Published in final edited form as:
Soc Sci Med. 2017 June ; 183: 142–150. doi:10.1016/j.socscimed.2017.04.043.

Contextualising renal patient routines: Everyday space-time contexts, health service access, and wellbeing

Julia McQuoid, PhD[*],
Center for Tobacco Control, Research, and Education, Cardiovascular Research Institute, University of California, San Francisco; and School for Physical, Environmental, and Mathematical Sciences, University of New South Wales, Canberra. Postal address: 530 Parnassus Ave, Suite 366, San Francisco, CA, 94143 USA, Tel: +1 415-502-4882; Fax: +1 415-514-9346

Tanisha Jowsey, PhD, and
Centre for Medical and Health Sciences Education, The University of Auckland; and Health Services Research Department, Australian National University. Postal address: CMHSE, Auckland City Hospital, Building 599, Level 12, room 12.025. 2 Park Road, Grafton, Auckland 1023. New Zealand. Tel: +64 9 923 5113

Girish Talaulikar, FRACP, DM
Director, Renal Services. ACT Health. ACT, Australia; and Associate Professor of Nephrology, Australian National University (ANU) Medical School. Postal address: Australian National University, Acton, ACT 2601 Australia

Abstract

Stable routines are key to successful illness self-management for the growing number of people living with chronic illness around the world. Yet, the influence of chronically ill individuals' everyday contexts in supporting routines is poorly understood. This paper takes a space-time geographical approach to explore the everyday space-time contexts and routines of individuals with chronic kidney disease (CKD). We ask: what is the relationship between renal patients' space-time contexts and their ability to establish and maintain stable routines, and, what role does health service access play in this regard? We draw from a qualitative case study of 26 individuals with CKD in Australia. Data comprised self-reported two day participant diaries and semi-structured interviews. Thematic analysis of interview transcripts was guided by an inductive-deductive approach. We examined the embeddedness of routines within the space-time contexts of participants' everyday lives. We found that participants' everyday space-time contexts were highly complex, especially for those receiving dialysis and/or employed, making routines difficult to establish and vulnerable to disruption. Health service access helped shape participants' everyday space-time contexts, meaning that incidences of unpredictability in accessing health services set-off 'ripple effects' within participants' space-time contexts, disrupting routines and making everyday life negotiation more difficult. The ability to absorb ripple effects from unpredictable

---

[*] Corresponding author.

health services without disrupting routines varied by space-time context. Implications of these findings for the deployment of the concept of routine in health research, the framing of patient success in self-managing illness, and health services design are discussed. In conclusion, efforts to understand and support individuals in establishing and maintaining routines that support health and wellbeing can benefit from approaches that contextualise and de-centre everyday human behaviour. Opportunities to support renal patients in managing illness and experiencing wellbeing outside the clinical setting lie in a space-time re-design of chronic care services.

Keywords

routine; self-management; health services; chronic kidney disease; space; time; everyday context; dialysis

Introduction

Stable everyday routines are important for the general functioning, wellbeing, and health of all individuals and groups (Zisberg et al., 2007). They are the behavioural material out of which the shape and texture of everyday life takes form and evolves. They provide important functions in helping people create order, organise and automate activities, conserve energy, economise memory, more efficiently allocate finite resources such as time and money, and cope with and adjust to change (Zisberg et al., 2007).

With changing social demography and increasing longevity in countries like Australia, an increasing proportion of the population is living with chronic illnesses (AIHW, 2016). Specialist care for these conditions is still provided through a health service system designed primarily for acute care treatment. This system is characterised by co-location of facilities on large campuses designed to ease flow of clinicians between acute and chronic care areas with little consideration for the impact on stable everyday routines of chronically ill patients who must regularly access these facilities.

For people with chronic illnesses such as chronic kidney disease (CKD), routines are especially important because they are linked to the survival of chronic illness self-management activities like adhering to medication regimens, following a diet, and accessing health services (Wagner and Ryan, 2004, Takahashi et al., 2001, Bytheway, 2001). Yet, people with chronic illness often find it difficult to establish and maintain routines that support faithful repetition of activities that may slow progression of disease and optimise wellbeing. Little is known about how chronically ill people establish and maintain routines, but it has been proposed that patient difficulties with routines may be due to lack of support from healthcare professionals as well as the ongoing challenge of having to adapt and re-adjust routines as illness trajectories shift (Haslbeck and Schaeffer, 2009).

It is important to understand individuals’ attempts to establish and maintain supportive routines within the broader contexts of their daily lives. These contexts are informed by, for example, the constraints imposed by employment, volunteer organisations, and children’s extra-curricular activities on where (space) and when (time) people can organise activities.

In other words, each individual has a particular space-time context they navigate in going about routine activities in everyday life.

In recent decades, individuals' schedules and lifestyles have appeared increasingly heterogeneous and individualised (Shove et al., 2009, Southerton, 2009), with a documented increase in individuals' mobility and dispersion of activities in space and time due to faster transportation, information and communication technologies, and socio-economic shifts such as greater participation of women in paid work and the proliferation of 'non-standard' working schedules (Cummins et al., 2007, Neutens et al., 2011, Perchoux et al., 2013, Couclelis, 2009). Some people find it more difficult than others to establish supportive routines due to varying complexity of tasks in relation to temporal-spatial pressure and socio-cultural factors. Factors may include caregiving responsibilities, conflicting family member schedules and movements, work arrangements, residential location, and transportation options. The complex management of such factors has often been referred to using the metaphor of juggling (e.g., Schwanen and De Jong, 2008).

Costantini and colleagues observe that individuals with CKD have "diverse lifestyles", and that this diversity presents "unique challenges" to "generic treatment recommendations" (2008). For individuals with CKD, the high frequency of health service access required to manage illness (Agrawal et al., 2012) is likely experienced as another 'ball to juggle' in what may be an already complex juggling act of everyday activities. Appointments with nephrologists, cardiologists, and other specialists are usually made weeks or months in advance, and may require patients to travel long distances due largely to the few specialists available within a given geographic region. Additionally, long wait times at specialist appointments are common (Victoria State Government, April 2016). Furthermore, managing CKD often imposes an exceptionally high oral medication burden to juggle throughout the day, particularly for those with a kidney transplant, receiving dialysis, and/or having other diagnoses (Rifkin et al., 2010). Medications further complicate daily life when multiple prescriptions run out at different times, requiring patients to frequently request and collect medication.

Dialysis is arguably the 'heaviest' health service ball to juggle. Those requiring renal replacement therapy, especially clinic haemodialysis, usually contend with highly inflexible demands on their time and physical presence at a dialysis clinic according to a thrice weekly schedule of four to five hour blood-cleaning sessions. The start of a dialysis session may be delayed for various reasons, including the unavailability of the dialysis machine or staffing shortages. In short, health services and locations – the doctor's office, pharmacy, satellite haemodialysis centres, and so forth – critically inform people's experiences of *living with* CKD. When frequently-accessed health services breakdown, run over-time or become inaccessible to the patient, the patient may experience potentially negative ricochet effects felt throughout the constellation of routine activities established in their everyday life – such as eating well, working, exercising, pursuing meaningful hobbies, following a medication schedule, and taking care of dependent others.

Despite the challenges chronically ill patients experience in establishing supportive routines, health care practitioners rarely acknowledge or actively support patients in developing and maintaining supportive routines (Haslbeck and Schaeffer, 2009). The unpredictability patients often experience in the direct temporal costs of accessing health services (Gupta and Denton, 2008) may introduce more fragility and complexity into everyday routines, and this could come at a direct cost to patient wellbeing.

This paper explores the importance of (un)predictability in people's everyday experiences of living with CKD, and the ways in which health services inform these experiences. We ask, what is the relationship between participants' space-time contexts and their ability to establish and maintain stable routines, and, what role does health service access play in this regard? We draw from a multi-method qualitative case study of people's experiences living with CKD in the Australian Capital Territory and surrounding region. An integrative inductive-deductive thematic approach was used to examine the embeddedness of participant routines within the space-time contexts of their everyday lives, and to observe ways in which routines are modified over time and disrupted.

Routines and the space-time contexts of everyday life

Based on a concept analysis of *routine* within health literature from 1977–2005, Zisberg and colleagues propose: "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," (Zisberg et al., 2007). Health scholarship on the nature of routines is notably "sporadic and inconsistent," (Zisberg et al., 2007), leaving much to learn about how and why routines that can support wellbeing and health are formed, disrupted, and displaced within the lives of individuals and groups.

One under-researched area in this regard is the role of everyday contexts in the growth, maintenance, and demise of routines. Dyck (2002) examined relationships between routines, habit, and environment for Canadian women with chronic illness. She found that participants restructure everyday routines and environments in response to changes in their bodies and others' marking of their bodies as 'deviant'. Rowles (2000) explored habitual uses of place by older residents of a small American town, finding that changes to the physical and/or social environment shifted routines at the collective community level. In his exploration of health routines of university students with Type 1 diabetes in the UK, Balfe (2009) employed the concept of 'fields' in understanding how routines are shaped, understood as "sets of mutually-related structures, activities, institutions and groupings." Gallimore and Lopez (2002) emphasised the role of culture in shaping routines and habits. Furthermore, in their work on young Irish adults' self-management of diabetes, Balfe and colleagues (2013) noted that the temporal characteristics of workplaces influence diabetes management routines. Several authors also noted that institutions of care, such as hospitals and homeless shelters, sometimes alter clients' and patients' routines such that readjustment to the home environment after leaving these institutions is more difficult (e.g., Borell et al., 1994, Schultz-Krohn, 2004).

Finally, insights into relationships between everyday contexts and the routines and practices of care are found in the caringscape/carescape framework (Mckie et al., 2002, Bowlby, 2012). Caringscape refers to “individuals’ organisation of their caring activities in time-space,” while carescape refers to “the resource and service context shaping the ‘caringscape terrain’” (Bowlby, 2012, p. 2112). Although this framework focuses on caregivers of dependent others rather than on individuals managing their own illness, both groups likely experience many of the same social relationships, practices, experiences, policies, and services of care highlighted by the authors (Bowlby, 2012). The framework stresses how time and space are each integral to care and caregiving relationships, citing the timescale of the human life course, the role of memory and habituation, embodied temporalities (e.g., bodily rhythms), logistical considerations of care, experiences of spatial confinement, and problems of spatial access (Bowlby, 2012).

Similarly, the conceptual starting point for our analysis of the routines of individuals with CKD is the premise that, due to the inherently temporal and spatial nature of routines, a framework for understanding the spatial and temporal characteristics of the environments in which they circulate is required. We refer to these dynamic, everyday environments as *space-time contexts* (see Schwanen and Kwan, 2012 on the entwined nature of space and time). While people experience space and time in many different ways in everyday life (Adam, 2013, May and Thrift, 2001) we simplify this diversity for the sake of analysis into: 1) space-time as a logistical resource needed to perform everyday activities (Hägerstrand, 1970, see also Rainham et al., 2010), and 2) space-time as rhythms that circulate within everyday environments and shape everyday life through repetition (see Lefebvre, 2004, Edensor, 2010a).

Space-time as a resource refers to the negotiation of the cultural constructs of clock/calendar time and universal space, both of which are conceived as absolute and external to the individual. Here, time is understood as progressing linearly at a predictable pace, and space takes on Cartesian properties with universal coordinates and distances.

Space-time resources shape, and are shaped by, social practice (Shove et al., 2009). For example, most doctors require patients to be present at the office waiting room, whether the doctor is running on time or not. As such, patients ‘spend’ space-time resources travelling to and accessing health services which, for some working individuals, may have to be ‘paid back’ to their employer if spent during working hours. Experienced this way, space-time is an important logistical resource needed to perform activities, and is finite and often in short supply. All activities have certain appetites for space-time in the absolute sense, and most have ideal locations and times for their performance (Hägerstrand, 1970, Shove et al., 2009). Thereby, regular activities consume, compete for, and shape the space-time contexts of people’s daily lives.

Space-time geography has long been concerned with understanding logistical constraints on and affordances to a person’s access to space-time resources, and ways in which their path through time and space, or space-time path (Hägerstrand, 1970), is shaped. For example, individuals relying on public transportation in American cities are likely to experience reduced speed and route selection, and thus, greater constraints on everyday activity participation, than those with a car (e.g., McQuoid and Dijst, 2012). In another example, the paths of people and instrumental objects often need to come together in time and space to complete an activity, as in the space-time coordination of machine and patient needed for haemodialysis therapy. In a final example, an individual's space-time path can be constrained by power relationships that regulate access to activity locations (Dijst, 2009), as in the case of an employee who feels compelled to prove themselves to their supervisor and therefore does not use legally entitled sick time when unwell.

The second experience of space-time embraced in our analysis – rhythm – is the embodied experience of repetition and difference in everyday life (Lefebvre, 2004). Rhythmanalysis offers an account of the synchronic practices that are the focus of time geography, but foregrounds the body, allowing "spatial qualities, sensations and inter-subjective habits" (Edensor, 2010b) to come to light. Rhythms are found, for example, in work schedules, seasonal patterns of influenza, the body's hunger, shopping centre crowds, night and day. Each rhythm is linked to its own place, and within a given place (or body), multiple evolving rhythms abound (polyrhythmia), playing in harmony (eurhythmia) or in discord (arrhythmia) (Lefebvre, 2004). These dynamic entanglements of rhythms are important components of people's everyday contexts, though not as readily apparent as the built environment or population density, for example. Thus, despite their ubiquity, rhythms wield particular power within individuals' lives because they often escape reflection and critique (Edensor, 2010b, see also Davies, 1994, Jowsey, 2016). Rhythms may have the capacity to increase or decrease the level of effort required to perform everyday activities, such as illness management, encouraging easy repetition or disrupting the mindless flow of routine. In short, the repeating, patterned behaviours of routines – and the sense of wellbeing and health that can be derived from routines – must be understood as playing out within the dynamic space-time contexts of renal patients' everyday lives and the logistical and rhythmic forces that shape them.

Methods

Participant recruitment and ethics approval

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

Participant characteristics

Twenty-six individuals (13 women and 13 men) participated in this study (see Table 1: Participant demographics). Sixteen were of working-age at the time of the study (ages 18 to 64 years). Of these working-age participants (nine women and seven men), eight worked full-time, four worked part-time, two were unemployed, and two were retired. The remaining ten participants (ranging 66 to 85 years) were retired, with the exception of one pro-bono consultant. All five disease stages, from very early stage CKD to End Stage Kidney Disease (ESKD) with dialysis, as well as individuals with a functioning kidney transplant, were represented in the working-age sub-set. All participants were required to regularly perform illness management activities (e.g., medication schedules, doctor appointments, diet restrictions, monitoring blood sugar, dialysis).

Study design and methods

In order to learn about participants' experiences of interacting space-time dimensions of everyday life, we 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).

Following Schwanen (2006), data were gathered pertaining to participants' everyday activities, the constraints and affordances experienced in how they can organise what, where, when, and how to perform activities, and rhythms circulating within everyday contexts and the body. Data on participants' movements between locations and activities performed over two sample days were recorded by participants on paper travel and activity diaries (see McQuoid et al., 2015, supplementary materials). The diaries provided a general picture of the number, types, and temporal demands of activities participants juggle (e.g., chauffeuring children, paid work, doctor appointments, volunteering), where these activities are located, and the transportation used. At the end of each sample day, participants completed a CKD management inventory of activities related to managing their illness and comorbid conditions, and rated the level of success they felt they had had in performing each activity (see McQuoid et al., 2015, supplementary materials). After searching for an existing, validated CKD management inventory, an inventory was created by reviewing the CKD management literature (Green and Ryan, 2009, Levin et al., 2008, National Kidney Federation, 2012). The inventory was checked for accuracy by a nephrologist working within the study context.

Participants were interviewed the day following the sample days, or in a few cases, within a few days, as was convenient for the participant. Initially, only one day was sampled in order to minimize data collection burden for participants. However, a pilot study of three participants revealed that variable schedules (i.e., dialysis treatment days versus non-dialysis treatment days) and fluctuating states of the body from day-to-day required a longer time sample from each participant. The remaining 23 participants provided two sample days, and those receiving dialysis were asked to sample both a non-dialysis and a dialysis day.

Interviews

The first author conducted the interviews. Most lasted 90 to 120 minutes (range: 1–3 h). Participants were asked to select the most convenient and comfortable location, providing it allowed for privacy and minimal noise. Most interviews were conducted in participants' homes, with others occurring in meeting rooms at participants' workplaces or university campuses, dialysis clinics, and one at a cafe.

The interviewer familiarized herself with the content of the diaries and inventories by reviewing and clarifying what participants had recorded at the beginning of each interview. A semi-structured interview format was undertaken in which the participant was asked to 'lead' the interviewer through the sample days. Participants were asked to provide such vivid ‘play-by-play’ detail of their activities, movements, and experiences that someone could make a movie of their day. 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.

Analysis

Interviews were audio recorded, transcribed verbatim, and then coded by the first author with the aid of QSR Nvivo10 qualitative data analysis software. Memos of initial impressions of the data were kept throughout data collection, transcription, and initial coding. Thematic analysis followed an integrative inductive-deductive approach (Bradley, Curry and Devers, 2007). An initial list of codes was developed during data collection, guided by the literature. Emergent themes in the data were accommodated by revisiting the literature and modifying the initial code list. Following Saldaña (2012), thematic analysis was undertaken in which repeated readings of the data was followed by grouping content to summarize literature-based and emergent themes.

For example, a key literature-driven focus of analysis was on the logistical space-time resource demands participants experienced in different parts of their everyday lives (Hägerstrand, 1970, Dijst, 2009, Rainham et al., 2010). However, during the coding process, the relevance of the repetitions of actions, intensities, and sensations in participants’ everyday lives to their experiences of living with CKD also emerged. After consulting the literature on rhythms (Lefebvre, 2004, Edensor, 2010a), codes for rhythms and their characteristics were integrated into the code list.

After repeated transcript readings and modifications to the code list, all transcripts were coded according to: 1) everyday activities (e.g., illness management, paid work, caregiving for dependent others, leisure); 2) spatio-temporal characteristics of everyday activities/ bodies/contexts (e.g., space-time resource demanding, rhythmic, (in)flexible, fluctuating, (un)predictable, (ir)regular, cyclical, episodic, (in)frequent, (im)mobile); 3) the origins of spatio-temporal characteristics (e.g., an ‘on-call’ work schedule that creates irregular work rhythms); and 4) spatio-temporal interactions between everyday activities/bodies/contexts (e.g, space-time resource conflicts, arrhythmias).

The first author exported the coded transcript content from QSR NVivo into Microsoft Word (everyday activities; spatio-temporal characteristics and their origins; and interaction of spatio-temporal characteristics). She 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, the first author developed an understanding of participants’ experiences of establishing and maintaining routines which integrated illness management and other everyday activities. These findings were then discussed by the whole team. The findings reported below focus on the role of health services in participant experiences.

Findings

In the sections below, we draw from participant accounts to describe: 1) the experience of everyday life with CKD as a complex juggling act due to space-time resource conflicts and arrhythmias between illness management and other everyday activities; 2) the particular space-time resource burden of factoring in frequent health service access into everyday life; and 3) experiences of unpredictability in accessing health services, as in having to spend longer than expected getting a prescription filled or seeing a doctor. Finally, we draw from a participant example to demonstrate that the ability to accommodate and absorb health service unpredictability into everyday life can vary by the particular conuration of an individual's space-time context.

Complex juggling act

For most participants, everyday life with CKD is experienced as a complex juggling act. This experience arises from space-time resource conflicts and arrhythmias between activities of managing illness and those of other parts of everyday life (e.g., paid work, leisure). Within this complexity, many participants find it difficult to establish and maintain stable routines that make it easier to juggle illness management with the rest of life, such as caring for others, working, and finding enjoyment through leisure. Illness management activities are space-time resource demanding, especially for those with ESKD, those who manage comorbid conditions (e.g., diabetes), and/or are living with a kidney transplant. These heavy space-time resource demands make everyday life organisation more complex and increase the likelihood of having to choose between and sacrifice otherwise routine activities. For example, 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 tasks, leisure, and other activities put-off for dialysis.

A particularly difficult juggling act is faced by participants who are employed and receive dialysis. Bernard's (age 40, public servant, clinic dialysis) space-time path, for example, is currently constrained by 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 to lose weight to qualify for a kidney transplant. The non-negotiable blocks of time occupied by work, dialysis, and exercise 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. The logistical complexity of his space-time context makes it difficult to establish routines wherein the puzzle pieces of everyday activities, such as buying groceries, exercising, or spending time with family members, come together with ease over the course of the week.

The embeddedness of participants' routines within their everyday space-time contexts was also evident with respect to the rhythms circulating within different environments. Medication adherence is one case in point. Participants' home environments typically offered more stable, predictable rhythms on which to 'hook' medication schedules, meaning that less effort is required to remember to take doses on time. Work environments, in contrast, are often subject to unpredictability in where and when participants are when they should remember to take their medication, as when a work meeting is called during a dosing time (see McQuoid et al. 2015, p. 89). Exercise routines important to managing CKD can also be disrupted by irregular rhythms in particular environments. For example, Mike, a transplant recipient in his early thirties, works for a political organisation. The intensity of his work is linked to the events of national political cycles, creating patterns of growth and decay in work rhythms. During slow times he is guaranteed a regular, flexible hour lunch break during which he regularly goes to the gym. During busier periods, he does not break for lunch and skips the gym to eat at his desk. When rhythms shift and work demand subsides again, Mike finds he faces an uphill battle to re-establish the workout in his daily routine:

> 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.

These types of difficulties in establishing and maintaining routines were echoed between many participant accounts, reflecting the complex juggling act of everyday life for many with CKD. It is well-known that people with chronic illness access health services with much greater frequency than the general population. What role, then, do health services play in shaping participants' everyday space-time contexts and their success in establishing and maintaining routines?

Factoring in health service access

Participants' travel and activity diaries reveal the extent to which they must accommodate the space-time demands of health service access into daily life. Health service locations were among the most common locations visited on sample days, second only to shops/retail, and ahead of workplaces. Health services location visits were much more common among participants with ESKD; 77% visited a health services location on at least one of their two sample days. Still, 33% of participants in stage 4 CKD, 31% of those with a functioning transplant, and 17% of those in early stage (2–3) CKD visited a health services location on at least one of their sample days. Health care locations included visits to specialist clinicians, laboratories to have blood work done, dialysis clinics, and trips to the chemist to refill drug prescriptions that run out at different times. In fact, several participants recorded additional travel time on their sample days in order to drive to distant chemists with better drug prices. 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."

Unpredictability in accessing health services

Another theme among participants was the ways in which unpredictability in health service access exacerbates this already complex juggling act of managing illness along with the rest of life. Having to spend longer than expected getting a prescription filled or seeing a doctor, for example, can generate ripple effects that disrupt other areas of participants' everyday space-time contexts unless routines are modified in anticipation of this kind of unpredictability. Cathy (age 69, pensioner, home dialysis), for example, finds that not knowing how long health services appointments will take means she can be less ambitious about what she plans to accomplish or enjoy within in any given week. She schedules all doctor appointments on non-dialysis days because she cannot predict if she will be able to get home soon enough to dialyze after appointments. This means that Cathy is further constrained in what she can do aside from managing illness in her retirement years:

> 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 [of] 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 unaccounted for “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 three 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 with the doctor. While frustration with unpredictable waiting times was a common theme among participants, many participants did express understanding about having to wait to see the doctor in the event that another patient has medical needs more urgent than their own.

Diverse space-time contexts

Finally, participant accounts suggest that differences between patients’ space-time contexts may influence how difficult it is for them to integrate health service access into everyday life and absorb the ripple effects that flow from doctor appointments, lab tests, and other health services that take longer than expected. Karen (age 26, full-time public servant, functioning kidney transplant) illustrated this as she compared and contrasted her experiences managing her kidney transplant within two very different space-time contexts. These differences, described below, were shaped by contrasting working conditions, health care scheduling arrangements, transportation options, and urban environments.

At the time of the study, Karen was working a standard ‘9-to-5’ job in suburban Canberra. Prior to this, she worked irregular work shifts in inner-city Brisbane. In Brisbane, physically getting to the doctor was more difficult than in Canberra. A trip to the doctor required a 45 minute bus ride, whereas in Canberra she arrives by car in 15 minutes. More importantly, Karen sometimes did not receive the week’s work roster in Brisbane until a couple days before the week began, meaning that an appointment scheduled months earlier with her kidney specialist sometimes landed on her work shift. Because her supervisor discouraged roster change requests, Karen could only keep these appointments if she found a colleague to swap shifts with. Compounding this, Karen’s specialist in Brisbane operated on a ‘first come first serve’ basis, resulting in wait times of up to three hours. Sometimes in order to arrange her shifts to accommodate one of these lengthy doctor visits, Karen worked difficult or extended hours, such as ending a shift at 11pm and starting another at 7am the next morning.

In her current job in Canberra, in contrast, Karen’s responsibilities can be taken over by a colleague if she needs time off for her health: “They can just hand over what I’m doing if it’s busy or whatever.” Her current job has “flex-time”, meaning any hours worked in a day over the standard 7.5 hours accrue for time off on another day. 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 is not unusual; Karen gave the example of long celebratory lunches taken with flex-time by her colleagues. Furthermore, her Canberra specialist assigns set appointment times, making it easier to predict how long appointments will take. Even so, her specialist is often behind schedule, “as all doctors are”, and Karen cannot get an early morning appointment with this particular specialist, meaning she must “break up” her work day after arriving and settling in at work to leave for appointments. Karen’s example shows that differences between the space-time contexts patients navigate can inform the level of difficulty they experience accommodating the space-time demands of health services and absorbing unpredictability in health services without disrupting routines.

Discussion

This paper contributes to our understanding of the role of everyday contexts in the growth, maintenance, and demise of health- and wellbeing-related routines. In doing so, it advocates for a deeper engagement with patients and their carers in design of chronic health care delivery systems. We explored the relationship between renal patients’ everyday space-time contexts and their ability to establish and maintain stable routines, and the role health service access plays in this regard. Participant accounts strongly suggest that poorly run health services are not only an inconvenience for patients, but potentially undermine the ability of chronically ill individuals to promote their own health and wellbeing.

Our findings highlight the frequent interactions renal patients have with health service providers and the flow on impact this has on everyday life activities and wellbeing. They suggest that people with CKD strive to create routines to help ease the juggling act of everyday life with chronic illness; that health services are a shaping force in participants’ already complex everyday space-time contexts; that participants' routines often evolve over time to accommodate health service unpredictability; and that space-time contexts can vary between patients, with these differences shaping the extent to which patients can absorb the ripple effects of health service unpredictability into other areas of life without disrupting routines.

Beyond the chronically ill population, participant accounts suggest the importance of the spatial and temporal characteristics of everyday environments in understanding the survival of routines related to health and wellbeing, more generally. Their routines did not appear as repeating, patterned behaviours operating in isolation; they were clearly embedded within the dynamic space-time contexts these individuals navigate in everyday life. This suggests that investigations into the establishment, maintenance, disruption, and evolution of routines linked to health and wellbeing (Zisberg et al., 2007) must contextualise routines within environments shaped by – not only factors such as culture, social norms, and changes to the physical environment (e.g., Dyck, 2002, Rowles, 2000, Balfe, 2009, Gallimore and Lopez, 2002) – but also the logistical and rhythmic forces that shape the space-time contexts people navigate in the everyday (see also Balfe et al., 2013, Takahashi et al., 2001).

De-centred approaches, such as the space-time geographical thinking applied here, offer novel insights into the struggles and successes of patient self-management of chronic illness. Most commonly, understandings of patient success in self-managing chronic illness emphasise individual-level factors, such as whether the individual has or lacks motivation or a sense of self-efficacy in managing illness symptoms and treatments (e.g., Curtin et al., 2008). Broadening the focus of analysis to also consider interactions between the individual and their space-time context reveals other complexities in establishing and maintaining supportive routines – complexities not bound to the individual level. While a juggling act like managing chronic illness can become a relatively mindless habit over time, freeing-up the juggler to do other things with their attention and energy, the juggler will almost certainly struggle and possibly falter when walking on unstable or shifting ground. Further research should explore the individual-environment interactions that can harness or hinder the force of habit in helping individuals adapt to the unique challenges of life with chronic illness (see Grosz, 2013).

On a more practical level, the apparent role of health services in shaping participants' everyday space-time contexts and disrupting routines calls for improvements to chronic care service delivery. Our findings suggest that space-time constraints surrounding health service access influence where, when, and how other activities in everyday life can be performed by many chronically ill patients. Not surprisingly, this seemed especially true for participants who most frequently access services, including dialysis, as well as those subject to the inflexible space-time constraints of employment. In Australia and many other countries, governments and health service providers repeatedly identify equity of access to health services, spatial proximity of care to patients' homes and workplaces, and patient participation in their own care delivery as desired objectives. These have resulted in the introduction of new models of care, such as community-based palliative care (Rosenwax et al., 2015), Hospital in the Home (Victoria State Government, 2016), and home dialysis. Whilst these have helped make progress in changing the organisation of health service delivery, they have not made a substantial difference in the way chronic care is provided to the vast majority of patients.

Reducing complexity in chronically ill patients' space-time contexts via better chronic care delivery design may support these individuals in establishing and maintaining stable routines that facilitate illness management and wellbeing outside the clinical setting. When the constraining effects of health services on other areas of life are exacerbated by unpredictable health service access, the ripple effect felt within patients' space-time contexts may result in instrumental or meaningful activities being sacrificed or disrupted (see also Klitzman, 2007). There is, therefore, an opportunity for health services to support patient wellbeing and health by: 1) reducing the space-time demands of health service access, and, 2) improving the level of predictability patients experience in where, when, and for how long they will need to access services.

Some challenges to reducing space-time demands and unpredictability for patients lie in the fragmented design of health service delivery systems. In particular, poor information flow has entrenched in providers a lack of trust in the patient information they receive from other providers, leading to unnecessary duplication of information and poor anticipation of patient needs. Reliance on paper medical records, resistance to using electronic records, legal restrictions on access to health records, as well as the high costs of developing health service infrastructure that reduces travel distances for patients are additional challenges. Finally, in sparsely populated geographic regions (e.g., rural Australia and Canada) the economies of scale do not justify developing health care delivery systems, such as dialysis units, closer to patients' homes.

Within the study setting of Canberra, however, renal health care practitioners are establishing service changes aimed at reducing the space-time costs of service access for renal patients (ABC News, 2015). The year after data collection for this study ended, haemodialysis clinics in the Australian Capital Territory began expanding opportunities to dialyse, with the goal of creating more flexibility for dialysis patients. More nocturnal dialysis options and self-care centres have been created where renal patients have swipe cards that allow them to dialyse when they choose instead of by appointment. The service also intends to implement strategies to optimise care coordination between multiple health care practitioners to enable dialysis patients to meet with a range of specialists while they dialyse. The service has also opened nephrology clinics in multiple community health centres across the region to facilitate ease of access and allow access to care at multiple locations. It would be valuable to conduct a follow-up space-time geographical study of renal patients in this setting in order to evaluate if and how these initiatives to promote patient-oriented flexibility influence patients' experiences of managing illness and sense of wellbeing in the everyday.

Finally, our findings suggest that patients may differ in the complexity of their space-time contexts, and, therefore, their ability to absorb the ripple effects of unpredictable health service access into other areas of life without disrupting routines. Quantitative space-time geographical analyses would be of value in measuring differences between patients' space-time accessibility and activity patterns (e.g., Kwan, 1999, Rainham et al., 2010) in order to identify those for whom health service access imposes the greatest burden within their everyday space-time contexts, and for whom routines are most vulnerable to disruption by unpredictable service access. These studies could compare everyday space-time activity patterns of chronically ill and healthy individuals, individuals with different chronic illnesses, those at different stages of disease progression, and individuals with different activity types, locations, and time constraints. With this knowledge, health systems modifications could be targeted to better accommodate the space-time constraints of the most space-time vulnerable patients.

Limitations

The transferability of our findings is limited by several factors. First of these are the particular characteristics of the study context. Canberra is easy to navigate by car as compared to congested urban environments such as Sydney or Los Angeles. This facilitates mobility between service locations, meaning that service changes such as co-locating haemodialysis and specialist appointments may not be feasible in other settings.

Second, experiences of individuals with chronic illness vary by the unique attributes of particular illnesses and their management. For example, serious mobility challenges often associated with illnesses like multiple sclerosis (Thapar et al., 2001), are not typically as great a concern for individuals with CKD.

Third, this study did not provide a detailed examination of how and to what extent a variety of individual characteristics and situations (e.g., gender, financial resources, transportation options, retirement activities, disease stage, co-morbidity, employment status, caregiving responsibilities) might drive differences between renal patients in terms of the complexity of their space-time contexts and their vulnerability to disruption of routines. Among our participants, those receiving dialysis and/or employed seemed to express the most difficulty in juggling everyday activities and maintaining stable routines. This is likely due to the highly inflexible space-time demands made by employers and dialysis clinics.

Other individual characteristics and obligations may also influence renal patients' experiences with everyday routines and health service access. Financial resources, for example, warrant further investigation, though they were not a strong theme in participants' accounts of juggling everyday life and accessing health services. This may be due to the Australian health care system, which has no out of pocket expenses, and the fact that, like most Canberran residents, virtually all participants had access to transportation by car, facilitating ease of movement to and from health service locations (Gordon, 2011). This contrasts with other cities, such as San Francisco, in which a clear transportation disadvantage is experienced by low-income people reliant upon slow and unreliable public transportation as compared to those who can afford to travel by car (McQuoid and Dijst, 2012). The potential influence of caregiving responsibilities on renal patients' routines and experiences of accessing health services should also be examined further. These responsibilities are an important driver of differences in space-time demands between men and women (Kwan, 1999). Caregiving in our sample was relatively low: seven had current caregiving responsibilities or described past caregiving responsibilities after the onset of

CKD. Caregiving and gender may emerge with more salience within a sample with more caregivers.

A fourth limitation is the likelihood of participant selection bias, as the renal patients who contend with the most severe space-time constraints in everyday life were probably less willing or able to volunteer for data collection activities. Therefore, the accounts of space-time conflicts provided here may not sufficiently indicate the extent of the problem for some renal patients in the study setting. Despite these limitations, the value of this type of case study is that it can sensitise 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.

Conclusion

In conclusion, efforts to understand individuals' successes and struggles with everyday routines linked to wellbeing, treatment of illness, and maintenance of health can benefit from approaches that contextualise and de-centre our understandings of everyday human behaviour. The space-time geographical approach taken in this case study of individuals with CKD highlighted the importance of patients' everyday space-time contexts to the establishment and survival of routines and illuminated the influence of health service access in shaping their everyday space-time contexts. Opportunities to support renal patients in managing illness and experiencing wellbeing outside the clinical setting lie in a space-time re-design of chronic care services that minimises space-time demands and unpredictability in health service access for these individuals.

Acknowledgments

The authors extend their gratitude to the participants of this study for generously sharing their time and experiences. This research was conducted with financial support from University of New South Wales, a National Cancer Institute Training Grant 2T32 CA113710-11, and recruitment assistance from Ms Patricia Johnson and The Canberra Hospital. The authors thank Dr Amy Griffin for feedback on earlier versions of this paper.

References

ABC NEWS. Kidney dialysis treatment sees major overhaul in ACT, as need for services dramatically increases. ABC. 2015. 23 Sep 2015. http://www.abc.net.au/news/2015-09-23/act-dialysis-treatment-sees-overhaul-as-patient-numbers-grow/6800142

ADAM, B. Timewatch: The Social Analysis of Time. Oxford: Polity; 2013.

AGRAWAL V, JAAR BG, FRISBY XY, CHEN SC, QIU Y, LI S, WHALEY-CONNELL AT, MCCULLOUGH PA, BOMBACK AS. Access to health care among adults evaluated for CKD: Findings from the kidney early evaluation program (KEEP). American Journal of Kidney Diseases. 2012; 59:S5–S15. http://dx.doi.org/10.1053/j.ajkd.2011.10.043. [PubMed: 22339901]

AIHW. Australia's health 2016. Canberra: AIHW; 2016. Australia's health no 15 Cat no AUS 199

BALFE M. Healthcare routines of university students with Type 1 diabetes. Journal of Advanced Nursing. 2009; 65:2367–2375. DOI: 10.1111/j.1365-2648.2009.05098.x [PubMed: 19747295]

BALFE M, BRUGHA R, SMITH D, SREENAN S, DOYLE F, CONROY R. Why do young adults with Type 1 diabetes find it difficult to manage diabetes in the workplace? Time pressures and lack of routine are key reasons. Health & Place. 2013; :26.doi: 10.1016/j.healthplace.2013.12.016

BORELL L, GUSTAVSSON A, SANDMAN PO, KIELHOFNER G. Occupational programming in a day hospital for patients with dementia. OTJR: Occupation, Participation and Health. 1994; 14:219–238. DOI: 10.1177/153944929401400402

BRADLEY EH, CURRY LA, DEVERS KJ. Qualitative data analysis for health services research: Developing taxonomy, themes, and theory. Health Services Research. 2007; 42:1758–1772. DOI: 10.1111/j.1475-6773.2006.00684.x [PubMed: 17286625]

BOWLBY S. Recognising the time-space dimensions of care: Caringscapes and carescapes. Environment and Planning A. 2012; 44:2101–2118. DOI: 10.1068/a44492

BYTHEWAY B. Responsibility and routines: how older people manage their long-term medication. Journal of Occupational Science. 2001; 8:5–13. DOI: 10.1080/14427591.2001.10597269

COSTANTINI L, BEANLANDS H, MCCAY E, CATTRAN D, HLADUNEWICH M, FRANCIS D. The self-management experience of people with mild to moderate chronic kidney disease. Nephrology Nursing Journal. 2008; 35:147–156. [PubMed: 18472683]

COUCLELIS H. Rethinking time geography in the information age. Environment and Planning A. 2009; 41:1556–1575. DOI: 10.1068/a4151

CUMMINS S, CURTIS S, DIEZ-ROUX AV, MACINTYRE S. Understanding and representing place in health research: A relational approach. Social Science & Medicine. 2007; 65:1825–1838. DOI: 10.1016/j.socscimed.2007.05.036 [PubMed: 17706331]

CURTIN RB, WALTERS BAJ, SCHATELL D, PENNELL P, WISE M, KLICKO K. Self-efficacy and self-management behaviors in patients with chronic kidney disease. Advances in Chronic Kidney Disease. 2008; 15:191–205. DOI: 10.1053/j.ackd.2008.01.006 [PubMed: 18334246]

DAVIES K. The tensions between process time and clock time in care-work: The example of day nurseries. Time & Society. 1994; 3:277–303.

DIJST, M. Time geographical analysis. In: KITCHIN, R., THRIFT, N., editors. International Encyclopedia of Human Geography. Amsterdam: Elsevier; 2009.

DYCK I. Beyond the clinic: Restructuring the environment in chronic illness experience. OTJR: Occupation, Participation and Health. 2002; 22:52S–60S. DOI: 10.1177/15394492020220S107

EDENSOR, T. Geographies of Rhythm: Nature, Place, Mobilities and Bodies. Surrey, England: Ashgate Publishing, Ltd; 2010a.

EDENSOR, T. Introduction: Thinking about rhythm and space. In: EDENSOR, T., editor. Geographies of Rhythm: Nature Place Mobilities and Bodies. Surrey, England: Ashgate Publishing, Ltd; 2010b.

FLYVBJERG B. Five misunderstandings about case-study research. Qualitative Inquiry. 2006; 12:219–245. DOI: 10.1177/1077800405284363

GALLIMORE R, LOPEZ EM. Everyday routines, human agency, and ecocultural context: Construction and maintenance of individual habits. OTJR: Occupation, Participation and Health. 2002; 22:70S–77S. DOI: 10.1177/15394492020220S109

GORDON C. Planning for structural transit in low density environments: the case of Canberra, Australia. Australian Planner. 2011; 48:148–159.

GREEN, F., RYAN, C. An overview of chronic kidney disease in Australia, Cat no PHE 111. Canberra: Australian Institute of Health and Welfare; 2009.

GROSZ E. Habit today: Ravaisson, Bergson, Deleuze and us. Body & Society. 2013; 19:217–239. DOI: 10.1177/1357034X12472544

GUPTA D, DENTON B. Appointment scheduling in health care: Challenges and opportunities. IIE Transactions. 2008; 40:800–819. DOI: 10.1080/07408170802165880

HÄGERSTRAND T. What about people in regional science? Papers in Regional Science. 1970; 24:6–21. DOI: 10.1007/BF01936872

HASLBECK JW, SCHAEFFER D. Routines in medication management: The perspective of people with chronic conditions. Chronic Illness. 2009; 5:184–196. DOI: 10.1177/1742395309339873 [PubMed: 19656813]

JOWSEY, T. Chronic illness: The temporal thief. Saarbrucken: Lambert Academic Publishing; 2016.

KLITZMAN R. “Patient-time”, “doctor-time”, and “institution-time”: Perceptions and definitions of time among doctors who become patients. Patient Education and Counseling. 2007; 66:147–155. DOI: 10.1016/j.pec.2006.10.005 [PubMed: 17125956]

KWAN MP. Gender and individual access to urban opportunities: A study using space–time measures. The Professional Geographer. 1999; 51:211–227. DOI: 10.1111/0033-0124.00158

LEFEBVRE, H. Rhythmanalysis. London: Continuum; 2004.

LEVIN A, HEMMELGARN B, CULLETON B, TOBE S, MCFARLANE P, RUZICKA M, BURNS K, MANNS B, WHITE C, MADORE F, MOIST L, KLARENBACH S, BARRETT B, FOLEY R, JINDAL K, SENIOR P, PANNU N, SHURRAW S, AKBARI A, COHN A, RESLEROVA M, DEVED V, MENDELSSOHN D, NESRALLAH G, KAPPEL J, TONELLI M. Guidelines for the management of chronic kidney disease. Canadian Medical Association Journal. 2008; 179:1154–1162. DOI: 10.1503/cmaj.080351 [PubMed: 19015566]

MAY, J., THRIFT, N. Introduction. In: MAY, J., THRIFT, N., editors. Timespace: Geographies of Temporality. London and New York: Routledge; 2001.

MCKIE L, GREGORY S, BOWLBY S. Shadow times: The temporal and spatial frameworks and experiences of caring and working. Sociology. 2002; 36:897–924.

MCQUOID J, DIJST M. Bringing emotions to time geography: The case of the mobilities of poverty. Journal of Transport Geography. 2012; 23:26–34. DOI: 10.1016/j.jtrangeo.2012.03.019

MCQUOID J, WELSH J, STRAZDINS L, GRIFFIN AL, BANWELL C. Integrating paid work and chronic illness in daily life: A space-time approach to understanding the challenges. Health & Place. 2015; 34:83–91. DOI: 10.1016/j.healthplace.2015.04.001 [PubMed: 25968586]

NATIONAL KIDNEY FEDERATION. NKF Controlled Document No 82 [Online]. Shireoaks, England: National Kidney Federation; 2012. Available: http://www.kidney.org.uk/Medical-Info/drugs/phosinf.html [Accessed Viewed 28 Nov 2015 2012]

NEUTENS T, SCHWANEN T, WITLOX F. The prism of everyday life: Towards a new research agenda for time geography. Transport Reviews: A Transnational Transdisciplinary Journal. 2011; 31:25–47. DOI: 10.1080/01441647.2010.484153

PERCHOUX C, CHAIX B, CUMMINS S, KESTENS Y. Conceptualization and measurement of environmental exposure in epidemiology: Accounting for activity space related to daily mobility. Health & Place. 2013; 21:86–93. DOI: 10.1016/j.healthplace.2013.01.005 [PubMed: 23454664]

RAINHAM D, MCDOWELL I, KREWSKI D, SAWADA M. Conceptualizing the healthscape: Contributions of time geography, location technologies and spatial ecology to place and health research. Social Science & Medicine. 2010; 70:668–676. DOI: 10.1016/j.socscimed.2009.10.035 [PubMed: 19963310]

RIFKIN DE, LAWS MB, RAO M, BALAKRISHNAN VS, SARNAK MJ, WILSON IB. Medication adherence behavior and priorities among older adults with CKD: A semistructured interview study. American Journal of Kidney Diseases. 2010; 56:439–446. DOI: 10.1053/j.ajkd.2010.04.021 [PubMed: 20674113]

ROSENWAX L, SPILSBURY K, ARENDTS G, MCNAMARA B, SEMMENS J. Community-based palliative care is associated with reduced emergency department use by people with dementia in their last year of life: A retrospective cohort study. Palliative Medicine. 2015; 29:727–736. DOI: 10.1177/0269216315576309 [PubMed: 25783598]

ROWLES GD. Habituation and being in place. Occupational Therapy Journal of Research. 2000; 20:52S–67S. DOI: 10.1177/15394492000200S105

SALDAÑA, J. The coding manual for qualitative researchers. California: Sage; 2012.

SCHULTZ-KROHN W. The meaning of family routines in a homeless shelter. The American Journal of Occupational Therapy. 2004; 58:531–542. DOI: 10.5014/ajot.58.5.531 [PubMed: 15481780]

SCHWANEN T. On ‘arriving on time’, but what is ‘on time’? Geoforum. 2006; 37:882–894. DOI: 10.1016/j.geoforum.2006.02.004

SCHWANEN T, DE JONG T. Exploring the juggling of responsibilities with space-time accessibility analysis. Urban Geography. 2008; 29:556–580. DOI: 10.2747/0272-3638.29.6.556

SCHWANEN T, KWAN MP. Guest editorial: Critical space-time geographies. Environment and Planning A. 2012; 44:2043–2048. DOI: 10.1068/a45437

SHOVE, E., TRENTMANN, F., WILK, R. Introduction. In: SHOVE, E.TRENTMANN, F., WILK, R., editors. Time, Consumption and Everyday Life: Practice, Materiality and Culture. Oxford and New York: Berg Publishers; 2009.

SMITH, JA., FLOWERS, P., LARKIN, M. Interpretative phenomenological analysis: Theory, method and research. London: SAGE Publications; 2009.

SOUTHERTON, D. Re-ordering temporal rhythms: Coordinating daily practices in the UK in 1937 and 2000. In: SHOVE, E.TRENTMANN, F., WILK, R., editors. Time, Consumption and Everyday Life: Practice, Materiality and Culture. Oxford: Berg Publishers; 2009.

TAKAHASHI LM, WIEBE D, RODRIGUEZ R. Navigating the time–space context of HIV and AIDS: Daily routines and access to care. Social Science & Medicine. 2001; 53:845–863. DOI: 10.1016/S0277-9536(00)00363-4 [PubMed: 11522133]

THAPAR SB, CANDY BHARDWAJ N, BHARDWAJ S, BHARDWAJ C. Multiple sclerosis in its context: Individual narratives. Disability Studies Quarterly. 2001; 21:29–41.

VICTORIA STATE GOVERNMENT. Hospital in the home [Online]. Melbourne: Victoria State Government; 2016. Available: https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/acute-care/hospital-in-the-home [Accessed Accessed 19 Sept 2016]

SERVICES, D. O. H. A. H.. , editor. VICTORIA STATE GOVERNMENT. Specialist clinics activity and wait time report. Melbourne: Victoria State Government; Apr. 2016 June quarter 2015–16 – PRELIMINARY

WAGNER GJ, RYAN GW. Relationship between routinization of daily behaviors and medication adherence in HIV-positive drug users. AIDS Patient Care & STDs. 2004; 18:385–393. DOI: 10.1089/1087291041518238 [PubMed: 15307927]

ZISBERG A, YOUNG HM, SCHEPP K, ZYSBERG L. A concept analysis of routine: relevance to nursing. Journal of Advanced Nursing. 2007; 57:442–453. DOI: 10.1111/j.1365-2648.2007.04103.x [PubMed: 17291208]

Research Highlights

- Renal patients navigate complex space-time contexts in everyday life
- Routines that support health/wellbeing are embedded within space-time contexts
- Routines are both shaped and disrupted by unpredictable health services
- Ability to absorb unpredictability without disrupting routines varies by patient
- Patient wellbeing requires a space-time re-design of chronic care services

Table 1

Participant demographics

	n	%
Age:		
18–29	2	8%
30–39	4	15%
40–49	5	19%
50–59	2	8%
60–69	6	23%
70–79	6	23%
80–89	1	4%
Gender:		
female	13	50%
male	13	50%
CKD disease stage:		
1–3	4	15%
4	6	23%
5 (with dialysis)	8	31%
functioning kidney transplant	8	31%
Cause(s) of CKD * **:**		
unknown	10	38%
co-morbidity (e.g., hypertension, diabetes)	9	35%
drug side-effect	4	15%
autoimmune disorder	4	15%
hereditary condition	4	15%
birth defect	3	12%
virus	2	8%
Employment status:		
full-time	9	35%
part-time	4	15%
retired	11	42%
unemployed (working age)	2	8%
Caregiving responsibilities (child or dependent adult):		
at time of study	4	15%
before the study while chronically ill	3	12%
none at time of study or prior while chronically ill	19	73%
Household composition:		
alone	7	27%
partner only	12	46%
partner and children	2	8%
partner and ageing parent	1	4%
adult relative(s)	4	15%

	n	%
Self-described race/ethnicity:		
European Australian	21	81%
Burmese Australian	1	4%
Filipino Australian	1	4%
Indian Australian	1	4%
Loa Australian	1	4%
South African	1	4%

[*] Participants selected multiple categories