



Contents lists available at ScienceDirect

## Social Science &amp; Medicine

journal homepage: [www.elsevier.com/locate/socscimed](http://www.elsevier.com/locate/socscimed)

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



Julia McQuoid, PhD <sup>a, b, \*</sup>, Tanisha Jowsey, PhD <sup>c, 1</sup>,  
Girish Talaulikar, FRACP, M Clin Epid <sup>d, e, 2</sup>

<sup>a</sup> Center for Tobacco Control Research and Education, Cardiovascular Research Institute, University of California, San Francisco, USA

<sup>b</sup> School for Physical, Environmental, and Mathematical Sciences, University of New South Wales, Canberra, Australia

<sup>c</sup> Centre for Medical and Health Sciences Education, The University of Auckland, New Zealand

<sup>d</sup> Director, Renal Services, ACT Health, ACT, Australia

<sup>e</sup> Associate Prof of Nephrology, Australian National University (ANU) Medical School, Australia

### ARTICLE INFO

#### Article history:

Received 21 October 2016

Received in revised form

22 February 2017

Accepted 25 April 2017

Available online 27 April 2017

#### Keywords:

Routine  
Self-management  
Health services  
Chronic kidney disease  
Space  
Time  
Everyday context  
Dialysis

### 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 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.

© 2017 Elsevier Ltd. All rights reserved.

\* Corresponding author. Postal address: 530 Parnassus Ave, Suite 366, San Francisco, CA, 94143 USA.

E-mail addresses: [julia.mcquoid@ucsf.edu](mailto:julia.mcquoid@ucsf.edu) (J. McQuoid), [T.jowsey@auckland.ac.nz](mailto:T.jowsey@auckland.ac.nz) (T. Jowsey), [girish.talaulikar@act.gov.au](mailto:girish.talaulikar@act.gov.au) (G. Talaulikar).

<sup>1</sup> Postal address: CMHSE, Auckland City Hospital, Building 599, Level 12, room 12.025. 2 Park Road, Grafton, Auckland 1023, New Zealand.

<sup>2</sup> Postal address: Renal Services, The Canberra Hospital, Yamba Drive Garran ACT 2605, Australia.

### 1. 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 5 h 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.

## 2. Routines and the space-time contexts of everyday life

Based on a concept analysis of *routine* within health literature from 1977 to 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)

Download English Version:

<https://daneshyari.com/en/article/5046560>

Download Persian Version:

<https://daneshyari.com/article/5046560>

[Daneshyari.com](https://daneshyari.com)