paths and bundles

The trajectories of space-time paths of individuals are associated with activities or goals, known in time geography as projects, as well as certain constraints. A project consists of “the entire series of sequential tasks necessary to the completion of any intention-inspired or goal-oriented behaviour,” (Neutens et al., 2011, p. 27). For example, the paths of household members depicted in the space-time aquarium in Figure 2.1 can be explained by projects like dropping children off at school, going to work, and going to the store. Time geography understands the individual’s experience of time and space as one of finite resources subject to trade-offs (Hägerstrand, 1970, p. 10), and the space-time paths people take are shaped by certain constraints.

Three space-time constraints are identified: capability, coupling and authority (Hägerstrand, 1970). Capability constraints arise from a person’s biological, mental and instrumental limitations, lack of knowledge and skills, and limited resources. For example, individuals relying on public transportation experience reduced speed and route selection and thus experience greater logistical constraints in everyday life than those with a car (e.g., McQuoid & Dijst, 2012; Palm & Pred, 1974).

Coupling constraints arise from the necessity for various paths of people and objects to come together at the same time and location to complete an activity. For example, parents in dual earner households with young children, especially mothers, often find it difficult to juggle
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paid work with domestic responsibilities such as chauffeuring children to and from school (e.g., Schwanen, 2006, 2007; Schwanen, 2008; Schwanen & De Jong, 2008). In another example, dialysis treatment requires the space-time coordination of person and machine several days per week. Due to its size, the machine is stationary in space, requiring the individual to travel to it at a time when the machine is unoccupied, and dedicate several hours to treatment.

Finally, authority constraints impose on the individual’s space-time path when an individual’s access to activity locations is regulated through social rules, laws, financial barriers and power relationships (Dijst, 2009). For example, an employee who feels compelled to prove themselves to their supervisor may not take time off work for an illness even if they are legally entitled to such time. Hägerstrand observed at the time of his presidential address that social scientists knew very little about how these three constraints interact at the level of the life-path of the individual, mistakenly considering activities as performed in isolation (Hägerstrand, 1970, p. 19).

People’s daily lives are typically organised around what time geography refers to as base locations. These are the places where certain recurring activities (such as sleep, bathing, working, or studying) take place in relatively fixed time frames. Home is the most obvious base location example, as individuals typically start and end the day at this location; eating breakfast in the morning and dinner in the evening, sleeping during night hours, bathing and dressing, and the like. The workplace is another commonly identified base location. The amount of time available to travel between base locations is known as a time interval. Depending on the length of the time interval, the speed of travel between bases, and the locations of activity possibilities, there may be flexibility to participate in other activities before needing to arrive at the next base location.

Figure 2.2 (below) is an example of a space-time prism and potential path area. The balloon shaped prism in this figure is a visualisation of all space-time constraints experienced by an individual within a time interval. The ‘shadow’ of the prism represents all the activity places that the individual could visit within the given time interval. This projection of the space-time prism onto the ground is known as the potential path area (PPA), or potential action space. The potential path area refers to the locations that are accessible to the individual given the space-time constraints that they experience within a certain time interval (see Ritsema van Eck, Burghouwt, & Dijst, 2005 for an example of an application of a potential action space model). The daily potential path area (DPPA) is derived by superimposing an individual’s potential path areas for all time intervals of the day (e.g., Kwan, 1999a; Weber & Kwan, 2002).
The nuts and bolts of classical time geography described here were, for Hägerstrand, the shift in theoretical attention needed by regional scientists in particular, and social scientists in general, in order to address the quality of life issues of developed industrial societies of the later 20th century: “It seems that the main focus of our practical problems are moving away from the allocation of money towards the physical allocation of the uses of space and time,” (Hägerstrand, 1970, p. 20).

One key area of contribution of time geography to researching everyday life has come from measures of accessibility, contributions to which have been increasingly prolific since the 1990s as the necessary geocomputational tools have become more available. Accessibility measures are generally used to evaluate the quality of a transportation network and to describe an individual’s ability to reach spatially distributed locations of interest within the urban environment (Neutens et al., 2011; Pirie, 1979). For example, in everyday life most people want and/or need to be able to reach places for activities like work, education, leisure and entertainment, shopping, exercise, financial transactions, and health appointments in addition to their home location.

The most common measures of individual accessibility apply a place-based approach, either in reference to zones or points. A zone-based framework of individual accessibility examines the physical separation between zones, such as census tracts or neighborhoods (e.g., Schuurman, Randall, & Berube, 2011). However, this approach has the ecological fallacy of endowing equal levels of accessibility to individuals falling within each zone, disregarding individual differences such as time-budgets and transportation options that may affect

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**Figure 2.2  Space-time prism and potential path area**

*Source: Lenntorp, 1976, In: Dijst, 2009, p. 3*
accessibility (Forer & Kivell, 1981; Miller, 1981; Neutens et al., 2011). Also, zone-based accessibility approaches are subject to the modifiable area unit problem, which refers to the ways in which statistical results can be influenced by how boundaries are drawn when creating geographic aggregates for analysis (Kwan, 2009; Neutens et al., 2011; Riva, Gauvin, Apparicio, & Brodeur, 2009; Weber & Kwan, 2002). A point-based approach can help overcome the modifiable area unit problem of zone-based measures of accessibility by referencing the physical separation between a single location (e.g., home or work) and desired destinations (e.g., hospitals) (Neutens et al., 2011). See, for example, Schuurman and colleagues’ (2011) estimation of rural population catchments for health service location planning (Figure 2.3).

![Figure 2.3 Two-hour travel time catchments to obstetrical services, British Columbia, Canada](image)

*Source: Schuurman et al., 2011, p. 285*

Place-based approaches like these are relatively easy to implement and aid in developing ‘big picture’ assessments of population accessibility to resources and services. However, the ecological fallacy problem of place-based measures remains. Neutens and colleagues (2011) argue that this fallacy has, in fact, become increasingly problematic in recent decades for two reasons. First, individuals’ increased dispersion of activity patterns in space and time renders a single base location such as home increasingly obsolete in assessing
accessibility, such that more personalised accessibility measures are required. This is supported by Southerton’s (2009) work comparing time use diaries from 1937 and 2000. His analysis found that individuals in 2000 had an increased level of need to coordinate activities in everyday life due to the greater malleability of temporal rhythms in 2000 as compared to 1937 (Southerton, 2009, p. 57).

A second effect of the ecological fallacy on place-based measures is that they fail to pick up on socio-demographic differences in accessibility. This is because place-based measures overlook differences in the origins of individuals’ projects, time budgets, and space-time constraints on activities. For example, place-based measures are not able to sift out gender differences in space-time accessibility within dual earner households. Because women tend to perform a disproportionate amount of in- and out-of-home domestic and caregiving tasks in addition to paid work, they experience more coupling constraints and less space-time accessibility in everyday life (e.g., Kwan, 1999a, 1999b, 2000; Palm & Pred, 1974; Strazdins et al., 2011). While the spatial distribution of accessibility for different groups has received extensive attention, the temporal dimension has largely been overlooked (Neutens et al., 2011, p. 36).

Space-time accessibility analysis, derived from classical time geography, integrates both space and time into analysis at the individual scale, helping to address the ecological fallacy that hampers place-based measures. Space-time analysis draws on time geography’s space-time prism model, discussed above, measuring individual accessibility in terms of the individual, land-use, and transport-related constraints affecting a person’s access to activity locations (Neutens et al., 2011, p. 29). In this way, individual differences between people are brought into analysis, facilitating research on socio-demographic variations in individual accessibility in everyday life.

For example, Kwan (1999a) applied a space-time accessibility measure in her study of gender and individual accessibility due to the inherent gender bias she perceived in conventional (place-based) accessibility measures. Kwan used a network-based GIS method to analyse travel diary data from participants, finding that women had lower levels of individual access to urban opportunities than men due to differences in space-time constraints. Kwan noted that the methodology would best be complimented by in-depth interviewing, or another means of contextualising her findings. Below is an example of a Daily Potential Path Area of one of Kwan’s study participants (Figure 2.4).
2.1.1.2 Criticisms of and advances in time geography

In the decades after Hägerstrand’s landmark 1970 publication, the time-geographical framework faded somewhat into the background due, in part, to the lack of robust geocomputational tools and the lack of georeferenced, individual-level travel data (Neutens et al., 2011, p. 26). Moreover, the foundations of the classical time geographical framework have been criticized on multiple fronts, predominantly from structuration theorists, feminist geographers, and those interested in a relational perspective on geography (Dijst, 2009, p. 11). Since the 1990s, however, time geography’s popularity has regained momentum once again among geographers and transport planners in particular due to the availability of and advances in GIS software. These technological advances have facilitated previously impossible empirical research using time geography’s conceptual apparatus (Neutens et al., 2011). Miller (1991) was the first to define a generic GIS procedure to compute potential path areas (Neutens et al., 2011, p. 30), and others have since expanded upon his work to accommodate several ‘real world’ analytical considerations (e.g., Kim & Kwan, 2003; Kwan, 1998). Today, a small number of free and publicly available time geographical software applications are available (e.g.,
Neutens, Versichele, & Schwanen, 2010; Shaw & Yu, 2009). These technological advances have led to a proliferation of time geographical studies, and efforts have increasingly been made to address the drawbacks and criticisms that have been aimed at the time geographical approach since the 1970s. The past decade, in particular, has seen an increase of publications at the intersection of time geography, transport planning, accessibility analysis, and geographical information science (Neutens et al., 2011).

Several improvements to the representational realism of accessibility analysis in time geographical analyses in recent years are worth mentioning (Neutens et al., 2011, p. 30). For example, the representation of urban opportunity locations has been improved by including opening hours and weighting the locations according to attractiveness (Weber & Kwan, 2002). The effects of spatial knowledge on accessibility have been incorporated (Kwan & Hong, 1998), as well as the impact of dynamic traffic flow and congestion (Wu & Miller, 2001), one-way streets, turn restrictions and over-passes (Kim & Kwan, 2003), and temporal preferences for service access (Neutens, Schwanen, Witlox, & De Maeyer, 2010). The over-simplification of activities as being either ‘fixed’ or ‘flexible’ has also been remedied to some degree by introducing fixity ratings based on level of commitment and adaptability of the activity to other locations and times (Cullen & Godson, 1975; Neutens et al., 2011, p. 27; Schwanen, 2008). However, the fixed/flexible dichotomy continues to be used in many space-time accessibility studies. Finally, the role of information and communication technologies (ICTs) have been considered in people’s travel behaviour and accessibility (for an overview see Neutens et al., 2011, p. 34-35).

One important critic of time geography is Anthony Giddens (1984), who criticized time geography for treating people as if they are independent of their social settings in everyday life, relying too heavily on description of behavioural routines without questioning the origins of the projects, constraints and base locations that shape routine. In this sense, Hägerstrand’s framework had a weak conceptualisation of norms, power and individuals (Dijst, 2009; Neutens et al., 2011). Since the beginning of the 21st century, noticeable efforts have been made in time geographical studies to hone in on the influence of norms, power relations and inequality in shaping spatio-temporal organization of daily life. Examples include the space-time constraints experienced by women in dual-earner households (e.g., Kwan, 1999a, 1999b, 2000), norm-derived expectations of mothers (Schwanen, 2006, 2008; Schwanen & De Jong, 2008), the varying impact of AIDS on young people depending on the space-times of sickness and death, young people’s lives, and family (Ansell, van Blerk, Hajdu, & Robson, 2011), and socio-demographic variations in space-time accessibility to public services (Neutens,
Schwanen, et al., 2010; Neutens, Schwanen, Witlox, & De Maeyer, 2012) such as the constraints experienced by lower income families (Hernandez & Rossel, 2015).

Another important critic of time geography is feminist geographer, Gillian Rose, who offered the insightful critique that most applications of the framework have reduced the body to a neutral vessel carrying the person along a path through time and space (Rose, 1993). Treating all bodies equally in relation to space has at least two implications. Firstly, differences between individuals, such as gender, race, age, physical wellness, are lost in understanding how the individual experiences and behaves within various contexts along their path through time and space. For example, women tend to have more concerns about safety when traveling (Root, Schintler, & Button, 2000), and therefore may be inclined to prefer more secure forms of transportation and/or avoid certain travel routes. Secondly, if the body is reduced to a neutral vessel of transport, the individual’s awareness of the internal flows of context are obscured, meaning that the information gathering capacity of the body within context – sight, sound, touch, taste and smell – and the impact of contextual information on the individual’s experience and behaviour is also lost. The integration of the concept of embodiment (e.g., Davidson, 2001) within time geographical studies helps to overcome this inadequate conceptualisation of the body in classical time geographical analysis and brings attention to different experiences had by individuals along their space-time paths (e.g., McQuoid & Dijst, 2012).

Classical time geography has also been criticised for its lack of attention to the agency of the individual. Hägerstrand later recognised the “physicalistic flavor” of his original proposal, which he regretted had laid too much stress on people as victims of their environmental circumstances: “It [time geography] did not include the intangible forces of society acting upon people’s minds or the ability of individuals to transform their situation,” (Hägerstrand, 1989, p. 2). Later time geographical work has stressed the strategies and tactics that people employ in working with and manipulating their spatio-temporal situation. Schwanen and colleagues, in particular, have noted the strategies employed by parents in ‘juggling’ paid and domestic responsibilities. For example, Schwanen’s (2007) study found that parents often work with and through artefacts in order to extend themselves across space and time, as in the examples of written instructions for child care center workers, the accompaniment of the child by a toy in the parent’s absence, or utilising information and communication technologies (ICTs) to coordinate child care from the workplace. His study re-invigorated conceptualisations of materiality in the time geographical framework by drawing on Actor Network Theory. In another example of agency, ‘cocooning’ tactics that individuals employ to improve emotional
experience in space-time have been described. For example, individuals may alter their space-time paths, select one transportation option over another, employ portable media devices, solicit the company of other individuals, or wear certain articles of clothing in anticipation of exposure to unpleasant situations within the urban environment (McQuoid & Dijst, 2012).

Furthermore, time geography represents activities that drive the space-time path as overly rational and goal-oriented, a reflection of the “rather narrowly cognitive model of the decision-making subject underpinning much social-scientific work,” (McCormack & Schwanen, 2011, p. 2813). Hägerstrand originally conceived of the individual as a “forward looking animal” who tries to anticipate what lies ahead in the interest of her/his life and the lives of members of her/his family (Hägerstrand, 1970, p. 11). While this is to some extent true, and anticipation is indeed important in shaping the space-time path, more recent work across multiple disciplines suggests that decision-making should be understood less as an instantaneous event experienced by a rational actor, and more as an unfolding and unpredictable process (McCormack & Schwanen, 2011, p. 2801).

For example, in Schwanen’s (2008) study of the way Dutch parents cope with coupling constraints, a respondent, Mila, described her shifting thoughts and feelings after leaving work too late to pick up her children ‘on-time’ at the school. At first she rushed on her bicycle toward the school, and crossed the street outside of the traffic lights in order to save time: “...because of that I hit the curb stone really hard and I thought: oh, it wouldn’t be handy if I get a flat tire or fall unexpectedly. This just didn’t happen but I did feel upset. [...] In fact I took more risk at the beginning and when this had happened I thought: no, this is not smart. [...] Then I thought I’d rather arrive late, because there are other parents and they know the situation and they’ll wait, for this is not quite the first time of course,” (Respondent, Mila, In: Schwanen, 2008, p. 346). At the on-set of Mila’s journey by bicycle from work to her children’s school, she was rushing and determined to get to the school as soon as possible in order to avoid being late. As the situations she experienced unfolded in unexpected ways, however, so too did her ‘decision’ to rush to the school. This respondent demonstrates not only how malleable ideas of arrival times are, but also how decisions can be situationally-dependent, spontaneously evolving, and emotionally engaged.

A final area of weakness in the classical time geographical framework is the fundamental issue of how time and space are conceptualized within the framework. Sui (2012) has made perhaps the most concerted effort thus far to step back and take inventory of this issue. Hägerstrand’s original proposal for the time geographical framework was based on abstract ideas of Newtonian time and Cartesian space. In his often overlooked publications in the
decades after “What About People in Regional Science?”, Hägerstrand explored ways to extend the framework to embrace lived experiences of space and time beyond the framework’s original abstract understandings (Hägerstrand, 1985, 1989, 2004). He called these human perspectives on space and time “the two vistas” (Hägerstrand, 2004, p. 315):

We humans have two vistas towards which we can turn our eyes. One consists of the heavens and the other the neighbouring landscape all the way to the horizon. In the sky above, the sun, the moon and the planets regularly pass by against a backcloth of seemingly fixed stars. The view towards the heavens exhibits stability and regularity. By contrast, the most characteristic trait of the view of the earth is the immense wealth of forms and complexities through which matter spontaneously manifests itself. The paraphernalia of human culture displays similar variation. The surrounding landscape meets us as a remarkable mixture of nature and man-made things, unpredictable life forms, conflicts and compromises. That part of the world enclosed within the skin of the observer also belongs to the landscape.”

On the one hand, humans seem capable of taking a perspective on space and time that is rather distant, controlled, clear, and finite. This perspective is quite a useful one to take when scheduling a meeting, for example. It is more efficient to meet at an ‘objective 3 o’clock’ time at an easy to identify place on a street grid than a subjectively defined time within an ambiguously defined area. On the other hand, the space and time of the world accessible to us through the reach of our senses “all the way to the horizon,” and through that world “enclosed within the skin of the observer” is far more ambiguous and difficult to comprehend but just as important in how we live in everyday life. Many illustrations of this can be found with regards to time (un)certainty. The certainty introduced by real-time bus arrival signs in bus shelters can make the experience of waiting for a bus seem shorter because we worry less. Similarly, caregivers of very ill patients in remote, rural areas often relate to the distance to the nearest hospital with much anxiety because of the uncertainty of road conditions during winter weather (Castleden, Crooks, Schuurman, & Hanlon, 2010). And, lower income families’ perceptions of the uncertainty inherent to the space-time demands of social services may discourage service access (Hernandez & Rossel, 2015). In a final example, many of us can relate to the childhood memory of summer holidays from school as lasting ‘forever’, when in calendar time the break was only a matter of weeks.

Sui (2012) proposes that we might take Hägerstrand’s ‘two vistas’ and understand them in terms of the Greek manifolds of space and time. Space, then, can be understood as the following: *choros* - an area defined by Cartesian coordinates, and/or *topos* - concrete place and landscape. Time can be understood as: *chronos* - Newtonian clock/calendar time, and/or *kairos* - embedded/event time (Sui, 2012, p. 4-5). The result is a time geographical framework
that embraces nine possible combinations of space and time conceptualizations. In Sui’s review of the time geographical literature, he finds that most time geographical work thus far still falls exclusively within the choros/chronos approach to space and time. This approach, not surprisingly, is the most easily quantifiable and mappable and is popular in studies on transportation geography, ride-sharing, joint activity participation, individual movement, urban service delivery and similar topics (see among others: Miller, 2005; Neutens et al., 2011; Neutens, Schwanen, et al., 2010; Shaw, 2010; Sui, 2012).

Some time geographical studies have addressed other conceptualisations of space and time. One example is Schwanen’s (2006, 2008) work with kairos (embedded/event time) and choros (Cartesian space) in which he challenges the usually fixed conceptualization of arrival and departure times in time geographical studies. These studies examine how parents manage tight schedules around paid employment and childcare/school pick-up and drop-off. Schwanen observes that the idea of an ‘acceptable’ arrival time to pick up one’s child(ren) often varies not only between men and women because of socially prescribed notions of father/motherhood, but also varies based on unfolding contextual situations such as how many children are also still waiting to be picked up. Exclusive reliance on Newtonian clock time obscures “the significance of other temporalities to the modes in which individuals synchronize their actions with their environment,” (Schwanen, 2006, p. 883). As Schwanen’s study demonstrates, how individuals perceive and cope with space-time constraints in everyday life is more complex than the chronos and topos conceptualisations of time and space can capture.

Sui provides several other examples of time geographical studies that have attempted to integrate one or more conceptual alternatives to the Newtonian time and Cartesian space of classical time geography (Sui, 2012, p. 6-7). He argues that no time geographical studies thus far have successfully integrated all four space-time conceptualizations (choros, topos, chronos and kairos). However, Sui proposes that Schwanen and De Jong (2008) have come the closest. In this study, they draw from qualitative GIS techniques in proposing an “ethnographic or narrative space-time accessibility analysis approach,” (p. 556). They suggest that maps and time-geographic diagrams should be considered not as “instruments for achieving a totalizing master vision, but instead as sensitizing devices,” that can alert researchers to certain aspects of the spatio-temporal organization of an individual’s life by means of a necessarily partial perspective (Schwanen & De Jong, 2008, p. 561, italics are authors’). Their ethnographic space-time analysis entails a “situated quantification” (Schwanen & De Jong, 2008, p. 561, italics are authors’) in which interview material is combined with space-time analysis in GIS. Interviews were used to select situations for GIS analysis worthy of scrutiny in the eyes of participants, to
determine certain aspects of the GIS analysis (e.g., the contents of the activity program, the length of the time window, the minimum duration of activity participation, the relevant space-time constraints, the number of possible paths, the minimum time required to complete a given activity), and to interpret the outcomes of the STA modelling (Schwanen & De Jong, 2008, p. 557). With this approach, the authors explored “how physical, institutional, and moral factors circumscribe employed parents’ opportunities for juggling responsibilities that bypass the binary distinction between quantitative and qualitative research,” (Schwanen & De Jong, 2008, p. 561).

In summary, while the body of work falling within space-time geography (Schwanen & Kwan, 2012) has its origins in Hägerstrand’s classical time geography, this original framework has been challenged and further developed in recent decades. Developments within space-time geography have included improvements to the representational realism of accessibility analysis, attempts to acknowledge the roles of power relations and norms, human agency, the unpredictable process of decision-making, the embodied nature of traveling a space-time path, and efforts to integrate space-time conceptualisations beyond abstract notions of space and time, as tensions between different conceptualisations and experiences of time and space inform how we perceive and engage with the world (Schwanen, 2006). The experiential aspects of space and time become more apparent when the space-time path is understood not as the navigation course of a neutral vessel (Kwan, 2007; Rose, 1993), but as a relational and embodied human-environment relationship.

2.1.2 Space-time as rhythm

In addition to the experience of space-time as a logistical resource needed for intentional and planned courses of action, many other senses of space-time are experienced in the everyday. Because the condition of the body is so fundamental to life with chronic illness, recognition of embodied space-times is essential to understanding negotiation of everyday activities. As Crang (2001) puts it, “time-geography too often ended up dealing with the measurable and evident – indeed the mappable,” (p. 192). It is a more phenomenological, difficult to measure sense of space-time to which I now turn.

2.1.2.1 Rhythmanalysis

One way to think of embodied space-time is in terms of rhythm (Lefebvre, 1995, 2004). Lefebvre’s rhythmanalysis offers an account of the synchronic practices that are the focus of classical time geography, but foregrounds the body, allowing “spatial qualities, sensations and inter-subjective habits” (Edensor, 2010b, p. 2) to come to light. As Schwanen and Kwan (2012) observe, “rhythms unite time, space, energy/matter, and experience” (p. 2043-2044). Rhythms
are found, for example, in work schedules, seasonal patterns of influenza, the body’s hunger, shopping centre crowds, night and day. And of course, rhythms happen somewhere, but not just anywhere. Rhythms are linked to their own places, “be that the heart, the fluttering of the eyelids, the movement of a street or the tempo of a waltz,” (Lefebvre, 2004, p. 89). Within a given place (or body), multiple evolving rhythms abound (polyrhythmia), playing in harmony (eurhythmia) or in discord (arrhythmia) (Lefebvre, 2004, p. 67-68). These dynamic entanglements of rhythms are important components of the everyday contexts of people’s lives, though they are not as readily apparent as the built environment or population density, for example. Thus, rhythms yield particular power within individuals’ lives because, despite their ubiquity, they so often escape reflection and critique (Edensor, 2010b, p. 8).

For Lefebvre, time and space are inseparable, and are manifested in the lived, corporeal experience of everyday life: “[R]hythms are folded in and through a permeable body,” (Edensor, 2010b, p. 4). Instead of space and time, with Lefebvre we can speak of a united spacetime (Harvey, 2009). Lefebvre develops this conceptualisation of time and space through the notion of rhythm; the rhythms of bodies, cities, families, capital, work, lunar cycles, and holidays, for example. Rhythm emerges through movement (or becoming), repetition, and difference: “For there to be rhythm, strong times and weak times, which return in accordance with a rule or law – long and short times, recurring in a recognizable way, stops, silences, blanks, resumptions and intervals in accordance with regularity, must appear in a movement. Rhythm therefore brings with it a differentiated time, a qualified duration,” (Lefebvre, 2004, p. 78).

Absolute repetition, meaning an identical replication of what came before, is a fiction of mathematical and logical thought. For example, the equation A=A must be corrected by the simple fact that the second A differs from the first because it is second (Lefebvre, 2004, p. 7). So, we can say that rhythms are manifested in the lived, corporeal experience of movement and repetition with difference in everyday life.

In the everyday, as in one’s own body, it is difficult to grasp the relationships of rhythms to one another because we live through them and live by them. However, we can become more aware of everyday rhythms by ‘stepping out of them’, into an overseas holiday, for example. Similarly, an individual experiencing a temporary heart murmur may be aware of the ‘normal’ rhythmic beating of their heart in a way they had never experienced before. So, a disruption of the relationships of rhythms provides an opportunity to observe rhythms and their relationships with one another. Similarly, a description of one rhythm and its characteristics is only possible when contrasted with another rhythm (Lefebvre, 2004, p. 10).
For example, we can only speak of the speed, frequency or consistency of a rhythm relative to another rhythm. The growing season of alpine plant communities within the rhythms of snowfall and temperature change in the mountains is ‘short’ only in comparison to year-round plant growth in the tropics.

One can focus on an immense variety of rhythms and their relationships, and “rhythmanalysis is particularly useful in investigating the patterning of a range of multiscalar temporalities - calendrical, diurnal and lunar, lifecycle, somatic and mechanical - whose rhythms provide an important constituent of the experience and organisation of social time,” (Edensor, 2010b, p. 1). For example, the everyday is shaped in part by the certain rhythms associated with social practices, as “every ‘doing’ has its time,” (Lefebvre, 2004, p. 74). Rhythms of social practice can be examined alongside, for example, rhythms of the body. The arrhythmia resulting from the subjugation of circadian rhythms of the body to the rhythms of night shift work offers insight into the different characteristics of these two rhythms; the former having a cyclical nature which involves renewal and the latter a linear nature of unceasing repetition.

Lefebvre also speaks of appropriated time: “... a time that forgets time, during which time no longer counts (and is no longer counted). It arises or emerges when an activity brings plenitude, whether this activity be banal (an occupation, a piece of work), subtle (meditation, contemplation), spontaneous (a child’s game, even one for adults), or sophisticated. This activity is in harmony with itself and with the world,” (p. 76-77). Lefebvre’s description of this experience of time resonates with the concept of flow, as advanced by Csikszentmihalyi (2000). Csikszentmihalyi uses the concept of flow to refer to “... a state of optimal experience that people report when they are intensely involved in doing something that is fun to do,” (2000, p. 381). In both accounts, this experience of time defies quantification, and brings a sense of satisfaction and pleasure.

Lefebvre suggests several categories (concepts) and oppositions that may be useful in analysing rhythms: Repetition and difference; mechanical and organic; discovery and creation; cyclical and linear; continuous and discontinuous; quantitative and qualitative (Lefebvre, 2004, p. 9). Through analysis, different kinds of rhythms – such as cyclical rhythms of the body or the seasons and linear rhythms of working hours or traffic lights - can be differentiated from one another, “but in reality interfere with one another constantly,” (Lefebvre, 2004, p. 8). This point is especially relevant to research on everyday life. Different kinds of rhythms are lived together, sometimes blending easily and sometimes creating incredible tensions in the lives of individuals, and ideally should not be examined in isolation. Most often, classical time

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geographical analysis selects for analysis the rhythms of clock time (e.g., work schedules) from the bundles of rhythms in individuals’ lives, and examines this sense of space-time as if existing independently from the rest.

More recent space-time geographical research, however, has shown how other rhythms, for example the rhythms of child-caring and children’s bodies, will lean into and disfigure the predictably linear rhythm and presumed universality of clock time for parents (e.g., Schwanen, 2006), demonstrating how different senses of space-time mingle, muddle and change as they are lived through the body in the everyday. Furthermore, while rhythmmanalysis “recognizes consistencies, repetitions and reproductions, moments of quietude” (Edensor, 2010b, p. 18), rhythms are very much open to change, mutation, growth and decay, difference as well as repetition (Crang, 2001; Edensor, 2010b, p. 13-14; Lefebvre, 2004). Therefore, while the rhythmic bundles individuals experience in everyday life are available for examination and characterisation, they are always fields of potential for change and transformation in the human-environment relationship.

2.1.2.2 Developments and applications of rhythmmanalysis
Human geographers have increasingly engaged with the concept of rhythm over recent decades, largely inspired by the writings of Lefebvre (see, as an exception, Henriques, Tiainen, & Väliaho, 2014). *Geographies of rhythm: Nature, place, mobilities and bodies* (Edensor, 2010a) offers a collection of works inspired by rhythmmanalysis (see also Crang, 2001; Edensor, 2010c; Edensor & Holloway, 2008; Kärrholm, 2009; McCormack, 2002; Schwanen, van Aalst, Brands, & Timan, 2012; Simpson, 2008; Vergunst, 2010). Many of the recent explorations of rhythm in human geography have been concerned with the rhythms of urban life. Crang (2001), for example, discusses the city as “an assemblage of different beats,” (p. 189) where a multiplicity of open and emergent rhythms interplay with one another. Urban times help shape the aesthetics of particular urban places (e.g., Fitzroy Square in London or Times Square in New York); these are intersubjective, place-specific, sensual, affective, and rhythmically expressive (Wunderlich, 2010). Gentrification of a neighbourhood, a form of urban transformation, can be examined in terms of rhythmic change, or shifts in “consumption of sensory rhythms: textures, sounds, smells and even tastes,” (Degen, 2010, p. 30). The inequalities of gender and race/ethnicity in consumption patterns of night-time economies (Schwanen et al., 2012), and practices of urban outreach workers (Hall, 2010) have also been examined through analysis of rhythms in urban environments. In a final example, rhythmmanalysis has been employed to examine the force of outdoor advertising in making and
re-making urban space, characterised as a “space of commodity rhythms” (Cronin, 2006, p. 615).

Others have drawn attention to relationships between rhythms circulating within human bodies and those of non-human organisms and objects. Insomnia provides an example of a corporeal rhythm marked deviant in relation to ‘normal’ sleeping patterns following day and night, and in relation to the “repetitive structure and institutions of everyday life,” (Meadows, 2010). Equestrianism has been discussed in terms of the “rhythmical structures and practices which make up the experience of horse riding” (Evans & Franklin, 2010, p. 173). According to this account, the relationship between horse and rider has the potential for “active unity of human and non-human” where “moments of rhythmic harmonisation” are one of the main goals of the horse rider, even if occurring fleetingly, rarely and only after significant investment in practicing (Evans & Franklin, 2010, p. 173). Spinney (2010), too, examines rhythmic relationships between humans and non-human entities; in this case the improvisational rhythms of urban cyclists who weave in and out of traffic, oriented to the world as bike-rider hybrid bodies. The author argues that urban cyclists are not simply defiant traffic rule breakers, but rather are “oriented differently to the material and immaterial affordances of the urban environment” as compared to car-driver hybrid bodies, and thus many engage in “a process of making do which involves improvising rhythms in order to navigate the city,” (Spinney, 2010, p. 119). This type of work highlights the permeability and mutual transformability of human rhythms and the rhythms of everyday contexts.

The rhythms of different forms of mobility have also been investigated. For example, the many rhythmic qualities of a coach tour can be understood as “part of the production of tourist identities, products and experiences,” (Edensor & Holloway, 2008, p. 499). The evolution of pedestrian rhythms over time can be traced, as seen in the advent of motorised vehicles and subsequent disciplining of pedestrian movements via sidewalks and crosswalks to keep pedestrians off the road (Hornsey, 2010). Distinct rhythms of walking contribute to the (re)production of place (e.g., the purposeful strides of an urban morning commuter in a CBD) (Edensor, 2010c). Edensor (2010c) proposes that different walking rhythms come about through “habitual interaction with spaces, nodes and paths,” “regulatory strategies through which walking is disciplined,” and “the material and organisational production of space and the stylisation” that may restrict walking practices (p. 77-78).

In short, rhythms abound in everyday contexts. They occur at multiple scales, influence one another, and shape and are shaped by human and non-human activities. The rhythms in a person’s everyday contexts and body have the capacity to increase or decrease the level of
effort required to perform everyday activities, and this may be especially relevant for individuals with chronic illness. For example, the states, capacities, and needs of the ill body may introduce particular rhythms into everyday life. Patterns of change in body states over a given period may be usefully conceived as body state rhythms, as in fluctuations in energy levels, mental clarity, or pain experienced by many with chronic illness.

When framed this way, the rhythmic characteristics of embodied experiences of chronic illness may be examined in relation to rhythmic characteristics of everyday contexts and other areas of a person’s life in order to identify arrhythmias. For example, unlike the fairly predictable energy decline most workers experience from Monday to Friday, workers with chronic illness may experience more unpredictable body state rhythms. Dyck’s (2002) account of the working experiences of women with multiple sclerosis highlights the uncertainty these individuals can experience regarding how well or ill their body will feel on any given day, meaning that planning and committing to future activities can be difficult. Unpredictable rhythms may clash with the demands of a standard working week, increasing the effort required to meet employer expectations, as well as worry and stress in anticipating such arrhythmias. In another example, the relationship between the human body and the dialysis machine through the course of dialysis treatment may lead to transformations in everyday rhythms, such as the rhythms of the body or the rhythms of routine activities.

When considering the often intense experiences people have with rhythms that circulate within and between their body and its surroundings, there is an obvious connection wanting to be made between rhythm and the spatiality and temporality of emotion. As Bondi, Davidson, and Smith (2005) have argued, geographical thought must resist the temptation to simplify emotions as objects or artefacts of study, but instead to embrace emotions as “relational flows, fluxes or current, in-between people and places” (p. 3). Rhythms are similarly dynamic, in that they cannot be bracketed off as ‘things’ in and of themselves that are easily located in space. Instead, they arise and decay in and through processes, movements, interactions, and repetitions of the shifting materialities of bodies and places.

Geographers of chronic illness and disability have been among the first geographers to openly engage with concepts of emotion within their work (Bondi, Davidson, and Smith, 2005, p. 4) See, for example, Dyck’s (1999) account of chronically ill women’s feelings of exclusion in the workplace. Arguably, this early engagement with emotion is due in great part to the ways in which chronically ill individuals experience the changing relationship of their body to their environment due to illness, which gives rise to emotional experiences including those of limitation, suffering, and loss (see Chapter 3 for more discussion on everyday life with chronic
illness). An analysis of the space-time resources and rhythms experienced by individuals with chronic illness may further elucidate how and why different emotions arise in everyday life and help to shape the chronic illness experience.

2.1.3 ‘Doing’ the everyday

2.1.3.1 Practice

As noted above (Chapter 2.1), different senses of space-time, such as those of space-time as a resource and space-time as rhythm, are often brought about through different domains of human practice (Adam, 2004, 2013; Crang, 2001; May & Thrift, 2001). And, as explored in the sections above (Chapters 2.1.1 and 2.1.2), different senses of space-time influence how people experience the performance of everyday activities, different places, relationships with non-human entities, and everyday mobilities, including feelings of being rushed, stuck, absorbed, relaxed, or ‘on-the-ball’. These feelings, in turn, influence what people do. For example, this may manifest in prioritising some activities at the expense of others (e.g., letting a hobby fall by the wayside in order to maintain paid work), or, conversely, introducing new activities into everyday life (e.g., a new exercise regimen).

Below, I briefly outline the notion of practice as explored by Shove, Trentmann, and Wilk (2009a) in order to better conceptualise the relationships between everyday activities and spatio-temporal contexts for people with chronic illness. The concept of practice places the individual’s behaviours within a broader societal and historical context of socially acceptable ways of ‘doing’ the everyday, and brings attention to how individuals’ patterns in time and space are reproduced in everyday life.

Practice can be defined as “a temporally unfolding and spatially dispersed nexus of doings and sayings,” (Schatzki 1996, p. 89 ln: Shove, 2009, p. 18). This perspective is concerned with what and how people do; their routines, ruptures in routine, and so forth. Practices require active reproduction and performance, shaping much of everyday life: “Since people engage in many practices (during a day, a year or a lifetime), any discussion of the temporal texture of everyday life has to take into account how practices intersect in time and space,” (Shove, 2009, p. 18).

Place is obviously important in how a practice can be ‘acceptably’ performed according to normative convention. Performance artists, for example, often take advantage of the place-(in)appropriateness of practice by, for example, offering an experience of absurdity in coming across a man bathing, as if at the beach, in a public fountain. Timing is also frequently important in how a practice is ‘done right’. Shove gives the example of eating a meal ‘in order’ and at the right time of day, as well as the great emphasis on timing needed for proper
preparation of a meal. Attention to practice as a fundamental driver of the individual’s space-time path assists time geography in overcoming some of the framework’s short-comings, especially Giddens’ (1984) criticism of time geography’s lack of attention to the individual’s social context and the origins of their projects.

Practice both uses and makes time and space. While practice consumes time in the sense that one has to allow more time for an eight pound beef roast to cook than a steak, many of the everyday conceptions we hold of time are constructed through practice: "[...] infrastructures of objective time - the day, the week, the morning routine, the annual holiday - are made so because they are made by distinctive kinds of practice," (italics are author’s) (Shove, 2009, p. 19). One example might be the egg-timer. It is precisely the ‘correct’ practice of cooking a whole egg (in water; not too hard, not too soft) that determines the temporal parameters of this object which is used as an objective point of reference in many other cooking projects, board games, and other activities.

Shove refers to the "embedded conventions of duration, sequence and timing associated with the competent performance of a practice” as practice-time profiles (Shove, 2009, p. 25). Similar to time, practice both takes up and creates space. For example, it is understood that a football team will take up much more space to practice than a yoga class. Practices also create certain kinds of spaces. For example, areas where the practice of using automotive transportation is dominant one usually finds a landscape with plenty of broad, multi-lane paved roads. Similarly, in societies where sitting on the floor of a building is not commonly acceptable, one finds rooms with furniture built to support bodies about a knee’s height off the floor.

At the societal as well as individual scale, practices compete for time, with some eventually nudging others out (Shove, 2009, p. 19). Shove gives the example of the ‘competition’ between gardening and television watching for the ‘prime time’ evening attention of men in the 1950s (Shove, 2009, p. 22). The introduction of new practices and fading away of the old often occurs, in part, through deliberate efforts to structure people’s routines and habits. For example, the notion of ‘prime-time TV’ is an outcome of conscious programming decisions by producers in conjunction with a co-evolving convention of gravitating toward the couch and TV at certain times of the day (Shove, 2009, p. 26).

In observations of changes in practice-time profiles at the societal scale, many authors have observed the seemingly apparent ‘speeding up’ of society, and have examined how arrangements previously ‘not done’ (e.g., the working lunch, eating ready-made meals) or very infrequently done (e.g., taking a day trip from London to Brussels) have become more the
norm. Shove suggests that instead of concluding that society is somehow ‘faster’ than ‘before’, it is more useful to pay attention to the way practices shift in new combinations and configurations that revolve around infrastructural affordances like those associated with mobile technologies or faster means and modes of travel (e.g., commuting, multi-tasking, day tripping) (Shove, 2009, p. 26).

The coordination of practices is a big part of everyday life for individuals, and the subject of several recent space-time geographical studies (e.g., Schwanen, 2006; Schwanen & De Jong, 2008). Some forms of coordination and synchronisation of practices come about through a socio-temporal order existing beyond the individual level at the collective level. We can take as examples the use of the Gregorian calendar and the elaborate international system of time-keeping that keeps clocks coordinated around the world. The national declaration of certain calendar days as working holidays is another example. Other practices require much deliberate planning and intervention on the part of individuals in order to assure their completion. For example, sharing child caring responsibilities with a partner with a rotating work schedule can require a proliferation of ‘family calendars’ and on-the-fly mobile phone coordination. Shove notes that the proliferation of autonomy between individual schedules and the proliferation of convenience devices observed over the past decades in wealthier countries is likely to increase the effort required to arrange the bringing together of people in the same place at the same time (Shove, 2009, p. 24).

2.1.3.2 Habit

Much of everyday practice is habitual in nature, and there is an intimate relationship between the habits a person forms and the everyday practices typical of a person’s environment (Ehn & Lofgren, 2009). Everyday life would be very difficult without the force of habit. Without it we would have to be mindful of every detail and every action that we normally take for granted in everyday living, such as assembling a coffee maker, brushing teeth, or finding car keys. Without the force of habit, life would be “an endless flow of calculated choices” (Wilk, 2009, p. 144). Ehn and Lofgren (2009) examine the habitual nature of everyday routines, noting that habit is “anchored in our bodies” (Ehn & Lofgren, 2009, p. 106), constituting part of who we are as individuals, and containing “constant possibilities of transformation,” (Ehn & Lofgren, 2009, p. 101). Furthermore, habit is “deeply embedded and encoded in our built environment and possessions” (Wilk, 2009, p. 146).

Habit plays an important role in the ability to adapt to and negotiate everyday life within different environments with minimal effort and attention, leaving room for other things like planning, reflecting, day dreaming, and experimenting. The way we conceptualise habit,
Therefore, will inform our understandings of chronically ill individuals’ experiences negotiating everyday activities (e.g., chronic illness management) within various spatio-temporal contexts, and provide insight into the ongoing, mutual transformation occurring between a person with chronic illness and their environment over time. I employ the notion of habit in my approach in order to understand how the things a person does (e.g., eating certain foods) can become part of who they are (e.g., a person who prefers certain foods), and how new, challenging activities or experiences can become effortless, taken-for-granted parts of everyday life (e.g., integrating a new medication schedule into everyday routines).

I draw on recent developments in geographical thinking on the nature of habit, which build on the work of Ravaisson and others in the vitalist tradition. Felix Ravaisson’s *Of Habit* (2008), originally published in 1838, provides an understanding of the nature of habit as a way of being, not just for humans, but for all living things throughout the natural world. For my purposes, I will focus on aspects of his discussion pertaining to humans. In this tradition, habit is understood as a force permeating life, which provides humans with a “generalised propensity for change” (Sharpe, 2013, p. 169) that allows a person’s past experiences to “act to anticipate” what may be required of the individual in future situations (Grosz, 2013, p. 220).

The force of habit is neither ‘good’ nor ‘bad’. It is simply part of being human. Mundane routines, tics, and helpful and harmful habits, such as smoking, using a computer, humming while working, and going for daily walks, all have “exactly the same source in the development of bodily intelligence,” (Sharpe, 2013, p. 169). This way of thinking about habit contrasts with the work of Descartes, Kant, Sartre, Durkheim, and Weber who conceived of habit as a mechanism that arrests and inhibits consciousness, thought and freedom (Grosz, 2013; Wilk, 2009). These theorists associated rationality and choice with liberation and freedom (Wilk, 2009), while the vitalist tradition thinks of habit as expressing a human being’s openness to the future, and connection to the past (Grosz, 2013, p. 224).

The heart of Ravaisson’s discussion on habit is the ‘double law’ of habit. The conscious mind, or the will, forms a goal, such as playing a musical instrument, and puts this goal into action through voluntary movement, which is enabled by sensations, knowledge, perception and judgment. Through repetition of the action, perception is ever sharpened and less effort is required for the action. All the while, and proportionately, the original sensations associated with the action diminish because we find less contrast between what we now sense and what we have sensed. The action moves further and further from consciousness into the unconscious ‘intelligence of the body’. The action in the body is ‘intelligent’ because it remains
imbuéd with the original goal of the mind. The body carries out the action with less and less mediation from the conscious mind.

Loss of consciousness of the action is due to the loss of effort to perform the action that slips away with repetition or continuity. This is because an individual is aware of themselves – is conscious – through effort and through feeling resistance to themselves: “Effort is therefore not only the primary condition, but also the archetype and essence, of consciousness,” (Ravaisson, 2008, p. 43). As the resistance or effort required to perform an action fades, the conscious mind loses its grasp on the action; its ability to reflect. This process explains why teaching something we are good at to someone else can be difficult. This is because habit has allowed the action to move far into the body and away from conscious thought; it has become an embodied intelligence. When teaching, we have to ‘pull’ this action back into consciousness and ‘relearn’ what we already know in the body, enabling us to reflect on our actions.

As demonstrated in the example of the musical instrument, while the original pleasurable sensations associated with first playing the instrument, such as the novelty of hearing the instrument create a tone, diminishes with repetition, the individual experiences more and more of a different form of pleasure. This pleasure is derived from the new, sharpened perception and skill the person has acquired for playing the instrument. Mastery is achieved, and the conscious mind has more capacity to engage with other perceptions and actions.

Ravaisson understands habit as a path for conscious beings to experience something akin to instinct, which he calls second nature. His thought is that as one moves up the hierarchy of beings, freedom of activity and consciousness increase. At the same time, there is greater mediation between the organism and its desires, and instinct weakens. Habit provides the conscious being with a way to get as close to instinct as possible: “Like habit, instinct is the tendency towards an end without will and distinct consciousness. Only, instinct is more unreflective, more irresistible, more infallible. Habit draws increasingly near to, perhaps without ever attaining, the reliability, necessity and perfect spontaneity of instinct,” (Ravaisson, 2008, p. 57). Habit, in Ravaisson’s thinking, exists as a kind of liaison between Nature and Will, pulling conscious beings back and forth along a continuum of the two extremes.

Ravaisson’s theory of habit ultimately addresses the very idea of being human. Habit is not just a state of the organism, but a “disposition, a virtue,” (Ravaisson, 2008, p. 25). When an idea of the conscious mind is put into action, and this action is eventually taken over through habit by the intelligence of the body, leaving the realm of consciousness, this idea of
the mind becomes a way of being; a part of the individual. In Ravaisson’s words: “The idea becomes being, the very being of the movement and of the tendency that determines it,” (Ravaisson, 2008, p. 55, italics are Ravaisson’s). Being and thought become one, and, thereby, Ravaisson rejects the body-mind dualism.

Recent work in geography has built on these foundations to try to develop an ecological understanding of habit as a “creative and unpredictable process through which bodies and environments mutually evolve and take shape,” (Bissell, 2013, p. 121). Or, put another way, “habits are how environments impact and transform the forms of life they accommodate and are themselves impacted and transformed by these forms of life,” (Grosz, 2013, p. 219). An important shift in the conceptualisation of habit is seen here, as 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. In other words, the observable patterned behaviours of everyday living may be better understood not as the collection of many habits in sequence, but rather as behavioural traces of the much more general force at work within the body-brain-environment circuit of habit (Bissell, 2013).

Comprehension of the challenges of everyday life with a chronic illness, then, such as coping with increasing complexity of illness management activities, must account for and investigate the force of habit as a way of being that is plastic and open to transformation, and intimately related to everyday practices and space-time environments. For example, a person can become accustomed to a renal diet over time and no longer miss having things like salt on their food or drinking alcohol. As part of this effort their household may stop buying salt and alcohol, changing the way other household members eat and drink as well. Understanding habit in this way puts the power of the conscious mind to influence the behaviour and decisions of individuals into perspective. And, it helps us to understand the conditions under which individuals are more likely to be able to adapt to change, such as starting diabetes self-management, losing the ability to walk, or moving house, and find a sense of stability (Grosz, 2013).

2.1.4 Space-time, practice, and habit
In summary, the approach I take in this thesis recognises that space and time, or space-time, are inseparable, and that multiple dimensions of space-time are experienced in everyday life. I draw from literature exploring lived experiences of different senses of space and time. I focus on the experience of space-time as a resource needed for everyday activities that are often governed and coordinated by clock time and the practicalities of getting from one location to another (e.g., making a doctor appointment ‘on-time’). I also focus on the embodied,
emotionally infused experience of space-time as bundles of dynamic and interacting rhythms within everyday contexts and the body (e.g., circadian rhythms and workplace demand cycles). Literature from social practice helps me understand how different senses of space-time are shaped through, and shape, everyday living. Finally, I understand the habitual nature of everyday life through the tradition of thought on habit that understands habit as open-ended plasticity allowing for mutual transformation between individuals and their environments.
Chapter 3 - A Review of Everyday Life with Chronic Illness

3.1 About chronic kidney disease
3.1.1 Characteristics
3.1.2 Risk factors and causes
3.1.3 Management

3.2 Potential contributions of a space-time approach to understanding everyday life with chronic illness
3.2.1 Patient self-management of chronic illness
3.2.2 Paid work participation
3.2.3 Caregiving and family
3.2.4 Leisure, recreation, and tourism

3.3 Chapter summary

In this chapter, I provide more information about chronic kidney disease; its characteristics, risk factors, and management. Then, I present four potential areas of contribution of my space-time geographical approach to understanding everyday life with chronic illness: 1) patient self-management of chronic illness; 2) paid work participation; 3) caregiving and family; and 4) leisure, recreation, and tourism. The dominant approaches to understanding each of these aspects of everyday life for people with chronic illness are presented. Then, I explore the spatio-temporal characteristics of each aspect of everyday life in order to demonstrate the usefulness of my space-time geographical approach for understanding each of them. I conclude with a chapter summary.

3.1.2 About chronic kidney disease

Characteristics

The kidneys are bean-shaped organs located in the back of the torso, above the waist and below the ribs, and are about the size of an adult fist. The main function of the kidneys is to remove wastes and excess water from the body by continuously filtering the blood stream and expelling excess quantities through the bladder in the form of urine. They not only remove excess substances and waste during the filtering process but also reabsorb vital substances such as glucose back into the bloodstream. Another important function of the kidneys is to
produce certain essential hormones (Green & Ryan, 2009; National Institutes of Health, 2012). When the kidneys are not efficient in performing these functions, waste and fluid builds up in the body and key hormones are not produced, creating serious complications.

The disease progresses slowly and has a five stage classification system. Stages 1 and 2 are defined by evidence of kidney damage, but are usually asymptomatic. In stage 3, substantial kidney function loss and signs of dysfunction in other organs is common, although symptoms may still not arise (Green & Ryan, 2009; National Institutes of Health, 2012). By stage 4, the individual experiences relatively mild symptoms shared with many other chronic illnesses, such as general ill feeling and fatigue, headaches, nausea, and weight loss (National Institutes of Health, 2012). More severe symptoms appear as kidney function decreases further, including bone pain, drowsiness or problems concentrating, numbness or swelling in hands and feet, muscle twitching or cramps, shortness of breath, sleep problems, and vomiting (National Institutes of Health, 2012). Many of these symptoms are not readily visible and fluctuate in intensity over the long as well as short-term; “hallmarks of the chronic illness experience” (Crooks et al., 2008, p. 884) shared with other chronic illnesses such as multiple sclerosis (Dyck, 2002) and fibromyalgia (Crooks, 2007a). In stage 5, a range of these symptoms is usually experienced, and the function of other organ systems is often affected. End Stage Kidney Disease (ESKD) refers to the point at which the kidneys are no longer able to remove enough waste and excess fluid to keep the body alive. At this stage, the individual requires either on-going dialysis treatment or kidney transplant (Green & Ryan, 2009, p. vi).

One common complaint of individuals living with CKD is extreme fatigue from anaemia, a shortage of red blood cells. This is due to the kidneys’ inability to produce erythropoietin (EPO), a hormone that signals bone marrow to make red blood cells. As red blood cells carry oxygen, a lack of red blood cells causes the individual to become tired much faster, even doing routine activities like climbing stairs. Other symptoms of anaemia that individuals with CKD can experience are muscle weakness, shortness of breath, pale skin, gums, and fingernail beds, feeling dizzy or lightheaded, feeling cold when others are not, erectile dysfunction in men, changed menstrual cycle in women, and pica (a desire to eat non-food items like ice, dirt, laundry starch, or clay) (The National Kidney Foundation, 2012). Cognitive impairment is another symptom of anaemia and is common among individuals with CKD. Cognitive impairment is often undiagnosed in people with ESKD and may accompany earlier stages of the disease, becoming more prevalent as kidney function fails. As many as two-thirds of dialysis patients may have moderate or severe cognitive impairment, a substantially higher rate than that found in the age-matched general population (Sorensen et al., 2012, p. 417).
Even mild cognitive impairment increases the likelihood of mortality, hospitalization, and health care resource use among CKD patients. Cognitive impairment also affects patient decision-making and self-care, including modifying dietary habits and adhering to complicated medication regimes, and is associated with poor quality of life and decreased emotional well-being (Post et al., 2010; Sorensen et al., 2012, p. 417).

Aside from anaemia, the kidneys’ diminished ability to remove excess water and toxins from the body through urination also produces several serious and uncomfortable complications. Firstly, individuals with CKD often experience swelling (oedema) in the feet, ankles, legs, face, and/or hands. As the kidneys become less able to remove water through urine, extra water can build up in the body, producing swelling or puffiness. In some cases fluid can build up in the lungs, making breathing difficult. A second effect of the kidneys’ reduced ability to remove excess water and toxins is changes in urination. This can be experienced as difficulty urinating, urinating markedly more or less often, making more or less urine than usual, getting up at night to urinate, and/or changes in urine appearance (colour, consistency).

Thirdly, a major complication of reduced kidney function is the build-up of toxins in the body (uraemia), resulting from the kidneys’ diminished ability to filter the blood and flush toxins from the body through urine. Uraemia can result in skin rashes, itchy skin, nausea and vomiting, loss of appetite (especially for meats/protein), a metallic taste in the mouth, bad “ammonia” breath, and weight loss from loss of appetite. And finally, some people with CKD have pain in the back or side of the torso on the side of the affected kidney (The National Kidney Foundation, 2012). Along with anaemia, oedema and uraemia and associated symptoms outlined above, CKD patients often have greater rates of depression than the general population, especially among those with ESKD requiring dialysis (Browne & Merighi, 2010; Chilcot, Wellsted, & Farrington, 2010; Green & Ryan, 2009; Sukolsky, 2004).

3.1.2 Risk factors and causes

While there are many causes of damage to the kidneys resulting in CKD, including birth defects, autoimmune disorders, viruses, and certain drugs, the most common causes are diabetes and high blood pressure (National Institutes of Health, 2012). Several decades ago, one of the leading causes of chronic kidney disease worldwide was glomerulonephritis, an inflammation of very small blood vessels in the kidney caused primarily by infections and immune diseases. Over the past several decades the underlying pathogenicity of CKD in wealthier countries seems to be shifting away from infections, and toward behavioural risk factors (Zhang & Rothenbacher, 2008). Evidence has also accumulated to implicate obesity as
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an independent risk factor for CKD and the development of ESKD requiring renal replacement therapy (MacLaughlin et al., 2010, p. 69).

In Australia, the causes of illness and disability, in general, have shifted away from infectious diseases to chronic illnesses, especially those influenced by lifestyle and behaviour, and chronic kidney disease is one such example (Green & Ryan, 2009). Australians with diabetes have more than double the chance of being diagnosed with CKD than those without diabetes (14.2% compared to 6.6%), and individuals with cardiovascular disease have almost double the chance of developing CKD than those without it (10.2% compared to 6.4%) (Green & Ryan, 2009, p. 7). Evidence suggests that, worldwide, diabetes and hypertension are now the two major causes of kidney disease (Zhang & Rothenbacher, 2008). The major risk factors for CKD can be grouped into three broad categories: (1) Fixed – family history and genetics, increasing age, previous kidney disease or injury, low birth weight, male sex; (2) Behavioural – tobacco smoking, physical inactivity, poor diet; and (3) Biomedical - diabetes mellitus, hypertension, cardiovascular disease, overweight and obesity, systemic kidney inflammation, metabolic syndrome (Green & Ryan, 2009; Stengel, Tarver-Carr, Powe, Eberhardt, & Brancati, 2003; Tsai et al., 2010).

3.1.3 Management

While CKD cannot be cured, its progression can often be slowed by working with modifiable risk factors such as smoking, exercise, nutrition, weight, diabetes and high blood pressure, and by improving disease treatment and management (Green & Ryan, 2009). A behavioural regimen for an individual with CKD often includes diet and fluid intake restrictions, physical exercise, weight reduction/maintenance, smoking cessation, management of co-morbid conditions like diabetes and hypertension, the highest pill burden of all chronically ill individuals, and dialysis or kidney transplant for those in ESKD (Browne & Merighi, 2010, p. 547; Levin et al., 2008).

Following a renal diet is important for individuals with CKD in order to reduce stress on the kidneys. A renal diet is often low in protein (especially meat-derived protein), fat, salt, sugar, and potassium (The National Kidney Foundation, 2012). Dietary requirements vary from patient to patient depending on things like the presence of co-morbid conditions like cardiovascular disease and high blood pressure, and the stage of CKD the person is experiencing. The only constants in renal diets between individuals with CKD are limitations on salt and fat (Kidney Health Australia, 2009). In the earlier stages of CKD when the kidneys are still functioning fairly well, the dietary focus is to lose weight if the person is obese or
overweight, or to maintain a healthy weight, and to thereby manage or prevent co-morbid conditions such as hypertension and diabetes (Levin et al., 2008). The purpose of dietary restriction in these stages is mostly preventative, aimed at slowing the loss of kidney function. In later stages of CKD, the damage of the kidneys limits the ability of the body to purge excess quantities of water, potassium, and other substances. At this stage, the diet has the same preventative goals of earlier stages of CKD, but with additional restrictions on fluid, potassium, and protein, due to the reduced ability of the kidneys to purge excess quantities of these substances from the body. Limits on fluid intake for dialysis recipients represent one of the most challenging aspects of the haemodialysis treatment regimen for patients (Sharp, Wild, Gumley, & Deighan, 2005).

CKD patients are strongly encouraged to reach and maintain a healthy weight. Obesity exacerbates co-morbid conditions like diabetes, cardiovascular disease, and hypertension which ultimately increases the comorbidity-adjusted relative risk of developing end-stage renal disease (MacLaughlin et al., 2010). Kidney transplantation is also clinically more challenging in obese patients due to increased risks such as delayed graft function (Jindal & Zawada, 2004; MacLaughlin et al., 2010).

Exercise is encouraged in order to improve or maintain cardiovascular health, lose weight or maintain a healthy body weight, improve physical functioning and reduce mortality risk among CKD patients (Delgado & Johansen, 2012). Thirty-to-sixty minutes of moderate-intensity exercise, four-to-seven days per week, in addition to muscle strengthening, flexibility and balance exercise tailored to the individual is recommended (Johansen & Painter, 2012; Levin et al., 2008, p. 1158; Toyama, Sugiyama, Oka, Sumida, & Ogawa, 2010).

For those with diabetes in conjunction with CKD, everyday chronic illness management includes taking additional medications for diabetes, monitoring blood glucose levels, following a diabetic diet, engaging in regular exercise, and caring for their feet (Heisler, Smith, Hayward, Krein, & Kerr, 2003).

Medication regimens are a big part of managing CKD and co-morbid conditions like diabetes and hypertension. This is especially true for those who have reached ESKD, as haemodialysis patients have the greatest pill burden of all chronically ill individuals (Browne & Merighi, 2010, p. 547). The most common oral medication taken daily by haemodialysis patients is phosphate binders, which are taken with meals to reduce the absorption of phosphorus that unhealthy kidneys are not able to flush from the body. Too much phosphorus can cause serious bone disease. Phosphate binders must be taken about 10 minutes before eating food containing protein and they should not be taken with foods that do not contain
protein. Therefore, more phosphate binders may be taken with certain meals than with others, and the patient must keep track in order to make sure a certain total number have been taken over the course of the day. The most common side effects of phosphate binders are constipation, diarrhoea, feeling sick, and a chalky taste in the mouth (National Kidney Federation, 2012). In addition to phosphate binders, haemodialysis patients often take numerous medications every day to control bone disease, cardiac illnesses, high cholesterol levels, infections, endocrine-related disorders, thrombosis, mental illness, sleeping disorders, restless legs syndrome, and gastrointestinal conditions. Additional daily oral medications may include vitamins, analgesic, and antipruritic medications. In total, these add up to least ten oral medications taken by dialysis patients at home to control kidney disease progression and comorbid illnesses and related symptoms (Browne & Merighi, 2010, p. 547).

Those with ESKD must start dialysis in order to survive and/or await a kidney transplant. Two main modalities of dialysis are typically available: haemodialysis (HD) and peritoneal dialysis (PD). The most common form, haemodialysis, is performed by a machine that serves some of the functions of the kidneys by removing toxins and waste from the blood by running the individual’s blood through the machine and back into the body. This procedure is typically done for three to six hours per day, three days per week at a satellite dialysis centre or hospital. With training, haemodialysis may also be performed at home by the patient, however this is less common. In these cases, dialysis may be performed during the day, or at night as in nocturnal home haemodialysis (Green & Ryan, 2009).

Peritoneal dialysis removes toxins from the body by cycling a fluid through the abdomen and back out again through a catheter that is installed in the individual’s abdomen. This modality is undertaken at home. There are two types of peritoneal dialysis: continuous ambulatory peritoneal dialysis in which a number of exchanges of fluid to and from the abdomen are performed each day, and nocturnal peritoneal dialysis. Nocturnal PD is performed overnight while the individual sleeps, offering some lifestyle advantages, especially for employed patients who can less easily spend time at the dialysis clinic during the day (Green & Ryan, 2009).

Dialysis treatment is often very disruptive for the lives of CKD patients and their family members. Dialysis performed during waking hours takes a lot of time away from daily and weekly activities and can lead to "major changes in established patterns of social and economic participation," (Chilcot et al. 2008 In: Green & Ryan, 2009, p. 19). Family relationships may also be altered if family members step-in to act as caregivers. Dialysis is also associated with physical complaints from vascular access sites and associated infections.
While kidney transplant is arguably the ideal response to ESKD, the shortage of donors, both living and deceased, means that this is an option for less than one third of patients facing ESKD in Australia (Green & Ryan, 2009). This trend of donor shortages is a worldwide problem as increasing numbers of individuals need a kidney transplant. A kidney from a deceased donor who has suffered brain or cardiac death is a first option for which the average waiting time in Australia is three to four years (Green & Ryan, 2009, p. 14). The waiting time for an expanded criteria donor, meaning a donor over the age of 60, is typically shorter. Finally, a living donor may provide one kidney to an individual with ESKD. Usually the donor is a blood relative or has emotional ties to the transplant recipient. This final donor option is considered ideal, as it dramatically shortens waiting time, increases long-term survival of the kidney and the recipient, and provides flexibility in scheduling surgery (Stanford Transplant Clinic, 2012).

Even after receiving a kidney transplant, patients have a lot to deal with. While patients in Australia have acknowledged increased freedom and energy provided by kidney transplantation, as well as the relaxed restrictions around eating, drinking and traveling, many expressed feeling “excessive pressure from donors and clinicians, family expectations, self-reproach for putting another person at risk, and fear of graft failure and side effects,” (Tong et al., 2009, p. 696). Additionally, it must be recognised that not all kidney transplants are successful and that the body may reject the kidney. One focus group participant in Australia said that losing her new kidney ‘hit the most’ - more so than starting dialysis - because she felt she had done something wrong to lose the kidney given to her by her live donor (Tong et al., 2009, p. 696). Additionally, the immunosuppressant medications that must be taken by the transplant recipient in order to decrease likelihood of their body rejecting the kidney have severe side effects, including cancer, meaning that not all recipients necessarily feel better after the transplantation (Tong et al., 2009).

In summary, the management of CKD, especially in later phases involving dialysis or kidney transplantation, often involves a lot of discomfort, time, coordination, and effort in managing several medications that must be timed and coordinated with food, a strict diet involving protein and fluid-intake restrictions, a constant battle with weight, visits to a clinic or time spent attached to an at-home dialysis machine several times per week for several hours, and for some, the long and risky process of kidney transplantation. But these treatment regimens pertain only to chronic kidney disease, and in fact, CKD patients “often carry several other chronic disease diagnoses, have several prescribing physicians, and use multiple medications by the time they are seen by a nephrologist,” (Rifkin et al., 2010, p. 439-440).
Clearly, CKD can initiate a fundamental shift in a person’s everyday life and outlook on their future.

3.1 Potential contributions of a space-time approach to understanding everyday life with chronic illness

A space-time approach, as outlined in this Chapter 2, is well-suited for making contributions to understanding at least four aspects of everyday life negotiation for people living with chronic illnesses like CKD: 1) patient self-management of chronic illness; 2) paid work participation; 3) caregiving and family; and 4) leisure, recreation, and tourism. The following sections (2.6.1 - 2.6.4) present the dominant approaches to understanding how individuals with chronic illness negotiate each of these aspects of everyday life, providing specific information on individuals with CKD where available. Then, the spatio-temporal characteristics of each of these aspects of everyday life are explored in order to demonstrate how a space-time geographical approach could be useful in understanding how different parts of everyday life with chronic illness interact with one another.

3.2.1 Patient self-management of chronic illness

3.1.1.1 Managing chronic illness in everyday life

Patient self-management of chronic illness refers to “the behaviors that the patient employs in managing and implementing the treatment regimen within his or her lifestyle routine and recognizes the individual’s central role in chronic disease management,” (Lorig & Holman, 2003; Sakraida & Robinson, 2009, p. 628). As noted above, chronic kidney disease cannot be cured, but its progression can often be slowed by controlling modifiable risk factors such as smoking, exercise, nutrition, weight, diabetes and blood pressure, and by improving disease treatment and management (Green & Ryan, 2009).

The great balance of control over these risk factors for health decline and illness progression lies within the everyday behaviours of the individual living with CKD. In practice, health providers prescribe chronic illness management regimens to address these risk factors, but it is up to the patient to figure out how to integrate these regimens into their everyday environments and activities (Costantini, 2006). Chronic illness self-management should be not be understood as a ‘special activity’, but rather as an unavoidable aspect of the day-to-day of living: “One cannot not manage,” (Lorig & Holman, 2003, p. 1). In other words, actions performed in everyday living inevitably contribute to, or undermine, one’s health. For individuals with chronic illnesses, these everyday behaviours are especially important to health outcomes.
In the field of chronic illness there has been a shift in the model of care involving how the role of the person living with chronic illness is framed with regards to the disease’s treatment and management. The shift is from framing the individual with the disease as a patient who should receive and comply with instructions, to the most important person on an interdisciplinary team tasked with the treatment and management of the disease (Browne & Merighi, 2010, p. 548). Wagner’s Chronic Care Model has been pivotal in this shift and is now widely considered a best practice for improving primary care for people with chronic illness in countries like the US and Australia (Coleman, Austin, Brach, & Wagner, 2009).

The two primary components of this model are collaborative care and self-management education. Collaborative care refers to the patient accepting the responsibility of managing their own health, and being encouraged by health professionals to solve their own problems with information and support by health providers. A key ingredient in collaborative care is motivation derived not from wanting to please the doctor and do what the doctor orders, but from internal motivation within the patient (Bodenheimer, Lorig, Holman, & Grumbach, 2002, p. 2470). Self-management education complements traditional patient education regarding disease and technical skills with problem-solving skills “to help patients make decisions, take appropriate actions, and alter these actions as they encounter changes in circumstances or disease,” (Bodenheimer et al., 2002, p. 2471). The traditional approach to managing illness, called patient compliance or patient adherence, is “most simply getting patients to do what they are told,” (Lorig & Holman, 2003, p. 2).

Lorig and Holman follow Corbin and Strauss’s (1988) research on the day-to-day work of managing chronic illness in assigning three kinds of tasks to patient self-management: 1) medical management; 2) role management; and 3) emotional management. The goal in focusing on these three types of tasks is to help patients “maintain a wellness in their foreground perspective,” (Lorig & Holman, 2003, p. 1). The first set of tasks, medical management, involves tasks most directly related to medical treatment, such as taking medication, following dietary restrictions, or using an inhaler. The second set of tasks, role management, involves “maintaining, changing, or creating new meaningful behaviours or life roles,” such as adapting the way one continues with a hobby like gardening or cooking holiday meals (Lorig & Holman, 2003, p. 1, p. 1). The third set of tasks, emotional management, has to do with dealing with the emotional aspects of having a chronic condition such as anger, fear, frustration and depression, and the implications of the disease for how one views one’s future (Lorig & Holman, 2003, p. 1).
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While most health promotion and patient education approaches address the medical and behavioural management tasks, most do not deal directly with all three tasks (Lorig & Holman 2003, p. 1-2). Lorig and Holman also present six self-management skills: 1) problem solving; 2) decision making; 3) resource utilization; 4) the formation of a patient-provider partnership; 5) action planning; and 6) self-tailoring. A big part of the aim of helping patients acquire these skills is to orient the management and treatment of the disease around patient-perceived problems. The depth and breadth of the role of the individual with chronic illness within the patient self-management approach stands in sharp contrast to patient compliance or adherence approaches in which a compliant patient follows doctor’s orders. In considering the patient self-management approach to chronic illness, it is remarkable how far into the fabric of the patient’s everyday life – including everyday environments, routine activities, and habits – that health care providers must hope to indirectly extend their efforts in order to influence disease outcomes.

The shift from ‘compliance’ to self-management can be viewed within the historically changing role of the health care provider. During the first half of the 20th century, health care was sought out primarily by individuals needing treatment for acute illness. The health care system during that time, therefore, was set up to provide care for acute illnesses, meaning that the role of the health care provider was to diagnose and treat and the role of the patient was to comply with medical instructions. As chronic illness has surpassed acute illness in health care system demand, the burden of long-term, day-to-day management of chronic illness has shifted by necessity onto the patient, and the health care provider has adopted the roles of teacher and partner as well as professional supervisor: “The patient must be able to report accurately the trends and tempo of the disease, make informed choices about treatment, and discuss these with the health care provider. Self-management training prepares people with chronic illness to undertake these tasks,” (Lorig & Holman 2003, p. 2-3).

The patient self-management approach has been adopted successfully in dialysis treatment (Browne & Merighi 2010) and its use among patients with earlier stages of CKD has been advocated (Costantini, 2006). The patient self-management approach has also been used with patients with other chronic illnesses such as arthritis, chronic back pain, and HIV/AIDS (Lorig & Holman 2003, p. 3). The approach is also in-line with the World Health Organization’s recommendations for chronic disease management (Browne & Merighi 2010, p. 548).

3.1.1.2 Difficulties self-managing CKD

It is difficult for many people with chronic illness, including those with CKD, to follow all of their doctors’ recommended chronic illness management regimens in everyday life. As
discussed in Chapter 3.1.3, this may include taking medications on a particular schedule, following fluid and dietary guidelines and restrictions, monitoring blood pressure and blood sugar, quitting smoking, resting, exercising and having treatments such as dialysis. In fact, between a third and a half of CKD patients are non-adherent with treatment regimens (Costantini, 2006, p. 22). While patient self-management has been studied among patients with ESKD on dialysis, little is known about patient self-management behaviours among individuals with earlier stages of CKD (Costantini, 2006; Curtin et al., 2008).

One of the few studies to examine self-management experiences of people with non-ESKD stages of CKD found that the participants (stages 1-3 CKD) may need further support and education with respect to medication management, monitoring, managing and reporting symptoms, and finding resources on their illness (Costantini et al., 2008). These participants from Toronto, Canada described a delay in realising that their condition is chronic and will never go away. When they did realise this, it helped motivate them to become more engaged in their self-management (Costantini et al., 2008, p. 150). Furthermore, the absence of symptoms in early stages of CKD meant that many participants have trouble seeing the value in following treatment regimens, especially medications (Costantini et al., 2008, p. 151).

One particular challenge for individuals with CKD is the remarkable oral medication burden prescribed to manage it, along with comorbid conditions such as hypertension (Rifkin et al., 2010). In one study of older CKD patients in the US (aged 55-84 years), participants had 5-14 prescribed medications, 2-9 physicians, and 5-11 comorbid conditions (Rifkin et al., 2010). Not surprisingly, research suggests that the greater the number of medications and the frequency of medication dosing, the lower patient adherence levels are to the medication regimen (Browne & Merighi, 2010). Many ESKD patients take about 10 oral medications per day, and many of these medications are phosphate binders. These binders must be timed with meals throughout the day, producing a high level of dosing frequency in the medication regimen (Browne & Merighi, 2010).

In addition to the number of oral medications required and the frequency of dosing, patient comprehension of medications is also a challenge. A study of chronic kidney disease medication recipients in Melbourne, Australia found that patients were not convinced of the need, effectiveness and safety of all of their medications (Williams, Manias, & Walke, 2008). The high rate of depression among CKD patients also increases risk for poor medication management. In addition, patients who smoke, drink alcohol, or use other intoxicating substances have a greater chance of not using medications properly due to the impact of these
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substances on cognition, especially the ability to make good judgments (Browne & Merighi, 2010, p. 549).

Individuals with ESKD who are receiving haemodialysis find it particularly difficult to follow the “complex and onerous behavioural regimen” involved in maintaining the body after the kidneys have failed (Sharp et al., 2005, p. 1046). And, compliance with treatment is a point of contention between dialysis patients and clinicians (Costello, 2012p., xxvii). Studies of patient adherence to haemodialysis therapy find that many patients are not successful in following treatment instructions, especially fluid intake restrictions (Tsay, 2003). It is estimated that more than 50% of haemodialysis patients do not follow fluid restrictions (Sharp et al., 2005, p. 1046). Haemodialysis patients have been characterized as an especially abusive, noncompliant and disruptive group of patients (Sukolsky, 2004). However, the level of frustration experienced by haemodialysis patients is perhaps unsurprising: “The thrice-weekly obligation to the machine, the constant attention to diet and medications, the fatigue, the complications, the access procedures, all can damage the person’s identity and invade his/her life even when he/she is not on dialysis,” (Costello, 2012, p. xxvii).

Studies have found that dietary restrictions are also very challenging for many patients with ESKD. Some study participants in a UK study reported feeling that dietary restrictions are ineffective and unnecessary given their belief that dialysis can purge their body of forbidden substances (e.g., the phosphorous found in chocolate) (Krespi, Bone, Ahmad, Worthington, & Salmon, 2004). In another study, high adherence to dietary guidelines was found among American dialysis patients who believed that dietary recommendations reduce disease severity and decrease their chances for hospitalisation (Thomas et al., 2001).

Patients with CKD are less physically active than sedentary individuals without CKD, and this is especially true for individuals with ESKD on dialysis (Delgado & Johansen, 2012). A study of dialysis patients in Northern California in the US found that most participants were very sedentary, spending an average of 25 minutes per week of walking or other light activity. Only 17% of participants performed moderate physical activity for at least 150 minutes per week (Delgado & Johansen, 2012, p. 153). This was despite an overwhelming majority (98%) agreeing that a sedentary lifestyle was a health risk and that increasing exercise was beneficial. Furthermore, 84% agreed that physical activity is as important as other issues (Delgado & Johansen, 2012, p. 153). Ninety-two percent (92%) reported at least one barrier to physical activity, and the most common of these were fatigue on dialysis days, shortness of breath, lack of motivation, and fatigue on non-dialysis days (Delgado & Johansen, 2012, p. 153-154).
The management of diabetes alongside CKD is another challenge for many individuals. These conditions often coexist due to the common causes they share, including ageing, vascular inflammation, hypertension, and dyslipidaemia (Lubowsky, Siegel, & Pittas, 2007, p. 865). Many people have difficulties adhering to the complex balancing act of a diabetes treatment regimen, which is aimed at preventing spikes or dips in blood glucose levels. Regimens include diet, physical activity, and glucose monitoring or glucose-lowering agents (Sakraida & Robinson, 2009). Patient-identified barriers to diabetes self-management include lack of knowledge about diet, a lack of understanding of the management plan and poor communication from health providers, difficulty using resources, and feelings of helplessness and frustration about glycaemic control and disease progression despite adherence to the treatment regimen (Nagelkerk, Reick, & Meengs, 2006; Sakraida & Robinson, 2009).

Finally, for those who smoke, reducing or quitting smoking in order to slow progression of CKD comes with the well-documented difficulties of nicotine addiction (Manley & Stack, 2008; Raymond & Naylor, 2010). In short, adherence to chronic illness management regimens is a challenging aspect of self-management of CKD for many individuals and at the same time very crucial to slowing progression of disease and maintaining the best quality of life possible.

3.1.1.3 Understanding difficulty & success with patient self-management

Explanations for the difficulties and successes people have in self-managing chronic illness in everyday life can be roughly grouped into those employing concepts from health behaviour change theories, and those concerned with the role of health routines and habits in people’s everyday lives. The Chronic Care Model of supporting patient self-management of chronic illness attributes success or failure in patient self-management not only to patient education, but also patient motivation and self-efficacy: “According to the Chronic Care Model, optimal chronic care is achieved when a prepared, proactive practice team interacts with an informed, activated patient,” (Bodenheimer et al., 2002, p. 2469). One of the central concepts of the Chronic Care Model is patient self-efficacy, or the “confidence to carry out a behavior necessary to reach a desired goal,” which, in partnership with education, is believed to be an important component of successful patient self-management of chronic illness (Bodenheimer et al., 2002, p. 2469).

Traditional models of the patient-doctor relationship regard physicians as experts and patients as passive consumers of disease-specific information and technical skills (Bodenheimer et al., 2002). However, it is increasingly accepted among health researchers that health education alone is not sufficient to change desired health behaviours. People need more than just information about good health behaviours in order to implement them in their
lives: “[In the last twenty years], we epidemiologists have suffered a whole series of embarrassing failures. [...] Our model is to identify the risk factors and share that information with a waiting public so that they will then rush home and, in the interest of good health, change their behaviours to lower their risk. It is a reasonable model, but it hasn’t worked. In intervention study after intervention study, people have been informed about the things they need to do, and they have failed to follow our advice,” (Syme, 2005, p. xi).

Certain traditions of thought from health behaviour change theories have informed the Chronic Care Model. The concept of self-efficacy employed in the Chronic Care Model comes from Bandura’s work on social cognitive theory (Bandura, 1986, 1994, 2010). Bandura argues that competent functioning in social, intellectual and physical pursuits requires both the skills to perform the goal and self-beliefs of self-efficacy. A person’s sense of self-efficacy, this theory posits, mediates health behaviour. Perceived self-efficacy is defined as “people’s judgements of their capabilities to organize and execute courses of action required to attain designated types of performances,” (Bandura, 1986, p. 94). Put another way, it is “people’s beliefs that they can exert control over their own motivation, thought processes, emotional states and patterns of behavior,” (Bandura, 1994, p. 2). A person with a high sense of self-efficacy will expect a positive outcome for their efforts, while a person with a low sense of self-efficacy will expect mediocre or negative outcomes. Self-doubt can override knowledge and self-protective action. Bandura clarifies that self-efficacy should not be confused with will power.

How, then, can a person acquire a sufficient sense of self-efficacy in order to be successful in patient self-management of chronic illness? Bandura argues that a strong sense of self-efficacy is built through mastery experiences (Bandura, 1986, p. 101). For example, in order to encourage less risky sexual behaviour that may lead to infection with HIV, Bandura advocates for social modelling that can show people how to handle different risky situations, and then to facilitate role playing in simulated situations to help individuals practice and master their behaviour in high risk situations (Bandura, 1994, p. 9-11).

The Health Belief Model has also informed much work on health behaviour over the past several decades, and includes the concept of self-efficacy (Glanz, Rimer, & Viswanath, 2008). This model predicts why people will be motivated and take action to prevent, screen for, or control health risks based on a person’s beliefs of their own susceptibility, the perceived seriousness of the health risk, perceived benefits and barriers to behaviour, cues to action, and sense of self-efficacy (Glanz et al., 2008, p. 46-47). The model has been adopted to also predict how a person will manage an established illness, including: “acceptance of the diagnosis,
personal estimates of susceptibility to consequences of the illness, and susceptibility to illness in general,” (Glanz et al., 2008, p. 46-47). Following this model, individuals who have accepted their diagnosis, understand the consequences of their illness, are well educated about how to manage their chronic illness, believe that the recommended treatment regimens are effective, and who feel confident in their ability to implement treatment regimens will have the most success in patient self-management of chronic illness.

There are many examples of employment of these concepts in studies of patient self-management of chronic illness. For example, efforts to improve adherence to treatment regimens and other healthy behaviours among patients with ESKD involve “increasing the knowledge and skills of haemodialysis patients, thereby promoting collaborative problem solving, decision making, and behavioral change,” (Browne & Merighi 2010, p. 547). While behavioural strategies have traditionally been used in interventions aimed at improving patient self-management, psychological interventions are receiving increasing attention in the literature, especially psychotherapeutic techniques such as cognitive behavioural therapy (Sharp et al. 2005, p. 1046). Sources of patient motivation for managing chronic illness have been examined; both internal and external to the individual (Jowsey, Pearce-Brown, Douglas, & Yen, 2011). Studies of self-management behaviour among patients with CKD have found that higher perceived self-efficacy is associated with increased communication and partnership with health care providers, better self-care and improved medication-adherence behaviours (Curtin et al., 2008, p. 191). Self-efficacy training among haemodialysis patients was found to significantly decrease fluid weight gains between treatments, indicating that those individuals were more compliant with fluid restrictions between haemodialysis sessions (Tsay, 2003).

Routines and habits related to a person’s health are also examined in relation to patient success in CKD self-management, although less explicitly than ideas of education, motivation and self-efficacy. For example, individuals with CKD are described as “renegotiating their days around” activities such as prescribed medications, and “integrating treatment recommendations into their preferred lifestyles” (Costantini et al., 2008, p. 151). Several studies have proposed that stable routines are important for successful patient self-management of chronic illness, more generally (e.g., Balfe, 2009; Balfe et al., 2013; Dyck, 2002; Fiese & Wamboldt, 2000; Haslbeck & Schaeffer, 2009; Takahashi, Wiebe, & Rodriguez, 2001; Wagner & Ryan, 2004). These studies argue that research on health routines is crucial both for understanding the barriers patients come up against in adhering to treatment regimens, and for designing more effective patient service plans and offering support. Although approximately half of chronic illness patients have difficulty adhering to prescribed treatment
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regimens (Denham, 2003), many health service providers do not recognise the difficulties patients often face integrating illness management activities into everyday routines, and rarely provide support or advice on how to do so (Haslbeck & Schaeffer, 2009, p. 190-191).

There is growing interest in the relationship between repetitive, predictable components of people’s everyday lives and their health, more generally. These are often discussed in terms of individual or group routines. Despite the apparent interest in the subject, the concept of routine is ill-defined in health research (Zisberg, Young, Schepp, & Zysberg, 2007). The nature of health routines has tended to be confined largely to behavioural or psychological spheres in which the individual is privileged as the locus of processes of establishment and decomposition of routines, which are subject to external environmental influences. Based on an exhaustive concept analysis of the use of the term within health research, Zisberg and colleagues proposed the following working definition of routine: “Routine is a concept pertaining to strategically designed behavioural patterns (conscious and subconscious) used to organize and coordinate activities along the axes of time, duration, social and physical contexts, sequence and order,” (2007, p. 446). According to the health literature, routines are characterised by overt behavioural patterns. They coordinate and organise timing, duration and order of activities. Routines are repetitive within a given time frame (e.g., day, week, etc.) and occur in contexts with social and physical characteristics. They involve automation of activities, allowing them to serve as resource conserving strategies. Routines occur at the individual, social group and community levels. And, finally, they can comprise the individual’s world, lifestyle and even identity (Zisberg et al., 2007, p. 445-446).

Getting a better conceptual grasp on the nature of health routines may have important implications for supporting patient self-management of chronic illness, as the advantages of positive health routines include diminishing fatigue in performing activities, sparing attention and cognitive resources for other aspects of everyday life, and an improved sense of well-being and mood (Zisberg et al., 2007, p. 448). The subject of health routines has received surprisingly limited empirical and theoretical attention in the health literature. In their exhaustive literature review of ‘routine’ in health publications from 1977-2005, Zisberg and colleagues (2007) found the small number of theoretical models of routine offered only “sporadic and inconsistent insights into the nature of the concept of routine,” (Zisberg et al., 2007, p. 443) and that there was sparse empirical work on the subject. Only 74 papers and book chapters met the following criteria: “(1) the concept of routine was at the centre of the theoretical discussion in the manuscript; (2) routine was discussed as one of the outcomes of the study; and (3) routine was measured in the study,” (Zisberg et al., 2007, p. 444).
Routines and rituals are often used interchangeably in the health literature. While they are similar, there are important distinctions. Rituals can be performed regularly and form part of routines, and routine activities can have symbolic, ritualistic characteristics. However, Fiese and colleagues (2002) and Denham (2003) contrast rituals and routines, characterising routines as stable, modifiable, primarily instrumental and unlikely to inspire reflection, and rituals as more symbolic acts having to do with identity and group values.

The concept of habit also often enters into discussions of the relationship between health and routines. Within the occupational therapy literature, it has been proposed that routines are “a type of higher-order habit that involves sequencing and combining processes, procedures, steps, or occupations. Routines specify what a person will do and in what order and therefore constitute a mechanism for achieving given outcomes and an orderly life,” (Clark, 2000, p. 128S). Gallimore and Lopez (2002) propose that habitual behaviours are embedded in everyday routines, and Dyck (2002) suggests that habits are constitutive of routines. In these works we find the idea that there is something inextricable about the nature of the relationship between routine and habit.

The occupational therapy and health literatures most often apply a psychology-based, acontextual conceptualisation of habit in which habit is characterized by automaticity of thought or action in response to a trigger. It is proposed that: “Habits are the relatively automatic things a person thinks or does repeatedly,” (Clark, 2000, p. 128S). Similarly, habit has been described as “an often involuntary pattern of behaviour acquired by frequent repetition,” (Rowles, 2000, p. 53S). John Dewey’s work on habit has been applied in occupational therapy literature in this sense: “...Dewey defined habits from a functionalist perspective as acquired predispositions to particular modes of response that equip a person with an economy of thought and action in dealing with new problems. [...] Thus Dewey conceived of habit as providing an economy of thought and action, a modifiable background structure on which new learning could be superimposed,” (Clark, 2000, p. 1295-1305). In their work, Gallimore and Lopez (2002) introduce the concept of habit as predominantly belonging to the domain of psychology, but do not offer a specific conceptualization of habit (Gallimore & Lopez, 2002, p. 705). In short, habit is usually understood within health literature as the end-product of past repetitions of an action or exposure to a stimulus; habits are understood as the automated building blocks of routines.

This use of this conception of habit in literature on health routines reflects the work of Descartes, Kant and others in understanding habit as “a form of mechanism that arrests and inhibits consciousness, thought and freedom,” (Grosz, 2013, p. 217). This contrasts with the
vitalist tradition of thought on habit as open-plasticity allowing for mutual transformation between a person and their environment, as described in Chapter 2.1.3.2. The psychological emphasis in the concepts of health routines and habits is not surprising given the predominance of psychology-based health behaviour change theories used to explain and intervene in problems of patient adherence to treatment regimens (Glanz et al., 2008). These approaches tend to privilege cognition and psychosocial factors such as the individual’s sense of self-efficacy, as previously discussed (Glanz et al., 2008), over other factors such as environmental influences or logistics.

Rare exceptions to drawing from psychological understandings of habit in the health literature include Balfe’s use of Bourdieu’s concept of habitus to describe the integration of diabetes management into the lives of university students: “The individual in a sense develops a ‘diabetes habitus’ (Bourdieu 1984), integrating past experiences to create resilient dispositions (informed by the goals of ‘good’ diabetes care) that direct their actions in particular ways (to control diabetes),” (Balfe, 2009, p. 2368). Effective management of diabetes is “predicated upon the efficient and habitual execution of diabetes self-care practices,” (Balfe, 2009, p. 2368). Balfe proposes that a well-developed diabetes habitus helps the student adapt their illness management routines to the shifting contexts of university life.

Occasionally, authors within the health literature link routine and habit to a person’s environment. Rowles’ (2000) consideration of the relationship between context and habitual behaviour is one such example. Rowles (2000) explores habitual uses of place by older residents of a small town. He uses the terms ‘habituation’ and ‘routine’ interchangeably, and employs a generally worded definition of habit as “an often involuntary pattern of behaviour acquired by frequent repetition,” (Rowles, 2000, p. 53S). However, Rowles draws a direct relationship between habit and environment: “The term ‘habituation’ is used here to signify the process of developing through repeated use a personal affinity with the environment, both the immediate proximate setting of one’s place of residence and sphere of everyday activity, and the large-scale environment beyond,” (Rowles, 2000, p. 54S). Rowles concludes that: “Even the most mundane dimensions of habit must be understood in context,” (Rowles, 2000, p. 53S).

In his exploration of the health routines of university students with Type 1 diabetes, Balfe (2009) employs Zisberg and colleagues’ (2007) concept of fields in understanding how routines are shaped. Fields, here, refer to “sets of mutually-related structures, activities, institutions and groupings, all of which relate to the individuals acting within the field,” (Balfe, 2009, p. 2368). Similarly, in their work on young adults’ self-management of diabetes in the...
workplace, Balfe and colleagues (2013) note that the temporal characteristics of workplace environments influence diabetes management routines. Finally, Gallimore and Lopez (2002) examine the role of environment in creating and maintaining habits within everyday routines. In this regard the authors emphasise the role of culture within a given environment in shaping routines and habits.

3.1.1.4 The space-times of patient self-management of chronic illness

Existing literature attributes patient success in self-management of chronic illness primarily to psychosocial factors, such as patient education, motivation, and self-efficacy, as well as the health routines and habits patients form in everyday life. It must also be acknowledged, however, that chronic illness self-management activities, like all activities, have spatial and temporal characteristics of their own that must be accommodated if the activity is to take root and persist within a person’s everyday life. People with CKD often find it difficult to integrate treatment regimens into their particular “lifestyles”, a term which I interpret to mean a person’s routines and everyday contexts, despite “genuine efforts to do so,” (Costantini et al., 2008, p. 151). Furthermore, not all everyday lives are the same. Costantini and colleagues (2008) observe that individuals with CKD have “diverse lifestyles”, and that this diversity presents “unique challenges” to “generic treatment recommendations,” (Costantini et al., 2008, p. 51). Patient success in self-management of chronic illness, therefore, should also be examined in terms of the ways in which the spatio-temporal characteristics of chronic illness self-management regimens interact with other aspects of a person’s everyday life.

Though not specifically concerned with patient success in self-management of chronic illness, a body of geographical literature has explored the spatial dimensions of everyday life with chronic illness, most often for Canadian women, finding that space and place are heavily implicated in how individuals with chronic illness navigate everyday life, experience changes in their body, and maintain or reconstruct identity. We now know that the onset of chronic illness can result in altered senses of place, uses of particular spaces, and spatial extents of everyday life (Crooks, 2007a, p. 579). The work of Isabel Dyck, Pamela Moss, Valorie Crooks, and others, has been particularly influential in this regard. Dyck (2002) has examined relationships between chronic illness, routines, habit, and environment for Canadian women with chronic illness “as seen through the lens of spatiality and a focus on the body,” (Dyck, 2002, p. 52S-53S). She finds that participants restructure their everyday routines and environments in response to changes in their bodies and the marking of their bodies as ‘deviant’ by others, thereby reconstructing their social identity with chronic illness.
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Dyck’s (1995a) study of Canadian women with multiple sclerosis and Crooks and Chouinard’s (2006) study of Canadian women with arthritic illnesses both uncovered the role space plays in shaping women’s chronic illness experiences and negotiation of identity through its interactions with physical impairment and gender (Dyck, 1995a). Racial and ethnic minority identity, Dyck found, also interweaves with space, place, and gender in shaping Canadian women’s experiences of health service access in managing chronic illness (Dyck, 1995b). Other notable scholarship within this body of literature on space, place, identity, and chronic illness includes the work of Moss and Dyck (2003), Dyck, Kontos, Angus, and McKeever (2005), Dyck (1998), and Crooks, Chouinard, and Wilton (2008).

As noted in the introductory chapter of this thesis, where the temporal dimension of chronic illness experience has been addressed in geographical scholarship, it is typically conceived over the long-term, wherein changes occurring in particular places in an individual’s life over extended periods of time (e.g., Wilton, 1996), or the individual’s framing of self in relation to and over time in response to chronic illness (Driedger, Crooks, & Bennett, 2004) are explored. Left unexplored are the many senses of time that are experienced in everyday life (Adam, 2013; Shove, Trentmann, & Wilk, 2009a), and the ways in which these may be implicated in the navigation of the everyday with chronic illness.

Thus, while the role of space has been established within health geographies of chronic illness, much is left to explore with regard to time. For instance, chronic illness self-management may compete with other activities in everyday life for temporal, as well as spatial, resources. As already noted, managing chronic illness is very time consuming in the absolute sense of the minutes and hours occupied each week by activities like taking medications and checking blood glucose and blood pressure levels (Charmaz, 1997; Jowsey, Yen, & Paul, 2012). People with ESKD have reported feeling ‘tied’ in space to dialysis treatment due to the necessity to be at a certain place at a certain time for several hours three or four days each week (Polaschek, 2003). Moist and colleagues (2008) found that longer travel time to dialysis for dialysis patients is associated significantly with greater mortality risk and decreased patient perceptions of health-related quality of life. Furthermore, access to health care services imposes rather strict space-time authority constraints on patients. A patient must be at the doctor’s office at the specified appointment time and wait for however long it takes if they want to see the doctor. In this way, the space-time demands of health care are similar to those of most employers, as space-time flexibility is the privilege of the employer and health care provider rather than the employee or patient.
The importance of access to health-related services and resources for people with chronic illness is obvious. For the general population, the impact of the level of provision of transportation services in neighbourhoods on neighbourhood residents’ ability to reach resources such as health care has been established (e.g., Church, Frost, & Sillivan, 2000). As noted in Chapter 2.1.1, the most common measures of individual accessibility apply place-based approaches that are limited by the ecological fallacy of treating all individuals equally within a defined area, and the modifiable area unit problem, which refers to the sensitivity of the level of access to resources to the scale and configuration of the partitioning scheme used (Neutens et al., 2011; Weber & Kwan, 2002). Takahashi and colleagues (2001) provide a rare example of a space-time approach to studying health-related service and resource access for people with chronic illness. This study in Orange County, California examined how individuals living with HIV and AIDS navigate access to services within the time-space windows of opportunity created by everyday routines and social network interaction. Based on survey data and in-depth interviews, this study concluded that the spatio-temporal characteristics of participants’ routines such as the frequency, heterogeneity, or social orientation of activities defined the availability of temporal and spatial windows of access to services. Furthermore, the nature of the relationship between routines and access to services varied depending upon the type of service in question (Takahashi et al. 2001, p. 845).

Besides requiring spatial and temporal resources, many CKD self-management activities have other particular spatio-temporal characteristics. For example, successful adherence to medication regimens requires the timing and sequencing of medication dosing throughout the day. This timing and sequencing must synchronise with a person’s space-time path so that they and the medications cross paths in space at the required times. This requires either carrying medication and remembering to take it throughout the day, or directing one’s space-time path to where the medications are stored (e.g., kitchen cupboard or work desk) at the time when medications must be taken. In another example, injecting insulin takes a couple of minutes, must be done before meals and after checking glucose levels, and requires a hygienic, socially acceptable setting. Tracking fluid intake throughout the day may require the development of a heightened awareness of the spacing and quantities of consumption of fluid throughout the day. As a participant in another study on CKD reported, managing their 250 millilitre per day fluid restriction took up a substantial amount of cognitive capacity: “[M]y whole days were preoccupied with where I was going to spend my liquid [allowance]” (Costantini et al., 2008, p. 151).
Thus, self-management activities not only require spatial and temporal resources to perform, but they are also often characterised by repetition, sequencing, timing, pacing, tracking, duration, synchronisation, and setting requirements. As Charmaz (1997) observes, individuals with chronic illness must perform a “juggling act” if they wish to engage in everyday activities alongside the activities of managing their illness (Charmaz, 1997, p. 136). One way to think about the repetition of self-management activities in everyday life is to employ the concept of rhythm (Lefebvre, 2004). As discussed in Chapter 2.1.2, rhythms are ubiquitous characteristics of people’s everyday environments that may result in harmonious combinations as well as arrhythmias when interacting with one another (Edensor, 2010b). As such, when a doctor requests that a patient introduce new chronic illness self-management activities into their everyday life, this implies the introduction of new rhythms into the already rhythmically dynamic contexts of a person’s everyday life; producing experiences of harmony or discord. For example, different contexts, such as the workplace, the home, or a volunteer organisation site, are home to different rhythms, such as work schedules, children’s energy and hunger cycles, and seasonal organisational activities, many of which are informed by the particular practices that are acceptable within each context. When repetition of an illness management activity integrates harmoniously with existing rhythms in a person’s everyday life, the activity repeats more easily, thereby encouraging the force of habit (Ravaisson, 2008) to develop. Habit, in turn, may reduce the amount of effort required to remember and perform the illness management activity alongside other activities of everyday life.

Therefore, the success a person experiences with patient self-management of chronic illness may be influenced not only by psychosocial factors such as the person’s education, motivation and self-efficacy, or their personal ability to establish and maintain stable routines. Their success may also be influenced by the interaction of the spatio-temporal characteristics of illness self-management activities with the spatio-temporal characteristics of other aspects of the person’s everyday life. This may manifest negatively as competition for space-time resources between illness self-management and other everyday activities (e.g., the time demands and logistics of caring for children, paid work, and leisure commitments), leading, perhaps, to some activities being sacrificed or compromised. Or, it could manifest as an arrhythmia resulting from the interaction of illness management activity rhythms with those of everyday environments. For example, the unpredictable needs of children or fluctuating work demands might interrupt the timing of a medication schedule in the home or work environments.
On the other hand, it is also possible that some chronic illness self-management activities actually ‘save’ people spatio-temporal resources, for example, if there were frozen meals that were renal diet appropriate. Or, some everyday contexts may have rhythms that are highly compatible with some self-management activity rhythms, making performance of self-management activities easy, and vice versa. For example, a workplace rhythm may pull a person past their desk where medications are stored at precisely the times when medications must be taken during the day. This rhythm would provide a trigger to take the medications, supporting faithful adherence to the medication regimen, and reducing the effort required to remember. These and other kinds of interactions between the spatio-temporal characteristics of chronic illness self-management and other everyday activities may be examined.

3.2.2 Paid work participation

3.2.2.1 Paid work participation and chronic illness

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). This proportion may grow with proposed increases to the retirement age (Commonwealth of Australia, 2014), as older Australians (age 55 and over) have increased risk for chronic illnesses and conditions such as cardiovascular disease, hypertension, high cholesterol and circulatory diseases relative to their younger counterparts (Australian Institute of Health and Welfare, 2010, 2014). Older Australians also have greater need for more frequent health service access (Australian Institute of Health and Welfare, 2007). The global backdrop of this shift in the age and health profile of the labour pool is one of increased life expectancy in populations around the world due in great part to reductions in deaths from infectious and parasitic diseases, in combination with a dramatic decline in fertility rates due to more effective birth control and improved education (Kulik, Ryan, Harper, & George, 2014).

The impetus behind government encouragement of sustained workforce participation for older Australians is the rapidly shrinking ratio of working age Australians to older persons needing government support. In 1970, there were 7.5 working age people for every older person in Australia. By 2010 this had fallen to five, and by 2050 it is projected that there will be fewer than three working age Australians for every older Australian (Commonwealth of Australia, 2010). Without enough younger people in the workforce to fund the public programs that provide services such as health care, pensions and other support systems for older generations, the sustainability of national Gross Domestic Product growth, the tax base, and social and health systems is threatened (Kulik et al., 2014). For this reason, the Australian
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government has proposed increasing the retirement age from 65 to 70 years old by 2035 (Commonwealth of Australia, 2014).

The implications of such a compositional shift in the health profile of the Australian 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., Chorus, Miedema, Wevers, & Van der Linden, 2001; Edwards & Boxall, 2010; Laires & Gouveia, 2014; Nilsson, Hydbom, & Rylander, 2011; Roessler, Hennessey, Neath, Rumrill, & Nissen, 2011; Wege & Angerer, 2013). While the relationship between health and labour force participation is complex and bidirectional (Baanders, 2002; Cai & Kalb, 2006), it is clear that poor health can ‘select’ people out of the labour force (Haahr, Frost, & Andersen, 2007; Pit, Shrestha, Schofield, & Passey, 2010), and, conversely, poor working conditions can negatively impact on workers’ mental and physical health (Karasek, Baker, Marxer, Ahlbom, & Theorell, 1981; Siegrist, 2009). Under favourable conditions, however, paid work participation can lead to improved health outcomes (Ross & 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, the kinds of jobs that support their health, and the implications therein for labour markets, workplaces, and health services.

The problem of workforce participation by people with chronic illness has been primarily explored either directly or indirectly through 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. The often unpredictable and/or progressive course of chronic illness, the wide range of symptoms that can be experienced, as well as fluctuations in physical functioning can all limit a person’s ability to perform job duties (Koch, Rumrill, Conyers, & Wohlford, 2013). Furthermore, paid work can negatively impact on chronic illness management (Gignac, Sutton, & Badley, 2006). 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 & Jongbloed, 2000) model of disability, which problematizes society’s attitudes towards and expectations of ill or disabled bodies. Research has established that many employers hold a “fundamental negative bias” toward workers with chronic illness (Koch et al., 2013). The social model of disability concludes that unsupportive organizational cultures (e.g., Edwards & Boxall, 2010), discrimination (e.g., Roessler et al.,
2011), and stigma (e.g., Shier, Graham, & Jones, 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). This model, however, is used less explicitly in understanding employment experiences for people with chronic illness than the first two models.

While chronic illness barriers to employment may exclude or drive out some people with chronic illness from the labour force, others with chronic illness may cut down or cut back on employment activity in order to stay employed (Koch et al., 2013). This may include reducing work hours from full- to part-time, turning down promotions or additional duties, changing to a less demanding job, using sick days and vacation days to rest and cope with symptoms (Koch et al., 2013), and hiding one’s chronic illness from employers and co-workers (Munir, Leka, & Griffiths, 2005). Individuals who cut down or cut back on employment activity in order to stay employed are at a higher risk of depression (Koch et al., 2013).

Ideally, people with chronic illness would obtain all required workplace accommodations from employers that they need in order to successfully obtain or persist in employment. In Australia, as in many other countries, the employment opportunities of individuals with disabilities are protected by legislation: Disability Discrimination Act 1992 (Australian Human Rights Commission, 2015). This legislation is meant to protect disabled individuals from discrimination in the hiring process, meaning that if the individual can perform the activities essential to the position in question, they should be able to compete equally with other job applicants. If the disabled person is the most competitive applicant for the job, the employer is required to make workplace adjustments or accommodations if they are needed in order for the person to perform essential job activities (Australian Human Rights Commission, 2015).

Workplace accommodation addresses “the specific needs disabled workers have with respect to the embodied practice of work” and involves “modifications to the work environment or labour process that allow disabled persons to be hired,” (Wilton, 2004, p. 420; 423). As impairments take diverse forms, including physical, psychiatric, sensory, and cognitive impairments, workplace accommodations can take equally diverse forms, including alterations to office furniture and electronic equipment, additional training time, and flexible work schedules. All of these changes “require employers to adjust how, when and where essential work tasks are performed to meet the needs of a disabled employee,” (Wilton, 2004, p. 423). Hall and Wilton (2011) note that programs and legislation aimed at creating employment opportunities for disabled people have too often focused on the hiring process rather than the
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potentially disabling characteristics of work environments and the workplace accommodations needed to address them (Hall & Wilton, 2011, p. 877).

Vocational rehabilitation research has suggested that individuals with chronic illness may have a better chance of persisting in employment if they proactively plan for the unknown. This requires that the individual have a comprehensive understanding of their chronic illness, including its anticipated course and progression, and its potential impact on their job performance into the future (Koch et al., 2013). This, it is argued, will assist the individual in evaluating their job environment and job demands, and anticipate the workplace accommodations they may eventually need from their employer (Koch et al., 2013). Furthermore, “anticipatory coping” is also identified as important, in that workers with chronic pain, fatigue or other symptoms may anticipate these symptoms by doing things like delegating non-employment tasks to others or giving up activities outside of work in order to have more energy and time to devote to work, or they may perform the most demanding job tasks when feeling best during the day (Gignac, 2005; Koch et al., 2013). Also, it has been suggested that rehabilitation counsellors may educate employers on chronic illness, thereby encouraging employers to promote a more supportive work environment for employees with chronic illness (Koch et al., 2013).

There are several acknowledged barriers to obtaining appropriate workplace accommodations for people with chronic illness. For one, employers may resist these changes if they reduce efficiency and their control over production (Wilton, 2004). Furthermore, the desire to maintain an identity as a ‘good’ worker in alignment with dominant workplace cultures, as well the anticipation of negative supervisor or colleague reactions can impel disabled employees to self-discipline themselves in the workplace, discouraging reasonable requests for workplace accommodation (Wilton, 2004). Furthermore, Wilton (2004) observes that the current employment context for many workers is characterised by employment insecurity and weakened unionization, with workers treated as ‘entrepreneurs’ who compete with one another for limited opportunities in the labour market. This, Wilton argues, may lead many non-disabled workers to view disabled workers as “problem workers” or individuals receiving “special treatment” (Wilton, 2004, p. 423), thus undermining solidarity in the workplace.

3.2.2.2 The space-times of paid work
In addition to the physical limitations of the chronically ill body and the attitudes and discrimination of employers and co-workers, the diversity of spatio-temporal characteristics of different forms of paid work may also play an important role in the paid work experiences of
people with chronic illness. Time and space, including how long people work, where, how fast and when, have been fundamental to the wage exchange underpinning employment since the inception of industrial capitalism, and power relations are reflected in who can decide the terms of this exchange (Thompson, 1967). Overwhelmingly, these decisions fall in favour of the employer, with work arrangements best suited for “unhindered” market subjects” (Hall & Wilton, 2011, p. 421). For this reason, employees often experience the space-times of paid work as predominantly rigid and highly fixed, especially disabled people (Hall & Wilton, 2011) and those with substantial responsibilities outside of work, such as women (McKie, Gregory, & Bowlby, 2002).

Contemporary workplaces have been described as spaces of greater and greater time pressure, where expectations of short-term financial performance are commonplace, and there is a general speeding up of the conduct of business (Thrift, 2000). Thrift argues that time is the “forcing ground” of the new managerial style (Thrift, 2000, p. 675). This intensification and speeding up of production in the workplace culture, in combination with the increasingly precarious position of workers in the labour market, creates a potentially more disabling work environment for individuals with impairments who may need additional time to complete tasks or to take time off work to attend to their health (Wilton, 2004, p. 430). Furthermore, some have observed a trend toward “boundarylessness” in some modern work arrangements, wherein management of worker output is shifting from controlling the hours a worker spends in the workplace to the output they produce within a given time frame (Kamp, Lund, & Hvid, 2011). Working time is more flexible with regards to when and where work is performed, is driven by deadlines, often has no upper limit, and is characterised by intensity and unpredictability (Kamp et al., 2011, p. 230). The burden of managing work time in conjunction with the rest of life, therefore, shifts to the worker (Kamp et al., 2011).

Two prominent approaches have been taken to researching the relationship between the characteristics of paid work, employee health, and employee exit from the labour force, and these incorporate, although not always explicitly, some of the spatial and temporal dimensions of paid work that may be relevant to employment experiences for people with chronic illness. These are Karasek’s (1981) job demand-control model and, more recently, Siegrist’s (2004) effort-reward imbalance model. Work characteristics underlying these two models seem to help explain worker health outcomes, as well as predict exit from paid employment (Robroek, Schuring, Croezen, Stattin, & Burdorff, 2013, p. 126). Both models aim to define and measure psychosocial characteristics of the work environment, the definitions of
which, despite the growing body of literature in this field, are still heavily debated (Siegrist et al., 2004, p. 1484).

The job demand-control model (Karasek et al., 1981) examines the interaction of two types of job characteristics - employee self-reported ‘job demand’ and ‘decision latitude’ - postulating that the joint effects of these produce psychological strain and subsequent physiological illness (Karasek et al., 1981, p. 694). Job demand is measured with two questions: “Is your job hectic?” and “Is your job psychologically demanding?” (Karasek et al., 1981, p. 696). Components of decision latitude include “control over use of skill, time allocation, and organizational decisions” and “whether the individual has control over his time schedule of participation in the work process” (Karasek et al., 1981, p. 697). Temporal dimensions are apparent in both measures. For example, a hectic quality of work as a measure of job demand arguably refers to the fast pace of work, and control over use of time and work schedule is an explicitly temporal dimension of work flexibility.

The effort-reward imbalance model (Siegrist et al., 2004) is based on the sociological concept of the norm of social reciprocity. It postulates that when the relationship between the ‘costs’ and ‘gains’ of the job becomes asymmetrical, employees experience negative emotions, which lead to subsequent illness susceptibility (Siegrist et al., 2004, p. 1485). Work effort is measured by items referring to quantitative workload, qualitative workload, and increase in total load over time (Siegrist et al., 2004, p. 1486). Reward is measured by items referring to financial reward, esteem reward, career promotion prospects, and job security (Siegrist et al., 2004, p. 1487). These effort and reward measures are then translated into a ratio. Again, temporal dimensions of work are hinted at, especially with regards to the workload an employee must negotiate within a given timeframe.

A substantial body of literature draws directly or indirectly from these models in examining the relationship between work characteristics and labour force exit among older workers, some of which incorporates health variables. While not specific to workers with chronic illness, older individuals have higher rates of chronic illness and greater physical limitations as compared to their younger counterparts, offering some insight into the spatio-temporal characteristics of work that may be relevant for job retention of individuals of any age with chronic illness. This literature has examined at least five spatio-temporal characteristics of paid work: duration (i.e., the amount of time spent working over a given time period); flexibility (i.e., the degree of control the employee has over their working times and locations); pace (i.e., the quantity of work that must be completed within a given time frame); sociability (i.e., the degree to which a work schedule and location synchronises with broader
social practices); *predictability* (i.e., how far in advance the employee knows when and where and for how long they will work); and *regularity* (i.e., how consistent or variable working time and location patterns are over a given time period).

Several studies have found that longer work hours (duration) are associated with workforce exit among older workers, perhaps due to the need for older workers to rest more than younger workers (e.g., Fleischmann, Koster, Dykstra, & Schippers, 2013; Krause et al., 1997; Nilsson et al., 2011). And, there is a tendency for older workers to choose part-time rather than full-time employment as a bridge between work and retirement (Blau, 1998; Cahill, Giandrea, & Quinn, 2006; Elder & Pavalko, 1993; Gielen, 2009). The effects of long working hours on health, however, are likely mitigated by the availability of paid working time flexibility. Ala-Mursula et al. (2006) explored the associations of all types of working hours (paid, domestic, commuting, and total) with sickness absence, and examined whether these associations vary according to work time control. They found that high control over working hours reduced adverse effects of long domestic and paid working hours on sickness absences, concluding that greater control over paid work times may protect worker health and help workers more easily combine full-time work with domestic work.

Greater control over working times (flexibility) has been found to encourage sustained workforce participation among older workers. Early-retired Dutch employees (age 60-64) reported that the desire to have more flexibility with time outside of work (i.e., being able to choose when to work/not work) was one of the factors pulling them out of the workforce (Reeuwijk et al., 2013). Also, the ability to reduce working hours gradually and the ability to vary hours per day, days per week, or weeks per month has been found to increase the prospective retirement age among American workers (Hurd & McGarry, 1993).

A positive effect of control over working times on employee health, more generally, has also been found. For example, a study of Finnish public sector employees examined the relationship between work time control and disability pension (Vahtera et al., 2010), finding that high worktime control was associated with a lower risk of disability retirement due to diseases of the musculoskeletal system, such as arthritis. Control over working times was defined as “an employee’s ability to control the duration, scheduling and distribution of his/her working time,” (Vahtera et al., 2010, p. 479). Worktime control was measured by seven items: 1) total length of a working day; 2) starting and ending times of a working day; 3) breaks during the working day; 4) taking care of private matters during the working day; 5) scheduling working shifts; 6) scheduling of vacations and paid days off; and 7) unpaid leave. The authors proposed that having low worktime control may increase the difficulty an employee
experiences in combining aspects of work and domestic life, obtaining working times that suit an employee’s resources, and optimising commuting hours. However, worktime control was not consistently associated with other causes of disability, such as mental disorders, tumours, diseases of the circulatory system, or diseases of the nervous system (Vahtera et al., 2010, p. 479).

Worktime control may have a greater impact on women’s health than on men’s health, presumably due to the disproportionate amount of domestic work performed by women. Baltès, Briggs, Huff, Wright, and Neuman (1999) examined whether the effects of work stress on sickness absence vary by the level of control employees have over their working times. The authors found that good control over working times reduces the adverse effect of work stress on sickness absence especially among female employees. In another study, worktime control was found to be an independent predictor of mental and physical health in women but not in men (Ala-Mursula, Vahtera, Kivimäki, Kevin, & Pentti, 2002).

Hall and Wilton’s (2011) exploration of alternative spaces of work for disabled people identified employee-centred flexibility as a key factor in successful workforce participation. For study participants in Canada, this manifested in terms of the structure of the workday and the employer’s accommodation of unexpected work absences due to health problems (Hall & Wilton, 2011, p. 873).

Employee-oriented flexibility, of course, is not only pertinent to when, but also where, people work. Telecommuting is a common form of distributed work. Distributed work refers to “arrangements that allow employees and their tasks to be shared across settings away from a central place of business or physical organizational location” (Belanger & Collins, 1998 cited in Gajendran & Harrison, 2007, p. 1524). Telecommuting “is an alternative work arrangement in which employees perform tasks elsewhere that are normally done in a primary or central workplace, for at least some portion of their work schedule, using electronic media to interact with others inside and outside the organization,” (Gajendran & Harrison, 2007, p. 1525). A meta-analysis of studies on the effects of telecommuting on employees found small but supportive effects on perceived autonomy, work-family conflict, job satisfaction, performance, turnover intent, and stress (Gajendran & Harrison, 2007). I was unable to find studies specifically examining the effects of distributed work on physical or mental health beyond the finding on stress reported in Gajendran and Harrison (2007). However, it is possible that distributed work forms such as telecommuting may provide more flexibility for individuals with chronic illness to integrate illness management activities into everyday life and accommodate fluctuations in bodily states from day-to-day.
The flexibility, predictability, regularity and sociability of working arrangements are particularly relevant for individuals with shift work. Prior research on shift work has found that shift work has a negative effect on personal health and family life while job schedule control has a positive impact on family functioning and lower levels of perceived stress among family members (Fenwick & Tausig, 2001, p. 1180). Fenwick and Tausig (2001) analysed the interacting effects of shift work and job schedule control on family life and health of American workers, finding that working shift work had far fewer negative impacts on family and health outcomes than lack of work scheduling control (Fenwick & Tausig, 2001, p. 1194). And, Tüchsen, Christensen, Lund, and Feveile (2008) found a moderate association between shift work and labour force exit among women in three waves of the Danish Work Environment Cohort Study.

Several studies have found clear relationships between unsociable work hours such as non-standard shift work and worker health. For example, a Canadian study of full-time workers (Jamal, 2004) examined the relationship between non-standard work schedules (shift work and weekend work) and job burnout, stress and psychosomatic health problems. Results showed that those employed in weekend work reported significantly higher emotional exhaustion, job stress and psychosomatic health problems than employees not involved with weekend work. Similar results were found for employees engaged in non-standard work shifts (other than fixed day shift, 9 a.m.-5 p.m.). These individuals reported significantly higher overall burnout, emotional exhaustion, job stress and health problems than employees on a fixed day shift. Furthermore, employees involved with both weekend work and non-fixed day shifts reported significantly higher emotional exhaustion and health problems than other employees. Similarly, Åkerstedt (1990) and Barton (1994) found that working non-social shift work hours has a negative effect on personal health.

Most studies have found that a faster working pace encourages workforce exit among older workers (Nilsson et al., 2011; Reeuwijk et al., 2013). A study of Finnish social and health care employees (Elovainio et al., 2005) examined whether early retirement thoughts can be explained by job demands, job control and their interaction, a hypothesis derived from the job demand-control model (Karasek et al., 1981). Results suggested that job demands and job control are independent predictors of early retirement thoughts even when adjusted for age, gender, educational level and self-rated health. Support was found for the interaction effect of job demands and job control on early retirement thoughts, especially among people over 45 years old. Temporal dimensions were included in the study’s measure of ‘job demands’ (e.g., ‘Time pressures and deadlines’, ‘I have too little time to do what is expected of me’, and ‘I
spend my time fighting fires rather than working to a plan’). However, ‘job control’ consisted of less explicitly temporal measures (Elovainio et al., 2005, p. 87).

In contrast, Gørtz (2012) examined the relationships between various working conditions and early retirement of Danish day-care teachers. One of these working conditions, work pressure, was measured by child-to-teacher ratio. No significant relationship was found between work pressure and early retirement. Similarly, Mein et al. (2000) found that job demand did not have an effect on early retirement for older United Kingdom civil servants during a 7-year follow up period (1988-1995). The job demand index was based on four questions about the pace, intensity of work, having enough time for tasks and difficulty in combining work tasks (Mein et al., 2000, p. 531). Other factors included in the study were found to have significant effects on workforce exit. Men and women with higher-paid employment grades, those with ill health, and those who were less satisfied with their jobs were more likely to retire early. These were all independent predictors of early retirement. Material problems (e.g., poor assets) encouraged continued workforce participation.

Wilton (2004) has emphasised the importance of working pace for disabled workers in particular. He observes ongoing intensification in the speed of the labour process in contemporary workplaces, and the negative impact this has on disabled individuals’ experiences in employment. In addition to not being able to ‘keep up’ with production expectations, many disabled workers are unable to take needed breaks during the workday due to high working pace demands. People with chronic pain, for example, may need to take regular breaks from sitting, and may pay an emotional toll if they endure more pain throughout the day due to skipped breaks from sitting (Wilton, 2004, p. 427). The problems encountered in contemporary employment for disabled workers include not only the fast working pace expectations of workplace cultures, but also expectations of greater multitasking and little need for training, and demands for emotional and aesthetic labour (e.g., being dressed and groomed in a certain way) (Wilton, 2004, p. 430).

3.2.2.3 The space-times of paid work and chronic illness
In summary, a substantial body of literature supports the idea that the spatio-temporal characteristics of work – including duration and pace, as well as the flexibility, predictability, regularity, and sociability of times and locations of work – interact with a person’s health (e.g., psychological distress, musculoskeletal diseases) and non-work activities (e.g., family, domestic work). And, the interaction of these dimensions in an individual’s everyday life will impact on the person’s labour force participation. This relationship may also be examined specifically for
individuals with chronic illness. For example, different spatio-temporal characteristics of work may interact with chronic illness management and experiences of symptoms.

As noted, paid work sometimes negatively impacts on chronic illness management (Gignac et al., 2006). Chronic illness management activities are very time consuming, costing individuals, on average, at least two hours per day (Jowsey et al., 2012). This suggests that illness management and employment activities may be in competition with one another for a person’s spatio-temporal resources. For example, clinic haemodialysis sessions are highly space-time resource demanding and inflexible in that patients are assigned a dialysis session day and time at the clinic, and at least three dialysis sessions must be spaced out over each week in order to cleanse the blood (Green & Ryan, 2009). This treatment, therefore, would likely be difficult to combine with paid work characterised by highly irregular spatio-temporal characteristics, such as a shift work schedule.

Furthermore, rhythms produced by workplace practices may impact on the level of effort required to perform illness management activities. For example, the seasonal demands for long hours in jobs with high and low work cycles (e.g., tax accounting) could possibly disrupt chronic illness management routines. Seasonal fluctuations in workload may dictate when an employee has the time to prepare healthy lunches outside of work hours and/or buy food from a venue serving renal diet appropriate food on their lunch break. It may be harder to get back into the habit (Ravaission, 2008) of eating renal appropriate foods after periods of high work intensity and time scarcity. Furthermore, following medication regimens and tracking blood glucose and pressure levels requires consistently remembering to perform these self-management activities. It also requires the synchronisation of space-time paths of the person and their medications and/or medical devices (e.g., glucose monitoring devices). Balfe and colleagues (2013) identify time pressure and lack of stable routines in the workplace as key reasons why young adults with Type 1 diabetes find it difficult to manage their condition at work. And, employees with disabilities report more time pressure than their non-disabled counterparts (Pagán-Rodríguez, 2013). It would be productive, therefore, for further research to identify what kinds of spatio-temporal characteristics of work would relieve time pressure and provide stable work rhythms on which to ‘hook’ chronic illness self-management activities in the workplace.

Furthermore, chronic illness symptoms may impact on a person’s experience as an employee to a greater or lesser degree depending upon the spatio-temporal arrangements of their work (e.g., having or not having a telecommuting option). Chronic illness symptoms are often characterised by fluctuating and unpredictable rhythms of appearance and
disappearance (Koch et al., 2013, p. 127). These may require emergency visits to the doctor or unexpected time off work. Crooks, Stone, and Owen’s (2009) study of Canadian academics with multiple sclerosis found that greater flexibility in when and where the participant worked, access to resources, and less extreme symptom fluctuation enabled these individuals to put strategies in place that facilitated their participation in paid work with chronic illness. In another study of the employment experiences of Canadian women with musculoskeletal diseases, participants stressed that the employment policies and programs they most desire are ones that accommodate their fluctuating and changing needs and abilities, such as having the option to telecommute if the body demands it (Crooks, 2007b).

How might unpredictable body rhythms combine with, for example, inflexible work hours in a job position that other colleagues cannot fill? Or, for someone with irregular shift work, how easy would it be to change shifts in order to attend an appointment with a renal specialist scheduled several months in advance? How would these situations influence an employee’s relationship with their employer and their ability to ‘keep up’ at work? And, how might an employee with chronic illness try to anticipate and compensate for these types of situations? These and other interactions between the spatio-temporal characteristics of paid work and chronic illness will be examined in the space-time analysis of this thesis (Chapters 6 and 7).

3.2.3 Caregiving and family

3.2.3.1 Family dynamics and chronic illness

The dynamics, wellbeing and adjustment of families to the chronic illness of a family member have been studied fairly extensively (e.g., Berg & Upchurch, 2007; Bruhn, 1977; Gregory, 2005; Lieberman & Fisher, 1995; Newby, 1996; Patterson & Garwick, 1994; Rolland, 1987). One approach to understanding this topic has been the application of family systems theory, in which the family is understood as a system “composed of a set of interactive elements and yet each system is distinct from the environment in which it exists,” (Newby, 1996, p. 788). This open system responds to the introduction of chronic illness, the psychosocial typology of which may vary in terms of onset, course, degree of incapacitation and severity of outcomes for the patient (Newby, 1996). Family systems respond to different phases of chronic illness, including those of crisis, chronicity and mortality (Newby, 1996; Rolland, 1987). Families have their own life-cycles involving “different transitional stages related to the coming and going of members, marriage, birth and raising of children, launching of children, retirement, and death,” (Newby, 1996, p. 788).
Research has examined relationships between family systems and functioning in families with a child with chronic illness (e.g., Atkin & Ahmad, 2000; Cohen, 1999; Fiese & Everhart, 2006; Shapiro, 2002; Williams, 1997). Likewise, studies have examined the impact of parental chronic illness on child functioning (e.g., Steele, Forehand, & Armistead, 1997).

“[R]elations and practices of care – things such as listening, feeding, changing clothes, and administering medication” (Conradson, 2003, p. 451) are central to family relationships. Caregiving has been broadly defined as “physical and emotional labour” (Conradson, 2003, p. 451) on behalf of some other(s) (Bowlby, 2012). The caregiving burden of family members in taking care of a person with a chronic physical illness has been studied extensively (see, for a critical review, Lim & Zebrack, 2004). This is also true of caregiving for persons with chronic mental illness (e.g., Schulz & Martire, 2004). And, the influence of family and friends on how individuals with chronic illness manage their health has also been examined (e.g., Boise, Heagerty, & Eskenazi, 1996; Gallant, Spitze, & Prohaska, 2007; Kerns & Weiss, 1994; Martire, 2005). However, little is known about the experience of providing care as a person with chronic illness.

3.2.3.2 Caregiving as a person with chronic illness

People living with chronic illness are not only frequently recipients of care, but are also providers of care for others; children or an ageing or ill spouse or parent, for example (Charmaz, 1997; Katz, 2004). While this topic has received relatively little attention in the literature, most existing literature focuses on the experience of motherhood with chronic illness. Scholarship overwhelmingly treated the subject of disability and chronic illness with gender neutrality until the 1990s (Thorne, McCormick, & Carty, 1997), blind to the highly gendered nature of caregiving (McKie et al., 2002). Since the 1990s, a small but growing number of studies have considered chronically ill women’s experiences, including the ways in which the socially constructed role of ‘mother’ intersects with illness and other roles such as ‘worker’.

Thorne (1990) examined the intersection of the roles of ‘mother’ and ‘chronically ill person’ in women’s lives in Canada. Mothers with chronic illness reported a contradiction between these roles, finding that fatigue, in particular, limits performance of mothering activities, both symbolic (e.g., family birthdays and holidays) and mundane (e.g., arguing with a teenage child). The ways in which chronic illness compromises their constant and on-going availability for their children was also discussed, due not only to fatigue, but also unpredictable acute episodes of illness as well as the possibility of death. A concern was also expressed about their children having to become too independent too soon, ‘robbing’ them of their childhood,
as well as the ill mothers becoming too dependent on their children’s help. Mothers also thought that their illness impacted on their children’s socialization, particularly with reference to familiarity with ill health, becoming either callous or becoming more compassionate than other children their age. Finally, mothers found that the expectations of health care providers did not integrate well with social expectations of mothering. For example, health care providers often request patients to adjust the way they live everyday life in order to manage their illness, without consideration for the way that the patient’s life is integrated into family everyday life. Also, mothers reported feeling that they had to be extremely ill and dependent in order to qualify for health services and support, but felt that they needed to be very independent and functional in order to keep their children (Thorne, 1990). Furthermore, women with multiple sclerosis have reported feeling conflicted about being unable to perform the domestic work often delegated to women in both single and dual earner households (Lyons, 1993). These kinds of difficulties in meeting the expectations and demands of mothering vary between individuals with different chronic illnesses due to differences such as levels of pain, fatigue, and level of day-to-day functioning (e.g., Poole, Hare, Turner-Montez, Mendelson, & Skipper, 2014).

A small but substantial body of literature has specifically examined motherhood among persons with HIV (e.g., Hebling & Hardy, 2007; Ingram & Hutchinson, 1999; Nelms, 2005; Sandelowski & Barroso, 2003; Street, 2012). A meta-synthesis of 56 qualitative studies from the US found that women with HIV who are pregnant or considering becoming pregnant struggle with the likelihood of transmitting HIV infection to their children, and justifying their choice to have children. As mothers, women work to resolve difficulties inherent to living with HIV infection and being a mother such as protecting their children from the stigma often associated with their illness and concerns for their children in the event of decline in health or their mortality. At the same time, being a mother is a key source of self-esteem, a sense of normalcy and well-being, and a sense of self as a ‘whole woman’ for many mothers with HIV (Sandelowski & Barroso, 2003).

Other work has drawn from the notion of biographical disruption (Bury, 1982) in understanding the impact of chronic illness on different sources of identity for caregivers, such as Wilson’s (2007) case study of HIV in motherhood in the UK. The study “highlights the need for analysis of the experience of illness that takes gender and caring responsibilities into greater account,” (Wilson, 2007, p. 611). The women in this case study carefully constructed identities as “good mothers” in compensation for the stigma attached to HIV. Also, they were intensely concerned with protecting their children by surviving until their children were adults.
and were particularly invested in their children having ‘normal childhoods’. Furthermore, a review of 13 studies regarding women’s experiences of mothering disrupted by illness found that for most women the role of mother is reframed by illness. A key priority for them is to protect their children from the effects of illness. Many experience guilt or shame, many have problems with healthcare professionals not acknowledging their mothering role alongside their patient role, and a bi-directional relationship between ‘living to mother’ and ‘mothering to live’ (Vallido, Wilkes, Carter, & Jackson, 2010).

A small case study of mothers with asthma in the Netherlands (Radtke & Van Mens-Verhulst, 2001) examined the intersection of the roles of ‘mother’ and ‘modern working woman’ with asthma, finding that while asthma required women to avoid asthma-triggering stresses of over-work; thereby threatening their role as ‘modern working woman’, motherhood offered them a socially sanctioned role. Another small case study of mothers with asthma from the Netherlands and Canada (van Mens-Verhulst, Radtke, & Spence, 2004) focused on how mothers manage their chronic illness. Their findings highlight the gendered nature of chronic illness management, finding downward “spirals” experienced by mothers. These downward spirals involve anxiety-triggering asthma symptoms, which produce more anxiety, and feeling guilty and/or depressed due to mothering limitations from asthma. This then triggers more symptoms and more limitations. Furthermore, over-doing it when compensating for limitations in mothering during ‘good times’ multiplies and worsens the frequency and severity of ‘bad times’ of asthma-related symptoms and limitations (van Mens-Verhulst et al., 2004, p. 84).

Literature discussing experiences of fatherhood as a person with chronic illness is far less developed (Barker, 2013, p. 39). An early study of American men with multiple sclerosis (Power, 1979) found that the role of fatherhood for participants mainly focused on providing family income, being the ‘authority figure’ at home, managing finances and helping make major family decisions such as child education. Day-to-day child rearing activities such as shopping and disciplining were left to their spouses (Power, 1979, p. 616). The debilitating effects of multiple sclerosis seriously threatened the role of provider. This was particularly true of the men who had to leave work, and some of them did not adopt new roles in the household by taking on domestic work or pursuing leisure activities. Instead, they assumed a “spectator role” (Power, 1979, p. 617). Other men were more adaptable after losing the role of full-time worker/provider and assumed a “participant role” at home in helping with domestic work or spending more time assisting children with homework (Power, 1979, p. 618). A positive sense of wellbeing was associated with the participant role but not the spectator role.
Chapter 3

Barker’s (2013) doctoral work on the experiences of parenting with cystic fibrosis in the United Kingdom is a rare exception in that it explores the topic for both fathers and mothers. The aim of the study was to understand participants’ hopes, beliefs and relationships as a parent and a person with cystic fibrosis. There was a temporal dimension to the analysis in that it explored participants’ experiences in the past, present and future time frames. Barker found that participants experienced time in unique ways characterised by temporal compression, surprise, and uncertainty in navigating parenthood and illness together.

Fathers had slightly different perspectives on parenting with cystic fibrosis than mothers. For example, fathers expressed a sense of responsibility to the whole family as a motivation for staying healthy (Barker, 2013, p. 78). This contrasted with mothers who were motivated primarily by their relationship between themselves and their child(ren) (Barker, 2013, p. 101). Fathers also discussed the need to adjust chronic illness management routines around the needs of their children, but felt that spending less time with their family in the short-term in order to manage their illness was justified by the possibility of spending more time with their family in the long term if they stayed healthier (Barker, 2013, p. 81). In contrast, mothers described more isolated parenting experiences in which their needs were often de-prioritised in favour of their children’s needs. Barker understands this difference between mothers’ and fathers’ experiences with cystic fibrosis from a social constructivist perspective, noting that fathers may be living up to dominant social narratives about fathers as ‘providers’, and mothers may be drawing from narratives which assign them the role of main caregiver for their children.

Very little has been written on caregiving for adults as performed by people with chronic illness. As with children, caregiving for disabled or sick adults is a gendered activity, with more women than men caring for another adult. For example, in Australia, about 16 percent of the population cares for someone with a disability, long-term health condition or frailty from age; of these, 70 per cent are women (Pocock, Skinner, & Williams, 2012, p. 68). In addition to the act of caring itself, the psychological distress of another adult’s poor health can be experienced differently depending on the person’s gender. A study of elderly couples in Groningen, the Netherlands found that women more often experience psychological distress due to their own ill health and their partner’s ill health while men more often experience psychological distress due only to their own ill health but not their partner’s ill health (Hagedoorn et al., 2001).

Charmaz has noted that for people with chronic illness, caregiving for a sick or ageing adult adds an additional, and sometimes overwhelming, activity to juggle and pace along with other everyday activities such as managing one’s own illness, a job, maintaining relationships
and dealing with family problems: “[O]rganizing, simplifying, reordering time, juggling, and pacing also become a part of caregiving. Whether or not caregiving can continue rests, in a large part, on effective control of these processes, particularly when the bulk of the work falls on one caregiver,” (Charmaz, 1997, p. 165-166). She notes that: “Juggling and pacing get complicated when both ‘patient’ and ‘caregiver’ have chronic illness,” (Charmaz, 1997, p. 165). This may increase the unpredictability of rhythms and potential for arrhythmias circulating in the chronically ill person’s life. Sometimes within a couple, a ‘patient role’ can become assigned to one person when they go through a period of particularly poor health, and this person may keep this role regardless of changes in the state of health of their caregiver partner, whose health may decline even further than their own. In other cases, partners may have long taken both of their needs into account, and they are able to exchange patient and caregiver roles as needed when the health of one partner shifts (Charmaz, 1997, p. 166).

3.2.3.3 The space-times of caregiving and family
Exploring the ways in which socially constructed roles like ‘mother’, ‘father’, ‘worker’, ‘patient’, and ‘caregiver’ interact with and sometimes conflict with one another, as explored in much of the literature above, is helpful for understanding how having a chronic illness may make being a caregiver more difficult. We may better understand how role conflict arises in the day-to-day from a logistical as well as embodied perspective by more explicitly examining the spatio-temporal characteristics that are particular to being a parent or caregiver, and then exploring how these interact with the spatio-temporal characteristics of chronic illness.

Geographers have built a substantial body of literature exploring the spaces, settings, practices, and embodied encounters that emerge from and shape relations of care (see Atkinson, Lawson, & Wiles, 2011; Conradson, 2003; McEwan & Goodman, 2010). For example, Milligan (2005) examined experiences of transition between settings of care for care recipients (e.g., from home to nursing home). Dyck (1990) examined relationships between particular domestic workplaces and women’s situationally defined identities as mothers. And, Wiles (2003) explored informal, at-home caregiving for frail, ill, or disabled elderly persons, highlighting, amongst other things, the spatial restrictions imposed by caregiving, and the contextual specificity of caregiving experiences. Geographies of care have also broadened their focus beyond the immediate sites of care and proximate bodies to “unseen neighbours and distant others,” (McEwan & Goodman, 2010, p. 103) as in individuals’ ethical considerations over choices in purchasing and consuming food grown and processed in other countries. However, for the purposes of this thesis I restrict my discussion to proximate caregiving and
care-receiving relationships. And, because participants discussed caregiving relationships primarily within familial contexts, I will focus mostly on caregiving within families.

As argued by Sophie Bowlby, Linda Mckie, Susan Gregory, and Isobel MacPherson, time, as well as space, is important to the social relationships, practices, experiences, policies, and services of care (Bowlby, 2012). Despite the inherently temporal dimensions of caregiving relationships to which I now turn, “in most geographical research on care, linkages of spatial and temporal processes are not considered explicitly or systematically,” (Bowlby, 2012, p. 2104). Most obviously, the everyday operation of a family unit requires the organisation and coordination of the repeating movements and activities of family members in time and space. The repetitive and regular spatio-temporal characteristics often typical for family life have been explored in research on family routines and rituals. The primary interest in family routines and rituals has been on their role in family functioning and the physical and psychological wellbeing of family members, especially for children (Boyce et al., 1977; Dickstein, 2002; Fiese & Wamboldt, 2000).

Routines are characterised as the observable practices of family members that are primarily instrumental and unlikely to inspire reflection by those performing them (Fiese et al., 2002). Boyce and colleagues define family routines as: “... those observable, repetitive behaviors which involve two or more family members and which occur with predictable regularity in the ongoing life of the family,” (Jensen, James, Boyce, & Hartnett, 1983, p. 194). See also the definition of routine put forward by Zisberg et al. (2007) in Chapter 3.2.1. Similarly, family rituals are “prescribed behaviour which is repetitive across time” and can be performed regularly and form part of family routines (Jensen et al., 1983, p. 193). However, they are distinct from family routines in that they have a “symbolic construction which affirms something of transcendent value” for the family (Jensen et al., 1983, p. 196).

A systems perspective on family routines and rituals understands that: “1) families are comprised of multiple levels that operate individually; interact with each other; and as a whole, reveal properties distinct from separate parts; 2) families tend toward stability in meaningful patterns of functioning; and 3) family functioning has meaning for individual outcomes,” (Dickstein, 2002, p. 441).

Family routines and rituals have been found to play an important role in family health and the psychosocial adjustment of family members (Kiser, Bennett, Heston, & Paavola, 2005), to “protect the health and well-being of family members by providing stability and continuity during periods of stressful change,” (Jensen et al., 1983, p. 193; Schultz-Krohn, 2004), to promote close and healthy family relationships (Evans & Rodger, 2008; Fiese & Parke, 2002;
Imber-Black, 2002), are linked to the health behaviours of family members (Denham, 2003), and help minimise the stresses and burden of managing chronic illness in a family member (Boyce et al., 1977; Fiese & Wamboldt, 2000). The extent and importance of routines and rituals in a given family “appears to be a reliable and valid measure of family cohesion, solidarity, order and overall satisfaction with family life,” (Jensen et al., 1983, p. 201). Family routines and rituals can be disrupted when family members’ movements and activities lack synchronicity, as in, for example, the case of families with a parent whose work takes them away from the family for extended periods of time, damaging family routines and cohesion (e.g., Thomas & Bailey, 2009).

The development and maintenance of family routines and rituals varies by ecological constraints and cultural values (Kellegrew, 2000), the introduction of new family members (Prentice, 2008), and specific space-time constraints of family members, as in, for example, dual earner house-holds or single parent households in which the parent(s) juggle work and care responsibilities (Carrigan, Szmigin, & Leek, 2006; Primeau, 2000), or low-income families with limited access to necessities such as childcare (Lowe, Weisner, Geis, & Huston, 2005) and transportation (Grieco, 1995; Roy, Tubbs, & Burton, 2004).

Much scholarship on contemporary family life describes day-to-day functioning as fast paced, time pressured, and difficult to coordinate between family members (e.g., Daly, 2002; Jarvis, 2005; Major, Klein, & Ehrhart, 2002; Pocock, 2003; Pocock et al., 2012; Southerton, 2009). While people report feeling busier and more time pressured, Southerton (2009) notes that time diary data consistently shows that people have longer durations of free time today than did previous generations (Robinson & Godbey, 2010).

There are several possible explanations for the paradox of people having more free time but feeling more time pressured. One of these is based on economic restructuring, and the impact of greater labour force participation by women who juggle domestic and workplace responsibilities (Southerton, 2009). This shift has created a fundamental shift for the family time economy of many families (Maher, Lindsay, & Franzway, 2008; Maher, Lindsay, & Bardoel, 2010). The impact of mothers’ labour force participation on families varies by differences between families such as composition (e.g., single/dual parent; number and age of children) (Nockolds, 2015), social and financial resources (Grieco, 1995; McQuoid & Dijst, 2012; Roy et al., 2004) and residential context (Schwanen, Ettema, & Timmermans, 2007). See also Schwanen and colleague’s work on parents’ lived experiences of juggling space-time constraints of work and care (Schwanen, 2006, 2007, 2008; Schwanen & De Jong, 2008). Greater limitations on children’s independent mobility (Fotel & Thomsen, 2002) and intensified
practices of chauffeuring children between locations (e.g., Dowling, 2000) may also be contributing factors.

While a more egalitarian division of child care and domestic work has emerged over the past few decades, women still perform the bulk of house-work, child care and organisation of family schedules, regardless of their employment status (Daly, 2002; Sullivan, 2000). The caregiving/work juggling act performed disproportionately by women has been shown to limit women’s individual access to urban opportunities in everyday life and impose greater fixity on women’s space-time constraints (Kwan, 1999a, 1999b, 2000; Schwanen, Kwan, & Ren, 2008). McKie et al. (2002) contend that this “has created many tensions for women as the rhythms and spaces of childcare, play, school and family provisioning (which themselves change over the life course) are not easily reconciled with the rigid time-space boundaries of most paid work,” (p. 912).

Another explanation for the pervasive experience of time pressure in households today, Southerton (2009) notes, is greater rationalisation of time in which the practices pertaining to different spheres of everyday life (work, domestic, inter-personal relationships) are increasingly organised into particular sequences and designated slots of time, producing the feeling that time is less ‘free’ (Hochschild, 1997). Others argue that people are working longer hours than did previous generations, due both to the ways in which this benefits employers as well as the consumption patterns of employees (Schor, 2008). However, not all researchers agree, and others contend that time spent at paid work has actually decreased over the course of the twentieth century (Gershuny, 2000). Either way, the larger number of women in the paid work force has increased the total amount of family members’ hours dedicated to work.

It has also been proposed that people feel more time pressured because leisure activities have become intensified and busyness has become a source of social status; a symbol of a full and valued life (Bauman, 1988; Gershuny, 2005; Giddens, 1991; Linder, 1970): “Being busy is hypothesized as a necessary requirement of reflexive identity formation,” (Southerton, 2009, p. 50). And, finally, others have proposed that innovations in communication technologies compress space and time (Giddens, 1991), accelerating the experience of everyday life (Rosa, 2003), and reducing the constraints of space and time on the tempo of activities (Southerton, 2009, p. 51), which results in the experience of time pressure. For families, communication technologies can connect family members outside the home context, blurring traditional boundaries of where and when family takes place (Wajcman, Bittman, & Brown, 2008).
Southerton (2009) argues that accounting for contemporary experiences of time pressure requires empirical analysis of past everyday lives. This is needed in order not to make assumptions about ‘past’ temporal conditions in which people had more time and everyday life was less complex. In a comparison of accounts of the daily lives of mothers in 1937 and 2000, Southerton found that contemporary mothers experience greater difficulty coordinating the space-time paths of family members: “The problems of coordination that affected the interview respondents of 2000 were less of a problem in 1937 because material constraints, working times and the local-ness of work meant that people within any given household came together at fixed times on a routine basis,” (Southerton, 2009, p. 56). By 2000 there were fewer fixed institutional events and the temporal boundaries of those events were less clearly defined. A crucial dimension of the space-times of family life, according to Southerton, lies in “understanding how temporal rhythms are ordered and re-ordered,” (Southerton, 2009, p. 61). An analysis of the interaction of rhythms within the lives of people with both caregiving responsibilities and chronic illness, therefore, may provide additional insight into understanding the conflicts and compatibilities inherent to everyday life negotiation for these individuals.

Another difference between the accounts of mothers in 1937 and 2000 was the notion of ‘quality time’ with family members. While this was not a topic of concern for respondents in 1937, Southerton’s respondents in 2000 were very concerned about the lack of and poor quality of time spent with family members; a pressing topic of contemporary concern for family wellbeing (e.g., Christensen, 2002; Kremer-Sadlik & Paugh, 2007; Roeters & Treas, 2011; Tubbs, Roy, & Burton, 2005). Southerton examined all comments referring to time spent with children, partners and friends in the 1937 diaries. Difficulties of childcare were expressed in terms of energy, but not of an impending need to create time to spend with the children. Children were referred to often as household helpers, potentially saving mothers time, and there was no implication that special measures were required to coordinate togetherness or quality time with children specifically (Southerton, 2009, p. 59). Spending time together in 1937 seemed to have been taken for granted as something that happened naturally within the spatio-temporal rhythms of the day. But it is unclear if this is due to spatio-temporal rhythms changing, or rather to changes in ideas of how time should be spent with people we are close to, and what constitutes a close relationship.

Understanding the space-times of family and caregiving, then, clearly requires more than an understanding of family member space-time paths and logistics. Davies (2001) stresses that caregiving relationships challenge notions of individually allocated space-time resources
wherein each individual receives their own share. The space-times of caregiving are relational and collective. Caregivers (most often women) share space-times with those they care for, meaning that where and when a caregiver finds herself is “importantly determined by the needs of others,” (Davies, 2001, p. 137). Many caregivers, therefore, constantly switch between different senses of space-time as they negotiate everyday life, including biological, social and chronological, processual, cyclical and linear experiences of space-time (Davies, 2001, p. 137). One of the consequences of the overlapping and interrupting space-times of caregiving is that it can be difficult for the caregiver to find opportunities for pause, restoration, and reflection (Davies, 2001, p. 140).

McKie and colleagues (2002) saw the need for recognition of the multiple and overlapping temporalities and spatialities embedded within caregiving. They drew inspiration, in particular, from Adam’s (2000) notion of timescapes to develop their caringscapes framework, citing the attention the framework brings to “the many temporal rhythms and varied human experiences of time that stem from physical and bodily processes, as well as the organisation of social institutions,” (Bowlby, 2012, p. 2110). The authors highlighted several aspects of caregiving relationships that have obvious spatio-temporal dimensions, including: “planning, worrying, anticipating, speculating, prioritizing, assessing the quality of care, accessing care, controlling care, paying for care, shifting patterns of work, job (in)security, the potential for promotion, moving home, managing family resources, supporting school work, being involved in the school or care group and so on,” (McKie et al., 2002, p. 915). Bowlby (2012) argues that time is as important as space in analyses of caregiving relationships, citing the “timescale of the human lifecourse and of intergenerational relationships to care,” “the role of memory and habituation,” “the effects of embodied temporalities on care exchanges and experiences,” and, “the effect of the time needed to move through space on the logistics of scheduling care activities” (Bowlby, 2012, p. 2105-2107). The emphasis on time, as well as space, illuminates the multi-dimensional and changing nature of the terrain of caregiving possibilities and obligations the individual negotiates (McKie et al., 2002). Later, Bowlby (2012) expanded upon this framework to differentiate between caringscapes, which focus on “individuals’ organisation of their caring activities in time-space,” and carescapes, which refer to “the resource and service context shaping the ‘caringscape terrain’,” (Bowlby, 2012, p. 2112).

I propose that in understanding the caregiving experiences of individuals with chronic illness, it is useful to think of two sets of overlapping caringscapes and carescapes; those associated with care for others, and those associated with care for the chronically ill body.
Understanding how the spatio-temporal characteristics of each interact with one another may illuminate unique aspects of being a caregiver as a person with a chronic illness. For example, as discussed above, families tend to try to coordinate the movements of family members in time and space through routines and rituals for practical reasons, but also to promote stability and resilience in the family. The activities and symptoms introduced by the onset of chronic illness may integrate into family routines, resist integration, or perhaps disrupt family routines. Furthermore, the dominant requirement of co-presence in caregiving creates a space-time coupling constraint that restricts caregivers’ space-time paths by where and when they are needed. Aspects of illness management such as dialysis or time in the hospital are likely to present serious challenges for a caregiver with chronic illness to ‘be there’ when needed. The notion of spending ‘quality time’ is felt by many contemporary caregivers as an indispensable part of a caregiving relationship in addition to the logistical and practical spatio-temporal aspects of caregiving. Quality time likely occurs in particular places, such as a campground during summer months or the family living room in the evening. The potential restrictions on a chronically ill person’s space-time path due to illness and illness management may reduce opportunities for ‘quality time’ to take place. Symptoms and illness management may also alter the qualities of spaces where time with family is spent.

Furthermore, contemporary accounts of family life describe time pressured lives for caregivers and difficulties synchronising family member space-time paths and juggling work demands. This is due, in great part, to changes to what are considered ‘normal’ practices for family members as compared to past generations. Chronic illness management activities, such as regular visits to the doctor and chemist, as well as the unpredictable nature of chronic illness symptoms, may add further complexity to this juggling act and increase the likelihood of arrhythmias in family member movements and activities. Mitigating and contend with such arrhythmias may make it less feasible for everyday activities to become habitual and effortless, such as when and where to pick up the kids, fit in a doctor appointment, have dinner, or buy groceries. This may mean that even more deliberate reflection, planning, coordinating, anticipating, and re-scheduling ‘on the fly’ may be required for individuals with both illness and caregiving responsibilities.

Finally, both caregiving and chronic illness are associated with unpredictable rhythms, which, in combination, increase the likelihood of experiencing arrhythmias in everyday life. The “fluidity of time and space” (McKie et al., 2002, p. 913) associated with being needed as a caregiver, including “planning, worrying, anticipating, speculating,” (McKie et al., 2002, p. 915) may be compounded by experiences of uncertainty surrounding the progression and
fluctuation of a caregiver’s chronic illness. Individual space-time resources are blurred by the collective sense of space-time experienced in providing care for others (Davies, 2001). The sometimes unanticipated needs and demands of the chronically ill body also likely compromise a person’s sense of ownership over their spatial and temporal resources. These experiences of uncertainty in how everyday life will unfold as a caregiver with chronic illness may undermine the force of habit in helping an individual to juggle both chronic illness management tasks and a caregiving and family member role. These and other aspects of overlap between the caringscapes and carescapes of providing care for others as well as a chronically ill body may be explored.

3.2.4 Leisure, recreation, and tourism

3.2.4.1 Leisure, recreation, and tourism by people with chronic illness

While leisure, recreation and tourism activities may not be as immediately pressing as non-discretionary activities, such as preventing a major health crisis, maintaining employment, or caring for a child, these activities are often key sources of meaning, enjoyment and sense of purpose for individuals. Leisure, recreation and tourism are interrelated and overlapping concepts, the definitions of which are contested (Hall & Page, 2014, p. 3). However, tourism and recreation are generally regarded as subsets of the wider concept of leisure (Hall & Page, 2014, p. 4). Therefore, and for the sake of brevity, I will refer to this category of activities as ‘leisure’. Leisure activities are often dismissed in scholarly work as unimportant, while the role of work activities is privileged in understanding how society is organised (Hantrais, Clark, & Samuel, 1984; Urry, 1994).

Urry (1994) notes that “the apparently simple category of leisure is diverse, complex, and impossible to capture in some simple definition,” (p. 132). One way of conceiving of leisure activities is to divide them into “casual leisure” and “serious leisure” (Stebbins, 2001). Casual leisure is an “immediately, intrinsically rewarding, relatively short-lived pleasurable activity requiring little or no special training to enjoy it,” (Stebbins, 2001, p. 53). Casual leisure includes activities like talking with friends, relaxing in a recliner, strolling in a park, or watching television, and is often used as a regenerative response to the strains and stresses of everyday life (Stebbins, 2001, p. 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. It is profound, long-lasting, and invariably based on substantial skill, knowledge, or experience, if not on a combination of these three,” (Stebbins, 2001, p. 54). Examples of serious leisure are having a committed volunteer role in an organisation, playing a musical instrument, cycling on a team or white water kayaking.
While casual leisure offers short-term respite and enjoyment, serious leisure can take on a significant role in how a person constructs their sense of self and builds their social world: “[S]erious leisure generates uncommon rewards for its participants. […] Among them are fulfilling one’s human potential, expressing one’s skills and knowledge, having cherished experiences, and developing a valued identity,” (Stebbins, 2001, p. 54). Serious leisure also comes with significant social rewards, making new friends, feeling a part of a group that has accomplished something significant (e.g., organising a community festival), and/or a sense of being needed and helpful (Stebbins, 2001, p. 54-55). Serious leisure may be particularly important for retired individuals who may miss the routine and sense of purpose of a full-time job (Stebbins, 2001, p. 56). These kinds of activities do not, of course, come without a cost, including concentration, preparation, perseverance, and dealing with group conflict, to a greater or lesser degree, and depending upon the type of activity (Stebbins, 2001).

The majority of research on the impact of chronic illness on everyday activities has focused on the individual’s ability to perform obligatory activities (e.g., hygiene, sleep) and, to a lesser extent, committed activities (e.g., paid work, child care) at the expense of leisure activities such as entertainment away from home, socializing, hobbies, public service, tourism and participating in clubs or religious organisations (Katz, 2004, p. 44). Katz (2004) argues for a broader understanding of activities that are relevant to people with chronic illness, conceived in terms of “valued life activities” (p. 41). Many of the activities that people with rheumatoid arthritis, for example, identify as most closely tied to their quality of life are not measured in conventional functional assessments (Katz, 2004, p. 45). Inability to perform these valued life activities may play a substantial role in how people with chronic illness perceive their own health, over and above other measures of health status, disease symptoms, and general physical functioning (Katz et al., 2009).

Furthermore, loss of valued life activities in a person’s life, which often include leisure, “is the aspect of functional decline that leads to the development of depressive symptoms,” (Katz, 2004, p. 48). Katz (2004) notes that depression, in turn, can inhibit recovery from surgery (Mutran, Reitzes, Mossey, & Fernandez, 1995), increase the risk of physical decline and mortality (Bruce, Seeman, Merrill, & Blazer, 1994; Covinsky et al., 1999; Penninx et al., 1998; Pulska, Pahkala, Laippala, & Kivelä, 1999), is associated with poor adherence to medication regimens or overmedication (DeVellis, 1993; Katon & Sullivan, 1990) and poor treatment adherence (Katon & Sullivan, 1990). Loss of ability to perform leisure activities may also mark for the individual “a biographical shift from a perceived normal trajectory”, experienced as a crisis of departure from how the individual anticipated their life would unfold (Bury, 1982, p.
Clearly, it is important to understand how people with chronic illness participate in activities of leisure, recreation, and tourism in addition to non-discretionary activities, such as cooking or being an employee, for the sake of individuals’ quality of life as well as their short and long term health.

Individuals with rheumatoid arthritis have reported that their illness negatively affects several discretionary activities of value to them, including: recreation activities (e.g., taking walks, gardening, bicycling) (74%); hobbies or crafts (57%); traveling or getting around the community (36%); social events (33%), religious activities (28%); and visiting friends or family at home (11%) (Katz, 2004, p. 47). Katz offers two suggested points of intervention in the relationship between chronic illness, valued life activities and depression. The first is to reduce the impact of functional limitations of illness on the person’s ability to participate in activities though modifications in the way activities are performed, replacing activities or pacing oneself. The second point of intervention is to reduce the psychological impact of a person’s inability to perform valued life activities through counselling in addition to rehabilitation services (Katz, 2004, p. 55-56).

Perhaps unsurprisingly, discretionary activities are often the first to go when a person’s functional abilities are impacted on by illness. Three months post-treatment, cancer survivors reported greatest reduction in activity in high physical demand leisure activities (34% reduction) and social activities (16% reduction), and to a lesser extent, instrumental activities (7% reduction) and low physical demand leisure activities (7% reduction) (Lyons, Lambert, Balan, Hegel, & Bartels, 2013). Reduction in discretionary activities may be due to the individual needing to reconsider how to spend limited energy (Lyons et al., 2013), less available time due to illness management activities (Katz, 2004), pain (Ahlstrand, Björk, Thyberg, & Falkmer, 2015), and decreased muscle strength (Marko, 2012).

3.2.4.2 The space-times of leisure, recreation, and tourism

What is known about the spatio-temporal characteristics of leisure activities in general? As noted by Stebbins (2001), there is an extraordinarily wide variety of casual and serious leisure activities that individuals may engage in, which likely come with an equally wide variety of spatio-temporal characteristics. Similar to discussions on problems of synchronisation between family member space-time paths (see Chapter 3.2.3), Urry (1994) has argued that there are indications of “time-space desynchronisation in many areas of leisure activity” between individuals due to greatly increased variation in people’s consumption patterns (Urry, 1994, p. 139). Put another way, there is a diminishing tendency for an individual’s leisure activities to coordinate in space and time to those of others in the individual’s social network. Examples
include not eating at fixed meal times and places with friends or family, the growth of independent travellers who avoid group participation, and the recording, storing, repeating and breaking-up of TV programs for later consumption. Greater difficulty in synchronising leisure activities may increase the difficulty households and families have in sharing leisure activities. This, he argues, may be related to the emergence of the notion of ‘quality time’ (see Chapter 3.2.3) for those experiencing desynchronisation. Quality time, for these individuals, may be an effort to ensure “short but sweet moments of uninterrupted ‘presence availability’, such as the candlelit dinner, the short break holiday, or the long weekend,” (Urry, 1994, p. 139). This desynchronisation of leisure is likely due to the decreasing importance of societal institutions such as family, religion and trade unions in directing people’s tastes, values and norms (Urry, 1994, p. 142).

Van der Poel (1997) examined leisure in terms of the commodification and consumption of time for leisure, and the many ways people may choose to consume leisure time. The choices people make in how to spend their leisure time are part of how the individual constructs their sense of self. Van der Poel notes that there are limits placed on how the individual can ‘play’ with their identity through leisure time consumption by restrictions regarding what is appropriate for a particular context (e.g., sexual subcultural group meeting places), normative expectations about social positions and roles (e.g., housewife) and the resources (including finances) that the individual can draw from (Van der Poel, 1997, p. 178-179).

In discussing these differences in access to and consumption of leisure, Van der Poel refers to “leisure-scapes”, as in the leisure-scape of a judge or the leisure-scape of a factory worker (Van der Poel, 1997, p. 178). For example, the leisure-scape of someone with substantial financial resources is likely to include privacy as a characteristic, as money can buy access to time and space away from scrutiny. Privacy may be used to enjoy leisure one would not want associated with oneself in public, such as consumption of illegal drugs. Indeed, leisure takes different forms depending on socio-political, cultural and economic context (e.g., Horne, 1998), gender, social class, paid work, cultural capital and household situation (e.g., Deem, 1996). Women in western societies, for example, are often expected to fit their leisure activities around family routines and care and support family members at the expense of time and space for leisure (Stalp, 2006). The social and physical nature of some sanctioned leisure spaces can prevent some women from experiencing leisure in these places at certain times. In response, some women create leisure experiences for themselves in spaces not traditionally conceived for leisure, such as terraces on urban streets (Mowl & Towner, 1995). What, then,
characterises the leisure-scape of a person with chronic illness, taking into account the particular constraints and characteristics of chronic illness? I will explore this question through the space-time analysis of this thesis (Chapters 6 and 7).

Until the mid-1990s, leisure and recreation researchers privileged the temporal dimension of leisure activities over the spatial (Mowl & Towner, 1995), describing the leisure experience “as consisting of time, activity, or a state of mind,” (Henderson & Frelke, 2000, p. 18). Social and cultural geographers, however, have provided rich exploration of the roles of place and space in leisure, recreation and tourism (e.g., Crouch, 2013; Hall & Page, 2014). Crouch (2000), for example, advocates for a highly relational understanding of the spatial dimension of leisure and tourism. Space can be understood simply as the background, distance to, container for, or location of leisure, such as a National Park (Crouch, 2000; Henderson & Frelke, 2000). In these senses it takes on absolute and relative meanings of space (Harvey, 2009). Place can also be understood as a cultural text that people read and recognise, as in an ‘exotic’ landscape advertised in brochures (Crouch, 2000), taking on the relational quality of place that is produced through meaning and experience (Harvey, 2009).

The relationship between place and leisure can also be understood as an encounter; in terms of the individual engaging, encountering and grasping the world through a process of embodiment (Crouch, 2000, p. 67). This perspective allows for recognition of the mutually transforming process occurring between people and places through leisure practices: “First, the person grasps the world multi-sensually. Second, the body is ‘surrounded’ by space and encounters it multi-dimensionally. Third, through the body the individual expresses him/herself through the surrounding space and thereby changes its meaning,” (Crouch, 2000, p. 68). An example would be the ways in which dancing and intoxicated bodies in a darkly lit night club contribute to ‘making’ the clubbing context that those bodies experience. Through past processes of embodiment, places can evoke intense memories, emotions and associations (Henderson & Frelke, 2000, p. 19), as in a summer home where one spent time as a child, a dusty work shed where one finds respite from the pressures of work and family, or a campground where old university friends gather.

Time, of course, is implicit in process and therefore integral to processes of embodiment in places of leisure. People must have access to certain places and spend time there at certain times and over certain intervals in order to be able to enjoy different leisure activities. Power relations manifest in what is deemed acceptable leisure behaviour for different people in different spaces, and, in fact, who has access to certain spaces of leisure in the first place (e.g., a legal drinking age required for access to a bar) (Henderson & Frelke, 2000, p. 19).
Furthermore, “each place presents us with a unique set of opportunities and constraints, not just in terms of its physical structure, but also its social environment,” (Mowl & Towner, 1995, p. 103).

A final note on the space-times of leisure must include tourism. Tourism is now a leisure expectation for most people in wealthier countries, and is the world’s largest industry (Hall & Page, 2014). Tourism may be regarded as “one of a range of choices or styles of recreation expressed through either travel or a temporary short-term change of residence,” (Hall & Page, 2014, p. 6). Mobility, then, is central to the tourism dimension of leisure. Arguably, tourism is directly linked to wealth and privilege: “[F]or those with sufficient income and time, particularly in the developed world, extended voluntary leisure or business travel (what we would usually describe as tourism) is part of their routine on a seasonal or annual basis, and for some highly mobile individuals, on a weekly or daily basis,” (Hall & Page, 2014, p. 7). Traveling vacations are often used to disrupt intensified, hectic lifestyles, unrelenting clock time and work routines (Deem, 1996). Hall and Page (2014) note that while people are more highly mobile than in past generations, space-time constraints still restrict the amount of time and spatial reach people have in enjoying tourism. Wealthier travellers, for example, may shift from one mode of transport to another faster mode, spending money in exchange for time (e.g., flying between cities within a country instead of taking the bus). Or, in another example, a less wealthy traveller may travel a shorter distance from home in order to be able to afford a longer period of time at their destination (e.g., spending a vacation down the coast instead of traveling abroad) (Hall & Page, 2014, p. 7).

In summary, the issue of engagement in leisure activities for people with chronic illness is rarely studied even though these activities are linked to individuals’ mental and physical health. Difficulties performing these kinds of discretionary activities are most often explained in terms of functional limitations of chronic illness, which can become more or less disabling depending on the type of leisure activity the person wants to perform (e.g., hiking versus lunching with friends). Literature on the space-times of leisure activities, more generally, has noted a de-synchronisation in leisure practices between individuals, the ways in which individuals use leisure time consumption choices to inform their identity, and the ways in which different individuals are constrained in participating in different leisure activities in different places and times. Furthermore, the ways in which individuals relate with, are transformed by and transform spaces of leisure has been studied.

Questions regarding an individual’s access to the times, spaces and places of leisure, synchronisation of practices, frequency, physical requirements and embodied engagement and
encounter with desired leisure may be especially pertinent to everyday life with chronic illness. The level of difficulty a person with chronic illness has persisting in enjoying leisure activities after the onset of illness likely varies depending on the interaction of the spatio-temporal characteristics of different types of leisure activities and with those of their illness. The wide variety of leisure activities that exist come with an equally wide variety of spatio-temporal characteristics. For example, a volunteer position may come with authority constraints imposed by the organisation a person is serving that restrict when and where volunteer services may be provided. Many recreational groups are associated with coupling constraints, wherein members must come to the same place at the same time in order to enjoy an activity together (e.g., an orchestral rehearsal). Furthermore, some leisure activities such as hiking may be hampered by capability constraints on the distance a person is physically capable of walking.

Given these types of spatio-temporal characteristics, many activities of leisure may compete for space-time resources with more pressing activities of survival and necessity associated with chronic illness. For example, basic activities of everyday living such as rest and physical therapy for people with rheumatoid arthritis are very time-consuming, leaving little time for other less immediately pressing, but still meaningful activities like leisure (Katz, 2004, p. 45). In another example, the restrictions of dialysis on individuals’ abilities to travel away from home are a recognised concern for those with ESKD and their family and caregivers. Patients with ESKD and their caregivers have reported that the ability to travel outside of their home region is one of the most important restrictions dialysis places on their lives, and this is particularly true for retired individuals who had imagined travel as a key aspect of their retirement (Morton, Tong, Webster, Snelling, & Howard, 2011; White & Grenyer, 1999). Dialysis patients have expressed feeling ‘tied’ to the machine, and that arranging to dialyze while on vacation was too stressful and medically risky. This prevents many dialysis patients and their family from having the benefits of relaxation and freedom from a regular schedule offered by a traveling vacation (Polaschek, 2003, p. 47).

Other illness management activities, such as complying with dietary restrictions, may also make a person more reluctant to venture beyond familiar environments, curbing participation in various kinds of leisure activities that require travel (e.g., a regional arts and crafts competition). Furthermore, stigma or shame associated with visible manifestations of chronic illness (e.g., the bulging and scarring of a dialysis access point on a limb) may discourage individuals from enjoying leisure activities associated with certain settings (e.g., sitting on a hot beach in shorts and a sleeveless shirt).
Finally, as noted above, some discretionary activities demand physical exertion or great concentration. Fluctuations in energy levels and physical functioning common among people with chronic illness may make regular participation in these activities difficult; particularly when they are meant to be performed in conjunction with other people (e.g., team sports or fishing trips). Furthermore, embodied rhythms of chronic illness may impede regular and frequent leisure activity performance. This, in turn, may disrupt the effortless skill afforded by habit (e.g., rehearsal of a musical instrument), and decrease the person’s experience of mastery and the pleasure they derive from the leisure activity.

3.2 Chapter summary

Literature on different areas of individuals’ lives with chronic illness has tended to form siloes of knowledge on each topic with little understanding for the overlaps between them. In this chapter, I have reviewed research relevant to patient self-management of chronic illness, paid work participation, caregiving and family, and leisure, recreation, and tourism for people with chronic illness.

Most commonly, chronic illness management has been understood primarily in terms of a problem of patient education, motivation and self-efficacy, as well as the health routines and habits the patient forms in everyday life. Paid work participation by people with chronic illness most has often been understood as a problem of the physical limitations of the chronically ill body and the attitudes of and discrimination by employers and co-workers. Caregiving as a person with chronic illness has been understood primarily as a problem of conflict between the socially constructed roles of ‘mother’, ‘father’, ‘patient’, and ‘worker’. Finally, the pursuit of leisure, recreation and tourism for people with chronic illness has most often been disregarded as secondary to obligatory activities (e.g., illness management, maintaining an income). What little has been written emphasises insufficient time and physical limitations associated with illness as barriers to leisure activity.

As outlined in the sections above, each of these aspects of everyday life have certain spatio-temporal characteristics. These characteristics may interact with the space-times of other aspects of everyday life, including the aforementioned spatio-temporal characteristics of chronic illness symptoms and management (Chapter 3.1; 3.2.1), which may include the space-time-consuming and highly structured routines of illness management, fluctuating patterns of symptoms and capacities of the body, shrinking spatial reach, and the unpredictable ways that illness may progress. A space-time geographical approach, as presented in Chapter 2, offers opportunities to examine the interface of these different parts of people’s everyday lives as experienced by the individuals. This offers avenues through which to identify points of
Chapter 3

intervention to more effectively address barriers that individuals with chronic illness face in trying to engage with and negotiate diverse aspects of everyday life.

In the following chapter (Chapter 4), I provide a description of the methodological choices I made and the methods I employed in my qualitative case study of individuals with chronic kidney disease in Australia.
Chapter 4 - Methodology

4.1 Methodology

4.2 Methods
4.2.1 Demographic and health survey
4.2.2 Travel and activity diary
4.2.3 Chronic illness management inventory and self-assessment
4.2.4 In-depth interviews

4.3 Recruitment, sampling and saturation
4.3.1 Recruitment
4.3.2 Sampling
4.3.3 Saturation

4.4 Ethics
4.4.1 Ethics approval
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4.5 Data collection procedures
4.5.1 Phone contact
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4.5.4 Interview
4.5.5 Thanking participants
4.5.6 Storing paper materials and audio recordings

4.6 Participants
4.6.1 Participant characteristics

4.7 Analysis

4.8 Summary

In this chapter, I describe the methodological orientation of the study and the methods I employed to address the study objectives and aim. First, I give an account of the methodological orientation of the study and the reasons for making these methodological choices. I describe the multiple methods I employed, including how they worked together.
Then, I discuss recruitment, sampling strategy, and saturation. I describe data collection procedures. I give participant characteristics and a description of pertinent study setting characteristics. Then, I describe my analysis and how I conducted it. I recount the process of obtaining ethics approval for the study (ETHLR.13.018), and the potential ethical issues of the study and how I addressed them. And, finally, I give a summary of the chapter and the ways in which I achieved qualitative rigour in this study.

The aim of this study was to understand experiences of time, alongside space, in negotiating everyday life with chronic illness (see Chapter 1.4.2). In order to reach this aim, I identified and strove to meet the following five objectives:

Objectives:

1) Identify the predominant activities in participants’ lives (e.g., managing chronic illness, working).

2) Describe the spatio-temporal characteristics of everyday activities and of chronic illness (e.g., (in)flexible, fluctuating, (un)predictable, (ir)regular, cyclical, episodic, (in)frequent, (im)mobile).

3) Understand the origins of these spatio-temporal characteristics (e.g., externally/internally imposed, the body, treatments, conventions of social practice, social institutions, individual habits).

4) Observe how spatio-temporal characteristics of activities and chronic illness interact (e.g., arrhythmias, conflicting demands on space-time resources).

5) Understand how participants experience the interaction of these spatio-temporal characteristics.

4.1 Methodology

A wide range of methods and methodological practices are applied in contemporary space-time geographical research in order to grasp different senses of space and time. Quantitative, qualitative and mixed-methodology approaches are all taken, and methods range from statistical analysis and interviews, to geovisualization and unstructured on-site observation (Schwanen & Kwan, 2012, p. 2045-2046). In order to learn about participants’ experiences of interacting spatio-temporal dimensions of everyday life, I took a multi-method qualitative case study approach. 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, p. 235).
This kind of on-the-ground learning has been accomplished in qualitative case studies in space-time geography, allowing researchers to approach the ambiguities, complexities, and contradictions of human experience as they unfold through time and across space. For example, Schwanen (2006) used one day travel and activity diaries completed by parents in dual-earner households to help inform discussion in subsequent semi-structured interviews. This approach allowed for more nuanced understandings of participants’ experiences, finding that boundaries defining what it means to be ‘on time’ are informed not only by clock time, but also the times of the body and relational events in the individual’s physical environment. The present study was similarly designed to gather data pertaining to participants’ everyday activities, the constraints and affordances experienced in how they can organise what, where, when, and how they perform activities, and everyday rhythms circulating within everyday contexts and the body. In particular, I hoped to gain insight into situations in which performance of a desired activity was especially easy or difficult.

In addition to the methodological orientation of this study, my own positionality as the researcher conducting the study must be acknowledged as a force shaping the knowledge embodied in this text (Rose, 1997). As stated in the introduction, I chose CKD for this case study because it shares similarities with many other 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). However, my motivations for choosing chronic illness, in general, as a topic must be recognised. I am fascinated by the slow, unremarkable transformations that thread through the experience of life, and the difficulties we often experience in perceiving and understanding these transformations in ourselves and in our surroundings. This has drawn me to the thinking on time and space reviewed in Chapters 2 and 3, as well as the very idea of chronicity.

On a more personal level, a close family member of mine has lived with multiple sclerosis for over 20 years. I chose not to conduct a case study of individuals living with multiple sclerosis for this reason, fearing that I would be too emotionally enmeshed in this particular disease to interpret participants’ stories. However, having a close family member with a chronic illness has motivated me to learn about others’ experiences living with chronic ailments. I deeply desire to understand how life can be lived to the fullest for individuals whose bodies demand the acceptance of limitation and suffering, and that motivation has likely coloured the interpretations I have made of participant accounts.

Finally, as a foreigner within the study setting, my nationality and cultural background shaped my interactions with participants. Although I have lived the better part of a decade
outside the US, I recognise that most people outside the US view me first and foremost as an American. I moved to Australia at the beginning of my PhD, and left three years and eight months later after submitting my thesis for examination. I doubt that after that relatively short amount of time that I can fully grasp the role my nationality played in my participants’ views of me. I do know that I have found that many, if not most, Australians enjoy explaining their expressions and cultural references to foreigners. I took advantage of this during interviews, finding that participants seemed to be pleased to explain things to me, like the meaning of “hard yakka” (hard work), and this served to build rapport. Also, I sometimes thought that participants were willing to elaborate on mundane day-to-day things in greater detail because they were aware of my ignorance of many Australian references. I will never know. I think it is almost certain that I misunderstood or missed some things participants were trying to convey, being a foreigner without the historical, linguistic, and cultural references of an Australian researcher. However, I will likely never understand the extent of these misunderstandings.

4.2 Methods

The five research methods I employed in this study are listed below, and an explanation of how I used these methods together is given. I then describe each method in full in separate subsections.

1) **Demographic and health survey.** This brief, one-page survey provided basic socio-demographic information, CKD disease stage and history, and key information about factors that influence spatio-temporal organisation of everyday life, such as caregiving responsibilities and employment status.

2) **Travel and activity diary.** The diaries provided a record of participant trips, activities, and arrival and departure times over two sample days.

3) **Chronic illness management inventory and self-assessment.** The inventory and self-assessments provided a record of the chronic illness management activities participants felt they should perform, and how well they felt they had done at performing those activities over two sample days.

4) **In-depth interviews.** Semi-structured, in-depth interviews explored the spatio-temporal characteristics of different aspects of participants’ everyday lives, how these characteristics interact with one another, and how these characteristics impact on participants’ experiences.

Participants recorded their movements between locations and activities performed over two sample days on paper travel and activity diaries (see Appendix 1: Travel and activity diary).
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The diaries provided a general picture of the number, types and temporal demands of activities participants juggle (e.g., chauffeuring children, going to work, visiting the doctor, volunteering), where these activities are located, and the transportation used. At the end of each of the sample days, participants completed an inventory of activities related to managing their illness and co-morbid conditions, and rated the level of success they felt they had had in performing each activity (see Appendix 2: Chronic illness management inventory and self-assessment). This provided a preliminary understanding of the illness management activities each participant must integrate into everyday life.

I interviewed participants the day following the sample days, or in a few cases, within a few days, as was convenient for the participant. Initially, I only requested one sample day in order to minimise the data collection burden for participants. However, a pilot study of three participants indicated that while the methods employed were successful in gathering the needed data, clear variations in participant 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. I asked the remaining 23 participants to provide two sample days, and asked those receiving dialysis to sample on a non-dialysis treatment day as well as a dialysis treatment day. While sampling more than two days would arguably provide a richer understanding of participants’ regular everyday activities, interactions with organisations, and experiences of illness, I chose to minimise 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.

The diaries and illness management inventories helped sensitise me to the organization of participants’ activities in time and space, and how successful each felt in managing their illness. This aided the me to probe for moments in the sample days in which balancing everyday activities and managing illness were especially difficult or easy, and interviewees also often offered examples of similar past situations. This multi-methods approach allowed situations to come to light that may otherwise have been overlooked in the interview. For example, if a participant indicated that they had felt very unsuccessful in following a renal diet on one of the sample days, I prompted for rich description around the situations on that day in which the participant had eaten. I familiarised myself with the content of the diaries and inventories by reviewing and clarifying what participants had recorded at the beginning of each interview. Diaries and inventories were not collected from participants prior to meeting for the interview, as this would have incurred additional temporal and logistical costs to the participant. Also, this had the benefit of reducing the amount of time between sample days
and the interview, meaning that participants’ memories of experiences and events of those days were arguably stronger.

4.2.1 **Demographic and health survey**

The demographic and health survey (see Appendix 3: Demographic and health survey) was a one-page survey participants filled out at their first meeting with me (see also ‘Data collection procedure’ sub-section below for the order and timing of data collection tool employment). It requested basic information about each participant regarding factors known to influence the constraints and affordances individuals experience on their space-time resources, namely, age, gender, residential location, employment status and occupation (if applicable), caregiving responsibilities (e.g., for children, a disabled/sick partner, or an aging parent), if the participant has access to a car (driven by themselves or another person in their household), financial resources (expressed as household size and a fortnightly household income range), and self-identified ethnicity (Janelle, Goodchild, & Klinkenberg, 1988; Kwan, 2000, 2008, 2013; McQuoid & Dijst, 2012; Palm & Pred, 1974; Schwanen, 2008; Thompson, 1967). Participants were asked to select an income range that represents their approximate fortnightly net household income. This strategy was chosen in order to make it easier for participants to select an income without having to know the exact figure, as only an approximate idea of their household income was needed for the study.

In order to also strive for a range of disease stages, physical functioning, and illness management experiences, participants were asked about their CKD disease stage, Glomerular Filtration Rate (GFR) which is a biomedical marker of level of kidney functioning, the year of CKD diagnosis, whether or not the participant is currently receiving dialysis treatment, and if the participant has a caregiver (e.g., someone who helps the participant with things like managing medications, grooming, chauffeuring, house-cleaning). Together, this information helped direct the purposive sampling of participants (described further below) to find participants with a range of different characteristics that may impact on the space-times experienced in everyday life with chronic illness.

4.2.2 **Travel and activity diary**

The travel and activity diary (see Appendix 1: Travel and activity diary) was adapted from McQuoid and Dijst (2012) and consisted of a one-sheet table which provided several rows for recording trips made on the diary. Column headings prompted for the departure time, destination address or street intersection, the time the participant felt they should ideally arrive at the destination, the transportation mode used (car, bus, etc.), the time the
participant actually arrived at their destination, and the activity or activities performed at the
destination location, including those performed via Information and Communication
Technology (ICT) devices. This provided information regarding the types of activities
performed, the duration and sequence of activities, and the transportation modes and ICT
devices used on the diary day. Participants were asked to record this information as soon as
possible during the diary day while the information was still fresh in mind. Participants were
asked to record the arrival time they felt was best or most appropriate for each activity in
addition to recording the actual arrival time. This provided an opportunity to understand the
degree of pressure the participant felt when departing one activity and travelling to another.

The travel and activity diary provided data regarding the spatial and temporal
characteristics of activities of a ‘typical’ week day which aided in assessing the level of
flexibility each participant had in how they organised their activities in time and space. The
diary was useful in in-depth interviews as a starting point for discussion regarding logistical and
embodied spatio-temporal characteristics of everyday life activities, regular practices, and
interaction with environments along the space-time path. The travel and activity diary served
primarily as the ‘jumping off point’ for structuring the in-depth interview (discussed below).
Also, the structured format of the diary itself ensured that all activities on the sample day were
recorded instead of only the ones the participant thought worthy of noting as is the case in
open format or verbal diaries (Minichiello, Aroni, & Hays, 2008, p. 110).

A limitation of the travel and activity diary method used in this study is that participants
were sampled for only two days, rather than a longer period (e.g., one week or one month).
While a one, two, or three day sample method is common in space-time geographical research
(e.g., Chen et al., 2011; Dieleman, Dijst, & Burghouwt, 2002; Dijst & Vidakovic, 2000; Janelle et
al., 1988; Kwan, 1999a), it has potential drawbacks. A small number of sample days may
overlook day-to-day differences in individual accessibility as demonstrated by Neutens,
Delafontaine, Scott, and De Maeyer (2012). This study found that “even for fulltime workers on
weekdays, considerable day-to-day variability in the accessibility level of a single person can
exist as a consequence of differences in space–time constraints,” (p. 81). This implies that
individual differences in accessibility levels detected in studies using pooled samples of travel
and activity diaries of various individuals collected on different days of the week may not
reflect the inter-personal space-time accessibility differences of interest to these studies, but
rather the way that space-time constraints tend to vary by days of the week.

The use of multiple methods in this study helped mitigate this risk. The strategy of
having participants ‘lead’ the interviewer through the sample days in a semi-structured
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interview (described below) allowed insight into the degree to which the sample days were similar to or contrast with participants’ usual routine and events in everyday life. Almost invariably, participants spontaneously compared and contrasted the events of those sample days with their ‘usual routine’. When this did not occur, the interviewer prompted for a comparison to gather information regarding participants’ general routines.

Another challenge of the travel and activity diary method used in this study was user error in filling out the survey. This is a concern with all diary methods (Bolger, Davis, & Rafaeli, 2003). This risk was mitigated by requesting that participants fill out the details of each trip and associated activities as it was taking place. In other words, to record the departure time at the time of departure, and the arrival time at the time of arrival, and so forth. However, there was still the risk that participants might fill out the diary at end of the day or even the next day, meaning that details and accuracy could suffer. However, the diary method is still more accurate than relying solely on participant recall of activities, trips and departure and arrival times after the sample day. While Takahashi, Wiebe, and Rodriguez (2001) did use this recall method, the data produced by the diary used in conjunction with participant recall during an interview is arguably more accurate.

A small, two day sample was selected for this study for several reasons. Firstly, participants in this study are chronically ill individuals with highly demanding treatment regimens. Requesting diary completion for more than two sample days may have created an unreasonable burden on participants, and may have decreased willingness to participate in the study. Secondly, the quality and consistency of diary completion would likely have dwindled over time as is common in longer duration diary samples regardless of the population (Bolger et al., 2003). And thirdly, the temporal, financial, and human resource limitations of this study did not permit additional data collection and analysis.

4.2.3  Chronic illness management inventory and self-assessment
The inventory and self-assessment was self-administered on paper by the participant at the end of the diary day and took approximately five minutes to complete (see Appendix 2: Chronic illness management inventory and self-assessment). It listed all chronic illness management-related activities that people with CKD commonly have to perform in everyday life, such as following a low-salt diet and checking insulin levels, as well as spaces for writing-in additional chronic illness management activities. There was a separate column for the participant to indicate if each activity was applicable to the particular sample day for which they were completing the inventory. If it was applicable, they were asked to use a Likert scale provided in additional columns to rate of the degree to which they felt they had successfully
performed the activity on that day. The Likert scale offered four categories: ‘Completely unsuccessful’, ‘Somewhat unsuccessful’, ‘Somewhat successful’, and ‘Completely successful’. The decision to use four categories was made in order to reduce the likelihood of participants too frequently choosing a neutral rating of their success in performing each activity.

Like all tools of measurement, Likert scales have their drawbacks. These scales collect ordinal data, meaning data in which an ordering or ranking of responses is possible, but no measure of distance is possible (Allen & Seaman, 2007). Therefore, there is no way of knowing if, for any given participant, the difference of intensity of experience between feeling ‘Completely unsuccessful’ and ‘Somewhat unsuccessful’ at an illness management activity was comparable to the difference between other categories in the scale (e.g., ‘Somewhat unsuccessful’ and ‘Somewhat successful’). The mixed-methods design of this study helped to compensate for this this limitation, as I did not rely solely on the ordinal data to assess participant experiences in self-management of chronic illness. Instead, I used the Likert scale data as a sensitising device or guide, which aided me in guiding discussion on chronic illness self-management experiences during in-depth interviews (discussed below).

A search of the medical literature was made to find an existing inventory of chronic illness management activities for people with chronic kidney disease. However, the search failed to find an existing inventory. Therefore, the list of CKD management-related activities used in the inventory created for this study drew upon the literature (Browne & Merighi, 2010; Green & Ryan, 2009; Levin et al., 2008; National Kidney Federation, 2012) and in consultation with a nephrologist working within the study context.

The purpose of the inventory was to obtain a general idea of the degree of chronic illness management burden experienced by each participant, to know what kinds of chronic illness management activities they feel are necessary to perform, and to know how successful they felt in doing these activities on the sample days. This information helped sensitise me to aspects of chronic illness management that may be more or less difficult for the participant, and to probe during the interview for moments in the sample day when other aspects of everyday life may have interacted with chronic illness management, making it more or less easy to perform.

While the overwhelming majority of participants did not appear to have any difficulty with the inventory and self-assessment, one participant used the tool to document what he generally has to do to manage his chronic illness, instead of what he had to do specifically on the two sample days. This came to light at the beginning of the interview when I was clarifying what he had written on the tool. We then went through the tool together and completed it
anew with the sample days in mind. Otherwise, participants seemed to have little or no difficulty using the tool.

Another challenge to using the inventory and self-assessment was the possibility that some participants would over-report their success in performing these activities on the sample day in order to present their management of their disease in the best possible light. Over-reporting self-management success is possible given the responsibility and even sense of guilt many renal patients feel about downward trajectories in their health. For example, recipients of a kidney transplant from a living family donor often feel guilt associated with the sacrifice made by the donor, amplifying feelings of failure when not compliant with the treatment regimen prescribed to maintain the transplant (Griva et al., 2002). I made an attempt to address this challenge by stating at the time I explained the inventory and self-assessment to participants that many individuals with CKD have troubles following all of the activities related to managing their disease, and that everyone’s situation is different. I asked the participant to please not judge themselves or feel badly about how many of the activities they were able to perform or how well they are able to perform them, but to accurately and honestly record what they did on the sample day.

Alternatives to the self-report CKD self-management assessment instrument created for this study include using an existing validated instrument, doing ethnographic fieldwork, or using biomedical markers (blood tests, urine samples, etc.). With regards to the first alternative, a literature search was conducted for existing, validated self-report CKD self-management assessment instruments. However, the search did not yield an appropriate tool for measuring patient compliance with treatment regimen activities related to all stages of CKD. The most relevant instruments found were the Dialysis Diet and Fluid Non-adherence Questionnaire (DDFQ), validated by Vlaminck, Maes, Jacobs, Reyntjens, and Evers (2001), which measures the frequency and degree of compliance to diet and fluid restrictions for individuals in stage 5D+ (dialysis) of the disease, and the Medical Outcomes Study (MOS): Measures of Patient Adherence Survey (Hays, nd), which measures adherence to treatment recommendations by patients with chronic illnesses, namely, heart disease, diabetes and hypertension. While neither of these tools were an exact match for this study’s focus on patient CKD self-management activities in everyday life for individuals in all stages of the disease, there was some overlap, and the wording of these validated tools was integrated into the inventory and self-assessment created for this study where appropriate.

The second alternative to the inventory and self-assessment method employed in this study was to conduct ethnographic fieldwork with participants. This would have involved
following participants and observing how activities related to self-management of CKD were carried out on the sample day. The strength of this approach would be to avoid, perhaps, the tendency of patients to represent their treatment adherence in a more positive light in self-reports as they may be less conscious of how they present their self-management than when asked directly. However, participants may have carried out self-management activities more diligently while being observed for similar reasons. Also, the time-consuming nature of ethnographic research, and the necessity to observe participants individually (as opposed to a group of people that can be observed together), would have meant needing to reduce the sample size.

A final alternative to using the inventory and self-assessment method employed in this study was collecting biomedical markers of patient adherence to treatment recommendations. For renal patients, these markers include blood tests and urine samples that indicate the levels of protein, fluid and glucose and other substances that should be monitored and controlled in order to stop or delay progression of CKD. While these markers provide a general indication of patient adherence to treatment regimens by proxy of physiological impact, they offer little insight into the particular chronic illness management activities that may be responsible for changes in biomedical markers, sacrificing opportunities for asking during the interview about each chronic illness management activity and how it fits into the fabric of the individual’s everyday activities. Furthermore, biomedical markers may be perceived as intrusive by those providing them, and this may have discouraged participation in the study.

4.2.4 In-depth interviews

I conducted the interviews. Most lasted between one-and-a-half to two hours (range: one to three hours). I asked participants to select the most convenient and comfortable location, providing it allowed for privacy and minimal noise. Most interviews occurred in participants’ homes, with others occurring in meeting rooms at participants’ workplaces or university campuses, dialysis clinics, and one at a cafe.

I took a semi-structured interview format in which I asked the participant to ‘lead’ me through the activities and experiences of the sample days. I asked interviewees to provide such vivid ‘play-by-play’ detail of their activities, movements and experiences that someone could make a movie of their day.

The interview format used in this study is very similar to the diary-interview method (Minichiello et al., 2008, p. 98) in which the participant provides the initial interview schedule by ‘leading’ the interviewer through their travel and activity diary day. This aided me in understanding the individual’s everyday life organisation and the origins of that organisation.
The survey informed how I, the interviewer, probed for instances in the sample day when the way activities were organised in time and space interplayed with chronic illness characteristics and management activities. Generally, I asked descriptive questions, feeling questions and sensory questions rather than ‘why’ questions or opinion questions (Minichiello et al., 2008, p. 98-100). This preference was taken because I was more interested in the way participants experienced the diary day than in their cognitive explanations of why they do things the way they do them. I sometimes presented hypothetical and ‘what if?’ scenarios (Minichiello et al., 2008, p. 101) to the participant in order to get a feeling for the range of possibilities they felt existed for how to organise activities in their lives. For example, if a participant described a medication routine that involved a particular object, action, timing, and setting, such as taking off their shoes and carrying them upstairs to where the medications are kept, I asked the participant if it ever happened that they did not carry their shoes upstairs, and if that changed what happened with their medication.

As I listened to the participant lead me through their sample days and asked probing questions, I had a list of pre-formed themes in mind to help me direct the interview within the structure of the participant leading me through their sample days. These themes were organised around the following topics: 1) spatio-temporal characteristics of everyday life organisation, 2) exposure to places and situations, and 3) habit and practice (see Appendix 4: Interview prompts). The first theme, spatio-temporal characteristics of everyday life organization, focused on the origins and spatio-temporal characteristics of activities, and how chronic illness and management activities interplayed with other activities on that day. In space-time geographical terms, this theme focused on identifying and understanding how space-time constraints (e.g., transportation options, distances, coordination of activities with others, opening/access hours to institutions and organisations) have an impact on the relative success or failure of the participant to perform CKD self-management activities (e.g., following a renal diet, exercising, checking glucose levels), as well as understanding how CKD self-management activities act as space-time constraints on other activities (e.g., hobbies, visiting family, working, etc.).

The second theme, exposure to places and situations, was employed to try to understand the role of the various contexts of the person’s life, such as home and work, in influencing how activities are performed and experienced, and to understand the characteristics of theses contexts. The final theme regarded the roles of habit and social practice in the space-time organisation of everyday life and performance of chronic illness management activities. I tried to understand to what extent the participant was aware of the
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origins of everyday activities and the paths they take through time and space. In other words, to what extent is it habitual? And, to what extent did the participant do activities in certain ways because they think that that is the socially acceptable way to perform the activity? In other words, to what extent do socially encouraged practices drive the way everyday life is organized and the paths the individual takes through time and space? Ultimately, this part of the interview aimed to understand how habit and (social) practice play a role in shaping everyday life organization and chronic illness management.

The diary-interview method is considered to be “one of the most reliable methods of obtaining information,” (Minichiello et al., 2008, p. 110). Also, working off of the diary and asking the participant to lead the interviewer through the events of the diary day provided a less confronting, more comfortable way to start the interview and build rapport.

4.3 Recruitment, sampling and saturation

4.3.1 Recruitment

Participants were recruited through Renal Services, The Canberra Hospital from May 2013 - April 2014. Renal Services provided a unique access point to the population because it is the primary provider of specialist renal services in the ACT and the surrounding region in New South Wales. The recruitment arrangement with Renal Services was established by approaching the Clinical Director of the department with the study idea and a request for recruitment assistance. Over several months, an agreement was reached for recruitment assistance, providing I give the Clinical Director all raw data collected in the study along with permission to use this data for future research.

A recruitment letter (see Appendix 5: Recruitment letter) from the Clinical Director of Renal Services was mailed to patients of Renal Services, the Canberra Hospital along with a Patient Information Sheet (see Appendix 6: Patient information sheet) describing the study aim, what was requested of participants, and any ethical considerations of the study. I was listed as the study contact person and interested individuals were invited to contact me by phone or email. I made follow-up phone calls to interested individuals as needed.

Recruitment letters were sent to patients of Renal Services who reside within the ACT or within a two hour drive as this roughly covers the service area of the department, and allowed for a variety of residential experiences among participants (i.e., urban versus rural/regional).

4.3.2 Sampling

Sampling is “…fundamental to our understanding of the validity of qualitative research” (Curtis, Gesler, Smith, & Washburn, 2000, p. 1002). I employed “stratified purposeful
sampling” (Minichiello et al., 2008, p. 172), also referred to as “purposive sampling” (Curtis et al., 2000), in order to obtain a range of different characteristics that may impact on experiences of chronic illness and the spatio-temporal characteristics of everyday life for participants. Purposeful (or purposive) sampling is commonly used in qualitative health research (Guest, Bunce, & Johnson, 2006; Minichiello et al., 2008, p. 172), and health geography more specifically (Curtis et al., 2000), wherein “participants are selected according to predetermined criteria relevant to a particular research objective,” (Guest et al., 2006, p. 61). It is a strategy for ensuring the most “information rich” sample possible (Morse, 1994, p. 229) given the particular criterion that applies to the sample group. Participant characteristics that were sampled for in this study are described below and are theoretically informed by the space-time geography and chronic illness literature.

I worked in conjunction with the research officer at Renal Services to direct and re-direct recruitment efforts over the course of data collection to provide for a range of disease stages, ages, gender, employment status, caregiving responsibilities, transportation options, residential location within the study setting and income within the study sample in order to gather a range of characteristics that could influence space-time organisation of everyday life and illness experiences. The research officer of Renal Services made follow-up phone calls to potential participants whose characteristics were under-represented at any given time in the recruitment and data collection process in order to even out the sample.

While qualitative case study methodology often involves small sample sizes, purposive sampling along with multiple methods helps ensure that the data collected with each individual is strategically targeted, intensive, and high quality. Paraphrasing Curtis et al. (2000, p. 1003), my sampling strategy sought to be:

- Relevant to the conceptual framework and research questions of this study;
- Likely to generate rich information on the phenomena which need to be studied;
- Able to enhance the analytic generalizability of findings;
- Able to produce believable descriptions/explanations of phenomena;
- Ethical; and
- Feasible given the resource and temporal constraints of the project.

Indigenous Australians were not recruited for or included in this study even though this group has the highest rate of CKD in Australia (Green & Ryan, 2009). I made this difficult choice because I did not feel I had the capacity during the PhD, for a variety of reasons I will discuss here, to provide an adequate account of this population’s experiences with CKD.
Extreme disparities exist between Indigenous and non-Indigenous Australians across a range of socio-economic and health measures (Cass, Cunningham, Snelling, Wang, & Hoy, 2004). Indigenous Australians’ life expectancy is approximately 20 years shorter than non-Indigenous Australians. A major contributor to this discrepancy is chronic diseases, such as heart disease, stroke, diabetes, and renal failure, which all occur at higher rates and at younger ages among Indigenous Australian’s than in the wider population (O’Dea, 2005). The prevalence of ESKD is nine times higher among Indigenous Australians (Cass, Cunningham, Snelling, Wang, & Hoy, 2004). Prior to the introduction of European foods and the violent disruption of Indigenous communities and lifestyles, Indigenous Australians lived as hunter gatherers with no evidence of the preventable chronic diseases plaguing them today (O’Dea, 2005).

A study of Indigenous Australians with CKD found that many of these individuals feel excluded from information about their disease and its causes, alienated from the health care system, and have difficulties trusting health providers and engaging in recommended treatments of CKD (Anderson, Devitt, Cunningham, Preece, & Cass, 2008). Given these important differences in Indigenous Australians’ experiences with CKD and other chronic illnesses as compared to the wider population, I felt that the inclusion of Indigenous Australians in my sample would have required a relatively large sample of Indigenous individuals (e.g., minimum 15 individuals) in order to grasp variations between the experiences of Indigenous Australians in negotiating everyday life with chronic illness, and be able to understand their experiences in relation to those of non-Indigenous Australians in my study.

This posed several challenges due primarily to limitations of my cultural and linguistic competencies, money, and time. First, as discussed at the beginning of this chapter, my non-Australian background limits, to some extent, my ability to relate to and interpret the accounts of my Australian participants. My cultural and linguistic limitations in relating to Indigenous Australians are far more pronounced. Due to limited funds, hiring an ethnically and linguistically matched Indigenous interviewer was not a possibility. Second, as described in this chapter, the mixed-methods approach used in this study is time and labour intensive. Given the inflexible time constraints associated with funding for this study, it would not have been feasible to collect data from enough individuals to appropriately sample both Indigenous and Non-Indigenous individuals. Third, guidelines for respectful and effective implementation of research with Indigenous Australians indicate several considerations, including frequent difficulty in achieving the desired sample size of Indigenous Australians, and the need for researchers to have the ability to allow for extended timelines in working with these groups.
(Jamieson et al., 2012). Again, the inflexibility of this study’s timeline prevented me from making these kinds of accommodations. Therefore, I made the decision not to include Indigenous Australians in this study, and am convinced that this group’s experiences of everyday life with CKD would be better addressed in a separate study.

4.3.3 Saturation

According to Guest and colleagues’ (2006) review of the health and social science literature, the qualitative research community agrees that the sample size required in a study using purposeful sampling depends upon the point at which saturation of research categories is reached. However, very little guidance is offered in the literature on how to determine when saturation has been reached (Guest et al., 2006). Minichiello et al. (2008) define saturation as “A situation in which no additional data can be found that would add to the categories being developed and examined, that is, you have reached saturation level,” (p. 332). In this regard, Morse (1994) states that over the course of data collection and sampling: “The researcher seeks indices of saturation, such as repetition in the information obtained and confirmation of previously collected data,” (p. 230). Saturation in this study was reached in the sense that I obtained enough data from participants with the desired range of characteristics purposefully sampled for. Conceptually and theoretically, saturation was reached when it became clear that there were fewer and fewer opportunities for adjusting the conceptual framework based on the discovery of new information in the data; and therefore no remaining need to gather new data. By this I do not mean to say that there are not still many aspects of everyday life for people with chronic kidney disease left to explore. However, sufficient data was gathered to discuss experiences of time and space in several meaningful areas of everyday life for participants; thereby meeting the aim of the study.

4.4 Ethics

4.4.1 Ethics approval

Ethics approval for this study was obtained from the ACT Health Directorate Low Risk Sub-Committee on 6 February 2013, submission no. ETHLR.13.018. University of New South Wales policy does not require submission of a separate ethics application to the university providing approval is obtained from an approved organisation. The ACT Health Directorate Low Risk Sub-Committee is one such organisation.

4.4.2 Ethical conduct

No ethical problems arose during the course of this research. Below, I explain the potential risks to participants and the strategies employed to manage these risks. Then, I describe
internal and external monitoring of the study. I describe the way data was stored, how I maintained confidentiality of participants during the study, how it will be maintained after the study, and how I obtained informed consent of study participants.

4.4.2.1 Potential risks to participants
As with virtually any study involving people, there were some potential risks to participants in this study. These risks were listed in the Participant information sheet (Appendix 6) mailed out during recruitment and reviewed again at the time of signing a Consent form (Appendix 7). First, there was the risk to participant confidentiality associated with the collection of location-specific information about participants. This information consisted of addresses of places where everyday life activities are carried out (e.g., home, work, doctor’s office). In order to reduce this risk, location-specific information about participants is presented in the results of the study without divulging streets or street names, and by referring to places where activities are carried out with generic place names (e.g., 'work', 'dialysis', 'child's school'), instead of specific place names (e.g., 'Systematica', 'Belconnen Community Health', 'Canberra Girls’ Grammar School'). Note that none of these place names cited above were relevant to participants in this study.

Second, this study asked participants to discuss their experiences managing chronic kidney disease. This involved discussing things like dietary and fluid guidelines, managing high blood pressure and diabetes, efforts to lose weight, or dialysis treatments. Discussing these topics may have caused distress for some individuals. If a participant became distressed, for any reason, during the course of their participation in this study, I would have encouraged them to speak with a counsellor or psychologist, and had appropriate referral information on-hand to give to the participant. However, this did not happen.

4.4.2.2 Monitoring
Internal monitoring of this study was conducted by me, my PhD supervisor, and a clinician at the hospital through which I recruited participants. I acted as study coordinator. I was charged with collecting, recording and analysing travel and activity diary, survey and interview data. Dr Amy Griffin, my PhD supervisor, took on an oversight role and regular meetings between Dr Griffin and myself occurred throughout the study period. Dr Girish Talaulikar, the clinical director at Renal Services, the Canberra Hospital, provided guidance regarding the relevance of findings from a health provider’s perspective. External monitoring of this study consisted of review by the respective Human Research Ethics Committees.
4.4.2.3 Storing data
Data was used at the University of New South Wales Canberra campus and the Department of Renal Services, Canberra Hospital. Data will be stored for seven years in locked filing cabinets or on password protected computers made available only to members of the research team.

4.4.2.4 Maintaining confidentiality
Several strategies were employed to maintain participant confidentiality during as well as after the completion of the study. Firstly, signed consent forms are kept at the Canberra Hospital, separate from the data, which was stored at the University of New South Wales Canberra. All collected data was de-identified (coded by number) and stored securely in both electronic and paper forms. The document recording participant names and corresponding participant numbers was kept separate from the data throughout the study and was destroyed on completion of the study. Audio-recordings of interviews were transcribed, and destroyed after completion of the study. Location-specific data are stored on a password-protected computer.

In all presentations of data to the public, textual or oral, substantial efforts were and are made to ensure participant anonymity. Strategies employed include not providing street level information about participants’ residences or places of work, and not providing employer or renal specialist names. Finally, participant names used in all presentations of data are pseudonyms. In order to acknowledge participants’ cultural diversity, I selected pseudonyms by searching online for baby names and selected one for each participant that aligned with their gender and self-identified cultural background.

4.4.2.5 Obtaining informed consent
The project was explained to participants: 1) in the letter of recruitment, 2) during the phone call in which an appointment is made to enrol in the study; and 3) when meeting in person to sign the consent form. The explanation of the project was given primarily in the Patient information sheet which was mailed out with the recruitment letter by Renal Services, the Canberra Hospital (see Appendix 6: Participant information sheet), but also verbally by myself during the phone call and again at the first meeting before the consent form was signed (see Appendix 5: Recruitment letter and Appendix 7: Consent form, for more details). Depending on where consent was witnessed, a clinician (renal nurse or clinical trials co-ordinator) or participant’s spouse or carer was the witness to the signing of consent to participate in the study.
4.5 Data collection procedures

Data was collected over 12 months, between May 2013 and April 2014. The figure below (Figure 4.1) describes the data collection procedures followed with each participant from the time they contacted me, or advised Renal Services at the Canberra Hospital that they would be interested in participating in the study, to the time their data had been collected and stored for analysis. The exception to this is the three participants in the pilot study who collected one, rather than two, sample days.

![Data collection procedures diagram]

Figure 4.1 Data collection procedures

4.5.1 Phone contact

After the Research Officer at Renal Services, the Canberra Hospital, received notification from a patient who had received the study recruitment materials that they would be interested in participating in the study, the Research Officer emailed me the contact information of the potential participant. Upon successful phone contact with the individual, I described the purposes of the study in the further detail, and described the data collection tools and what participants were being asked to do in the study. I asked the individual if the study still felt like something they would want to be a part of. In almost all cases the answer was yes, and I then proceeded to arrange an initial meeting with the participant at a place and time that was convenient for them. The one individual who declined to participate during the initial phone call was having a sudden downturn in his health and did not feel he would be able to participate.
4.5.2 First meeting

The first meeting with each participant lasted about 30 minutes. First, I asked the participant to again review the participant information sheet that had been mailed out to them in the recruitment efforts, and asked about and answered any questions they had (see Appendix 6: Participant information sheet). Then, I provided the participant with a consent form to read, and asked about and answered any questions they had (see Appendix 7: Consent form). The participant signed the consent form. Then, the participant completed the demographic and health survey.

Next, I explained how to use each of the data collection tools the participant would be using on their two sample days. I provided an example of how to log trips and activities in the travel and activity diary. I went through the chronic illness management inventory and self-assessment with the participant, including asking them to read the list of management activities and tell me if any of them were not clear. I explained how to indicate if an activity applied to the participant on the sample day, and how to rate their feeling of success on that particular day with that particular activity with the Likert scale provided. I clarified that the participant should record information specific to the sample day in question; not information pertaining to illness management activities that did not take place on the sample day (e.g., a yearly bone density test that did not happen to take place on the sample day).

The participant and I worked together to select two sample days from their upcoming week; ideally within a day or two of each other in order to encourage good recall of those days in the interview. I asked participants to select two ‘typical’ days; clarifying that if their weekly schedules were varied, that they should pick two contrasting days in order to get the best insight into how different parts of everyday life interact with one another. If the participant was on dialysis, I asked them to provide one dialysis day, and one non-dialysis day.

Then the participant and I worked together to schedule an interview, ideally the day following their final sample day in order to encourage good recall of those sample days in the interview. I provided the participant with a mobile phone number on which to reach me, and encouraged them to call me if they had any trouble or questions on the sample days with data collection.

After the first meeting, I securely stored the consent form in a locked filing cabinet at the university, scanned the demographic and health survey and saved it to a secure server, and securely stored the paper copy of the survey in a locked filing cabinet. Periodically, I brought the consent forms over to the Research Officer at Renal Services, the Canberra Hospital, for storing.
4.5.3 Two sample days
Participants independently collected data. They used the travel and activity diaries and chronic illness management inventories and self-assessments on the two sample days that were previously identified in the first meeting.

4.5.4 Interview
Interviews were held after the two sample days at a location that was convenient for the participant, providing it was not too noisy or lacking privacy. I asked the participant for their consent to record the interview. In all instances the participants agreed. At the start of each interview, the participant gave me the data collection tools they had used over their sample days (travel and activity diary and chronic illness management inventory and self-assessment).
I went through the paper materials with the participant and clarified any hand-writing or information that was not clear to me. This provided an opportunity to orient myself to the general structure of the two sample days, and to make observations about the chronic illness management activities the person had felt necessary to perform on those days, and to note any that seemed particularly difficult or easy for the participant. I thanked the participant for collecting this data. Then, I prompted the participant to ‘lead’ me through the two sample days with as much ‘play-by-play’ detail as possible so that someone could shoot a movie of their day.

4.5.5 Thanking participants
A day or two after the interview, I mailed the participant a hand-written thank you card, expressing my gratitude for their unique contribution to the study and the time and effort they had given in collecting data and giving an interview. The $20AUD gift card redeemable at a large supermarket chain was included in the envelope as a “small expression of gratitude” for their participation.

4.5.6 Storing paper materials and audio recordings
Finally, I scanned the paper data collection materials used on the sample days and saved them to a secure server. I locked the paper materials in a filing cabinet at the university. I downloaded interview audio recordings to a secure server.

4.6 Participants
4.6.1 Participant characteristics
Twenty-six individuals participated in this study. In order to preserve participant anonymity and confidentiality, a comprehensive description of each participant’s individual characteristics will not be provided. However, the following is a summary of participant characteristics as a
group, namely, disease stage, age, gender, employment, caregiving responsibilities, transportation options, residential location, income, ethnicity and foreign/domestic birth, and medical histories in brief.

4.6.1.1 Disease stage
All five disease stages, from very early stage CKD through to ESKD with dialysis, as well as individuals with a functioning kidney transplant, are represented in the full sample as well as the working-age sub-set (Table 4.1). Four participants had early-stage CKD (stages 1, 2 or 3) at the time of the study. This is the least represented CKD stage in the sample and was the most difficult to recruit for, likely due to asymptomatic nature of early stages of CKD which often results in late detection of CKD (Chadban et al., 2003). Furthermore, even when CKD is detected in its early stages in primary care services, many patients are not referred to a nephrologist by their primary care physician until later stages of CKD when symptoms begin to present (Locatelli, Vecchio, & Pozzoni, 2002). Six participants were in stage four. Eight participants were in stage 5 ESKD and were receiving dialysis treatment. A final eight participants had a functioning kidney transplant at the time of the study.

Table 4.1 Disease stage

<table>
<thead>
<tr>
<th>Disease stage</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-3</td>
<td>4</td>
</tr>
<tr>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>5 (with dialysis)</td>
<td>8</td>
</tr>
<tr>
<td>functioning kidney transplant</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td>26</td>
</tr>
</tbody>
</table>

Five participants had lost a kidney transplant at some point prior to the study and were either receiving dialysis or living with a new kidney transplant at the time of the study. All participants had instructions from their health care providers to regularly perform health-related activities to manage their illness (e.g., medication schedules, doctor appointments, diet restrictions, monitoring blood sugar, and dialysis).

4.6.1.2 Participant history of CKD
The causes participants reported for their CKD were sometimes very specific and attributable to a certain event (e.g., a cancer treatment drug side-effect), but more often were vague and multiple (e.g., occurring around the same time as the onset of high blood pressure) (Table 4.2). Ten participants reported some uncertainty as to the underlying cause of their CKD, however almost all of these participants reported that co-morbid conditions like hypertension and diabetes were at least partly responsible. A total of nine participants attributed their CKD to co-morbid conditions. To a lesser extent, participants cited drug side-effects (four
participants), autoimmune disorders (four participants), hereditary conditions (four participants), birth defects (three participants), and viruses (two participants) as causing their CKD. The large number of participants citing co-morbid conditions is consistent with evidence that, worldwide, diabetes and hypertension are now the two major causes of chronic kidney disease (Zhang & Rothenbacher, 2008).

### Table 4.2 Causes of CKD

<table>
<thead>
<tr>
<th>Causes of CKD</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unknown</td>
<td>10</td>
</tr>
<tr>
<td>Co-morbidity (e.g., hypertension, diabetes)</td>
<td>9</td>
</tr>
<tr>
<td>Drug side-effect</td>
<td>4</td>
</tr>
<tr>
<td>Autoimmune disorder</td>
<td>4</td>
</tr>
<tr>
<td>Hereditary condition</td>
<td>4</td>
</tr>
<tr>
<td>Birth defect</td>
<td>3</td>
</tr>
<tr>
<td>Virus</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>36</strong></td>
</tr>
</tbody>
</table>

*number of causes exceeds number of participants

The length of time participants had been living with a CKD diagnosis at the time of the study ranged from a few months to 45 years. The median was 15.5 years since receiving a diagnosis.

#### 4.6.1.3 Age

Participant ages ranged from 18 to 85 years of age. Sixteen participants were of working-age at the time of the study (ranging 18 to 64 years) (Table 4.3). Ten were of retirement age (ranging 66 to 85 years). The youngest age group (age 18-29) and those in their 50’s were the least well represented. Those in their 60s and 70s were best represented, which is not surprising given that increasing age is a risk factor for CKD (Green & Ryan, 2009), and indicators of kidney damage are more prevalent in both men and women over 65 years old (Chadban et al., 2003).

### Table 4.3 Age

<table>
<thead>
<tr>
<th>Age</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-29</td>
<td>2</td>
</tr>
<tr>
<td>30-39</td>
<td>4</td>
</tr>
<tr>
<td>40-49</td>
<td>5</td>
</tr>
<tr>
<td>50-59</td>
<td>2</td>
</tr>
<tr>
<td>60-69</td>
<td>6</td>
</tr>
<tr>
<td>70-79</td>
<td>6</td>
</tr>
<tr>
<td>80-89</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>26</strong></td>
</tr>
</tbody>
</table>

#### 4.6.1.4 Gender

Half of participants were female (13) and half were male (13). Thirteen participants were female and thirteen were male. None identified as another gender category. Female ages ranged 18 – 85 years of age. Male ages ranged from 33 to 77 years of age. All disease stages are represented within the females of the group (CKD stages 2, 3, 4, 5 with dialysis and
functioning kidney transplant). Among the males, stages 4, 5 with dialysis, and functioning kidney transplant are represented.

4.6.1.5 Household composition

At the time of the study, most participants were living either with a partner (twelve participants) or living alone (seven participants) (Table 4.4). Of those living alone, four were men and three were women. All female participants living alone were retired. Three out of four men living alone were working. Four participants lived with other adult relatives (e.g., a sister, independent parents). Two participants (one man, one woman) lived with a partner and children. One lived with a partner and an ageing parent who lived in a granny flat attached to the main house.

<table>
<thead>
<tr>
<th>Household composition</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alone</td>
<td>7</td>
</tr>
<tr>
<td>Partner only</td>
<td>12</td>
</tr>
<tr>
<td>Partner and children</td>
<td>2</td>
</tr>
<tr>
<td>Adult relative(s)</td>
<td>4</td>
</tr>
<tr>
<td>Partner and ageing parent</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>26</strong></td>
</tr>
</tbody>
</table>

4.6.1.6 Employment

Thirteen participants were working at the time of the study (nine full-time and four part-time) (Table 4.5). Eleven were retired. Two participants of working-age were unemployed. The occupations of the nine participants working full time were public servant (five participants), sales consultant (one participant), small-business owner (one participant), pro-bono research consultant (one participant), and information and technology specialist (one participant). The occupations of the four participants working part-time were retail supervisor (one participant), teacher’s assistant (one participant), taxi driver (one participant), and administrative assistant (one participant). The most recent occupations of the two unemployed working-age participants were postman and skilled physical labourer.

Of the sixteen working-age participants, nine worked full-time, four worked part-time, two were unemployed, and two were retired. Nine were women and seven were men. The remaining ten participants (ranging 66 to 85 years) were all retired, with the exception of the pro-bono consultant who is also drawing a pension. That participant has been counted under ‘full-time’ in the table below rather than under ‘retired’.
### Table 4.5 Employment status

<table>
<thead>
<tr>
<th>Employment status</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full-time</td>
<td>9</td>
</tr>
<tr>
<td>Part-time</td>
<td>4</td>
</tr>
<tr>
<td>Retired</td>
<td>11</td>
</tr>
<tr>
<td>Unemployed (working age)</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>26</strong></td>
</tr>
</tbody>
</table>

4.6.1.7 Caregiving responsibilities

Four out of the 26 participants had caregiving responsibilities at the time of the study. For three participants, these responsibilities were just for dependent children. One participant had caregiving responsibilities for an ageing parent and also discussed past caregiving responsibilities for children at length. Three other participants who have no current caregiving responsibilities discussed their past caregiving responsibilities for children at length.

4.6.1.8 Transportation options

Overwhelmingly, participants had access to a car that was driven by either the participant or someone in their household (24 out of 26 participants). However, one participant is no longer allowed to drive because he had a car accident during a diabetic episode. Another participant cannot drive due to vision and breathing impairments, and neither can his partner due to her own chronic illness. Both participants who do not have access to a car live in Canberra. One is able to walk to the local shops and to public transport, although he cannot stand for long periods. He also receives transportation to dialysis through a community service. The other participant is unable to walk to the local shops or walk to public transport due to physical impairments. He relies on relatives and friends for transportation to medical appointments and basic services.

4.6.1.9 Residential location

Ten participants lived in the north side of Canberra. Ten lived in the south side of Canberra. Another six participants lived in New South Wales regional and rural towns, namely Queanbeyan (one participant), Goulburn (two participants), Pomeroy (one participant), Crookwell (one participant), and Long Beach (one participant). See Chapter 5 for a map of Canberra and surrounds, and information about and descriptions of Canberra and the six New South Wales towns where participants lived at the time of the study.

4.6.1.10 Income

The average personal wage and salary income in Canberra is about $61,000 AUD per year (Australian Bureau of Statistics, 2015) (Table 4.6). This translates into about $1860 per fortnight.
Table 4.6  Net per capita household income per fortnight (AUD)

<table>
<thead>
<tr>
<th>Fortnightly household income</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-999</td>
<td>7</td>
</tr>
<tr>
<td>1000-1999</td>
<td>6</td>
</tr>
<tr>
<td>2000-2999</td>
<td>5</td>
</tr>
<tr>
<td>3000-3999</td>
<td>1</td>
</tr>
<tr>
<td>4000-4999</td>
<td>4</td>
</tr>
<tr>
<td>5000-5999</td>
<td>2</td>
</tr>
<tr>
<td>6000 or more</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>26</strong></td>
</tr>
</tbody>
</table>

The figure below (Figure 4.2) shows all participants’ incomes, expressed as per capita household income per fortnight. This number was derived by taking the mid-point of the income range selected by the participant, and dividing that number by the participant’s household size.

Figure 4.2  Net per capita household income per fortnight (AUD)

4.6.1.11 Ethnicity and foreign/domestic birth

Overwhelmingly, participants self-identified as White Australian or European Australian, with some specifying certain countries: Ireland, England, Greece, and Switzerland (Table 4.7). Two of the 21 participants identifying themselves in this way were born outside Australia, and one spoke English as a foreign language. Four self-identified as South or Central Asian Australian, specifying the countries of Burma, the Philippines, Laos, and India. Three of these participants were born outside Australia, and two spoke English as a foreign language, with one of the three foreign-born having been born in a non-Australian English speaking country. The remaining participant is from South Africa and is in the process of applying for permanent residency in Australia.
Table 4.7  Self-identified ethnicity and origin of birth

<table>
<thead>
<tr>
<th>Self-identified ethnicity</th>
<th>Number of participants</th>
<th>Number of foreign born</th>
</tr>
</thead>
<tbody>
<tr>
<td>European Australian</td>
<td>21</td>
<td>2</td>
</tr>
<tr>
<td>Burmese Australian</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Filipino Australian</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Indian Australian</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Lao Australian</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>South African</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>26</strong></td>
<td><strong>6</strong></td>
</tr>
</tbody>
</table>

4.7 Analysis

I entered the travel and activity diaries, the demographic and health surveys, and the chronic illness management inventories and self-assessments into Excel. This allowed for analysis and presentation of basic descriptive information about participant activities and trips made on the sample days, general participant characteristics, and chronic illness self-management burden.

Interviews were recorded and transcribed, resulting in over 500 pages of interview transcripts. I transcribed sixteen of the interviews. A professional transcription company transcribed the remaining ten interviews. I read these company-transcribed interviews, made corrections where required, and added affective information that I remembered from the interview (e.g., crying, laughing, pauses).

I coded the transcripts with the aid of NVivo, a qualitative data analysis software. I performed coding and analysis of transcripts thematically (Minichiello et al., 2008, p. 208). During repeated readings of the transcripts, I grouped content to summarize themes, guided by the study objectives. I also coded content for unexpected themes that emerged from the data. I modified the objectives of the study and the coding system as needed to accommodate unexpected themes. For example, I had originally focused on the space-time resource demands of different activities and aspects of participants’ lives. However, it soon became apparent that there was something important about the way actions, intensities, and sensations repeat in a person’s everyday life, and the characteristics of these repetitions. I consulted the literature on rhythms, and then started coding for rhythms in my analysis. I also adjusted the wording of Objective 2 to incorporate not only the constraints and affordances on participants’ space-time resources, but also the characteristics of rhythms (e.g., episodic, cyclical).

Below, I describe how I addressed each of the study objectives through the coding and analysis process:

**Objective 1:** Identify the predominant activities in participants’ lives (e.g., managing chronic illness, caregiving and family, working, leisure).
Chapter 4

I coded the activities participants discussed in the interviews according to activity type. The most common and prioritised of these activity types for participants were those related to managing CKD and co-morbid conditions (e.g., diabetes and hypertension); paid work; caregiving (e.g., for children, or a partner or relative who is ageing and/or living with chronic illness); and activities related to recreation and enjoyment (e.g., hobbies, recreational travel, and volunteering). The findings are presented in two chapters: one providing a sketch of participants’ everyday lives based on the travel and activity diary and illness management inventory data; and one that is organized into four sub-sections for each main activity type, derived from the interview data.

Objective 2: Describe the spatio-temporal characteristics of activities and of chronic illness (e.g., (in)flexible, fluctuating, predictable, regular, cyclical, episodic, (in)frequent, (im)mobile).

The spatio-temporal dimensions of everyday activities, bodies and contexts were coded according to emergent themes which were, foremost, logistical space-time resources and rhythms.

Objective 3: Understand the origins of these spatio-temporal characteristics (e.g., externally/externally imposed, the body, treatments, conventions of social practice, social institutions, individual habits).

Codes were given to the origins of the spatio-temporal characteristics of activities and chronic illness, for example, health services access or job position type.

Objective 4: Observe how spatio-temporal characteristics of activities and chronic illness interact with one another (e.g., arrhythmias, conflicting demands on space-time resources).

I selected participant narrative examples that demonstrated an interaction of spatio-temporal characteristics of different parts of participants’ everyday lives. Analysis did not stop after interview coding, but continued well into the writing-up phase of this thesis (Minichiello et al., 2008, p. 293). For example, I knew that I wanted to organise the findings by activity type (i.e., chronic illness management, paid work, caregiving and family, leisure) so that I could relate my findings to the dominant perspectives on these topics in the literature. However, I did not know until these sections had been written, and I was able to reflect on them as a whole, how these different parts of participants’ lives and their respective spatio-temporal characteristics related to one another in the big picture. Without the opportunities for further analysis offered through the writing process, I would have found it difficult to meet the aim of the study.
**Objective 5:** Understand how participants experience the interaction of these spatio-temporal characteristics in the everyday.

I exported the coded transcript content pertaining to objectives 1 through 4 into Word (everyday activities; spatio-temporal characteristics and their origins; and interaction of spatio-temporal characteristics) from NVivo. Then, I printed and re-read this content with a focus on participant experiences within different situations or scenarios wherein the spatio-temporal characteristics of different aspects of everyday life were interacting. In an iterative process of reading the printed transcript and consulting the theoretical literature reviewed in Chapters 2 and 3, I developed an understanding of participants’ experiences of time, alongside space, in negotiating everyday life with chronic illness, presented in the findings chapters of this thesis (Chapters 6 and 7).

### 4.8 Summary

This study took a multi-method qualitative case study approach. It applied a space-time geographical method, which in this case meant that two sample days were recorded by participants in travel and activity diaries that were then used to loosely structure subsequent, in-depth interviews. These methods were complimented by a demographic and health survey, and a chronic illness management inventory and self-assessment. These data collection tools provided the information needed to meet the study objectives, as well as to guide the purposive sampling process undertaken with assistance by Renal Services, the Canberra Hospital.

I have described data collection procedures so as to allow for an understanding of the ways in which the data collection tools were employed in practice by participants and myself. Coding and analysis of transcript content was guided by the research objectives. I modified these objectives as needed in order to accommodate unexpected emergent themes in the data. I have described participant and study characteristics so as to allow the reader an opportunity to consider the influences of these characteristics. While this study posed some potential ethical risks for participants, I addressed these risks through strategies outlined in this chapter.

Following Baxter and Eyles (1997), this study design established qualitative rigour through the following strategies:

- A rationale for the chosen methodology was given.
- Multiple methods were used, and how they were used together was explained.
Participants were purposively sampled to gather a range of characteristics that could influence space-time organization of everyday life and participant characteristics are described.

The selection of interview quotations made during analysis was driven by theory and the study objectives.

Interview practices were described.

Procedures for analysis were described.

Appeals were made to the interpretive community through reference to the existing bodies of literature.

Next, in Chapters 6 and 7, I present the findings of the space-time analysis of this study.
Chapter 5 - Study Setting

<table>
<thead>
<tr>
<th>5.1</th>
<th>Canberra (ACT) and New South Wales region</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.2</td>
<td>A brief history of Canberra and region</td>
</tr>
<tr>
<td>5.3</td>
<td>Canberra’s urban design</td>
</tr>
<tr>
<td>5.4</td>
<td>New South Wales regional towns</td>
</tr>
<tr>
<td>5.5</td>
<td>Health services in Canberra and region</td>
</tr>
</tbody>
</table>

5.1 Canberra (ACT) and New South Wales region

The study setting for this project was Canberra, the national capital of Australia, as well as nearby regional and rural towns within the surrounding state of New South Wales. Twenty of the 26 participants lived in Canberra, while the remaining six lived in regional and rural towns shown in Figure 5.1. As the capital city, Canberra is a self-governing city-state with its own administrative territory, the Australian Capital Territory (ACT) (Warhurst, 2015). Canberra and the ACT are often used interchangeably in reference to the same place. Canberra is located 150 kilometres inland from the Pacific Ocean, and 281 kilometres from the closest major city, Sydney, to the northeast, and 660 kilometres from Melbourne to the southwest (VisitCanberra, 2015).
Canberra is a small but growing city with a population of about 375,000 at the time of the study (Australian Bureau of Statistics, 2015). It is projected that the population will grow to 390,100 persons in 2019 (Australian Capital Territory, 2009). Canberrans are slightly younger and wealthier than the Australian population as a whole (Australian Bureau of Statistics, 2011b). The mean age of the Canberra’s population is 34.5 as compared to 37.3 for Australia. The average personal wage and salary income in Canberra is about $61,000 AUD per year, as compared to $52,000 AUD per year for the average Australian (Australian Bureau of Statistics, 2011b). As with the rest of Australia, Canberra’s population is ageing. It is projected that the percentage of the ACT’s population aged 65 years and over will rise from about 10% in 2007 to 14% percent in 2019 (Australian Capital Territory, 2009).

Canberra’s main employing industry is public administration and safety, which includes employers such as Parliament, public service departments, and the Australian Defence Force (Australian Bureau of Statistics, 2015). Canberra also has four university campuses: the Australian National University, the University of Canberra, the Australian Catholic University, and the University of New South Wales satellite campus located at the Australian Defence

Figure 5.1  Participant locations in the ACT and regional NSW

Source: Data from Sensis (2013) and naturalearthdata.com (2015)
Force Academy. The main offices of the Commonwealth Scientific and Industrial Research Organisation (CSIRO), Australia’s national science agency, are also located in Canberra.

The land surrounding the ACT is governed by the state of New South Wales. This area are characterised by livestock farms, wilderness areas such as the Snowy Mountains, and small and mid-size regional towns such as Queanbeyan, Yass, Bungendore and Goulburn. The quality of the soil in this area is too poor for large-scale crop farming, but has been used for grazing livestock, mainly sheep and cattle, since the early 1800s.

5.2 A brief history of Canberra and region
Canberra was first occupied by and is home to the Ngunnawal people. Europeans first came to live in Canberra in the 1830’s. Following the creation of the Commonwealth of Australia in 1901, the small “bush town” of Canberra was selected as a site for the nation’s capital in 1913 where the Parliament moved from its temporary location in Melbourne in 1927 to what is now known as the Old Parliament House in Canberra. Canberra remained a small, rather isolated town set in a rural farming and wilderness region for several decades; its growth hindered by the Great Depression, then World War II, as well as logistical challenges of transportation to and communication with the closest major cities of Sydney and Melbourne. In the 1950s and ‘60s, however, the public service departments were relocated from Melbourne to Canberra, and major construction efforts in the city commenced, such as Lake Burley Griffin, which divides the city into north and south, and in 1988, the new Parliament House opened (see Figure 5.2 for a visual overview). Canberra is home to many social and cultural institutions of national significance to Australia, such as the Australian War Memorial, the National Library, National Gallery, National Portrait Gallery, National Archives, and National Museum, Australian Institute of Aboriginal and Torres Strait Islander Studies and the Australian Institute of Sport. Canberra also houses the national headquarters of Australia’s major political parties, and national groups such as the National Farmers Federation (Warhurst, 2015).

Figure 5.2 View of downtown Canberra and Lake Burley Griffin.

Source: Photo credit to JJ Harrison;
http://commons.wikimedia.org/wiki/File:Canberra_From_Black_Mountain_Tower.jpg
5.3 Canberra’s urban design

Canberra is relatively unique in that it is completely designed and constructed for the purpose of being the nation’s capital (Figure 5.3). In this way it has similarities with Washington, DC and Brasilia. Its particular design shapes population density, where amenities are located, and how movement around the city takes place. As Canberra was essentially rolling scrub country with little infrastructure or buildings at the time it was selected as the new capital in 1913, it provided a blank slate for city planning. The government organised an international competition for the design of the new capital. The winning design was created by American architects, Walter Burley Griffin and his partner, Marion Mahoney Griffin.

Figure 5.3 The winning design for Canberra. View from summit of Mount Ainslie, 1912, watercolour


The designers took a modular approach to the city, organising it by small suburbs, each with local shops and amenities, which is spreading outward from the core downtown and Parliamentary areas. A large lake, Lake Burley Griffin, was constructed to divide the city into north and south. Downtown (‘Civic’) lies to the north of the lake, while Parliament House and many other national monuments and institutions lie to the south (see Figure 5.4 for a map and Figure 5.5 for a street view). The plan also included a tram system connecting these suburbs to downtown. However, the tram was not built. A light rail system was in planning stages at the time of the study.
Figure 5.4  Canberra City

Source: Data from Sensis (2013) and naturalearthdata.com (2015)
A unique feature of Canberra’s design that was implemented is the preservation of 33 separate plots of land as Canberra Nature Park. These areas contain hiking, mountain biking and equestrian tracks in natural bushland and grassland, preserve endangered ecological communities, and afford habitat for more common wildlife such as the Eastern Grey Kangaroo, as well as for rare and threatened species. The majority of Canberrans are within walking distance of a Canberra Nature Park (Territory and Municipal Services, 2015). Hence, Canberra is often called “The Bush Capital” (Figure 5.6).

Today, Canberra maintains the dispersed, ‘Garden City’ intention of the original design, and most suburbs have at least basic amenities such as a small grocer (Figure 5.7). However, to reach greater amenities and services such as larger shops and health services, Canberrans have
to drive, cycle or take a bus. The bus system attracts relatively low levels of ridership, and overwhelmingly, the car is the main mode of transport: about 70% of journeys to work are made by car drivers (Gordon, 2011).

![Local shops at a Canberra suburb.](http://www.hackett.org.au/page/9/)

**Figure 5.7** Local shops at a Canberra suburb.


### 5.4 New South Wales regional towns

Five regional and rural towns in New South Wales are home to six of the 26 participants in the study: Queanbeyan, Goulburn, Pomeroy, Crookwell and Long Beach. These six participants travel to Canberra for specialist health services required for their chronic illnesses, and for this reason were included in the study. From downtown Canberra, these towns are reachable by car in the following amounts of time (calculated with Google Maps): 21 minutes (Queanbeyan; one participant), 62 minutes (Goulburn; two participants), 78 minutes (Pomeroy; one participant), 86 minutes (Crookwell; one participant), and 118 minutes (Long Beach; one participant).

Queanbeyan (population 40,568) is located just across the southeast border of the ACT, has several major stores and amenities, and many of its residents commute to Canberra for work (Queanbeyan City Council, 2011). Goulburn (population 21,282), is a mid-size regional town 95 kilometres northeast of Canberra (Australian Bureau of Statistics, 2011a). It has a hospital, grocery stores and other major services and amenities (Figure 5.8).
Crookwell (population 2,014) is a much smaller rural town 110 kilometres north of Canberra. The largest town nearby with substantial amenities and services is Goulburn, a 34 minute drive away. It has a small regional hospital with emergency services, a general health practice, grocery stores, post office, and other basic services and amenities.

Pomeroy (population 422) is a collection of about 200 households (Australian Bureau of Statistics, 2011a) scattered across a rolling wooded and grassland area with several large livestock paddocks. It is about 19 kilometres to the northeast of Goulburn and about 99 kilometres north of Canberra (Figure 5.9). Pomeroy residents typically travel to Goulburn for services and amenities.
Finally, Long Beach (population 1,379) is a collection of households on the coast of the Pacific Ocean, about 154 kilometres southeast of Canberra. Residents travel by car nine minutes to Batemans Bay (population 11,334) for services (Australian Bureau of Statistics, 2011a). Batemans Bay is a coastal holiday town with a large permanent resident population that supports a district hospital, several other health and aged care organisations including a dialysis unit, several grocery and retail stores, and many other services and amenities (Anonymous, 2015) (see Figure 5.10).

**Figure 5.9** Livestock paddock in Pomeroy, New South Wales. A rural area with no services.

*Source: http://www.homehound.com.au*

**Figure 5.10** Waterfront cafe in Batemans Bay.

5.5 Health services in Canberra and region

Canberra is the centre of health services for its region. In order to reach comparable services in terms of the range and specialisation of services, patients must travel to Sydney, a three hour drive. The Australian health care provision and funding arrangement is complex, with funding derived from all levels of government, private health insurers and individual Australians (see Figure 5.11 below). The Australian national health care system (Medicare) provides all Australians with free, rebated or subsidised hospital, medical, and pharmaceutical treatment (Australian Institute for Health and Welfare, 2013). Australians also have the option to purchase additional private health insurance and obtain health services from private health practices. Public health services in Canberra are administered by the ACT Health Directorate, an ACT government agency (ACT Health Directorate, 2014).

Figure 5.11 Australian health services and funding responsibilities

Source: Australian Institute of Health and Welfare (2008, p. 9)
Canberra has three main hospital campuses (see Figure 5.4: Canberra City). On the southside of Canberra is the Canberra Hospital, a public hospital, the National Capital Private Hospital which is co-located on the Canberra Hospital campus, and Calvary John James Hospital, a private hospital also located on the south side of Canberra. On the north side of Canberra is Calvary Health Care ACT, a public hospital, and Calvary Bruce Private Hospital. The two emergency departments in Canberra are located at Calvary Health Care ACT, in the north, and the Canberra Hospital, in the south.

The ACT Health Directorate administers a wide range of health services for the region, including emergency services, general practitioners which are located across the Canberra suburbs, pathology services, two walk-in centres for minor injury or illness, Aboriginal and Torres Straight Islander services, alcohol and drug services, cancer services, aeromedical rescue service, community health centres, dental care, immunisation, infection prevention and control, intensive care, surgery, medical services (cardiology, neurology, and psychology), mental health services, nutrition, justice services, outpatient services, rehabilitation, aged and community care, sexual health, a facility for women and children, and diabetes services (ACT Health Directorate, 2015a).

Of particular relevance to this study are the chronic disease management services of the ACT Health Directorate that are administered primarily through the Canberra Hospital. These include: care coordination, advanced care planning clinics, home telemonitoring, telephone coaching, and services targeting the management of chronic obstructive pulmonary disease (COPD), chronic heart failure (CHF), Parkinson’s disease and other movement disorders, and obesity (ACT Health Directorate, 2015a).

Canberra is also the hub for renal services in the region, concentrated within the Renal Services Department of the Canberra Hospital through which participants of this study were recruited. Renal services offers comprehensive clinical care for people with renal problems, including transplant, outpatient services such as high blood pressure management, CKD management, and general nephrology, inpatient services, nutritional counselling, social work, and home and nocturnal dialysis training (ACT Health Directorate, 2015b). Canberra has three haemodialysis clinics: two in the south and one in the north of Canberra. The only other haemodialysis units within the study setting are located in Queanbeyan (20 minutes southeast of Canberra), Goulburn (an hour north of Canberra) and Moruya (21 minutes south of Batemans Bay and just over two hours from Canberra) (Kidney Health Australia, 2015).
Chapter 6 - Findings: A Diary Sketch of Everyday Life

6.1 A diary sketch of everyday life
   6.1.1 Trips
   6.1.2 Transportation
   6.1.3 Locations
   6.1.4 Activities
   6.1.5 Travel and activity diary summary
   6.1.6 Chronic illness management inventory results
   6.1.7 Chronic illness management inventory summary

In this chapter, and in the following (Chapter 7), I present the findings of this case study on CKD in Australia, which is aimed at understanding experiences of time, alongside space, in negotiating everyday life with chronic illness. I begin in this chapter by sketching the predominant activities, locations and trips made in participants’ everyday lives (objective 1; see Chapter 1.4.2 for statement of aim and objectives). Drawing from the travel and activity diaries, I describe the trips, transportation options, locations of activities, and activity types that motivated trips recorded by participants on their two sample days. Then, I draw from the chronic illness management inventories that participants completed at the end of each of their two sample days to provide a sketch of the chronic illness management burden among participants.

6.1 A diary sketch of everyday life

The travel and activity diaries (n=49) offer a bare bones sketch of participants’ trips outside of home, locations visited, and activities that motivate trips in everyday life. Some differences in sample day travel and activity patterns are suggested between participants of different CKD stages, employment statuses and genders. A few of these variations are highlighted below. See Appendix 8: Travel and activity diary results for a full summary of results. Please note that the diary sample sizes are particularly low for participants in CKD stage 2 (two sample days) and participants who are on sick leave or are unemployed (four sample days each). Therefore, results for these participant characteristics may not adequately describe the everyday movements and activities for these categories.
6.1.1 Trips
Altogether, participants recorded a total of 225 trips. On average, participants took about five (4.9) trips outside the home on their diary days, ranging from zero to 10 trips per diary day. The term trip refers here to departure from one location (e.g., house, building, park), travel, and arrival at another location. Five diaries reported no trips away from home. These corresponded to three retired individuals, two of whom have severely limited mobility due to physical problems, and one unemployed person who worked on a fencing project on the family property all day. The diaries recording the most trips (8-10 trips) corresponded to individuals representing a variety of CKD stages, employment statuses and genders. Motivations for trips made in this highly mobile group ranged from commuting to work, a trip to the chemist (i.e., pharmacy), work-related trips around town, hardware store trips for a house renovation project, several trips to a bookstore, and guitar lessons.

The number of trips recorded in the travel and activity diaries varied slightly by CKD disease stage. Participants with earlier disease stages (stages 2 and 3) took, on average, five to six trips (Figure 6.1). The two stages with fewest trips were stages 4 and 5 with dialysis. Stage 4 took the fewest (3.4 trips), likely due to physical impairments resulting from more severe illness symptoms that develop at this stage. Stage 5 with dialysis took slightly more trips (4.2) than stage 4, likely because participants receiving dialysis were asked to record a dialysis day, which, for all but one participant, required a trip to a dialysis clinic. The average number of trips taken by participants with a functioning kidney transplant (5.4 trips) is similar to that of participants in earlier stages of CKD. This is perhaps due to the improved physical functioning and reduced burden of illness treatment associated with having a functioning transplant. There was very little variation between the number of trips made by participants with different employment statuses or between men and women.
Findings: A Diary Sketch of Everyday Life

Figure 6.1  Average number of trips per diary by CKD stage

6.1.2  Transportation

Overwhelmingly, driving a car was the most prevalent mode of transportation used by participants on the sample days (n = 36 sample days), reflecting the transportation patterns of the wider Canberra population (Figure 6.2; and see Chapter 5.3). Driving was followed in prevalence by short walking trips (16 sample days). The short walking trips primarily served such purposes as connecting to a bus or walking from the office to get lunch on a work day. To a far lesser extent participants took the bus (six sample days), were a passenger in a car (four sample days), rode a bicycle (two sample days) and took community transportation (two sample days). Community transportation refers to publicly funded shuttle bus services specifically targeting individuals who are unable to drive or utilise public transportation such as bus due to mobility impairments (e.g., ACT Government, 2008). Due to the small number of trips recorded for transportation modes other than driving a car and walking, I will focus on participant variations within those two modes.

Participants in CKD stages with the most pronounced symptoms and illness management burden (stages 4 and 5 with dialysis) were less likely to drive a car than other participants. Those receiving dialysis were the least likely to drive a car, presumably due to their lack of confidence to safely operate a vehicle after dialysis treatment given the dizziness and fatigue many experience after treatment. The only diary entries with trips taken as a car passenger (four diaries) or by community transportation (two diaries) were participants in stages 4 and 5 with dialysis.


Figure 6.2 Car drivers by CKD stage

Participants receiving dialysis were the least likely to take short walking trips during the day (Figure 6.3). This aligns with findings that individuals who receive dialysis are more sedentary than individuals in other stages of CKD due, in particular, to fatigue and shortness of breath associated with dialysis treatment (Delgado & Johansen, 2012).

Figure 6.3 Walking by CKD stage

Retired participants were the least likely to drive a car on a diary day (50%) as compared to non-retired participants (ranging from 75-100%). Retired individuals were also the only participants to record trips made as a car passenger (4 diaries) or on community transportation (2 diaries). This likely due to the greater number of health problems experienced by older, retired age groups.

Both men and women drove cars at high rates (75% of females; 72% of males). Men took more short walking trips on average than women (21% female; 44% male).
6.1.3 Locations

Next, I examine the types of locations participants visited on their sample days (Figure 6.4). Not surprisingly, participants’ homes were recorded as a destination for a trip made on all sample days. The most prevalent locations outside of home recorded on a sample day were grocery shops or other retail stores (30 sample days), health and medical services such as the chemist, doctor’s office or dialysis clinic (20 sample days), and workplaces (19 sample days). Participants also recorded visits to other miscellaneous locations (13 sample days) such as the library, a labour club, the gym, car registration or service, movie theatre, veterinarian, guitar lessons, and a dance performance. Food outlets were also visited (10 sample days), including restaurants and take-away eateries, as well as exercise routes such as a walking circuit around the neighbourhood (eight sample days), the homes of friends or family (eight sample days), and, finally, a child activity location such as a school (four sample days). As child activity location visits were only recorded for four sample days these will not be examined by participant characteristics.

![Locations Prevalence Chart](chart.png)

**Figure 6.4 Prevalence of location types visited**

Participants with a functioning kidney transplant were far more likely to visit a workplace on a sample day than participants in other CKD stages\(^1\) (Figure 6.5). Because these individuals have a functioning kidney they do not tend to experience as many symptoms and physical impairments as individuals with declining kidney function in other disease stages. Therefore they may feel more able to participate in paid work.

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\(^1\) One participant visited a work location to pick up his partner, although he did not work on his sample days.
Figure 6.5  Place of work visit by CKD stage

Health services location visits, such as to the chemist, a dialysis clinic or a doctor’s office were much more common among participants in stage 5 with dialysis (77%), highlighting the intense illness management burden associated with this stage of CKD (Figure 6.6). This high proportion is partly due to a visit to the dialysis clinic on one of the two sample days recorded by participants receiving dialysis.

Figure 6.6  Health services location visit by CKD stage

Participants receiving dialysis were the least likely to visit an exercise route (0%), such as a walking circuit around a neighbourhood, on their diary day (Figure 6.7). This may be because these individuals feel less able to venture out on foot away from home or another base location due to the fatigue and dizziness associated with dialysis treatment.
Figure 6.7 Exercise route visit by CKD stage

Participants in stage 5 with dialysis and those with a functioning kidney transplant were more likely to visit a food outlet location such as a restaurant or take-away eatery than participants in other disease stages (Figure 6.8). For individuals receiving dialysis, buying prepared food may be advantageous given the space-time constraints imposed by dialysis or a lack of energy to cook. For individuals with a functioning transplant this may be due to the greater freedom they have in their diet as compared to other CKD stages.

Figure 6.8 Food outlet visit by CKD stage

As may be expected, participants with fewer space-time constraints derived from paid work were more likely to visit shops and other retail outlets on a sample day (70-75%) as compared to full- and part-time workers (46-50%).

Retired (50%) and unemployed participants (50%) were more likely than the others to visit a health services location on a sample day (Figure 6.9). This is probably because
individuals who work experience inflexible space-time authority constraints imposed by their employer, and they may try to make fewer trips to health services by grouping their health service appointments and errands together, thereby reducing disruption to their work schedule.

Figure 6.9  Health services location visit by employment status

Only slight variations in the types of locations visited on sample days were observed between men and women. The only notable differences were in visiting an exercise route on a sample day (8% women; 24% men) and in visiting a food outlet (13% women; 28% men).

6.1.4 Activities

The most prevalent activity type that motivated trips on the sample days was domestic work (36 sample days; see Figure 6.10). This included tasks like going to the grocery store, dropping the cat off at the vet, going to the bank, registering the car and getting a haircut. Illness management activities and leisure and recreation were the next most prevalent activity types, occurring on 27 sample days. Paid work motivated trips on 18 sample days. Four sample days recorded a caregiving activity as motivating a trip.

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2 While domestic work was the most prevalent activity type within the sample, I chose to analyse interview content according to the next four most prevalent activity types (illness management, leisure, paid work, and caregiving) due to the greater meaning participants attributed to these activities in their interviews.
Findings: A Diary Sketch of Everyday Life

Figure 6.10  Prevalence of activity types performed

Participants who receive dialysis were the most likely to make trips motivated by illness management activities on their sample days (77%; see Figure 6.11). However, all other stages had quite high rates of illness management activities as well (50%), highlighting the substantial overall burden of disease management experienced by the study sample (disregarding the misleading figure for CKD stage 2).

Figure 6.11  Illness management activity performance by CKD stage

Participants with a functioning kidney transplant participated in paid work on their sample days at higher rates than participants in other CKD stages, as may be expected, due to generally improved physical functioning experienced after receiving a transplant (Figure 6.12).
Participants working full-time were the least likely to make trips motivated by leisure and recreation activities on their sample days, likely due to the space-time constraints of paid work (Figure 6.13).

No notable differences in activity types recorded on sample days were observed between men and women. With a larger sample, however, differences in caregiving activities may have been observed. In this sample, one man recorded one sample day with trips motivated by caregiving while three women recorded the same.

6.1.5 Travel and activity diary summary

In general terms as a group, participants took about five trips per diary day, usually drove themselves in a car and/or took short walking trips, often made at least one visit to a retail,
health services or paid work location, and were most often motivated to make trips in order to perform domestic, illness management, leisure and recreation, and paid work activities.

CKD stages with more pronounced symptoms and illness management burden (stages 4 and 5 with dialysis) had the lowest average number of trips on a diary day, had lower rates of driving themselves in a car, lower rates of making short walking trips, were the least likely to visit a workplace, the most likely to visit a health services location, the least likely to travel an exercise route, the most likely to make trips motivated by illness management, and the least likely to make trips motivated by paid work. In all of these cases, results for participants receiving dialysis were more pronounced than those for stage 4. Furthermore, individuals receiving dialysis, along with transplant recipients, were the most likely to eat food prepared at a food outlet.

At the other extreme (and disregarding the low numbers of CKD stage 2 participants), participants with a functioning kidney transplant made the most trips, were the most likely to drive themselves in a car or make short walking trips and were the most likely to visit a workplace. Along with dialysis patients, they were also the most likely to eat food from a food outlet. They did, however, visit health services locations at rates similar to CKD stage 4 participants, and were slightly less likely to visit an exercise route than participants in CKD stage 3.

Participants who are unemployed or retired were more likely to make a visit to a health services location than other participants. Meanwhile, participants working full-time were the least likely to make a trip motivated by leisure and recreation activities.

Very few gender differences were observed in travel and activity diary data. Men were more likely to make short walking trips as a mode of transportation than women, were more likely to travel an exercise route such as a walking circuit or bushwalking track than women, and were more likely to visit a food outlet. Finally, while inconclusive due to the small sample size, it appears women may make more trips motivated by caregiving activities than men.

### 6.1.6 Chronic illness management inventory results

Table 6.1, below, lists the most common chronic illness management tasks that people with CKD are assigned by their health care providers to manage their CKD and co-morbid conditions like diabetes and hypertension (Green & Ryan, 2009; Hays et al., 1994; Levin et al., 2008) (see the inventory and self-assessment tool used in this study in Appendix 2: Chronic illness management inventory and self-assessment). The tasks an individual needs to do varies by the stage of their CKD and the co-morbid conditions they may have.
Table 6.1  Common Chronic Illness Management Activities

<table>
<thead>
<tr>
<th>Eating, drinking</th>
<th>Medications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Follow a low salt diet</td>
<td>Take pills for hypertension (blood pressure)</td>
</tr>
<tr>
<td>Follow a low fat or weight loss diet</td>
<td>Take pills for cardiovascular problems (heart)</td>
</tr>
<tr>
<td>Watch and limit my protein intake</td>
<td>Take pills for cholesterol</td>
</tr>
<tr>
<td>Follow a diabetic diet</td>
<td>Take pills for albuminuria (protein in urine)</td>
</tr>
<tr>
<td>Watch and limit my potassium intake</td>
<td>Take phosphorus blocker pills</td>
</tr>
<tr>
<td>Watch and limit my phosphorous intake</td>
<td>Take kidney transplant pills*</td>
</tr>
<tr>
<td>Drink enough water to keep kidney(s) always hydrated*</td>
<td>Take pills on a certain schedule (E.g., before food)</td>
</tr>
<tr>
<td>Carry something with sugar in it as a source of glucose for emergencies (diabetes)</td>
<td>Take insulin shots or use insulin pump (diabetes)</td>
</tr>
<tr>
<td>Exercise</td>
<td>Attend a medical appointment</td>
</tr>
<tr>
<td>Stop or cut down on smoking</td>
<td>Renal replacement therapy (dialysis)</td>
</tr>
<tr>
<td>Cut down on the alcohol I drink</td>
<td>Perform peritoneal dialysis at home during the day</td>
</tr>
<tr>
<td>Monitoring the body</td>
<td>Perform peritoneal dialysis at home during the night</td>
</tr>
<tr>
<td>Take (monitor) blood pressure</td>
<td>Perform haemodialysis at home</td>
</tr>
<tr>
<td>Check my blood for sugar</td>
<td>Perform haemodialysis outside my home</td>
</tr>
</tbody>
</table>

*item not included on inventory and self-assessment tool but written in by participants

The figure below shows the number of participants reporting that they should perform each chronic illness management task on one or both of their sample days (Figure 6.14). The most common chronic illness management activities participants reported feeling they should perform were exercise (21 participants), take medication on a set schedule (19 participants), take medication for hypertension (18 participants), take medication for cholesterol (16 participants), and check blood pressure (14 participants). Between 11 and 14 participants reported needing to limit the amount of fluid consumed in the day, follow a weight-loss diet, limit potassium in their diet, limit salt in their diet, and/or limit phosphorous in their diet.
Findings: A Diary Sketch of Everyday Life

Figure 6.14 Participants’ most common chronic illness management tasks

Eight to nine (8-9) participants reported needing to check blood glucose levels, follow a diabetic diet, attend a medical appointment, and take medications for cardiovascular health, a kidney transplant, and/or other medications on one or both of their sample days. Five to seven (5-7) participants reported needing to limit protein in their diet, limit or stop drinking alcohol, drink enough water during the day to keep their kidney(s) hydrated, take medication to block phosphorous absorption, carry sugar in case of a diabetic emergency, and/or receive dialysis at a clinic. Four participants had to inject insulin. Three had to take medication for albuminuria.

The one participant (Cathy) who dialyses at home was one of three in the pilot study who did not provide two sample days. She did not dialyse on her sample day, however, her home dialysis has been included in the figure. No participants reported needing to cut down or stop smoking, or perform peritoneal dialysis on either sample day.

Participants self-rated their level of success in performing each of the chronic illness management activities they indicated they should have performed on each of their sample days. Self-ratings were recorded on a scale of zero-to-three, with zero indicating ‘Completely unsuccessful’, one indicating ‘Somewhat unsuccessful’, two indicating ‘Somewhat successful’, and three indicating ‘Completely successful’. The figure below (Figure 6.15) provides an average performance score for each chronic illness management activity taken from all participants’ self-rated performance scores from their sample days.
Overall, participants reported feeling most successful about taking medications. Attending dialysis at a clinic, attending a doctor appointment, injecting insulin, staying hydrated and carrying sugar also received average scores that were closer to ‘Completely successful’ than ‘Somewhat successful’. Activities that seem more difficult for participants but still received more than a ‘Somewhat successful’ rating were the activities of limiting substances from participants’ diets (protein, salt, fluid, potassium), following a diabetic diet, and limiting or cutting out alcohol. Activities that participants had the most trouble with, and received average scores between ‘Somewhat unsuccessful’ and ‘Somewhat successful’ were checking blood pressure, checking blood glucose levels, limiting phosphorous in their diet, exercising and following a weight-loss diet. The success of the group in performing illness management activities may influenced by a self-selection bias in sampling. Participants who feel less overwhelmed in everyday life may be more willing to participate in this kind of study. Or, participants feeling that illness management activity performance is a problem that needs attention may have been more drawn to this study. These limitations of study design will be discussed further in Chapter 8.4 (Discussion and Conclusion).

The figure below compares the number of chronic illness management activities participants had to perform on each of their sample days (Figure 6.16). While there is a lot of similarity between the number of activities participants had to do on each of their sample days there is also some variability for some individuals. The most common reasons for this were activities participants do not feel they should or need to perform every day, such as dialysis, exercise, checking blood pressure, or attend a medical appointment. In the following chapter, I
describe how participants who dialyse, in particular, group their medical appointments and exercise around days without dialysis.

Figure 6.16  Comparison of number of management activities between sample days

The number of chronic illness management activities participants report needing to perform on any given sample day ranged from three to 18. The figure below (Figure 6.17) shows how the maximum burden of chronic illness management activities increases within the group by disease stage, peaks during stage 5 (End Stage Kidney Disease) requiring dialysis, and then drops down to early stage CKD management intensity after a successful kidney transplant. However, within each disease stage, the illness management burden varies, most likely depending upon the number and extent of co-morbid conditions.

Figure 6.17  Chronic Illness Management Burden by Disease Stage
The average number of chronic illness management activities for each disease stage also follows this general pattern, with stages 2 and 3 having the lowest burdens, stage 4 showing a substantial increase in illness management burden, stage 5 with dialysis having the highest burden, and transplant recipients having a lower burden around the same levels as early stage CKD (Figure 6.18).

![Figure 6.18 Average Illness Management Burden by Disease Stage](image)

**6.1.7 Chronic illness management inventory summary**

In summary, all participants reported needing to perform chronic illness management activities on all sample days. The number of activities reported for any given sample day ranged widely (range: 3 to 18). The management burden is highest for those in ESKD requiring dialysis, but also varies within disease stages. The five most common illness management activities identified by participants were exercise, following a medication schedule, taking medication for hypertension, take medication for cholesterol, and checking blood pressure.

Most participants reported about the same number of activities on both of their sample days. Where there was variation between the sample days, this was due to chronic illness management activities that participants do not feel they should or need to perform every day, such as dialysis, exercise, checking blood pressure, or attend a medical appointment.

Overall, participants feel most successful about taking medications. Performance ratings for attending dialysis at a clinic, attending a doctor appointment, injecting insulin, staying hydrated and carrying sugar also were also fairly positive. Activities that participants had the most trouble with were checking blood pressure, checking blood glucose levels, limiting phosphorous in their diet, exercising and following a weight-loss diet.
Chapter 7 - Findings: Interacting Space-times of Everyday Life

7.1 Patient self-management of chronic illness
   7.1.1 Dominant approaches revisited
   7.1.2 Findings from a space-time analysis

7.2 Paid work participation
   7.2.1 Dominant approaches revisited
   7.2.2 Findings from a space-time analysis

7.3 Caregiving and family
   7.3.1 Dominant approaches revisited
   7.3.2 Findings from a space-time analysis

7.4 Leisure, recreation, and tourism
   7.4.1 Dominant approaches revisited
   7.4.2 Findings from a space-time analysis

7.5 Findings summary
   7.5.1 Trips, locations, and activities
   7.5.2 Time, space, and everyday life
   7.5.3 Interacting space-times

In this chapter, I provide a space-time analysis of participant’s experiences in negotiating the four areas of everyday life that emerged as most important to them, based on their interview accounts: (7.1) Patient self-management of chronic illness; (7.2) Paid work participation; (7.3) Caregiving and family; and (7.4) Leisure, recreation, and tourism. In each of these sections, I apply my space-time approach (see Chapter 2) to describe the spatio-temporal characteristics of activities and chronic illness (objective 2), describe the origins of these spatio-temporal characteristics (objective 3), observe how these characteristics interact with one another (objective 4), and, finally, understand how participants experience the interaction of these spatio-temporal characteristics (objective 5). I conclude the chapter with a summary of findings.

7.1 Patient self-management of chronic illness

“The more you make something normal, the less it seems... unusual?” - Sarbajit
7.1.1 Dominant approaches revisited

The degree of success a person has in managing chronic illness in everyday life is usually conceptualised at the scale of the individual patient, working in partnership with a team of health professionals (Bodenheimer, Lorig, Holman, & Grumbach, 2002). Having the education and skills needed to manage illness (e.g., Browne & Merighi, 2010; Costantini et al., 2008), having a positive sense of self-efficacy (e.g., Bodenheimer et al., 2002; Curtin et al., 2008; Tsay, 2003), being motivated (e.g., Jowsey, Pearce-Brown, Douglas, & Yen, 2011), believing in one’s own susceptibility to poor health, perceiving the benefits of treatment regimens, accepting the diagnosis of illness (e.g., Costantini et al., 2008; Glanz, Rimer, & Viswanath, 2008), and being able to establish ‘healthy’ routines and habits (e.g., Balfe, 2009; Balfe et al., 2013; Costantini et al., 2008; Dyck, 2002; Fiese & Wamboldt, 2000; Haslbeck & Schaeffer, 2009; Takahashi, Wiebe, & Rodriguez, 2001; Wagner & Ryan, 2004) have all been identified as factors associated with successful self-management of chronic illness (see Chapter 3.2.1 for a more extensive discussion).

7.1.2 Findings from a space-time analysis

In the sections below, I broaden the focus of analysis of patient success with chronic illness self-management from the scale of the individual, to examine the spatio-temporal characteristics of illness management activities, the space-time contexts in which they take place, and the spatio-temporal characteristics of health services access. I argue that everyday logistics and contexts influence a person’s ability to establish healthy routines and habits, and to possess some of the psychosocial factors that have been identified as important for success in patient self-management, such as motivation and a positive sense of self-efficacy.

7.1.2.1 Space-time resource conflicts

First, I will highlight the logistical challenges participants face in managing their illness due to the heavy demands chronic illness management activities place on their finite spatio-temporal resources. These demands sometimes come into conflict with those of other everyday activities. Space-time resource conflicts between illness management and other everyday activities will be explored in more detail later in this chapter in the sections discussing paid work, caregiving and family, and recreation and hobbies (Chapters 7.2; 7.3; 7.4). The purpose here is to provide a general description of the space-time demands of chronic illness management activities that participants described as particularly taxing. I will show how these demands often fundamentally shift how everyday life is organised and restrict a person’s potential path area. This often creates logistical conflicts with other areas of life, thereby disrupting stable routines and habits that might decrease the effort required to adhere to
chronic illness treatment regimens. I describe some of the challenges participants face in mitigating these effects of the space-time demands of chronic illness.

7.1.2.1.1 Dialysis
Among the chronic illness management activities performed by participants, dialysis and doctor appointments emerged from participants’ accounts as the most space-time resource taxing. For the 15 participants who receive or have ever received dialysis, beginning treatment was described as a fundamental reorganisation of everyday life. The extent of the constraints imposed on how everyday life can be organised depends, in part, on which mode of dialysis treatment is received. The most prevalent dialysis treatment mode among participants was haemodialysis. This mode of therapy involves circulating the person’s blood through a large, stationary machine in order to clean the blood and remove excess fluid. Therein lies a coupling constraint on a person’s movements in time and space with the location of the machine and times the machine is available.

Typically, haemodialysis therapy is received three times a week for four or five hours per session. For participants receiving dialysis at a clinic, the clinic becomes an additional base location in their lives, in addition to places like the home or work. For example, Gio (age 66, pensioner, clinic dialysis) emphasizes the extent to which haemodialysis has re-organized his life by saying that he has two homes instead of one, the second being the dialysis centre. Participants receiving dialysis in a clinic spend time travelling to the centre and then waiting for a dialysis machine to become available, which can take up to an hour if the person before them had complications with their dialysis session, producing some unpredictability around temporal cost of the treatment. Then, once seated at a machine, there is time spent taking readings, preparing the access point and equipment for dialysis, and, the four to five hours spent while the machine cleans the blood and removes excess fluid. During dialysis the individual must sit very still in order not to disturb the access point. In fact, if the person moves too much, the machine will sound an alarm. Furthermore, the chairs are spaced apart, making it difficult to chat with other people, especially for those like Mary (age 75, pensioner, clinic dialysis) who is hard of hearing. As such, haemodialysis imposes a substantial capability constraint on what a person can do during the four to five hours of a dialysis session, restricting people to activities like watching TV and reading:

You go in there [dialysis centre] and you’ve got rows of people just s-i-t-t-i-n-g like this [sits back and lays arms on arm rests]. Just watching their life tick away.

- Cathy (age 69, pensioner, home dialysis)
Then, time is spent getting off the dialysis machine, waiting for the access point to stop bleeding, and waiting for blood pressure to return to normal before being allowed to leave the dialysis centre, also making the temporal cost of dialysis more unpredictable. The unpredictability of when a person can get on the machine, and how long it will take to get off, further disrupts any routine activities on dialysis days. Mary, for example, once waited an hour before her blood pressure recovered enough to leave the centre. For this reason, her husband insists on driving her to and from dialysis. While this is helpful, it also creates a coupling constraint with his day’s activities. She dialyses early in the morning so that he has time to run errands and go to the gym while she is at the clinic. This, however, means that the rest of the day is spent recovering from dialysis in bed, instead of getting off dialysis in the evening and going to bed for the night, preventing her from establishing routine activities earlier in the day before dialysis. Cathy (age 69, pensioner, home dialysis) reflects on how her life changed when she started dialysis, at first at a clinic:

Your whole life changes anyway when you do dialysis. Everything changes. You’ve sort of got to restructure your life. I mean, you can’t, you know (hesitates), you’re ruled by, I mean I had to go to the hospital, um, to do dialysis three times a week and there’s a set time you’ve got to go. You don’t know how long you’re going to be there because if the person in front of you things go wrong with their dialysis, you could have to sit and wait an hour until you can get on. [...] There’s a lot of time spent at the doctor’s, hospitals and blood tests and a lot of things.

The space-time costs of clinic dialysis are even more imposing for participants living in rural areas outside the city of Canberra. Larry (age 77, pensioner, clinic dialysis), for example, lives in a mid-size regional town about an hour from Canberra. While he waited three months for a dialysis chair to become available in his small local clinic, he travelled to Canberra three times a week for treatment. He would leave home at 12:30pm, drive to Canberra, get settled on the machine around 2:30pm, dialyse for about four hours, and not arrive home until about 9:30pm. This fundamentally disrupted his weekly schedule of activities during that period.

Participants who juggle paid work with dialysis also face more extreme space-time conflicts. For example, Bernard’s (age 40, public servant, clinic dialysis) space-time path is currently constrained by fulfilling a standard working week (Mon-Fri, 9-5pm), receiving dialysis for four hours at a clinic three times per week after work, and cycling on non-dialysis days in order to stay healthy and lose weight for a kidney transplant. The non-negotiable blocks of time occupied by work and dialysis during the week leave little flexibility for other activities: “[W]e need to get that time on the machine after work. [...] You’ve got to swap things for dialysis,” says Bernard.
Due to the extreme space-time costs of clinic haemodialysis therapy, many participants described dialysis days as “nothing days” or “write-off’s”, and non-dialysis days as “run-around days” or “hectic catch-up” days into which they try to fit all appointments, domestic activities, leisure and the like. The logistical space-time conflicts of dialysis with the rest of life’s activities make it difficult for participants on dialysis and their loved ones to establish routines wherein everyday activities, such as buying groceries or spending time with family members, happen with ease over the course of the week.

There are alternatives to clinic haemodialysis, and participants discussed the pros and cons of these other modes of dialysis. Performing haemodialysis at home instead of in a clinic is one way to partially alleviate the space-time costs of the therapy. Home dialysis eliminates the need to travel to an additional base location, and offers more choice with regards to the time of day dialysis can be performed. This, in turn, provides more flexibility for other activities in a day. For several participants, however, getting set up to perform haemodialysis at home is prevented by the spatial demands of the machine. Mary (age 75, pensioner, clinic dialysis) and Larry (age 77, pensioner, clinic dialysis) report that the cost of remodelling their home in order to accommodate a dialysis machine and associated plumbing is a barrier. Martin (age 43, unemployed, clinic dialysis) also recognises the potential space-time benefits of dialysing at home, but does not want the presence of the machine to treatment ‘contaminate’ his home space:

You want to go see the doctor or the dentist and get treated, and you want to go home. You don’t want to see this [dialysis machine] every day.

Similar to Larry (age 77, pensioner, clinic dialysis) and Mary (age 75, pensioner, clinic dialysis), accommodating a dialysis machine at home posed a problem for Cathy (age 69, pensioner, home dialysis) and her partner. Their house in Canberra was small, and the machine took up a lot of space in the bedroom and had too much of a presence in everyday life. However, adding on a room to the house for the machine was too expensive and would have to have been accessed from the outdoors. Eventually, they purchased a house with an extra room with adjacent bathroom for the dialysis machine and its plumbing about an hour from Canberra in a mid-size regional town. Without the financial means to have moved to a more suitable house, Cathy’s home dialysis situation would be much less comfortable.

Home dialysis also imposes a space-time coupling constraint on participants and their loved ones, as they expressed the need to have another person present to help set them up and take them off the machine, as well as be available in the case of an emergency. Even if Larry could afford to renovate his house to accommodate the machine, his hands shake too
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much to insert a needle, and his wife is not confident she would be able to do it. Also, he does not want to disrupt his wife’s routines in order to accommodate home dialysis. Gio (age 66, pensioner, clinic dialysis) would also prefer home dialysis, but he does not have anyone to assist him during treatment.

Cathy was the only participant receiving dialysis in her home at the time of the study. She prefers dialysing at home due to the degree of flexibility it provides her and her partner: “It does free you up to make adjustments.” While she usually dialyses in the afternoon so that she can have dinner and then go to bed while feeling the post-dialysis fatigue, once in a while she dialyses in the morning in order to accommodate a dinner invitation or her partner’s evening activities. Nocturnal dialysis was proposed to her by health care professionals as a way to further alleviate space-time constraints. However, neither Cathy nor her partner could sleep through the treatment. While Cathy’s home dialysis routine is functioning well, she is dependent upon her partner’s assistance in dialysing and being available in case of emergencies. Indeed, Cathy told stories of malfunctions in dialysis equipment that caused a small fire and a flood on separate occasions, requiring her partner to help her execute an emergency end to the dialysis session.

Participants discussed peritoneal dialysis as the dialysis treatment mode with the least space-time resource demands. None were receiving peritoneal dialysis at the time of the study, but several had in the past. Peritoneal dialysis performs its cleansing function through fluid introduced into the abdominal cavity. This fluid is drained out and refilled through tubing and a bag, usually four times a day for an hour, or over the course of the night. Martin (age 43, unemployed, clinic dialysis) and Larry (age 77, pensioner, clinic dialysis) both lamented that the therapy was no longer an option for them. Larry developed very bad peritonitis, an infection in the abdominal cavity, which, in Larry’s case, was caused by forgetting to replace tubing between sessions. After that he started haemodialysis:

Although I was carrying around two and a half litres a day [in my abdomen] which was uncomfortable and restricted you from drinking, eating sorts of thing, I found I liked it better. [...] Haemodialysis, it takes a big chunk out of your day. A big chunk out of your week actually; it’s 15 hours that you’re sitting around immobile, doing nothing. Then when you come off, it’s too late in the day to do anything anyway, so they’re just three wasted days of the week.

Martin received peritoneal dialysis until his peritoneal membrane no longer functioned properly enough to allowed undesired substances to be purged from his body through the treatment. He liked that peritoneal dialysis allowed him more freedom: “It just gave me the chance to get up and go around.” He had some flexibility with the times of day he changed the
fluid. This allowed him to continue working as a postman, although his work schedule prevented him from spacing the draining and refilling sessions properly. His commute at the time was 1.5 hours with a 5:30am start. This meant he got up around 2:30am, spent an hour draining and refilling the fluid, got ready for work, commuted, worked until 4pm, and arrived home at 5:30pm. From 5:30pm until he went to bed he squeezed in three more peritoneal bag changes. Ultimately, Martin thinks the improper spacing of the peritoneal sessions caused the therapy to fail, and fluid and toxins built up in his body. Nevertheless, he put off haemodialysis as long as possible due to the way he anticipated it would constrain his life:

I was puttin’ it off and puttin’ it off and puttin’ it off ‘cause I wasn’t – I just didn’t want to face this thing here [gestures to dialysis machine]. [...] I just didn’t want [laughs] to face sitting here [dialysis clinic] for that amount of time and... basically missing out on everything.

Ultimately, the space-time demands of Martin’s commute and paid work disrupted his peritoneal dialysis treatment routine. When peritoneal dialysis failed, and he started clinic haemodialysis, the space-time demands of haemodialysis disrupted his work routine, making it impossible for him to continue working. In short, clinic haemodialysis places extreme, and sometimes unpredictable, space-time demands on participants and their loved ones. This makes it difficult to integrate haemodialysis into a weekly routine that accommodates other everyday activities easily. As a result, participants feel rushed in ‘fitting in’ other everyday activities, have to make an extra effort to coordinate activities, and sometimes sacrifice other activities for haemodialysis. While there are other less space-time demanding dialysis modes, such as home haemodialysis and peritoneal dialysis, logistical barriers can make it difficult to adopt and sustain treatment with these modes.

7.1.2.1.2 Doctor appointments

In addition to dialysis therapy, participants discussed frequent doctor appointments as making particularly heavy demands on their space-time resources, thereby complicating everyday routines and increasing the effort required to juggle activities. As Madeline (age 57, part-time teaching assistant, functioning kidney transplant) put it: “There’s not just one doctor’s appointment. There’s always... quite a few doctor’s appointments.” For some participants, limited transportation options further complicate this juggling act. For example, Larry (age 77, pensioner, clinic dialysis) has to make all his appointments in the afternoon on non-dialysis days when his partner is not working so that he can coordinate use of their shared car.

Deny (age 70, pensioner, stage 4 CKD) is almost blind and has several chronic illnesses aside from CKD, including chronic pulmonary obstructive disease and sleep apnea. His partner
has diabetes and was recently diagnosed with multiple sclerosis. The doctor appointments to manage these conditions add up, meaning he and his partner feel they organise much of everyday life around medical appointments. Getting to and from appointments is made more difficult because, due to their medical problems, neither can drive a car and they have to rely on others to transport them to appointments.

For many participants receiving dialysis, the options for scheduling doctor appointments are restricted to non-dialysis days. Martin (age 43, unemployed, clinic dialysis) has check-ups for his eyes, skin and teeth every six to twelve months due to the side-effects from the years of taking immunosuppressant drugs prior to his kidney transplant failure. He schedules these along with other regular appointments, such as those with the renal specialist, on non-dialysis days. In another example, Gio (age 66, pensioner, clinic dialysis) sees a doctor for an injection in his eye every eight weeks, and has regular appointments with a diabetes specialist, kidney specialist, and dentist, as well as visiting the dialysis clinic three days per week. Because his blood pressure is often problematic after dialysis, he has to schedule his medical appointments on non-dialysis days. He tries to group these appointments as closely as possible, even three in one day if feasible, so that he can have free days in the week to do other things. Getting to and from appointments is difficult now that he cannot drive and has an amputated leg. The prosthetic leg limits the distances he can walk in connecting his public transport trips to doctor appointments. And, because his prosthetic leg looks real, he often stands on full buses because people do not offer him a seat. He does not mention this leg to other passengers because he prefers to feel “normal”.

Many participants described acute periods of ill health when doctor appointments are much more frequent than usual, such as around the time of a kidney transplant, or in the event of an infection like peritonitis. Karen (age 26, full-time public servant, functioning kidney transplant) describes the period immediately after her kidney transplant:

All the extra tablets and I had to have appointments every day for the first four weeks, so going into the hospital and I couldn’t drive for the first couple of weeks so that made it hard, getting lifts and things. And yea, each appointment I’d get a blood test as well and they’d go through if I needed to change any medications, which happened, obviously, quite a lot in the start. [...] In Brisbane the hospital was on the other side of town so it was a bit annoying having to go there every day.

Karen said it took 40-45 minutes to get to these appointments. Sandi (age 30, part-time administrative assistant, functioning kidney transplant) described a similarly acute period of frequent doctor appointments after her transplant, especially since there were problems at first with the transplant:
I was there quite a bit and then it came down to every two weeks, then every three weeks, then once a month, then after that it came down to two months. Now we’re at three months but we don’t want to go any further than three months.

Ella-Jane (age 18, part-time retail supervisor, stage 4) is currently doing the work-up for a kidney transplant. She has so many appointments that most of her days off have at least one appointment: “It’s sort of scattered everywhere, just depending on my days off.”

The services of specialist clinicians impose particular space-time costs on participants, and all participants have at least one specialist. Given that there are a limited number of specialists in a given field (as compared to general practitioners (GPs)) within a geographical area, appointments must sometimes be made months in advance, and some participants reported travelling long distances to see a specialist. For example, Wanda (age 58, business owner, stage 3) is a 10-minute drive from her GP, but lives almost two hours from her renal specialist in Canberra. Wanda’s kidney problems are related to an autoimmune disorder, which was treated with chemotherapy. For nine months she made regular trips to Canberra for chemotherapy, at first every two weeks, then gradually decreasing to every six weeks. Whenever possible, the renal specialist’s office tried to coordinate her appointments with chemotherapy sessions. Once the renal specialist visited her in the chemotherapy ward in order to save her a trip to Canberra and the time of an additional appointment, which she very much appreciated.

Samantha lives in a small town 1.5 hours away from her renal specialist in Canberra, and two hours from her rheumatology specialist near Sydney. She and her GP in her town often web conference with her rheumatology specialist. When she goes to her renal specialist in Canberra she leaves mid-day in order to avoid traffic, meaning most of the day is taken: “I just drive over and come back... That’s the day.” Similarly, Martin (age 43, unemployed, clinic dialysis) lives 1.5 hours from his renal specialist. Where he lived previously, he was six hours from his renal specialist in Sydney. When he moved to his current location he had to switch specialists to Canberra.

Like Martin, Cathy (age 69, pensioner, home dialysis) was also faced with switching renal specialists if she and her partner moved too far from Canberra. When they were looking for a new house that could accommodate a dialysis machine, they wanted to move to the country, and as close to her daughter in Sydney as possible. However, in order to keep her renal specialist, they had to stay within a certain range of Canberra, restricting the search area for their move. And, in a final example, when Ella-Jane (age 18, part-time retail supervisor, stage 4) was in high school she had to travel an hour out of Canberra to see the only paediatric renal
specialist in the region. This meant taking an entire day off school. For those like Karen and Mike who currently live in Canberra and have all their doctors in Canberra, the small-scale of the city and lack of congestion makes it faster to travel to the doctor as compared to other larger and more congested cities where they previously lived, such as Brisbane.

Finally, participants highlighted the unpredictability of the space-time demands required to see the doctor. Cathy (age 69, pensioner, home dialysis) finds that doctor appointments occupy a lot of her non-dialysis days, in part, because of the unpredictability associated with the spatio-temporal cost of seeing a doctor:

All those extra things tend to come in on the couple of [week] days that we have off [from dialysis], you know (laughs)? And it’s really hard. And we keep Tuesdays and Thursdays, really for appointments and things like that because you sit in a waiting room – sometimes for the cardiologist it can be two hours. It’s not good looking at your watch and thinking ‘Oh, ya, I’ve gotta get home and do five hours dialysis.’

Bill (age 40, full-time public servant, clinic dialysis) expressed, perhaps, the strongest opinion in this regard, characterising the hospital as “a black hole of time.” Bill’s renal problems were developed in childhood, so he has been accessing health services frequently his entire life. Over the years, he has become aware of how much time he spends in the “down time” of doctor appointments:

I think in general if you ask people what time did they spend on their health issues, a lot of them will discount the hour that they spent waiting to see the doctor. [...] I don’t think they think that the time not spent on the actual medical thing is time. So the downtime, the waiting in the waiting room is not time. The walking from place to place is not time. But it turns out it is time. And you wonder, like you actually think to yourself, ‘I was going to see the doctor, I knew that would take half an hour, yet I’ve just had 3 hours off work.’ Like and you go, ‘Oh well, whatever.’ And then when you’ve done it as many times as me you start to get really, really, really pissed off with the system.

Indeed, the overwhelming majority of participants described regularly waiting 10-20 minutes or more beyond their appointment time to see the doctor. While unpredictable waiting times were a common complaint among participants, many participants expressed understanding for having to wait to see the doctor in the event that another patient has urgent medical needs and needs to be seen first. Samantha (age 43, on sick leave, stage 2 CKD):

I know being sick I often jump the queue. If I ring my doctor and I go bla bla bla’s happening, she goes, ‘Get down here now,’ everybody else sits and waits and she sees me and that might be for 45 minutes. So when I have to sit and wait for somebody else for 45 minutes or an hour, I just go oh geez somebody’s sick and I don’t really think about it.
Similarly, Chen is very understanding about how often he waits for the doctor, not just because he sees that wait time as having to do with someone else’s medical misfortune, but also because he values the quality of the health care system in Australia compared to his home country of Burma.

Despite the strong opinions Bill expressed regarding the unpredictable waiting times of accessing health services, he too sympathises with wait times associated with another person’s urgent medical needs. One of his main complaints, rather, has to do with what he perceives as a lack of communication and coordination on the part of health services, which creates unnecessary demands on his space-time resources. He complains that even when he asks the dialysis clinic to call his mobile phone if there is a delay with his dialysis chair, they do not call, meaning that he leaves work and has to wait at the clinic where he is unable to continue working:

Fifteen more minutes at work for me is like three more emails, two more phone calls that I don’t have to do the next day.

Bill would like health services to use email and phone more to alleviate some space-time demands on patients. Chen, however, reports good use of phone and email from his doctors’ staff members. Wanda (age 58, business owner, stage 3 CKD) has been impressed with her renal specialist’s awareness of the travel costs she has living 2 hours from Canberra, and the way he has tried to alleviate these by trying to schedule appointments for her with other specialists on the same day he makes the referral in order to save her a trip. However, she has been disappointed with the scheduling procedures of some of the new doctor’s office staff, saying that she has to do more work to schedule and confirm appointments: “Now that’s another thing I’ve got to remember, to ring and remind.”

In addition to doing a better job of communicating with patients, Bill wishes health service providers would communicate better amongst themselves in order not to cause unnecessary delays in services. He gave the example of a medical routine procedure he has every few months which should require just one day off work. On one occasion he coordinated with his supervisor to take the day off, but due to poor communication between two hospital departments, the procedure took 10 days:

Urology didn’t talk to [breathes in] renal, and renal didn’t want to do anything ‘cause it was urology’s job and, just like I was on – after they finally worked out that they were actually going to do to the surgery in Canberra, I was on the surgery list like four days in a row where I’d like didn’t eat from midnight until – and then at 11pm they’d go, ‘Well, obviously it’s not happening today, so you’ve got an hour where you can eat and then you’re back on no food.’ And like for four
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days I was like that and I [stutters] – the closest I’ve ever thought of going... mad, basically.

In contrast, Deny (age 72, pensioner, stage 4 CKD), reports very good coordination between his doctors. He assumes they consult with each other about his care.

In short, frequent doctor appointments are part of everyday life for participants, complicating the task of coordinating and performing other everyday activities. The logistical demands of this can be exacerbated during acute periods of illness requiring even more frequent appointments, as well as by limited transportation options, long travel distances to specialists, spatial restrictions on residential moves due to specialist locations, and the unpredictable space-time demands of varying waiting times and poorly coordinated care.

7.1.2.1.3 Mitigating drug side-effects

Participants emphasised how side-effects from drugs used to treat their conditions restrict their potential path area. Neal (73, pensioner, clinic dialysis) and Chen (age 64, part-time taxi driver, functioning transplant recipient) both report frequent urination, to the point they try to know where toilets are within the area of an activity they are planning. For Chen, wide knowledge of toilet locations is most important when he drives his taxi, as he could be anywhere in the Canberra area when he needs to urinate. While Chen was uncertain as to the cause of his frequent urination, Neal’s is directly related to the diuretics he has to take to reduce fluid retention in his body. He describes how his potential path area is limited, in part, to the locations of known toilets:

Anything I drink goes straight through me, and that is a bit of a nuisance and I have to, sort of, organise my life around all the public toilets when I’m out.

Another drug side-effect that constrains participants’ potential path areas is the need for some participants to restrict where they go in order to avoid sun exposure. This is due to the increased cancer risk associated with immunosuppressant drugs taken to maintain a kidney transplant. James (age 66, pro bono consultant, functioning kidney transplant) provided a more extreme example of the relationship between skin cancer risk and immunosuppressant drugs. He has had many surgeries to remove skin cancers over the past 20 years and sun burns very easily. His potential path area, therefore, has been limited by avoiding sun exposure as much as possible, making outdoor activities like taking a walk or riding a bicycle difficult:

Moving from one sheltered location to sheltered location is what I’ve been stuck with.

Vulnerability to infection is another drug side-effect restricting the potential path area of many participants. This is another side-effect of immunosuppressant drugs used to maintain a
kidney transplant. Some participants reported feeling anxious about being in contexts where they could be exposed to contagions, as their immune-suppressed body would have difficulty fighting infection. Brian (age 38, unemployed, failing kidney transplant), for example, would like to get dental work done in Asia because it is cheaper than in Australia, but he thinks there may be a higher risk of infection and thinks it is too risky given he is immune-suppressed. Sarbajit (age 38, full-time public servant, functioning kidney transplant) is cautious about any situation that may give him an infection. He avoids elevators, cold environments and crowded rooms. In fact, he refused to move to an open plan office around the time of his transplant because it would mean exposure to more people:

You’re constantly cautious of anytime you see – whenever I hear or see anyone sneeze or cough my automatic instinct is to walk the other way and hold my breath.

In short, drug side-effects place constraints on where and when participants are able to go in everyday life, further complicating how everyday activities can be organised into comfortable routines.

7.1.2.1.4 Prescription drug refills

Regular trips to the chemist also cost participants space-time resources and make juggling everyday activities more complex. This is because most participants have multiple drug prescriptions that run out at different times. Several participants mentioned travelling to chemists that are further away from home or work than their local chemist because they are cheaper. Karen (age 26, full-time public servant, functioning kidney transplant) and Jasmine (age 49, full-time administrator, stage 4 CKD) both added additional travel time on one of their sample days to visit a more distant chemist with cheaper prices. Samantha (age 43, sick leave, stage 2 CKD) lives in a small town and says that between her drugs and her partner’s, they can save $20 per month by travelling to the chemist in the larger town 35 minutes away.

7.1.2.1.5 Diet and exercise

Diet and exercise were discussed as being both helpful for managing chronic illness, and in competition with other areas of life for spatial and temporal resources. Bernard (age 40, full-time public servant, clinic dialysis) described the challenge of meeting the space-time resource demands of diet and exercise in conjunction with work and dialysis treatment. In order to stay as healthy as possible and to qualify for a kidney transplant, Bernard has made a goal of losing weight and exercising regularly. Along with the cycling schedule discussed above, Bernard has tried to improve his diet within the space-time constraints of full-time work and dialysis.
Instead of home-cooked meals, the viable option for him has been ‘Light and Easy’ frozen weight loss meals that are delivered to his house:

It makes it easier for me, having to work every day, and then, ya, three nights a week I have to dialyse. So instead of coming home late at night and having to prepare a meal or spending the nights that I don’t dialyse preparing meals [laughs] for the rest of the week – I just don’t have time for it.

He feels he can better assess what is in each Light and Easy meal than in other processed or restaurant foods, but they still save him precious time by not needing to cook. Bernard views this as a vast improvement over his previous diet, which consisted primarily of take-away and delivery food:

I was the only [dialysis] patient that had – I had six or seven menus in my folder depending on whatever mood I was in. But that’s changed since being on Light and Easy. I just bring my Light and Easy meal. They heat it up for me.

In several examples, diet and exercise were ‘sacrificed’ with more or less frequency in order to meet the space-time demands of social institutions participants must access or participate in. A simple but pertinent example of space-time resource competition comes from Madeline, who works part-time at a school. Part of maintaining her transplant involves eating well and attending a cluster of doctor appointments every three months. On one of her sample days she had a routine, lunch-time doctor appointment. Usually on appointment days Madeline buys a salmon wrap at the hospital café - a food allowed in her diet – eats it in the car, and returns to work in time for a shift at the front desk. However, on this day, she had to wait longer than usual for the doctor and her healthy lunch ‘fell off’ in the space-time squeeze between work and health service space-time demands:

I drove to the hospital and had to wait for [renal specialist]… which… happens. And I went to him, and then I went downstairs and I thought ‘Oh, I’ll go get my lunch now’. And the line was 10 miles long. And then I thought, ‘Oh, no I’ll never get back to school in time to do the office.’

Employer and health service space-time authority constraints limited Madeline’s alternatives to the hospital café to a small potential path area between the hospital and work with very few choices for a fast lunch. The only feasible option she could think of was to “quickly gobble in” a savoury pasty from a bakery near her workplace. As such, her normally healthy lunch was swapped for an unhealthy alternative. Even though Madeline describes her employer as being understanding, she felt pressed to get back in time to relieve the woman at the desk; a coupling constraint of her job position:
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Because we’re a smallish school, and we don’t have a lot of people to do that, I had to be back to make sure she got her break.

Madeline’s experience highlights the ‘squeeze’ employers and health service providers place on many participants’ space-time resources. Due to the frequency of health service access, employed participants can regularly experience these squeezes and may allow activities like diet to ‘fall off’ the everyday routine. Madeline’s exercise routine has also ‘fallen off’ in everyday life. This fall off was due, not to institutional space-time demands, but, in part, because the care her mother required intensified, leaving her with less time to take care of herself.

Mike’s previous job as a chef also made it difficult for him to maintain the diet and exercise he would have liked in maintaining his kidney transplant. Long hours, sometimes 16 hour work days, absorbed virtually all of Mike’s space-time resources. Without access to the space-time resources needed to take care of himself, he observed his health decline. The conditions around that job coincided with the failure of his first kidney transplant:

I wasn’t the best because of the stress. I wasn’t eating properly. I wasn’t looking after myself. I never had time to go to the gym. Days off I was too tired. I wasn’t doing – I wasn’t looking after myself. And I think I got down to 63 kilos at one stage. Ya, it was ridiculous.

Hannah (age 60, pensioner, stage 3) and Sarbajit (age 38, full-time public servant, functioning kidney transplant), on the other hand, have both commuted to work by bicycle, either currently or in the past. They have found it easy to maintain exercise when it is integrated into their everyday routine, almost completely eliminating additional space-time costs. Hannah explains:

I make it part of the routine so that I’m always doing some, without noticing it and having to set – go to a special place, or set time aside and all that sort of stuff. It just – it just happens.

Both participants were quick to emphasise, however, that their cycling routines are dependent upon their workplaces providing showers and locker rooms, and on their homes being close enough to work to cycle in. In short, diet and exercise are sometimes sacrificed when coming into competition for space-time resources with other activities, especially those framed by authority constraints, such as those of employers, dialysis clinics, and doctors’ offices.

7.1.2.1.6 Taking medication, checking blood glucose and blood pressure
To a lesser extent, participants discussed the spatial and temporal costs of taking medications and tracking blood glucose and blood pressure. While each of these activities only takes a few
minutes to complete, they are usually performed every day, multiple times a day. Furthermore, checking blood glucose and injecting insulin, in particular, require an appropriate setting. Several participants with diabetes felt that other people would not want to see them check their blood glucose levels and inject insulin before a meal outside their home, and therefore have to find a bathroom hygienic enough to perform the task before eating. At work, Bernard (age 40, full-time public servant, clinic dialysis) does not feel that he can check his glucose levels in the office, and does not feel the bathroom is hygienic enough. This contributes to his failure to check his glucose levels during the work day, and is one of the reasons he chose not to receive peritoneal dialysis, with its multiple bag changes during the day:

If it’s to be done here at work it will have to be, well – one, I can’t do it at my desk. I have to do – well I suppose I can ‘cause it’s only a pin prick for the finger, um... but you have to be conscious of people that are going to be around you if they’re... ya... I don’t want to do it in the bathroom ‘cause it’s not hygienic. [...] Which is another reason I didn’t opt for the peritoneal dialysis because of the change of bags and things like that.

In summary, the heavy space-time demands of chronic illness management activities create logistical challenges in participants’ lives, making it difficult to establish daily and weekly routines wherein everyday activities from all aspects of life can run smoothly without much thought. The heaviest space-time demands are associated with dialysis treatment and doctor appointments. The space-time resources needed to mitigate the side-effects of drugs can limit participants’ potential path areas. To a lesser extent, refilling prescription drugs, diet and exercise, and taking medications and checking blood glucose and pressure also detract from the number of hours available to participants for other activities in a day or week, and restrict the freedom participants have to access different places. These space-time demands require substantial, and sometimes fundamental, shifts in how everyday life is organised. While participants try to mitigate these space-time demands, financial barriers, caregiving roles, obligations to employers, and conditions of health care providers, and other constraints reduce their ability to do so. The logistical conflicts that chronic illness management activities introduce into participants lives make it necessary to put more effort into organising everyday activities, restraining the force of habit in helping participants establish and maintain routines. Without uninterrupted, stable routines to fall back on, participants require greater effort to perform everyday activities.
7.1.2.2 Embodied space-times and rhythm

While the previous section examined chronic illness management in terms of its absolute spatial and temporal costs, this section focuses on the role of rhythms in making chronic illness management activities more or less difficult. I observe the rhythms circulating within participants’ everyday environments, as well as their bodies. I find that some environments are more hospitable than others to the establishment and maintenance of illness management supporting routines. Where rhythms are unfavourable, participants experience diminished ability to remember and feel less motivated to perform illness management activities, as well track fluid and dietary intake in everyday life. Where they are favourable, participants experience more ease with their illness management activities. This, however, can foster reliance on certain familiar environments for successful illness management.

7.1.2.2.1 Remembering

Participant accounts of their experiences with following medication schedules illuminated a strong link between rhythms and the task of remembering chronic illness management activities. Successful medication schedule compliance has been attributed to strong routines (e.g., Haslbeck & Schaeffer, 2009; Wagner & Ryan, 2004). As noted in Chapter 3.2.1, the literature on health routines tends to de-contextualise routines, focusing on predictable patterns of human behaviour without much consideration for the influence of rhythms surrounding and within the individual. As participants stepped through their sample days in the interviews, they described routines very much embedded within rhythm-entangled contexts. Below is an example of a routine that is clearly embedded within “a seething space pulsing with intersecting trajectories and temporalities,” (Edensor, 2010b, p. 7). Hannah (age 60, pensioner, stage 3 CKD) describes her morning routine, providing a glimpse into the interacting rhythms that entwine with morning activities in her home. Hannah is recently retired, stage 3 CKD, and struggles with depression. She lives alone in a house with a dog and a resident colony of magpies:

My first thought in the morning is, ‘Oh no, I don’t want to get up, I don’t feel like it, I’m still tired’. Any of those. And then of course the magpies arrive, and the dog jumps off the bed and it’s like, ‘Oh god, here we go’. The birds get me up more than anything, because, ‘Here we go, got to feed the vultures’. So I climb out of bed and I walk to the fridge and I get their mince and I feed them. So I’m already up by then so it’s just swing into the routine. The mince sits out on the bench-top for when they come back, the computer gets turned on to warm up, I put the kettle on, while that’s boiling I grab all the coffee and the pills and stuff out of the pantry, they go on the bench - the breakfast bench - coffee goes beside the kettle, grab the mug out of the cupboard, walk to the fridge, grab the milk, put that down. [Hannah takes her pills, makes coffee, and sits down at the now-warmed-up...}
Then, ‘Right, that’s it’. So off I go, get dressed, wash hair, whatever. Dog, dog who sits in his bed patiently looking at me or he decides, ‘Oh you’re going to be there for ages aren’t you? Well I’m going to go back to bed’. And off he goes. So if he’s in his bed and I go in the bathroom he follows me, and he waits while I do what I do. He tries to help me get dressed, he especially likes to help me put my shoes on... Because he knows I’m going for a walk you see, and he loves his walks. This is why I can’t ignore him in the morning because he’s jumping about like a spring lamb, wanting to go for his walk, so it’s much easier to take him before I do anything else. So off we go and then come back. He gets his treat if he’s been good and I give him his treat, he takes it and runs under the bed and eats it there. I get my breakfast and that’s the start of the day.

In this glimpse of a morning routine, we find not only “strategically designed behavioural patterns” (Zisberg, Young, Schepp, & Zysberg, 2007, p. 446) with their own rhythms of movement, timing, and tempo of human action, but also “the complex array of non-human rhythms that impose upon, exist separately and are entangled with human rhythms,” (Edensor, 2010b, p. 7). Hannah’s morning illness management activities (getting out of bed despite her depression, taking medications and exercising) are shuffled along unnoticeably within the pulse of rhythms carrying Hannah into the day – the magpies’ cries for food which draw Hannah out of bed even when she feels “Oh no, I don’t want to get up”; the desire for hot coffee which takes her to the cupboard where the coffee and medications are kept; and the dog’s “jumping about like a spring lamb” for his morning walk, encouraging her to exercise at the beginning of each day.

Sarbajit (age 38, full-time public servant, functioning kidney transplant) provides a glimpse into the process his medication routine took to become established within the rhythms of his home context. Like all transplant recipients, Sarbajit had to get used to following a strict immunosuppressant tablet schedule every morning and evening at 12-hour intervals. He describes how about three months after the transplant he became what he describes as a bit “comfortable”, and when the alarm on his phone would go off to remind him to take his immunosuppressant tablet, he started hitting ‘Dismiss’ and putting off getting up to take the medication until he was done with whatever he was doing at the moment. Then he would often forget, and the medication schedule would get thrown off and it would take him several days to get that schedule back on track again. So, this was becoming very stressful for him:

Sometimes, ya, when the alarm goes off you just go ‘ya, ya, ya’ ‘Dismiss’. And I’ll get up in a minute’ and that can trip me up. And it tripped me up for little while, actually, early on in the - well, not early on – mid-range, about 3 months when I got a little bit comfortable. The alarm would go off and I’d go ‘ya, ya’ and I’d turn
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it off and then I wouldn’t get up and go take my meds straight away, say, ‘I’ll do it in a minute’. And then I’d forget.

Sarbajit was one of the most motivated and educated of the study participants with regards to taking care of his kidney transplant. He has a long history of cycling, yoga, and healthy eating. He cut out alcohol and is extremely conscious about keeping his transplant hydrated. When doctors told him the kidney would likely last 30 years, his response was that he would make it last 40. When encountering this case, a social cognitive theory perspective might ask whether this individual has a good sense of self-efficacy (Bandura, 2010), and whether he has had positive past experiences with similar challenges to give him confidence that he can overcome this challenge of following the medication schedule. So I ask him, “How did you get past that, the ‘Dismiss’ and then forget?” He says:

I just got out of the routine of dismissing and forgetting.

So it would seem that this individual not only understood how important compliance with the immunosuppressant tablet schedule was, but also felt empowered to overcome the resistance to getting up and taking the medication when the alarm went off. However, I go on to clarify:

Julia: Ok, you just got up right away?

Sarbajit: Well, now I’ve got it to the point where I don’t even wait for the alarm. I’ve trained myself into having certain things that I do which triggers me to take my medicine. So in the morning [laughs], it’s funny, in the morning when I get up, I’m usually the first one up so the cat’s going to gnaw my leg off. So the first thing I do is, the cat wants to be fed, I take my meds. [...] ‘Cause the cat needs to be fed – I go, ‘Oh, the cat needs to be fed. That’s right, meds’. Meds, feed the cat. So that works.

The cat pulls him from where he harasses Sarbajit in the bedroom, past where the medications are kept on the kitchen counter, to her cat food bowl every morning. The force of habit had been harnessed in Sarbajit’s favour because the meds have ‘hooked onto’ an established, strong, stable and very difficult to ignore rhythm that repeats every day at the same time: the cat’s hunger. Sarbajit goes on to connect this relationship that has established between his medication schedule and his cat’s hunger to his attitude about taking care of his health:

Sarbajit: I’ve worked out that if I attach taking the meds to something I do routinely every day it works quite well. I mean the alarm works too, but I find the alarm annoying. I hate being reminded by my alarm to do something.

Julia: Why do you think that alarm is so annoying?
Sarbajit: [Breathes out] ‘Cause it’s constricting. It’s telling me to do something. I don’t like being told what to do [laughs] generally anyway, so. It’s just, ya, it’s just a reminder. Like if I remember to take my meds and I take them, then I’ve taken them. But I don’t think about it. But it’s the reminder, saying, ‘You have a kidney condition. Make sure you take your medicine.’ Like that’s the thing that I don’t like coming back to me. That it’s that important that I have to have an alarm set is the thing that annoys me I guess.

The rhythm of the alarm is an unwelcomed intrusion that reminds him of how serious his health condition is and the fact that it will be with him forever. The cat’s hunger, however, does not have this negative association, and its rhythm not only reduces the effort he needs to put into complying with his medication schedule, but helps him maintain a more positive, motivated attitude about life with a chronic illness. Sarbajit describes how these illness management activities become “normal” as they are absorbed into the space-times of everyday life:

It feels normal. [Pauses] I feel normal as a person. I don’t feel like I’ve got, you know, a kidney sitting in the front here [abdominal cavity]. I don’t feel that I’m on 11, 12 different types of tablets every day. [...] I don’t marginalise it, but I just make it part of routine. A normal part of life. The more you make something normal, the less it seems... unusual?

The crucial question, then, is how does the illness management activity become part of routine? Sarbajit attributes his success to self-discipline, yet alludes to something that takes over after self-discipline and perpetuates the activity:

To get to the point where you’re doing those sorts of things is a discipline, but once you start doing them regularly, that discipline then I think takes less effort because they are self-perpetuating.

While self-discipline was an important ingredient in establishing this medication routine, the stability and insistence of the rhythms in Sarbajit’s home environment also played an important role via the force of habit in helping this new activity settle into his everyday life. Furthermore, we will see later in Chapter 7.2.2.2 that the same self-disciplined individual was unsuccessful in establishing a medication routine in a different space-time context.

Another example of the role of rhythm in remembering medication schedules comes from Madeline (age 58, part-time teacher assistant, functioning kidney transplant). This rhythm, however, is dependent upon, not only the home environment and activities that take place there, but also unique rhythms of Madeline’s body. After decades of immunosuppressant drugs, the bones in Madeline’s ankles and feet are badly damaged. After a full day’s work, her feet are very sore. Below Madeline describes how the end-of-day-soreness offers a rhythm on which to hook her afternoon medication schedule. Her tablets
“live” on her bedroom dresser. As soon as she gets home, she walks up to her bedroom to take off her shoes at which time she sees her tablets on her dresser and takes them. She says that afternoon dose is “probably not the one I would miss”. I asked her if she can always count on her sore feet to help her remember her medication, to which she replied:

Madeline: Oh, I can count on my sore feet, yes [laughs]! Well, because of my fused ankle and my... other replaced ankle, shoes are not very comfortable because they're either too heavy or they don’t fit right – it’s quite hard on my feet.

Julia: Do you ever just kick off your shoes downstairs?

Madeline: Um, no I usually take them up to the room. Sometimes I do it in the lounge room, ya, if I come in sometimes I’m wearing my track shoes I come in and sit down straight in the chair and I just kick them off there. But I’ll still take them up to the bedroom and get my tablets.

Again, we find a relationship between an everyday environment (the layout of the home and the upstairs location of the tablets), an insistent, stable rhythm (end of day foot pain), and patterns of individual behaviour (get home and take off shoes upstairs). This strong link between rhythm, materiality and the force of habit provides Madeline with a sense of confidence that she can “count on” this relationship to help her remember her afternoon immunosuppressant dose.

Mike also has a sensation-based rhythm that assists him in remembering one of his medication doses. After his batch of morning pills, Mike has to wait an hour to take another three tablets that upsets his stomach if taken with the rest. An hour after breakfast Mike is at work. I asked him how it happens that he remembers those three tablets after arriving at work:

I’ve got a little pocket within my suit pants. So ya, a tiny little pocket within a pocket. So they sit in there. I put them in there... all the time. And they’re a little bit spiky ‘cause they’re still in their packet. I cut them up individually still in their packet and the edges are a little bit spiky so I can feel them going through the fabric into my leg [laughs]. Every morning I know they’re there every time I go to – like I have my keys in there, or whatever, if I take them out I’ll know they’re there.

Intermittently on the short trip to work Mike feels the scratching of the tablet packaging on his leg. When he gets to his office door, an additional reminder is there as he reaches into his pocket for his keys, also feeling the tablet packaging.

For Jasmine (age 49, full-time administrator, stage 4 CKD) morning medications are the easiest to remember because they are hooked onto making lunches for her children. Weekday
mornings, therefore, have a stable rhythm on which morning medications are hooked. Weekends and evenings, however, can be riskier:

I realise ‘Oh I haven’t taken my medication’ because on weekends you don’t do lunches. But weekdays it’s like a ritual. When I switch the kettle on and I get the bread and take out the margarine and the cheese or whatever, then I take out the tablets. But in the evenings there’s no particular ritual. It’s when I go maybe and pack the dishwasher and then I realise ‘Oh I’m going to bed now, let me take my [tablets]...’

Jasmine has come to rely on this relationship between lunch packing and her medications so much that she continues packing her children’s lunches into their teenage years, in part, because it helps her remember her medications:

Julia: Why do the kids’ lunches always happen? [...]

Jasmine: Because they go to school every day.

Julia: Well, I mean – devil’s advocate – maybe you could say ‘Pack your own lunches’.

Jasmine: I know, but then I’m going to forget about my tablets, too [laughs].

The strong drive behind packing the kids’ lunches is a feeling of caring for her children and maintaining the kind of role as mother that her children are attached to.

Deny (age 72, pensioner, stage 4 CKD) provides an example of someone trying to integrate a very new medication schedule into everyday life. His wife was recently diagnosed with multiple sclerosis, and has started treatment injections every other day. While taking insulin is an established habit for her, the new injection is proving difficult to remember. As a reminder, they are leaving the informational paperwork for the injection on the kitchen table. Their evening activities pull them past the table, providing a visual reminder to take the drug:

Deny: Just leaving it there reminds, ya, that she’s got to take that tonight. [...]

Julia: Do you think eventually you can put it away?

Deny: Ya, I reckon we will be able to. Well, we did try to and then we forgot – she forgot to do it on Friday.

These examples demonstrate the importance of consistent contexts (e.g., the home), regular behaviours (e.g., morning or evening routines), and regular, insistent rhythms that encourage the force of habit to take over the task of remembering. Important characteristics of these insistent rhythms are that they are sensation-based – a loud meowing cat, aching painful feet, prickly packaging against the skin – or emotionally based – the drive to provide for loved ones.
7.1.2.2 Feeling motivated

Other chronic illness management activities were challenging for some participants, not so much because they had troubles remembering to do them, but rather because they felt they lacked motivation. Many participants expressed an urge or feeling of being pulled toward an activity that they had been performing regularly for some time. When unable to do the activity, there was a feeling of “dissatisfaction” when these activities were skipped or cut short; as in Kye’s (age 70, pensioner, stage 4), feeling of “missing something”, or “feeling short of something” when he is unable to go on the daily walk he has been taking for over 20 years. Again, rhythms in participants’ bodies and in their everyday contexts played a role in the motivation participants feel to persist in regular illness management activities day after day. Just as everyday rhythms have the power to nudge forward certain activities, encouraging repetition and the force of habit in our favour, rhythms in everyday contexts have the power to disrupt repetition and prevent the force of habit from encouraging the desire to perform an activity.

This was especially true with exercise. A good example comes from Mike (age 33, full-time public servant, functioning kidney transplant). Mike is an employee in a political organisation. The intensity of activities is coupled to the events of political cycles, creating a cycle of growth and decay in work demand. For example, during slow times, Mike may receive three or four emails a day. During slower times Mike is guaranteed a regular and flexible hour lunch break, during which he regularly goes to the gym. Exercising is important to Mike because he sees it as a way to support his kidney transplant. However, during busier periods of work Mike may field up to 200 emails a day. During these times he does not break for lunch, eating at his desk instead of going to the gym:

I have a pretty good gym at work so, um, and it's not very expensive and you know I usually have an hour lunch break every day. Lately, because of the change of government, I have not had a chance. It's probably been six weeks, maybe more that I haven't had a chance to go to the gym because it's been that busy. It's probably been longer, actually, um, so that's [laughing] upset my routine severely, 'cause, one, I have to eat my lunch at my desk in a hurry, because there's just so much on. [...] I mean even though it's gone on however long now with the election, I know that there's gonna come a time when I'll have plenty of time to go to the gym. And it's gonna be back to an everyday occurrence for me. [...] It's not like I'm a gym junkie and I need to go. It's just that... I like to go because being a kidney transplant patient I want to give my kidney every chance possible to last as long as it can.

The interactions of rhythms circulating at different scales (i.e., national political cycles and workplace rhythms) influence Mike’s routine activities and the force of habit. These
rhythms sometimes interfere with the force of habit and the desire to go to the gym. This makes for an uphill battle to re-engage the force of habit and get back into the practice of going to the gym on lunch breaks even when the necessary the space-time resources become available again:

Since I haven't been going to the gym, I haven't felt [stutters] 'cause before when I was in the routine of going to the gym, it's like I was wanting to go, constantly. Come to 12 o'clock, alright, it's time to go to the gym. [Breathes in] I don't have that feeling anymore, even though I've been taking my gym bag to work just in case I got time, I just haven't had that feeling of wanting to go? Ya, so it's been hard getting out of that routine of, of not going to the gym. [...] Once you get into a routine it's just mindless. It ends up being mindless where you don't even have to think about it, right? It's time to go to the gym, and off you go. [...] It just happens. Ya, ya, so whereas now I'm out of that loop, um, I sort of have to think about: 'I should be trying to go to the gym. I should be trying to.'

It has been argued that an “erosion of the rhythms and routines of work, including the routines of joint breaks,” (Kamp, Lund, & Hvid, 2011, p. 231) may be observed in modern workplaces. Mike’s example points to the impact of irregular workplace rhythms on the difficulty employees experience in performing health-related activities during work. Similarly, Balfe et al. (2013) found that unstable workplace activities make managing of Type 1 Diabetes particularly difficult for young adults. Mike’s example demonstrates that attempts to create healthier work environments and support employee health behaviours must take into account the role of the space-time contexts of work.

Ella-Jane (age 18, part-time retail supervisor, stage 4) provided an example of an attempt to create a relationship with a rhythm in her context in order to increase motivation to exercise regularly. Ella-Jane lives with her mother, a housemate, and two dogs. One of the ways she wants to take care of her health is to exercise. On both of her sample days she felt completely unsuccessful meeting this goal. When asked what she usually tries to do for exercise, she responded that she tries to take the dogs for a walk: “They need to walk. They keep breaking out of the yard. [...] They like to drive me along.” Unfortunately, she cannot handle both of them at the same time, so she waits until either her mother or housemate are home to walk the dogs together.

The housemate’s comings and goings are often unpredictable, and her mother’s work schedule is irregular, making it difficult for the paths of these individuals to come together with Ella-Jane regularly to walk the dogs. Although the pestering from the dogs upon arriving home could provide an insistent rhythm which might “drive” Ella-Jane along in her exercise, the routine activities of Ella-Jane and her two potential dog-walking partners do not synchronise.
This stalls Ella-Jane’s efforts to ‘out-source’ her motivation to a rhythm in her environment. These examples make it clear that sources of motivation are not, at least entirely, internal to the individual. The difference between “wanting to go, constantly” to the gym and not having “that feeling of wanting to go” is linked more to rhythms of demand in Mike’s workplace than his own personal drive to exercise. Perhaps, provided with a different rhythmic context, Ella-Jane would easily meet her exercise goals.

7.1.2.2.3 Tracking

Tracking fluid intake was relevant for many participants, either in terms of limiting fluid consumption for those with poorly functioning kidneys in order to reduce fluid build-up in the body, or in terms of meeting a daily quota of fluid to keep the kidney(s) hydrated for those with a functioning transplant or gradually failing but still performing kidneys. Participants expressed difficulty in meeting fluid requirements both because of perceived lack of self-discipline and feelings of either denying oneself the satisfaction of drinking or forcing oneself to drink. For example, Mary (age 75, pensioner, clinic dialysis) describes her struggle to limit water intake when she started dialysis:

> All my life the doctors had said ‘Drink water. Drink lots of water’. And *suddenly*, there was a limit of a litre of fluid a day. And I have *fought* that all along. It’s a *fight*. I *love* water, still. [...] I just love water going ‘glug, glug, glug’ down me. And that’s just a ‘no, no’.

Mary tries sucking on small ice blocks to satiate her thirst. Hannah (age 60, pensioner, stage 3) on the other hand, is tasked with increasing her water intake to 2.5 litres per day in order to extend the life of her failing kidney:

> That is a strain. [...] It feels like I’m force feeding myself if I try and reach that figure.

Mike (age 33, full-time public servant, functioning kidney transplant) provides an example of the potential for the force of habit to pull a person ‘too far’ in one direction with a behaviour. His kidney problems reach back to childhood. He described the fight against his parents’ instruction to drink more water as “painful”. But by the time he was a teenager he was “drinking water constantly”. He cannot pinpoint the time when the habit took hold. Yet, the force of habit became so strong, that he started to compulsively over-drink water, and his dietician instructed him to cut down so as to not deplete his body of important substances:

> [I]t was so much of a routine and habit, um, even though I felt like I was thirsty which I always felt like I was thirsty, I *wasn’t*. So, the feeling of being thirsty plus seeing my water bottle being good for my kidney sort of combined for me just drinking every time I saw it.
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Mike’s compulsion to drink water was a habit lying at one extreme of “the necessity of ease and the torment of need, one side directed to making the world readily habitable, and making the living being at home in the familiar; the other directed to a trajectory of infinite repetition, a tic, an addition, a limitation and a constraint on life,” (Grosz, 2013, p. 220). These participant accounts describe emotions and sensations of compulsion, “strain”, “force” and “fight” in struggling against established habits of the amount of water that feels like ‘enough’. Participants described an additional challenge: that of tracking the amount of fluid they consume in a day. In order to track fluid intake, participants need to establish stable rhythms of fluid intake. This necessitates a way of tracking quantity, a way of spacing those quantities throughout the day, and consistent, controlled contexts. Many participants who are required to limit fluid have cups of particular volumes that they use to measure out fluid in a day. For example, Larry and Martin have 200 ml cups and Jasmine has a 250 ml cup. Others who are required to meet a minimum of fluid consumption each day have particular water bottles from which they drink and then refill several times a day in order to meet their consumption goal (e.g., Ella- Jane has a 750 ml bottle, Sarbajit has a 650 ml bottle, and Mike has a 1.5 litre bottle).

Martin’s (age 43, unemployed, clinic dialysis) fluid intake is strictly limited to 500-600 ml per day. To put that into perspective, he offered the comparison of a bottle of beer, which is 400 ml. He measures all of his fluid with the same 200 millilitre cup, including the milk on his cereal. He has tried strategies to pace his fluid consumption during the day, including writing down every amount he drank, but he says that did not work for him because: “They’re only figures on a piece of paper.” Instead, he now focuses on establishing a stable, slow tempo rhythm of consumption throughout the day:

[I] still have what I want to have, but only do it every four hours. Four to five hours. I’m trying to really concentrate on spacing them right out. That seems to be working.

When Martin goes to dialysis, the machine provides a reading indicating how much excess fluid it has to remove. When he has put on a lot of fluid (e.g., 5 litres) since the last dialysis session, Martin calls these “blow outs”. He describes a ‘blow out’ resulting from attending a cricket game:

Martin: I wasn’t focused. And I thought I was sweating, especially at the cricket, I thought I was sweating out more than I was. If you could measure sweat it’d be nice [chuckles] but you just can’t measure it. [...]  

Julia: What do you mean you weren’t focused?
Martin: Just lost... ‘Oh, I can have that now. I’ve sweated it out.’ But I couldn’t and you’re hot and you’re sweaty, ‘Ah, I’ll just have a mouthful here, and a mouthful there.’ I wasn’t at home, focused. And I didn’t have that measuring cup. That 200 mil cup. [...] So you’re really – when you’re away from your own, you know, dung hill – house – it’s a different scenario. You’ve got to really knuckle down. Ya, so once you’re outside your own environment it’s a bit harder. A lot harder, actually. So you mainly stick to your own home, but then you can’t be cooped up in your house the whole time ’cause you’d go nuts. You still have to get out. [...] You want to forget about it for a little while.

Martin highlights the importance of a stable context where a controlled fluid intake rhythm has a chance of more reliably circulating. The stability of the home space-time context supports chronic illness management, but it also implies being ‘tied’ to the home, or “cooped up” as Martin puts it. Indeed, encouraging stable rhythms for chronic illness management seems to be, in part, dependent upon restricting one’s potential path area to familiar environments like the home. But this runs against the desire for novelty, variety, and the opportunity to “forget about it for a little while”. In a slightly different way, Bill and Hannah use context and quantity to try to influence the rhythm of fluid consumption over the period of a day. Bill would like to reduce the amount of Coca Cola he consumes, and Hannah would like to reduce her alcohol consumption. Both have resolved not to drink these substances at home as a way of slowing the tempo of their fluid intake rhythm.

The participants who work to maintain enough fluid also try to maintain a stable rhythm of fluid intake throughout the day, albeit at much higher tempos and quantities. Sarbajit (age 38, full-time public servant, functioning kidney transplant), like Martin, relies on certain contexts to help him sustain stable fluid intake rhythms. He has the goal of not letting more than 15 minutes pass without sipping water, and he carries a 650 ml bottle with him almost everywhere, including to his work station.

I have a big ‘Post-It’ note on the bottom of my screen that says ‘Drink’ [laughs]. So I know that when I glance up and I’m looking at the bottom of the screen I say, “Right”. I don’t generally need to do that. But what I find is that if I don’t have that sign there, I can go for an hour and a half, two hours, without drinking water. Anyone can. But I shouldn’t.

Sarbajit introduced a visual trigger to drink into his work station environment. The regular, high tempo rhythm of his eyes glancing down at the screen provides a rhythm on which to hook the trigger to drink, encouraging regular and frequent fluid intake throughout the workday. Other contexts, however, can be more challenging. Sarbajit tries to overcome this by modifying contexts through the introduction of “a water container for every situation,”
including a Camel Back bladder, a satchel for carrying a water bottle, and an insulated water bottle for his car.

These examples suggest that complying with fluid recommendations is less a struggle of self-discipline than a matter of having a way of tracking the quantity of fluid intake, a way of controlling the spacing of those quantities throughout the day, and having consistent, controlled contexts that facilitate appropriate repetition of fluid intake.

In short, rhythms play an important role in supporting or diminishing the ability to remember activities (e.g., medication schedules), feel motivated to persist with activities (e.g., exercise), and track consumption (e.g., limiting fluid to a certain amount per day). Sticking to familiar contexts (e.g., the home) is a necessary strategy for encouraging helpful rhythms to circulate for many participants.

To conclude, dominant approaches to understanding patient success in managing chronic illness emphasise psychosocial factors such as patient education, motivation, sense of self-efficacy, acceptance of diagnosis, and their ability to establish health-supporting routines and habits. The findings presented here show that logistical challenges derived from the competing space-time demands of different activities, as well as the characteristics of the rhythms in everyday environments and participants’ bodies, can also influence a person’s ability to establish and maintain chronic illness-supporting routines in everyday life. When logistics and everyday environments encourage regular and reliable repetition of illness management activities, the force of habit is harnessed in participants’ favour. Thereby, participants experience less effort associated with managing their illness, feel more in control, motivated, and ‘normal’. This suggests that when we try to understand patient self-management of chronic illness, we must pay attention to the spatio-temporal contexts of individuals’ everyday lives, as they play an important role in shaping the terms under which success may take place, and a sense of motivation and positive self-efficacy may be experienced.

7.2 Paid work participation

“The stuff I do at my job is just as important as the stuff you do at your job.” -Bill

7.2.1 Dominant approaches revisited

As I discussed in Chapter 3.2.2, paid work participation by people with chronic illness has often been understood as a problem of the physical limitations of the chronically ill body that limit a person’s ability to perform job duties (Boot et al., 2013; Chorus, Miedema, Wevers, & Van der Linden, 2001; Koch, Rumrill, Conyers, & Wohlford, 2013). 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). Unsupportive organisational cultures, and the discrimination and stigma of employers and co-workers toward individuals with chronic illness, have also been emphasised as barriers to labour force participation (e.g., Edwards & Boxall, 2010; Koch et al., 2013; Roessler, Hennessey, Neath, Rumrill, & Nissen, 2011; Shier, Graham, & Jones, 2009). Legislation protecting the hiring process for individuals with chronic illness (e.g., Australian Human Rights Commission, 2015) as well as educating employers about chronic illness (Koch et al., 2013) are strategies that have been used to address these barriers.

However, there may be other sources of difficulty in paid work participation. As reviewed in Chapter 3.2.2, a substantial body of literature supports the idea that the spatio-temporal characteristics of work – for example, duration and pace, as well as the flexibility, predictability, regularity, and sociability of times and locations of work – interact with a person’s health (e.g., psychological distress, musculoskeletal diseases) and non-work activities (e.g., family, domestic work). And, the interaction of these dimensions in an individual’s everyday life will impact on the person’s labour force participation. How might the interaction of spatio-temporal characteristics of work interact with those of chronic illness management and symptoms?

7.2.2  Findings from a space-time analysis

In the sections below, I explore the interaction of the various spatio-temporal characteristics of work, health services, and symptoms of chronic illness experienced by participants. I find that different combinations of these characteristics produce difficulties and supports for participating in paid work with chronic illness. Participants have strategies for mitigating and anticipating difficulties, but these often come at a cost to their mental and physical health.

7.2.2.1 Space-time resource conflicts

I first consider ways in which participants experience time and space as finite resources that are needed for juggling paid work and illness management activities, and are subject to constraints and affordances. Because both employment and health services are governed by clock and calendar time, a space-time geographical perspective is helpful in seeing how managing a chronic illness and holding down a job compete for space-time resources in the absolute sense.

An example of space-time resource conflicts comes from Mike (age 33, full-time public servant, functioning kidney transplant). Mike contrasts his current job to the eleven years he worked as a chef. Consistent with existing literature on diagnosis disclosure and employer
discrimination (e.g., Roessler et al., 2011), after revealing his health condition to interviewers, Mike was not offered six chef positions in a row for which he applied, yet landed the seventh job after deciding not to disclose. As a chef, Mike found balancing the activities needed to care for his transplant and the space-time demands of the job very stressful. He described often going to work when he was not feeling well because he felt there was no one to fill in for him, and that he had to ‘bank’ time for medical appointments or emergencies. As described in Chapter 7.1.2.1.5, Mike’s performance of health-supporting behaviours diminished during this time, and his health suffered:

Being a chef, it’s high pressure. There’s no one to take your job once you’re sick. [...] Basically you have a set job. You’re that person for that role, and there’s no one else who can take over [...] And so, you couldn’t have days off. I very rarely had days off. Even when I was feeling sick. Which was hard. So of course that stressed me out. A lot. And the pressure of [breathes in] having time off, but needing to be there. [...] It was frowned upon to have days off because the other guys were working so hard.

Mike’s job as a chef imposed heavy authority and coupling constraints, as he was the only person who could complete his tasks within the work day, and there was very little flexibility around when and where tasks could be performed. These practical stresses were exacerbated by an intensified work pace, itself demanding of the body, and a workplace culture that “frowned upon” having time off even if it was legally available. Mike goes on to compare the years as a chef with his current job as a public servant:

Whereas now in this job, I have the flexibility of calling up... for instance if I’ve forgotten that I have a blood test, I could call up tomorrow or today and say to my boss, ‘Sorry, mate, I’ve forgot I need to have a blood test this morning.’ No dramas. There’s so much more flexibility. [...] [B]efore whenever I’d have appointments I’d try to get to work as soon as I could afterwards. And if an appointment - if I sit in a doctor’s surgery for an hour, I’d be getting stressed. Like what’s going on? Whereas now, I can sit there for two hours, no dramas. Wouldn’t feel anything like I need to get back to work because I know they’re so fine with it.

While waiting for the doctor was an anxious experience while contending with inflexible work demands, Mike’s current work arrangements change the experience of waiting. Although his work is spatially inflexible, meaning he has to be at the workplace in order to perform work, he benefits from the ability to transfer his responsibilities to a co-worker as needed in order to accommodate the unpredictable space-time costs of health services access.

Also a full-time public servant, Bill dialyses at a clinic three evenings per week for five hours. His workload fluctuates widely over the year, and when it intensifies again, he will need to bring work to dialysis to keep up while ‘getting his time in’ on the machine. During these intense times of the work year, Bill’s work takes on some of the characteristics of
“boundarylessness” as described by Kamp and colleagues (2011). Bill’s work is, to some extent, measured in terms of product, meaning that it is more important that he finishes his tasks by particular deadlines than it is that he is physically present at work at particular times. Furthermore, the work can be performed remotely with the aid of a laptop and mobile phone, adding a degree of spatial flexibility to his work. However, the burden of managing the logistics of work and illness is carried by Bill, rather than his employer. Some supervisors are more willing to grant spatial flexibility than others; regardless of the need for physical presence at the office. Bill had to fight for the spatial flexibility he needed in order to accommodate the space-time demands of both dialysis and periods of heavy workloads. After “bringing up some bits of law” to his employer, Bill obtained written agreement from his employer that work performed while on dialysis counts as attendance at work. Differences in supervisors’ attitudes have affected his experience of juggling paid work and illness:

The one I’ve got now [supervisor] – is anal. And the other boss was like ‘Eh, if you’re not here, you’re not here. I don’t care. As long as you get the work done at the end of the day.’ So I could just duck off to [doctor] appointments whenever I wanted. But he [current supervisor] wanted to know where I was going and what I was doing and wanted it all documented. It was just terrible.

Samantha (age 43, on sick leave, stage 2) worked 30 hours per week and studied while her four children were young. Managing this with the demands of an emerging and serious autoimmune condition was made possible, Samantha thinks, only by the flexibility and trust given her by her employer. Samantha was responsible for the bookkeeping and other administrative tasks of a small printing company. Her work was project-based, and spatially and temporally flexible, allowing her to take it home with her when she or one of her kids were sick, or defer tasks when she needed to see a doctor. However, as evidenced in the quote below, there was no upper limit to the time she spent completing the work that needed to be done, and the burden of managing work, health, and caregiving activities was on her. The benefit of this arrangement, however, was that it reduced the experiences of stress and guilt of having to take time off work in order to manage her illness, cope with symptoms, and care for her children:

[T]here was no doubt, it was just complete trust. Which is really lovely and it was too much strain, because as much as I only supposedly worked school hours, I didn’t. I’d go in and I’d work in weekends or I’d take work home. Whatever needed to be done got done sort of thing, so it was a really nice relationship that we had. [...] If I felt like I was having a really bad day or one of the kids was sick or something, because that’s really hard as a working mum, too. If my kid’s sick, what do you do? So it was always really nice that I could either take the kids in, or
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if they were too sick to go anywhere, then I could stay home with them and just duck around to work and just grab some stuff.

When the spatio-temporal demands on the physical presence of employees are inflexible, they clash with frequent medical appointments, unforeseeable health problems requiring time off, and thrice-weekly dialysis sessions for some. The unpredictable nature of health service provider space-time demands exacerbates feelings of time pressure. Bill’s interview occurred while he dialysed, providing insight into the physiological effects of these stressful space-time conflicts:

I understand better than anyone on this planet that doctors sometimes get held up, but if you know you’re going to be late or somebody’s going to be late, give me a call. The stuff I do at my job is just as important as the stuff you do at your job […] - [dialysis machine alarm goes off]. My blood pressure is going up [whispers].

Bill offered another example of the unpredictability of health service space-time demands. After a lifetime with renal problems, Bill knows the signs of a bladder infection. He tried to coordinate antibiotic pick-up from the doctor with his morning dialysis session, both located on the same campus. This way he could go straight to work after dialysis with antibiotics in hand. He rang the hospital before dialysis to request his lab results be checked and a prescription drawn up while he dialysed:

I sat here [dialysis] for 4 hours. […] I literally got to work and got the phone call, ‘Ah could you come in and get a script?’ What about the four hours that I sat there? […] And then you know what happened? The script wasn’t the right script. […] So I had to wait another hour while I got the right script for the drug I needed. […] If you’re talking about time, that’s where all the time goes.

These kinds of experiences have led Bill, like Mike, to ‘bank’ time off work by working even when not feeling well, and to always try to be a week ahead in his workload. In doing so he tries to anticipate and mitigate negative effects at work from unpredictable health problems and space-time resource costs of health services:

I’m always like a week ahead – if I can be. […] And I guess that’s how I’ve always lived, essentially. […] So that I can let people [at work] know what’s going on. So I don’t really find any tensions apart from myself – for example, the last time I was sick, I had a temperature of 38.8. I went in to see [renal specialist] and I went to work. And he said - basically said I was an idiot. Which I was, but [breathes in] - I don’t know. Basically the only time I’m not at work or doing something is when I’m... being dragged into hospital.
Furthermore, Bill makes himself remotely available to his employer when he is away for medical reasons. Bill describes how he prepares his supervisor when Bill has to go in for a routine medical procedure:

I would draft a really long email, um, ‘If this happens, then this happens. If this happens, then you might need to call these people and here’s their phone numbers. And if this happens, this happens. And, you know, apart from when I’m actually under the anaesthetic, feel free to give me a call on the mobile.’

Bill attempts to transcend his physical absence by anticipating his supervisor’s needs, and makes himself available via Information and Communication Technologies (ICT). In this way, Bill tries to overcome the finitude of his space-time resources and supply both his employer and his illness with the space-time resources they demand. Planning in order to accommodate the space-time demands of work and chronic illness may be required in other ways. Bernard (age 40, full-time public servant, clinic dialysis) describes all the planning and arrangements he is required to make in order to be able to travel for work within Australia now that he has to dialyse:

Gotta be very organised [laughs]. Once I establish when I have to - the dates and where I’m going - I usually just give that to the clinic and tell [...] I need to be on a plane by this time, can I dialyse in the morning? They arrange that. But while I’m there - if I’m only there you know for two nights I’ll come back the third night I’ll - hopefully the flight’s not delayed [laughs] - and I’ll come back on the third day and I might skip or I’ll probably come straight to work or I’ll skip work on the third day and go straight to dialysis. But if it’s longer than that, um, they - they [stutters] they try to book me in a clinic close to where I’m staying. So, that helps. It’s not always easy because sometimes you still have to travel and a clinic might be an hour away. [...] So, but that’s part of if I want to work and keep up my work I’ve got to plan those things.

Traveling for work as a person on dialysis means having to contend with the spatio-temporal logistics of an additional base location (i.e., the dialysis clinic), as well as the hotel and the work site. Furthermore, upon returning home, a disruption to the work schedule may be necessary in order to maintain the proper spacing of dialysis treatment.

Karen’s (age 26, full-time public servant, functioning kidney transplant) experiences offered insight into the impact of different combinations of spatio-temporal arrangements of work and health services on the difficulty of balancing paid work and chronic illness. For the past three years, Karen has worked a standard 9-to-5 work week in the public service in suburban Canberra. Prior to this, she worked irregular shifts in hospitality in inner-city Brisbane. In hospitality in Brisbane, breaks were for a half hour and were inflexible, meaning you had to take it at a set time and get back to work at a set time: “You’re lucky to even get a break,” she says. This meant that going to the doctor on her lunch break was impossible.
Furthermore, her role was non-transferable in the sense that her responsibilities could not be filled without a replacement staff member taking over her shift. Also, even though she works roughly about the same number of hours per week in her current job, the irregularity of the work schedule made it seem to her that she had less free time, making her sacrifice less prioritised health-activities like cooking:

[M]y hours fluctuated so it was usually like seven till three or three till eleven. So yeah, you’d have those times after or before work but, I don’t know, I didn’t find as much time. [...] I didn’t do a lot of cooking back then.

Now, Karen works a set schedule during sociable hours in public service. She finds this less tiring:

It makes life a lot easier when you’ve got a schedule and you are working the hours that everyone else is working and you’re less tired as well.

As opposed to hospitality, her current responsibilities in the public service can be taken over by a colleague if Karen needs time off for her health: “They can just hand over what I’m doing if it’s busy or whatever.” Furthermore, her current job has “flex-time”, meaning that any hours worked in a day over the standard 7.5 hours accrue for time off on another day.

Not only were the prior spatio-temporal arrangements of work very different from what they are now, the spatio-temporal constraints of Karen’s previous kidney specialist and the context within which she accessed health services are very different now. To begin with, a trip to the doctor in Brisbane meant a 45 minute bus ride; whereas in Canberra it is a 15 minute car ride. Perhaps more importantly, Karen’s specialist in Brisbane operated on a ‘first come first serve’ basis, meaning that Karen sometimes waited up to three hours for a regular appointment. Her specialist in Canberra assigns each patient a set appointment time, making it easier to predict how long an appointment will take. Even so, her specialist is often behind schedule, “as all doctors are”. Furthermore, Karen finds it difficult that she cannot get an early morning appointment with her specialist in Canberra, the consequence being she has to “break up” her work day because she arrives at work, settles in, and then leaves to go for a doctor appointment and returns to work later. However, the ability to accrue time off with ‘flex-time’ makes this workable.

The ways in which the spatio-temporal characteristics of work and health services interact in Karen’s ‘before’ and ‘now’ scenarios is informative. Working shifts in hospitality in Brisbane, Karen sometimes did not receive the week’s roster until a couple days before the week began, meaning that an appointment with a specialist scheduled months earlier sometimes landed during her shift. Her supervisor did not like Karen to request changes to the
roster, meaning that Karen often had to find a colleague to swap shifts with her in order to be able to keep her doctor appointment:

He wasn’t happy with getting them them. He was like, “You have the roster, that’s how you have it”.

Sometimes in order to arrange her shifts to accommodate a doctor appointment, Karen would work difficult or extended hours; for example, work a shift that ends at 11pm and start a shift at 7am the next morning. The space-time arrangements of this job meant that all health service access had to happen completely outside work hours. However, the positive aspect of her irregular shift schedule was that she usually had at least one weekday off. This meant she saw the doctor on her days off and could accommodate the very long waits at her doctor’s office: “If I had to do it in my current job, how I had it there with a three-hour wait, it would just take way too much time out of my workday.”

The way Karen manages doctor appointments with her current 9-5 job is that she takes advantage of the flex-time arrangements. Like many other working participants, Karen ‘banks time’ off work by not using accrued sick leave and flex-time unless she really needs to. This means she can use her flex time to go to a doctor appointment in the middle of the day. Because all employees have and use flex-time, her absence during the middle of the day is not unusual; Karen mentioned her colleagues using flex-time for a very long celebratory or farewell lunch during the work day, for example. Karen supposes taking more than two hours away from the workday with flex-time would be unacceptable, but notes, “It doesn’t really matter.” The option to accrue time off is also very valuable for Karen as she, like many other participants, is wary of uncertainty about her health and when and where her kidney transplant might fail, requiring time off work.

Despite these much more favourable working and health service spatio-temporal conditions, Karen still finds a tension in taking time away from work to care for her health. If she goes to the doctor during the day she will eat her lunch at her desk, sacrificing rests and breaks in order to reduce the impact of accessing health services during work hours.

7.2.2.2 Embodied space-times and rhythm

Next, I consider the interactions of everyday rhythms such as those produced by the chronically ill body, illness treatment regimens, and paid work. In the previous section, I focused on how participants often contend with the logistical predicament of being ‘pulled’ between the space-time demands of work and illness. Here, I turn attention to the ways things repeat in a person’s life, and how these repetitions influence the degree of difficulty experienced in balancing chronic illness with paid work.
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The sometimes unpredictable rhythms of changes in the states, needs, and capacities of the chronically ill body are dominant themes in the everyday lives of participants. Some are related to recurrent fluctuations of symptoms, such as fatigue or nausea. These body state rhythms can produce arrhythmias when combined with work demand rhythms. For example, although Samantha's (age 42, stage 2, on sick leave) CKD is not very advanced, she experiences a variety of symptoms related to an additional undiagnosed illness, including joint stiffness, vomiting, ulcers and fatigue. These symptoms come and go unpredictably, making combining illness and work a bit of a 'luck of the draw'. She describes a period of bouts of illness, which fortuitously synchronised with her rotating work schedule:

I started having these really weird episodes where I couldn’t eat for three or four days and I would just vomit constantly. I just felt absolutely horrible [...]. And then I'd suddenly just be fine. [...] But it hadn't really had any massive impact. It had sort of fallen on days where I was off work. When I was in the [company] store you’d work a rotating roster because it's seven days a week.

Samantha’s current schedule is standard, working 9-5, Monday through Friday. She is on sick leave due to the unpredictability of how well she feels and how much she can do on any given day. “I have good days and bad days,” she says. Samantha describes her first sample day as “definitely a good day” on which she did a lot:

I did lots. I had a busy day Wednesday because I felt good. [...] If I feel good, I feel really, really good.

In contrast, on the second sample day, she felt so poorly that doing basic activities like making a cup of tea was “a really major chore.”

When I have a really, really bad day, my arms and legs just feel like they’ve been injected with lead and everything is just way heavy.

Yet, on the third day (the day of the interview), she woke up feeling “pretty good”. Even though this individual has the ‘lump-sum’ time to devote to at least a part-time job, the unpredictability of her corporeal rhythms makes it too difficult to commit to an employer.

Some participants with standard work schedules are allowed enough flexibility in work rhythms to accommodate these kinds of unpredictable body state rhythms. Sarbajit (age 38, full-time public servant, functioning kidney transplant) had a recent kidney transplant at the time of the interview. His standard work week schedule is relatively flexible, allowing him to adjust when he goes into work in the morning depending on how he feels:

If I’m not feeling right in the morning and I wake up - I set my alarm for, say, 6 o'clock, and I wake up and I’m like ‘Oof, this is just not working for me,’ I’ll re-set it
for 8:30 and I’ll try again and I’ll get up a second time and I’ll feel like I’m waking up and I’ll be like ‘Ok, better now.’ And then I’ll pick it up and I’ll go to work.

This kind of flexibility reduces the energy-sapping stress of negotiating work demands and managing his new kidney transplant:

So it’s just mentally you’re not stressed about when you’ve got to do those things. [...] I don’t have to tell anyone or ask permission or any of those things.

Participants also described body state rhythms produced by illness treatment. In particular, dialysis was attributed to episodic changes in feelings of energy and wellness, and to disruptions to sleeping patterns. Most participants who dialyse during the day (as opposed to evenings or overnight) are retired or no longer working. They describe dialysis days as ‘nothing days’ when they feel too tired after dialysis to do anything. Non-dialysis days, then, are ‘run around’ days for accomplishing as much as possible while there is energy to do it. Bernard (age 40, full-time public servant, clinic dialysis) dialyses three evenings per week after work. He describes feeling “wide awake” by the time he gets home around 10 pm and finds it difficult to fall asleep until late at night. The next morning, he says, “You’re just lazy and you don’t want to go to work.” The interference of dialysis with Bernard’s circadian rhythm makes it difficult to comply with the work demand rhythm the next morning.

A dialysis-related arrhythmia heavily contributed to one participant, Martin (age 43, unemployed, clinic dialysis), quitting his part-time job as a postman. Martin recently started receiving dialysis three times per week after his transplant failed. His energy levels and feeling “yucky” started swinging up and down between dialysis sessions. Although he had the absolute space-time resources needed to work part-time as a postman and ‘get his hours in’ on dialysis, this episodic body state rhythm conflicted with shift demands:

I just got to the point where ... it just wasn’t happening. [...] I call it like a Yo-Yo. You get off here [dialysis], you feel good, you’re about here [indicates high level with hand], then you go to work, you’re feeling pretty good, but by the end of the day you’re down here [low level], so come.... Ya, say I start here on a Monday [high level], I’m good. Tuesday morning I’m in, Tuesday afternoon I’m here [indicates very low level with hand]. [...] Tuesday afternoon crashed. You come in here [dialysis], you’re here [low level]. Cleans you up, you’re here [high level]. [Pauses] So you go to work Thursdays, I’m here [slightly lower level].

A final point on the role of everyday rhythms is the way workplace rhythms can facilitate or hinder repetition of illness management activities. Participants stressed the need for rhythms associated with workplace practises to occasionally yield to rhythms of the body. However, they also emphasised the importance of stable workplace rhythms, such as those produced by personal routines, for the persistence of illness management activities (e.g.,
following a medication schedule). ‘Slip-ups’ in participants’ health regimens usually correspond with a disruption of routine, such as an over-sleep that compresses the morning into rushed activities done ‘all at once’. Stable rhythms produced not only by social practices (Shove et al., 2009a), but by bodies, the behaviours of pets, and a multitude of other aspects of everyday environments influence how easily activities are performed in different contexts, including chronic illness management in the workplace.

Like all transplant recipients, Sarbajit had to learn to comply with an immunosuppressant medication schedule after his kidney transplant. While morning and evening doses seemed to happen fairly easily at home, he struggled to integrate a mid-day dose into his workday:

> It depends on where I am. So if the alarm goes off when I’m in a meeting then I have to remember to either... snooze the alarm for an hour’s time and then go back and take it, or if I’m somewhere else I forget the tablet which happened as well... often enough. [...] But ya, it was just too difficult to try to remember because it wasn’t part of my routine. I’m used to: my drugs sit on the kitchen counter. I walk past them. It’s in a central part of the house. I see them. [...] So you’ve got the corridor one way, the front door the other way, and it’s on a corner of the kitchen. So you kind of go past it to go anywhere in the house.

In contrast to the workplace, Sarbajit’s home rhythms help him remember his morning and evening medications because routine activities around the house, such as feeding the cat (see Chapter 7.1.2.2.1) inevitably ‘pull’ him past the centrally located kitchen counter with the medication box. The regularity of the cat’s hunger, her insistence on being fed, and the layout of the house provide a hard-to-ignore rhythm on which to ‘hook’ the timing of the medication. At work, in contrast, the mid-day dose ‘floats’ without a rhythm to hang onto, meaning he often forgot to take the medicine. His ability to establish a stable rhythm at work is likely hampered by the priority given to work-related activities, such as a meeting, over ‘personal' routines. Sarbajit does not lack health knowledge, motivation or a supportive social network; personal attributes often emphasized in health behaviour change theories (Glanz et al., 2008). For the same educated and motivated individual, whereas the dose was a stressful obligation and struggle to remember in one rhythmic context, in another, it is part of the everyday routine that ‘just happens anyway’.

In summary, the spatio-temporal characteristics particular to paid work, health services access, and the symptoms of chronic illness also play a role in making it more or less difficult to sustain employment. These spatio-temporal characteristics vary depending on the arrangements of paid work and health services, and the types and severity of symptoms experienced. The spatio-temporal characteristics of paid work that emerged as particularly
relevant were derived from: whether productivity is measured more in time spent in the workplace or in product; the potential transferability of work responsibilities to another co-worker; the spatial flexibility of work (e.g., work from home); the temporal flexibility of work (e.g., defer tasks when needed); the ability to accrue time off; whether there are upper limits to work hours; the sociability, regularity, and predictability of work schedules and locations; and the rhythms of workplace practices (e.g., how activities are coordinated between co-workers).

The spatio-temporal characteristics of health services that most influenced participants’ experiences in paid work had to do with: the individuals’ frequency of health service access; the distance to and mode of travel to health services from home and work; appointment scheduling style (i.e., first come, first serve; or set appointment times); how long in advance appointments had to be scheduled; appointment opportunity windows (i.e., days of the week and times of the day made available to them by their provider); the duration and predictability of waiting times before appointments; and the degree of need for coordination of services between departments (i.e., the number of opportunities for miscommunication and delays). Finally, the spatio-temporal characteristics of chronic illness symptoms that most influenced participant experiences of paid work were associated with: the degree of unpredictability of rhythms of wellness; the circulation of work-incompatible rhythms (e.g., energy fluctuations from dialysis; inability to sleep after dialysis); and sudden and unpredictable episodes of illness.

Some combinations of spatio-temporal characteristics are particularly unfavourable, such as highly unpredictable and frequent health service access in combination with low transferability of job responsibilities, inability to accrue time off, and low spatio-temporal flexibility in where and when tasks can be performed. Participants attempt to anticipate and mitigate the negative effects resulting from the interaction of these characteristics. Their strategies include banking time off work, swapping shifts with a co-worker, being ahead in their workload, carefully planning ahead, making themselves remotely available to their employer, sacrificing health-supporting activities such as home cooking and exercise, and skipping work breaks. These strategies are often stressful, tiring, frustrating, and detrimental to their mental and physical health. As Hall and Wilton (2011) argue, efforts to address barriers to employment too often focus on the hiring process rather than the potentially disabling characteristics of work environments. The findings presented here suggest that the spatio-temporal characteristics of work – in combination with those of health services and chronic
illness symptoms – are important environmental characteristics that must be taken into account when designing workplace accommodations for those with chronic illness.

7.3 Caregiving and family

“It was dinner time, bed time, and no family.” - James

7.3.1 Dominant approaches revisited

As I discussed in Chapter 3.2.3, caregiving for others as a person with chronic illness has been understood primarily as a problem of conflict between the socially constructed roles of ‘parent’ and ‘patient’ (e.g., Lyons, 1993; Poole, Hare, Turner-Montez, Mendelson, & Skipper, 2014; Radtke & Van Mens-Verhulst, 2001; Sandelowski & Barroso, 2003; Thorne, 1990; Vallido, Wilkes, Carter, & Jackson, 2010; van Mens-Verhulst, Radtke, & Spence, 2004; Wilson, 2007). Identified sources of role conflict include fatigue; unpredictable episodes of acute illness; possibility of death; ‘overdoing’ it’ thereby exacerbating symptoms; and disease stigma. Gender has been identified as heavily influencing experiences of parenting with chronic illness (e.g., Barker, 2013). Yet, the experiences of mothers with chronic illness have been explored to a far greater extent than those of fathers (Barker, 2013). The experiences of caring for an adult as a person with chronic illness have also received very little attention (see, however, Charmaz, 1997).

Authors such as McKie, Gregory, and Bowlby (2002) and Davies (2001) have emphasised the unique spatio-temporal characteristics of caregiving. Caring for others is enmeshed in relational, fluid space-times oriented toward anticipating and fulfilling the needs of others. Opportunities for pause and reflection are few. Furthermore, caregiving, particularly within a family setting, requires effort to coordinate and synchronise heterogeneous family member space-time paths (e.g., Southerton, 2009), and to contend with the logistics of chauffeuring, procuring, cooking, and other domestic tasks in and outside the home (e.g., Kwan, 1999a, 1999b, 2000; Schwanen, Kwan, & Ren, 2008). These efforts have not only logistical ends, but also aid in the maintenance of stable family routines and rituals which are linked to family functioning and the physical and psychological wellbeing of family members (Boyce et al., 1977; Dickstein, 2002; Fiese & Wamboldt, 2000). Also, feelings of urgency around providing uninterrupted ‘quality time’ with family members preoccupies many caregivers in contemporary families (e.g., Christensen, 2002; Kremer-Sadlik & Paugh, 2007; Roeters & Treas, 2011; Southerton, 2009; Tubbs, Roy, & Burton, 2005).
7.3.2 Findings from a space-time analysis

In this section, I argue that role conflict between being a person with chronic illness and a caregiver and family member arises, in great part, from the interaction of the spatio-temporal characteristics associated with these two aspects of everyday life. I propose that in understanding the caregiving experiences of individuals with chronic illness, it is useful to think of two sets of caringscapes and carescapes (Bowlby, 2012); those associated with care for dependent others, and those associated with care for the chronically ill body. As outlined in Chapter 3.2.3.3, caringscapes refer, in general terms, to “individuals’ organisation of their caring activities in time-space,” while carescapes refer to “the resource and service context shaping the ‘caringscape terrain’,” (Bowlby, 2012, p. 2112). Understanding how the spatio-temporal characteristics of the caringscapes and carescapes of chronic illness and caregiving interact with one another may illuminate unique aspects of being a caregiver as a person with a chronic illness.

As revealed in the passages below, participants with caregiving roles have an ideal caringscape, meaning an ideal for how they should organise and provide care for others. This is driven by the desire to ‘be there’ for others, as in their child(ren), an ill spouse, or an ageing parent. For participants, the meaning of ‘being there’ includes: orienting themselves to, being constantly available for, anticipating and fulfilling the needs of others; providing safe, happy spaces of childhood or older age; providing stability in the form of routines and rituals; providing breaks from routines (e.g., holidays); facilitating ‘normal’ childhood activities such as extra-curricular activities and play in the case of children; providing co-presence; and sharing uninterrupted ‘quality time’ with loved ones.

For people with chronic illness, however, their ideal caringscape is necessarily driven also by the desire to provide care for and accommodate the needs and demands of their own body. This includes: resting and taking breaks as needed; having stable routines that support faithful adherence to treatment regimens; anticipating, preventing, and accommodating sudden, acute episodes of illness or symptoms; anticipating and accommodating fluctuations in feelings of wellness and energy; and accommodating routine as well as unanticipated health service access.

Therefore, individuals with chronic illness who provide care for others contend with two not-always-compatible ideal caringscapes; that of caring for others, and that of caring for their own body. In the passages below, I explore participant experiences of conflict between these two ideals, finding that their actual caringscapes are shaped by: 1) the logistics of providing care for others and managing chronic illness, and 2) embodied space-times that make being
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engaged and present with loved ones difficult. Due to logistical and embodied incompatibilities in the caringscape, participants tend to spend energy worrying, anticipating, and planning for conflicts between the two ideals. This often involves having to prioritise between activities and sacrificing some in order to perform others. The resulting feelings of guilt, sadness, and inadequacy are manifestations of the role conflict documented in the literature on caregiving as a person with chronic illness. Emotional geographical concepts aid in understanding the emotional dimension of the space-times of chronic illness and caregiving.

7.3.2.1 Space-time resource conflicts
Below I demonstrate that, while participants’ actual caringscapes are driven by their ideals for providing care for others and their own body, they are constrained by logistical factors. The logistics participants face are influenced by things like service and resource contexts, or the carescapes (Bowlby, 2012) of caring for dependent others as well as the chronically ill body, the space-time paths of family members, the extent of the individual’s chronic illness management burden, and the spatio-temporal characteristics of other commitments such as paid work.

7.3.2.1.1 Carescape constraints
Often, the carescapes participants navigate in relation to their illness can constrain their caringscape in providing care for others. As described in Chapter 7.1.2.1, managing CKD can place severe limitations on participants’ potential path areas, especially for those receiving haemodialysis treatment. The carescape of ESKD can conflict with the obvious “dominance of co-presence” required in caregiving relationships (McKie et al., 2002, p. 906), meaning the necessity “to be able to physically interact with the other people involved” (Bowlby, 2012, p. 2111). This is especially true in cases where family members do not live locally. For example, Cathy’s (age 69, pensioner, home dialysis) ESKD carescape prevented her from being able to go to London to visit her daughter who was distraught due to a sudden divorce. The only option for dialysis open to Cathy in London was in the centre of the congested city and too far from where her daughter lived. So, Cathy stayed home and dialysed at the local clinic while her partner travelled to London.

Similarly, the spatio-temporal restrictions of the CKD carescape can impede coordination of family member space-time paths and the co-presence required to maintain some family rituals, such as spending holidays together. For example, Larry’s (age 77, pensioner, clinic dialysis) dialysis prevents him from going to Melbourne for Christmas, meaning that his wife also does not want to go. But, he feels conflicted because he wants his wife to spend Christmas
with her mother as “it might be her last one”. As in Cathy’s case, the problem is not the availability of a dialysis chair in the Melbourne area, per se, but the distance from where they would be staying, and difficulties in transportation to and from dialysis given energy fluctuations after dialysis:

They could have got me one spot, but it was an hour and a half away, and that’s just too far to drive, especially when you’ve had dialysis. It’s alright getting there, but it’s coming back is the problem, because 9 times out of 10, I’m really washed out. [...] It’s no good [my wife] coming with me because she’s nothing to do for five or six hours. [...] So consequently, her mum’s 95 and I’ve said to her, like ‘Stay for Christmas. Have Christmas with your mum,’ but she wants to come home.

For Chen, (age 64, part-time taxi driver, functioning kidney transplant) not being able to visit his family and friends in Burma due to dialysis was a serious concern for his mental health, highlighting the reciprocity and importance of friendship as well as family as sources of care, and the need for “bodily co-presence” and “embodied communication” (Bowlby, 2011p. 612). Chen’s friends and family in Burma went to great lengths to help him get a transplant in order to keep this area of terrain open to him:

I go and see them every year. Every year without fail. And my friends, very good friends since childhood. Classmates. Very, very good friends. And when I’m on dialysis, you can’t go anywhere. Do you understand? I can’t go overseas. [...] And every year I would go to them and be close with them and we have very strong family ties. And they were getting worried that I won’t be able to go out anymore. Like my life would be quite, I mean, uh… they think I’d be in great… in depression or stuff like that. They were very worried for me.

The carescape of ESKD can also place limits on family activities that provide a break from the day-in, day-out repetition of family routines. For example, after James’ transplant had settled and he no longer needed dialysis, he and his wife took advantage of his expanded potential path area to take their two young children on a holiday in Queensland. Prior to that, the spatial limits of family activities precluded these kinds of activities. James explains, “You can’t go to the camping because – you’d like to do it, but we have to think about dad all the time.”

At the time of the interview, Neal (age 73, pensioner, clinic dialysis) had resolved to stop dialysis treatment a few months after the interview on the 100th anniversary of the Battle of Gallipoli. He chose this date to honour his grandfather who was there during World War I. While he was aware that this would certainly result in the deterioration of his body, and ultimately his death, he did not think that the quality of life on dialysis was worth the extended years of life it could give him:

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I’ve spent nearly six and a half thousand hours attached to a machine with needles in my arm, that's enough for any human being.

His plans for the period immediately after stopping dialysis treatment reveal how much the carescape of his illness has restricted his caringscape and his ability to engage with his family around Australia:

So all this [gestures to dialysis clinic], April the 24th, I’m giving up dialysis. April the 25th I hope to be in Melbourne, because that’s where I come from; and I want to do ANZAC day ceremonies down there. And then I want to get as much done as I possibly can while I still can do something. So I’ve got places to go, and people to see. My daughters, I’ve got two daughters in Perth; I’ve got one daughter on King Island, I’ve got one daughter in Melbourne, and I want to see if I can get round and see all of them. [...] And I’ll have my first great-granddaughter born in December this year - they know it’s a she. Lots of little targets here and there.

In short, the service and resource context associated with ESKD greatly shrinks the spatio-temporal extent of participants’ potential caringscapes, making bodily co-presence with loved ones living out of town difficult, and reducing opportunities to share in family rituals and have breaks from family routines. While participants are aware that opportunities exist to dialyse outside of their residential area, the difficult space-time logistics of these dialysis opportunities prevent them from extending into their ideal caringscape and ‘being there’ for and with loved ones outside of their hometown.

7.3.2.1.2 Juggling activities

In addition to shrinking the family caringscape and curtailing out-of-town trips, the complexity of navigating the day-to-day family caringscape is compounded by the many spatio-temporal logistics associated with chronic illness, including attending regular doctor appointments and refilling prescriptions, as well as attending dialysis for those in ESKD. Madeline (age 57, part-time teacher assistant, functioning kidney transplant) has an aging mother in Canberra with declining health. Her mother recently moved into an assisted living home and needs logistical help in getting to and from doctor appointments and managing her finances, as well as social support in the form of regular visits from family members:

[My sister and I] do a lot of the running around, and the... taking her to appointments and all that sort of stuff. [...] Means you have to go visit her twice a week. I haven’t been this week so I’m already feeling guilty, ‘cause I haven’t been. [Breathes in] Um, and, um so it – it impacts on your life, like you’ve got to remember, can you go away? Because there’s somebody here to visit her and all that sort of stuff. Normally, I would actually, on a Wednesday I would go and see mum, but because I needed to go to the chemist I didn’t go see mum, so, um, and then I would have gone on Thursday except we had the book fair [at work] and
then I was tired and I thought, ‘No, I won’t see mum today.’ [...] And because there are – we try and coordinate it so that everyone doesn’t go on the same day.

Madeline describes the effort of trying to coordinate her space-time path with those of her siblings, taking her mother to doctor appointments, managing her mother’s finances, satisfying work demands, and managing her own chronic illness activities, such as going to the chemist and resting when tired. The week of the interview, Madeline was so fatigued by juggling the space-time demands of work and caring for her body that she had to let the visit to her mother fall off her ideal caringscape, making her feeling “guilty”.

Juggling paid work and family within the particularities of James’ (age 66, pensioner, functioning kidney transplant) dialysis carerscape disrupted his family’s routines. During this period, his two children were very young and James was dialysing in the afternoon, finishing at 11 pm. He chose this dialysis schedule so that he could work in the mornings. His household needed both his and his wife’s incomes to keep their house. The consequence was a disruption of family routines three times a week due to his absence: “It was dinner time, bed time, and no family.” James took the bus to the clinic, but he could not take it home as he was too fatigued from dialysis and the buses were too infrequent at that time of night. To complicate things further, his partner could not come pick him up because they did not want her to get their two young children out of bed. So, church friends arranged to take turns picking him up and dropping him off at home. The carerscape and carerscape (Bowlby, 2012) of James’ chronic illness management, including the location and time of his dialysis, the availability of public transport services, and the rhythm of fatigue following dialysis treatment, conflicted with the carerscape of his family, wherein waking young children and taking them out of bed in the middle of the night was unacceptable. These conflicts in negotiating the terrains of chronic illness and raising children required a third party to step in, highlighting the importance of non-familial networks of support in relations of care (Bowlby, 2011).

Another difficulty during this period was trying to facilitate the activities James and his partner thought were “normal” for their children to participate in at that age, often without the help of a second parent to chauffeur children to and from activities. His memories of family life during that period reflect contemporary accounts of family practices in which each member has their own personalised schedule, requiring greater effort on the part of caregivers to coordinate family member space-time paths (Southerton, 2009). For James, the added complexity of the space-time demands of his illness forced his family to further prioritise, sacrifice, and juggle activities:
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[T]his is that period of reality where choices have to be made and our aim to keep our kids having normal activities, Little As, Little Athletics, soccer, cricket, softball, gymnastics. My daughter was selected at a primary school as a child that had a perfect body for Olympic Gymnastics. She came home one day and said, “They want me to go train at the AIS.” Yeah, wow. Right next to the Olympic athletes. And then you can’t say no to that, you know? And so you now have to start adding that juggling in. [...] That meant trying to work out how you’re going to get people there and back and then you start, like with softball and soccer and all those things, you start relying on the people who share that sport with you and calling on them from time to time to pick somebody up, drop somebody off, overnight them. [...] 

So those crunch periods are periods where the kids and [my partner] in particular have to then figure out where are our priorities and how do we juggle this. [...] Other times are in crisis, the blood infections—you just drop everything. And somehow you pick up the pieces.

Samantha (age 43, on sick leave, stage 2) described a period in her life when she experienced the on-set of rheumatoid arthritis, had four children (three school age, one with autism, and one in day care), was single, represented herself in the legal proceedings of her divorce, worked 30 hours per week, and was studying toward a diploma in accounting. In order to combine care for her children with paid work, she worked during school hours and was constrained by after-school pick-up times and locations of three different schools and a day care centre. After-school hours were occupied with children. Studying happened by “cramming at night” after the kids were in bed and on every second weekend when her children were at their father’s house.

Amongst these already difficult space-time logistics, Samantha had monthly appointments with a rheumatologist an hour’s drive from home. Despite an understanding employer, it was more difficult to take time off to see the doctor because she only worked a part-day and had to pick-up her children when school was out. So, the overall impact of her illness carescape on work was larger than for someone working full-time or without children:

I’d be working school hours. You haven’t really got a whole lot of time to be - it’s not like you’re working full time and you can take a morning off and go sort of thing. You’re only working five or six hours a day, people kind of frown on that a little bit more, and I was in court at the same time.

Given this space-time context of Samantha’s everyday life, she had to prioritise some activities over others, and let some activities ‘fall off’ her ideal caringscape. She made strict rules for herself about how much time she spent on domestic chores like cleaning and doing laundry during the week in order to have time to spend ‘quality time’ with her children:

I wasn’t allowed to beat myself up that the washing wasn’t done or the kids had enough uniforms to get through the week. Then Saturday morning I would wash,
and I did that for years and years, pretty much all the time I was single I did that. Because I found otherwise it was this, ‘Oh my god the house isn't clean!’, instead of going, ‘Oh hang on, that kid hasn't had a story today,’ or ‘He hasn't had the chance to tell me about what happened at school.’ You know, all those really important things. Because let's face it, at the end of the day, whether or not the floor’s clean really isn't the end of the world.

Samantha was also “determined to have independent kids” in order to assist her in juggling the shifting logistics of her caringscape, even to the point of teaching them to be able to make their own sandwich by the age of two:

I was determined to have independent kids, and yeah and particularly having [my son] who was autistic it pushed me more and more and more to make them do their own thing. [...] ‘Ben I can't put your top on because your brother’s on the floor and I've got to hold him,’ whatever. [...] It was busy, and if I didn't teach them to do their own stuff, I never would have got anything done. [...] If I was flat out doing something else or somebody had slept in or someone else was sick, someone else could jump in and make sandwiches for them all too.

Overall, Samantha describes the caringscape during this period of her life juggling her children, her own illness, the divorce, work, and study as being in a state of never quite fitting together. When asked to recall an incident in which these different parts of everyday life did not fit together well, she replied:

God every day, every day, it seriously was either - I was late to pick that one - the kids finished school at the same time and they were about five k’s apart. So it was physically impossible for me to pick them both up at the same time, physically impossible. Then of course you only had to have the compounding factor of one took a little bit longer to walk out, or stopped to talk to their friend or whatever, then suddenly all hell's broken loose.

Samantha had to accept that a ‘ball had to drop’ regularly in this juggling act in order to cope with the stress:

I had to just go with the flow [...]. Because it didn’t - it didn’t happen, nothing was that simple and it couldn't be. One person trying to juggle four kids of varying ages and even things like when [my son] was little and we were having him diagnosed. Trying to fit in running him to the doctors around other kids or then later trying to fit in his early intervention. So right from the get go it was busy, it was this ‘Got to be in all these different places’.

Jasmine’s (age 49, full-time administrator, stage 4) current caringscape for her children is shaped not only by her CKD management, but also by the Australian immigration system, the Australia labour market, and the very traditional gender roles upheld in her family. Jasmine’s partner works, but she is compelled to continue working even as her health declines toward ESKD. Continuing to work may strengthen the family’s appeal for Australian permanent
residency which was rejected on the basis of Jasmine’s CKD, and the family needs two incomes in order to afford the expensive school tuition that they pay as non-residents. Even as her health declines, she continues to perform the bulk of the household’s domestic work. Before moving to Australia from South Africa, the family had a live-in domestic worker who did much of the domestic work, including making the kids’ lunches. Now that they are in Australia, they cannot afford a domestic worker, and these activities have all shifted to Jasmine. This she attributes to her husband being “sexist”: “The female does all the work. We learnt a lot when we moved here to Australia.”

In addition to performing domestic chores, Jasmine is the household activity coordinator, making sure the kids have clean uniforms for different sporting activities, dealing with her family members’ last-minute needs, and reminding the kids to do chores. She describes her home life as without “down time”:

Even at night when I’m sitting and watching TV, then I’ll get up and I’ll take the dishes to the sink and I’ll pack some of the… you know? [...] I don’t know if it’s just a mum thing or what, but I just can’t sit. I’ll be watching some TV and then the adverts will come on and then I’ll get up and I’ll ‘Oh where do I have to go? Let me go and… ‘Did you pack your lunch already?’ I’ll ask the kids, ‘Did you pack the dishwasher already?’ and I’ll go and check. Like a typical mum [laughs]. [...] And they say to me “Why don’t you just sit and relax mum?” Or I’ll see the kitchen needs sweeping and I’ll just quickly sweep, or… on a Sunday night they normally do their ironing, like their school clothes and stuff, but maybe [my daughter] would need a shirt… now suddenly she needs this—like [my son] needed a shirt for today for cross-country carnival, so I had to and look for a shirt again, go and help. So it’s those typical mum things. There’s no down-time. It was a shock learning about this kidney condition, but I don’t think that it’s really changed the way we operate; we still operate like we operated in the past.

Jasmine is always trying to anticipate what her family members need, saying that her partner does not do this. I asked Jasmine how she thinks the family life will be in the likely event that she has to start dialysis:

I don’t know. I don’t know, because my family depends on me a lot, so I don’t know how they’re really going to cope. [...] At this point in time it hasn’t affected the way we operate yet. There are some days; like I say, there are some days that I do feel a bit more tired than usual, but then I just go and lie down and say to the kids “look, I’m not feeling well, I’m just going to go and take half an hour nap or a 15 minute nap” and they leave me, they leave me to go and take a nap.

Jasmine tries to make her CKD management activities, such as attending doctor appointments, as invisible as possible to her loved ones by ‘hiding’ them in her caringcape within working hours so that it doesn’t impact them. She says, “It is important that we still continue as normal.” As discussed by Charmaz (1997), Jasmine is an example of a caregiver
who has become seriously ill but is not shifting (or being allowed to shift) out of the caregiving role and into the patient role. Therefore, she tries to “continue as normal,” accommodating all of the activities of caring for her body, caring for her family members, and participating in paid work within the same caringscape.

Martin (age 43, unemployed, clinic dialysis) has also made shielding his family from his illness a priority in his caringscape, although this is constrained by his illness carescape. Martin has a partner and two children, ages six and seven. Starting clinic dialysis meant re-allocating at least 18 hours per week to driving to the clinic and dialysing. Martin lives outside a rural town, and the nearest dialysis clinic is small. The only scheduling options offered are in choosing days of the week, with all sessions given in the morning. Martin chose to dialyse on weekdays in order to be able to attend his kids’ weekend activities and spend time with his family. However, this dialysis schedule contributed to his inability to continue working, a major activity ‘fall off’ that meant reliance on his wife’s income as a teacher. He describes money as “very tight”.

I went Monday, Wednesday, Friday so I could have the weekends off. Kids’ ball, everything like that. So I chose family over – but, we’re doing all right.

Weekday morning dialysis sessions prevented Martin from continuing in his usual role in the morning family routines. To help compensate for this, Martin gets up earlier than everyone else so that he can get the fire going in the stove, pack the kids’ lunches, feed the dog, wake the kids, dress them, feed them, and then wake his wife shortly before he leaves at 7:15 for the dialysis clinic in town. She then finishes getting the kids ready for school, takes them to the bus stop, and goes to work. Martin also picks up the kids after school, a couple hours after he finishes dialysis and makes them dinner. He describes himself as “the stay at home mum,” now that he is not working; doing laundry, dish washing, ironing, and some cleaning. In describing himself in this way he reveals the traditional gender roles he associates with these activities.

Despite his efforts to take on more domestic activities, his partner has had to accept that he cannot do all the needed activities at home. For example, he can no longer do extensive physical work on the property. And, he used to also help the kids with their homework after school, but finds that he cannot concentrate well enough to continue. Here, we find that logistics alone do not shape the caringscape, but also the capacities and states of the chronically ill body.

In short, participants described the logistical challenges of the caringscape as person with chronic illness, with the necessity to juggle chronic illness management alongside caregiving activities for loved ones and paid work within the particular service and resource
context of each individual. Prioritising and sacrificing activities is often necessary, and chronic illness management increases the complexity of the juggling act participants perform as caregivers in everyday life. Due to this complexity, the force of habit (Ravaissón, 2008) takes hold less readily, and more conscious effort is required to navigate the caringscape terrain each day. I turn now to the influence of embodied experiences of space-time associated with chronic illness in participants’ caringscapes.

7.3.2.2 Embodied space-times and rhythm
The ability to be present and engaged in providing care for others is influenced, not only by logistics, but also by the embodied space-times associated with chronic illness, such as rhythms of energy, pain, wellness, and need for rest, unpredictable ‘failures’ of the body (e.g., acute illness or symptoms; death), and the ways in which spaces of ‘quality time’ can be altered by illness.

7.3.2.2.1 The unpredictable body
The extent of the caringscape is not only limited by the space-time demands of chronic illness activities, but also by anticipation of possible ‘failures’ of the ill body. For example, for years, Madeline limited her potential path area in order to reduce risks to her health. This was in response to the “other oriented” nature of being a caregiver (Davies, 2001, p. 139) converging with the unpredictability and fragility of her chronically ill body. Because she knows that her kidney transplant could go at any time, Madeline did not go overseas until her daughter became an adult because of the health risks involved resulting, perhaps in her kidney transplant failing, or even in her death. In Madeline’s mind, it was better to restrict her own potential path area in order to reduce the risk of not being able to be there for her daughter:

Madeline: Well, because you don’t know when you get a kidney, you don’t know how long it’s gonna last. Or whether it’s gonna reject. [...] To me every year was... another year that you weren’t gonna – you might not make it. [...] I don’t really plan. I – like going overseas, that was a big thing. ‘Cause I would never have done that before [starts to cry]. [...] But [my daughter] is grown up now, so...

Julia: How does that change things?

Madeline: Well, [crying] she’s married now, so, she’s got her own life as well. So I – I can feel that I can do those things.

The unexpected ‘failures’ of the body in the caringscape can result in situations where participants feel like they are, or are at risk of, ‘letting down’ loved ones. In the most extreme sense of their body ‘failing’ them, participants talked about the possibility of their own death and the way this would prevent them from being there for their loved ones in the most
fundamental sense. This kind of uncertainty about participants’ bodies also of course impacts on their partners. James (age 66, pensioner, functioning kidney transplant) describes the period when he was on dialysis as a “trauma” for his partner, as she was faced with losing the house, the possibility of his own death or serious disability, having two young children, maintaining paid work, and providing care for him. In the everyday, James felt that his body’s energy ‘failures’ “separated out” his children from their peers in group family activities. His description of one such failure on a church community hike paints this picture:

It was easy going down the stairs and then we had [my partner] and I and our two kids. And as we started walking along it became obvious to me that I didn’t have enough haemoglobin to really do this and I started falling further and further behind. And of course the day is starting to draw to a close and we still have this hill to climb. And so one of the people there is a fitness fanatic because of a health problem he had, he just picked one of them up, put them on his shoulders and he ran off literally up the hill. And a while later he came back down and grabbed the other one and ran off and up the hill. And so [my partner] stayed with me and one of our other friends and we just slowly made it up the hill. And so at that point you’re now starting to separate the kids out as ‘Oh, you’re the one that’s got... Or we can’t do those things that everybody else does’.

The inability to predict when and where disabling symptoms may suddenly arise introduces heightened levels of unpredictability into the caringscape. In these cases, participants often restricted their activity participation and potential path area in order to reduce the likelihood of symptoms arising. Samantha (age 43, on sick leave, stage 2), for example, has a heart condition that prevents her from doing any activities that may produce too much adrenaline. This precludes her from joining her kids on roller coasters or other activities of that kind. James provided a more extreme example, this time from his wife who has also had serious chronic health problems that James described as “the weird screaming type problems.” She had a condition called trigeminal neuralgia while the children were still young. The condition involves the nerves in the face. James explains, “A breath of air that you can only feel on your fingertips is enough to set it off and setting it off is the equivalent of putting a high heat iron to your face.” The family was apprehensive moving around outside of the house or the car, and they tried to anticipate any stimuli in the environment that could set it off, an instance of which he described as encountering her “huddled there holding her face, screaming”:

We used to walk with [my wife] with my hat on her face like that [demonstrates covering side of his face]. Everywhere we went. When she wasn’t in the car that’s how we did it. [...] We had one of the kids go in before us so that whenever we - when you go through the doors of any mall you get a rush of air, okay. You go around a corner you have to know whether you’re going to walk into wind.
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After James’ wife’s trigeminal neuralgia was treated with an operation, the family went on a drive in the countryside. They were worried about whether or not the condition was really resolved, and apprehensive about exposing her to potential stimuli in the environment. However, it was resolved, and this allowed them to “resume life as something of a normal family”:

So we all got in the car and off we went because it was cherry season [...]. And besides, we haven’t been out as a family and doing anything that we like to do. And the kids were still reasonably young. And so off we went. And it’s magnificent countryside up that way. Anyway, we got there and then the question is: Do we need the hat? Oh, well you can imagine we were walking around on very troubled feet wondering whether we’re going to kick the minefield, or kick a mine and have it go off on us and then just turn around and go back. [...] And so we got out of the car and we started proceeding down the main street, and there was a cross breeze and I thought, ‘Oh, I don’t know about this... it’s supposed to be fixed.’ Anyway, it was fixed. And so we were able to enjoy our visit to Young and it’s been a very nice spot for us since. But it was that time as a family we could share in the joy that we were past a health issue and we could resume life as something of a normal family and enjoy going out and visiting some place strange and treating the kids and what have you.

In short, the potential for the body to unexpectedly ‘fail’ participants as they navigate the caringscape is a source of anxiety. Strategies participants use to anticipate and mitigate the impact of unpredictable symptoms include reducing participation in certain activities and restricting their own potential path area. This in turn, however, changes the kinds of things families can do together, from the everyday trip to the mall to enjoying a trip abroad.

7.3.2.2 Caregiving arrhythmias

Another experience of embodied space-time that shapes participants’ caringscapes is derived from the rhythms of change in the body’s energy and symptoms, and the need for periodic rest. These fluctuations of the body can sometimes create arrhythmias with the needs of others, making navigation of the caringscape more difficult. One participant, Jasmine, (age 49, full-time administrator, stage 4) offered a temporal metaphor for the constant availability demanded by caregiving when she referred to her daughter as her “alarm clock” that pulls her into the space-times of the needs of her family. Samantha (age 43, sick leave, stage 2) described the incompatibility between the incessant nature of caregiving space-times and the unreliable abilities of the chronically ill body:

It is literally like trying to mix water and oil, literally the two will just constantly pull apart. [...] I think the fact that kids are so busy constantly and for me chronic illness has always meant really severe fatigue.
When arrhythmias between fluctuations in the body and caregiving demands arise, participants described ‘pushing through’ or ignoring corporeal rhythms in order to meet caregiving demands. When this is not possible, activities must drop off the caringscape in order to accommodate rhythms of fatigue and pain. For example, Madeline (age 57, part-time teacher assistant, functioning kidney transplant) described regularly denying the reality of her corporeal rhythms in order to meet the constant need to be available to her daughter when she was an infant. Like many participants, Madeline felt ‘flat’ and had low blood pressure after getting off of dialysis. She was advised by the dialysis staff not to drive home until her body had recovered to a certain extent. But, because her husband had to work, she had to pick up her daughter at child care after dialysis at a certain time. So, she pushed through the post-dialysis fatigue and low blood pressure and drove home anyway:

Even when [my daughter] was young, my blood pressure sometimes when I got off the machine would be 60/40. And the guy who was in charge would say, ‘You can’t go home with that.’ And I said, ‘Ya, I am. I have to pick up [my daughter].’ And he said, ‘You can’t,’ I said, ‘Look, I’ll be fine. I’m going to get in the car. I’m going to pick up [my daughter], I’m gonna put her in the car, I’m gonna drive home and I’ll be at home and I’ll lie on the lounge.’ And that’s what I used to do.

When Samantha’s children were young she experienced rheumatoid arthritis symptoms that were especially painful in the evenings after she had worked. This episodic rhythm of pain peaked in the evenings at the time when the children were all there and needing her attention and assistance. Samantha described getting through these periods of pain by literally crawling:

I used to get it really badly in my feet, so I’d come in from the dairy at night and I’d run around and I’d get dinner ready. Then I’d sit and I’d eat tea and literally I could not stand up, literally from the chair I would have to crawl across the floor because I could not put any weight on my feet at all. So yeah I would just crawl around and I’d go and chuck the kids in the bath and put them to bed, yeah.

Additionally, Samantha regularly abused Prednisone (oral steroids) when her children were young in order to have energy and to reduce her arthritis pain in order to be able to juggle all the aspects of her life as described above. She remembered a doctor “yelling” at her not to take so much Prednisone. Her response was: “You tell me how to get through the day!” Similarly, Wanda (age 58, small business owner, stage 3) ignored the onset of ESKD while her father was in a health crisis. It took until she “nearly collapsed” to go to the doctor and discover she had 17% function left in her kidneys.

Other times, participants are not able to push through rhythms of fatigue and symptoms and must sacrifice some activities from their ideal caringscape. Martin’s (age 43, unemployed, clinic dialysis) energy rhythms associated with dialysis along with paid employment prevented
him from sufficiently performing domestic and caregiving activities. Quitting his job allowed him to be more active on non-dialysis days and participate more in the household:

Martin: Like doing – making beds, doing the household chores on those Tuesdays and Thursdays I was just so tired from the, um... [gestures to dialysis machine]. [...] So it was like a Yo-Yo. It’s up and down. Up and down, up and down [makes motion with hand]. Rather than being like this [makes even motion with hand].

Julia: You mean being kind of sustainable and even?

Martin: Ya. Ya, plateauing at a set level where you can... still function and do what you got to do... help around the house, pick up kids and do all this and that.

While sacrificing paid work is an extreme case of activity fall-off due to corporeal rhythms, more commonly, participants described sacrificing activities such as playing actively with or being attentive to children, or skipping a visit to an ageing parent. Or, in the case of one of Samantha’s sample days, it meant stripping down her caringscape to only the activities pertaining to meeting the needs of others because her energy level was so low. On her sample days she was taking care of a friend’s six-year-old child:

I literally got up, got [my friend’s son] ready for school and took him and come back and went back to bed. Got up to feed [my partner] lunch and then went back to bed, and got up to go and get [my friend’s son] from school and survived until he went to bed at quarter past seven and then I pretty much went back to bed.

When everyday caregiving activities fall off the caringscape this can cause considerable emotional distress for participants. For example, Madeline desires to fulfil the intergenerational relationship of care (Bowlby, 2012) she has with her mother who raised her and then helped care for Madeline’s child. She also experiences the difficulties of finding pause that are inherent to the space-times of care (Davies, 2001). However, periodically, her body demands that she stop and take a break, and when she has to stop, she feels intense guilt and sadness:

Sometimes with mum I have to... step back and say, ‘I can’t deal with that.’ And I have to think of myself. [...] I try not to do that... [begins crying] because she was there for me, but sometimes I feel I just can’t cope with all of it so... and, then I feel selfish. So, but sometimes I say to [my partner], ‘No, I can’t do it today,’ so... [continues crying].

Madeline described a cycle of exhaustion that peaks every year around October when she feels she can no longer cope with taking care of her ageing mother, taking care of her own health, and working part-time.

Sometimes, um, when it gets too much in a year... about October, it usually is [...] I’ve had to actually go away. And have time to myself. [...] Now I know the signs
when I’m getting really tired and I get all tensed up and stuff. And I know I’m getting to the point where I’m so tired I need to just stop. So, it didn’t happen last year ‘cause we went away. So that was fine. But, um, about October I always think to myself, ‘I should take a week off now.’

When this cycle of exhaustion peaks around October, Madeline has learned she has to take a break from caring for her mother. Similarly, Samantha says, “Now I’ve learnt that if I keep pushing it just gets worse.” The last time this happened, Madeline went to stay with her cousin in Sydney so that she could “just do nothing”.

Martin (age 43, unemployed, clinic dialysis) and Jasmine (age 49, full-time administrator, stage 4) described feeling the need to carve out regular moments of respite in the everyday, in between caregiving and family, managing illness, and other activities such as paid work. For Martin, these regular moments of respite come after he finishes dialysis and waits for his children’s school to let out a couple of hours later so he can pick them up and take them home. During this time he sits in a local café, eats his lunch and reads the newspaper or does Sudoku: “Ya, ‘cause I get off [dialysis] and I’m famished. [...] You’re just too... recuperate, and have a feed and as soon as you pick the kids up again it’s just full on after that.” For Jasmine, these moments of respite are built into her daily schedule in the form of her solo bus ride to and from work. Her partner does not understand why she prefers to take the bus when he can drive her to work. But this half hour bus rides provides her with a rare opportunity for rest; in contrast with the work or home environments, which require her constant attention:

Jasmine: That’s why I like going on the bus, because I get on the bus and I take out my book, and I sit and read, and I just relax. [...] It’s so relaxing. It is so relaxing. When I have to take the car to come to work I actually get irritated because I know I’m not going to be able to read, because that’s the only time I read, is on the bus.

Julia: Why is that?

Jasmine: Because I don’t get time at home to read. There’s always something to do or there’s the TV to distract, so I can’t read and watch TV at the same time, so the bus is like... I’m just cut off from the rest of the world and I’m just sitting there, and it’s just half an hour of ‘me time’ [laughs]. So for me that’s been... it’s really just been a wonderful thing.

The bus ride suspends Jasmine in a time and space when she cannot engage in caregiving or paid work activities. It provides an opportunity within her caringscape for immersion in “appropriated time” (Lefebvre, 2004, p. 76) and the enjoyment of experiencing “flow” (Csikszentmihalyi, 2000, p. 381) while reading her book. This is particularly valuable considering her difficulty in finding rest even when she takes a rare day off from paid work on particularly bad illness days. On one of her sample days, she stayed home from work because
she felt especially unwell. Even so, her ‘day of rest’ ended around 2pm when she started doing caregiving activities. She walked to the store, bought groceries, talked to her daughter about her day when she got home from school, prepared a full dinner, picked her son up from school and went to the chemist: “So we had dinner and they were all impressed because mum was home, so mum made chicken and rice and vegetables and... yeah.”

In short, participants described an incompatibility between the unceasing availability and orientation to the space-times of others inherent to caregiving, and the fluctuating rhythms of the chronically ill body and periodic need for moments of pause and rest. This incompatibility creates difficulties in navigating the caringscape. When confronted with arrhythmias between care and the chronically ill body, participants ‘pushed through’ the rhythms of their body, and/or prioritised and sacrificed activities within their caringscape. Finding moments of pause for rest is challenging. However, some participants build regular moments of respite into their caringscape.

7.3.2.2.3  Altered spaces of ‘quality time’

A final observation on the intersection of the space-times of caregiving and chronic illness in participants’ lives is the ways in which chronic illness can alter the qualities of spaces where ‘quality time’ with loved ones takes place. Participants expressed a desire to provide safe, happy spaces for their loved ones within the caringscape terrain (McKie et al., 2002). Chronic illness can alter these spaces, and this was especially relevant with regards to medical equipment introduced into the home or participants’ bodies.

For example, Madeline (age 57, part-time teacher assistant, functioning kidney transplant) had access, several decades ago, to a portable dialysis machine that was eventually discontinued by her health care providers. It provided her with an expanded potential path area to take holidays with her family, and spend more time with the family instead of going to a clinic. She dialysed in the dining room because it had a vinyl floor while her partner and daughter watched television in the adjacent living room that had carpet: “I could still watch telly from there and be part of the family going on.” While the machine facilitated the coordination of the space-time paths of family members in order to share ‘quality time’, its presence in the house exposed her daughter to the sometimes confronting clinical side of managing her illness. Madeline recounts an incident when she was dialysing at home and her family left to run an errand. Upon their return they were confronted with a frightening sight:

I wanted some ice. So I got up out of the chair with my things in my arm and I walked around the chair and thought, ‘Now if I just reach round I can open the fridge and get some ice out of the fridge, right? So I did that. But I fell faint. And,
um, started to fall and the things came out of my arm and when they came back there was blood everywhere. So, that really frightened her actually.

Later, after the machine was discontinued, Madeline’s doctor encouraged her to do nocturnal haemodialysis at home, thinking it would be a better option for someone with a young child. Madeline, however, thought that doing the treatment regularly at home and having the large machine in the house would be too disruptive for her family. Instead, she opted for putting her child in child care while she went to a dialysis clinic during the day, even though it was very expensive:

I said, ‘Look, I’ve got a young baby.’ I said, ‘I’ve got a new marriage,’ I said, ‘I don’t need a machine at home.’ […] I think that would put more stress on your family, you know? […] It’s a matter of getting it organised, being sterile, having a room of its own, having plumbing… […] Um, And it – it you know, it means you’ve got to be home three nights a week. If the baby wakes up it’ll be up to [my partner] to do it all. And all that. So, and surely it’s better for [my partner] to go off to work, [my daughter] to go to a centre, and for me to go do dialysis in the day where it doesn’t interfere with our home life.

Similarly, Martin (age 43, unemployed, clinic dialysis) decided not to dialyse at home although it would allow him more flexibility in when to dialyse and eliminate the half-hour commute to the clinic. Instead, he protects the quality of the home space in his caringscape terrain in order to help compensate for his inability to do as much with his kids as he would like to do:

They got to face it too and they got to look at it and... you know, my kids are 6 and 7. I don’t know if it’s – I don’t do enough with them as it is ‘cause I just don’t have the energy sometimes. […] ‘Come and kick the ball. Come and... Come on dad! Let’s jump on the bikes and go.’

James (age 66, pensioner, functioning kidney transplant) also expressed anxiety about the way that his illness altered the spaces of his children’s childhoods. He describes them visiting him in places of “various forms of distress and anguish” like the hospital, where he might be “stretched out with a vascular catheter in the chest.”

In short, medical equipment and practices of treatment can alter places where ‘quality time’ with family takes place, discouraging the kind of ‘normal’ childhood and family experience participants wish for their family members. Sometimes, choosing a treatment option that is more difficult to negotiate within the caringscape in logistical terms is a more desirable option when it protects the spaces of quality time with loved ones.

In summary, dominant approaches to understanding experiences of providing care for others as a person with a chronic illness have focused on the experience of conflict between the socially constructed roles of ‘parent’ and ‘patient’. A more nuanced understanding of how
role conflicts can arise emerges when individuals’ everyday experiences are understood as motivated by two ideal sets of caringscapes; that of caring for others and that of taking care of one’s own chronically ill body. While motivated by these ideals, participants’ actual caringscapes are shaped by logistical conflicts and embodied space-times. Logistical conflicts in participants’ caringscapes arise from: 1) restrictions placed on participants’ potential path areas by the illness carescape, which makes bodily co-presence with loved ones living out of town difficult, and reduces opportunities to share in family rituals and have breaks from family routines; and 2) the necessity to juggle activities of caregiving and chronic illness management that compete for space-time resources, often resulting in some activities being prioritised over others, and some being sacrificed. The embodied space-times that complicate participants’ caringscapes are derived from: 1) the unpredictability of the body in when and where it might ‘fail’ participants as they navigate the caringscape; 2) fluctuations in the energy levels and symptoms of the body that often conflict with the constant need for availability in caregiving relationships; and 3) the ways in which the qualities of spaces of ‘quality time’ with loved ones can be altered by illness.

7.4 Leisure, recreation, and tourism

“You have to claw something back for yourself.” -Bill

7.4.1 Dominant approaches revisited

As discussed in Chapter 3.2.4, the pursuit of leisure, recreation, and tourism for people with chronic illness has received very little attention in the literature despite the importance of these kinds of activities for quality of life, as well as short and long-term health (Katz, 2004; Katz et al., 2009). Most research on the impact of chronic illness on everyday activities has focused on the individual’s ability to perform obligatory activities (e.g., hygiene, sleep) and, to a lesser extent, committed activities (e.g., paid work, child care) at the expense of ‘discretionary’ leisure activities such as socializing, hobbies, public service, tourism and participating in clubs or religious organisations (Katz, 2004, p. 44). Reduced participation in leisure activities has been attributed to such factors as the individual needing to reconsider how to spend limited energy (Lyons, Lambert, Balan, Hegel, & Bartels, 2013), having less available time due to illness management activities (Katz, 2004), pain (Ahlstrand, Björk, Thyberg, & Falkmer, 2015), and decreased muscle strength (Marko, 2012).

7.4.2 Findings from a space-time analysis

When participants discussed the subject of finding enjoyment in life, there was often a tension expressed between living life in a way that feels meaningful and enjoyable, on the one hand,
and, on the other, restraining oneself, spending time, and limiting mobility in managing chronic illness. There is risk in this balancing act, which participants recognise. 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 very rare night out after dialysis with friends to loud bars and clubs. When he got home late that night he had 45 missed calls on his phone from the hospital, missing the transplant opportunity, which was devastating for him. While he could have chosen to sit by his phone waiting for a possible kidney 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 not to feel that illness is 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 one small beer 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.” 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, but he felt that 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 more serious leisure pursuits (Stebbins, 2001) in enjoying life and not feeling that they are ruled by illness. Sandi (age 30, part-time administrative assistant, functioning kidney transplant) talked about how important developing writing as a hobby has been for her 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. I found writing to help me out with everything back then. Distract yourself, pick up hobbies and do it.
In the sections below, I argue that we can use a spatio-temporal approach to better understand the tension participants express between enjoying life and managing illness, and why leisure activities are so often scaled back or discontinued after the onset of chronic illness. First, I explore how the logistical conflicts between chronic illness and leisure shape the leisure-scapes (Van der Poel, 1997) open to participants to enjoy. Then, I examine ways in which the embodied space-times of chronic illness inform the kinds of encounter participants have through leisure practices (Crouch, 2000).

7.4.2.1 Space-time resource conflicts

Financial resources and normative regulation have been shown to inform the “freedoms people are entitled to” in their leisure-scape (Van der Poel, 1997, pp., p. 171). Participants’ accounts demonstrate that a person’s health can be another force that shapes the terrain of leisure and what can be enjoyed there. The most obvious example of this is how the spatio-temporal characteristics of chronic illness management shrink the potential path area available for travel. The constraints of dialysis in this regard are known (e.g., Polaschek, 2003), and, earlier in this chapter, I described the logistical difficulties participants on dialysis face when needing to travel for work (Chapter 7.2.2.1) or wanting to spend time with family (Chapter 7.3.2.1). These space-time constraints also impact on participants’ desire to reward themselves with touristic travel after a lifetime of working, or to travel in order to feel that they have lived a full life (see also Ettema & Schwanen, 2012). For example, Cathy (age 69, pensioner, home dialysis) described the disappointment after her kidneys failed:

We worked hard all our lives and saved and what have you and we were going to go visiting friends in America and all this. Well, that came to an absolute stop.

Bill (age 40, full-time public servant, clinic dialysis) says that the only reason he ever wanted a kidney transplant, and would be willing to go through another transplant now that the previous one has failed, is to have the ability to travel. His previous transplant operation was so traumatic that he has considered living the rest of his life on dialysis. Yet, the appeal of travel is stronger:

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.

To borrow the language of Bowlby (2012), participants described contending with space-time constraints on travel derived from variations between different countries’ carescapes in terms of the availability, affordability and quality of health services. For example, on one of his sample days, Gio (age 66, pensioner, clinic dialysis) went to the Swiss Embassy not only
because of an event there, but also because he wanted to know if he can receive free dialysis in Switzerland as a Swiss national, given that the Australian health system would not pay for dialysis abroad. And, when James (age 66, pensioner, functioning kidney transplant) received word from his doctor that he would need dialysis within six months, he promised his wife that they would go to Venice before he had to start treatment. During his following appointment, his specialist told him that his window of good health for travel was closing more rapidly than expected, and advised him on a contingency plan should he take the trip:

[The doctor said], ‘You know that six months, I think it’s going to be closer to six weeks and you have to decide whether you’re going to go.’ And he said, ‘The only thing I can offer you if you do go is this advice: If you get in trouble run to either Italy or England because Australia has healthcare agreements with those two countries.’

James and his partner took the trip, but as his haemoglobin levels dropped, they had to modify their itinerary. They took bus tours, boat trips, and James sat while his partner walked in museums. Upon return to Australia, James immediately started dialysis.

Bernard (age 40, full-time public servant, clinic dialysis) has family in the Philippines he would like to see more often. However, dialysis produces many considerations for this kind of trip. He pays for dialysis out-of-pocket when travelling abroad, and different countries have different rates: “Forget about going to the United States ‘cause it’s too expensive [laughs].” The Philippines is more affordable, but Bernard had to learn how to navigate the particular carescape of the Phillippines in order to feel confident about the quality and availability of medical care if something should go wrong while dialysing:

I was able to find a hospital that's certified. I mean they have - it costs more, but they also have clinics like [my dialysis clinic]. They have clinics like that in the Philippines all over the place. It's – it's cheaper, but you don't have the back up of if something goes wrong you have the hospital right there. So I prefer to just stay at the hospital then... um... but that was out of my pocket.

Other participants expressed anxiety about the unpredictability of when and where their body might fail while traveling and require medical attention. For example, Lynn (age 71, pensioner, stage 4) and her partner would like to travel abroad but she cannot get traveller’s insurance due to her pacemaker. Without traveller’s insurance, Lynn and her partner face the financial risk of a lost plane ticket in the event of her becoming too ill to travel right before the trip, and/or having to pay for health care in another country. Due to this risk, they do not travel overseas.
Logistical space-time conflicts between chronic illness management and leisure activities can also arise locally. For example, Cathy (age 69, pensioner, home dialysis) had to give up many of her roles in community organisations after the on-set of ESKD:

Well, to start with if you belong to organisations, which I belonged to quite a few, um, you can’t continue it if it interferes. If you've got to be at the hospital at a certain time to do dialysis that’s it! You've got to do it. And that's your life. [...] So all of those - you know, I had activities, [my partner] had activities and all of a sudden, you know you've got to be thinking all the time and we keep a diary there so that we, you know, because you've got to attend all those [medical] things.

Like the other participants, Cathy (age 69, pensioner, home dialysis) expressed the need to feel like she has some control over her own challenges given that so many are imposed on her externally by illness and its management. One way to exert control is to take on a new leisure activity:

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. Taking on a new leisure activity can be challenging within the space-time constraints of managing and living with chronic illness. While the exams to become a judge were a worry for Cathy, the space-time logistics of juggling dialysis with regional travel to different judging events was even more of a potential barrier:

[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 by assigning her to those within an hour of her home. Still, Cathy is less active in the organisation than she would like to be, and cannot stay for the social gathering after meetings because she has to get home to start dialysis in the evening.

For participants who are working and have heavy space-time demands from chronic illness, leisure activities are further constrained; mostly to weekends. 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 after work. One night a week he might go for a drink with work friends but that is
“hardly ever.” “So it’s usually just being at home,” he says. Weekends are the only times he can do activities not related to managing his health or working, such as visiting with family or going fishing.

Illness management activities can also complicate the synchronisation of space-time paths needed in order to participate in group leisure activities. Joan (age 85, pensioner, stage 4) is so fed up with missing an annual reunion of friends in Sydney because of doctor appointments that she has decided to simply skip the doctor appointment if they cannot reschedule her, even if it is a risk to her health. In running this risk, she is engaging 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. And [my doctor] said, ‘No we can't change it, you won't get in till January.’ 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 that I will highlight is not the difficulty of accessing spaces and times of leisure activities due to being ‘pulled away’, but rather due to the necessity to avoid certain kinds of places. For example, as noted in Chapter 7.1.2.1.3, James (age 66, pensioner, functioning kidney transplant) has to avoid exposure to the sun due to his greatly heightened risk for skin cancers after years of taking kidney transplant supporting drugs. This greatly restricts outdoor activities like watching a sports game, walking, or cycling to shaded areas and evening hours:

I went to the Prime Minister’s 11 cricket match, because my best friend is on the board of ACT Cricket, and I was sitting at the same row that the Prime Minister does only the bay over and within a half an hour I was burnt. [...] If I go into a sporting fixture like the baseball for example, I’ll go to the evening match that starts at 6:00 and I’ll sit in the heavily shaded areas. But it’s a bit of a pain.

In short, the spatio-temporal characteristics of chronic illness shape the leisure-scapes open to participants. The space-time constraints of the chronic illness carescapes that participants navigate restrict their potential path areas, curtailing their ability to enjoy touristic trips and participate in organisations. Illness management logistics also make the synchronisation of the space-time paths of people more complex, making participation in group leisure activities more difficult. Finally, the need to restrict one’s potential path area in order to avoid certain kinds of places at certain times in order to protect the body can curtail participation in some leisure activities.
7.4.2.2 Embodied space-times and rhythm

‘Doing’ leisure cannot simply be understood in terms of how people spend segments of time at particular places. While in the previous section I focused on logistical access as key to opening up a person’s leisure-scape, the “sensuousness of practice” (Crouch, 2000, p. 68) fundamental to enjoying oneself through leisure amust 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 in their lives due to physical impairment. This loss was especially keenly felt when it was a serious leisure activity (Stebbins, 2001) involving a skill that the participant had been developing over some years. Brian (age 38, sporadically employed, failing kidney transplant) described his love for outdoor adventure sports, a pleasure that will be more difficult to access as his transplant is failing. He directly connects what he learns from engaging with the world in this embodied and often risky way to his adaptation to living with 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].

As Crouch argues, Brian’s experiences with rock climbing can be understood as encounters with the world through leisure: “Leisure/tourism become ways of making knowledge: the individual comes to know about the world in new, more complex ways,” (Crouch, 2000, p. 65, italics are Crouch’s). For Brian, this knowledge is about his capacities in relation to his world with chronic illness, and the scary possible events that may unfold as his transplant fails. This “knowledge making” is less a cerebral knowledge of facts about the world, or even an embodied knowledge and associated memories 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 his environment (Ravaisson, 2008).

Why would someone facing so many challenges and risks to their health constantly pursue the incorporation of “the knife-edge of fear” (Sharpe, 2013, p. 170) into his hobbies?
One explanation is that Brian becomes more practised in handling fear and uncertainty through increasingly challenging leisure activities via the anaesthetising effects of habit. In other words, “as habit evolves, our perception of both internal and external stimuli decreases,” (Sharpe, 2013, p. 170) and Brian’s experience of feeling fear becomes less and less remarkable to him, helping him to adapt to the shifting terrain of chronic illness and, perhaps, having 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.

The pleasure and ‘aliveness’ experienced by engaging in leisure activities also provides an alternative experience of one’s own body that contrasts the ‘problem body’ defined by illness. One of Neal’s (age 73, pensioner, clinic dialysis) lasting loves in life has been riding motorcycles; ever since he was a teenager. He lit up during the interview in the dialysis clinic describing riding his motorcycle down a windy 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, p. 68). It is a time of flow (Csikszentmihalyi, 2000) in which Neal is deeply engrossed in what he is doing:

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 weathers 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; it is also the experience of relating with his body in negotiating “the border between ease and resistance, the former being experienced as the pleasure of the graceful, mastered movement and the latter being felt as the body senses itself in effort,” (Sharpe, 2013, p. 171). Serious leisure practices, like Neil’s motorcycle riding, are clearly situated within the body-brain-environment circuits of habit (Bissell, 2013). We can better understand the loss or
diminishment of serious leisure activities due to physical impairments of chronic illness as disruptions to the body-brain-environment circuit within which skilful performance can arise.

Earlier in this chapter (Chapter 7.1.2.2), I described how rhythms in participants’ everyday contexts can encourage or discourage skilful performance of illness management activities by interfering with the repetition of these activities in everyday life. Rhythms “folded in and through a permeable body” (Edensor, 2010b, p. 4) also play a role in participants’ abilities to sustain serious leisure in their lives. The transformation of rhythms of the body, as in the unpredictable and fluctuating rhythms of energy many participants attribute to dialysis treatment, can rupture the body-brain-environment circuit of habit 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 his dialysis treatment:

The problem is that I have waves of tiredness [...]. I don’t go to sleep, I just feel weary, and I’m very limited in the distance I can ride. In a car, you get tired, you pull over, you recline the seat and just have a quick snooze. You can’t do that on a motorbike.

The introduction of this new rhythm into the body-brain-environment circuit 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 points out, the motorcycle does not afford him with a way to easily accommodate this new rhythm into his practise. And, as a result, he rides much less frequently and for shorter distances, which provides him with fewer opportunities to experience the pleasures of flow (Csikszentmihalyi, 2000) and immersion in appropriated time (Lefebvre, 2004).

Maintaining serious leisure activities in everyday life with chronic illness, therefore, can require individuals to adapt to transformations in the “entangling of rhythms that circulate in and outside the body” (Edensor, 2010b, p. 5). Deny (age 72, pensioner, stage 4) has adapted by developing new bodily knowledge and sources of pleasure within a body-brain-environment circuit dramatically shifted by the impacts of his illnesses on his body. In addition to CKD, cardiovascular disease, and near blindness, Deny also has chronic obstructive pulmonary disease (COPD). COPD limits the airflow into Deny’s lungs, meaning that, with each inhalation of air, his body absorbs far less oxygen than would a healthy individual. Deny’s body’s rhythm of oxygen absorption is greatly mismatched with what is demanded by a normal walking gate, meaning he is limited to walking very short distances. Neither he nor his partner is able to 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 through technology and acquiring this new proficiency is a source of pleasure and pride. Deny and his partner took an adult computer course together several years ago. As his vision and mobility has declined, his son has installed a magnifying program for him on his computer that helps him see screen content. It is an important window of engagement with the world for him now; to read news, visit different 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.

To conclude, the space-time logistics of chronic illness management and symptoms shape participants’ leisure-scapes in specific ways. The need to access health services restricts participants’ potential path areas for touristic travel and volunteer commitments, and makes the synchronisation of space-time paths for group leisure more complex. Sometimes, the necessity to avoid certain places at certain times in order to protect the body can also present logistical challenges to leisure activities. Within a leisure-scape already shaped by these logistical factors, the embodied space-times of chronic illness can also change how individuals engage with leisure activities. In particular, skilful leisure activities can provide the pleasure of mastery, awareness, skill, and confidence that supports these participants in dealing with the uncertainties of life with chronic illness. However, as the space-times of the body shift with chronic illness, displacing previously stable corporeal rhythms with unpredictable and/or fluctuating ones, participants must acquire new bodily intelligences that thrive within these new body-brain-environment configurations in order to continue enjoying and benefiting from serious leisure activities.

7.5 Findings summary

7.5.1 Trips, locations, and activities

Findings from travel and activity diaries and chronic illness inventories suggest that, generally, these renal patients juggle multiple activities in everyday life aside from illness management. Still, within this juggling act, chronic illness management activities, including health service access, feature prominently. All participants reported needing to perform chronic illness management activities on both sample days. On their sample days, participants often made at least one visit to a retail, health services, or a paid work location, and were most often motivated to make trips in order to perform domestic, illness management, leisure, and paid work activities.
Participants’ everyday activities vary, in particular, by disease stage and employment status in the degree to which they make trips outside the house, the kinds of activities they juggle, and the kinds of locations they visit. As compared to other participants, everyday life for participants in stage 4 and, to a greater degree, participants with ESKD who receive dialysis, seems most dictated by chronic illness management, including health services access, and is characterised by lower levels of mobility outside the home. At the other extreme, participants with a functioning kidney transplant were the most mobile and active outside the home. They did, however, have relatively high rates of health service access.

The travel and activity diaries also suggest that employment status influences how participants’ navigate everyday life with chronic illness. Participants who are unemployed or retired were more likely to visit a health services location. Meanwhile, participants working full-time are least likely to make a trip motivated by leisure.

Some illness management activities are more difficult to perform in everyday life than others. The most common illness management activities identified as required by participants were exercise, taking medications, and checking blood pressure. Overall, participants felt most successful in taking medications, and had the most trouble checking blood pressure, checking blood glucose levels, limiting phosphorous in their diet, exercising, and following a weight-loss diet.

7.5.2 Time, space, and everyday life
I was able to grasp a better understanding of what it is like to navigate these kinds of activities in everyday life by extending my analysis beyond the rather flat depiction of individual characteristics and patterns of behaviour recorded in the diaries, to the textured and dynamic terrain of experiences of time and space had by participants as they navigate the everyday.

Each aspect of everyday life has its own set of typical temporal and spatial characteristics, as do the symptoms and activities of managing chronic illness. Some of these are experienced as clock/calendar time and points, distances, and areas on a map, as in how far away health services are from home, the need for coordination with other people for group leisure activities, the degree of flexibility an employee has in where and when to perform work, opening and closing times of stores and doctor’s offices, and the locations and times of a child’s extra-curricular activities.

Other experiences of space-time are sensually experienced through the body, as in perceived patterns of repetition and difference within an individual and their environment. For example, participants described rhythms of energy, pain, and the need for rest, seasonal periods of intensity at work, the shifting moods of a tired child, being prompted into action by
the routine behaviours of family, pets, and work colleagues, and uncertainties about how events will unfold given the unpredictability of the body’s capacities and survival.

7.5.3 Interacting space-times
Participant accounts suggest that a unique dimension of living with chronic illness is the negotiation of the spatio-temporal characteristics of chronic illness, which weave through, and sometimes clash with, other pressing areas of everyday life. As individuals move through time and space in the everyday, these characteristics shape the complexity and difficulty of the individuals’ terrain, and the kind of engagement that takes place there.

Self-management of chronic illness. The logistical challenges derived from the competing space-time demands of different activities, as well as the characteristics of the rhythms in everyday environments and participants’ bodies, can influence participants’ abilities to establish and maintain health-supporting routines in everyday life. When logistics and everyday environments encourage regular and reliable repetition of illness management activities, the force of habit is harnessed in participants’ favour. Thereby, participants experience less effort associated with managing their illness, feel more in control, motivated, and ‘normal’.

Paid work. The spatio-temporal characteristics particular to paid work, health services access, and the symptoms of chronic illness play a role in making it more or less difficult to sustain employment. These spatio-temporal characteristics vary depending on the arrangements of paid work and health services, and the types and severity of symptoms experienced. Some combinations of spatio-temporal characteristics are particularly unfavourable, such as highly unpredictable and frequent health service access in combination with low transferability of job responsibilities, inability to accrue time off, and low spatio-temporal flexibility in where and when tasks can be performed. Participants attempt to anticipate and mitigate the negative effects resulting from the interaction of these characteristics. Their strategies include banking time off work, swapping shifts with coworkers, being ahead in their workload, carefully planning ahead, making themselves remotely available to their employer, sacrificing health-supporting activities such as home cooking and exercise, and skipping work breaks.

Caregiving and family. Experiences of role conflict as a caregiver and ill person arise when participants are unable to reconcile their ideal caringscape (Bowlby, 2012), or way of organising their activities in space-time so that they are oriented to the needs of others, with their ideal for orienting themselves to the needs of their own chronically ill body. While motivated by these ideals, participants’ actual caringscapes are shaped by logistical conflicts
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and embodied space-times. Logistical conflicts arise from: 1) restrictions placed on participants’ potential path areas by the service and resource context of managing illness, which makes bodily co-presence with loved ones more difficult, and reduces opportunities to share in family rituals and facilitate breaks from family routines; and 2) the necessity to juggle activities of caregiving and chronic illness management that compete for space-time resources, often resulting in some activities being prioritised over others, and some being sacrificed. The embodied space-times that shape participants’ caringscapes are derived from: 1) the unpredictability of the body in when and where it might ‘fail’ participants as they care for others; 2) fluctuations in the energy levels and symptoms of the body that often conflict with the constant need for availability in caregiving relationships; and 3) the ways in which the qualities of spaces of ‘quality time’ with loved ones can be altered by illness.

**Leisure.** The space-time logistics of chronic illness management and symptoms shape participants’ leisure-scapes (Van der Poel, 1997) in specific ways. Health service access restricts participants’ potential path areas for touristic travel and volunteer commitments, and makes the synchronisation of space-time paths for group leisure more complex. Sometimes, the necessity to avoid certain places at certain times in order to protect the body can also present logistical challenges to leisure activities. Within a leisure-scape already shaped by these logistical factors, the embodied space-times of chronic illness can also change how individuals engage with leisure activities. In particular, skilful leisure activities provide the pleasure of mastery, awareness, skill, and confidence that supports participants in dealing with the uncertainties of life with chronic illness. However, as the space-times of the body shift with chronic illness, displacing previously stable corporeal rhythms with unpredictable and/or fluctuating ones, participants must acquire new bodily intelligences that thrive within these new body-brain-environment configurations (Bissell, 2013) in order to continue enjoying and benefiting from serious leisure activities.

With this space-time geographical perspective, it is apparent that different parts of everyday life with chronic illness are highly interactive. The ‘chronic illness experience’ of any one individual, which may include feeling overwhelmed, in control, worried, (un)motivated, or (in)adequate, will vary by, not only how many different areas of life they are juggling, but the particular combinations of spatio-temporal characteristics therein.
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I begin this chapter by discussing the contributions of this study to space-time geography and health geography. Then, I discuss contributions to health geographies of chronic illness, along with specific implications of findings for understanding chronic illness experiences in: patient self-management of chronic illness, paid work participation, caregiving and family, and leisure, recreation, and tourism. Subsequently, I consider study limitations. I conclude the thesis by revisiting the aim of the thesis, summarising main findings, and indicating directions for future research.

8.1 Space-times of everyday life

On the most basic level, this thesis highlights the importance of health status as a factor shaping space-time organisation of everyday activities and space-time accessibility. Among other space-time constraints, participants highlighted ways in which a frequent need to access health services imposes substantial authority constraints on organising activities, travel, and synchronising with the space-time paths of others. Furthermore, unpredictability in health service access exacerbates space-time resource conflicts between illness management and other areas of life, and disrupts everyday routines. Other chronic illness management activities, such as frequent trips to the chemist, or the need to be home at a certain time in order to reliably take a medication, are also space-time resource demanding, adding to the
complexity of negotiating everyday life ‘on the ground’. Importantly, these kinds of space-time constraints are unevenly distributed between individuals, and the impacts of each on experiences of negotiating everyday life vary, depending on factors such as disease stage, employment status, and caregiving responsibilities. These findings contribute to the body of knowledge in space-time geography that recognises the influence of norms, power relations, and inequality in space-time variations between individuals, and has already identified, in particular, the influences of gender (e.g., Kwan, 1999a, 1999b, 2000; Schwanen, 2006, 2008; Schwanen & De Jong, 2008), and socioeconomic situation (e.g., Hernandez & Rossel, 2015; Neutens, Schwanen, Witlox, & De Maeyer, 2010; Neutens, Schwanen, Witlox, & De Maeyer, 2012).

My initial approach to understanding everyday life negotiation with chronic illness leaned on the most common conceptualization of time: clock time, characterised as “decontextualized and quantified”, and “product, money and profit,” (Adam, 2004, p. 101). This sense of time illuminated conflicting demands made on participants by institutions and organisations that regulate access and participation through clock time and Cartesian space, such as health service providers, employers, youth sports teams, and volunteer organisations. However, the embodied experiences of individuals with chronic illness felt “within the skin” of the individual (Hägerstrand, 2004, pp., p. 315) often defy this unrelenting sense of time. Body states and abilities can fluctuate from day-to-day due to illness and treatment, reflecting the “rhythmic repetition with variation... temporality, timing, tempo, intensity” and contextual specificity so characteristic of embodied time (Adam, 2004, p. 101).

Engaging with the everyday experiences of individuals with chronic illness draws the body clearly to the fore of space-time geographical analysis, supporting arguments for treating the body not as a neutral vessel on the space-time path, but as engaged in a relational and embodied human-environment relationship (Kwan, 2007; McQuoid & Dijst, 2012; Rose, 1993). In my case, I found Lefebvre’s work on rhythms particularly useful due to its foundations in “the lived, the carnal, the body” (Lefebvre, 2004, p. 9). As May and Thrift have indicated, “the means by which a particular sense of time comes into being and moves forward to frame our understandings and actions – is in turn both multiple and dynamic,” (May & Thrift, 2001, p. 3). Recognition of the multiplicity and dynamism inherent to experiences of space-time was indeed necessary in order to grasp participants’ experiences.

This perspective led to the emergence of the four Greek manifolds of space and time within analysis, similar to the extensions to classical time geography proposed by Hägerstrand following his seminal 1970 paper (Sui, 2012). Choros, an area defined by Cartesian coordinates,
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was reflected in, for example, participants’ experiences of feeling residually restricted to within a certain distance of their health care specialists. The experience of topos, a concrete place or landscape, emerged in the ways in which chronic illness can change how people relate to certain places, such as a sunny park that ceases to be a place of recreation and becomes a dangerous environment leading to skin cancer. Chronos, the time of Newton, clocks and calendars, was observed in, for example, the sheer amount of time some participants spent accessing health services, leaving less time for other activities in the week. Finally, kairos, or embedded/event time, was clearly evident in caregiving relationships, wherein the constant orientation to the space-times of another clashed with the periodic emergence of the need for rest and recuperation from symptoms (see Sui, 2012, p. 8-9).

I grappled, with varying degrees of success, with the integration of these different senses of space-time over the course of this project. I found myself in an analytic tension between the “two vistas” (Hägerstrand, 2004, p. 315) of participants’ experiences; that of the abstract and sometimes unyielding world ‘out there’ of appointment times and distances between loved ones, versus the more immediate, dynamic, entangled, and sometimes unpredictable world of rhythms that circulate within and around bodies. Sometimes, these two vistas seemed to exist almost separately in participants’ lives. But, when they interacted, the effects were powerfully influential.

8.1.1 A window into transformation

The incorporation of embodied perspectives on space-time led, to my surprise, not further into focus on the body, but rather to a more de-centred perspective on some of participants’ experiences in negotiating everyday life. Namely, the possession of attributes like motivation, the ability to remember, a good sense of self-efficacy, and the ability to adapt to life’s emergent challenges seems to be situated less within the individual, per se, and more within the process of mutual transformation occurring between the individual and their environment over time.

Key aspects of everyday life with chronic illness that require skilful performance are situated within relationships between participants and rhythms in their everyday environments. I observed rhythms tangled up with the ability to remember to take medications on-schedule, to track consumption of fluid and foods, to feel motivated to perform activities such as exercise, and to engage in leisure activities that support adaptation to the uncertainties of life with chronically poor health. Sometimes, as in the case of Madeline’s end-of-day sore feet, or Sarbajit’s predictably hungry cat (see Chapter 7.1.2.2.1), everyday rhythms support skilful performance needed to negotiate everyday life with chronic
illness, such as adherence to a medication schedule. These rhythms in everyday contexts are regular, compelling, and insistent, driving along consistent repetition of activities and encouraging experiences of ease. However, rhythms are, by nature, open to change, mutation, growth and decay, difference as well as repetition (Crang, 2001; Edensor, 2010b, p. 13-14; Lefebvre, 2004). Mike’s usually stable lunch time rhythm at work, for example, is temporarily disfigured by rhythms at the scale of the national political system, disrupting his lunch-time gym routine and weakening his motivation to exercise (see Chapter 7.1.2.2.2). Neal’s motorcycle riding practice is threatened by the emergence of irregularity in his body’s rhythms of energy and fatigue, diminishing the sense of pleasure he gets from this leisure activity (see Chapter 7.4.2.2). Rhythms not only have the potential to provide a stable undercurrent in everyday life, but are also fields for change and transformation in the human-environment relationship.

The recent resurgence of interest in the nature of habit among cultural geographers and others (e.g., Bissell, 2013; Carlisle, 2013; Dewsbury, 2011; Ehn & Lofgren, 2009; Grosz, 2013; Malabou, 2008; Sharpe, 2013; Sinclair, 2011; Wilk, 2009) aided my understanding of participants’ experiences of effort, ease, pleasure, and frustration within these shifting rhythmic contexts, and led me toward what could be called a space-time ecology of habit. The vitalist tradition cautions against conceiving of habit as simply a mechanistic bi-product of repetition (Carlisle, 2013). Repetition or continuity is, however, a key condition for the Ravaisson’s ‘double law’ of habit (2008), whether that be in the individual passively perceiving something (e.g., fear) or actively initiating an action repeatedly over time (e.g., tracking fluid consumption) (Grosz, 2013, p. 222). As habit evolves through repetition, proficiency and familiarity grow, and the experience of effort and consciousness of the action or sensation diminishes (see Chapter 2.1.3). Conceiving of habit in this way helps us understand how embodied intelligences emerge over time, as in those critical to negotiating everyday life with chronic illness, which may include effortlessly injecting insulin, or getting a ‘feel’ for appropriate quantities and spacing of potassium-containing foods.

Geographies of rhythm (e.g., Edensor, 2010a; Lefebvre, 2004) bring our attention to the dimension of repetition and difference that we experience in ourselves and our environments over time. I suggest that rhythms can encourage or impede repetition of action or stimulus, as described in participant accounts above, thereby mobilising or thwarting the force of habit. This can occur in the form of creating an (in) hospitable environment, in the logistical sense, for repetition to occur and the force of habit to take hold and persist, as when rhythms deny or provide regular access to the space-time resources needed to repeatedly perform an activity,
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or for the individual’s space-time path to repeatedly put them in the right place at the right
time to be exposed to a sensation or experience. Mike’s regular lunch break rhythm, for
example, allowed trips to the on-site gym to become an experience of ‘it just happening’ with
little effort on Mike’s part. The cyclical rhythm of the political system ‘severely upsets’ habit in
supporting Mike’s exercise regimen by taking away the time needed to visit the gym. Once the
time is available again, Mike has an effortful uphill climb in order to re-establish his effortless
gym habit.

Rhythms can also work with the force of habit by pulling individuals into repetition
through compelling sensations or emotions. In Chapter 7.1.2.2, I documented how the
morning ruckus of Hannah’s magpie colony pulls her into the day with the impulse to feed
them, despite her depression. The urge to satiate her morning caffeine craving with a steaming
cup of coffee takes her to the cupboard where her medications sit alongside the coffee. Many
other examples of linkages between compelling rhythms and (un)desired action were observed
in participants’ everyday lives. Following Merleau-Ponty (2012 [1945]), we can understand the
compelling nature of these rhythms in terms of the affective dimension of perception, which
fosters the experience of perceiving one’s surroundings as requiring certain forms of behaviour
(Romdenh-Romluc, 2010, p. 78). Hannah has, over time, come to perceive the birds as
creatures worthy of care and food, and the coffee cupboard as a source of satisfaction for a
craving. Her way of perceiving these objects is itself the work of habit. The affective impact of
these objects in her environment occurs harmoniously in space-time with actions that support
her wellbeing (i.e., getting up in the morning and taking medications on-time). Instead of the
morning being an experience of battling with depression and a struggle to remember
medications, Hannah’s actions are carried along within the relationship between everyday
rhythms, materiality, and the force of habit.

A space-time ecology of habit, I suggest, examines relationships between rhythm,
materiality, and the force of habit in order to acquire a window into the transformative
relationship between the individual and their environment on the space-time path. This
perspective embraces “a much more ‘displaced’ understanding of habit where habit does not
reside within bodies but is the more creative and unpredictable process through which bodies
and environments mutually evolve and take shape,” (Bissell, 2013, p. 121). The viewpoint of
the individual’s path through time and space provides an opportunity to observe this process
given that, as Gren has argued, it insists we appreciate the body in relation with matter (2001,
p. 216). Habit is a force of evolution and accommodation between bodies and environments
over time. As such, the force of habit begs further exploration within space-time geographies and geographies of temporality, more generally.

One avenue of exploration concerns the ways in which we conceive of goals, decision-making, and the pursuit of projects by individuals in space-time geographical research. As McCormack and Schwanen (2011) and Schwanen, Banister, and Anable (2012) have argued, geographical thinking must continue to move beyond the idea that decision-making happens in a bounded moment within a rational individual, abstracted from context. There is a theoretically sophisticated, growing body of literature on the distributed, transformative potential of habit reaching back to Aristotle, advanced by thinkers like Ravaission, Bergson, Merleau-Ponty, and Deleuze, and more recently brought into contemporary geographical research. However, it has proven challenging to establish robust connections between this often highly abstract body of work with the empirically focused concerns of practitioners and policy makers (Middleton, 2011, p. 2865). Observing how the force of habit engages with observable rhythms and materiality in people’s lives may offer one way to more concretely engage with habit in empirical research, offering practical implications for behaviour change in transport, public health, energy use, and other pressing fields.

8.2 Place and health
In recent years, others have advocated for the incorporation of both the spatial and temporal dimensions of human activity in health research (Kwan, 2013; Rainham, McDowell, Krewski, & Sawada, 2010; Richardson et al., 2013). These approaches tend to mobilise particular (conventional) notions of space and time that make representation of context feasible within ‘big data’ analyses of exposure and accessibility. These approaches have immense value in that they improve conceptualisation of context by observing the spatial and temporal movements of individuals (Rainham et al., 2010). An important contribution of this thesis to health geography is its incorporation of multiple senses of time and space. This conceptual choice both reflects and contributes to advancements in the conceptualisation of place in health research, which has evolved with the sub-discipline of health geography over recent decades (see Andrews, Evans, Dunn, & Masuda, 2012; Andrews, Hall, Evans, & Colls, 2012; Cummins, Curtis, Diez-Roux, & Macintyre, 2007; Kearns, 1993; Kearns & Joseph, 1993; Kearns & Moon, 2002).

The work I have presented here rides on the wave of increasingly complex and dynamic appreciations for relationships between people and their environments in the sub-disciplines of both health geography and space-time geography. Conventional spatial characteristics such as distance and proximity were relevant to participants’ experiences in this study, as in the
distances between their homes and medical specialists. More prominently, however, I have focused on “the ‘insider’ experience of place” (Kearns & Joseph, 1993, p. 715) and the intersection of people, places and processes in health and health services (Kearns, 1993; Kearns & Joseph, 1993). The use of a space-time geographical perspective sheds light on the ways participants experience their everyday contexts in intensely socially constructed ways. This is shaped by factors such as the employment of clocks, calendars, and maps by institutions to regulate where, when, and by whom activities such as paid work and health service access may be performed. Where and when it is socially acceptable to perform illness management activities (e.g., checking blood glucose) also shapes experience of place. And, in a final example, the sprawling suburban character of the study setting which inhibits mobility for some participants is itself informed by the socio-historical moment in which Canberra was planned and the ongoing process of its development (see Chapter 5).

This thesis has also benefited from the appreciation for embodied understandings that has emerged in health geography (e.g., Andrews, Hall, et al., 2012; Dyck, 1999; Hall, 2000; Moss & Dyck, 1996, 1999). If we recognise that spaces are not simply containers, we must also recognise that “people are not objects that move and flow uniformly through these spaces,” (Andrews, Hall, et al., 2012, p. 1929). Furthermore, people experience places differently through their body’s capacities, sensations, and how the body is ‘read’ in various socio-political contexts (Moss & Dyck, 1999). These dimensions of place experience are becoming increasingly acknowledged within space-time as well as human geography (e.g., Kwan, 2007; McQuoid & Dijst, 2012; Rose, 1993). Paying close attention to the embodied experiences of participants as they negotiate everyday life illuminated important rhythmic characteristics of contexts relevant to illness management, health service access, and participants’ sense of wellbeing in life with chronic illness. Beyond their implications for chronic illness, the findings presented here highlight the contribution of an embodied perspective to picking up on subtler and less easily measured characteristics of place relevant to people’s health, such as rhythms of pet behaviour in the home that prompt participants to do health-supporting activities like exercise and take medications (Chapter 7.1.2.2) (see also, for example, Cutt, Giles-Corti, Knuiman, & Burke, 2007 for a review of dog ownership and physical activity).

This thesis also contributes to the “relational turn” in health geography (Andrews, Hall, et al., 2012, p. 1930) as advanced by Cummins, Curtis, Diez-Roux, and Macintyre (2007). A call has been made for “recognizing that individuals become relationally embedded in multiple health damaging and health promoting environments, across time and space, and at multiple scales,” (Cummins et al., 2007, p. 1835). The space-time geographical perspective revealed
various environments relevant to participants’ everyday lives with chronic illness. Participant accounts reflect multiple scales of interaction with environments, the most immediate being the chronically ill body itself, and specific sites such as the home, the workplace, places of leisure, and health services. Participants’ experiences with health and health care are also embedded within the particular services, resources, and characteristics of the city of Canberra and regional New South Wales towns, as well as the space within the region of renal specialist service delivery defining participant recruitment for this study. The influence of the national scale was also observed by the influence of the Australian health care system, national political cycles, and procedures for permanent residency in Australia. Finally, experiences of living with chronic illness stretch across the globe through uncertain experiences of international travel and difficulties navigating foreign health services in order to visit family and friends.

Furthermore, multiple temporal scales are clearly implicated in participant experiences. As noted in Chapter 1, health geographies of chronic illness have most often conceived the temporal dimension of chronic illness over the long-term scale of individuals’ lives (e.g., Driedger, Crooks, & Bennett, 2004; Wilton, 1996). However, participant accounts show many temporal scales at work. For example, fluid consumption and medication schedules are often spaced by the hour, bone pain can build up by the end of the day, energy and fatigue sometimes fluctuates day-to-day, health service appointments and dialysis sessions are scattered throughout weekly schedules, the need for substantial breaks and rest from caregiving and paid work comes up periodically throughout the year, most participants have thrice-yearly routine appointments with each of their health care specialists, skilful leisure activities that bring pleasure and confidence are developed and mastered over years, and, in a final example, most participants live with long and short-term uncertainty about disease progression and the possibility of sudden ill health or death.

The space-time approach taken in this thesis also illuminated the mutual influence and transformation that occurs between participants and their everyday environments over time. This highlights the limited value of maintaining the “false dualism of context and composition” (Cummins et al., 2007, p. 1825), and weakens assumptions about deterministic influence of environments on health (Andrews, Hall, et al., 2012; Cummins et al., 2007). I focused on examining “the processes and interactions occurring between people and places over time which may be important for health,” (Cummins et al., 2007, p. 1828). Participants in this study are not passively influenced by the space-time conflicts that emerge in everyday life with chronic illness. They are very much engaged in modifying, strategizing, anticipating, and mitigating these situations along their space-time path. Furthermore, relationships between
Discussion and Conclusion

rhythms, materiality, and the force of habit are linked to important health-related behaviours (e.g., illness management) and the sense of wellbeing participants have about their lives (e.g., feeling motivated versus incompetent).

This brings me to a final contribution offered by embracing multiple senses of space and time, which is the ability to challenge the Cartesian dualism of body and mind, wherein the body is over-simplified as a “machine made up of many parts,” (Hall, 2000, p. 23). Without appreciation for embodied senses of time and the body’s relation with materiality, the concept of habit as modification of both body and mind (Carlisle, 2013, p. 44) would not have had an entry point into analysis.

In short, space-time geography and the concept of habit have much to offer health research and conceptualisations of place therein. I suggest that incorporation of multiple senses of space and time in these types of analyses opens up productive avenues for understanding multiple dimensions of human-environment interactions and processes and their relevance to health.

8.3 Health geographies of chronic illness

Health geographies of chronic illness comprise one area of research poised to benefit from this type of approach. Health geographers have provided rich explorations of the spatialities of chronic illness, but have left the dimension of time underexplored (e.g., Crooks, 2007a; Driedger et al., 2004; Dyck, 1995a, 2002; Dyck & Jongbloed, 2000; Wilton, 1996). This thesis addressed a significant gap in health geography literature on chronic illness by attending to the temporalities and spatialities of everyday experiences with chronic illness. My analysis explored the temporal dimensions of where illness is ‘placed’ (e.g., home, health care sites, work), and mapped out arrhythmias within and between sites and bodies.

Literature on experiences of different parts of everyday life for people with chronic illness has tended to examine these aspects of life in isolation, forming silos of knowledge. This space-time approach helped to thread through these silos, revealing their highly interactive nature. All participants share that they interact more frequently with health services than the general population, that they have to engage in illness management activities every day, and that they experience sometimes disruptive changes in the sensations and capacities of their body due to illness. However, the impact of, for example, health services access unpredictability, is different for different people, depending on the configuration of other parts of their life.

Samantha exemplified this well in her experience of accessing the services of a specialist while working part-time and single parenting school aged children (see Chapter 7.3.2.1.2). Her
work, home, and children’s school locations were close to one another, but she had to drive an hour to the specialist, imposing a greater space-time cost than if there was a specialist nearby. Single parenting meant that she had to be the one to be at the schools when school let out, and then care for her children for the rest of the day. This constrained her working hours to school hours, and meant that she could only access the specialist during work hours while the children were at school. To compound this further, her workplace ‘frowned upon’ part-time employees who took time away from work, as it was assumed that those employees should easily be able to schedule non-work activities outside of work hours as compared to full-time employees. Therefore, Samantha’s difficulty accessing health services was exacerbated if there was a service delay and she returned even later to work than the time she had told her supervisor.

Research on chronic illness experiences has drawn productively from models of disability (see Chapter 1.1). My findings support some propositions of the medical model of disability and some of the social model of disability, although neither sufficiently explains the experiences of participants. The biopsychosocial model, however, draws attention to relationships between “biological, psychological, and social dimensions of illness” (Borrell-Carrió, Suchman and Epstein 2004, p. 576); all clearly present in my findings. A space-time geographical approach makes an important contribution to health geographies of chronic illness because it reveals how these dimensions interact in everyday life. It provides other pathways into people’s lives to understand how socially-informed practicalities and bodily conditions unique to life with chronic illness play-out through time as the individual interacts with various contexts, people, and institutions in everyday life. Importantly, a space-time approach offers opportunities to identify practical points of intervention for reducing the difficulty of juggling chronic illness and other parts of everyday life. In short, it offers new insight into how difficulties can arise in balancing chronic illness with the rest of life and thereby offers potential solutions. Next, I discuss some of the insights offered by a space-time geographical approach to understanding patient self-management of chronic illness, paid work participation, caregiving and family, and leisure, recreation, and tourism for people with chronic illness.

8.3.1 Patient self-management of chronic illness

Participant accounts show that managing chronic illness in everyday life does, in accordance with previous findings, involve experiences of having or lacking motivation (e.g., Jowsey, Pearce-Brown, Douglas, & Yen, 2011), a sense of self-efficacy and control (e.g., Bodenheimer, Lorig, Holman, & Grumbach, 2002; Curtin et al., 2008; Tsay, 2003), and the ability to stabilise
one’s life through routines (e.g., Balfe, 2009; Balfe et al., 2013; Costantini et al., 2008; Fiese & Wamboldt, 2000; Haslbeck & Schaeffer, 2009; Wagner & Ryan, 2004). The space-time geographical approach used in this study re-frames the importance of these experiences by grasping their embeddedness within relationships between participants and their everyday space-time contexts. This embeddedness has implications for how chronically ill patients can be supported in managing their health and having a greater sense of wellbeing, and for health behaviour change, more broadly.

The health care provider’s perspective on the problem of patient self-management of chronic illness was nicely expressed to me by a clinician working within the study setting when he remarked, “We develop these treatments, and then we turn them loose into suburbia.” So far, it has been up to the renal patient to figure out how integrate chronic illness management into everyday environments and activities (Costantini, 2006). Health care providers want to support patients in performing illness management activities in order to slow progression of disease and improve patient quality of life. The findings of this study strongly suggest that, in order to be more effective, patient self-management support must be informed by an awareness of the space-time contexts into which illness management activities are being introduced, and an understanding of how these contexts vary between patients and settings.

This awareness could be fostered in a variety of ways. One option could be the use of a patient space-time assessment in which the health care provider orients themselves and the patient to factors that may influence what a particular patient will confront when trying to integrate chronic illness management activities into their life. For participants in this study setting, those factors include employment status and the space-time arrangements of workplaces, caregiving activities that may, at times, take priority over illness management, organised leisure activities (e.g., community organisations), and residential location (e.g., rural vs urban). In other populations or settings, other factors could be more highly pressing, such as income (e.g., Roy, Tubbs, & Burton, 2004). With this information, the health care provider and patient can strategize together to mitigate, for instance, the negative impact that many workplaces have on illness management activities (e.g., Balfe et al., 2013).

An obvious further implication is that health care providers need to recognise their own role in shaping patients’ space-time contexts and the level of complexity patients face in navigating everyday life. Reducing complexity in patients’ space-time contexts may support their ability to establish stable routines that support chronic illness management and wellbeing (Zisberg, Young, Schepp, & Zysberg, 2007). Findings of this study strongly suggest that space-
time constraints surrounding health service access factor extensively into where, when, and how other activities in everyday life can be performed by chronically ill patients. This is especially true for participants who access health services with high frequency due to factors such as management of co-morbid conditions or dialysis treatment. When patients experience unpredictability in accessing health services (see, for example, Klitzman, 2007; McQuoid, Welsh, Strazdins, Griffin, & Banwell, 2015), the constraining effects of health services on other areas of life are further exacerbated, and a ripple effect is seen in other activities being sacrificed or disrupted (e.g., a good diet). Therefore, two points of intervention are: 1) reducing the space-time constraints of health services on chronically ill patients; and 2) reducing unpredictability in health service access.

Within the study setting, renal health service providers are embarking on service changes to support renal patients through the first point of intervention (ABC, 2015). The year after data collection for this study ended, haemodialysis clinics in the ACT began expanding opportunities to dialyse, with the goal of creating more flexibility for dialysis patients. This includes creating more nocturnal dialysis options and self-care centres where renal patients have a swipe card that allows them to dialyse when it suits them best instead of by appointment. Also part of the plan is making it possible for dialysis patients to meet with a range of specialists while they dialyse (e.g., podiatrist, nephrologist, dietician), further reducing health service access space-time constraints on patients. As highlighted in Chapter 7.1.2.1.1, participants in this study who dialyse experience the most constraints on how they can organise everyday activities, and have lower levels of mobility outside the home, as compared to other participants. It would be valuable to conduct a follow-up space-time geographical study of renal patients in this study setting in order to see if, and to what extent, this group experiences greater freedom in organising everyday life activities after the expansion of services.

Finally, there are broader implications of this study for how we frame and approach health behaviour change, including patient self-management after the onset of chronic illness. A link is clearly made in models of patient self-management between feeling motivated and capable of effecting positive change in one’s health, and self-managing chronic illness (Bodenheimer et al., 2002). Where, then, do these experiences of one’s self come from? Psychology-based approaches emphasise the importance of mastery experiences in building a strong sense of self-efficacy (Bandura, 1986, 1994; Tsay, 2003). The origins of motivation toward protecting one’s own health have often been linked to beliefs and attitudes about
medical treatments and susceptibility to poor health held by the individual and those around them (Glanz, Rimer, & Viswanath, 2008).

The findings from this study, however, point to an important nuance in understanding how health behaviour change happens in practice. Participant accounts show that the experiences they have of themselves as motivated, lazy, (in)capable, and so forth, are often wrapped up in relationships between rhythms, materiality, and the force of habit in everyday life. Rhythms in everyday contexts can support the ease with which mastery experiences are had, and, therefore, the ease with which a strong sense of self-efficacy is developed. For example, Sarbajit attributes the way he overcame the difficulty of remembering his morning medication schedule to his own mastery over the situation, even though his remembering was very much supported by his medication dose ‘h hooking’ onto a stable rhythm that circulates within his home environment (his cat’s insistence to be fed). Furthermore, the experience of feeling (un)motivated to perform health-supporting activities (e.g., exercise) can come about via the force of habit being encouraged or disrupted by rhythms in everyday contexts. A good example was Mike’s account of feeling that his motivation to go to the gym dissipated after his lunch-time gym habit was temporarily disrupted by work rhythms.

Further investigation is needed to inquire: Where do attitudes and beliefs about health and health-related activities come from? Meaning, where do we locate them on a conceptual level? For example, do we locate them as generated within individuals, or as coming from their environments? Or, do we situate them more relationally as arising from interactions and processes between the two? Specifically with regard to chronic illness self-management, does overemphasising the roles of the patient ‘getting it’, being motivated, and having self-discipline cause unintentional harm to patients by generating unnecessary feelings of guilt and inadequacy? In conclusion, the ideal circumstance for chronic illness self-management includes not only treatment adherence, but also feelings of ease and confidence in living with chronic illness. Re-framing chronic illness self-management as occurring within the interaction of patients and their everyday space-time contexts sheds light on new avenues through which to pursue this ideal.

8.3.2 Paid work participation
Like others have found (e.g., Boot et al., 2013; Chorus, Miedema, Wevers, & Van der Linden, 2001; Koch, Rumrill, Conyers, & Wohlford, 2013), the physical limitations of the chronically ill body do indeed limit participants’ abilities to perform paid work responsibilities. For example, Samantha’s extreme fatigue makes work almost impossible on some days. Also in agreement with previous findings (e.g., Edwards & Boxall, 2010; Koch et al., 2013; Roessler, Hennessey,
Neath, Rumrill, & Nisen, 2011; Shier, Graham, & Jones, 2009), unsupportive organisational cultures, and the discrimination and stigmatisation by employers and co-workers of individuals with chronic illness has a substantial and negative impact on participant experiences with employment. For example, Mike was turned down for several jobs until he decided to conceal his health condition during the interview process.

The contribution of this space-time approach has been to highlight how paid work participation is made more difficult by interactions between multiple factors, such as the chronically ill body, attitudes of supervisors, spatial and temporal arrangements of work, and characteristics of health services access (see McQuoid et al., 2015). Different senses of space-time are bound up in these interactions, as observed in collisions between the embodied space-times associated with illness and treatment, and the absolute space-times of employer-employee exchange and health services access. My findings highlight a tension between the need for stability as well as employee-oriented flexibility in work rhythms.

Similar to Hall and Wilton’s (2011) findings for disabled workers, favourable spatio-temporal characteristics of employment for participants include employee-oriented flexibility. In other words, tasks can be deferred when needed (e.g., Sarbajit starts work late when he wakes up feeling poorly), or performed elsewhere (e.g., Bill brings work to dialysis). Positions in which responsibilities can easily be covered by a co-worker in the case of an unexpected health need are also favourable (e.g., Mike’s co-workers can fill in if he has an unexpected blood test). However, ideal workplace spatio-temporal characteristics also include stability, in order to encourage stable workplace rhythms and activity locations that support repetition of illness management activity routines. For example, Sarbajit found remembering his transplant medication difficult during work hours due to irregular workplace rhythms that unpredictably pull him away from his desk, while his home rhythm environment facilitates his remembering his medication by reliably pulling him past the kitchen bench where medications are kept.

The space-time arrangements of work in post-industrialised countries are more diverse now than they were several decades ago, reflecting widespread political and industry support for ‘flexible’ labour markets (Dixon et al., 2013). Alongside this trend is the increasing prevalence of people managing chronic illness (World Health Organization, 2008), and the push to encourage people to work longer and retire later in response to dilemmas posed by ageing populations in countries like Australia (Commonwealth of Australia, 2010). Therefore, important questions arise regarding the conditions under which people with chronic illness may be able to persist in employment in the coming decades. For example, who has access to the types of workplace spatio-temporal characteristics favourable to managing chronic illness?
The answer in most countries is likely to be highly skilled workers. In Australia, for example, only 40% of workers have a say over their start and finish times, and just over a third can work extra hours to ‘bank’ time off (Australian Bureau of Statistics, 2012). Those benefiting from these space-time affordances are generally in managerial, professional, and clerical and administrative positions (Australian Bureau of Statistics, 2012). Furthermore, analyses of contemporary labour markets in wealthier nations have signalled a polarizing trend, with a growing pool of workers facing unpredictable and inflexible worktime regimes, and a smaller group of privileged workers enjoying more space-time autonomy, albeit often with long hours (e.g., Standing, 2011). This raises questions regarding how lower-skilled and precarious workers will fare if they must also manage chronic illness. Accommodations to working conditions allowing individuals, such as the participants with chronic illness in this study, to engage in paid work constitute “a challenge to the logic of contemporary capitalist economies, where flexibility is first and foremost a privilege of capital,” (Wilton, 2004, p. 423).

Other important questions are: What are the health implications for people with chronic illness working in space-time conditions unconducive to chronic illness management, and, what can be done within those workplaces to mitigate those negative effects? As Wilton (2004) and other disability advocates have argued, we must not make the mistake of reproducing exclusionary frameworks by making individuals responsible for ‘choosing’ jobs that protect health and are compatible with the affordances of their bodies. In essence, this implies that individuals should self-select out of opportunities in order to accommodate existing work regimes. Instead, we should ask: How can the disabling spatio-temporal characteristics of jobs be modified to accommodate a more diverse workforce?

Perhaps the most unanticipated finding of this study is that possible interventions for reducing barriers to workforce participation for people with chronic illness lie not only in the workplace, but also in health services design and execution. Bill’s experience, in particular, highlights the need for health services to better integrate into the everyday lives of individuals, including workers, given the frequency of service access among chronically ill people (see also Jeon et al., 2010). While policies and strategies exist to reduce the financial burden of accessing health services (e.g., universal public health insurance schemes like Medicare Australia), the space-time imposes of health services on chronically ill people remain under-recognised and poorly addressed. My findings stress the impact of health service space-time costs on the ability of individuals with chronic illness to perform their jobs and earn an income. Unpredictability in these costs can ripple through other areas of a person’s life, including work, further compounding the difficulty of meeting employer expectations and managing illness.
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conclusion, the findings presented here suggest that labour force participation for people with chronic illness must be supported, not only by focussing on barriers in the hiring process, limitations of chronically ill bodies, or attitudinal barriers within workplaces. The spatio-temporal characteristics of work, in combination with those of health services, must also be targeted as potentially disabling characteristics of work environments requiring accommodation for people with chronic illness.

8.3.3 Caregiving and family

This space-time geographical study contributes to geographies of care by explicitly examining the spatialities and temporalities of caregiving relationships. As Bowlby (2012) has observed, most geographical research on care has not explicitly or systematically examined the spatial and temporal dimensions of care relations and processes. Time, as well as space, is an important dimension of experiences of providing care for others (e.g., Davies, 2001; Jowsey, 2011), as well as providing care for one’s own body, as demonstrated throughout this thesis. Both projects, so to speak, require the individual to orient themselves toward the needs, capacities, and wellbeing of some body. It struck me that some participants seem to experience an amplified sense of ‘otherness’ in relating with their own body because of the intense awareness of, attention to, and effort toward the body demanded by chronic illness. For example, Sarbajit regularly referred to his body as ‘telling’ him what it needs and wants. This observation could be pursued further through Helmhuth Plessner’s idea of “eccentric positionality”, which refers to the way in which we humans “...stand not only at the center of things, but over and against ourselves at the same time, in the middle and on the periphery at once,” (Prusak, 2006, p. 55). Living with chronic illness perhaps requires the individual to spend more time ‘standing on the periphery’ in relating with their body in order to care for it. For people with caregiving responsibilities as well as chronic illness, this may mean experiencing the everyday as being positioned in relation to two bodies (your own and someone else’s).

The caringscape framework (Bowlby, 2012; McKie, Gregory, & Bowlby, 2002) provided a useful heuristic device for detecting interactions between the spatio-temporal dimensions of these two projects: care for others and care for one’s own chronically ill body. The metaphor of the caringscape was useful for realising that many caregiving participants have two not-always-compatible ideals for organising everyday activities: one oriented toward the needs of others, and one oriented toward the needs of the chronically ill body. For example, Madeline has an ideal of constant availability for her mother’s care, but also has an ideal of keeping her kidney transplant healthy. This sometimes requires betraying the former ideal by temporally and spatially confining her mother’s care (see Davies, 2001, p. 143) in order to take time away
to rest (see Chapter 7.3.2.2). Conversely, many examples were seen where the participant’s ideal illness caringscape is compromised in order to enact the caregiving ideal. When unable to enact one of their ideal caringscapes, participants, like Madeline, expressed feelings of guilt, sadness, and distress.

Furthermore, the notion of carescape (Bowlby, 2012) sensitised me to the ways in which the terrain participants navigate in the everyday is shaped by the service and resource context of caring for others (e.g., child care centres; care services for ageing adults), as well as the service and resource context of their illness (e.g., health services access; dialysis transportation). For example, Jasmine’s terrain is shaped by the expensive school tuition for her children that is charged to non-permanent residents, which requires her to continue working while sick. Her terrain is further shaped by the doctor appointments that she tries to fit into working hours in order to preserve her ideal caringscape for her children and shield them from her illness (see Chapter 7.3.2.1).

Observing these two sets of caringscapes/carescapes in participants’ everyday lives offered insight into the processes and interactions through which role conflict can arise for people with chronic illness who provide care for others. In agreement with previous findings, participants expressed a sense of conflict between expectations held by others and themselves about their roles as a mother, daughter, father, patient, spouse, and/or sick family member (e.g., Lyons, 1993; Poole, Hare, Turner-Montez, Mendelson, & Skipper, 2014; Radtke & Van Mens-Verhulst, 2001; Sandelowski & Barroso, 2003; Thorne, 1990; Vallido, Wilkes, Carter, & Jackson, 2010; van Mens-Verhulst, Radtke, & Spence, 2004; Wilson, 2007). And, gender did factor substantially into these caregiving experiences (McKie et al., 2002), such as when Martin referred to his performance of the bulk of domestic household activities as making him ‘the stay at home mum’ (see Chapter 7.3.2.1.2). A space-time approach contributes to understandings of role conflict through the approach’s ability to identify situations on the space-time path where conflicts arise and activities are sacrificed, and then to trace these situations back into the space-time fabric of everyday life.

For example, James expressed his experience of role conflict between being a renal patient and a father with the statement: “It was dinner time, bed time, and no family,” (see Chapter 7.3.2.1.2). The deep sense of regret and sadness expressed in this statement arose from the divergence of James’ space-time path from those of his family members’ during the period of his life when he received dialysis at a clinic three evenings per week. For James’s family, as for many families (see Fiese et al., 2002), co-presence at home with family members during times like ‘dinner time’ and ‘bed time’ has highly symbolic, ritualistic value for doing
‘family’. James’ space-time path divergence from his family was due to the combined space-time constraints of needing to continue working in order to keep the family house, the space-time inflexibility of dialysis treatment, and the space-time inflexibility of his job, which required him to be present at the office and interact with co-workers in person.

In conclusion, the caringscape framework (Bowlby, 2012; McKie et al., 2002) can be usefully applied to understanding people’s experiences of caring for others while caring for their own chronically ill body, as it attunes the researcher to the interactions of space-times associated with bodily processes as well as the organisation of social institutions (Bowlby, 2012, p. 2110), and the ways in which experiences of role conflict can arise from these interactions. Further research can use this kind of space-time approach to examine potential role conflict in, for example, the experiences of the rising number of ageing adults who provide grandchild care for dual-income families (e.g., Young & Denson, 2014).

8.3.4 Leisure, recreation, and tourism

The findings from this study stress the importance of leisure activities for the wellbeing and quality of life of people living with chronic illness. I agree with Katz (Katz, 2004; Katz et al., 2009) that researchers and practitioners must take this category of activities more seriously, alongside obligatory and committed activities, such as eating and working. In fact, it is, I argue, the voluntary – rather than obligatory – nature of leisure activities that allows them to have such a positive influence on a person’s outlook on life with chronic illness. Bill’s statement that, “You have to claw something back for yourself,” (Chapter 7.4.2) provides a visual metaphor for the feeling that chronic illness takes away too many valued things, and that, too often, you have to deny yourself experiences due to illness.

Participant accounts of skilled leisure activities, in particular, reveal how valuable these activities and the places they occur are, not just for granting opportunities to passively experience pleasure, but for opportunities to voluntarily engage in a challenge, and to experience a heightened awareness of oneself at the border between ease and resistance (Sharpe, 2013). For example, Cathy’s decision to sit the exam to be a baking judge was not just about wanting to do an enjoyable activity (see Chapter 7.4.2.1). It was also about turning the tables on her illness, which for too long had been ‘throwing her’ challenges not of her ‘own choosing’, as she put it. Furthermore, Neal’s experience of ‘aliveness’ while motorcycling down a winding road provides an alternative experience of his body that contrasts with the ‘sick body’ that demands attention and care and limits ability (see Chapter 7.4.2.2). Furthermore, leisure activities provide opportunities for making knowledge (Crouch, 2000, p. 65) that facilitates adaptation to changes and uncertainties in life, such as those brought on by chronic
illness. Brian’s rich descriptions of outdoor rock climbing and ocean swimming demonstrated this link (see Chapter 7.4.2.2). He practices with fear through extreme sport to help him generate 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 (Chapter 7.4.2.2).

These “relational dimensions of the self-landscape encounter” (Conradson, 2005, p. 338) described by participants in leisure activities are important components of the therapeutic landscape experiences of chronic illness. The concept of therapeutic landscape (Gesler, 1992) is helpful for understanding the importance of place for, not only healing and recovery from illness (e.g., English, Wilson, & Keller-Olaman, 2008), but also maintenance of health and wellbeing (e.g., Williams, 2002). The chronicity of illnesses like CKD implies a need to live well with illness, as putting life ‘on hold’ until good health returns is not an option. Further research is needed to explore the potential of leisure in the therapeutic landscapes of chronic illness for encouraging wellbeing.

The space-time geographical approach aided me in understanding how chronic illness shapes participants’ leisure-scapes (Van der Poel, 1997), and the kind of encounter (Crouch, 2000) that takes place there. In addition to factors such as financial resources and normative regulation of behaviour within different settings (Van der Poel, 1997), the spatio-temporal characteristics of chronic illness symptoms and management also shape participants’ leisure-scapes. Previous research on chronic illness and leisure has found that reduced participation in leisure activities is due to barriers like needing to reconsider how to spend limited energy (Lyons, Lambert, Balan, Hegel, & Bartels, 2013), having less available time due to illness management activities (Katz, 2004), pain (Ahlstrand, Björk, Thyberg, & Falkmer, 2015), and decreased muscle strength (Marko, 2012). My findings stress barriers to leisure activities derived from logistical space-time conflicts, and difficulty synchronising with the space-time paths of others, due to the need to access health services, (e.g., dialysis and doctor appointments) and to avoid certain environments in order to protect the body (e.g., a sunny sports venue).

Furthermore, attention to relationships between rhythm, materiality, and the force of habit in participants’ accounts gave insight into the relational dimensions of leisure activities that make them so meaningful to participants. The notion of the body-brain-environment circuits of habit (Bissell, 2013) was useful in understanding how a shift or mutation in one of its components (e.g., changes to rhythms of the body) can disrupt the skilful performance of a
valued activity, such as riding a motorcycle, and associated experiences of flow (Csikszentmihalyi, 2000) and appropriated time (Lefebvre, 2004) (see Chapter 7.4.2.2).

Further research on relational encounter within therapeutic landscapes could draw productively from the concept of habit as applied in this study. For example, Conradson (2005) described the emergence of new dimensions of self-hood for guests of a rural respite care centre for individuals with physical impairment. These transformations of the individual involved the creation of new embodied intelligences that the individual was then able to enact within their home environment. For example, one participant experimented with taking greater risks on her scooter within the barrier-free environment crafted by staff at the centre. Through this, she developed the confidence to make solo trips on the scooter to her neighbourhood shops. These transformations in the individual emerged from within body-brain-environment circuits of habit circulating within the “space of experimentation” (Conradson, 2005, p. 345) provided by the unique environmental attributes of the centre.

The findings of this study highlight the importance of spaces of experimentation, more generally, for individuals to encounter themselves in relation with the world in new ways. The mastery of skills and knowledge acquired through embodied encounter in leisure activities helps participants adapt to and cope with the limitations and uncertainties of chronic illness. Humans need opportunities to engage in this kind of knowledge-making in order to develop resilience to life’s varying challenges, and this has implications for what is prioritised in the design of human habitats. For example, a substantial body of literature has explored relationships between access to green spaces in urban environments and outcomes such as positive mental health (e.g., Cohen-Cline, Turkheimer, & Duncan, 2015). 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 a mediator and confounder in this relationship (p. 524). However, the authors note that greater understanding of the mechanisms linking neighbourhood characteristics to mental health is still needed (Cohen-Cline et al., 2015, p. 528). Opportunities for knowledge-making through leisure, as described in participant accounts, may be an important link between environmental characteristics and mental health outcomes. This kind of knowledge-making requires spaces that facilitate, not only physical activity, relaxation, and socialising, but also experimentation, play, and ‘surround sound’ sensory engagement in order to support positive mental health. Creatively planning and developing these kinds of places in human habitats may encourage habit’s “fundamentally creative capacity that produces the possibility of stability in a universe in which change is fundamental,” (Grosz, 2013, p. 219).
8.4 Study limitations

There are several limitations that must be taken into account when considering the findings I have presented, which are derived from the qualitative case study design of this thesis. Firstly, the findings from this case study are based on the historically and contextually-informed experiences of participants with CKD in the Australian Capital Territory and nearby rural communities in Australia. As such, there are some causes for reservation as to the transferability of my findings. One notable consideration lies in the Australian health care system, which provides all Australians with free, rebated or subsidised hospital, medical, and pharmaceutical treatment (Australian Institute for Health and Welfare, 2013). This means that the affordability of health care for individuals is not directly linked to employment as in some other countries. This difference can change chronically ill individuals’ experiences with employment. For example, in the United States, chronically ill workers have experienced vastly decreased job mobility, or “job lock”, when dependent upon their employer for health insurance, compared to those not reliant upon an employer for health insurance (Stroupe, Kinney, & Kniesner, 2001). Furthermore, as indicated by the expansion of renal services in the ACT (Chapter 8.3.1), the contextual specificity of chronic illness experiences can vary by health service jurisdictions within, as well as between, countries.

Secondly, the specificities of CKD should also be taken into account when considering these findings. Experiences of individuals with chronic illness vary by the unique attributes of particular illnesses and their management. For example, the great degree of social stigma attached to chronic illnesses such as HIV/AIDS (e.g., Wilson, 2007), or the serious mobility challenges often associated with illnesses like multiple sclerosis (e.g., Thapar, Candy Bhardwaj, Bhardwaj, & Bhardwaj, 2001), are not typically as great a concern for individuals with CKD. In another example, the burden of illness management varies by disease stage, as well as by disease. In this regard, haemodialysis patients have been highlighted among chronically ill patients as experiencing a particularly great illness management burden, which includes the severe space-time constraints of dialysis treatment and the greatest oral medication burden of all chronically ill individuals (Browne & Merighi, 2010; Costello, 2012, p. 547). These kinds of illness and treatment attributes may shape the space-time context that an individual negotiates in everyday life in very different ways. Furthermore, chronic illness experiences vary by individual differences within the same chronic illness, such as severity, co-morbidities and life circumstances. However, many of the characteristics and circumstances that informed my participants’ experiences (e.g., spatio-temporal characteristics of work and health service arrangements, and disease stage and treatment circumstances) may provide insight into the
Chapter 8

kinds of space-time conflicts and difficulties that may be experienced by other people with chronic illness as they go about negotiating everyday activities.

A third important limitation of this study is the likelihood of participant selection bias. As noted in Chapter 4.3.2, participants were purposively sampled (Minichiello, Aroni, & Hays, 2008) for a range of characteristics, such as employment status and disease stage, that impact on experiences of chronic illness and shape a person’s everyday space-time context. The findings from this study clearly show that participants do a great deal of ‘juggling’ in everyday life due to the space-time constraints of chronic illness symptoms and management. Therefore, it is likely that the renal patients in the study setting who contend with the most severe space-time constraints in everyday life were less likely to volunteer for the data collection activities of this study, given the additional complexity this would add temporarily to everyday life. The implication of this study limitation is that the account I have provided of the space-time conflicts experienced by renal patients may not sufficiently indicate the extent of the problem for some individuals living with CKD.

Despite these limitations, this type of case study has considerable value in that it sensitises practitioners and researchers to the kinds of questions that are helpful to ask within their setting or disease context in order to improve services and treatments for chronically ill individuals. Technological advances have led to greater representational realism in space-time analysis (Neutens, Schwanen, & Witlox, 2011). However, qualitative inquiry allows researchers to engage with individuals as they encounter and experience the interactions and processes occurring in ‘real life’ situations on the space-time path that relate to health and wellbeing.

8.5 Conclusion

This thesis endeavoured to understand experiences of time, alongside space, in negotiating everyday life with chronic illness. Implicit in this aim is the idea that space-time is heavily implicated in what being chronically ill means as a lived, everyday experience. Findings from my case study do show that chronic illness shapes how individuals organise everyday activities in time and space, and influences the level of freedom they enjoy in moving through time and space in order to participate in activities.

It is also clear that various parts of everyday life have different spatio-temporal characteristics, and that these characteristics interact with one another as the individual negotiates their space-time path and engages with different contexts. For instance, often times, the space-time resource demands of paid work are rigid, being needed as a caregiver is hard to ‘contain’ in space-time, unpredictability in accessing health services is common, and habits that support medication, fluid, and diet regimens are vulnerable to spatio-temporal
disruptions in routines. The unfolding interactions between the space-times of different parts of life on the individual’s space-time path can lead to the emergence of experiences like ease, difficulty, frustration, feeling ‘stuck’, succeeding or failing in different life roles (e.g., parent), and feeling overwhelmed or in control in everyday life.

These kinds of emergent experiences likely inform a person’s overall sense of wellbeing, quality of life, social inclusion, productivity or purpose, and ability to explore the self in relation with the world while living with chronic illness. I propose, therefore, an important link between everyday experiences of space-time and quality of life with chronic illness. Because different people negotiate different spatio-temporal characteristics, depending on things like being a caregiver, or the type of job a person has, quality of life with chronic illness should be understood as deeply embedded within the particular spatio-temporal characteristics at play in a person’s life. It is vital, therefore, when framing the problem of chronic illness, that we incorporate individuals’ experiences of multiple dimensions and scales of space-time in our understandings.

Future work should continue to pursue embedded, embodied, and relational understandings of experiences of living with chronic illness. We should continue to broaden our analytical focus on the ‘problem’ of chronic illness in everyday life beyond the sick body or particular sites, such as the home, beyond the individual’s psychosocial assets (e.g., motivation), or their relationships with any particular social institution (e.g., health care providers or employers), and beyond any particular life role (e.g., parent). More holistic understandings are required in order to grasp the effects of the permanent, permeating, fluctuating, and sometimes invisible influence of the symptoms and management of chronic illness on different people’s lives in different places.
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References


References


References


References


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References


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References
References


Appendices

Appendix 1: Travel and activity diary
Thank you for your contribution to this study of the daily lives of individuals living with Chronic Kidney Disease! Please write down EVERY trip you make on your diary day, being as detailed as possible. It is best to write down each trip as soon as possible during your day so that you don’t forget things like the exact times and addresses.

Today's date: ____________

Where I started the day ([address]):

<table>
<thead>
<tr>
<th>Departing</th>
<th>Destination</th>
<th>Should arrive</th>
<th>Transportation</th>
<th>Actual arrival</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>What time are you leaving?</td>
<td>Where are you going? (Street Address or Intersection)</td>
<td>What time should you ideally arrive?</td>
<td>Drive my car, took bus route #34, got a ride from family/friend, took bicycle, walk, etc.</td>
<td>What time did you actually arrive?</td>
<td>What did you do there? Example: Bought groceries and talked on mobile with daughter. (Please include also talking on phone, using computer, etc.)</td>
</tr>
<tr>
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</tbody>
</table>

Chronic Kidney Disease and Daily Life Organisations Study - University of New South Wales & Canberra Hospital
Appendix 2: Chronic illness management inventory and self-assessment
<table>
<thead>
<tr>
<th>Activity related to chronic kidney disease</th>
<th>It was supposed to do this today?</th>
<th>If yes, how successful were you in doing this today?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Follow a low salt diet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follow a low fat or weight loss diet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Watch and limit my protein intake</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Watch and limit my potassium intake</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Watch and limit my phosphorus intake</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Watch and limit my fluid intake</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cut down on the alcohol I drink</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relax</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stop or cut down on smoking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Take medications for hypertension (blood pressure)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Take medications for cardiovascular problems (heart)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Take medications for cholesterol</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Take medications for aluminium (protein in urine)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Take phosphorus blocker medications</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Take medications on a certain schedule (e.g., before food)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Take (measured) blood pressure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Check my blood for sugar</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carry something with sugar in it as a source of glucose for hypoglycaemia (diabetes)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Take insulin injection or use insulin pump (diabetes)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attended a medical appointment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perform peritoneal dialysis at home during the day</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perform peritoneal dialysis at home at night</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perform homehaemodialysis at home</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perform homehaemodialysis outside my home</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (write here):</td>
<td></td>
<td></td>
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<tr>
<td>Other (write here):</td>
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<td>Other (write here):</td>
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<td>Other (write here):</td>
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<td>Other (write here):</td>
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<tr>
<td>Other (write here):</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Chronic Kidney Disease and Daily Life Organisation Study - University of New South Wales & The Canberra Hospital
Appendix 3: Demographic and health survey
<table>
<thead>
<tr>
<th>Demographic and Health Survey</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Age:</strong></td>
</tr>
<tr>
<td><strong>2. Race/Ethnicity:</strong></td>
</tr>
<tr>
<td><strong>3. Gender (circle one):</strong></td>
</tr>
<tr>
<td><strong>4. Is which state is your chronic kidney disease? (circle one):</strong></td>
</tr>
<tr>
<td><strong>5. What is your Glomerular Filtration Rate (GFR)? (circle one):</strong></td>
</tr>
<tr>
<td><strong>6. Do you receive dialysis treatment? (circle one):</strong></td>
</tr>
<tr>
<td><strong>7. In which year were you diagnosed with Chronic kidney Disease?</strong></td>
</tr>
<tr>
<td><strong>8. Do you work in paid employment? If ‘yes’ skip to question 10 (circle one):</strong></td>
</tr>
<tr>
<td><strong>9. If ‘yes’, what is your occupation?</strong></td>
</tr>
<tr>
<td><strong>10. Are you a student?</strong></td>
</tr>
<tr>
<td><strong>11. How many people are in your household (excluding yourself)?</strong></td>
</tr>
<tr>
<td><strong>12. Do you take care of anyone besides yourself on a daily basis? (example: children, disabled/old partner, aging parent, etc.):</strong></td>
</tr>
<tr>
<td><strong>13. Does someone help you care for yourself on a daily basis? (example: cooking, transportation, housecleaning, erruning, etc.):</strong></td>
</tr>
<tr>
<td><strong>14. Do you have access to a car that either you drive or someone else drives?</strong></td>
</tr>
<tr>
<td><strong>15. What is your household’s gross income per fortnight? (circle one):</strong></td>
</tr>
</tbody>
</table>

Chronic Kidney Disease and Daily Life Organization Study - University of New South Wales & Canberra Hospital
Appendix 4: Interview prompts
Interview Prompts

The interview will occur in a meeting held within a few days of collection of the Travel and Activity Diary and the Survey. The essential structure of the interview consists of asking the participant to ‘lead’ the interviewer through his/her travel and activity diary day. The following list of themes will help prompt the interviewer during this recounting of the diary day in order to meet the aim of the study.

1. Daily life organisation
   - What are the **origins behind the diary day activities**? (i.e., why did she/he do these activities?)
   - What **transportation** options does she/he have?
   - Does the individual have **help** from another person or persons in juggling daily life activities (if any)?
   - Where and when in the day did she/he feel **pressed for time**? Why?
   - Which **space-time constraints** contribute to these moments of feeling pressed for time? (i.e., lack of good transportation, inflexibility in where, when and how activities can be performed, difficulty in performing activities or making trips, lack of financial resources, the distances between activity locations, etc.)
   - In which moments of the day was she/he was supposed to **carry out self-management activities** (e.g., check blood sugar, limit salt intake, etc)? In which instances was she/he successful? In which was she/he less successful? Why?
   - **How (in)flexible is each self-management activity** in terms of where/when it can be performed?
   - Are there ways in which **treatment of Chronic Kidney Disease (CKD) shapes how she/he can organise her/his daily life** activities in terms of location, timing and sequence? If so, how does this have an impact on non-CKD related activities?

2. Exposure to places and situations in daily life
   - What **kinds of places and situations** does his/her daily path take him/her through? (i.e., waiting at a bus stop at night, walking through a pleasant park, eating with co-workers, etc.)
   - What is it about the **way his/her daily life is organised that causes her/him to be exposed** to these places and situations?
   - Were there instances on the diary day in which **being exposed to certain places and/or situations had an impact** on the way this individual managed her/his CKD?
• How did exposure this place influence self-management?
• Did the way that places and situations made the participant feel when she/he was experiencing them or anticipating them influence how she/he self-managed CKD on the diary day?

3. Habit and Practice
• To what extent is the individual aware of the origins of daily activities and the paths she/he takes through time and space? (i.e., to what extent is it habitual?)
• To what extent is the individual aware of how she/he reacts to places and situations she/he encounters? (i.e., to what extent is it habitual?)
• To what extent does the participant do activities in certain ways because she/he thinks that that is the socially acceptable way to perform the activity? (i.e., to what extent do socially encouraged practices drive the way daily life is organised and the paths the individual takes through time and space?)
Appendix 5: Recruitment letter
10 May 2016

Name: 
Address

Re: Invitation to participate in a study on daily life activities and Chronic Kidney Disease

Dear Name

I am writing to tell you about a collaborative research project between Renal Services ACT Health Directorate and the University of New South Wales. The study is being run by Julia McQuoid, MSc who is a PhD Student at University of New South Wales at Canberra.

The aim of the study is to understand the way a person's daily life activities are organized in space and time (i.e., where and when activities occur) and how that relates to the way that person self-manages their chronic kidney disease (for example, following a low salt diet, taking medications, performing dialysis, checking blood sugar levels, etc.). Results from this study could contribute to more personalized health services planning in area health services.

This study has been approved by ACT Health Ethics Committee. Your participation is voluntary and you can withdraw at any time.

Along with this letter you will find a ‘Participant Information Sheet’ which has more detailed information on the study and what it would mean to participate in the study. If you are interested in learning more about this study, please review the ‘Participant Information Sheet’ and register your interest with Patricia Johnson on:

Email: patricia.johnson@act.gov.au -or-

Phone: (02) 6244 2146

Thank you for your consideration.

Sincerely,

Dr. Girish Talaulikar
Appendix 6: Patient information sheet
PARTICIPANT INFORMATION SHEET

RESEARCH PROJECT

Patient Self-Management of Chronic Kidney Disease and Space-Time Organization of Daily Life

The aim of this study is to understand the way a person’s daily life activities are organized in space and time (i.e., where and when activities occur) and how that relates to the way that person self-manages their chronic kidney disease (e.g., following a low salt diet, taking medications, performing dialysis, checking blood sugar levels, etc.).

This study is being conducted by Julia McQuoid, MSc who is a PhD Student at University of New South Wales at Canberra. Ms. McQuoid’s office is located at University of New South Wales at Canberra, Building 22, Room 301, Northcott Drive, Australian Defence Force Academy, Canberra, ACT. Please feel free to contact Julia if you have any questions regarding this study.

Mobile: 0405 047 078
Email: j.mcquoid@unsw.edu.au

If you have any comments or complaints that you do not feel comfortable discussing with study staff, you may contact the ACT Health Human Research Ethics Committee as follows:

- Phone: 02 6205 0846
- Email: acthealth-hrec@act.gov.au

Canberra Hospital, Building 10 Level 6

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

1. ‘What is the purpose of this study?’

The purpose is to have a better understanding for the way the daily lives of individuals with chronic kidney disease are organized (e.g., what kinds of activities individuals have, how far apart activities are, the kinds of places activities occur, what kinds of transportation options the person has, how long activities take to perform, etc.), and how this daily life organization relates to how individuals self-manage their chronic kidney disease (e.g., monitor blood sugar levels, attend medical appointments, following a renal diet, etc.).
This information may help health service providers understand barriers that individuals with chronic kidney disease face in following their treatment regimens in daily life. It might also help service providers understand how the treatment regimens that they ask patients to follow can impact the rest of a person’s daily life activities.

2. ‘Why have I been invited to participate in this study?’
   You are eligible to participate in this study if you meet all of the following:
   1. You reside in the ACT or nearby communities (i.e., within a 2 hour drive of the ACT),
   2. You have been diagnosed with Chronic Kidney Disease (i.e., Chronic Renal Failure), and
   3. You do not identify as Indigenous Australian.*

   *Indigenous Australians are not included in this study because the study investigators believe that the experiences of Indigenous Australians regarding this topic can be better addressed in a separate study.

3. ‘What if I don’t want to take part in this study, or if I want to withdraw later?’
   Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with the staff caring for you.

4. ‘What does this study involve?’

   The activities of this study DO NOT interfere with your medical treatment.

   Study participants will be asked to:
   1) Fill out a brief survey regarding basic information about you,
   2) Fill out a travel and activity diary for two days (i.e., where you go, what you do, how you get there, arrival/departure times),
   3) Carry a Global Positioning System (GPS) device on those two days. The GPS will record where you go,
   4) Fill out a survey regarding your chronic kidney disease self-management activities at the end of each of the two days (e.g., following a low salt diet, taking medications, dialysis, checking blood sugar levels, etc.), and
   5) Have an interview with the researcher regarding how and why daily life activities are organized the way they are, and how this relates to self-management of chronic kidney disease. These interviews will be recorded and transcribed.

   This will require that you meet with the researcher at a location of your convenience on two separate occasions over a period as long as two weeks.

5. ‘How is this study being paid for?’
   The study is being sponsored by the University of New South Wales and is a not for profit research study. Participation in this study will not cost you anything. Participants will be given
a small ‘gift’ in the form of a gift certificate upon completion of the study as a thank you for their time and contribution to the study.

6. ‘Are there risks to me in taking part in this study?’
   - Risk #1: This study collects location-specific information about participants. This information consists of addresses of places where daily life activities are carried out (e.g., home, work, doctor’s office). It also collects the paths each participant takes on two sample days from a GPS logging device carried by the participant. This kind of location-specific information could potentially be used to identify participants if not protected.
     Strategy to reduce risk: Participant confidentiality will be protected by presenting location-specific information about participants in the results of the study in maps that do not contain streets or street names, and by labelling places where activities are carried out with generic place names (e.g., ‘work’, ‘dialysis’, ‘child’s school’), instead of specific place names (e.g., ‘Systematica’, ‘Belconnen Community Health’, ‘Canberra Girls’ Grammar School’).
   - Risk #2: This study asks participants to discuss their experiences managing Chronic Kidney Disease. This may involve discussing things like dietary and fluid guidelines, managing high blood pressure and diabetes, efforts to lose weight, dialysis treatments. Discussing these topics may cause distress for some individuals.
     Strategy to reduce risk: If a study participant becomes distressed for any reason during the course of their participation in this study, the chief investigator will encourage the participant to speak with a counsellor or psychologist and will have appropriate referral information for a counsellor or psychologist on-hand to give to the participant.
   - In addition to understanding the potential risks of the study and the strategies to minimize risk, please also understand that this study may not directly benefit you.

7. ‘How will my confidentiality be protected?’
   Of the people interacting with you for this study, Julia McQuoid or necessary others (e.g., medical staff involved in your care) will know whether or not you are participating in this study. Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. Only those listed above will have access to your details and results that will be held securely at University of New South Wales at Canberra in a locked filing cabinet or a password protected computer.

8. ‘What happens with the results?’
   Results from this study will contribute to the PhD thesis of Julia McQuoid at University of New South Wales at Canberra. Results may also be published in peer reviewed journals, authored by Julia McQuoid and collaborators, and/or presented at conferences.

   In any publication, information will be provided in such a way that you cannot be identified. Results will be provided to you, if you wish.
9. ‘What happens to my treatment when the study is finished?’
During the course of this study, there will be no changes to your medical treatment due to your participation in the study.

Decisions about your continuing care will be made in consultation between you and your treating doctor.

10. ‘What should I do if I want to discuss this study further before I decide?’
When you have read this information, the researcher Julia McQuoid will discuss it with you and answer any queries you may have. You are also able to take this information away with you and discuss with your family, friends, treating doctor or any other person you choose. If you would like to know more at any stage, please do not hesitate to contact Julia on:

Mobile: 0405 047 078   Email: j.mcquoid@unsw.edu.au

11. ‘Who should I contact if I have concerns about the conduct of this study?’
This study has been approved by the ACT Health Directorate Human Research Ethics Committee (or sub-committee). If you have any concerns or complaints about the conduct of this study, and do not feel comfortable discussing this with study staff, you may contact the Committee secretariat who is nominated to receive complaints about research projects. You should contact the secretariat on 6174 7968 or acthealth-hrec@act.gov.au

Thank you for taking the time to consider this study.

If you wish to take part, please sign the attached consent form.

This information sheet is for you to keep.
Appendix 7: Consent form
Consent Form to Participate in a Research Project.

1. _______________________________ (name of participant)

of _______________________________ (address)

have been asked to consent to my participation in a research project entitled: Patient Self-Management of Chronic Kidney Disease and Space-Time Organization of Daily Life.

In relation to this study I have read the Patient Information Sheet and have been informed of the following points:

1. Approval has been given by the ACT Health Directorate Human Research Ethics Committee. □

2. The aim of the study is to understand whether and how the way a person's daily life activities are organized in space and time (i.e., where and when activities occur) has any relationship with how that person self-manages their chronic kidney disease (CKD) (e.g., following a low salt diet, taking medications, dialysis, checking blood sugar levels, etc.) Chapter 9 - □

3. The results obtained from the study may or may not be of direct benefit to my medical management. □

4. The study procedure will involve: 1) filling out a brief survey regarding basic information about you, 2) filling out a travel and activity diary for two days, 3) carrying a Global Positioning System (GPS) device on those two days that will record where you go, 4) filling out a survey regarding your chronic kidney disease self-management activities at the end of each of the two days (e.g., following a low salt diet, taking medications, dialysis, checking blood sugar levels, etc.), and 5) having an interview regarding how and why daily life activities are organized the way they are, and how this relates to self-management of chronic kidney disease. This interview will be recorded and transcribed. □

5. Possible adverse effects or risks related to this study may include:

   Risk #1: This study collects location-specific information about participants. This information consists of addresses of places where daily life activities are carried out (e.g., home, work, doctor's office). It also collects the paths each participant takes on two sample days from a GPS logging device carried by the participant. This kind of location-specific information could potentially be used to identify participants if not protected.

   Strategy to reduce risk: Participant confidentiality will be protected by presenting location-specific information about participants in the results of the study in maps that do not contain streets or street names, and by labelling places where activities are carried out with generic place names (e.g., 'work', 'dialysis', 'child's school'), instead of specific place names (e.g., 'Systematica', 'Belconnen Community Health', 'Canberra Girls' Grammar School').
Risk #2: This study asks participants to discuss their experiences managing Chronic Kidney Disease. This may involve discussing things like dietary and fluid guidelines, managing high blood pressure and diabetes, efforts to lose weight, dialysis treatments. Discussing these topics may cause distress for some individuals.

Strategy to reduce risk: If a study participant becomes distressed for any reason during the course of their participation in this study, the chief investigator will encourage the participant to speak with a counsellor or psychologist and will have appropriate referral information for a counsellor or psychologist on-hand to give to the participant.

My involvement in this study may be terminated if I become unable or unwilling to complete the travel and activity diary, survey, and/or hold the interview for any reason.

6. Should I develop a problem which I suspect may have resulted from my involvement in this project, I am aware that I may contact Julia McQuoid on j.mcquoid@unsw.edu.au or 0405 047 078 (mobile).

7. Should I have any problems or queries about the way in which the study was conducted, and I do not feel comfortable contacting the study staff, I am aware that I may contact the ACT Health Directorate Human Research Ethics Committee Secretariat, on 02 6205 0846 via acthealth-hrec@act.gov.au

8. I can refuse to take part in this study or withdraw from it at any time without affecting my medical care.

9. Participation in this project will not result in any extra medical or hospital costs to me.

10. I understand that while the results of the research will be made accessible my involvement and my identity will not be revealed.

11. I have not participated in any other research study in the past 3 months.

After considering all these points, I accept the invitation to participate in this study.

Name: (please print) __________________________ Date: __________

Witness: (please print) __________________________ Date: __________

Signature (Participant) __________________________

Signature (Witness) __________________________

Signature (Investigator) __________________________
Appendix 8: Travel and activity diary results
TRIPS TAKEN FROM HOME

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<tr>
<th>AVERAGE NUMBER OF TRIPS (ALL PARTICIPANTS)</th>
<th>N</th>
<th>Total Trips</th>
<th>AvgNo.Trips</th>
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<tbody>
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<th>AvgNo.Trips</th>
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## TRANSPORT TYPES

### TRANSPORT TYPES (ALL PARTICIPANTS)

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### TRANSPORT TYPES BY DISEASE STAGE

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### TRANSPORT TYPES BY EMPLOYMENT STATUS (TOTAL NUMBER OF DIARIES)

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TRANSPORT TYPES CONTINUED...

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<th>exercise route</th>
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<th>shops &amp; other</th>
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### LOCATIONS VISITED CONTINUED...

#### LOCATION TYPES BY EMPLOYMENT STATUS

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<th>medical &amp; health</th>
<th>exercise route</th>
<th>friend/ family home</th>
<th>child activity</th>
<th>food outlet</th>
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<td>30%</td>
<td>30</td>
<td>50%</td>
<td>8</td>
<td>16%</td>
</tr>
</tbody>
</table>

#### LOCATION TYPES BY GENDER

<table>
<thead>
<tr>
<th>Gender</th>
<th>N</th>
<th>home</th>
<th>work</th>
<th>shops &amp; other retail</th>
<th>medical &amp; health</th>
<th>exercise route</th>
<th>friend/ family home</th>
<th>child activity</th>
<th>food outlet</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Ttl</td>
<td>%</td>
<td>Ttl</td>
<td>%</td>
<td>Ttl</td>
<td>%</td>
<td>Ttl</td>
<td>%</td>
</tr>
<tr>
<td>Female</td>
<td>24</td>
<td>24</td>
<td>100%</td>
<td>10</td>
<td>42%</td>
<td>14</td>
<td>58%</td>
<td>10</td>
<td>42%</td>
</tr>
<tr>
<td>Male</td>
<td>25</td>
<td>25</td>
<td>100%</td>
<td>9</td>
<td>36%</td>
<td>16</td>
<td>64%</td>
<td>10</td>
<td>40%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>49</td>
<td>49</td>
<td>100%</td>
<td>19</td>
<td>30%</td>
<td>30</td>
<td>50%</td>
<td>8</td>
<td>16%</td>
</tr>
</tbody>
</table>
### ACTIVITIES THAT MOTIVATED TRIPS

#### ACTIVITY TYPES RECORDED FOR TRIPS TAKEN (ALL PARTICIPANTS)

<table>
<thead>
<tr>
<th>All</th>
<th>N</th>
<th>domestic work</th>
<th>illness manag’t</th>
<th>leisure</th>
<th>paid work</th>
<th>caregiving</th>
</tr>
</thead>
<tbody>
<tr>
<td>All diaries</td>
<td>49</td>
<td>36</td>
<td>27</td>
<td>27</td>
<td>18</td>
<td>4</td>
</tr>
</tbody>
</table>

#### ACTIVITY TYPES BY DISEASE STAGE

<table>
<thead>
<tr>
<th>CKD Stage</th>
<th>N</th>
<th>domestic</th>
<th>illness manag’t</th>
<th>caregiving</th>
<th>paid work</th>
<th>leisure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Ttl</td>
<td>%</td>
<td>Ttl</td>
<td>%</td>
<td>Ttl</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>2</td>
<td>100%</td>
<td>0</td>
<td>0%</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>6</td>
<td>4</td>
<td>67%</td>
<td>3</td>
<td>50%</td>
<td>0</td>
</tr>
<tr>
<td>4</td>
<td>12</td>
<td>7</td>
<td>58%</td>
<td>6</td>
<td>50%</td>
<td>1</td>
</tr>
<tr>
<td>5D+</td>
<td>13</td>
<td>9</td>
<td>69%</td>
<td>10</td>
<td>77%</td>
<td>1</td>
</tr>
<tr>
<td>transplant</td>
<td>16</td>
<td>14</td>
<td>88%</td>
<td>8</td>
<td>50%</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>49</td>
<td>36</td>
<td>27</td>
<td>4</td>
<td>18</td>
<td>27</td>
</tr>
</tbody>
</table>

329
ACTIVITIES THAT MOTIVATED TRIPS CONTINUED (PART 1)...

<table>
<thead>
<tr>
<th>Employment</th>
<th>N</th>
<th>Domestic</th>
<th>Illness mg't</th>
<th>Caregiving</th>
<th>Paid work</th>
<th>Leisure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td>Ttl</td>
<td>Ttl</td>
<td>Ttl</td>
<td>Ttl</td>
<td>Ttl</td>
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<tr>
<td></td>
<td></td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Full time</td>
<td>13</td>
<td>11</td>
<td>85%</td>
<td>6</td>
<td>46%</td>
<td>1</td>
</tr>
<tr>
<td>Part time</td>
<td>8</td>
<td>6</td>
<td>75%</td>
<td>4</td>
<td>50%</td>
<td>0</td>
</tr>
<tr>
<td>Retired</td>
<td>20</td>
<td>12</td>
<td>60%</td>
<td>14</td>
<td>70%</td>
<td>0</td>
</tr>
<tr>
<td>Sick leave</td>
<td>4</td>
<td>4</td>
<td>100%</td>
<td>1</td>
<td>25%</td>
<td>2</td>
</tr>
<tr>
<td>Unemployed</td>
<td>4</td>
<td>3</td>
<td>75%</td>
<td>2</td>
<td>50%</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>49</td>
<td>36</td>
<td>27</td>
<td>4</td>
<td>18</td>
<td>27</td>
</tr>
</tbody>
</table>
### ACTIVITIES THAT MOTIVATED TRIPS CONTINUED (PART 2)...

<table>
<thead>
<tr>
<th>Gender</th>
<th>N</th>
<th>domestic</th>
<th>illness manag't</th>
<th>caregiving</th>
<th>paid work</th>
<th>leisure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Ttl %</td>
<td>Ttl %</td>
<td>Ttl %</td>
<td>Ttl %</td>
<td>Ttl %</td>
</tr>
<tr>
<td>Female</td>
<td>24</td>
<td>19 79%</td>
<td>13 54%</td>
<td>3 13%</td>
<td>10 42%</td>
<td>11 46%</td>
</tr>
<tr>
<td>Male</td>
<td>25</td>
<td>17 68%</td>
<td>14 56%</td>
<td>1 4%</td>
<td>8 32%</td>
<td>16 64%</td>
</tr>
<tr>
<td>Total</td>
<td>49</td>
<td>36</td>
<td>27</td>
<td>4</td>
<td>18</td>
<td>27</td>
</tr>
</tbody>
</table>