CHRONIC ILLNESS TIME

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Thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy

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Thesis Declaration

I hereby declare that the work presented is an accurate account of research performed during the academic program towards the degree of Doctor of Philosophy of the Australian National University. This is a thesis by compilation. My contribution to the manuscripts included in this thesis was not uniform; therefore individual statements are included for each manuscript and these statements have been approved by the co-authors as well as my primary supervisor, Dr Simone Dennis. All references to ideas and work of other researchers have been specifically acknowledged. I hereby certify that the work embodied in this thesis has not already been accepted in substance for any degree, and is not being currently submitted in candidature for any other degree.

Signed:

Name: Tanisha Jowsey
Date: 27/08/2013
For Dad and Mum, who encourage me to think

&

For Hugh, who provides timely hugs

“Waste your money and you’re only out of money, but waste your time and you’ve lost part of your life”

– Michael LeBoeuf
ACKNOWLEDGEMENTS

My PhD studies were, for the most part, good fun. I have several people to thank for this positive experience. First and foremost, my deep gratitude goes to my primary supervisor and chair of my panel, Simone Dennis. Simone understands time and how much time should be spent on particular academic enterprises. Simone also has a keen sense of timing; she knows when a student needs coffee, when they need cake, and when they need that gentle push off a precipice. The cross-disciplinary nature of this PhD, as well as the format of thesis by compilation has made the PhD a very difficult enterprise, one that was made possible by unshaking support, generous feedback and encouragement from Simone. I hope to continue our friendship and collaborations long into the future.

Second to thank are my other PhD supervisory panel members: Laurann Yen, Karen L Gardner, Christine Phillips and Robert Wells. The panel supported my vision and each member contributed to my understanding of the topic in diverse and important ways. For this I am grateful. Third, I thank each of the members of the SCIPPS for their guidance and encouragement, and for the opportunities they provided me. In particular, I thank Jim Gillespie, Steve Leeder, Beverley Essue and my departed friend, Marjan Klijakovic.

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For their support throughout all my academic enterprises I thank my encouraging and loving family: Gran, Mum, Dad, Karla and Nik. Thanks go especially to my Dad, who spent countless hours talking me through some tricky aspects of the PhD. During my second year, Dad told me that when I cannot see the trees for the forest, to find my way back to the last time when I was at the edge of the forest and then re-enter from there. I’ve found this nugget of wisdom to be quite the lifesaver (both for my thesis and my sanity).

I thank my husband Hugh Brocklebank for laughter and countless hugs. I thank Sherlock for his wagging tail. I thank the Brocklebank family and my friends for encouraging words. Specifically, I am very grateful to Ginny Sargent, who has provided enormous practical support in the months leading up to this thesis submission.

In undertaking this research, I was supported financially by an Australian National University Post-graduate Award and a scholarship from the Australian Primary Health Care Research Institute. The Australian Primary Health Care Research Institute also provided me with ongoing work during my candidature. For this I am very grateful. It has kept me off the streets for all 33 months. Thank you.

Finally, I thank all those folk, including fellow science fiction geeks, who have inspired me by theorising about time. Time travel and intersecting temporalities are fun to ponder. I’m keen to make the most of time. May we all live long and prosper.
ABSTRACT

As the term ‘chronic’ suggests, the chronically ill body is one that reorients itself to the ways in which time is perceived, experienced and used, in a multiply of ways. New practices are developed and routines are established to manage chronic illness in personal and social contexts. As rhythms of bodily life change one’s expectations for the future might change, and their relations with other people (who have their own temporal rhythms) might also change. Meanings attributed to past and present experiences and practices, as well as future plans and imaginings, acquire new significance with chronic illness. Through public health and anthropological lenses this thesis investigates some of the intersections between chronic illness and time.

In his tone-setting analysis of the ways in which chronic illness influences relationships with and to time, Bury (1982) argued that chronic illness invariably creates a ‘biographical disruption’ for the individual with chronic illness. This thesis provides empirical evidence collected in Australia, including self-reported calendar and clock/ed time spent on managing illness, much of which broadly supports Bury’s analysis.

However, this thesis also questions the veracity of Bury’s sure and certain claim; while acknowledging that chronic illness can be and often is disrupting of the biography, I suggest that there is more variety in experiences of chronic illness than Bury’s theory allows. For instance, people may feel their biographies to be initially disrupted, but the profundity of disruption that Bury attends to may absent itself after a time, as the management of chronic illness fades into the background of habitual life. So too, can chronic illness create cycles of disruption even as the illness moves between stable and unstable phases. Alternatively, people may find that the onset of chronic illness was something they had expected, and experience the illness not so much as disruption but as confirmation to their biography. This thesis identifies several ways in which Bury’s thesis may be nuanced and challenged. Using data gathered over a number of different fields, and covering a wide range of illnesses, I show in this thesis that factors influencing biographical disruption, including the type and severity of illness; the stage of life that the individual is in when they become ill; their previous relationships to their body and to time; the self-management behaviour in which they engage; the amount of time they spend on health practices; and the sense ill persons have of their own agency, impact on whether and how much of a biographical disruption chronic illness is to the person.

As I will demonstrate throughout this thesis, the importance of time in the experience of chronic illness is not sufficiently recognised by the primary and secondary health care sectors. It is very common, for instance, for a chronically ill person to access multiple care providers – each of whom provide management of illness advice (and possibly medication prescriptions) into a kind of time vacuum – without reference to the ways in which the person’s time is already accounted for – including time spent attending to the advice, management and medication regimes of other health care providers. It is very often the case that a time burden of chronic illness arises from information provided to the patient whose time is assumed to be wholly available. The development of a care plan, which I propose at the close of this thesis, provides a device for enabling those with chronic illness to anticipate and plan for a future where illness will move them into different phases of experience. It also enables aligning of otherwise singularly administered regimes in and through the defining feature of chronic illness – time.

Keywords: chronic illness; disrupted biography; health practices; health service provision (Australia); time; worry time
THESIS OUTLINE

This thesis demonstrates that people experience time in different ways when they become chronically ill and as their disease progresses. It also establishes the ways in which temporal structures inform people’s experiences of chronic illness. In order to determine this, the thesis utilises four datasets. Three datasets were collected by the Serious and Continuing Illness Policy and Practice Study (SCIPPS); a study that ran for nearly six years until 2012 in Australia. I was a staff member on SCIPPS for the duration of the study and contributed to data collection and analysis on all three datasets. I was based in Canberra at the Australian National University during this time.

The three SCIPPS datasets are:

- SCIPPS Qualitative Project
- SCIPPS Indigenous Project
- SCIPPS Work of Being Ill Survey

The fourth dataset is the Chronic Illness Time Fieldwork; a small confirmatory research project that I undertook in Canberra during 2012. All data were analysed during my PhD candidature (the methods are outlined in Chapter two).

I worked with members of the SCIPPS team to analyse and publish SCIPPS data.

Findings of the thesis have been published during my candidature in peer-reviewed international journals. The format of this thesis is what the Australian National University terms ‘by compilation’. This thesis by compilation includes six published articles and one manuscript (under review), along with supporting text.
Chapter 1  Introduction
The introduction articulates the thesis topic as one centrally concerned with chronic illness and time. The chapter provides background information on previous academic attempts to chart connections between chronic illness experiences and time. Bury’s theory of disrupted biographies is identified as a key analytical space. Temporal components that inform biographical disruption are introduced.

Chapter 2  Methods
Four datasets are described, upon which this thesis’ findings rest. The chapter presents an overview of my contribution to the methods undertaken with these datasets. I also include detail on the reasons underpinning utilisation of these methods as well as on methods employed in working with others to create manuscripts for publication. Methods are also included in each of the article chapters (Chapters 4–10).

Chapter 3  Case studies
The experiences of four people with chronic illness, including myself, are described to demonstrate the way people’s relationships to time are informed by chronic illness. The case studies illustrate nuances of biographical disruption; past, present and future time; and calendar and clock/ed time (CCT). Other temporal structures are introduced to demonstrate the multiplicity of time that people experience through chronic illness.

Chapter 4  Time use literature review
Time use studies are becoming common internationally. They broadly capture people’s practices in terms of an important structure of time: CCT. This manuscript presents a review of literature concerning time use of people with chronic illness and
informal/family carers. A scoping method is utilised. Areas for further research are identified.

For author contributions see Appendix 1.

Chapter 5  Time use of people with COPD

Chapters five to seven present important steps towards understanding a complex thing: the quantifiable aspects of one kind of temporal experience – CCT. Importantly, quantifiable temporal experiences are readily translated into health service delivery and self-management options than other temporal experiences, as this thesis demonstrates. In presenting the time use of people with chronic illness I follow general methods employed by time use studies globally (Bittman and Thomson, 2000; Bittman et al., 2005; Russell et al., 2008; Russell et al., 2007; De Vaus, 2004).

Chapter five reports findings from the SCIPPS ‘Work of being ill’ survey. It demonstrates that management of COPD is associated with high time use. Surprisingly, the amount of time spent on health practices fluctuates minimally over time. I suggest here that a high quantity of time spent on health practices may be indicative of biographical disruption. For author contributions see Appendix 1.

Chapter 6  Time use of people with multi-morbidity

The prevalence of multi-morbidity is rapidly rising in Australia and internationally. Yet multi-morbidity was identified in Chapter seven as an area that has not received any attention concerning measured time use. The policy and health service implications of time use associated with multi-morbidity are manifold. Chapter six reports findings from the SCIPPS ‘Work of being ill’ survey. The manuscript reports time spent on health-
related activity HRA, tracking the rise in time expenditure alongside increasing number of chronic illnesses. This focus on time use of people with multi-morbid chronic illness is the first of its kind.

For author contributions see Appendix 1.

Chapter 7  Time use of informal carers

Chronic illness does not just alter the relationships that people diagnosed with it have to time; it also informs those who live with and/or provide informal care. Although previous studies have reported the time use of family carers in Australia, this manuscript is the first to explore the time use implications of family carers who themselves have chronic illness. It is also the first to break down time components of caring into specific health-related activities.

For author contributions see Appendix 1.

Chapter 8  Process time

Chapter eight explores a methodological issue associated with measuring time use, following Davies’ work (1994) on process time. It illustrates how multiple processes undertaken each day can be difficult to measure in terms of time use due to their being interrupted and interconnected. This manuscript also introduces worry time as an intrinsic aspect of chronic illness experience, which is another temporal structure not easily measured and almost never reflected in time use studies. I argue that worry time disrupts and informs rhythms such as sleep time (as indicated in Chapter five: case study three). This chapter makes clear that for some informal carers the demanding and ongoing nature of chronic illness can create disruptions to biography.

For author contributions see Appendix 1.
Chapter 9   Spaces and time use

Findings from the SCIPPS Indigenous study concerning Aboriginal and Torres Strait Islander patient and carer experiences are reported. Chapter 9 details how different health care services structure patient time use and patient experience through use of space and clinician time availability. Time spent waiting is experienced differently in the compared spaces (Aboriginal and mainstream health services).

For author contributions see Appendix 1.

Chapter 10   Agents in time

Chapter 10 presents findings from the SCIPPS Indigenous project, on people’s experiences of chronic illness as biographically disrupting and their efforts to manage disruptions. This is framed in terms of agency. The findings are also understood in relation to Zimbardo’s (2002; Zimbardo & Boyd, 1999) Time Perspectives Theory. I suggest that the application of Time Perspectives Theory to psychological elements of support services may help those living with chronic illness to undertake biographical work. The findings are discussed in terms of implications for self-management programs in Aboriginal and mainstream health services.

For author contributions see Appendix 1.

Chapter 11   Practical application of findings

A model is presented for understanding the intersections between chronic illness, time, and society; and how the individual negotiates these intersections. The model shows how people with chronic illness move between different phases of illness (experienced in and through the body), which determines their capacity to fulfil social roles and responsibilities. I contend that findings and the model emerging in this thesis are relevant
to health care providers because they provide insight into the lived experiences of people living with chronic illness. Further, a care plan is proposed to enable people with chronic illness to anticipate change and manage the temporal components of managing their health.

Chapter 12 Discussion

The discussion synthesises findings from the thesis. I conclude that the chronically ill body is one that establishes new rhythms and practices, which become habituated over time and which alter to accommodate changes in the body and in social life. Such establishments and habituations usually bring with them experiences of disruption to biography as well as to the way the individual experiences past, present and future time. The time required to take on new practices and manage chronic illness in the context of an existing life can be substantial and while this is usually associated with biographical disruptions it is not always so. This is informed by several temporally-gauged factors, which are outlined in the discussion.

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Alicia, who is 80 years old, has several chronic illnesses. She is shown here sorting medications for the week; a task that takes thirty minutes each week due to the number of medications and the difficulty of the task (some pills require cutting in half, which is difficult because of severe osteoarthritis in Alicia’s hands).

Photos taken by T. Jowsey, August 2012.
PUBLICATIONS AND PRESENTATIONS ARISING FROM THIS RESEARCH

Articles


Nb. Author contributions are detailed at the end of each article and are further detailed in Appendix 1.
Articles (related but not included in the thesis)


Invited letter


Invited speaker

Jowsey, T. *Time, chronic illness and health services*. *Canberra Lung Life Support Group*, Burns Club, Kambah, Canberra. 14 February 2013, [60 minutes]


Jowsey, T. *Weighing a witch: scientific facts to help weigh up your thesis choices*. Thesis by Compilation Panel discussion. *National Centre for Population Health and Epidemiology*, Australian National University, August 2012 [15 minutes, then 30 minutes as panel speaker]

Jowsey, T. *Chronic illness & consumer voices: building a research program in Australia to inform health policy*. *Department of Primary Health Care*, Oxford University, Oxford. 05 September 2011 [60 minutes]

Jowsey, T. *People I can call on: Aboriginal and Torres Strait Islander stories of chronic illness*, *National Health & Medical Research Council*, *NAIDOC week staff celebration meeting*, NH&MRC, Canberra. 08 July 2011 [20 minutes].

*NAIDOC stands for National Aboriginal and Islander Day of Celebration; NH&MRC stands for National Health and Medical Research Council*
Conference presentations

Jowsey, T., McRae, I., Yen, L. Multi-morbidity - Time's up! PHC Research Conference, 10–12 July 2013, Sydney [speaker]

Yen, L., Jowsey, T., McRae, I. Time waits for Norman. PHC Research Conference, 10–12 July 2013, Sydney [speaker]

Jowsey, T. Chronic illness: entering a time warp! PHC Research Conference, 10–12 July 2013, Sydney [poster]

Jowsey, T., Yen, L., Banfield, M., Gillespie, J., McRae, I. and the SCIPPS Team. Chronic illness: time to care. PHC Research Conference, 18–20 July 2012, Canberra, Australia [speaker]


Jowsey, T., Yen, L., McRae, I. Perceptions of time: chronically ill health service users and their family carers. 10th global conference: making sense of health, illness and disease. 6–8 September 2011, University of Oxford, U.K. [speaker]

Jowsey, T., Ward, N.J. Experiences of chronic illness: disrupted biographies and locations of agency. Commitment to indigenous health: local and national contributions to meeting the challenges. 22 November 2010 Australian National University, Canberra, Australia. [speaker]

Awards

NSW Health 2012 Aboriginal Health Awards. ‘Closing the gap in Aboriginal health through excellence in research, evaluation and building evidence.’ This was awarded to the Serious and Continuing Illness Policy and Practice Study for its research on Indigenous health. Tanisha Jowsey was a primary investigator in that research.


### ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
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<tr>
<td>ACCHS</td>
<td>Aboriginal Community Controlled Health Services</td>
</tr>
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<td>ACT</td>
<td>Australian Capital Territory</td>
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<tr>
<td>AIDS</td>
<td>acquired immunodeficiency syndrome</td>
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<td>AMSs</td>
<td>Aboriginal Medical Services</td>
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<td>ANU</td>
<td>Australian National University</td>
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<tr>
<td>BGL</td>
<td>blood glucose level</td>
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<td>CCT</td>
<td>calendar and clock/ed time</td>
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<tr>
<td>CHF</td>
<td>chronic heart failure</td>
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<tr>
<td>CHF</td>
<td>congestive heart failure</td>
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<tr>
<td>CI*</td>
<td>chronic illness</td>
</tr>
<tr>
<td>CI</td>
<td>confidence interval</td>
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<tr>
<td>COAD</td>
<td>chronic obstructive airways disease</td>
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<tr>
<td>COPD</td>
<td>chronic obstructive pulmonary disease</td>
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<tr>
<td>Diabetes</td>
<td>complicated type 2 diabetes</td>
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<tr>
<td>DOA</td>
<td>dose administration aids</td>
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<tr>
<td>Dr</td>
<td>Doctor</td>
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<tr>
<td>GP</td>
<td>general practitioner</td>
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<tr>
<td>GPMP</td>
<td>general practitioner management plan</td>
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<tr>
<td>HbA1c</td>
<td>glycated haemoglobin or glycosylated haemoglobin</td>
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<tr>
<td>HCCA</td>
<td>Health Care Consumers’ Association of the ACT</td>
</tr>
<tr>
<td>HIV</td>
<td>human immunodeficiency virus</td>
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<tr>
<td>HRA</td>
<td>health-related activity</td>
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<tr>
<td>HSUs</td>
<td>health service users</td>
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<tr>
<td>IHIG</td>
<td>Indigenous Health Interest Group</td>
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<tr>
<td>MBS</td>
<td>Medicare Benefit Schedule</td>
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<tr>
<td>MHSs</td>
<td>mainstream health services</td>
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<tr>
<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
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<tr>
<td>NSA</td>
<td>National Seniors Australia</td>
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<tr>
<td>NSW</td>
<td>New South Wales</td>
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<tr>
<td>PMP</td>
<td>Patient-led Management Plan</td>
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<tr>
<td>SCIPPS</td>
<td>Serious and Continuing Illness Policy and Practice Study</td>
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CHAPTER 1 INTRODUCTION

Chronic illnesses are “health problems that require ongoing management over a period of years or decades” (World Health Organization, 2002). Although chronic illnesses have different physiological, biological and pathological properties, they share a common thread – time. They last for a long time and they require management over time. They induce different temporal rhythms and different relationships to time than are experienced by the healthy person, or even the person with acute illness. Chronic illness is responded to in specific social and biographical ways by people who have chronic illness and by those people who care for them. Adam writes: “in spite of its omnipresence, time is curiously invisible and constitutes one of the most taken for granted features of our lives” (1995: 30). In this thesis I contend that chronic illness provides a lens through which time becomes visible, at least for a while, and that experiences of time previously taken for granted take on new valence. The omnipresence of time and its multi-layered value in society must be reflected in policy and service provision of those living with chronic illness for effective care and illness management. It is for these reasons that my thesis centralises time as an analytic lens for understanding chronic illness experiences.

As Townsend (2011) asserts, chronic illness is very well researched. Qualitative studies from sociology, anthropology and public health have reported experience in terms of: identity (Charmaz, 1995; Adams et al., 1997; Larun and Malterud, 2007; Goldman and Maclean, 1998; Hagger and Orbell, 2003), discourses and narratives (Horton-Salway, 2001; Greenhalgh et al., 2010), individual/bodily experience (Faircloth et al., 2004a; Aujoulat et al., 2008), normalcy (Sanders et al., 2002; Scambler and Hopkins, 1986) (Kelleher, 1988), and social interaction (Corcoran et al., 2012; Vassilev et al., 2011; Jeon
et al., 2010; Guell, 2009). Analysis has also been framed in terms of emotion (Furler et al., 2008), risk (Karademas et al., 2008; Martensson et al., 1997; Rhodes and Bowles, 2002) and uncertainty (Carricaburu and Pierret, 1995), self-management (Vassilev et al., 2011; Lorig et al., 1999; Telford et al., 2006), multi-morbidity (Townsend, 2011; Jowsey et al., 2009) and interactions with health services (Arney and Bergen, 1983; Aspin et al., 2012; Greenhalgh, 2009; Townsend 2011).

Chronic illness research has focused on either determinants of behaviour (Strazdins et al., 2011), or on exploring lived experiences (Jeon et al., 2010). Townsend accounts for the sociologically constituted field, broadly, in terms of the orientation of work around either outsider or insider perspectives. She notes that:

> Outsider approaches use variable-based explanations for behaviours, for example how cultural components and social disadvantage impact help-seeking. Insider approaches prioritise illness experience as an interpretive social process, best understood by examining meanings of action in context. From the layperson’s standpoint; living with chronic illness requires hard practical, biographical, emotional and moral work. Individuals negotiate symptoms and mobilise strategies in an attempt to maintain daily life, familiar selves and moral identities. Illness puts one at risk of ‘failure in everyday life’ and ‘getting through the day’ is a practical and moral priority (2011: 90).

Both categories flow from Parsons’ pioneering 1967 work, which sought to push through and beyond the then dominant medical model of disease to assert that illness might be alternatively conceptualised. In his view, it was most fruitfully understood as a ‘disturbance in the normal functioning of the individual’, requiring restorative action. Those who became ill felt the pressure to recover quickly, so as to effectively carry out their social roles. In Bury’s (1982) ground-breaking work, the moral dimensions of taking up and then relinquishing the sick role are clearly evident. While Parsons’ work is obviously concerned with the temporary nature of being sick, rather than being
chronically ill, his reach is evident in work on chronic illness since the late 1960s. Bury notes, for instance, that:

Two traditions have been available to medical sociologists interested in chronic illness. The first stems from the debate over the usefulness or otherwise of Parsonian conceptions of illness and the sick-role. On a negative level, it is maintained that chronic illness appears to deny many of Parsons' assumptions about the patterning of sickness; on a more positive note it suggests separating and developing deviance and adaptive perspective from his theory (Gerhardt, 1979; Gallagher, 1976)…[despite the fact that Parsons' study is concerned with sickness and not chronic illness] my [Bury's] study shows, for example, that a chronically ill person can make adaptations to his lifestyle and still have access to periods of [the] classic sick-role behaviour [that Parsons described] when such events as surgical intervention or sudden exacerbations of symptoms occur (1982: 168).

While Townsend’s rough categorising is made on valid differences between insider and outside orientations as she has described them above, there is considerable variation in the offerings contained within each category, and the impact of works contained therein is unevenly arrayed. Bury, for instance, is keen for his work, which Townsend categorises in the ‘insider’ group, not to be associated with a second tradition in work on chronic illness deeply concerned with experience, namely the ‘interactionist’ tradition. He notes of it:

As one would expect, this has concentrated on empirical enquiry, detailing the strategic handling of symptoms and disabilities … but the approach has often been frankly descriptive, with only passing reference to wider theoretical concerns… interactionism has been preoccupied with fieldwork rather than explicit theorising. In particular, a willingness to move from descriptive categories of interaction to a wider analysis of cultural and structural forms has been limited (1982: 169).

Instead, Bury proposes an approach that he borrows from Giddens’ (1979) appreciation for ‘the critical situation’ posed by the onset of chronic illness, in which radical disturbances to routine settings and ordinary lives allow analysts insight. The ‘sick role’
posed by Parsons in the 1960s is theoretically reflective of the times; developed when acute sickness was a focal point, and prior to the rise of chronic illness incidence. The chronically ill individual, Bury suggests, is not subject to the same social obligations of the individual with acute sickness. Instead, the very nature of chronicity suggests that the individual cannot return to prior ‘healthy’ modes of social obligation. Bury notes, however, “that a chronically ill person can make adaptations to his lifestyle and still have access to periods of classic sick-role behaviour when such events as surgical intervention or sudden exacerbations of symptoms occur” (Bury, 1982: 168). That is, the individual whose health is in such crisis that they require surgical or medical intervention is released from social obligations, including self-management, for the duration of the exacerbation or crisis phase (phases of illness, including the crisis phase are described further in Chapter 11). Chronic illness does not usually begin with the individual in a crisis phases of this magnitude, however. Often small indicators, symptoms, annoyances become the subject of the individuals’ attention, and upon medical enquiry, become diagnoses of chronic illness. “Non-communicable diseases” writes Bury, “do not ‘break-out’ they ‘creep-up’” (1982: 170). This creeping, my research shows, may continue for years before any formal diagnosis of chronic illness is made. It is most often the point of diagnosis that catapults the individual into a ‘critical situation.’ This critical situation arises from the radical disturbance of habited routines and practices, of “the structures of everyday life” (Bury, 1982: 169). The individual is rapidly required to undertake new tasks associated with managing their health and illness.

Bury draws away from the broadly sociological to focus on biographical events:

My contention is that illness, and especially chronic illness, is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted. Chronic
illness involves a recognition of the worlds of pain and suffering, possibly even of death, which are normally only seen as distant possibilities or the plight of others. In addition, it brings individuals, their families, and wider social networks face to face with the character of their relationships in stark form, disrupting normal rules of reciprocity and mutual support. The growing dependency involved in chronic illness is a major issue here. Further, the expectations and plans that individuals hold for the future have to be re-examined. Thus, I want to maintain that the development of a chronic illness like rheumatoid arthritis is most usefully regarded as a 'critical situation', a form of biographical disruption, not only as a way of describing what happens, but also to provide a more explicit analytic focus (1982: 169).

Bury’s intention to examine chronic illness as a biographical disruption is noteworthy for two reasons. The first concerns the enduring presence of ‘disruption’ in analyses of chronic illness experience – and this is especially pertinent to those studies which privilege the temporal aspects of being ill, since these studies focus on how one’s future, having been imagined and even planned for, might unfurl awkwardly in the wake of a diagnosis. Bury (1982) argued, the onset and establishment of chronic illness can disrupt a person’s hitherto habitual experience of time – the rhythm of the social world in which one might be entailed and, more broadly, the anticipation a person has of living out their days into old age along the lines of the established temporal rhythms of childhood, adolescence, adulthood, and old age. In work that focused closely on the chronic – that is the temporal – aspects of chronic illness, conducted among people with rheumatoid arthritis, Bury identified how this latter sense of time might be disrupted. He coined the phrase ‘biographical disruption’, which has since become synonymous with anthropological and cognate work focusing on the experience of those with a chronic illness.
So enduring and powerful was Bury’s turn of phrase that 26 years later Morris (2008) writing on diabetes, took it up to show that those with diabetes could not take up the adult roles of caring for the self from their parents; for instance, in deciding when to eat or how long to stay out (and away from one’s insulin). These people, he argued, were, ultimately, slaves to temporal rhythms beyond their control, just as such rhythms had been beyond their control when they were infants and children, when they ate and slept in the patterns set by adults. Morris concludes that full membership into the adult world cannot be accomplished; thus, the biographical potentials of those with diabetes remain necessarily unfulfilled, so profoundly are they temporally infantilised.

While these two theoreticians begin from different starting points, and deploy different analytic tools from one another – in contrast with Bury’s modification of Giddens’ approach to critical events, Morris makes use of embodiment from the point of view of continental philosophy – both their accounts share in common a strong sense that the relationship the chronically ill person has with and to time is necessarily disrupted and brings about a future that is less enticing, hopeful and exciting than the future the person had prior to diagnosis. This sense of disruption and the spectre of future failure typifies approaches to the study of chronic illness, irrespective of what kind of chronic illness is being studied. The explanatory force of ‘disruption’ also stretches back across the history of the study of chronic illness; I have already made mention of the analytic force that Giddens saw in it, most especially for examining the ordinary structures of life, and Parsons, too, left a clear legacy off the back of his observation, that ‘disturbance in the normal functioning of the individual’ requires restorative action on the part of the ill person.
Also revealing of the analytic force shouldered by disrupted biography are the ways in which others have attended to it in their work, from the time that Bury published his seminal piece to the present. Indeed, one can scarcely mention chronic illness experiences in sociology without reference to Bury. In their study of HIV-positive men, Carricaburu and Pierret (1995) found that although many participants experienced profound uncertainty (an indicator of biographical disruption), that they established modes of managing the disruption caused by HIV (especially participants who had haemophilia). However, some participants experienced HIV as ‘biographical reinforcement’ rather than disruption (especially for participants who had had contracted HIV through homosexual practices). That is, their present identity constitution was reinforced by the illness because the illness linked them to their “individual and collective pasts” (Carricaburu and Pierret, 1995: 80). HIV, they argue, did not pose a biographical disruption; rather it was merely one aspect of the biography – the story of the individual’s life – that was connected to past practices and collective identity.

Similarly, both biographical disruption and reinforcement were identified in Harris’ study of hepatitis C (Harris, 2009). This biographical reinforcement was again identified recently by Olsen and colleagues in their study of women living with hepatitis C (Olsen et al., 2013).

In work conducted by Sanders et al. (2002) concerning people living with osteoarthritis, most participants had lived with osteoarthritis for more than ten years and had normalised illness by accounting for the cause of its onset in the context of their lives. This is similar to the findings of Pound et al. (1998) concerning normalisation through contextualisation of events that had occurred during an individual’s life that may have been related to their
stroke. In Sanders et al.'s study, although participants “‘played down’ the significance of arthritis as being normal in the context of their age” (2002: 241) they still reported severe symptoms, disruptions to biography and a keen sense of stigma associated with their illness. They experienced symptoms of illness as disruptive yet minimised the meaning of such disruption in an effort to normalise their embodied state of being (cf. Faircloth et al., 2004b).

Pound and colleagues note that in their qualitative study of elderly people who had survived strokes, that stroke as causal of disrupted biography was not a key aspect of participant experiences. Rather, participants reported that in the context of their lives, chronic illness was “not that bad” (Pound et al., 1998). The authors suggest that the reason for this may be age-related; that stroke was perceived by some participants as a part of normal ageing. Bury also noted this link, but from the opposite age-related direction; whereby young participants in his study who were diagnosed with arthritis saw the illness as particularly disruptive due to their cultural perceptions and assumptions that arthritis is an illness for older adults (Bury, 1982: 171). The timing of the illness onset was identified as influential in whether or not a chronic illness was perceived of as disrupting to the individual’s biography (see also, Sanders et al., 2002). Disturbance and disruption, then, are perhaps just as valid an insight into how the field of chronic illness study has shaped up as ‘insider’ and outsider’ approaches might be.

Bury’s use of ‘disruption’ is also noteworthy for a second reason – and that is I see the terrain of this thesis as chiefly concerned with analysing whether, as Bury suggests, chronic illness is necessarily and always disruptive; and to what extent such disruption can be viewed through time. Based on close analysis of a number of existing data-sets and
periods of fieldwork among chronically ill persons living in Canberra, I pose an argument that calls terms like ‘disruption’ and ‘failure’ – even ‘biography’ – into question. I do so emphatically not to insist that chronic illness is generally positively experienced, or that a person can expect to be entirely unhindered by chronic illness, or, contra Morris, to contend that those with a chronic illness do succeed at the manifestations of adulthood despite their illness. Rather, I call for the unsettlement of the surety of biographical disruption on the basis of what my own data, collected amongst a range of people with several chronic illnesses, suggests.

On its strength, I propose the notion that there is a range and diversity in how it is that people experience chronic illness. It is, according to my data, entirely possible that in some cases – especially severe cases such as those which constitute Bury’s dataset – people with chronic illness may experience a disruption in biography, and they may stay profoundly disrupted. They may feel the kinds of (perhaps even as yet unnamed or unknown) potentials they possess will remain unrealised, and that their future is bleak – perhaps because, as Morris argues, there is nothing unknown about the way time will unfold for them. It will be predictably punctuated by this or that medication, exacerbation, or intervention, and nothing will be more important than the person’s resentful progression towards the next lifesaving act they will do in a timetable set beyond or even against their will. Indeed, I have documented many such cases. But in some other cases, the sense of disruption may be unrealised, short lived, or diminish to the point where disruption does not manifest in many meaningful ways at all, or is embodied, become accustomed to, over time, as habitual practice. Failures to accomplish something of one’s potential may be redrafted to become instead peculiarities and especial practices of the person who can access a world inaccessible to others. Some of my data describes the
kinds of worlds that have been built up by individuals and communities on the basis of their perceived especial membership in an exclusive grouping not available to persons living without illness. This was the case for several Aboriginal elders who used their experiences and knowledge of diabetes as a form of cultural capital, which they referenced to teach children in their community how and why to avoid diabetes. Their direct experiences with diabetes entailed upon them a sense of authority unavailable to those without diabetes. My thesis, then, is an invitation to the diversity of experiences which are to be found under the umbrella of the experience of chronic illness, as these can be captured through a lens privileging the temporal aspects of life.

In suggesting that biographical disruptions are not sufficient to account for the range of experiences that constitute chronic illness experience and behaviour, I am essentially arguing against the onset of what Turner (1987) might have called permanent liminality. Liminality is described in van Gennep’s preceding and seminal work *Rites of Passage* (1908:189), which set out the tripartite process of change to an individual's status in society. Rites of passage, those changes from one state in the life course to another, are conceived as three stages: separation (preliminal), transition (liminal), and incorporation (post-liminal). Rites of separation symbolically detach the individual from their state, so as their former social status no longer applies. During the liminal stage, the individual is a symbolic outsider who has no clearly defined status. During the incorporation stage, the individual acquires and is fully endowed with a new social status, with which they re-enter society. Turner suggested that “a liminal state may become ‘fixed’, referring to a situation in which the suspended character of social life takes on a more permanent character” (1987: 54).
Willet and Deegan (2001) have argued that just such a situation, of permanent liminality, besets those with disabilities. They argue that:

Physical disability functions in modern society as a status betwixt and between everyday assumptions about "normal" physical strength and functioning. This creates a situation of permanent liminality, or a failure to be incorporated, in hypermodern society especially in the economic marketplace and architectural construction of everyday life and movement (2001: 137).

Is it possible that those who are chronically ill fail to fit into existing recognised temporal states of the life course, such as adulthood? As I have already indicated, Morris (2008) argues that those with diabetes cannot accomplish the state of adulthood, instead remaining caught someplace between the temporal regimes of infancy and those which, at least in his view, confer upon the individual the full status of independent adulthood.

Willet and Deegan argue that those who are disabled are forever caught in the liminal phase because society “fails to provide them with stable, socially valued roles” (2001: 137) into which they can be incorporated (see also Davis 1962; Deegan 1975, 1978, 1997, 2000; Deegan and Brooks, 1985; Goffman, 1963; Roth, 1963; Roth and Eddy, 1967).

However, my own research suggests that those with chronic illness (who may or may not become disabled through their illness) can experience times of liminality – induced, for example, by exacerbations of illness – but that the overall time for which the individual has chronic illness is experienced as a new state of being. I suggest that the initial sense of liminality experienced is one brought on by bodily change that leads to a formal diagnosis of chronic illness – the transition – that catapults the individual into a new state: one that is not necessarily experienced thereafter as constantly liminal, rather it can be experienced as a new state of being that brings with it changes to identity, social roles and relationships to time. This is not a permanent liminality so much as a permanent new
status conjured up by illness that will continue, most likely, for the remaining duration of the individual’s life. At times it may become central to the individual’s experience and at other times it may dissolve into the background of daily rhythms.

While Willet and Deegan (2001) focus on how society fails to accommodate disabled bodies in socially viable and recognised roles, Morris’s (2008) work focuses on how individuals are unable to fulfil the statues society provides for them that are normally attained over time – i.e., adulthood. In this thesis, I move beyond how social contexts fail to accommodate individuals, and how individuals fail to attain socially valued statuses in favour of an approach that centralises how chronically ill individuals experience illness. This is in direct opposition to Bury’s (1982) claim, that research on those with chronic illness focused too much on experience in the interactionist vein – and mistook it for analysis. In contrast, I take experience to be the basis for a rich analysis that centralises embodied experiences of time, and that makes evident the multiple relationships between chronic illness and time.

Much of the work that privileges illness experience as it is lived by people with chronic illness and their informal carers is best characterised as interpretive in that at its heart is an intention to examine the reasons and meanings behind the actions that those living with chronic illness take. Interpretive analysis, otherwise called an interpretive approach, interpretive methodology or interpretive description, is a form of research whereby the researcher seeks to understand human experience as meaningful and historically contingent (Yanow & Schwartz-Shea, 2006; Thorne et al., 2008). Bevir & Kedar (2008) observe that the interpretive approach has developed from an anti-naturalist philosophy. They write, “anti-naturalists argue that constitutive features of human life set it apart from the rest of nature to such an extent that the social or human sciences cannot take the
natural sciences as a model. The relevant features of human action are that it is meaningful and historically contingent” (2008: 505). Meanings, from this perspective, are constitutive of human action. To employ an interpretive approach is to centralise human experience – historically-located action and meaning-making – and to derive from there understanding of wider social processes and phenomena. For instance, Townsend and colleagues draw attention to how living with chronic illness “requires hard practical, biographical, emotional and moral work” (Townsend, 2011:90) (see also, Townsend, et al., 2006; Corbin & Strauss, 1985). Bury (1982) is interested in how ill persons engage in and enact strategies to maintain orderly lives in the face of what he insists is biographical disruption; and Charmaz (2002) looks closely at illness narratives in order to analyse how the self is torn down and then reconstructed in the context of chronic illness with special attention to how a familiar self and a moral identity of person might be preserved or refashioned in the wake of disruption. Even my own previous work with Jeon and colleagues has identified struggles people face in attempting to balance the management of their illness/es in the context of existing social worlds (Jeon, et al., 2010).

In this thesis I apply an interpretive approach to examining experiences of chronic illness by looking at the time people spend on particular health practices and the meanings that people living with chronic illness ascribe to experiences of illness and practice. Thorne et al. write:

The foundation of interpretive description is the smaller scale qualitative investigation of a clinical phenomenon of interest to the discipline for the purpose of capturing themes and patterns within subjective perceptions and generating an interpretive description capable of informing clinical understanding. Such studies often build upon relatively small samples, using such data collection methods as interviews, participant observation and documentary analysis to articulate a coherent and meaningful account of the experiential knowledge that such methods render accessible. Interpretive descriptions often involve multiple data collection strategies to avoid what Sandelowski (2002) refers to as a naïve overemphasis on interview data combined with a neglect of the material world that has led to research that
does not offer comprehensive and contextualized interpretations of its central phenomena of interest (2004: 3).

This thesis is informed by a wealth of empirical evidence from multiple sources and in various forms, and as such it addresses the concerns raised by Sandelowski (cited by Thorne et al. above) and by Townsend (2011), that interpretive studies have frequently had little empirical evidence to support their claims.

The reason for utilising an interpretive approach in this thesis arose first from my observation that health policies and health service provision often develop independently from the experiences of those people they seek to support, and that when those people are involved their level of involvement is often masked or unclear (Jowsey et al., 2010). While ‘patient-centric’ models of care have recently become a catch phrase among health policy makers, public health researchers and even health service providers, patient experiences and the ‘translation of evidence’ are not always reflected in decision-making processes and policy outcomes (Dwan & McInnes, 2013), nor health service provision. This is essentially due to the focus of healthcare systems solely on calendar and clock/ed time (CCT), which denies diversity in time and in patient experience (Ellingsen et al., 2013).

In order that future health policy and service provision decisions can be informed by patient experience, I suggest that not only is a body of quality evidence needed, but that the framing of such evidence through interpretive analysis will keep at the heart of health policy and service provision the most important players – people with chronic illness and their informal carers. I suggest that the interpretive approach is perhaps the most ‘patient
centric’ mode of analysis available due to its focus on how individuals behave and derive meaning from their experiences.

By employing an interpretive approach – to look closely at peoples’ experiences of chronic illness – I identify diversity of experience that has not been sufficiently accounted for in the works of others, such as Bury (1982), Morris (2008), and Corbin & Strauss (1985). The diversity, which I have mentioned above, for example, in terms of individuals who do not experience disruptions to biography or for whom disruptions are only felt for short duration, is identified in this thesis through attending to associated meanings and practices (including those concerning time use).

**Anthropology of time and its location within chronic illness research**

An exploration of time – how it is perceived and experienced, and its value to individuals and to society – could begin in a myriad of places. As a beginning, I propose to outline temporal structures. I suggest that people are informed by multiple temporal structures, which interweave in peculiar ways. The most obvious structure is CCT – a linear motion upon which calendars and clocks operate (Adam, 1995; Postill, 2002). It has been understood both socially and analytically as a key temporal structure underpinning Western society (Fabian, 1983; Griffiths, 1999; Postill, 2002). CCT includes regular and predicted beats of 60 seconds to a minute; 60 minutes to an hour; 24 hours to a day; seven days to a week; 52 weeks to a year; 100 years to a century, and so on. Minor adjustments to calendars are made so that the number of days in a year matches other rhythms. Some months have an extra day or two and some years have an extra day in order to align the beats with earth and moon orbits. It is the linear and predictable aspects of CCT that make it critical to social daily life. Events and meetings can be scheduled and synchronised; a
sense of order and orderliness can be facilitated. CCT can be used to measure how long activities, tasks and procedures take; and that length of time can be assigned value – in the duration of a friendship or of someone’s life, or even the variable amount of money it might cost to recompense a professional for an hour of work.

CCT is one of many temporal structures that intersect and through which time can be perceived. Geertz writes:

There are many ways in which men [sic] are made aware, or rather make themselves aware, of the passage of time – by marking the changing of the seasons, the alterations of the moon, or the progress of plant life; by the measured cycling of rites, or agricultural work, or household activities; by the preparation and scheduling of projected acts and the memory and assessment of accomplished ones; by the preservation of genealogies, the recital of legends, or the framing of prophecies. But surely among the most important is the recognition in oneself and in one’s fellowmen of the process of biological aging, the appearance, maturation, decay, and disappearance of concrete individuals. How one views this process affects, therefore, and affects profoundly, how one experiences time (Geertz, 1966: 374).

People who experience chronic illness either as those with illness or as carers of those who are ill, are faced with the certain decay and disappearance of concrete individuals. Regardless of whether this happens rapidly or over decades, the individual with illness is faced with increasing restrictions in their body and incapacity to maintain previously held rhythms and practices. The carer or family member who bears witness to such change is faced with the disappearance of concrete individuals, which additionally raises for them questions about their own future – their own disappearance. Surely observations of the passing of time rendered in such obvious biological terms must, as Geertz asserts, profoundly affect how the person living with chronic illness experiences time (see also Munn, 1992). It is through the habitual daily ideas, routines, and practices, that people’s relationships to time can be observed. Just as people’s practices associated with agricultural work occur at specific times, so too do their practices concerning health and
the body. Health-related practices change as people age, as their health status changes, and in relation to social factors. Such practices are dependent on people’s awareness of change, of their bodies, and of health practices available to them (which has elsewhere been described as health literacy (Nutbeam, 2000), and in terms of self-determination, patient activation and self-management (Jowsey et al., 2011)).

This thesis provides empirical evidence to demonstrate that the chronically ill body is one that brings about changes to people’s ordinary practices and rhythms. Although chronic illness can create disturbances to rhythms and routines, I argue that they are not necessarily experienced also as disruptions to biography. The example of chronic obstructive pulmonary disease (COPD) is useful here to illustrate; as COPD progresses the individual’s capacity to absorb oxygen decreases and so their speed of movement slows. This gradual change in speed, say in their walking, is experienced in the body as a gradually habituated change to rhythm and time – one that may or may not take on new meanings associated with disruption (Bury, 1982; Adam, 1995; Ellingsen et al., 2013).

The ideas pertaining to time and its socio-physical impact posited by Geertz have been elaborated by Adam (1995). Adam writes:

> Time forms an integral part of our lives that is rarely thought about. … Everyone, it seems, holds a very exclusive, personal meaning-cluster of time, a distinct but not fixed composition, one open to changes and linked to shifts in personal circumstances, emotional states, health, age and context (Adam 1995:5).

Following Adam, this thesis brings time to the forefront of discussion and by so doing illuminates the taken-for-granted yet fundamental ways in which multiple concepts and structures of time inform people’s lived experiences. It explores such ‘meaning-clusters’ and ‘compositions’ of time and how they intersect with shifting health contexts.
While chronic illness itself is well researched (Townsend, 2011) few studies from the disciplines of sociology, anthropology and public health have centralised time as a key lens through which chronic illness experiences can be understood (Morris, 2008). Those that have done so usually only centralise one main temporal structure, and most are disease-specific – only exploring one type of chronic illness (McKenna et al., 2009; Rittman et al., 2004; Morris, 2008; Pound et al., 1998; Sanders et al., 2002; Faircloth et al., 2004b). Bury (1982), Corbin and Strauss (1985, 1992), and Charmaz (Charmaz, 1993) have each included time in their work concerning all kinds of chronic illnesses, and each emphasise self-identity. Bury (1982) (informed by data from his rheumatoid arthritis study) describes the changes to identity that occur in response to chronic illness in terms of changes to biography (which may be interpreted as biographical time; or past, present and future time). Like Bury (1982), Corbin and Strauss (1985) also describe ‘biographical work’ undertaken as a result of chronic illness, however they note that ‘illness work’ and ‘everyday life work’ are also required (which they describe as three separate aspects of work) (1985, 1992). The focus of Corbin and Strauss’ theory is essentially self-management. Charmaz (1993) identified more than one temporal structure to understand experiences of chronic illness; however her focus remained on how time and chronic illness inform self-identity. Charmaz writes “the struggle for control over illness and for control over time is a struggle to control the defining images of self” (Charmaz, 1993: viii). The main temporal structure referenced in her work is past, present and future time. There is also reference to calendar and clock/ed time (CCT) and routines. The literature has scarcely explored how multiple temporal structures relate to the experiences and practices of people with different kinds of chronic illnesses. Ellingsen et al., (2013) have recently made a start in addressing this dearth in chronic illness literature concerning multiple temporalities with their phenomenological study of 23 people with chronic
illness (22 had cancer) who were in palliative care. In their attention to embodied time and rhythms, Ellingsen et al., suggest that people experience ‘outer time’ that links the individual with cultural contexts and setting, ‘relational time’ that links them through time to other people, and ‘inner time’ that is time experienced in the body. They explore how these times intersect and are experienced by the palliative person. Their study presents insight into the experience of time of people with cancer who are nearing death, however other chronic illnesses are not addressed, nor the experiences of people who consider death to be in the distant future.

I see my scholarly contribution, as I have described it above, as my response to an existing set of field-defining affirmations and theses about ‘the’ [singular] experience of temporality one might expect of a chronic illness diagnosis and manifestation. My thesis seeks to question how it is that we ‘think up’ the analytic space of chronic illness and to unsettle some existing powerful ideas that presently dominate that space – such as a singular relationship to time and necessarily negative disruptive experiences of chronic illness. I seek here to closely explore the specifically temporal components of biographical disruption and propose that time use can indicate circumstances whereby biographical disruption may be felt more keenly. I suggest, however, that biographical disruptions are not sufficient to account for the range of experiences that constitute chronic illness experience and behaviour.

Unlike Bury and Morris, and unlike Townsend, I focus on how time forms up as rhythm. This is not to say that disruptions to time flow (Bury, 1982; Morris, 2008) are non-existent, nor to say that power and social structure are not to be found in time (Townsend, 2011). Rather, I propose that rhythms of the body change with chronic illness and thereby
change experience and practice. I am concerned more with extending on the work of Ellingsen et al., (2013); suggesting that internal rhythms (‘inner time’) inform the individual’s interaction with external ones – with the rhythms of other people, of health services, of spaces, of cultural, social and political processes – and that these interactions inform people’s experiences. The interaction becomes evident in the chronically ill individual’s time use – their time spent on health-related practices and, consequently, their time no longer available to spend on other practices. It also becomes evident in the individual’s ideas and meaning-making.

**Rhythms, anthropology of the body and time**

A rhythm is a sequence of events or processes that occurs with regularity. Regular cycles are repeated in a rhythm, such as with the predictable changing of seasons or ocean tides. Rhythm has been described elsewhere in terms of cycles and cyclicity (Subrt, 2001; Rutz, 2012), with emphasis on epoch time¹ (Fabian, 1983; Gell, 1992) and external rhythms. This thesis, however, is more concerned with phenomenological rhythms of the body and of individual practices. Adam writes:

> We eat, sleep, breath, use energy, digest, perceive, think, concentrate, communicate, interact and work in a rhythmic way. All processes of our body are accurately timed and paced so that our organs, tissues and hormones are produced at mutually related rates (Adam, 1995: 46).

As Adam has noted, bodies manifest a multiplicity of processes; each with their own distinct yet interconnected timings, tempos and rhythms. There are multiple temporalities

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¹ Epoch time is a grand scale of time that people use to reference time scales, not by calendar and clock/ed time (CCT), but by socio-cultural or environmental events. In referencing epoch time a person might state, for example, that their chronic illness became exacerbated just after the town flooded, or the heat wave ended, or the president was elected. Fabian (1963) describes epoch time as referencing primarily environmental change. In my fieldwork, participants often used epoch time to explain their experience in reference to when an environmental event happened. However, the most common epoch that almost all participants referenced was their time of diagnosis – a bodily ‘inner’ time of such personal magnitude and so widely understood socially that it was discursively used as epoch time.
at play at any given moment in the functioning body. For example, the process of sleeping is undertaken after approximately 15 hours of waking time. Certain processes occur at different speeds (Griffiths, 1999) according to whether the body is in waking or sleeping mode and whether the body had approximately the right amount of time in the previous mode. The production of enzymes, the growth of muscle tissue, the digestion of food are ‘mutually related’ to sleeping and waking time (Kenny 2010). Adam writes,

As living beings we are permeated by rhythmic cycles which range from very fast chemical and neuronal oscillations, via the slower rhythms of heartbeat, restoration and circadian rhythms, to menstrual and reproductive cycles, and to the very long-range recurrences of seasonal and even climactic changes (1995: 45).

When combined at ‘mutually related rates’, rhythmic processes produce a functioning body. Rhythmic processes are experienced in the body and it is through the body that the individual experiences life. As Merleau-Ponty (2002) has noted, it is the body that posits around us a biological world though which we come to experience external phenomena, and develop perception and representation. Extending on Heidegger’s (1962; 1992) hermeneutical device (and unfinished work) that ‘being in time’ is a context with which the individual cannot be separated, Merleau-Ponty (2002) notes that time as a dimension of being is observable through bodily experience and practice. Ellingsen and colleagues agree: “The ambiguity of being in-the-world is translated by the body and understood through our relation to time. By considering the body in movement, we can see how it inhabits time, for example the mobility of the older person may be compromised, reflecting the passage of time (Ellingsen et al., 2013: 166).” Thusly, it is through the body that both time and the external world are perceived, and through the body’s rhythms – including the individual’s mobility – that these perceptions are informed.
Yet despite their omnipresence, rhythms of the body often go unnoticed until they change or fall out of sync with one another. The chronically ill body is one that manifests a multiplicity of altered temporalities whereby previously trusted rhythms morph into new and unknown irregular timings. I now introduce examples from my fieldwork to demonstrate these relationships between rhythms, the body and time; and how bodily rhythms and their disturbance are perceived. Felix, a 70 year old man with the onset of atrial fibrillation started “waking up feeling sluggish despite having enough sleep. We would check my heart beat and it was down at 42 [beats per minute].” His usual sleeping and waking rhythm meant that Felix expected to awake feeling a rested level of energy, however the sluggish feeling indicated a change had occurred in his usual bodily rhythm processes and the low heart beat – which was tracked through time and the body, as Heidegger (1962) and Merleau-Ponty (2002) suggest – confirmed a disturbance to his health. Similarly, his wife Lucy, also 70 years old, reported that her underactive thyroid and high blood pressure caused her to constantly feel “not in rhythm, not in sync.” Jill, a 71 year old woman with a rare illness called Padget’s disease reported that her “bones grow too quickly,” which had caused overgrowth of her skull and headaches. Spurts of overgrowth were experienced as interruptions to regular bone growth and caused other neural rhythms to become disturbed, signalled by headaches. Asynchronies to rhythm, such as these, are almost always reported as the first noticed sign by the person with chronic illness that they may be unwell. As 34 year old Ben reported on facebook: “I pulled out of my usual [exercise] routine about 2 months ago because of my chest pains (which were particularly intense when I ran or cycled).” These chest pains stimulated medical enquiry, which led to his diagnosis of cancer (see Chapter three: case study two).
Such asynchronies are managed with one or more of three strategies. First, in some cases asynchronies can be realigned through the consumption of medication. In his exploration of the temporal nature of diabetes, for example, Morris (2008) notes that the routine injection of insulin provides a temporality otherwise lost to the diabetic body. Similarly, ventolin consumed by the asthmatic body will contribute to relaxation of muscles and consequently, the restoration of healthier breathing rhythms. Second, the temporal asynchronies of some chronic illnesses can be adjusted through technology. A pacemaker for the body with atrial fibrillation will restore a regular – temporally predictable and rhythmic – heart beat. Renal dialysis machines will extract and clean blood for the body with renal (kidney) failure. And thirdly, asynchronies caused by chronic illnesses can be influenced by changes to physical bodily movements and practices. The individual with angina, for example, can rest in an upright position to reduce fluid congestion in the chest and improve sleep safety; the individual with type-2 diabetes or lung disease can undertake physical activity to improve overall health of the body and thus bring closer alignment to previously held body rhythms. Participants in my fieldwork with a variety of chronic illnesses demonstrated utilising one or more of these strategies to manage asynchronies.

Such strategies are strongly articulated within chronic illness self-management experience and program literature. These strategies are employed to address asynchronies (although other language is used in public health literature to describe this). Attempts to manage asynchronies caused by chronic illness include recognition of these changes in bodily rhythms and techniques for restoring previously held rhythms or striving for biomedically approved ones in the context of expectations that certain stages of chronic illness bring.

Roberto, a 74 year old man with diabetes and COPD, said:

I have to eat at a particular time and that annoys me because I like to eat when I want to. Oh, it’s irritating because you have to do the blood test for
the insulin and wait ten minutes and then you have to put the insulin in and then you have to wait a certain period of time again so it’s frustrating.

Roberto experienced frustration and hunger because his normal bodily rhythms associated with food consumption were altered by what Ellingsen et al., (2013) and Morris (2008) might call ‘outer’ or external temporalities ‘injected’ through medicine. Yet these injected temporalities were essential to the management of his diabetes. This example signals the tension Heidegger (1962) describes between the body sensing ‘being in the world’ and simultaneously ‘being in time.’ Roberto’s bodily experience of hunger signalled rhythms and time in his body, however the medicalisation of his chronic illness was at odds with Roberto’s body because the rules of timing insulin with food consumption were foreign to Roberto’s previously held bodily ways of being. These experiences of Felix, Lucy, Jill, Ben and Roberto as relayed above demonstrate that time is experienced in the body. The chronically ill body is one that develops new relationships to time through perceived disturbances to previously trusted rhythms, asynchronies, and the development of new rhythms and practices. Additionally, new processes of practice are taken on with chronic illness and these processes can be difficult to measure in terms of the time needed to undertake them because of the complex ways in which they interweave with other aspects of social life. This is what Davies calls ‘process time’, which will be explored in Chapter eight.

My ethnographic research, which included discussions with both younger and older adults with chronic illness, was conducted in 2012; thirty years after Bury proffered his influential theory. The research identified multiple examples of biographical disruption, which I shall now briefly introduce. Participants reported feeling overwhelmed by the extent that chronic illness had transformed their behaviours and ideas about their lives.
Bill, for example, was a 68 year old man who had diabetes for 12 years, calcification of his arteries for two years, and medicated depression for 20 years. He was undertaking biographical work on several fronts, including his self-management practices and ideas about chronic illness (Bury, 1982, Corbin and Strauss, 1985). Two years prior to our first interview Bill underwent surgery to replace some of his calcified arteries and during this hospitalisation a ‘critical situation’ arose (Bury, 1982). Six days after the surgery Bill’s heart stopped. “I died. The body just stopped,” he said. “That kind of freaked me out no end.” He was revived and monitored closely for several weeks.

The incident caused a very dramatic disruption to his biography; it almost ended it. It brought the possible timing of his death to the foreground of his mind. He decided to increase his efforts to self-manage chronic illness, with the hope of delaying his next death experience. Bill said his social eating and exercise practices had been severely informed by chronic illness. He changed his daily routines and rhythms; avoiding socialising during meal times or with friends who were heavy alcohol drinkers, which made it easier to manage his diabetes, and he avoided situations that required walking, which reduced the pain in his legs from calcified arteries. Bill’s ideas about his future biography were informed by his health. The significance of the illness was manifest in his worries. He worried about his capacity to maintain paid employment; his current job required long periods of standing on a concrete floor which was painful due to his arteries and associated swelling in his legs; on days after work he noticed he had low blood glucose levels (BGL). He worried about dying at home and nobody noticing, he worried about whether his dog would be cared for after he died. He tried not to worry “because” he said, “worrying makes your BGLs go up.” His biography was heavily informed and disrupted by chronic illness. He could not return to a prior ‘healthy’ mode of sociality.
Each day, in the context of chronic illness, he developed new ideas and practices. His thoughts about his future, including his worries, demonstrated the biographical disruption. While ‘worry time’ is not accounted for in Bury’s (1982) theory, nor in Corbin & Strauss’ (1985) description of types of work that surface in response to chronic illness, in my research worry time featured prolifically as contributing to profound senses of disruption and work resulting from chronic illness. Many other research participants demonstrated that chronic illness disrupted their biographies. Reports of biographical disruption were reported most often by people aged between 20 and 50 years, by those experiencing economic hardship, and by those who had impaired mobility due to illness. Biographical disruption was uniformly experienced by informal carers, independent of the carer’s age, the care recipient’s type of disease, whether the carer was still in paid work or was retired, and whether they cared for a spouse or family member.

For people with chronic illness, biographical disruptions were consistently observed in younger adults, often observed in older adults, and for several people who were aged eighty years or more, disruptions to biography were rarely or less profoundly experienced. As with Bury’s (1982) research, disruptions to my participants’ biographies were informed by the individual’s age when diagnosed. These observations are also line with those of Pound et al. (1998), and Sanders et al (2002). Disruptions to biography were also informed by the phase of life cycle people were in when diagnosed and when interviewed (including whether they were in paid work) (see also, Sanders et al., 2002, Carricaburu and Pierret, 1995, Bury, 1982), the severity of illness in terms of its impact on the body and sociality, and the individual’s previously formed thoughts about what their biography would entail. As Pete, an eighty year old man with a chronic lung disease and atrial fibulation explained, “I don’t have any concerns for the future. When I was
born men were expected to live to 70 if they were lucky. Well I’ve already beaten those odds. I’ve lived a full life.” When Pete was born his “expected” biography was to “live to seventy.” He was diagnosed with pulmonary fibrosis at age 76 and with atrial fibrillation a year later; illnesses that can cause severe symptoms and even death. However, these illnesses did not fundamentally disrupt his biography because he had already “lived a full life” and the timing of chronic illness onset synchronised with his ideas about ageing and what his future would entail. This focus on the timing of chronic illness onset in line with Pete’s beliefs allowed him to not focus so much on the daily limitations and rhythms imposed by illness on his present experience. Rather, he looked beyond his present experiences to consider the role and timing of chronic illness in the context of his entire biography.
Pete, connected to his oxygen concentrator by tubing, walking four metres to sit in his favourite chair while I watched, a task that took several breaths and 44 (seemingly long) seconds. 2012.

I also noticed that for the few people I spoke to who had lived with chronic illness since they were children, the ‘disrupted biography’ was not uniformly experienced. Ray, a migrant from Africa in his sixties had post-polio syndrome. He said “it’s not as bad if you get it early on either. I got polio when I was two months old, so I’ve never experienced life any other way.” Ray was an infant when he became ill. He lived with the effects of poliomyelitis for most of his life. His biography was shaped with reference to poliomyelitis; without the possibility of a future where the effects of poliomyelitis would be absent. Ray could have interpreted this as entirely biographically disrupting, but instead when telling me of his condition he down-played it. When I asked him about daily difficulties he encountered such as walking or sitting, he pragmatically responded “well you’ve just got to get on with things, don’t you?” Poliomyelitis had left him disabled; it informed the rhythm of his movements. However, his formation of his own biography was akin to the HIV positive participants in Carricaburu and Pierret’s study (1995); he explained that he was one of many European children born during the Second World War
who contracted poliomyelitis. The illness placed him in a particular historical and cultural context. Ray had lived practically his entire life with the external evidence of this context.

My research identified that, in the case of younger adults, experiences of change to biography are experienced largely prospectively (whereby the individual reconsiders their possible future), while for older adults experiences of change to biography are also experienced retrospectively (whereby the individual reconsiders how past experiences and actions have influenced their current situation and their possible future). Therefore, age is one temporality that engages with past, present and future time; which inform people’s experiences and the extent to which chronic illness is biographically disrupting.

Additionally, I noticed that although people reported feeling that their lives had been disrupted by chronic illness, there were times when they intentionally disallowed disruption to occur in their immediate experiences and practices. In the case of Bill, for example, although he clearly experienced biographical disruption he chose to minimise the role of chronic illness in the context of his sociality at certain times. When he was at home alone he paid special attention to his BGLs;

I do my blood tests every morning. If my BGLS are higher than normal I go back over what I had the previous day or what happened the previous day and I invariably find that I’ve eaten something I shouldn’t have. Like the other night I was just sitting here and my hands started shaking, going crazy, and I thought ‘Geez am I having a hypo?’. So I did a BGL and I was at 3.5, a bit low. So I just got into the jelly beans and the following morning woke up with [a BGL level of] 6.5! So yeah.

However, when socialising Bill reported abandoning certain rhythms and practices in order to privilege his desire to enjoy meal times with friends. He said,
If I go down to Melbourne to where my mate is, he’s got diabetes as well, I don’t do my BGLs cos I know I’m gonna be high cos I’m eating a full meal. His wife cooks really well. So I just don’t bother then. I’m normally there for four or five days and I do all my normal regime but I don’t test my BGLs. There’s no point. … If it’s really bad I don’t change the rhythm [of timing food consumption] I just change what I’m eating. I’ll just have half the meal. And his wife is really good, she understands.

For Bill, managing his diabetes was a top priority most of the time and he managed oscillations in his BGLs by consuming particular foods at particular times to control them. However, occasionally his attention to this management task was intentionally altered in order for sociality to take precedence.

Although these examples above clearly demonstrate a sense of immediate and personal bodily change informing perceptions and practices, I am also interested in the subjective experiences people have of chronic illness as it effects the bodies of other people. Again, it is through the individual’s body that perception of the external world – including other people – arises (see Haney, 1994). I have mentioned above that informal carers are included in this research and this is because chronic illness is not only experienced by the person afflicted but also by those around them, most notably, their informal carers. Chronic illness is however, increasingly experienced by all members of society in one form or another. As the incidence and prevalence of chronic illness rise, so too do the number of people who experience chronic illness indirectly; through family members and close friends having illness, and also through daily life encounters with those who are ill (see Chapter 10: agents in time).

Take the rhythm of breathing. Our own breath is generally something we become familiar with as we age. We feel it, most often as a comforting, yet practically invisible rhythm of the body. At times our breath becomes something we can hear, an auditory aspect of the
breath takes form; we cough, yawn, the nose whistles as air is sucked in, we snore. In some cases breath can be heard by others, but generally breathing is something we seldom hear others do unless they are in close proximity or their breathing is exacerbated. At a conference I attended in 2013 concerning breathlessness, Sam was present who had with him a portable supplementary oxygen unit. The guest speaker described two parts of the brain that inform breath; one that ensures we keep breathing and maintain a breathing rhythm that can support the body’s needs; and the other that can consciously inform change, such as when we intentionally hold our breath. As he spoke, the otherwise silent room was interjected with a regular sound of supplementary oxygen being expelled from Sam’s portable oxygen unit, which I heard and interpreted through my own body. Every four or five seconds a sound could be heard in the background of the speaker’s presentation that was something akin to ‘kr-sh-k’. Sam was sitting at a table directly behind me. The ‘kr-sh-k’ sounds coming from his machine made audible to those around Sam his breathing rhythm. The usually internal sensation of breathing, this predominantly hidden and ‘inner time’ process (Ellingsen et al., 2013), was externalized and took on new currency as the auditory senses of other people in the room were involved.

For me, this regular ‘kr-sh-k’ sound quickly disappeared into the background soundscape of the room. However, when the rhythm changed, even slightly, as Sam sighed or took a deep breath, the change to the ‘kr-sh-k’ rhythm returned my focus to his breath. In amongst my furious scribbling of notes from the seminar my mind noticed this change and I thought ‘Is he alright?’ At one point I turned to look at Sam to check and as I did so the now-familiar sound of ‘kr-sh-k’ suddenly filled the crisp air. I relaxed in the knowledge that Sam, a man I had not even met, was breathing. The thought of other
people’s breath or even my own breath did not enter my mind. The concern for Sam’s breath emerged through my seeing his breathing device and hearing his breathing rhythm.

What I have just described is a commonly understood experience among informal carers and people who live with people who require supplementary oxygen to help them breath. Carers of people with lung disease have described to me the inability for them to ever truly be at rest because they are always listening and alert to changes in the sounds of the care recipient’s breathing rhythm. Even as they rest and attempt to sleep carers report reserving a part of themselves for the task of monitoring other bodies and technology. This is why when I asked them how much time they spent caring they sometimes reported “24 hours a day”, and some reported that this had been the case for several years (see Chapter three: case study one and Chapter seven: time use of informal carers). This constant disruption to the rhythms of carers has been reported by Wilkinson and Pickett (2010) as creating a weathering effect. It has also been found in sleep studies to lead to health problems (Knutson et al., 2006). This thesis suggests that the changes to previously habituated rhythms, including bodily rhythms, brought about by chronic illness (and in Sam’s case externalized and made auditory by technology) are disruptions. They contribute to an individuals’ perception of disturbance and interruption to their ways of being, and over time can contribute to ‘disruptions to their biography’ (Bury, 1982) not only for the individual with chronic illness but also for those charged with their care. I therefore include in this thesis analysis of the experiences of informal carers.

However, while changes to previously habituated rhythms can inform biographical disruption they can also be incorporated into the fabric of daily life and, over time, become less significant to what Heidegger (1962) calls ‘the conscious mind’. The
established habitual rhythms of breathing and of the sounds associated therewith – whether they be assisted by technology or not – can dissolve into the background of one’s perception. As such, it is entirely possible that the individual does not experience such rhythms as disruptive. When change to the (possibly subconsciously observed) rhythm occurs, the sense of disruption can re-emerge. That is, as with my experience of hearing Sam’s supplementary oxygen unit working, the regular predictable beat caused for me a commotion, only when it changed, when it became unpredictable and the rhythm changed. Returning to Bury (1982), I am suggesting here that even new practices and rhythms forged through chronic illness can become so familiar and predictable that they cease to contribute to the individual’s perception that their lived experience has been ‘disrupted.’

This thesis suggests then, that the extent to which an individual’s biography is disrupted is founded on several temporal factors:

a. the person’s age of chronic illness onset (which speaks to the significance of the illness in terms of the individual’s biography);

b. how long the individual has had chronic illness at point of data collection (which relates to the trajectory of illness and the extent to which illness-related health practices are habituated and normalised);

c. the amount of time spent on health-related activity as a result of chronic illness;

d. the type and severity of the illness at point of data collection, and the number of co-morbid chronic illnesses (which inform points b and c); and

e. the individual’s capacity and agency to habituate new rhythms and practices (a new sense of time) in response to chronic illness.

As outlined above, few of these temporal factors have been identified in previous research. Biographical time, as addressed by Bury (1982), is but one temporal structure
that is experienced in different ways through chronic illness. I suggest that a rich analysis of chronic illness experiences through a temporal lens must address additional temporal structures. I am therefore following a path more closely aligned with the one that Ellingsen and colleagues (2013) have embarked on, rather than on a path that follows time [singular].

The thesis proposes that other forms of time are essential to understanding the lived experiences of those with chronic illness and their informal carers; the most notable of which is CCT, and this is for several reasons. First, CCT is salient across experience of people living in Australia today. Second, it permeates ‘outer time’ (Ellingsen et al., 2013) and social structures (see Armstrong, 1985; Bittman et al., 2000, 2004, 2005; Strazdins et al., 2011; Townsend, 2011). It is entrenched in the discourses and practices of the primary and secondary health care sectors, and therefore governs much of the way people interact with health care professionals and experience ‘management’ of their health. Third, as Benjamin Frankly so famously pointed out, time – and specifically, CCT – is money. Health care policies and services are often informed by cost-benefit analyses – of employees, programs and services – whereby CCT is assigned monetary value and calculated in terms of efficacy or potential cost effectiveness. This ‘cost’ to the patient or carer is seldom calculated or factored in (Krueger, 2009), but I argue that it must be if we are to perceive how ‘effective’ policies and services are in serving the needs – and informing the experiences – of those living with chronic illness. What are the time costs (CCT) of chronic illness to those living with it? Can it be measured and calculated? Can it be assigned value? I contend that the time use information presented in this thesis, provided by those living with chronic illness, goes some way to answering these questions.
Also in focus throughout this thesis is the way chronic illness informs people’s relationship to past, present and future time. Chronic illness informs the individual as they explore their past and import new meanings and practices into the present and future. An exploration of chronic illness experiences through the temporal lens must, in my view, include attention to past, present and future time because chronic illness has the potential to inform so profoundly one’s relationship to this temporal structure, and counter-wise, because this temporal structure has the potential to inform one’s experience of chronic illness. That is, as Bury (1982) has suggested, the onset of chronic illness manifests in the individual new ways of thinking about their future. Although Bury’s attention is concerned more with the future than the past, I suggest that chronic illness also informs people’s thinking about their past – their actions, ideas and beliefs, as well as their previous experiences of health and illness – that may now be viewed as linked to illness onset and/or that inform current experiences and practices. Indeed, the orientations towards past, present and future time, I argue, fundamentally inform how the future for the chronically ill individual will unfurl (see Chapter 10: agents in time). In addition, it is these temporal orientations upon which self-management and self-determination chronic illness literature and services rely. The individual whose orientation is solely concerned with past or present orientations cannot be expected to engage in practices that will inform better future health outcomes. Rather, it is the orientation towards one’s future experiences that propels them into (self-management) action (see Chapter 10: agents in time).

Past, present and future time is included in Boxenbaum’s 1986 extensive list of temporal structures, thought he does not define it. This may be because definitions of it can markedly differ according to discipline, whereby past, present and future time in temporal physics or mathematics may be perceived differently from in sociology or psychology, for example. See also, Chernus, 2011; Cockburn, 1997; Fabian, 1983; Geertz, 1966; Zimbardo 2002; Zimbardo & Boyd, 1999.
Part of the difficulty in exploring past, present and future time, however, arises in its being identified in several disciplinary ways (see footnote 3). At its heart, it is a way of perceiving both linearity and cyclicity of time through the progression of events through tense. Sociologist Adam (1995) has demonstrated that the past can be experienced as present; the Zen philosopher Suzuki (1970) has illustrated how time can be perceived as moving forward from the future to the past; and metaphysics philosopher Cockburn (1997) has located this temporal structure in articulation of the place of our thought, suggesting that tense shapes our understanding of events when ‘reasons of emotion’, he argues, would be more appropriate to this task. For the purpose of this research I walk a different path. I seek to locate this temporal structure as progressing in linear fashion from past to present to future; both within the individual and with reference to social others. This is not to dispute those who contend it moves in cycles or in reverse order, or that past is present is future, or is indeed, all in the mind; but instead to settle on a singular, and therefore simpler, way of perceiving the import of how past, present and future time relates to individual experiences of chronic illness and how this plays out in daily life. Viewing past, present and future time in this way also serves to provide information that translates into health service implications for supporting those living with chronic illness.

**Practical application of this research**

With Townsend (2011), I share a desire to make a practical difference to the provision of health care to the chronically ill on the basis of what my study has revealed. In my own case, this has manifested in the development of a new care plan template, for use by people with chronic illnesses, that references the possibility of multi-morbidity as well as accounting for the temporal circumstances under which illness is experienced. My early
forays into the domains of medical and health care professionals, as well as consumers, to introduce this possibility, have been met with excitement and willingness to make currently available plan templates more user-friendly.

As an individual who is involved in the analysis of data that impacts how people experience and receive primary health care, I am keen for a practical outcome to occupy an important space in my thesis that takes it beyond the scholarly terrain of my analytic work. In terms of practicality and insight, I see the work as operating on the rich vein where anthropological insights and methods meet public health concerns.

This practical outcome of my thesis begins with an analysis of just how much time the individual with chronic illness and their informal carer/s must dedicate to managing illness. Such a calculation seems simple, but it is deceptively so, especially when the individual has more than one chronic illness (an increasingly common situation in Australia (Aspin et al., 2010; Jowsey et al., 2009) or/and when the person’s carer (should they have one) is also afflicted with an illness (see Chapter seven: time use of informal carers). My data clearly show that managing a chronic illness is to a large extent about managing time: chronic illness is all about time not just in the sense that the term ‘chronic’ is ostensibly meaningful in the term ‘chronic illness’ where it flags the persistence of the condition over a long period. It is equally the case that chronic illnesses manifest in the present and immediate experiences a person has of time. Its management takes up a significant amount of time in the present, and must be planned for in the immediate future. Chronic illness can be a time thief both in the senses of diminishing a future, and in gobbling up the present. Additionally, chronic illness can bring about new
ways of perceiving one’s past, and in this sense is disruptive to the future, present and past.

Because managing chronic illness can take up so much of present and immediate future time, time is of critical importance to the care plans that those with chronic illnesses follow. These plans typically follow a template (often provided by health departments) and are developed by healthcare professionals and researchers, often with limited input from those afflicted. They include elements of ‘timing’, such as taking medications at the right intervals and times of the day or night, setting exercise and weight goals to achieve in agreed time frames, identifying correctly when to seek medical intervention for exacerbations of illness; and doing things like scheduling (future oriented) appointments with health care professionals. However, my data show that those with chronic illnesses also have to factor in how much time something, like taking medication, actually takes up, as well as planning for those events, and planning around having to carry out health-related tasks in the context of the routine commitments of one’s day, which might still include work, family and other sorts of activities that also take up their fair share of time. Such issues, I suggest, are reflected in low uptake of disease-specific care plans, and a stated concern among health professionals that deviation from care plans is common.
CHAPTER 2 METHODS

The methods are described separately in each published manuscript. This chapter provides supplementary information about the overall thesis project and processes.

As outlined in the introduction, this thesis is concerned with bodily experience – with experiences of chronic illness, of daily rhythms and health-related practices, and of interactions with health care providers and other people. The methodology underpinning research undertaken here is one that has been taken up by anthropologists – the interpretive approach. As aforementioned, this approach lends itself to understanding the myriad meanings behind actions connecting experience, chronic illness and time. To support the methodology, triangulation was utilised. Triangulation draws on different types of data to draw conclusions (in this case, both qualitative and quantitative data was analysed). When conclusions from different datasets point to the same finding they contribute to the overall validity of the conclusions (Rothbauer, 2008).

Anthropological methods were selected – fieldwork (including participant observation) and semi-structured interviews – to gather data that would enable thorough exploration of the connections between meaning-making and action. My choice in utilising qualitative data was further grounded in the observation that many experiences of temporality (such as biographical time; embodied time; worry time; and past, present and future time) cannot be easily quantified but can be, at least to some extent, articulated. Therefore qualitative methods were needed. Three qualitative datasets were gathered and analysed (described below).
In order to understand meanings and actions that participants located in relation to calendar and clock/ed time (CCT) the *time use* of people living with chronic illness was measured in a national self-reported point-in-time time use questionnaire. The dataset provided quantification of the actions people take over time to manage chronic illness.

In total, four datasets were gathered and analysed to support the interpretive methodology:

- Chronic Illness Time Fieldwork
- SCIPPS Qualitative Project
- SCIPPS Indigenous Project (also qualitative)
- SCIPPS Work of Being Ill Survey.

This chapter presents an overview of my contribution to the methods undertaken to gather and analyse data. As this is a thesis by compilation that presents a series of published manuscripts, I also include detail on the methods employed in working with others to create manuscripts for publication.
Ethics approval

Human research ethics approval was obtained prior to commencement of data collection for each dataset.

SCIPPS Qualitative study and SCIPPS Indigenous study

Study approval was obtained in 2006 from the Australian National University Human Research Ethics Committee, the ACT Health Human Research Ethics Committee, the University of Sydney Human Research Ethics Committee, Sydney West Area Health Service Human Research Ethics Committee.

For the SCIPPS Indigenous Study approval was also obtained from the Aboriginal Health and Medical and Research Council of NSW.

The Scientific Project Title for which approval was awarded was: “Optimising prevention and the management of care for Australians with, or at risk of, serious and continuing chronic illness.”

For the SCIPPS Indigenous study, following ethical conduct of research concerning Indigenous peoples, the research team also sought manuscript approval from our partner organisations and the Aboriginal Health and Medical and Research Council of NSW prior to submission of manuscripts arising from this research.

SCIPPS Time use survey

Study approval was obtained in 2010 from the Australian National University Human Research Ethics Committee. The Scientific Project Title for which approval was awarded
was: “The work of chronic illness; practice affiliation, co-ordination and time spent on health care.”

**Chronic illness time**

Study approval was sought in 2011 (protocol 2011/656) and obtained in 2012 from the Australian National University Human Research Ethics Committee. The Scientific Project Title for which approval was awarded was: “Chronic illness time fieldwork.”

**Privacy statement**

To protect the privacy of research participants identifying markers have been changed in this thesis. Pseudonyms are used throughout and some personal details have also been changed.

**Choice of chronic illnesses**

Bury’s theory of disrupted biography emerged from his analysis of people experiencing a single chronic illness (arthritis). As I am interested in how experience of chronic illness varies according to disease type, or multiple disease occurrences, I have included a wide range of chronic illnesses in this investigation. I have also focused on common illnesses that are associated with high management needs (including time management needs) such as highly prevalent respiratory, cardiovascular, renal and musculoskeletal diseases. Additionally, the thesis project includes people with multi-morbid illnesses in order to explore the links between temporality and multi-morbid illness experiences, and to identify temporal experiences that are common to a wide range of chronic illnesses. Each of the four datasets utilised in this thesis have included people with multiple chronic illnesses.
Cancer is often categorised as acute or terminal, rather than chronic. However, cancer is included in the Australian National Chronic Disease Strategy, in which it features as the sole subject of one of five national service improvement frameworks (Australian Government Department of Health and Ageing, 2005). Cancer may be classified as a chronic illness because a person who is diagnosed with cancer cannot ever be ‘cured’ as such, and at best can ‘go into remission’. The very state of remission requires that the individual always maintain a relationship to the illness; in that state they may undergo check-ups, engage in behaviour that they believe may reduce the risk of more cancer, and construct their identities in relation to the cancer experience (Jowsey, 2003). Additionally, many people live with cancer for several years or move in and out of states of remission over several years. Following the Australian National Chronic Disease Strategy, I have included cancer in this research as a kind of chronic disease.

**Age of participants**

Most people with chronic illness are not born with it; they develop it later in life. Almost all older adults (65–85 years) with chronic illness can recall what life was like before they had it and thus have a comparative point of reference in temporal experiences. One of the temporal structures of interest in this thesis is past, present and future time. This research focuses on older adults rather than on people of all ages because older adults are most likely to have experienced a past – both with and without chronic illness – which provides them a rich perspective on this temporal structure. Additionally, this age group represents the largest age group of people living with chronic illness in Australia.
People aged less than 65 years have also been included in the research in order to explore the relationship between age/life course/time and meanings associated with chronic illness. Bury (1982) noticed that profound disruptions to biography were experienced by young adults with arthritis. In order to establish whether his finding was disease specific, and to what extent it was age specific, my exploration of this phenomenon included participants with different chronic illnesses and of different ages.

Adults aged older than 85 years were excluded on the grounds that they constitute a much smaller demographic; one for which memory loss and cognitive impairment is a known common factor, and one for which the effects of chronic illness cannot be as easily untangled from the processes of natural ageing.

Datasets

Due to the time required to gather each dataset I chose to use two existing qualitative ones and then supplement them with the time use survey and my own fieldwork, the data for which was collected during my candidature.

SCIPPS Qualitative Study

The qualitative study comprised 66 semi-structured interviews with people who had at least one of three chronic illnesses: COPD, chronic heart failure, and/or type 2 diabetes mellitus. The interviews were conducted in 2008 and participants were recruited from the Australian Capital Territory (ACT) and New South Wales. Participants were asked to describe their experiences of chronic illness and their interactions with health care
services. The study methods are described elsewhere (Jeon et al., 2010; Jowsey et al., 2009).

I utilised NVivo8 software to assist secondary analysis of the qualitative study data. Content and thematic analysis was undertaken of the transcript data. Although participants were not asked specifically about their temporal experiences of chronic illness, early analysis indicated that this issue spontaneously emerged during participant interviews and further analysis was warranted.

I iteratively established a short coding scheme based on analysis of the transcripts and this scheme was used to code all transcripts (Greenhalgh and Taylor, 1997). I used content analysis to identify issues in the data that were commonly raised by participants (Morse and Field, 1995). Greenhalgh and Taylor describe content analysis in the following way:

Drawing up a list of coded categories and "cutting and pasting" each segment of transcribed data into one of these categories. This can be done either manually or, if large amounts of data are to be analysed, via a tailor-made computer database. The statements made by all the subjects on a particular topic can then be compared with one another, and more sophisticated comparisons can be made such as "did people who made the statement A also tend to make statements B?" (Greenhalgh and Taylor, 1997: 742).

Content analysis was assisted by frequency matrix coding using NVivo8 software. These issues were further explored thematically in terms of the associations between particular topics (Aronson, 1994). I describe the thematic analysis below. This secondary analysis of this dataset informed the overall thesis findings in the following ways: participants with a broad range of chronic illnesses and demographic characteristics were identified; participants described their meanings and actions associated with chronic illness and time, allowing for greater data saturation within and between datasets; and participants
discursively referenced multiple temporal structures, from which I was able to deduce salient temporal structures with which this thesis is consequently chiefly concerned. Participants from this dataset have been included to demonstrate thesis findings in Chapters one, three and eight.

**SCIPPS Indigenous Project**

In 2009 SCIPPS undertook further research with Indigenous Australians to allow data saturation to be reached in relation to key issues establish from the initial qualitative study (described above). The same index chronic illnesses were used for recruitment and the dataset was closed with 19 participants. The areas where the methods differed from the SCIPPS Qualitative Project are detailed here.

I engaged the local Indigenous community through the local Aboriginal Medical Service (AMS) and I sought culturally appropriate expertise to inform the project from the ANU Indigenous Health Interest Group (IHIG). I attended IHIG meetings monthly for three years, throughout the duration of the project and sought their advice at each stage of the project. Upon their advice, I revised the interview questionnaire with what they termed ‘culturally safe’ questions.

I undertook content analysis following the same method detailed above. In addition I undertook thematic analysis. This involved reading the entire dataset multiple times to become very familiar with each informant’s interview story. Common themes were identified from across the interviews. I checked the validity of the final set of themes against the findings from the content analysis. There was considerable alignment, although the thematic analysis enabled a deeper exploration of people’s experiences than
that of the content analysis. Content analysis on its own led to more superficial descriptive findings than the thematic analysis. The manuscripts arising from this project included both content and thematic findings.

I sought Indigenous AMS staff and Indigenous academics to co-author the manuscripts arising from the project to ensure quality in our work. Despite these efforts, only one manuscript (not included in this thesis) had an Indigenous author. However, all of the manuscripts included authors who had extensive expertise in working with Indigenous Australians. All of the manuscripts, including those presented in this thesis, were informed by Indigenous members of the community and were approved by the AMSs as well as the Aboriginal Health and Medical Research Council prior to publication. Members of the AMSs and research participants were invited to the launch of the community report at Parliament House, many of whom attended.

Primary analysis of this dataset informed the overall thesis findings and participants from this dataset have been used to demonstrate thesis findings in Chapters three, nine and ten.

**SCIPPS Work of Being Ill Survey**

In 2010 I worked with SCIPPS members to create a survey designed to capture co-ordination of care for people with chronic illness as well as to measure the time it takes to manage many aspects of living with chronic illness. The survey was administered nationally in February and March 2011. Three sampling groups were used to send out the surveys: the National Lung Foundation, Diabetes Australia and National Seniors Australia. 2,519 people responded and 2,519 responses were included in the final dataset.
Most respondents reported having at least one chronic condition and 330 respondents indicated they were an informal carer.

**My contribution to the project**

I was one of the original seven team members who developed the survey (Laurann Yen, James Gillespie, Paul Dugdale, Marjan Kjlakovic, Tanisha Jowsey, Ian McRae, Beverley Essue). Laurann Yen and I researched other time use surveys to model our own on. The group met numerous times in order to discuss potential questions for the survey, which were refined over several months. No one person was responsible for a particular question. However, I did contribute heavily to the time use categories (see Appendix 2) and the inclusion of allied health professionals in the survey.

This iterative development process took place over six months in 2010 to establish the SCIPPS time use and care co-ordination survey. The survey was independently reviewed by an external survey specialist. Amendments to the survey were made, after which time I facilitated a focus group with 14 members of the Health Care Consumers Association of the ACT to workshop the survey (14 November 2010). Most participants in the focus group had more than one chronic illness and provided key insights on ways to improve the efficacy of the survey. The survey was administered in February and March 2011.

During the early stages of development the team discussed potential manuscripts that could arise from the survey. I wrote up a publication plan, which helped guide the survey development and order in which analysis was later undertaken. At this stage other people joined the team to help with formatting and dissemination of the survey. I researched and
recommended that the survey be scannable by computer for electronic data retrieval, to which the group agreed.

Data analysis

The senior biostatistician was Dr Ian McRae and he was initially assisted by Dr Michelle Banfield and later by Dr Nasser Bagheri to undertake statistical queries using STATA and SPSS software. Authors for each paper requested specific queries to be undertaken. I was provided with the results of my queries in tabulation, which I interpreted and wrote up into the findings sections of the included manuscripts.

On the three manuscripts included in this thesis from the survey (Chapters five to seven), I was first author and as such I managed the first draft of the manuscript and the revision process. I undertook research of the background literature and wrote the introduction. I wrote the methods and analysed data (with assistance from Dr McRae). I wrote the discussion and conclusion. Considerable revisions were undertaken on the manuscripts by various authors, including myself (author contributions are detailed in Appendix 1).

Chronic Illness Time Fieldwork

The Chronic Illness Time Fieldwork was undertaken solely by me and was a small confirmatory ethnographic project whereby I engaged in participant observation and interviews with people in Canberra who live with chronic illness. The purpose of undertaking this research was to have an opportunity to experience a shared time with people (Geertz, 1966; Jeffrey and Troman, 2004) and in doing so share their experience of chronic illness and further understand how these intersect with temporal structures.
Wolcott (1995), citing Malinowski’s fieldwork as precedence, has suggested that ethnography should be undertaken for an ideal period of two years (either onsite continually for two years or regular visits onsite over a two year period, the latter becoming more common due to academic financial and temporal pressures). However, Jeffrey and Troman (2004) argue that a two year period is not always necessary, and that a ‘compressed time mode’ – “a short period of intense ethnographic research ... from a few days to a month” (2004: 538) – may prove adequate to ethnographic practice.

Following Jeffrey and Troman, I commenced a compressed ethnographic practice in short bursts over a twelve month trajectory.

I undertook participant observation over seven months with members of the Canberra Lung Life Support Group. Over twelve months I undertook participant observation with other research participants; I attended their support group meetings, spent time in research participants’ homes; attended information sessions with research participants; and conducted semi-structured interviews with 25 people living with various chronic illnesses (including eight informal carers). For participant details see Appendix 5. Since the conclusion of the compressed fieldwork period I have maintained contact with several of the research participants, which Jeffrey and Troman (2004) note is often the case in ethnographic research. They observe that this can muddy the waters concerning the exact length of fieldwork undertaken.

This ethnographic method lent itself to observing the immediacy of experience and “seeing into the life of things” (Woods, 1996: 77). It facilitated my understanding of the ways in which temporalities intersect and are negotiated through the chronically ill body (Wolcott, 1995; Jeffrey and Troman, 2004) by giving me an opportunity to experience
firsthand the timing and rhythms imposed by chronic illness (which I have described in the introduction in my experiences of hearing Sam’s portable supplementary oxygen unit function, and watching Pete walk slowly to sit in his favourite chair, for example).

**Participant eligibility criteria**

I interviewed family carers and people with chronic illness (not necessarily related to each other). People who were included in the fieldwork met the following eligibility criteria:

- has had a formal diagnosis of chronic illness and/or cares for someone with a formal diagnosis of chronic illness
- has no diagnosis of cognitive impairment
- resides in the Canberra region (including Queanbeyan).

**Recruitment**

I attempted to recruit participants with the help of Health Care Consumers’ Association of the ACT (HCCA). HCCA advertised my study in their newsletter *Consumer Bites*, Issue 9, May 2012.

An information sheet was also provided to HCCA to encourage participation (see Appendix 3). Unfortunately, nobody responded to this advertisement or the information sheet through HCCA.

I spoke to a friend who had diabetes about my trouble with recruitment. She suggested I interview her friend who met the eligibility criteria. I interviewed her friend, who recommended another friend and yet another. Word of my project spread quickly and I
interviewed sixteen people. This method of participant recruitment is often referred to in anthropology as ‘snowballing’ or ‘snowball sampling’ (which is not to be confused with the ‘snowballing technique’ often utilised in literature reviews). Snowballing is a non-probability technique whereby research participants recommend their peers to participate in the study (Heckathorn, 1997). While this technique is often effective for small or hidden populations, it also makes variety in the study sample (usually achieved through purposive sampling) difficult to attain and can instead result in community bias. Despite having to resort to this method, I was able to achieve variety on most demographic and illness characteristics. The interviews followed a semi-structured interview question guide that I developed prior to conducting the fieldwork (see Appendix 4).

I then approached the Canberra Lung Life Support Group and asked if I could attend their monthly meetings, to which they agreed. I attended four meetings in 2012 and another three in 2013. I interviewed several group members a number of times and also joined the group for lunches on multiple occasions. Following Sanjek’s definition of what can constitute data, I took field notes in multiple settings – during meetings, interviews, and lunches – which formed a further data source (Sanjek, 1990).

Data saturation is a term used to identify a point in the data collection when early analysis of the data suggests that the same kinds of information are arising in a frequency deemed saturated and new ideas are no longer arising; at which point the inclusion of further research participants is unlikely to generate new information (Morse & Field, 1995). I determined that data saturation had occurred in August 2012; having completed 25 formal interviews and countless informal conversations. At this point recruitment of further participants ceased, although I continued to attend support group meetings.
Working with others to create manuscripts for publication

People from multiple institutions and sites were involved in writing manuscripts for publication. This increased the difficulty in completing manuscripts. To manage this several protocol were followed. The first author on the manuscript was responsible for undertaking the majority of the work needed to see the manuscript completed, including data analysis, writing the first draft and managing the revision process. The first author usually determined order of authorship based on contribution to the project and/or manuscript. The last author listed on the SCIPPS manuscripts was a chief investigator or the leader of the SCIPPS project that underpinned the manuscript. The first, second and third authors were often involved in undertaking most of the analytical work as well as the formal revisions of the manuscript as requested by reviewers. The MS Word ‘tracked change’ functions were used in all manuscript revisions.

Several of the manuscripts included in this thesis involved substantial analysis work to be undertaken by multiple authors. Chapters six and 10 took longer to complete due to both the amount of analysis involved and having very busy authors located in multiple time zones. Manuscripts that had fewer authors, with the majority of them located together, were completed more easily and quickly.
CHAPTER 3  CASE STUDIES

Thus far, the thesis has introduced multiple temporal structures that are salient across chronic illness experiences, including: biographical time (described in terms of biographical disruptions); past, present and future time; and calendar and clock/ed time (CCT). It has also signalled a strong intention to attend to the lived experiences – the bodily and social aspects of chronic illness – that play out through time. It is in close examination of lived experiences that the individual’s changing relationship to time becomes evident.

The following four case studies come from the three qualitative datasets and from my own personal experience. They serve to illustrate the sophisticated interactions between multiple temporal structures that are brought to bear on the individual living with chronic illness. They also demonstrate the ways in which chronic illness creates tension in the body and in social contexts, and how such tension is managed over time.

Included in these case studies are people living with various chronic illnesses and varying degrees of chronicity. The diverse experiences of a female carer of an older man with chronic obstructive pulmonary disease (COPD), a young man with cancer, a young woman with an acute infection (and the possibility of kidney disease), and a middle-aged Aboriginal woman with diabetes are presented.
Case 1  Carer Caitlin and the disrupted biography

Roger had extremely severe COPD. The severity of his condition was recognisable by several indicators; including the high volume of supplementary oxygen (eight litres per minute) he used to assist his breathing. His movements were slow, he tired easily, and he had to stop regularly during interviews to catch his breath and increase oxygenation of his blood.

Roger’s portable supplementary oxygen unit and medicines

Caitlin was 60 years old when I first interviewed her. When I asked about what it was like caring for her husband Roger she framed her response in terms of both CCT and biographical disruption:

Well that’s a pretty broad question, isn’t it? It’s fairly demanding or I should say, more than fairly demanding when you have somebody who has basically a chronic disease and is basically on life support as on supplementary oxygen 24/7. Because it’s unpredictable when he will need any help, so basically I need to be available 24 hours a day, seven days a week.
Caring required her entire CCT and the “demanding” and “unpredictable” nature created what Bury refers to as a ‘critical situation’. Caring for the chronically ill body, and in this case a body that is extremely sick with COPD and possibly dying, is not something relegated only to the individual with chronic illness. It is undertaken and often profoundly experienced by ‘caregivers’ such as informal carers (family and friends), nurses, doctors, physiologists, dieticians and other health service providers. Caitlin had been married for many years to her beloved husband. His breathing became shallow, his cough became more frequent and more phlegmy, his energy dissipated, and he was diagnosed with emphysema in 1996. Caitlin did not think of herself as a carer until, due to pneumonia one day her husband slipped into a coma. At that point Caitlin was catapulted into a medicalised world, one where the inhabitants wore white, spoke quietly and calmly but in a foreign language; one where her husband lay still, not fighting the invading tubes, not disturbed by the constant beeps of machinery. This sudden and severe change in Roger’s condition required Caitlin’s “mobilisation of resources to respond to the life disruption” (Faircloth et al., 2004b:243) by making herself available to him 24 hours a day.

Minutes ticked into hours, ticked into days, ticked into weeks. She recalled:

In 2001 he contracted a very severe pneumonia and he was in hospital for five months. Seventy days on a ventilator and he was not expected to survive because they were waiting…everything was maxed to the max and they were waiting for some other bodily function, some other organ to give up and then they would have sort of then pull the plug on the life support. But nothing happened and after 70 days, he resumed breathing on his own. During that time, of course, he had been tube fed and IV fed and so he was pretty scrawny. He lost about 40 pounds and he wasn’t fat to start off with. They took him out of the hospital after five months and we started this part of the adventure.

Roger’s anticipated fate was measured and judged by health professionals on the basis of his bodily functions and rhythms. If one more organ had failed he would have had life
support removed. He would have the biological temporal rhythms created by external supplementary oxygen and intravenous nutrition support removed. Thus his biological time, his life cycle, would be ended as a direct result of chronic illness.

Caitlin was in the hospital every day, watching over her comatose husband for months. To call this time in her life ‘time consuming’ is somewhat of an understatement. Her normal routine ended abruptly. She could do nothing but wait for his status to change. Finally Roger awoke and Caitlin took him home. There at home she quickly learned how to operate the supplementary oxygen equipment and to administer prescribed medication, without which he would die. Caitlin gave Roger her CCT time, her limited resource, to care for him. For years thereafter Caitlin maintained a constant 24 hour mode of caring for Roger. I asked her about her experience of this caring time and very rarely during our 90 minute interview was Caitlin even able to describe her own emotions and experiences because they were so intertwined with Roger’s; he was her number one priority. She responded:

Today is actually the 10-week anniversary of him coming out from the last hospitalisation. And I think that we’ve now got him, more or less, to the stage where he was well enough to be discharged from hospital. So the reason that he was discharged at that time was because basically nothing more could be done for him medically, although he still needed a lot of care. But the specialists were of the option that it was more dangerous for him to stay in hospital than to be discharged. So we basically set up a hospital-like environment at home where he’s in isolation. For that ten weeks, he’s only been out of the house three or four times, all of which have been to medical appointments and I’m very careful of where I go, my association with anybody else. If anybody comes to visit, we make sure that they don’t have any sort of an infection because the carer and visitors are the most likely sources of infection for somebody who’s basically in isolation.

Caitlin’s movements were dictated by Roger’s health. Even her time away from Roger, which was severely limited due to her worry for his health, was informed by Roger’s needs. She continued: “I guess it’s like, you know, the disease is a third party in the marriage, basically”. This ‘third party’ was constantly demanding and requiring Caitlin’s
attention and time. She reported cancelling her own appointments with friends and with health professionals in order to care for Roger during his periods of exacerbated illness.

I asked about her experiences of rest and respite. She responded:

So as you’ll hear, you know, this machine periodically makes that whistling noise and that’s because it’s at its maximum capacity. Now sometimes if it’s, most of the time it will then just go back and it will be working, but there are periods, there have been times, and we don’t know what it is that does it, and it stops. So it’s like he’s not got oxygen, okay? So I have to be aware of ‘oh there’s a change in the sounds of the house’, leap up to see what needs doing and either get him some supplementary oxygen while I figure it out or sometimes I’ll find, you know, he’s already on the supplementary oxygen plus the concentrator and there’s been some interaction and that’s why it stops so we sort of, you know, sort it out but there’s that sort of constant level of care needed that is unpredictable and which certainly, if the machine goes off, he’s not able to get to it to do anything about it and so, it’s sort of pretty risky to leave anybody else in charge, because they don’t know.

The unpredictability of Roger’s condition and needs means that Caitlin felt unable to leave Roger in someone else’s care so that she could take respite. This meant Caitlin was constantly on sensory alert, on care time. Even as Caitlin slept she was aware of Roger’s biological time through the timing and sound of his breathing rhythms.

Caitlin consumed different foods at different CCT times to Roger and consequently spent a lot of time preparing food each day and managing Roger’s eating rhythms:

“We can’t leave too long between meals and because he’s… he doesn’t feel hungry then he won’t actually initiate getting any food, so I have to be aware all of the time, ‘Oh it’s two hours since he last ate’, okay it’s time to ensure… it’s time for a piece of fruit or something like that.”
While Caitlin was able to maintain her own food consumption patterns despite Roger’s illness, her sleeping patterns were completely altered to cater for his needs;

I mean our nights are very bad. We’re up at least – well he’s up at least, so I am – at least twice a night. He has these very bad nights where he has to change – sometimes we have to change the bedding and we have a cup of tea and some biscuits because he’s hungry and that sort of stuff so, you know, it’s even… What I’ve tried to do is, he has one or two naps during the day and I will often have a half an hour nap then and in the evenings, I go to sleep in front of the TV, so that by the time we go to bed I’ve had some rest. It’s a bit like having a colicky baby.

As a wife and carer, Caitlin altered her time, her rhythms and her actions to accommodate those of her husband. She likens it to “having a colicky baby”, thus referencing her past experiences of motherhood, a past time that she shared with Roger and was now reliving with him in the role of care recipient. She did not know how long she would need to maintain these altered patterns. Caitlin was constantly exhausted and was constantly caring. “Twice this year”, she explained, “the doctors have said: ‘Okay that’s it. Call in the family because he’s not going to make it.’ But he has. So that’s the sort of knife edge that you are living on all the time [my emphasis].”

Throughout Caitlin’s interview she used several temporal structures to illustrate how much Roger’s chronic illness and caring needs informed her practices and experience. The temporal structures employed include CCT, life cycle time, biological time, and past, present and future time. The severity of Roger’s condition was gauged, for example, by CCT and life cycle time. “Twice this year” Caitlin experienced the “near death” of her husband. The fact that these experiences came close together validated her following statement that she was living on a “knife edge … all the time”. In other parts of the interview Caitlin provided CCT and cyclical time references to illustrate both the severity of the situation and the constant nature of her caring experience; for example, she fed
Roger every two hours, he was in hospital for five months in 2001, and her cycle of disrupted sleeping/waking times was reported in present tense as ongoing.

Caitlin’s husband died 18 months later.

When I bumped into her some time later, Caitlin said “I spent so long looking after Roger that I don’t know who I am anymore, I don’t know what I want. I think maybe I’d like to be an editor”. The disruption to Caitlin’s biography had been profoundly experienced. Upon the death of her beloved husband she was free to reassess her biography; to think of herself as something other than a wife and carer. Her time was now her own.

“I’d like to interview Caitlin again”, I said to Fiona, a mutual friend. “Isn’t she running that COPD support group?”

“That will be hard”, Fiona replied. “She’s overseas, needed to get out and explore. I think she’s in Turkey now. She might respond to an email though, I think she’s still involved in the group.” Caitlin’s time had been returned to her through the death of her husband and she was spending her time exploring and returning to her biography, but in the context of an immediate past that has been shaped by her late husband’s illness and death.

In this case study it is clear that Caitlin’s relationship to time was fundamentally altered by her husband’s chronic illness. The COPD and resulting coma were experienced as biographically disrupting as Caitlin took on full-time caring status. This is evident in her practices; she gave up previous practices and devoted herself to new practices associated with managing chronic illness, such as managing oxygen cylinders and concentrators. She changed her previously held circadian and eating rhythms (she slept lightly with disturbed
sleeping patterns, and she spent more regular time intervals preparing food). Caitlin
dedicated CCT to learning how to look after Roger and she mobilised resources to help
her adapt. The death of her husband created an opportunity for Caitlin to restore her
biography, something not often available to people who have chronic illness. As a carer,
whose caring time reached a peak of intensity before being suddenly over, Caitlin was
positioned into a new phase of her life where new options, ideas and practices were
available to her. The possibility of this restoration is evident in Caitlin’s ideas about
becoming an editor, and her practices of travelling abroad (something she felt she could
not previously do while her husband was chronically ill).
Case 2 Young Ben has cancer time on Facebook


“Oh”, he said. “Yeah, I’m sick.” And by sick he meant possibly dying. Ben is a non-Indigenous Australian. He is married and has two children. We had been good friends since we met at university in 2005. At the time this conversation took place it was May 2011. Ben was 34 years old; I was 32 years old.

A fundamental aspect of the intersection between time and illness is present in the moment when one’s mortality is brought sharply into focus. That conversation with Ben reminded us both of our own mortality. I will die. It is inevitable. The timing of that death is of utmost importance to me. It is something that I cannot control but will do my best to exert power over. When I heard that Ben was sick I immediately made a comparison with myself. We are both in our thirties, we expect certain life cycles, certain futures, and we expect long happy lives. His sickness created a disruption to the playing out of these expectations in his life, and by so doing created disruption for me. This was also the case for Ben and for his wife. Kate later told me that while Ben was sick, “Those daydreams about the future, I couldn’t bear to think of them. We just had to focus on the present”. Time that Ben and Kate thought they had was no longer necessarily there. This awareness inspired prompt action.

I asked more questions, he smiled weakly and while holding the hand of his six year old son said, “We don’t like to discuss it in front of George. We don’t want him to worry”.


I looked at Kate who had their four month old baby in a sling around her waist. What would her future hold?

In the month that followed, Ben had multiple biopsy procedures. He described how the timing of his biological rhythms and health was brought into focus during such procedures:

   It was almost too hard to look, I didn’t know where to look, the screen was right there and I could see the needle going in a millimetre away from my lung. I was scared to breathe. I had to lie there for an hour after the biopsy just in case my lung collapsed.

He was scared to breathe because he thought that movement in his lungs as a result of breathing (a biological temporal rhythm) might increase the possibility of the needle puncturing his lung. He smiled while he said this as if the smile somehow reduced that terror in his words. The biopsy results showed Primary Mediastinal B-Cell Lymphoma (Non-Hodgkins); in other words – cancer. The large lymphoma wrapped around his lung and heart, thus deeming it too risky for surgical removal.

Ben then was subjected to intense medicalisation, chemotherapy and radiation therapy. A semi-permanent cannula was inserted into his chest so that chemicals could be directed into the lymphoma. His usual daily practices were disrupted; he ceased going to work, his eating patterns changed, he spent a lot of time interacting with health services, and he spent more time on Facebook (especially during hospitalisations).

Facebook is an international electronic social networking site where people can have so-called ‘real-time’ conversations, leave messages for one another, and post and view photos (among other things). Some messages
(called ‘comments’) are left for friends on a page where all the individual’s friends can see them. These comments are posted alongside a CCT record that indicates when the comment was made (such as ‘5.55am 02.06.2012’ or ‘5.55am yesterday’). The individual’s friends can reply to the comment and can read both their own reply and the replies posted by the individual’s other friends.

One of the interesting things about Facebook as a site for gleaning people’s experiences of chronic illness, and of health services, is that comments are recorded in CCT and recorded on a visual Facebook ‘Timeline’. The provision of CCT details alongside comments offer an indication of the timing of events and sometimes indicate how long the events take. In the example of his biopsy experience and other hospital-based experiences, the reader is left with awareness of periods of time where Ben has usual embodied temporal rhythms interfered with through medicalisation; procedures such as ‘nil by mouth’ and the insertion of a catheter illustrate.

When people who are not on Facebook at the moment when a comment is posted see the comment they experience it in present time. Ben’s friends read: “Biopsy in. Primary Mediastinal B-Cell Lymphoma (Non-Hodgkins). Game on”, and suddenly imagined the health status of Ben as different from his health status yesterday. But they have been fooled before, so the reader quickly looks to the CCT index to check how current the comment is. The reader checks for a more recent posting that will make this comment a thing of the past and no longer relevant; hoping for a new comment that says “I’m recovered! I’m healthy again!” But this “Game on” comment is just three hours old, Ben has not posted another comment, now there are 96 responses to the comment, and the reader realises that Ben is presently sick.
Ben and the reader of Facebook comments experience Ben’s illness in terms of past-present-future time, also evidenced through use of tense. Ben knew he had health problems in the past: “I pulled out of my usual routine about 2 months ago because of my chest pains (which were particularly intense when I ran or cycled)”. He references the past through present experience: “I don't remember ordering a chest wax for breakfast”. He writes in present-tense of past experience: “It’s funny ... until the answer to one of their bodily function enquiries is ‘no’. Trust me”, and of present experience in present tense: “Game on” and “Ben has radioactive wee”. The use of past tense has the effect of distancing both Ben and the reader from Ben’s healthy phase when he had been able to exercise without pain. The use of CCT (“two months”) further distances the reader from Ben’s health phase. Additionally, Ben writes his imaginings in future tense: “I’ll be asking about what exercise I can do during treatment for sure”. Skipping between different temporal references to past, present and future was something common among people in this study. References to the future took on new meaning with chronic illness. Ben was careful in his Facebook postings to have a positive future outlook (the implications of which are detailed in Chapter 10: agents in time). In the example above concerning exercise Ben assumed that he would be able to engage in some form of exercise in the future, something he wanted to do.

Ben had suddenly entered the health system environment as a medicalised body; one that was subject to foreign rhythms where meals and medications were provided and consumed at routine times. Although Ben was accustomed to eating meals he was unaccustomed to the kinds of food provided, the way they were cooked and the timing of their provision. If he desired familiar food or provision of food at times that fell outside of the health service rhythms he had to source it elsewhere; which meant he had to rely on a
friend or family member to obtain it for him since his movements were severely limited by tubes and post-surgical pain. His agency in the hospitalised context was limited. His consumption of both food and medication was monitored by nurses who enquired also about his bodily bowel movement and urination rhythms. These personal rhythms became subject to interrogation by health professionals such as “enquiries into bowel movements” and his agency to consume according to his own desires and habits were also repressed, most dramatically by ‘nil by mouth’; as Ben wrote: “nill [sic] by mouth – hospital speak for starve the bugger”.

In this acute medical setting Ben was faced with different kinds of timings and rhythms that were foreign to his way of being. This contributed to his feelings of being overwhelmed, sick, and powerless (feelings which have been widely reported by other people with chronic illnesses; see for example Jeon et al., 2010). One of the avenues through which Ben managed this was by communicating his experiences to friends via Facebook. On Facebook he expressed many changes in his bodily temporal rhythms and his daily practices.

Several temporal structures associated with Ben’s chronic illness experience were made visible through the messages he posted on Facebook in the months that followed. They include past, present and future time; CCT; the acute phase of illness; bodily rhythms and the temporal tensions induced by Ben’s engagement with health service rhythms. These temporal structures intersected with one another and with other rhythms such as day and night, and meal times.
At 6am one morning Ben, lying in a hospital bed after an operation, wrote:

Hospital survival mantra 1 (particularly post-op): "do a little wee, and they can't touch me! If it just can't be done, then RUN RUN RUN".

In this amusing mantra Ben explains that he was required to urinate on demand. If he managed to urinate the hospital staff would let him rest but if he was unable to urinate they would not let him rest. Forty minutes later a friend of Ben replied on Facebook, “It's funny how much attention bodily functions get after a bit of an op!” To which Ben responded, “It’s funny until the answer to one of their bodily function enquiries is ‘no’. Trust me”. Ben did not explain this matter further but the implication was that his experience of being unable to urinate or undertake other “bodily functions” at the appropriate time led to unpleasant experiences. Thus, there was a temporal tension born of change between Ben’s expected biological rhythms and his actual biological rhythms, and this tension manifested in Ben’s experiences with hospital staff.

This tension was again experienced during the middle of Ben’s chemotherapy treatment, with the onset of a chest infection. He wrote, “in hospital for the night with some sort of chest infection. On the plus side, I'm in the isolation ward and feel very important”. One hour later Ben wrote: “Antibiotics well underway – and apparently my white blood cell count is ok. Crisis averted (although 24 hours in isolation ward without TV remains an ongoing concern)”. The onset of a chest infection during a stage in Ben’s treatment when his immunity to infection was low posed an acute threat to Ben’s life. He was isolated to reduce the risk of further infection and he remained there until his biological rhythms had restored his white blood cell count to within appropriate parameters. At 6.09pm on Monday 2.07.2012 Ben wrote, “Ok – I can take the illness, the chemo, the hospital visits, the constant nurse enquiries into bowel movements (still tip top BTW) and the isolation.
But what God did I offend to warrant the mistaken delivery of fish for dinner. Where's my frigg'n spanish omelette?”. One minute later, “Oooh look .... custard! As you were”.

More often than not, waiting time features highly in people’s accounts of their experiences with health services (see Chapter nine: spaces and time use). They wait in ‘waiting rooms’ and in hospital beds for health care professionals to attend to their health needs and for their health to improve. They report feeling disempowered, bored, and restrained. Ben was no exception:

- “24 hours: hospital speak for >= 24 hours”
- “I refer to the fact that my ‘24 hour stay’ has now reached its 55th hour ... oh, but with another ‘24 hours’ of observation ahead.”
  03.07.2012

Ben was frustrated by having to spend so much CCT in the hospital isolation ward and yet his state of illness required it. This clear example of waiting time is additionally laced with reference to past, present and future time; points in time that are all referenced in these two Facebook comments. Each referenced point is associated with waiting, lending more weight to his tone of frustration. Even the future offers no remission from his disempowered status.

In this case study I briefly explored the ‘untimeliness’ of cancer in terms of Ben’s young age. Cancer could have caused him to die in his thirties, and this realisation brought into focus a sense of biography and life cycles for both his wife and myself. I then explored how Ben’s awareness of bodily rhythms and his practices changed during the acute phase of his illness. Facebook was identified as a social media through which CCT is made visible, and as Ben used Facebook to communicate his illness experiences, CCT featured
strongly in this case. I also observed that Ben referenced his experiences in terms of past, present and future time; as well as waiting time.
Eric Michaels (1997) wrote an anthropological diary, depicting and analysing his final years of living with a chronic illness. Following Michaels, I present my own experience of chronic illness for the purpose of illustrating how my relationship to time and my practices of health management were informed by chronic illness.

Doctor Rachel is not my usual doctor who I always make a point of joking with, she is the other one. The one I get when my usual doctor is too busy to see me. The one who charges extra for the advice I neither asked for nor desire. I had to go see her because there was a problem with my foot. My usual doctor was too busy to see me, and I could not wait any longer, I was simply out of time. I felt I had to see a doctor, even if it meant seeing her. The biological changes of my body occurred quickly and the immediacy of need they created was at odds with the timing of availability of my usual doctor. The acute illness had a sudden onset and called for immediate attention. It was autumn in 2012 when I went to see her. The medication Doctor Rachel prescribed for my foot required that I undergo fortnightly blood tests to check for medication side effects.

A month passed. I was cleaning and medicating my foot, a task that took about ten minutes every morning and every night. I had just thrown the used cotton pad in the bin when Doctor Rachel called me on the phone. It was early, 8am on a Monday morning, an hour before the general practice was due to open. Too early, I thought, for the doctor with expensive advice to be calling me, unless there was a problem that could not wait another hour to discuss. Her untimely call confused me. “Your kidneys aren’t good, you better get in here now”, she said.
I hurried to my car. By the time the engine started I was having trouble breathing, my chest felt tight. “I’m sick.” I wasn’t sure if this was a statement or a shocked stunned disbeliefing question. My kidneys had been secretly going about their business of failing to function, without me realising. I had recognised no symptoms of their diminished function. If they stopped working I could die and yet I had not felt a thing. How could I have not noticed? They must have been failing on the day before but I had felt fine.

I imagined my kidneys, podgy little round worker men, sitting in the lunch room, leaning back on chairs, smoking, farting, lazily scratching their noses. They had let me down. I imagined my future, sitting in a satellite hospital, on dialysis treatment; tubes attaching to my body, draining my blood, cleansing it and sending it back in for another round. I wondered, what would it be like to have my blood sucked out of my body? Would I be completely alone? My cheeks were wet. I said a prayer: “Don’t let me die yet”; I’m not ready. “Don’t let my kidneys fail”; I’m not ready. The illness posed what Bury calls a ‘critical situation’. My daily life and usual practices were obstructed as the needs of the body took precedence.

My kidneys were functioning poorly due to the medicine that I had been taking for a combined fungal and staph infection. Doctor Rachel called it staph, as if everyone knows what staph is (Staph is short for Staphylococcus, and is a type of bacteria that can live in the human body for a number of years and can cause serious complications to one’s health). I did not know what it was. I just knew that my toes were black and swollen like fat blueberries. Fat, insanely itchy blueberries. And now this ‘medicine’ was jeopardising my kidneys.
I had the fungal infection for more than a year, thus deeming it chronic. When it began it was just an ‘acute’ infection, but as time wore on it took on meanings and it required actions that indicated it had entered the realm of ‘chronic’. As my kidney function diminished I found myself contemplating chronic kidney disease as part of my possible future. I had previously interviewed people who were in end-stage kidney failure and I had found it frightening. The reason I found it so frightening, aside from my fear of the medical interventions necessary to clean blood and to manage the disease, was also forged out of a sense of untimely illness and untimely death. Thirty-two years did not seem like a very long life. People, I thought, were not meant to get kidney disease until later in life.

I had to get blood tests every three days. Each test took an hour. After a few weeks the rhythm was changed and I had to get blood tests weekly, and then fortnightly, and then monthly. My relationship to CCT was informed by the illness. One day the nurse accidentally pushed the needle through my vein. I had a painful bruise the size of a tennis ball, bouncing out of the side of my arm. I could not use my arm all week. I became nervous. I wanted to avoid her so instead of going for the blood test on Tuesday I went on Wednesday.

My elbow 30 minutes after the blood collection

I allowed illness to regulate my time use by giving up an hour to undergo the blood test and I altered my CCT timing in order to access another nurse. In order to do get the many
blood tests I had to manage other aspects of my life, my usual practices of working, eating, socialising and so forth, around the needs (and temporal commitments) induced by illness.

Eventually I realised that my life was no longer in jeopardy and that my kidneys were recovering. I did not know if the staph had cleared, my toes were red with white spots and the skin was cracked. This was an improvement. I lived in fear. When I got out of the shower in the morning I looked at my toes, assessing how red and inflamed they were and whether they were worse than the day before. I did not have any alcohol for eight weeks, I maintained a low salt diet and, following Doctor Rachel’s instructions, I tried not to ‘overdo it’ on anything (whatever that meant). I managed my time and my health. I awoke with the same anxious feeling I went to sleep with; it was the feeling that I was out of control of my body, my health, my life. A woman at the park asked me “are you better yet?” I did not know. Better than what? Perhaps I would magically be better when three months had passed, perhaps when the fear was gone, perhaps when the toes were the right colour. The presence of fear influenced my temporal experiences of illness; the memory of past sickness and danger was experienced presently as a possibility of the future.

Between the hours of 0300 and 0430 each morning time seemed to pass very slowly as I contemplated worries about my health in the context of my ambitions and desires, including the desire to live a long and healthy life. The way these worries and anxieties permeated my experience is not unusual; most people in this thesis study reported the same.

Another month passed. I, an agent in my own health practices, skipped a blood test. It had seemed unnecessary. I had established a clear record of gradual improvement over the
past three blood tests and was almost within normal kidney function parameters. I decided that there was no point in risking another needle through my vein. One day, however, I felt the stinging pain I had feared. The fungus was back. The staph was no longer dormant. I rushed into the health service and waited 42 long minutes for my usual doctor to call my name. Remembering the swollen blueberries, imagining the rebel kidneys on lunch break and tubes that could make me cyborg, I described my terror. He examined the foot. He chastised me for not getting the timely blood test. I was made to feel guilty for my deployment of agency manifested in the decision not to have another blood test. Then as if to chastise me further, he added “if only you weren’t also allergic to neomycin”. Miserable, I lowered my head and looked at the worn blue carpet, keenly aware that this consultation would be over in two minutes and that I, with my non-compliant body, would be sent directly to the pathology laboratory for a blood test.

I felt that I had lost some amount of control over my body. The fungal infection and staph posed a serious and painful threat to my sense of wellbeing and the diminished kidney function added yet another layer of unseen mysterious illness that was, to some extent, beyond my control. I tried to restore this sense of loss by following the instructions of my health care providers, taking medications, and having blood tests. Like Caitlin and Ben, I experienced a disruption to my biography. The illness posed a very real threat to my longevity, as well as my assumptions about the world and my role in it. Amidst this ‘critical situation’ (Bury, 1982) I questioned myself a lot; I questioned my beliefs about my body, my so-called ‘health’, and my future. I also worried. The amount of time spent worrying is hard to measure, it was experienced keenly as disruptive to my previously held sleep rhythms, but it also permeated my waking life. There were numerous worry triggers each day; from deciding not to go shoe shopping to the application of creams to
my foot, and to my putting on a sock each week during my remedial massages so that the massage therapist would not notice it, and so I would not have to defend it. The triggers extended to seeing children play in the park, which made me worry about whether I would survive and be healthy enough to have my own children. The constant knowledge of chronicity within my body created a seemingly constant state of underlying worry and disruption. My worries and thoughts about my health more generally informed my practices.

Chronic illness informed my thoughts about the past – how had I become ill, could I have avoided it? It informed my present thoughts and practices, and it informed my imaginings (and worries) of the future. The phone call from Doctor Rachel had catapulted me into the realm of undertaking ‘biographical work’ (Corbin and Strauss, 1985; Corbin and Strauss, 1992). I attempted to employ agency in my management of the illness by changing the timing of my blood tests; however my doctor (and thus I) deemed this attempt foolish (so I did not manifest agency in that way again). My relationship to time was governed by chronic illness. This case study has identified chronic illness as informing my experiences of CCT, disrupted biography, worry time, and past, present and future time.
Vera, a married Aboriginal Ngunawal\(^3\) woman, was aged 54 years when I interviewed her. Vera had repetitive strain injury in her shoulders and had been diagnosed with diabetes for 14 years. She was also going through menopause. I arrived at her house for the interview and was greeted warmly with a cup of tea and a large tin full of chocolate and iced biscuits. When I asked her about how she managed diabetes she told me she watched what she ate, used natural products, and exercised occasionally. She said she knew the dangers of diabetes because she had seen other members of her family with diabetes have limbs amputated and some had died horrible painful deaths in hospital, away from family and disconnected from their land. Her experiences of the past informed her present relationship to diabetes.

Vera was an informal carer for her parents who both had chronic illness. Her mother died a year before our interview, at which time: “all the pain of my mother’s death came out through my arms”. Her frail father had dementia and required a lot of support from Vera. Even though he lived a four hour drive away, she stocked his fridge each week with fresh food and did his washing. She spent a lot of CCT time caring for other people.

When I asked her about her experiences with health services, Vera said she had experienced severe racism and discrimination from a non-Indigenous optometrist a couple of years ago. The experience was so traumatising that she refused, these days, to see non-Indigenous health care professionals. Her past experience of racism informed her current and future health practices. This made managing her illness in terms of health services

\(^3\) The spelling the Ngunawal people generally use is with one n. The official state spelling is Ngunnawal.
very time-consuming because there are so few Indigenous health care professionals and she had to travel a long way to see them. Once a month Vera took an entire day off work to attend the diabetes clinic.

On days when Vera attended the clinic she was unable to pick her grandchildren up from school and she was unable to help her father. In this way she could not synchronise her health needs with the needs of others through time.

Vera’s ideas about time and her illness informed her behaviour. She only needed half an hour with the doctor, but it often took a whole day just to get in to see him. Sometimes she felt she wanted to spend more than half an hour with her doctor to get the answers she needed in order to manage her diabetes well. However, she knew many people were waiting in the waiting room and she said she felt deeply guilty about taking up too much of the doctor's time and wasting not only the doctor’s, but also other patients’ time. So she often left with questions unanswered. She spent “quite a lot of time” trying to figure out the answers to questions on her own. She ran little experiments, to establish whether, for example, taking fish oil tablets would help her get her sugar levels to go higher. The process of trial and error was very time-consuming for her but it was something she could do on her own, in her own time, and without bothering other people.

Vera, like so many of my research participants, described complex interactions between her chronic illnesses and her social world. She deployed ontologies for chronic illness and pain, and she undertook steps to avoid experiences of racism in health care services. The biggest challenges for Vera were balancing social obligations with meeting the needs of her body (in a timely manner).
Vera’s activities of caring for others were disrupted by her chronic illness every month while she attended the clinic. But more than this, her imaginings about her future biography were informed over time by chronic illness. She had first-hand experience of seeing other people become debilitated by chronic illness and die. She had been given a diagnosis of an illness that had the potential to send her down the same track. While Vera at one stage imagined living to be a healthy elder in her community, the chronic illness informed her ideas about her future biography. The extent to which her future would be informed by chronic illness was partly shaped by her current self-management practices, which in turn were informed by her sociality. If her illness moved from a mundane management phase into a crisis phase requiring urgent health service intervention then the illness management would take priority over her sociality. But until that happened her sociality, including social obligations to care for others, took precedence.

**Discussion**

These four case studies illustrate intersections between health, illness, sociality and time. Present in these cases are a multitude of temporal experiences that overlap and interconnect with one another. In all four case studies CCT and time use is present. Evidence of biographical disruptions, present and future time orientations, and worry time are also evident in each of the case studies. These temporal structures will be explored during the course of this thesis.

With reference to these times, data saturation and validity of findings was reached across the four datasets underpinning this thesis project. In the four case studies above I have illustrated how peoples’ relationships to time are informed by chronic illness. Theorists
such as Corbin and Strauss (1985), Adam (1995), Bury (1982), and Davies (1994) have previously identified changing relationships to time. Corbin and Strauss have focused on the types of work involved in self-management, including ‘biographical work’. Adam has focused on time as experienced in social life. Bury has described ‘biographical disruptions’ that result from chronic illness, and Davies has described the multiple processes that people engage in over time.

However, these theorists (with the exception of Adam) have presented a focus on one or two temporal lenses. Bury, for example, is concerned with the biographical disruption that is created by chronic illness (Bury, 1991; Bury, 1982) and Davies is concerned with the intersections between CCT and process time (1994) and with women’s life cycles (1996). As illustrated above, this thesis provides empirical evidence to show that people experience time in different ways, often simultaneously. Thus it is useful to consider temporal interactions and their combined shaping of chronic illness experiences and sociality.

What is it like for people who are past the expected half way mark of life? My research is predominantly concerned with people living with chronic illness who are 45 years or older. Is it still as shocking to have a diagnosis of chronic illness later in life as it is to have early in life? Is it still biographically disrupting? I suggest that death is part of the life cycle that is brought into focus in specific ways by chronic illness. The timing of chronic illness in people’s lives is intersected with their ideas about the timing of their death in interesting ways. Some participants, such as Vera, reported feeling that their illness was untimely, and as such could not be attended to as a priority. However, for most, they reached a point of realisation that the illness could impact on how long they
would live, on how much time they had left to live, and what the quality of that time could be. Many participants in this project reported that their perception of the possibility of untimely death and their desire to manifest control over that informed their motivation to engage in self-management behaviour; to change their health practices. This perception of untimeliness is of critical importance to understanding lived experiences of chronic illness. As Bury (1982) pointed out, people who associated arthritis with stages of life (old age) they had yet to experience found their illness to be profoundly disruptive. Their social expectations about the timing of illness onset, and their ideas about stages of life and life expectancy, clashed with the timing of their illness onset, which shaped the magnitude of experienced disruption. It is, therefore, not only people’s ideas about the timeliness of death, but also about the timeliness of illness that are unveiled.

People were also faced with potentially years of observing their health or the health of a loved one decline, and potentially years of having their life experiences increasingly informed by illness; which is what Geertz calls the “loss of concrete individuals” (Geertz, 1966). Many participants in this project reported having lived with chronic illness for years, even decades. Some could no longer recall their life before illness. Had their ideas about chronic illness and timeliness changed over time? To what extent were their current health practices informed by beliefs about possible futures? The answers to these questions are complex but will become evident throughout the duration of the thesis.

The chapters that follow this one explore in more depth each of the focal temporal structures described in this chapter. The first temporal structure explored is CCT in terms of time use. This is followed by process time, biographical time, and past, present and future time.

**Abstract**

The management of health care, particularly for people with chronic conditions, combines the activities of health professionals, patients, informal carers and social networks that support them. Understanding the non-professional roles in health management requires information about the health-related activities (HRA) that are undertaken by patients and informal carers. This understanding allows management planning that incorporates the capacity of patients and informal carers, as well as identifying the particular skills, knowledge and technical support that are necessary. This review was undertaken to identify how much time people with chronic illness and their informal carers spend on HRA.

Literature searches of three electronic databases (CINAHL, Medline, and PubMed) and two journals (Time and Society, Sociology of Health and Illness) were carried out in 2011 using the following search terms (and derivatives): chronic illness AND time AND consumer OR carer. The search was aimed at finding studies of time spent on HRA. A scoping literature review method was utilised.

Twenty-two peer reviewed articles published between 1990 and 2010 were included for review. The review identified limited but specific studies about time use by people with a chronic illness and/or their carers. While illness work was seen as demanding, few studies combined inquiry about both defined tasks and defined time use. It also identified methodological issues such as consistency of definition and data collection methods, which remain unresolved.
While HRA are seen as demanding by people doing them, few studies have measured actual time taken to carry out a comprehensive range of HRA. The results of this review suggest that both patients with chronic illness and informal carers may be spending 2 hours a day or more on HRA. Illnesses such as diabetes may be associated with higher time use. More empirical research is needed to understand the time demands of self-management, particularly for those affected by chronic illness.

**Keywords:** time; time use; health related; chronic illness; carer; patient; survey; literature review

**Background**

The management of health care for people with chronic illness is a time consuming business for both patients and carers. It is usually carried out in the home, or from the home, and is largely invisible to institutional health care providers. The Serious and Continuing Illness Policy and Practice Study (SCIPPS) undertook qualitative research with people living with chronic illness to understand their experiences and interactions with the Australian health system (Jeon et al., 2010). The study sample consisted of people diagnosed with, or caring for someone with type 2 diabetes mellitus, chronic heart failure (CHF) and/or chronic obstructive pulmonary disease (COPD). One of the findings that emerged was that both patients and informal carers described experiencing a significant time burden due to managing chronic illness. They reported a constant sense of having to juggle the commitments in their lives, and saw the demands of managing health related activities (HRA) as a key element in that struggle.
The idea of ‘illness work’ carried out by people with chronic illness has been a key concept in the literature since Corbin and Strauss’ (1985) foundational qualitative study. The three types of ‘illness work’ they identified include: 1) “regimen work, crisis prevention and management, symptom management, and diagnostic-related work”; 2) everyday life work, that includes practical tasks “that keep the household going”; and 3) biographical tasks that are done as the person and their family re-conceptualise and re-construct the ‘story’ about their lives.

This concept identifies work domains of people affected by chronic illness, but does not identify specific HRA undertaken, or how much time people spend on doing them.

Information about the time demands of health management have implications for many life areas, such as patient or carer capacity to stay in the workforce, to manage family and social activities, or to maintain usual domestic and personal activities. It may assist health providers to co-ordinate and manage formal care in a way that optimises time use for both health care providers and health care receivers.

Information concerning health and about time use is sought through national surveys of many countries, as can be seen from the data base of time use surveys held by the Multinational Time Use Survey at the Centre for Time Use Research in the UK (Fisher et al, 2011). However, the health data tend to be reported in aggregate with other activities, or are general rather than specific.

The Australian Bureau of Statistics (ABS) runs a number of national surveys that include questions on health, caring and time use. The Australian Time Use Survey (5) asks respondents to complete diaries about time, and includes as health activity personal
medical care (taking medications, injections, vitamins, exercising for specific conditions, reading or writing in relation to personal medical care, preparing medications), rest because of illness, and health treatments (not mainstream conventional medicine with the exception of ante-natal classes). Health care, in the ABS Disability, Ageing and Carers Survey, includes foot care, and “other tasks, such as: taking medication or administering injections; dressing wounds; using medical machinery and manipulating muscles or limbs”. Statistics Canada, in their General Social Survey – Time Use – utilise a diary to record personal medical care (by self, other person in the home, or formal care), but do not provide a detailed definition of the specific activities included. The UK Household Survey similarly uses a diary to identify activity undertaken at multiple points in time, but does not specify on its public website how activities are coded.

This review aims to summarise the current literature that:

1. specifies HRA undertaken by people with chronic illness (patients hereafter) and their informal carers; and
2. quantifies the time spent or required to carry out HRA.

Methods

A scoping literature review was undertaken during January to May 2011. Scoping reviews are useful studies that summarise what is known on a specific topic and are often followed by systematic literature reviews (Ridde et al., 2012). In this scoping review literature has been collected, evaluated and presented according to methods laid out for rapid review by Arksey and O’Malley (2005). Both qualitative and quantitative studies have been included for review.
We conducted an electronic literature search of peer-reviewed English-language articles in the Medline, CINAHL and PubMed databases which contained the desired terms in the title, abstract or keywords. Furthermore, two journals Sociology of Health and Illness and Time and Society were hand-searched in order to locate relevant articles not catalogued in the databases.

The following search terms, and derivatives, were used: Chronic AND time AND treatment/management AND consumer/patient/carer AND health. The full set of terms and derivatives are shown in Table 1. We decided to use the terms “chronic illness” and “chronic disease” rather than “long term conditions” to provide a specific focus on HRA linked to chronic illness. In addition, we included the specific illnesses of diabetes, heart disease and chronic obstructive pulmonary disease as they were sentinel diseases in our main study.

Table 1: Search Strategy

<table>
<thead>
<tr>
<th>Search terms:</th>
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<tbody>
<tr>
<td>• Chronic disease OR chronic illness OR diabetes OR chronic heart failure OR chronic obstructive pulmonary disease</td>
</tr>
<tr>
<td>• Time use OR time management OR waiting time OR time burden AND</td>
</tr>
<tr>
<td>• Health treatment OR health consultation OR management OR self-manag* AND</td>
</tr>
<tr>
<td>• Health care consumer OR patient or carer AND</td>
</tr>
<tr>
<td>• Health OR health care OR primary health care OR access</td>
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<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
<th>Resources searched</th>
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<tbody>
<tr>
<td>• English language</td>
<td>• Concerned with health professional time only</td>
<td>Medline</td>
</tr>
<tr>
<td>• Peer reviewed</td>
<td>• Non-specific descriptions of time and health related activities</td>
<td>PubMed</td>
</tr>
<tr>
<td>• Publication dates between 1990 and 2010</td>
<td></td>
<td>CINAHL</td>
</tr>
<tr>
<td>• Concerned health related activities undertaken by the individual with</td>
<td></td>
<td>Two journals:</td>
</tr>
<tr>
<td>chronic illness and/or a carer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Reported qualitative or quantitative findings</td>
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<tr>
<td></td>
<td></td>
<td>Snowballing based on references in selected articles and “related articles”</td>
</tr>
</tbody>
</table>
As illustrated in Figure 1, searches identified 29 items in CINAHL, 544 items in Medline, 14 items in PubMed, 210 items in Sociology of Health & Illness, and zero items in Time & Society. Twenty-one duplicated items were identified, leaving 776 unique references.

Two stages of screening were used to identify those studies that matched the inclusion and exclusion criteria shown in Figure 1. Using and extending the ABS definition of personal medical care, we looked for activity that would meet that definition, in addition to activity related to contact with non-inpatient health services. HRA were included if they were carried out by an individual with a chronic illness or a carer; and, as stated above, were concerned with personal health care including monitoring, management/treatment; or directed to activities undertaken to support health, including travel to and attendance at health services. Articles were excluded if they dealt with health professional, rather than health service user time, or where no specific activities or times were included.

From the 776 articles identified in the database and journal searches, only 6 articles met the inclusion criteria. Of those excluded, almost all addressed either HRA or time, but without providing both specific activity and specific time. One article addressed health professional time, rather than patient/carer time. A further 25 articles were identified by bibliography and citation-searches of the 6 included articles, from which a further 16 articles met the inclusion criteria. We selected a final set of 22 articles for full review.
All authors were engaged at each stage of the design and conduct of the review. Each search was run by all reviewers to ensure consistency and certainty of data extraction since many fewer articles were identified than we expected. Articles which met the inclusion criteria were read by all three reviewers before being included for review. Articles included for review were analysed for emerging themes. We manually extracted details of the time use measures.

Having read all 22 papers in detail, we identified three principal themes: 1) time spent by individuals on specific HRA; 2) time spent by carers on HRA; and 3) the methodological difficulties associated with time use studies.
Where studies reported time spent in hours, such as ‘1.43 hours’ we have taken this to mean one hour and 43 minutes rather than one hour plus 0.43 of an hour. We have used the same convention when the time is reported in minutes, so that 19.02 minutes means 19 minutes and 2 seconds.

**Results**

**Study characteristics**

Table 2 and Table 3 detail the scope of reviewed articles.

**Table 2: Scope of articles addressing time use and chronic disease**

<table>
<thead>
<tr>
<th>Region</th>
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<td>Australia</td>
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<tr>
<td>United Kingdom</td>
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<td>4</td>
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<tr>
<td>Canada</td>
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<tr>
<td>Italy</td>
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<th>Time users</th>
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<td>Informal carer only</td>
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<tr>
<td>Patient and informal carer</td>
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<tr>
<td>Other (method focus)</td>
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<table>
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<tr>
<th>Article type</th>
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</tr>
<tr>
<td>Method used: time use diary</td>
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<td>12</td>
</tr>
<tr>
<td>Method used: qualitative (interview or focus group)</td>
<td>7</td>
<td>28</td>
</tr>
<tr>
<td>Method used: descriptive</td>
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<tr>
<td>Method used: modeling or RCT</td>
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<td>8</td>
</tr>
<tr>
<td>Methodological issues (Informal carer)</td>
<td>4</td>
<td>16</td>
</tr>
</tbody>
</table>

^ Some articles used more than one method
Study characteristics are outlined in Table 3. Studies were conducted in five countries, with almost half the articles reporting studies from the United States of America (n=12). Twelve studies provided information about time use or time management among patients (n=12). Six studies reported carer time use only (Braithwaite, 1990; Ironmonger, 1994; Jenkins, 1997; Langa et al., 2002; Paoletti, 1999; Bittman and Thomson, 2000) and two articles concerned time use of both patients and carers (Corbin and Strauss, 1985; Bittman et al., 2004). Most studies reported either survey data (n=13) or qualitative data (n=7). Four articles focused on methodological issues associated with measuring time use by carers (Bittman et al., 2004; Bittman et al., 2005; Bittman and Thomson, 2000; Wolf, 2004), but none focused on methodological issues associated with measuring time use exclusively by patients.

**Time spent by individuals on specific health related activities**

Two studies provided information about how much time people spend on certain private or household tasks such as sleeping, leisure, grooming, and on HRA including exercise, which was reported as a separate item (De Vaus, 2004; Adams, 2010).

Three articles reported time use in terms of patient compliance and adherence. McCoy (2009) notes a broad range of potential reasons for non-compliance with self-care and medication regimens. They conclude that medication adherence by people with chronic illness is complex and labour-intensive (McCoy, 2009). Russell et al. (2005) conclude that factors other than knowledge are needed to achieve necessary behavioural change and compliance. However, “scant attention has been paid to time requirements and little is known about how much time current recommendations take” (Russell et al., 2005:53; see also, Safford et al., 2005).
The most comprehensive information about actual time spent on HRA was found in studies based on the USA Bureau of Labour Statistics’ American Time Use Surveys (2003–09). These surveys provide a comprehensive set of statistical data (http://www.bls.gov/tus/). Russell et al., (2007) reports that for the 11.3% of adult Americans surveyed who indicated that they had spent time on HRA in the previous 24 hour period (their ‘designated day’), the average time spent overall was 108 minutes. Those engaging in personal health self-care reported it to take an average of 86 minutes. Medical and care services reportedly took 123 minutes, and sports, exercise and recreation reportedly took 114 minutes. Those caring for others reported spending between 78 and 115 minutes in activities related to the health of others. This contrasts with the findings of McKenna and colleagues (2009) in an Australian qualitative study comparing people who had suffered a stroke with those who had not that HRA was the least time consuming of their measured activities and the average time spent was around 30 minutes each day.

Two studies identified time spent attending health service appointments. Russell et al. (2008) reported on three years of the American Time Use Survey data, showing that of 1621 patients seeking medical care on a ‘designated day’, mean time spent was 35 minutes for travel, 42 minutes for waiting and 74 minutes for receiving services. Accompanying carers spent an average of 124 minutes for each encounter. Yabroff et al. (2005) estimated patient time costs associated with colorectal cancer care using data from several surveys and physician-reported time data. They estimated that each office visit required 1.43 hours or 1 hour 43 minutes for patients in metropolitan areas and 1 hour 58 minutes for those living outside metropolitan areas. Yabroff et al. (2005) cite other instances of time measurement, associated with screening activity.
One study, Hu & Reuben (2002), focused on the length of time elderly patients spent with physicians during ambulatory visits and reported an average of 19.02 minutes for elderly patients, 27 minutes for new patients and 18.03 minutes for established patients, concluding that the effects of managed care on the duration of visits appear to be related to the structure of the managed care plan. Pritchard (1992) also focused on consultation times and how patients and GPs negotiated and managed this time use, but did not specify the time actually spent.

Two studies examined the additional time spent on HRA due to diabetes, over and above the time people would usually spend on HRA. Using surveys and phone interviews, Ettner et al. (2009) studied the impact of socio-economic status on time spent on self care for people with diabetes, looking specifically at time spent on foot care, shopping for and cooking special foods, and undertaking recommended exercise. Ettner et al. found that those spending "extra time" on HRA as a result of having diabetes spent on average an extra 13.41 minutes daily on foot care, 38.57 minutes on exercise and 42.42 minutes on shopping and cooking. About two thirds of Ettner et als’ respondents spent extra time on foot care and exercise, and about half spent time on shopping and preparing food specifically for their health condition. Safford et al. (2005) also used surveys to identify HRA of patients with diabetes. They report similar findings to Ettner et al., with 75% of patients spending at least 19 minutes daily on self-management. The focus of their discussion is on how many patients did not spend time on specific recommended activities.

Only two studies estimated the overall time required for HRA over a 24 hour period. Russell et al (2005) used a convenience group to establish that the time required for self
care of diabetes was approximately 120 minutes daily. Safford (2005) quantified how much time diabetics spent on self care, with a mean time of 58 minutes per day. These included foot care (13 minutes), exercise (32 minutes) and food shopping and preparation (48 minutes). Safford also identified that over a third of respondents spent no time on either foot care or exercise, and over half spent no time on food shopping and preparation.

In summary, studies included for review suggest that over a 24 hour period patients are likely to spend 86 minutes on HRA (Russell et al., 2007); less time if they have had a stroke (McKenna et al., 2009), more time if they have diabetes (Ettner et al., 2009; Russell et al., 2005; Safford et al., 2005). If patients also engage in exercise they spend in the order of 35 minutes each day. Those who care for someone else spend an extra 78 to 115 minutes daily (Russell et al., 2007). Access to health services is not a daily occurrence for most, but each event may require between 104 minutes and 151 minutes, which includes 35 minutes for travel to health services, 42 minutes for waiting for health services and 74 minutes receiving health services (Russell et al., 2008). If the patient lives in a metropolitan area Yabroff suggests the time to access health services is 103 minutes (Yabroff et al., 2005). So, if a patient with diabetes engages in HRA (including exercise), and also accesses health services on a given day they may spend (120 diabetes self-care + 35 exercise + 151access) 306 minutes (5.06 hours) doing so. If they also care for someone else on that day their care duties could consume another 78–114 minutes, a total of almost 7 hours.

Combined, these studies present a picture of high time expenditure on daily HRA for those with diabetes. Consistent definition is lacking about the specific tasks carried out by people in managing their health, as is the time taken, every day, or over longer periods, to
do them. In addition, apart from estimates of time needed for care of diabetes, there is almost no information available about the time costs of health management for people with other chronic conditions, and no information concerning time use of people with multiple conditions.

**Time spent by carers on health related activities**

A third of the articles included for review approached time use specifically from a carer’s perspective (Ironmonger, 1994; Jenkins, 1997; Braithwaite, 1990; Langa et al., 2002; Paoletti, 1999) or in combination with patients (Corbin and Strauss, 1985; Russell et al., 2007). A further two papers (Ng, 2008; Schofield et al., 1997) provided characteristics or profiles of carers, but did not report their time use. None of these articles specified the HRA carried out or provide specific measures of carer time spent on HRA for self. Only one paper reported carer time spent on HRA for care recipient (Russell et al., 2007). Russell et al (2007) used American Time Use Study data to measure time use among American adults, and found that people reported spending 78–115 minutes per day on HRA (unspecified) in support of both household and non-household members.

Bittman & Thomson (2000) and Bittman et al (2004, 2005) found the ABS’ Disability, Ageing and Carers Survey (2003) and Time Use Survey (1998) contained limited and problematic information about the time devoted to care. The broad ABS categories include meal preparation, property maintenance, housework, transport, paperwork, health care, cognition or emotion, communication, and mobility, but the data provide no details of what some of these may involve, nor how much time is spent for each except with cross tabulations with other variables such as carer’s and care recipient’s age group,
disability level (which may or may not include a chronic illness), or years of care provided, at best revealing an average weekly range of 6 to 27 hours, climbing to over 105 hours depending on the severity of disability. “Consequently, there is hardly any systematic knowledge about what determines the quantity of labour required for informal care, its nature or its intensity and the demands it places on families. Therefore it is not possible to estimate the demands placed on carers, how they vary according to changes in circumstances and to make informed judgements about the supply of caring labour” (Bittman et al., 2005:57).

Langa et al (2002) report that individuals with chronic lung disease and activity limitations received an additional 5.1 h/wk of informal care compared to those with no lung disease, and therefore, if the full societal costs of chronic lung disease are to be calculated then the costs to families and society must be accounted for.
<table>
<thead>
<tr>
<th>Author, Title &amp; Year</th>
<th>Country</th>
<th>Disease (if specified)</th>
<th>Design and methods – survey, RCT, qualitative study</th>
<th>Sample size</th>
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<tbody>
<tr>
<td>Bittman et al. Making the invisible visible. The life and time(s) of informal caregivers. 2004.</td>
<td>Australia</td>
<td></td>
<td>Method: survey and diary. Quantitative data from surveys and diaries from Canadian (N= 10,749) and Australian (N= 14,000 approximately) bureaux used to explore and compare time burden and time use among carers and non-carers, as well as methodological issues in obtaining data and measuring time use and caring activities. Main variables are co-residency and non-care responsibilities.</td>
<td>Multiple samples: patients and carers</td>
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<tr>
<td>Bittman, M. et al. The time cost of care. 2005.</td>
<td>Australia</td>
<td></td>
<td>Method: survey and diary. This paper contrasts two different measures of care time using survey questions or a diary.</td>
<td>Multiple samples: carers</td>
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<tr>
<td>Braithwaite, V. Bound to Care. 1990.</td>
<td>Australia</td>
<td>Mainly cardiovasc</td>
<td>Method: qualitative, descriptive and survey. Overall, takes a sociological view of what a caregiver is/does and means, it's not just tasks and burden, but a relationship and a responsibility. Although dated, and focused on care-givers, does provide some early basic data on time and other burdens in caring.</td>
<td>138 carers</td>
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<tr>
<td>Corbin, J. &amp; Strauss, A. Managing chronic illness at</td>
<td>USA</td>
<td>Mainly cardiovasc</td>
<td>Method: qualitative. Interviews and (auto) biographies of people with CI* and their spouses.</td>
<td>60 couples: patients and</td>
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<tr>
<td>home: Three lines of work. 1985.</td>
<td>ular diseases, cancer, stroke, &amp; spinal injuries.</td>
<td>Uses the concept of &quot;work&quot; in managing CIs and types of work: illness, everyday and biographical work.</td>
<td>carers</td>
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<td>6 Ettner, S. et al. Investing time in health: do socio-economically disadvantaged patients spend more or less extra time on diabetes self-care? 2009.</td>
<td>USA Diabetes Method: survey. Comprehensive survey and statistical analysis, using several variables (education, marital status, income, minority group/ethnicity status, work status, clinical characteristics) but limited to one CI; looks at only foot care, exercise and (conflates) shopping/cooking. Objective: To examine associations between socio-economic position and extra time patients spend on foot care, shopping/cooking, and exercise due to diabetes.</td>
<td>11,927 patients</td>
<td></td>
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<tr>
<td>8 Infante, et al. How people with chronic illnesses view their care in general practice: a qualitative study. 2004.</td>
<td>Australia Method: qualitative. 12 focus groups. Objectives: To explore the perceptions of patients with chronic conditions about the nature and quality of their care in general practice.</td>
<td>76 patients</td>
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<td>9</td>
<td>Ironmonger, D.</td>
<td>The value of care and nurture provided by household work.</td>
<td>1994</td>
<td>Australia</td>
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<td>12</td>
<td>McCoy, L.</td>
<td>Time, self and the medication day: a closer look at the everyday work of ‘adherence’.</td>
<td>2009</td>
<td>Canada</td>
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<td>13</td>
<td>McKenna, K. et al.</td>
<td>Comparison of time use, role participation and life satisfaction of older people after stroke with a sample without stroke.</td>
<td>2009</td>
<td>Australia</td>
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<td>14</td>
<td>Paoletti, I</td>
<td>A half life: Women caregivers of older disabled relatives.</td>
<td>1999</td>
<td>Italy</td>
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<td>15</td>
<td>Pritchard, P.</td>
<td>Doctors, patients and time</td>
<td>1992</td>
<td>UK</td>
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<td>16</td>
<td>Reed, et al.</td>
<td>Economic evaluation of home blood pressure monitoring with or without telephonic behavioural self-management in patients with hypertension.</td>
<td>2010</td>
<td>USA</td>
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<tr>
<td>18</td>
<td>Russell, L. et al.</td>
<td>Health-related activities in the American Time Use Survey.</td>
<td>2007</td>
<td>USA</td>
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<td></td>
<td>Author(s)</td>
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<td>21</td>
<td>Wolf, D.</td>
<td>Valuing informal elder care.</td>
<td>2004</td>
<td>USA</td>
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<tr>
<td>22</td>
<td>Yabroff, K. et al.</td>
<td>Estimating patient time costs associated with colorectal cancer care.</td>
<td>2005</td>
<td>USA</td>
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</table>
Discussion

Comparison – limitations of studies included for review

Studies included in this review reported encountering multiple methodological difficulties that limited their capacity to comprehensively measure total time use for patients or carers. Key limitations of the studies included in this review concern secondary analysis, mode of time measurement, values attributed to time, and the lack of consistency in what is measured across studies.

Studies that undertook secondary analysis of large datasets were unable to report detailed information on the elements of HRA because they were not included in the survey questions. As an example, the Australian National Health Survey (2007–2008) records activities undertaken by people with self-reported conditions, but does not identify what time is taken to carry out any of these activities (Australian Bureau of Statistics, 2009a). Similarly, the Australian Time Use Survey: How Australians Use Their Time, 2006 (Australian Bureau of Statistics, 2006a) identifies health as one of the activities on which time is spent, but does not specify or quantify particular activities or the time taken (see for example, Bittman et al., 2005).

Studies were also limited by their mode of time measurement. Bittman et al (2005) examined two datasets on time use from the ABS that utilised two different methods (the 1998 Australian Survey of Disability, Ageing and Carers, which included time use estimates based on a question concerning hours spent weekly on activities, and diary estimates from the 1997 national Australian Time Use Survey). They argue there is an inconsistency in the two estimates, and this may be because of methodological reasons such as; "the time use data may well miss out some
supervisory time, and not always indicate the extent to which carers rearrange their schedules to be nearby to the care recipient in case they are needed” (Bittman et al., 2005:62). Regardless of which mode of time measurement is utilised by a study there are likely to be aspects of time use which, for whatever reason, are not captured. With regards to the studies included in this review, this limitation does not reflect the quality of research undertaken as much as the complex nature of defining and measuring time use.

The reviewed studies presented different classifications of time use. Underestimation of patient time costs may result from misclassification. For example, Bittman et al (2004) report that food preparation and cooking may be under-reported or classified as a “domestic” activity rather than a caring task. In other cases there may be incomplete information on travel or service time, as well as counting multiple therapeutic claims or procedures within a short period as one episode; and in monetary terms, the extrapolation of the wage rates used in the computation of the value of patient-costs take no account of how sick or retired persons may value their time consumption. This is evident in Reed et als’ (2010) paper that compared three forms of care for hypertension, valuing the patients’ time, based on information from the USA Bureau of Labor Statistics. They showed that the 3 interventions were cost-additive to the health-care system; that patients’ time costs were not trivial, and the interventions took no account of how time was valued by patients.

Extending on this problem of classification, subjective terminology was used in some time use surveys. Jenkins (1997) identifies several limitations of question styles employed in the 1988 National Survey of Families and Households, such as the
restrictions created by respondents being asked if they care for someone who is seriously ill or disabled. 'Seriously' is a somewhat subjective term, and all data concerning care recipients which was not deemed 'seriously ill' by respondents was therefore not measured. McKenna et al. (2009) in their study of time use after stroke excluded people from participating if they had cognitive impairment; however they note that as cognitive impairment is a result of stroke in 60% of cases this somewhat limited the generalisability of their data. Similarly, Bittman and Thompson (2000) note that the ABS data does not separate caring for disabled/handicapped from caring for chronically ill people, limiting the specificity of Bittman and Thompson’s time use analysis.

Other methodological limitations noted in the literature were concerned with whether or not studies were longitudinal or cross-sectional (Yabroff et al., 2005), or if they compared time use amongst those with and without chronic illness (Bookman and Harrington, 2007). Schofield et al (1997) note that time use studies are often based on small samples, reducing the power of the findings. Folbre (2006) argues that small time use studies may be gender or otherwise biased.

Discussion of findings
This review set out to establish, from existing literature, which HRA undertaken by patients and informal carers has been measured; and how much time they are reported to have spent on HRA. The kinds of HRA that is measured and reported in the reviewed studies have limited alignment with the ‘illness work’ outlined by Corbin and Strauss (1985). Some studies did measure exercise and access to health services (for example, Russell et al., 2007), which could be seen as part of the first
kind of ‘illness work’, which is regimen and diagnostic related activity. Others looked broadly at HRA, which is the everyday life work described as the second kind of ‘illness work’; however in these papers time spent on specific HRA was seldom reported. Diabetes care work was measured by two studies and others included medication adherence (for example, Ettner et al., 2009; McCoy, 2009). Other types of HRA such as food preparation and consumption or obtaining medicine prescriptions were not reported specifically. The biographical tasks outlined in the third kind of ‘illness work’ did not have a strong presence in the studies, although McCoy (2009) and Paoletti (1999) make a start. It is likely that studies focusing on the biographical tasks of ‘illness work’ do exist but did not meet our inclusion criteria. Such papers could inform researchers of specific HRA that are not currently measured.

There are only a small number of studies which reported patient and carer time use in relation to chronic illness. Five key articles (Safford et al., 2005; Bittman and Thomson, 2000; Braithwaite, 1990; Ettner et al., 2009; Russell et al., 2005) detail that time use and how it affects lifestyle and wellbeing. Armstrong (1985) observed that there is a lack of accurate and comprehensive information about the time spent by people who themselves have a chronic illness in looking after their health. It is a point emphasised by Singleton (2002:692) who says that “the voices of patients are disturbingly absent” from the literature on time use, and which is addressed only superficially by, for example, Corbin & Strauss (1985), McCoy (2009) and Paoletti (1999). This review identified a small number of articles, which, when combined, lead us to conclude that these observations by Armstrong, Singleton, and others remain the case.
These limitations notwithstanding, the available literature indicates that the time use and burden associated with managing a chronic illness is sizable (Bittman et al., 2004; Reed et al., 2010; Yabroff et al., 2005). Patients with chronic illness and informal carers may be spending 2 hours a day or more on HRA. Measurements of time spent on specific activities are needed to inform our understanding of the real time burden associated with ‘illness work’. Additionally, the available literature indicates that approximately 2 hours are required for every health system contact, to which can be added the same amount for the time of a carer accompanying the patient. These estimates of time spent on HRA are likely to under represent actual patient and informal carer time use, and as Yabroff suggests, may increase with progression of the illness. If time were consumed in one block it might be more readily accommodated into a person's life style. However, HRA are often spread across a whole day and therefore may be found to be simply disruptive, a burden, and de-motivating, as McCoy (2009) has demonstrated for HIV-infected persons. Additionally, we know almost nothing of how much illness-related time burden impacts people’s overall wellbeing, motivation, and even access to medical care.

Conclusion

This review shows that little is reported about the specific activities undertaken by patients and carers to manage chronic illness. The results suggest that patients with chronic illness and informal carers may be spending 2 hours a day or more on HRA. For specific chronic illnesses, such as diabetes, for which some estimates of time use exist, time use may be higher. More precise and rigorous measurement of activities and commensurate time commitments with which carers and the chronically ill
engage are necessary to better understand the work of chronic illness, its impact on life choices, and its true cost.

**Acknowledgements**

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CHAPTER 5 TIME USE OF PEOPLE WITH COPD


Abstract

Since Bury’s 1982 proposal that chronic illness creates biographical disruption for those who are living with it, there has been no effort to quantitatively measure such disruption. “Biographical disruption” refers to the substantial and directive influence that chronic illness can have over the course of a person’s life. Qualitative research and time use studies have demonstrated that people with chronic illnesses spend considerable amounts of time managing their health, and that these demands may change over time. This study was designed to measure the time that older people with chronic illnesses spend on selected health practices as one indicator of biographical disruption. We look specifically at the time use of people with chronic obstructive pulmonary disease (COPD). As part of a larger time use survey, a recall questionnaire was mailed to 3,100 members of Lung Foundation Australia in 2011. A total of 681 responses were received (22.0% response rate), 611 of which were from people with COPD. Descriptive analyses were undertaken on the amount of time spent on selected health-related activities including personal care, nonclinical health-related care, and activity relating to health services. Almost all people with COPD report spending some time each day on personal or home-based health-related tasks, with a median time of 15 minutes per day spent on these activities. At the median, people also report spending about 30 minutes per day exercising.
2.2 hours per month (the equivalent of 4.4 minutes per day) on nonclinical health-related activities, and 4.1 hours per month (equivalent to 8.2 minutes per day) on clinical activities. Excluding exercise, the median total time spent on health-related activities was 17.8 hours per month (or 35.6 minutes per day). For people in the top 10% of time use, the total amount of time was more than 64.6 hours per month (or 2.2 hours per day) excluding exercise, and 104 hours per month (or 3.5 hours per day) including exercise. The amount of time spent on health-related activity, such as engaging in personal care tasks, may be regular and predictable. The execution of these tasks generally takes relatively small amounts of time, and might be incorporated into daily life (biography) without causing significant disruption. Other activities may require large blocks of time, and they may be disruptive in a practical way that almost inevitably disrupts biography. The amount of time required does not appear to alter in relation to the time since diagnosis. The scale of time needed to manage one’s health could easily be interpreted as disruptive, and for some people, even overwhelming.

Keywords: chronic illness, chronic obstructive pulmonary disease, disrupted biography, experience, self-management, time use

Introduction

Bury (1982) proposes that chronic illness is experienced as a disruption to the individual’s biography, to their living out the life they imagine. “Chronic illness”, writes Bury, “is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted” (Bury, 1982: 169). Such disruption, he observes, can be responded to through the mobilisation of resources, including the use of time. This observation is based on his study, which
was conducted in the early 1980s, involving 30 people who had rheumatoid arthritis. Later, in their seminal paper on the home-based management of chronic illness, Corbin and Strauss (1985) said that chronic illness is experienced in terms of work; including the time people spend on “illness work”, daily health practices and “biographical work”. “Management of an illness in the home”, they write, “is not accomplished without difficulty and a great deal of effort, unless the regimens are relatively simple and do not greatly interfere with the normal flow of life” (Corbin and Strauss, 1985:224–225). This difficulty and effort born of chronic illness is created by work and by the amount of time spent incorporating the needs arising from chronic illness into the fabric of daily life. Taking these notions of “biographical disruption” and “work” as a platform, our study seeks to explore whether the amount of time spent on illness work and daily health practices might cause biographical disruption, and whether such disruptions increase or decrease over time. In doing so, we take the case of people with chronic obstructive pulmonary disease (COPD). Drawing on the findings from a time use survey we conducted in Australia in 2011 (Yen et al., 2013), we have established that people with arthritis spend approximately 7.8 hours (median) per month on health practices. We also identified that people with COPD spent more time overall on health practices than those with arthritis or other chronic illnesses (Yen et al., 2013). Returning to Bury’s study (Bury, 1982), and combining his findings with our own, if people with arthritis spend about 7.8 hours each month on health practices, and they experience this time as contributing to a sense of disruption, then people with COPD – an illness associated with a higher magnitude of time use – may experience the same, or even a greater sense, of disruption.
This paper details the “work” of COPD in terms of the amount of time that people with COPD spend on particular health practices, which may be driven by COPD or other conditions, and which informs our understanding of the reality faced by COPD patients. We assess to what extent that time use is informed by how much time has passed since the patients were diagnosed with COPD. Doing so allows for a direct comparison to be made with the time demands faced by people with arthritis, as reported in Bury’s study (Bury, 1982), although the explicit impact of these time demands cannot be assessed in the context of a time use survey.

In addition to the theoretical driver, biographical disruption, behind this article, the impact of COPD time use information can be seen in public health and service terms. Not only is COPD associated with high time use, but it is also a major cause of morbidity and mortality worldwide (World Health Organization, 2013). Acute exacerbations of COPD are common; they often require hospitalization and are associated with high mortality rates (Groenewegen et al., 2003). Research shows mortality rates as high as 23% after 1 year from COPD-related hospitalisation (Groenewegen et al., 2003). In Australia, COPD remains a leading underlying cause of death and disability. The average length of stay in hospital due to COPD exacerbation in 2007–2008 was 6.9 days, which was double the average time spent in hospital due to other reasons (3.3 days) (Dunt and Doyle, 2012).

While some aspects of the health system and personal costs of COPD in relation to the use of hospital services are known (Gysels and Higginson, 2008; Kirby et al., 2010), very little is known about management of COPD outside of hospital settings. Qualitative studies have shown that COPD contributes to patient and carer burden, it
informs their help-seeking behaviours, and can come at considerable personal cost (Gysels and Higginson, 2008; Gysels and Higginson, 2009; Corcoran et al., 2013; Habraken et al., 2008). It is within such literature that the kinds of “work” that Corbin and Strauss have outlined can be identified (Corbin and Strauss, 1988).

Gysels and Higginson (2009) note that people’s experiences of time can be disrupted by COPD, as evidenced by their narratives, which lack reference to any future orientations. Pinnock et al (2011) have also identified the role of time in COPD experiences, suggesting that the illness becomes “a way of life” (that is, over time), which contributes to difficulties in identifying when support, including palliative support, is needed. However, despite the ubiquitous influential nature of time on experience, qualitative studies concerning COPD experience seldom account for time use beyond the observations that some tasks take longer to complete due to breathlessness and reduced mobility.

Many people with COPD have a range of comorbid conditions, and these conditions will also make demands on their time, so time use by people with COPD is not necessarily the same as the time demands directly associated with COPD per se. However, the health related time demands of the community of people with COPD, regardless of other co-morbidities, are material and measurable.

The nature of the health-related activities undertaken by people with COPD and the time required to do them has not been examined. Specific practices of self-management and the amount of time spent in rehabilitation programs may require considerable time commitments from the patient. Further, as the disease progresses,
the time spent by people with COPD on health practices (“work”) may change dramatically in terms of the activities undertaken and the quantity of time required.

Methods

The data collection and analysis methods have been described in full elsewhere (Yen et al., 2013). Recruitment was undertaken through three national organizations, Lung Foundation Australia (LFA), National Seniors Australia (NSA), and the National Diabetes Services Scheme (NDSS). This article reports only findings from the LFA sample.

Sample

Participants were selected from members of Lung Foundation Australia (LFA, a national non-profit, advocacy, education, fund raising and support organisation with over 14,000 members). All those members aged over 50 years and recorded by the LFA as having COPD were included in the study (a total of 3062 people), although as we see later, not all of these people actually have a diagnosis of COPD. Data were collected on standard demographic variables, the respondents’ perceptions of their own health (using the Short Form-12 and the EuroQoL – both standard measures of self-assessed health) and the chronic illnesses with which they had been diagnosed. A series of questions related to health services use – including the type and number of health professionals consulted in the previous 3 months and attendance at emergency departments in the last 12 months – were investigated. Three multipart questions were designed to obtain information about time use on personal home-based activities, nonclinical, and clinical activities (see Table 1). Respondents who were also carers
were asked additionally about the same activities from the perspective of their caring role.

Table 1: Time Questions

<table>
<thead>
<tr>
<th>Activity type</th>
<th>Task</th>
<th>hours</th>
<th>minutes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home activities</td>
<td>On most days how much time do you generally spend on each of the following?</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Sorting your medications</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Preparing your medications</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Taking your medications</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Carrying out treatments</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Testing or monitoring your health</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Preparing special foods</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Taking exercise/stretching</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-clinical</td>
<td>In the last month how much time did you spend on each of the following?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>activities</td>
<td>• Shopping for medicines, equipment or disposables, other necessary health items for yourself</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Shopping for special foods you may need for yourself</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Attending rehabilitation programs</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Attending health education of self-management programs</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Attending support groups such as cancer or diabetes groups</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Looking for and reading health information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical activities</td>
<td>In the last month how much time did you spend on each of the following?</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Organising appointments for yourself</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Organising travel to and from health-related appointments</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Travelling to and from health-related appointments, including support groups</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Sitting in waiting rooms</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• With the doctor or other health professional for consultation, advice or treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Having blood tests, x-rays or other tests</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Having other medical treatments (eg dialysis, chemotherapy, radiotherapy)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The questionnaire was piloted with 28 people from an earlier survey who had indicated an interest in being involved in further research, and following their feedback, the questionnaire was modified and retested with a group of members of a local health service consumer network. The final survey was mailed to selected individuals with the option to complete it on line using SurveyMonkey® (Palo Alto, CA, USA), a proprietary survey tool, or to complete the form and return it by prepaid post.

Data collection and analysis

Data were entered into SPSS files for analysis. Online responses were merged electronically. Analysis was undertaken using IBM SPSS Statistics for Windows, Version 19.0 (IBM Corporation, Armonk, NY, USA) and Stata 11 (StataCorp LP, College Station, TX, USA). Confidence intervals were derived using bootstrapping techniques within Stata 11. Descriptive analysis was used to explore the components of time use and the relationship between self-assessed health, the numbers of medications taken, the amount of time since diagnosis, and other selected time components.

Time measurement

We asked how much time was spent “on most days” for frequent, regular activities, such as managing and taking medication, and “in the last month” for less regular activities, such as shopping for special food, attending support groups, or visiting a doctor. The times reported have been trimmed to remove impossible and implausible values for each component question and for aggregates. Times reported were
converted by dividing monthly figures by 30 to give daily time use, or multiplying daily time use by 30 for a monthly figure.

The time distributions are highly skewed, being truncated at zero, but frequently have a small number of very large values, so medians are used rather than means. Since one of the major questions is which groups face the greatest time demands, the 90th percentiles are also discussed to show the time demands experienced by the top 10% of respondents.

The last component of home activities relates to engaging in exercise and stretching. Exercise time is discussed separately, and has been excluded from some totals as exercise times were variable, and we were unable to identify whether the respondent was exercising for recreation, or for a specific health reason.

While almost all respondents reported spending time on many health-related activities, few reported spending time on all of them. Therefore, the estimates of the amount of total time included all observations (including the relatively small numbers of zeros), but for the amount of time spent on individual activities, we reported on both the proportion of respondents undertaking these tasks and the amount of time spent by those undertaking them.

**Ethics**

Study approval was obtained from the Australian National University Human Research Ethics Committee (Protocol number: 2010/468).
Results

Six hundred and eighty-one people returned completed surveys (a response rate of 22.2%). Six hundred and eleven reported having had a formal diagnosis of COPD; the other seventy were probably family members who joined LFA as COPD members, but did not have COPD themselves. The analysis that follows is based on only those individuals with COPD (N=611). As indicated in Table 1, the survey categorized time use questions into those concerning home activities, clinical activities, or nonclinical activities.

The total time spent on health-related activity by people with COPD (median times: 17.8 hours per month excluding exercise or 31.7 hours per month including exercise) is three times greater than the amount of time spent by older adults in the general population, in each of the three categories of activity (which we have reported previously, (Yen et al., 2013)). As indicated in Table 2, most respondents spent time sorting medications (66.4%), preparing medications (53.1%), and/or taking medications (90.1%). The median time reported as being spent on each of these three activities was 5 minutes daily.

Most respondents (69.5%) spent time exercising or stretching; the median time spent on exercising or stretching was 15 hours per month or 30 minutes daily. Only 9.0% of respondents engaged in the preparation of special foods, but for those who did this, the activity was associated with high time use (median time spent was 15 hours per month or thirty minutes daily). While there was little difference in the proportion of males and females shopping for or preparing special foods, females spent around twice as much time preparing these foods as males (Table S1). Most
respondents (96.7%) spent time on at least one daily home activity, and the median time spent on all home activities was 45 minutes per day or 22.5 hours per month (including time spent on exercise). Excluding the amount of time spent on exercise, the total time spent (by 95.6% of respondents) on home activities was considerably less, with a median of 7.5 hours per month or 15 minutes per day.

Two other activities were identified as having relatively high time use by those who engaged in the activities. The median amount of time spent carrying out treatments was 5.0 hours per month (undertaken by 24.6% of respondents) and the time spent attending rehabilitation programs was 4.0 hours per month (undertaken by 19.6% of respondents).

Fewer respondents spent time on clinical activities (88.6%) than on home activities, and overall, the clinical activities required less time (median of 4.1 hours per month by those engaging in clinical activities). Overall 78.3% of respondents reported spending any time waiting in waiting rooms, and the median time reported was 1 hour per month. Most respondents spent time in consultations or having treatments (73.9.0%), travelling to and from health appointments (67.1%), and/or organizing appointments (62.3%). The median time spent on each of these activities was 0.8 hours, 1.5 hours, and 0.3 hours per month, respectively.
<table>
<thead>
<tr>
<th>Activity</th>
<th>Proportion undertaking this activity (N=611)</th>
<th>Median time if undertaking this activity</th>
<th>90th percentile of time if undertaking this activity</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% active (95% CI)</td>
<td>Median (95% CI)</td>
<td>90th percentile (95% CI)</td>
</tr>
<tr>
<td><strong>Personal care activities (minutes per day)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sorting your medication?</td>
<td>66.4%</td>
<td>5 (4.0–6.0)</td>
<td>20 (11.5–28.5)</td>
</tr>
<tr>
<td>Preparing your medication?</td>
<td>53.1%</td>
<td>5 (5–5)</td>
<td>15 (12.6–17.4)</td>
</tr>
<tr>
<td>Taking your medication?</td>
<td>90.1%</td>
<td>5 (5–5)</td>
<td>20 (10.2–29.8)</td>
</tr>
<tr>
<td>Carrying out treatments?</td>
<td>24.6%</td>
<td>10 (5.2–14.9)</td>
<td>120 (83.7–156.3)</td>
</tr>
<tr>
<td>Testing or monitoring your health?</td>
<td>22.1%</td>
<td>5 (2.3–7.7)</td>
<td>30 (14.6–45.4)</td>
</tr>
<tr>
<td>Preparing special foods?</td>
<td>9.0%</td>
<td>30 (19.5–40.5)</td>
<td>120 (13.5–226.5)</td>
</tr>
<tr>
<td>Exercising/stretching?</td>
<td>69.5%</td>
<td>30 (30–30)</td>
<td>90 (63.5–116.5)</td>
</tr>
<tr>
<td><strong>Total home activities (minutes per day) excluding exercise</strong></td>
<td>95.6%</td>
<td>15 (11.8–18.2)</td>
<td>78 (63.5–92.5)</td>
</tr>
<tr>
<td><strong>Total home activities (minutes per day) including exercise</strong></td>
<td>96.7%</td>
<td>45 (41.3–48.7)</td>
<td>150 (125.0–175.0)</td>
</tr>
<tr>
<td><strong>Non-clinical activities (hours per month)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shopping for medicine, equipment or disposables, other necessary health items for yourself?</td>
<td>71.5%</td>
<td>0.5 (0.5–0.5)</td>
<td>2 (1.3–2.7)</td>
</tr>
<tr>
<td>Shopping for special foods you may need for yourself?</td>
<td>17.9%</td>
<td>1 (0.7–1.3)</td>
<td>6 (2.6–9.4)</td>
</tr>
<tr>
<td>Attending rehabilitation programs?</td>
<td>19.6%</td>
<td>4 (3.7–4.3)</td>
<td>16 (10.3–21.7)</td>
</tr>
<tr>
<td>Attending health education or self-management programs?</td>
<td>13.9%</td>
<td>3 (1.9–4.1)</td>
<td>16 (6.9–25.1)</td>
</tr>
<tr>
<td></td>
<td>Hours per Month</td>
<td>95% CI</td>
<td>Hours per Month</td>
</tr>
<tr>
<td>-----------------------------------------------------------------</td>
<td>----------------</td>
<td>--------</td>
<td>----------------</td>
</tr>
<tr>
<td>Attending support groups, such as cancer or diabetes groups?</td>
<td>14.4</td>
<td>2 (1.6–2.4)</td>
<td>12 (2.8–21.2)</td>
</tr>
<tr>
<td>Looking for and reading health information?</td>
<td>42.7</td>
<td>1 (0.9–1.1)</td>
<td>5 (3.7–6.3)</td>
</tr>
<tr>
<td><strong>Total non-clinical activities (hours per month)</strong></td>
<td><strong>85.0</strong></td>
<td><strong>2.2 (1.8–2.5)</strong></td>
<td><strong>16 (12.8–19.2)</strong></td>
</tr>
<tr>
<td><em>Health services related activities (hours per month)</em></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Organising appointments for yourself?</td>
<td>62.3</td>
<td>0.3 (0.3–0.3)</td>
<td>1 (1–1)</td>
</tr>
<tr>
<td>Organising travel to and from health-related appointments?</td>
<td>30.8</td>
<td>0.5 (0.45–0.55)</td>
<td>2.5 (1.3–3.7)</td>
</tr>
<tr>
<td>Travelling to and from health-related appointments, including support groups?</td>
<td>67.1</td>
<td>1.5 (0.9–2.1)</td>
<td>8 (5.3–10.7)</td>
</tr>
<tr>
<td>Sitting in waiting rooms?</td>
<td>78.3</td>
<td>1 (1–1)</td>
<td>4 (3.6–4.4)</td>
</tr>
<tr>
<td>With the doctor or health professional for consultation, advice or treatment?</td>
<td>73.9</td>
<td>0.8 (0.6–1.1)</td>
<td>3.5 (2.1–4.9)</td>
</tr>
<tr>
<td>Having blood tests, x-rays or other tests?</td>
<td>55.2</td>
<td>0.7 (0.4–1.0)</td>
<td>3 (2.3–3.7)</td>
</tr>
<tr>
<td>Having other medical treatments?</td>
<td>5.1</td>
<td>1 (0–2)</td>
<td>16 (10.5–21.5)</td>
</tr>
<tr>
<td><strong>Total Health services related activities (hours per month)</strong></td>
<td><strong>88.6</strong></td>
<td><strong>4.1 (3.4–4.8)</strong></td>
<td><strong>18 (15.3–20.7)</strong></td>
</tr>
<tr>
<td>Total activities (hours per month) excluding exercise</td>
<td><strong>98.1</strong></td>
<td><strong>17.8 (15.4–20.3)</strong></td>
<td><strong>64.6 (53.6–75.7)</strong></td>
</tr>
<tr>
<td>Total activities (hours per month) including exercise</td>
<td><strong>98.6</strong></td>
<td><strong>31.7 (28.9–34.4)</strong></td>
<td><strong>104 (92.4–115.6)</strong></td>
</tr>
</tbody>
</table>
As shown in Table 3, many respondents took multiple prescribed medications in order to help manage their health. These medications could have been prescribed to manage COPD, as well as other chronic illnesses. As would be expected, greater numbers of medications were associated with increased amounts of time spent sorting, preparing, and taking medications. Ten percent of respondents, however, recorded that although they took medications, this activity required no time at all. It is possible that these respondents did not understand the survey question, or they did not answer the question because they considered the quantity of time

Table 3: Number of medications and time taken for each medication activity

<table>
<thead>
<tr>
<th>Activity</th>
<th>N</th>
<th>Proportion undertaking this activity</th>
<th>Median time if undertaking this activity</th>
<th>90th percentile of time if undertaking this activity</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of medications</strong></td>
<td></td>
<td>% active (reporting time)</td>
<td>Median (95% CI)</td>
<td>90th percentile (95% CI)</td>
</tr>
<tr>
<td>Min (95% CI)</td>
<td></td>
<td>Minutes per day</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Activity: Sorting your medication?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1–2 medications</td>
<td>53</td>
<td>34.0</td>
<td>2 (0.0–4.5)</td>
<td>5 (0.0–13.5)</td>
</tr>
<tr>
<td>3–5 medications</td>
<td>206</td>
<td>63.8</td>
<td>5 (5–5)</td>
<td>15 (9.9–20.1)</td>
</tr>
<tr>
<td>6–10 medications</td>
<td>262</td>
<td>73.5</td>
<td>5 (0.3–9.7)</td>
<td>20 (10.5–29.5)</td>
</tr>
<tr>
<td>&gt;10 medications</td>
<td>78</td>
<td>77.1</td>
<td>10 (6.5–13.4)</td>
<td>30 (14.1–45.9)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>611</td>
<td>66.4</td>
<td>5 (5–5)</td>
<td>20 (11.5–28.5)</td>
</tr>
<tr>
<td>Activity: Preparing your medication?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1–2 medications</td>
<td>53</td>
<td>35.3</td>
<td>1 (0.3–1.7)</td>
<td>5 (0–14.2)</td>
</tr>
<tr>
<td>3–5 medications</td>
<td>206</td>
<td>45.5</td>
<td>5 (4.3–5.7)</td>
<td>10 (8.0–11.0)</td>
</tr>
<tr>
<td>6–10 medications</td>
<td>262</td>
<td>63.4</td>
<td>5 (5–5)</td>
<td>15 (12.4–17.6)</td>
</tr>
<tr>
<td>&gt;10 medications</td>
<td>78</td>
<td>55.5</td>
<td>10 (5.5–14.5)</td>
<td>30 (17.4–42.6)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>611</td>
<td>53.1</td>
<td>5 (5–5)</td>
<td>15 (12.0–17.6)</td>
</tr>
<tr>
<td>Activity: Taking your medication?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1–2 medications</td>
<td>53</td>
<td>81.4</td>
<td>2 (0.2–3.8)</td>
<td>10 (1.9–18.1)</td>
</tr>
<tr>
<td>3–5 medications</td>
<td>206</td>
<td>89.9</td>
<td>5 (4.8–5.2)</td>
<td>20 (9.9–30.1)</td>
</tr>
<tr>
<td>6–10 medications</td>
<td>262</td>
<td>93.8</td>
<td>5 (5–5)</td>
<td>20 (9.9–30.1)</td>
</tr>
<tr>
<td>&gt;10 medications</td>
<td>78</td>
<td>90.3</td>
<td>5 (1.0–9.0)</td>
<td>30 (17.6–42.4)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>611</td>
<td>90.1</td>
<td>5 (5–5)</td>
<td>20 (10.1–29.9)</td>
</tr>
</tbody>
</table>
required for such tasks to be inconsequential. Indeed, for many respondents, the median times spent on these tasks appear to be relatively small, with between 2 minutes and 10 minutes required for each task, depending on the number of medications taken. However, for those respondents in the 90th percentiles, the median times are between three and four times higher. The top 5% of respondents spend 1 hour or more on these three tasks, and the top 10% spent 45 minutes or more.

**Self-rated health and time spent**

Time spent on each activity group generally increased as self-rated health declined, although the small number of respondents reporting excellent health meant that the estimates for this group had very wide confidence intervals, and while the patterns were stable, few of the differences were significant. The tables outlining this result are shown in the supplementary file (Tables S2–S5). The differences between those in good health and those in poor health were highly significant for the amount of time taken for home activities (particularly if exercise was not included) and health service-related activities. There were no significant differences between levels of self-reported health in the amount of time spent on nonclinical activities.

**Does having a partner matter?**

One factor that was seen as likely to impact the time spent on health care was whether a patient had a partner. Comparing those with a partner to those with no partner, but who had been married, shows that those with partners spent more time on their health than those without partners, with the difference at the median being statistically significant.
Does the quantity of chronic illness work change over time?

The survey asked respondents how old they were when they were first told of their diagnosis of COPD. Of the 611 people with COPD who returned completed surveys, only 537 provided this information: 194 people had been diagnosed with COPD for 5 years or less; 148 people had been diagnosed between 6 years and 10 years; and 195 people had been diagnosed for more than 10 years. For the majority of the activities for which time use was measured, there was little relationship between time use and time since diagnosis.

One exception to this finding was the amount of time spent carrying out treatments where the patterns were suggestive of more time being spent by those who were diagnosed less recently (more than 5 years previously), although none of the differences are significant. There is also a weak indication that there are more people spending very large amounts of time preparing special foods among the more recently diagnosed (those diagnosed within 5 years or less). There is a weak suggestion that those who had been diagnosed the longest may spend longer preparing and taking medications which, if true, may relate to age and the number of medications taken. Other suggestive patterns include a decline in time spent on shopping for special foods among those diagnosed long ago, and a similar pattern was indicated for the amount of time spent attending rehabilitation clinics. A larger sample may allow for significance to be reached in some of these patterns.

Discussion

People with COPD among their conditions spend more time on managing their health than people with arthritis, whom Bury found encountered biographical
disruption (Bury, 1982). As previously mentioned, our survey is not exhaustive, and is likely to under-represent the amount of time and disruptive elements associated with hospitalizations. It also has not captured those temporal elements of chronic illness experiences that are spent planning or worrying about illness, nor did the survey capture which activities were foregone due to spending time on health-related activities, and the impact of that on the individual’s lived experience.

The findings suggest that some people with COPD spend considerable amounts of time managing their health, both in clinical and nonclinical settings – much of which is likely to be spent managing their COPD, but some of which will be related to other comorbid conditions. Some activities require daily commitments, such as managing and taking prescribed medication, and undertaking exercise to maintain or improve health. Other activities require larger amounts of time less frequently. The median amount of time required to manage tasks (excluding exercise) amounts to 17.8 hours per month (equivalent to 35.6 minutes daily), and for those in the top 10%, the total amount of time spent was at least 64.6 hours per month (more than 2 hours daily).

The less-than-daily clinical and nonclinical activities are likely to be experienced in a different “rhythm” than every-day activities. Rather, a task may occur just once a month and instead of taking 30 minutes, it may take 2 hours. This oscillation between smaller rhythmic activities and larger time-intensive, sporadic activities informs the individual’s perception of the “work” associated with managing chronic illness. Activities that occur frequently, but for shorter durations, actually amount to a greater quantity of time over 1 month than do the less frequent, but time-intensive
activities. However, it is often these latter activities that cause the greatest sense of disruption to daily life, as it is more difficult to habituate these tasks into familiar routines and rhythms.

In our study, fewer respondents reported spending time on clinical activities (88.6%) than on home activities (96.7%), and overall, the clinical activities required less time (median of 4 hours per month by those engaging in clinical activities). However, our survey was sent to people in the community, and it did not examine the amount of time spent as a patient in hospital – a common and time-consuming occurrence for many people with COPD (Groenewegen et al., 2003). The findings reported here represent only a specific portion of time spent on health-related activities, and thereby underrepresent the possible disruption that chronic illness can cause.

The findings also indicate that the amount of time people spend on health work is associated with sex. While a similar number of females and males prepared special foods each day, females spent significantly more time on this task than males. Stronger associations were evident with self-reported health status than sex for the amount of time spent on home and clinical activities. People with partners spend significantly more time on their health care than those without partners (although the differences are not large), possibly suggesting that those with partners are able to share more day-to-day work, and thus have more time to address their health care needs.

We were surprised to find that the amount of time that had passed since a person was diagnosed with COPD did not strongly impact their time spent on health work. We
had suspected that time requirements would be significantly greater either at the time immediately leading up to and following diagnosis, or for people who had been diagnosed for many years and whose speed in carrying out tasks could be slowed. However, such patterns were not strong. Alternatively, it is possible that as people’s illnesses progress, their capacity to undertake certain health-related activities decreases to a point where they require others – such as informal carers – to take over the management of such tasks. If this is the case, we could expect to see less time spent on tasks by people with COPD over time.

Returning to Bury (1982) and to Corbin and Strauss (1985), the question remains as to whether COPD is a cause of biographical disruption and work. After consideration of the findings, we suggest that the amount of time spent by people with COPD on home, clinical, and nonclinical activities is substantial, and that time spent on these tasks constitutes work. The overall quantity of time spent, the diversity of tasks undertaken, the timing and rhythms associated with each task, and the different amounts of time required for each task, all contribute to the extent to which chronic illness is experienced as disruptive in daily life, and to the individual’s overall biography. The disruption to biography is keenly felt through one’s sense that time spent on health-related activities robs the individual of time they could otherwise spend on other valued activities in other aspects of their lives. This article has provided information on several of these factors and in doing so, we suggest, contributes to quantifying the ways in which chronic illness contributes to biographical disruptions and a reshaping of biography. The future biography of an individual with COPD entails the moments shaped by illness, which are identifiable in terms of time spent on its management.
We have previously noted that “Health policies in most Western systems encourage patients and their carers to use self-management approaches to remain as healthy as possible, and so to live independently for longer and avoid unnecessary hospital admissions” (Yen et al., 2013). Self-management though, as the findings here indicate, can come at considerable time costs to people with chronic illness. Even if engaging in self-management activities does enable people to remain as healthy as possible, live independently, and avoid unnecessary hospitalizations, it can still be experienced as an ongoing disruption to daily life and to biography as a whole.

**Strengths and limitations of the study**

This is the first study that attempts to measure the amount of time spent by people with COPD on health-related activities, and it provides a base for further research in the field. It is also the first to draw conclusions about the theories posed by Bury (1982) and Corbin and Strauss’ (1985) investigations of self-reported time use data. We have previously noted the limitations of the survey method (Yen et al., 2013). The use of recall estimates rather than diaries is associated with recall bias (Dumont et al., 2010). However, one of the key strengths of recall estimates is that they do provide a snapshot of time use, which minimizes the burden on participants, and which can (as in this study) cover a longer period of time than diaries can usually address, thereby giving much more meaningful distributions of time use over longer periods.
The sample was drawn from a single member organisation whose purpose is to promote knowledge about the illness and to support its members. Likewise, the response rate of 22% may cause biases. Those who chose to respond may be more motivated, and/or may be in better health than those who did not, although basic testing of age, sex, and region responses showed reasonable representation of the LFA population. While we have made attempts to capture diverse aspects of COPD management, we have not attempted to identify all health-related activities. That being the case, it is likely that the time estimates provided here under-represent the true time costs associated with COPD. In particular, we have not measured the amount of time people with COPD spend on activities of daily living (ADL), such as running errands or getting dressed or, as stated previously, time spent as an inpatient in hospital. ADL are likely to take longer to complete, or they may be beyond the individual’s capability due to the nature of COPD (Garrod et al., 2000; McSweeny et al., 1982).

The amount of time spent on ADL may further indicate biographical disruption. The application of time use data to sociological theory has some limits. In this case, the data do not provide information on how the time spent on tasks was experienced. While we have suggested that substantive quantities of time spent on managing health could create disruptions to daily life and to overall biography, such findings would be strengthened by qualitative research that explored the way this time was experienced and how it shaped people’s ideas about their biographies.
Conclusion

People with COPD report spending a median of 15 minutes each day on personal or home-based tasks. At the median, those who exercise report spending about 30 minutes per day exercising, 2.2 hours per month (or 4.4 minutes per day) on other nonclinical activities, and 4.1 hours per month (equivalent to 8.2 minutes per day) on clinical activities. For people reporting times in the top 10% of time use, the total time excluding exercise amounts to 64.6 hours per month, which is equivalent to 2 hours and 9 minutes daily. The amount of time spent on health-related activities, such as personal care tasks, may be regular and predictable. The execution of these tasks generally takes relatively small amounts of time, and might be incorporated into one’s biography without causing significant disruption. However, these are the tasks that are done every day of the year and must, of necessity, substitute for other activities. Other activities may require large blocks of time, and they are so clearly practically disruptive that they will almost inevitably be biographically disruptive. The time required does not appear to alter in relation to the time since diagnosis.

We conclude that the amount of time spent on tasks associated with managing one’s health constitutes a significant part of what Corbin and Strauss call the “work” of chronic illness. This study identifies that those with the highest levels of time spent on a selection of health-related activities (or “work”) spend an average of more than 3 hours a day on these tasks alone. These time use findings suggest the likelihood that COPD is experienced as disruptive to the individual’s daily rhythms and to his or her overall biography.
Acknowledgements

This research was undertaken as part of The Serious and Continuing Illnesses Policy and Practice Study (SCIPPS), an NHMRC-funded program (no: 402793) conducted at the Australian National University and the University of Sydney and administered by the Menzies Centre for Health Policy. The authors would like to thank Lung Foundation Australia for their assistance in carrying out this study. In particular, we thank the members of this organisation who completed the survey. We also thank our colleagues in the Serious and Continuing Illnesses Policy and Practice Study for their contributions. Ms Jowsey is undertaking post-doctoral research at the Australian National University and this article forms part of her thesis.

Contribution of authors

L Yen, T Jowsey and I McRae contributed to the conception of the study and the development of the tool. L Yen and I McRae managed the survey process. T Jowsey, I McRae and N Bagheri carried out the statistical analyses. T Jowsey led the development of the manuscript and data analysis. All authors contributed to the discussion of the findings and their implications and to the development of this paper.

Disclosure

The authors report no conflicts of interest in this work.

Note

Since the publication of this article Tanisha has been contacted by Mike Bury who kindly sent through a paper by Green, Todd and Pevalin (2007). The paper measures biographical disruption for people with multiple sclerosis. Had this paper been identified in our review of the literature it would have informed the present article.
Supplementary materials

Table S1: Shopping and preparing special foods

<table>
<thead>
<tr>
<th>Sex</th>
<th>N</th>
<th>Proportion undertaking this activity</th>
<th>Median time if undertaking this activity</th>
<th>90th percentile of time if undertaking this activity</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>Median (95% CI)</td>
<td>90th percentile (95% CI)</td>
<td></td>
</tr>
<tr>
<td>Preparing special foods (minute/day)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>285</td>
<td>8.3</td>
<td>20 (9.9–30.1)</td>
<td>60 (0.0–209.5)</td>
</tr>
<tr>
<td>Female</td>
<td>319</td>
<td>9.8</td>
<td>60 (31.1–88.9)</td>
<td>120 (9.3–230.7)</td>
</tr>
<tr>
<td>Total</td>
<td>611</td>
<td>9.0</td>
<td>30 (19.5–40.5)</td>
<td>120 (13.5–226.5)</td>
</tr>
<tr>
<td>Shopping for special foods (hours/month)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>285</td>
<td>18.5</td>
<td>0.6 (0.2–1.1)</td>
<td>3 (1.5–4.5)</td>
</tr>
<tr>
<td>Female</td>
<td>319</td>
<td>17.0</td>
<td>1 (0.1–1.9)</td>
<td>8 (5.1–11.4)</td>
</tr>
<tr>
<td>Total</td>
<td>611</td>
<td>17.9</td>
<td>1 (0.7–1.3)</td>
<td>6 (2.6–9.4)</td>
</tr>
</tbody>
</table>

**Note:** Time spent by people managing chronic obstructive pulmonary disease indicates biographical disruption.

Table S2: Time spent on home activities including exercise and self-reported health

<table>
<thead>
<tr>
<th>Self-reported health</th>
<th>N</th>
<th>Percent with home activities time greater than zero</th>
<th>Home activities including exercise (minutes per day)</th>
<th>Median and percentile including zero values</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>%</td>
<td>Median (95% CI)</td>
<td>90th percentile (95% CI)</td>
</tr>
<tr>
<td>Excellent/very good</td>
<td>30</td>
<td>100</td>
<td>50 (35.6–64.4)</td>
<td>94 (0.0–386.3)</td>
</tr>
<tr>
<td>Good</td>
<td>115</td>
<td>94.7</td>
<td>39 (31.1–46.8)</td>
<td>125 (88.9–161.0)</td>
</tr>
<tr>
<td>Poor/fair</td>
<td>464</td>
<td>96.9</td>
<td>45 (40.9–49.0)</td>
<td>160 (134.1–185.8)</td>
</tr>
<tr>
<td>Total</td>
<td>611</td>
<td>96.7</td>
<td>45 (41.4–48.6)</td>
<td>140 (117.1–162.8)</td>
</tr>
</tbody>
</table>

**Note:** Time spent by people managing chronic obstructive pulmonary disease indicates biographical disruption.

Abbreviations: N, number; CI, confidence interval.

Table S3: Time spent on nonclinical activities and self-reported health

<table>
<thead>
<tr>
<th>Self-reported health</th>
<th>N</th>
<th>Percent with nonclinical time greater than zero</th>
<th>Nonclinical but health-related activities (hours per month)</th>
<th>Median and percentile including zero values</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Excellent/very good</td>
<td>30</td>
<td>88.8</td>
<td>1.5 (0.3–2.7)</td>
<td>15 (4.5–25.5)</td>
</tr>
<tr>
<td>Good</td>
<td>115</td>
<td>87.4</td>
<td>1.5 (0.6–2.4)</td>
<td>16.2 (3.8–28.5)</td>
</tr>
<tr>
<td>Poor/fair</td>
<td>464</td>
<td>84.3</td>
<td>1.8 (1.3–2.3)</td>
<td>12.2 (8.9–15.5)</td>
</tr>
<tr>
<td>Total</td>
<td>611</td>
<td>85.0</td>
<td>1.5 (1.0–1.9)</td>
<td>13 (9.7–16.3)</td>
</tr>
</tbody>
</table>

**Note:** Time spent by people managing chronic obstructive pulmonary disease indicates biographical disruption.

Abbreviations: N, number; CI, confidence interval.
### Table S4 Time spent on clinical activities and self-reported health

<table>
<thead>
<tr>
<th>Self-reported health</th>
<th>N</th>
<th>Percent with clinical activities time greater than zero %</th>
<th>Clinical activities (hours per month)</th>
<th>Median and percentile including zero values</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Median (95% CI)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>90th percentile (95% CI)</td>
</tr>
<tr>
<td>Excellent/very good</td>
<td>30</td>
<td>78.6</td>
<td>2.5 (0.2–4.8)</td>
<td>13.2 (0.0–27.1)</td>
</tr>
<tr>
<td>Good</td>
<td>115</td>
<td>87.2</td>
<td>2 (1.1–2.9)</td>
<td>11 (5.8–16.2)</td>
</tr>
<tr>
<td>Poor/fair</td>
<td>464</td>
<td>89.9</td>
<td>3.7 (3.0–4.3)</td>
<td>18 (15.2–20.8)</td>
</tr>
<tr>
<td>Total</td>
<td>611</td>
<td>88.6</td>
<td>3.2 (2.7–3.7)</td>
<td>16.3 (13.5–19.0)</td>
</tr>
</tbody>
</table>

**Note:** Time spent by people managing chronic obstructive pulmonary disease indicates biographical disruption.  
**Abbreviations:** N, number; CI, confidence interval.

### Table S5 Time spent on home activities excluding exercise and self-reported health

<table>
<thead>
<tr>
<th>Self-reported health</th>
<th>N</th>
<th>Percent with home activities time greater than zero %</th>
<th>Home activities excluding exercise(minutes per day)</th>
<th>Median and percentile including zero values</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Median (95% CI)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>90th percentile (95% CI)</td>
<td></td>
</tr>
<tr>
<td>Excellent/very good</td>
<td>30</td>
<td>96.0</td>
<td>7 (2.5–11.4)</td>
<td>30 (0.0–140.7)</td>
</tr>
<tr>
<td>Good</td>
<td>115</td>
<td>93.0</td>
<td>10 (8.2–11.8)</td>
<td>45 (27.5–62.5)</td>
</tr>
<tr>
<td>Poor/fair</td>
<td>464</td>
<td>96.2</td>
<td>20 (16.4–23.6)</td>
<td>90 (74.9–105.1)</td>
</tr>
<tr>
<td>Total</td>
<td>611</td>
<td>95.5</td>
<td>15 (14.0–16.0)</td>
<td>75 (62.4–87.6)</td>
</tr>
</tbody>
</table>

**Note:** Time spent by people managing chronic obstructive pulmonary disease indicates biographical disruption.  
**Abbreviations:** N, number; CI, confidence interval.
CHAPTER 6  TIME USE OF PEOPLE WITH MULTI-MORBIDITY


Abstract

Most Western health systems remain single illness orientated despite the growing prevalence of multi-morbidity. Identifying how much time people with multiple chronic conditions spend managing their health will help policy makers and health service providers make decisions about areas of patient need for support. This article presents findings from an Australian study concerning the time spent on health-related activity by older adults (aged 50 years and over), most of whom had multiple chronic conditions.

A recall questionnaire was developed, piloted, and adjusted. Sampling was undertaken through three bodies: the Lung Foundation Australia (chronic obstructive pulmonary disease (COPD) sub-sample), National Diabetes Services Scheme (Diabetes sub-sample) and National Seniors Australia (NSA) (Seniors sub-sample). Questionnaires were mailed out during 2011 to 10,600 older adults living in Australia. 2,540 survey responses were received and analysed. Descriptive analyses were completed to obtain median values for the hours spent on each activity per month.

The mean number of chronic conditions was 3.7 in the COPD sub-sample, 3.4 in the Diabetes sub-sample and 2.0 in the NSA sub-sample. The study identified a clear trend of increased time use associated with increased number of chronic conditions. Median monthly time use was 5–16 hours per month overall for our three sub-
samples. For respondents in the top decile with five or more chronic the time use was equivalent to two to three hours per day (90th percentile was 80.1 hours per month (CI 60.2–100.0) for the Diabetes sub-sample, 109.5 hours per month (CI 85.7–133.3) for the COPD sub-sample and 71.5 hours per month (CI 34.0–109.0) for the NSA sub-sample), and if exercise is included in the calculations, respondents spent from between five and eight hours per day: an amount similar to full-time work.

Multi-morbidity imposes considerable time burdens on patients. Ageing is associated with increasing rates of multi-morbidity. Many older adults are facing high demands on their time to manage their health in the face of decreasing energy and mobility. Their time use must be considered in health service delivery and health system reform.

**Keywords:** chronic illness; disease; multi-morbidity; multi-morbid; co-morbid; time; time use; health services; public health; Australia; older adult; COPD; diabetes; cancer; arthritis; heart disease; self management

**Introduction**

Research on multi-morbidity (defined as the presence of two or more chronic illnesses in an individual (Valderas et al., 2009)) has shown an increase in its prevalence over the last decade in Australia and elsewhere (Glynn et al., 2011; Holden et al., 2011; Caughey et al., 2008). Recent research has focused on tracking patterns of multi-morbidity (Glynn et al., 2011; Holden et al., 2011; Caughey et al., 2008), prescription medication issues (Roughead et al., 2011; Caughey et al., 2010a; Caughey et al., 2010b), the complexity of providing primary care (Glynn et al., 2011; Gilbert et al., 2011; Soubhi et al., 2010; Bower et al., 2011; Roughead et al., 2011),
co-ordination (Jowsey et al., 2010) and self-management (Morris et al., 2011; Noffsinger and Seiler, 2009).

There is a gap in our knowledge of how people with multi-morbid chronic conditions (multi-morbidity hereafter) use time when undertaking health-related activity (HRA). Recently Krueger (2009) noted that “Failing to take account of patient time leads us to exaggerate the productivity of the health care sector, and to underestimate the cost of health care”. Drawing on the American Time Use Survey, he estimates that in 2007, Americans spent an average of 1.1 hours each week obtaining health care. This time, he argues, is an unseen cost in health care (see also, Jonas et al., 2011; Russell et al., 2007; Russell, 2009). Other studies have measured the use of time as an unseen cost in health care (Jonas et al., 2011; Russell et al., 2007; Russell, 2009). Large surveys such as the American and Australian time use surveys provide limited detail about the time people spend on HRA. Current health care models and clinical guidelines can pose unrealistic expectations in terms of the burden of self-management for people with multi-morbidity; who may be prescribed multiple doses of multiple medications each day, and who may also be undertaking several non-pharmacological activities such as exercise, or attending support groups, rehabilitation services or health care services in any given week (Boyd et al., 2005). Research is needed to address this gap on how people with multi-morbidity spend their time on health care.

**Time to manage: priorities in self-management and HRA**

Management of chronic conditions includes self-management as well as interactions with health services, which together comprise HRA. Knowledge of the self-
management tasks people perform and their duration has the potential to inform the planning and design of services to support efficient self-management and optimal health outcomes (Safford et al., 2005), as well as contributing to an understanding of the overall cost to the community of chronic conditions.

Self-management encompasses a range of tasks including managing the medical aspects of the condition (taking medications, testing), maintaining or changing the ways that necessary or meaningful tasks are completed (maintaining a healthy diet, exercising), and coping with the emotions experienced (Bodenheimer et al., 2002; Corbin and Strauss, 1988). Performing these tasks is time consuming (Jonas et al., 2011; Safford et al., 2005) and is thought to vary between conditions and with severity (Jonas et al., 2011). Few studies have described the characteristics of people who are likely to spend more or less time managing their health (Safford et al., 2005). People with multi-morbidity have management tasks for each condition which can be overwhelming (Safford et al., 2005; cf. Dixon et al., 2009; Boyd et al., 2005).

Patients self-manage because they live with their condition on a daily basis and need to develop strategies to care for themselves (Barlow et al., 2005). A certain amount of time spent on self-management of chronic condition is inevitable and is necessary (Cheffins T. E. et al., 2012; Zwar et al., 2006). Some activities such as taking prescribed medication cannot be delegated to the system unless a person goes into formal care (Morris et al., 2011). Growing evidence supports the effectiveness of self-management to improve health and quality of life outcomes for people with chronic condition (Iversen et al., 2010; Zwar et al., 2006), and a range of programs are available in Australia to support self management (for example, the Chronic
Disease Self Management Program (Lorig et al., 1999) and the Flinders Program (Battersby et al., 2007). Primary health care services are key spaces in which people learn self-management strategies.

In Australia’s health system clinical guidelines, health policies and care pathways have been developed largely in relation to single illnesses and are focused on achieving optimum medical outcomes for single conditions. The efficient use of patient time may be taken into account, for example, in guidelines for cycles of care for people with diabetes that optimise the time period between various tests (Diabetes Australia 2009 National Evidence Based Guidelines for the Management of Type 2 Diabetes). However, when multiple care pathways are brought into play because a patient has multi-morbidity, the impact on patient time will be quantitatively and perhaps qualitatively different.

The social value of time has been addressed by other research (Adam, 1995) and is not addressed in this study. However we do explore the quantum of time used by people with multi-morbidity to allow some consideration of its impact on their lives. The aim of this study was to quantify the time people with multi-morbidity spend on HRA and its relationship with the number of chronic illnesses using data from The Serious and Continuing Illness Policy and Practice Study (SCIPPS), an Australian study that included research on time use and co-ordination.

**Methods**

The survey built on an earlier qualitative study of 61 patients and 17 informal carers, living with chronic illness in the western suburbs of Sydney and the Australian
Capital Territory (Jeon et al., 2010; Jowsey et al., 2009). The survey was piloted, revised, then mailed to the following groups of older Australians: 5,000 members of National Seniors Australia (NSA – a private body of Australians aged 50 and over with 285,000 members); 2,500 registrants on the National Diabetes Services Scheme (NDSS – a government funded service which provides subsidies for diabetes materials with 280,000 registrants aged over 50); and 3,100 members who had chronic obstructive pulmonary disease (COPD) of the Lung Foundation Australia (LFA – a private body which supports people with lung conditions).

The sample drawn from NSA members was stratified by State and age (50–64, 65–74, 75 years and over), with an oversampling of older members to increase the proportions with chronic illness. The sample of registrants aged 50 years or over from the NDSS register, was stratified by State, age (50–59, 60–69, 70–79, 80 years and over) and gender with no oversampling as the scheme operates specifically to subsidise costs for persons with diabetes. Samples were selected using simple random sampling within each stratum. All 3,062 members of Lung Foundation Australia with COPD were surveyed. Estimates are weighted by stratum response rates, and analyses undertaken separately for each sub-sample.

The rationale behind this complex sampling framework was that NSA respondents may provide an overview of the problem in the elderly, whereas NDSS targets patients with diabetes, a condition usually associated with a high burden of co-morbidity (Valderas et al., 2009). The LFA also provides an illness-specific focus. For ease of reading we use the terms ‘COPD sub-sample’ to reference the LFA sample, and ‘Diabetes sub-sample’ to reference the NDSS sample.
Ethics statement

Ethics approval for the survey was obtained from the Australian National University Human Research Ethics Committee (Protocol number: 2010/468) in 2010. All respondents provided informed consent to participate by returning completed questionnaires. As well as taking care over the issues of confidentiality and consent, we were at pains to avoid any additional time burden on the respondents. We therefore tested the length of the questionnaire in the pilot.

Data collection

A questionnaire collected data on time use (see Attachment 1). Recall questionnaires were used in this study rather than diaries to limit the burden of the research on the respondents and to encourage response (Bittman et al., 2005; Safford, 2005; Russell et al., 2008). Time use was defined as the time reportedly spent on any activity in three groups of health-related activities:

1. Activities related to use of medical and allied health services in the previous month; such as making appointments, travelling to health services, waiting in waiting rooms, attending appointments and having medical treatments. These activities are referred to as ‘clinic activities’.

2. Activities related to obtaining information, support or products in the previous month; including attending rehabilitation programs, education programs and support groups, shopping for special foods and looking for/reading health information. These activities are referred to as ‘other activities’.

3. Activities undertaken in domestic spaces on most days (such as time spent on exercising, preparing/consuming prescribed medications, and undertaking tests at home such as blood glucose monitoring). These activities are referred to as ‘home activities’.

The questionnaire also collected data on a range of demographic and other variables including whether people lived in major cities, regional or remote areas, and self-reported use of health services. Australia is a large country where most people live in major cities. The number of chronic diseases was also self-reported, a well-established method for the measurement of multi-morbidity (Huntley et al., 2012). Respondents were asked “Has a doctor ever told you that you had any of the following illnesses?” This was followed by the list of conditions in Table 1 (see also Attachment 1) and allowed for other conditions to be reported under ‘other’.

**Analysis**

Results are presented in terms of hours per month on each activity. As the distribution of time use is highly skewed, results are presented using medians. In order to examine the groups with the highest time use we also examined the time spent by individuals in the top decile of time use. The measure of total time used here excludes exercise unless otherwise stated, as it is not possible to differentiate ‘social’ and ‘health’ exercise. While the majority of respondents spent some time on HRA, many people did not spend time on every specific HRA included in the survey (e.g. attending rehabilitation, preparing special foods). When reporting on more detailed components of time use, we therefore report on both the proportion of people undertaking these tasks, and time spent by those undertaking them. Standard errors
and confidence intervals were derived using bootstrapping techniques within Stata11 (Stata Corp L P, 2009). The Cuzick test for trend was applied for testing trends (Cuzick and Wilcoxon, 1985).

Results

Survey response

Overall 2,540 responses were received reflecting an overall response rate of 24.0%, with 427 respondents in the Diabetes sub-sample (16.8% response), 681 in the COPD sub-sample (22.0% response), and 1,432 in the NSA sub-sample (28.4% response). More details of the response rates are shown in Attachment 2. Details of the socio-demographic and chronic disease characteristics of the three sub-samples (weighted for non-response) are shown in Table 1. As expected almost all (94%) of the members of the Diabetes sub-sample reported that they had diabetes and almost all (90%) of the members of the COPD sub-sample reported having COPD. Of the more general NSA population over 40% had hypertension, 35% had arthritis, and over a quarter reported having ever had cancer. Respondents from the COPD and Diabetes sub-samples had on average more co-morbid conditions than the NSA sample (mean number of chronic conditions is 3.7 for the COPD sub-sample, 3.4 for the Diabetes sub-sample and 2.0 for the NSA sub-sample, with COPD/Diabetes difference significant (p=0.010) and other differences highly significant (p<0.001)). The Diabetes and COPD sub-samples were also prescribed more medications than respondents in the NSA sub-sample (with mean values 4.8, 4.3 and 2.5 respectively, and all differences significant with p<0.001).
Table 1: Socio-demographic and chronic disease characteristics of samples
(Estimates weighted for non-response)

<table>
<thead>
<tr>
<th></th>
<th>Diabetes Sub-sample (N=427)</th>
<th>COPD Sub-sample (N=681)</th>
<th>NSA Sub-sample (N=1,432)</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Percentage of sub-sample population</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
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<td></td>
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<tr>
<td>Male</td>
<td>56.5</td>
<td>42.0</td>
<td>39.9</td>
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<tr>
<td>Female</td>
<td>43.5</td>
<td>58.0</td>
<td>60.1</td>
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<tr>
<td>Less than 60 years</td>
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<td>11.3</td>
<td>26.9</td>
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<tr>
<td>60–69 years</td>
<td>35.6</td>
<td>34.4</td>
<td>49.5</td>
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<td>70–79 years</td>
<td>24.8</td>
<td>37.5</td>
<td>15.3</td>
</tr>
<tr>
<td>80 years and over</td>
<td>14.7</td>
<td>16.9</td>
<td>8.2</td>
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<td>Major Cities of Australia</td>
<td>56.7</td>
<td>58.5</td>
<td>57.6</td>
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<tr>
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<td>29.9</td>
<td>32.5</td>
<td>27.9</td>
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<tr>
<td>Outer Regional Australia</td>
<td>12.0</td>
<td>8.5</td>
<td>11.3</td>
</tr>
<tr>
<td>Remote and Very Remote Australia</td>
<td>1.4</td>
<td>0.5</td>
<td>3.2</td>
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<td>Qualifications</td>
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<td></td>
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<tr>
<td>No qualifications</td>
<td>23.2</td>
<td>18.8</td>
<td>7.4</td>
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<td>Year 9 or year 10 schooling</td>
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<td>26.9</td>
<td>26.0</td>
</tr>
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<td>Year 11 or year 12 schooling</td>
<td>10.2</td>
<td>11.6</td>
<td>9.2</td>
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<tr>
<td>Trade qualification</td>
<td>13.5</td>
<td>11.3</td>
<td>7.2</td>
</tr>
<tr>
<td>Certificate/diploma</td>
<td>17.5</td>
<td>19.2</td>
<td>26.3</td>
</tr>
<tr>
<td>Degree or higher degree</td>
<td>14.5</td>
<td>12.3</td>
<td>23.9</td>
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<tr>
<td>Household Income (Australian dollars)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $20,000 per year</td>
<td>30.7</td>
<td>43.0</td>
<td>10.6</td>
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<tr>
<td>$20–40,000 year</td>
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<td>27.4</td>
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<td>$60–80,000 year</td>
<td>6.8</td>
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<td>13.7</td>
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<td>$80–100,000 year</td>
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<td>1.6</td>
<td>8.8</td>
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<td>$100,000 year or more</td>
<td>9.5</td>
<td>3.3</td>
<td>16.3</td>
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<tr>
<td>Number of chronic conditions ever diagnosed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Zero conditions</td>
<td>1.4</td>
<td>1.0</td>
<td>15.9</td>
</tr>
<tr>
<td>One conditions</td>
<td>12.7</td>
<td>12.0</td>
<td>27.2</td>
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<tr>
<td>Two conditions</td>
<td>25.1</td>
<td>18.3</td>
<td>25.8</td>
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<td>Three conditions</td>
<td>21.2</td>
<td>18.5</td>
<td>14.4</td>
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<td>Four conditions</td>
<td>15.4</td>
<td>19.6</td>
<td>8.1</td>
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<tr>
<td>Five or more conditions</td>
<td>24.1</td>
<td>30.6</td>
<td>8.5</td>
</tr>
<tr>
<td>Number of medications regularly taken</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No medication</td>
<td>6.2</td>
<td>2.8</td>
<td>21.1</td>
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<tr>
<td>One medication</td>
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<td>4.0</td>
<td>17.7</td>
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<td>Two medications</td>
<td>6.7</td>
<td>5.8</td>
<td>17.8</td>
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<td>Three medications</td>
<td>14.1</td>
<td>8.5</td>
<td>12.8</td>
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<tr>
<td>Four medications</td>
<td>16.7</td>
<td>12.9</td>
<td>10.1</td>
</tr>
<tr>
<td>Five medications</td>
<td>13.5</td>
<td>12.2</td>
<td>6.7</td>
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<tr>
<td>Six or more medications</td>
<td>39.1</td>
<td>53.9</td>
<td>14.0</td>
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<td>Conditions ever diagnosed</td>
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<td></td>
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<td>Cancer</td>
<td>24.5</td>
<td>23.8</td>
<td>25.9</td>
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<td>Heart disease</td>
<td>23.9</td>
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<td>12.7</td>
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<td>Hypertension</td>
<td>60.8</td>
<td>42.7</td>
<td>41.9</td>
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<td>Condition</td>
<td>Time Spent (HRA)</td>
<td>Median (Hours)</td>
<td>95% CI (Hours)</td>
</tr>
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<td>-----------------------------------</td>
<td>------------------</td>
<td>----------------</td>
<td>----------------</td>
</tr>
<tr>
<td>Stroke</td>
<td>8.9</td>
<td>6.0</td>
<td>3.0</td>
</tr>
<tr>
<td>Diabetes Mellitus</td>
<td>93.6</td>
<td>11.4</td>
<td>11.5</td>
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<td>Kidney disease</td>
<td>8.0</td>
<td>4.9</td>
<td>3.5</td>
</tr>
<tr>
<td>Asthma or hay fever</td>
<td>18.5</td>
<td>37.4</td>
<td>19.1</td>
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<tr>
<td>Chronic Obstructive Pulmonary</td>
<td>Disease</td>
<td>5.1</td>
<td>89.5</td>
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<tr>
<td>Arthritis</td>
<td>34.2</td>
<td>37.6</td>
<td>35.0</td>
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<tr>
<td>Osteoporosis</td>
<td>9.0</td>
<td>30.8</td>
<td>10.1</td>
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<tr>
<td>Chronic pain, including back pain</td>
<td>25.3</td>
<td>31.2</td>
<td>19.5</td>
</tr>
<tr>
<td>Depression or anxiety</td>
<td>20.4</td>
<td>28.0</td>
<td>17.4</td>
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<tr>
<td>Other mental health condition</td>
<td>5.0</td>
<td>2.6</td>
<td>1.4</td>
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</table>

**Time spent on HRA**

The time spent on HRA by people in the different demographic and health categories is shown in Table 2 (respondents who spent no time on HRA are included). The reported total median time use per month on HRA excluding exercise was 11.1 hours (95% confidence interval (CI) of 9.3–12.8 hours) for the Diabetes sub-sample, 16.5 (14.7–18.3) hours per month for the COPD sub-sample, and 5.2 (4.7–5.6) hours per month for the NSA sub-sample.

There are few significant differences in time use between age, region, qualifications and income categories although some weak patterns are apparent. The one really clear set of statistically significant time relationships across all three sub-samples is with number of conditions. The number of conditions is related to time use in all three sub-samples and is highly significant in all samples ($p<0.001$ using the Cuzick test for trend (Cuzick and Wilcoxon, 1985)). An alternate view of health care complexity is to look at the number of medications taken, particularly since some of the time components relate to medication management. The patterns are broadly in the expected direction for the targeted samples, with the unexpected values for those in small sample categories, and the Cuzick test again shows a very strong relationship ($p<0.001$) between number of medications and time reported for each sample.
Table 2: Time spent on HRA across sub-samples
(p values to test for trend using the Cuzick trend test)

<table>
<thead>
<tr>
<th></th>
<th>Diabetes Sub-sample (N=427)</th>
<th>COPD Sub-sample (N=681)</th>
<th>NSA Sub-sample (N=1,432)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Median Times reported in hours per month (95% CI)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Respondents who spent no time on HRA are included</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total time</td>
<td>11.1 (9.0–13.2)</td>
<td>16.5 (14.7–18.3)</td>
<td>5.2 (4.7–5.6)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>11.0 (8.1–13.9)</td>
<td>17.7 (14.2–21.2)</td>
<td>4.8 (4.0–5.6)</td>
</tr>
<tr>
<td>Female</td>
<td>11.1 (7.5–14.7)</td>
<td>15.9 (13.4–18.4)</td>
<td>5.3 (4.8–5.9)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 60 years</td>
<td>13.8 (9.1–18.4)</td>
<td>28.0 (17.3–38.7)</td>
<td>5.0 (3.3–6.7)</td>
</tr>
<tr>
<td>60–69 years</td>
<td>10.3 (7.0–13.6)</td>
<td>16.3 (13.4–19.3)</td>
<td>4.5 (3.8–5.2)</td>
</tr>
<tr>
<td>70–79 years</td>
<td>10.6 (6.7–14.5)</td>
<td>17.5 (14.6–20.4)</td>
<td>5.3 (4.5–6.2)</td>
</tr>
<tr>
<td>80 years and over</td>
<td>10.0 (4.2–15.8)</td>
<td>11.9 (6.9–17.0)</td>
<td>8.7 (6.4–11.0)</td>
</tr>
<tr>
<td><strong>Test for trend (p-value)</strong></td>
<td>0.544</td>
<td>0.005</td>
<td>&lt;0.001</td>
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<td><strong>Region</strong></td>
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<td></td>
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<tr>
<td>Major Cities of Australia</td>
<td>10.5 (7.8–13.2)</td>
<td>16.5 (14.0–19.0)</td>
<td>5.4 (4.8–6.0)</td>
</tr>
<tr>
<td>Inner Regional Australia</td>
<td>12.5 (9.6–15.4)</td>
<td>17.6 (14.1–21.1)</td>
<td>4.8 (3.9–5.8)</td>
</tr>
<tr>
<td>Outer Regional Australia</td>
<td>15.0 (8.1–21.9)</td>
<td>17.5 (10.6–24.4)</td>
<td>3.7 (1.5–5.8)</td>
</tr>
<tr>
<td>Remote and Very Remote Australia</td>
<td>NA</td>
<td>NA</td>
<td>5.2 (0.5–9.9)</td>
</tr>
<tr>
<td><strong>Test for trend (p-value)</strong></td>
<td>0.711</td>
<td>0.984</td>
<td>0.473</td>
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<tr>
<td><strong>Qualifications</strong></td>
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<td></td>
<td></td>
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<tr>
<td>No qualifications</td>
<td>7.6 (3.0–12.2)</td>
<td>13.5 (9.3–17.7)</td>
<td>4.5 (1.4–7.6)</td>
</tr>
<tr>
<td>Year 9 or year 10 schooling</td>
<td>10.3 (6.1–14.4)</td>
<td>16.5 (12.0–21.0)</td>
<td>5.1 (4.1–6.1)</td>
</tr>
<tr>
<td>Year 11 or year 12 schooling</td>
<td>13.6 (7.7–19.5)</td>
<td>15.0 (9.6–21.4)</td>
<td>6.0 (3.9–8.1)</td>
</tr>
<tr>
<td>Trade qualification</td>
<td>10.5 (5.7–15.3)</td>
<td>23.0 (17.6–28.4)</td>
<td>4.3 (1.8–6.7)</td>
</tr>
<tr>
<td>Certificate/diploma</td>
<td>16.3 (11.7–21.0)</td>
<td>16.0 (12.7–19.3)</td>
<td>5.7 (4.7–6.6)</td>
</tr>
<tr>
<td>Degree or higher degree</td>
<td>18.5 (9.3–27.7)</td>
<td>21.3 (12.4–30.0)</td>
<td>4.3 (2.9–5.7)</td>
</tr>
<tr>
<td><strong>Test for trend (p-value)</strong></td>
<td>0.011</td>
<td>0.025</td>
<td>0.678</td>
</tr>
<tr>
<td><strong>Household Income (Australian dollars)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $20,000 per year</td>
<td>10.3 (6.8–13.8)</td>
<td>18.3 (15.5–21.1)</td>
<td>8.5 (6.2–10.8)</td>
</tr>
<tr>
<td>$20–40,000 per year</td>
<td>10.5 (6.2–14.8)</td>
<td>15.6 (11.4–19.8)</td>
<td>6.0 (4.8–7.2)</td>
</tr>
<tr>
<td>$40–60,000 per year</td>
<td>12.5 (7.0–18.0)</td>
<td>18.0 (13.5–22.5)</td>
<td>4.0 (2.7–5.3)</td>
</tr>
<tr>
<td>$60–80,000 per year</td>
<td>9.0 (3.3–14.7)</td>
<td>12.3 (5.2–19.5)</td>
<td>4.75 (2.9–6.6)</td>
</tr>
<tr>
<td>$80–100,000 per year</td>
<td>10.8 (0.5–21.0)</td>
<td>NA</td>
<td>2.8 (1.5–4.2)</td>
</tr>
<tr>
<td>$100,000 per year or more</td>
<td>15.0 (6.2–23.8)</td>
<td>19.5 (0–41.4)</td>
<td>5.0 (4.0–6.0)</td>
</tr>
<tr>
<td><strong>Test for trend (p-value)</strong></td>
<td>0.332</td>
<td>0.439</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td><strong>Number of chronic conditions ever diagnosed</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Zero conditions</td>
<td>NA**</td>
<td>NA**</td>
<td>1.4 (0.8–2.0)</td>
</tr>
<tr>
<td>One conditions</td>
<td>5.8 (0.7–10.8)</td>
<td>13.3 (8.6–18.1)</td>
<td>3.0 (2.7–3.3)</td>
</tr>
<tr>
<td>Two conditions</td>
<td>6.6 (4.3–8.9)</td>
<td>12.8 (7.5–18.0)</td>
<td>4.9 (4.3–5.5)</td>
</tr>
<tr>
<td>Three conditions</td>
<td>11.4 (9.2–13.7)</td>
<td>13.8 (10.6–17.1)</td>
<td>10.2 (8.9–11.4)</td>
</tr>
<tr>
<td>Four conditions</td>
<td>16.0 (9.5–22.5)</td>
<td>15.7 (12.0–19.3)</td>
<td>9.5 (6.6–12.4)</td>
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</tbody>
</table>
### Components of HRA

As shown in Table 3 almost all respondents spent some time on HRA. People in the COPD sub-sample were most likely to spend time on HRA (97.8% for COPD sub-sample, 95.1% for Diabetes sub-sample and 92.6% for NSA sub-sample). Time use was significantly the highest in the COPD sub-sample (p=0.017 compared the Diabetes sub-sample and p<0.001 compared with NSA sub-sample). The median time spent on HRA by those who spent time on it was also significantly higher (p<0.001 compared to both other both samples) for the COPD sub-sample (17.5 hours per month) than the Diabetes sub-sample (12.3 hours per month) or the NSA sub-sample (6.0 hours per month).
Table 3: Structure of time use: reported activities and median time spent on each

<table>
<thead>
<tr>
<th>Activity Type</th>
<th>Diabetes Sub-sample</th>
<th>COPD Sub-sample</th>
<th>NSA Sub-sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage reporting the activity</td>
<td>(Estimates and 95% CI)</td>
<td>(Estimates and 95% CI)</td>
<td>(Estimates and 95% CI)</td>
</tr>
<tr>
<td>Home activities excluding exercise</td>
<td>91.2 (88.3–94.1)</td>
<td>94.5 (92.7–96.3)</td>
<td>76.4 (74.0–78.7)</td>
</tr>
<tr>
<td>Home activities including exercise</td>
<td>93.2 (91.2–95.4)</td>
<td>96.2 (94.8–97.7)</td>
<td>92.4 (90.9–93.8)</td>
</tr>
<tr>
<td>Clinic activities</td>
<td>82.4 (78.3–86.6)</td>
<td>87.8 (85.4–90.3)</td>
<td>76.7 (74.8–78.7)</td>
</tr>
<tr>
<td>Other activities</td>
<td>80.8 (76.9–84.8)</td>
<td>84.6 (81.5–87.7)</td>
<td>75.2 (73.3–77.1)</td>
</tr>
<tr>
<td>Total time excluding exercise</td>
<td>95.1 (93.1–97.1)</td>
<td>97.8 (96.7–98.8)</td>
<td>92.6 (91.4–93.8)</td>
</tr>
<tr>
<td>Total time including exercise</td>
<td>95.5 (94.0–97.1)</td>
<td>98.3 (97.4–99.2)</td>
<td>96.4 (95.4–97.4)</td>
</tr>
</tbody>
</table>

Median Time spent by those spending time on these activities (hours per month)

<table>
<thead>
<tr>
<th>Activity Type</th>
<th>Diabetes Sub-sample</th>
<th>COPD Sub-sample</th>
<th>NSA Sub-sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage reporting the activity</td>
<td>(Estimates and 95% CI)</td>
<td>(Estimates and 95% CI)</td>
<td>(Estimates and 95% CI)</td>
</tr>
<tr>
<td>Home activities excluding exercise</td>
<td>7.5 (6.3–8.7)</td>
<td>7.5 (6.7–8.3)</td>
<td>3.0 (2.5–3.5)</td>
</tr>
<tr>
<td>Home activities including exercise</td>
<td>20.5 (17.6–23.6)</td>
<td>22.5 (21.1–23.9)</td>
<td>18.0 (17.1–18.9)</td>
</tr>
<tr>
<td>Clinic activities</td>
<td>2.2 (1.9–2.5)</td>
<td>4.0 (3.3–4.6)</td>
<td>2.4 (2.2–2.6)</td>
</tr>
<tr>
<td>Other activities</td>
<td>1.0 (0.76–1.24)</td>
<td>2.0 (1.6–2.4)</td>
<td>0.7 (0.5–0.8)</td>
</tr>
<tr>
<td>Total time excluding exercise</td>
<td>12.25 (10.0–14.5)</td>
<td>17.5 (15.5–19.5)</td>
<td>6.0 (5.6–6.4)</td>
</tr>
<tr>
<td>Total time including exercise</td>
<td>26.2 (22.6–29.7)</td>
<td>31.5 (29.5–33.5)</td>
<td>23.0 (21.3–24.7)</td>
</tr>
</tbody>
</table>

Median Times reported in hours per month across all respondents (Estimates and 95% CI)

<table>
<thead>
<tr>
<th>Activity Type</th>
<th>Diabetes Sub-sample</th>
<th>COPD Sub-sample</th>
<th>NSA Sub-sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage reporting the activity</td>
<td>(Estimates and 95% CI)</td>
<td>(Estimates and 95% CI)</td>
<td>(Estimates and 95% CI)</td>
</tr>
<tr>
<td>Home activities excluding exercise</td>
<td>6.0 (4.6–7.4)</td>
<td>7.5 (6.8–8.2)</td>
<td>1.5 (1.0–2.0)</td>
</tr>
<tr>
<td>Home activities including exercise</td>
<td>19.0 (16.2–21.8)</td>
<td>21.0 (19.3–22.7)</td>
<td>16.5 (15.9–17.1)</td>
</tr>
<tr>
<td>Clinical visits</td>
<td>1.7 (1.4–1.9)</td>
<td>3.0 (2.5–3.5)</td>
<td>1.5 (1.3–1.7)</td>
</tr>
<tr>
<td>Other activities</td>
<td>0.5 (0.4–0.6)</td>
<td>1.5 (1.2–1.8)</td>
<td>0.3 (0.3–0.4)</td>
</tr>
<tr>
<td>Total time excluding exercise</td>
<td>11.1 (9.0–13.2)</td>
<td>16.5 (14.7–18.3)</td>
<td>5.2 (4.7–5.6)</td>
</tr>
<tr>
<td>Total time including exercise</td>
<td>25.8 (22.0–29.5)</td>
<td>31.2 (29.1–33.2)</td>
<td>21.7 (20.3–23.0)</td>
</tr>
</tbody>
</table>

Note: These numbers do not add to the totals as each percentage or median is based on a different group of people who have provided valid responses.

Table 3 also shows that, excluding exercise, median time spent by all people in the COPD sub-sample (i.e. including those with zero time) and the Diabetes sub-sample on daily home activities was significantly higher (p<0.001) than the time spent on clinical activities or “other” activities. People in the Diabetes sub-sample spent 6.0 hours in the past month on daily activities compared to 1.7 hours on clinic activities.

People in the COPD sub-sample spent 7.5 hours on daily activities compared to 3.0 hours on clinic activities. People in the NSA sub-sample spent the same amount of time on daily activities as on clinic activities, but spent less time on the ‘other’
activities. People in the NSA sub-sample were less likely to spend time on all categories than people in the other sub-samples (with differences significant at $p<0.001$) except the estimated clinic time use for the Diabetes sub-sample and NSA sub-sample were not significantly different). For example the median time spent on daily activities was only 1.5 hours per month compared to the 6.0 and 7.5 hours per month referred to above.

The reported total median hours (95% CI) on HRA including exercise were 25.8 (22.0–29.5) hours per month for the Diabetes sub-sample, 31.2 (29.1–33.2) hours for the COPD sub-sample, and 21.7 (20.3–23.0) hours for the NSA sub-sample. Exercise therefore on average added 14–16 hours per month to median activity, or around half an hour per day. It roughly doubled the estimated median time spent on HRA for the targeted samples and quadrupled it for the NSA sub-sample. Sixteen percent of the NSA sub-sample undertook exercise but no other daily HRA, while there were very few such people in the other samples as nearly all were engaged in some other daily HRA.

**Time use for the highest time users**

To provide an alternate perspective Table 4 provides the distribution of times for each sub-sample. As can be seen in Table 4, 5.6% of those in the COPD sample reported spending more than 100 hours per month on HRA. Table 5 provides the 90th percentile times showing the total time used (excluding exercise) by the top 10% of the population in each of these categories. The top 10% of time users spent over 51.4 (43.0–59.8) hours per month in the Diabetes sub-sample, over 62.6 (53.5–71.7) hours per month in the COPD sub-sample, and over 34.1 (30.7–37.5) hours per month in
the NSA sub-sample on HRA. However, those people with five or more conditions spent 30 to 40 hours per month more than that, with those in the top quintile of the COPD sample who had five or more conditions spending more than 109.5 (85.7–133.3) hours per month which is equivalent to 3.5 hours per day on managing their conditions.

Table 4: Distribution of Total time use by sample component

<table>
<thead>
<tr>
<th>Total time use (hours per month)</th>
<th>Diabetes Sub-sample</th>
<th>COPD Sub-sample</th>
<th>NSA Sub-sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nil</td>
<td>4.9</td>
<td>2.1</td>
<td>7.4</td>
</tr>
<tr>
<td>20 Hours or less</td>
<td>64.1</td>
<td>53.3</td>
<td>73.2</td>
</tr>
<tr>
<td>20–40 hours</td>
<td>16.0</td>
<td>25.9</td>
<td>11.3</td>
</tr>
<tr>
<td>40–60 Hours</td>
<td>7.4</td>
<td>8.1</td>
<td>3.6</td>
</tr>
<tr>
<td>60–80 Hours</td>
<td>2.7</td>
<td>3.6</td>
<td>1.9</td>
</tr>
<tr>
<td>80–100 Hours</td>
<td>2.8</td>
<td>1.3</td>
<td>0.7</td>
</tr>
<tr>
<td>100 Hours or more</td>
<td>2.1</td>
<td>5.6</td>
<td>1.9</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>100.0</strong></td>
<td><strong>100.0</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

Table 5: Total time use by top 10% in each category by number of chronic illnesses and sample component (the top 10% in each category use more time each month than the 90th percentiles reported below)

<table>
<thead>
<tr>
<th>Number of chronic illnesses</th>
<th>Diabetes Sub-sample</th>
<th>COPD Sub-sample</th>
<th>NSA Sub-sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>NA</td>
<td>NA</td>
<td>19.3(8.7–29.8)</td>
</tr>
<tr>
<td>1</td>
<td>26.2(16.0–36.4)</td>
<td>40.0(11.0–69.0)</td>
<td>23.0(15.4–30.6)</td>
</tr>
<tr>
<td>2</td>
<td>36.1(20.8–51.4)</td>
<td>43.5(34.2–57.8)</td>
<td>31.0(23.4–38.6)</td>
</tr>
<tr>
<td>3</td>
<td>41.5(28.9–54.1)</td>
<td>44.0(33.7–54.3)</td>
<td>37.5(30.6–44.4)</td>
</tr>
<tr>
<td>4</td>
<td>83.0(45.0–121.0)</td>
<td>56.3(41.0–71.6)</td>
<td>44.5(27.1–61.9)</td>
</tr>
<tr>
<td>5 or more</td>
<td>80.1(60.2–100.0)</td>
<td>109.5(85.7–133.3)</td>
<td>71.5(34.0–109.0)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>51.4(43.0–59.8)</td>
<td>62.6(53.5–71.6)</td>
<td>34.1(30.7–37.5)</td>
</tr>
</tbody>
</table>
Discussion

This study has been the first to quantify the time spent on HRA by older Australians with multi-morbidity. The study found that the more chronic illnesses a person had the more time they spent managing their health (especially if they had COPD). Median total time spent in the past month on HRA (excluding exercise) was 16.5 hours for people in the COPD sub-sample, 11.1 hours for people in the Diabetes sub-sample, and 5.2 hours for people in the NSA sub-sample. People in the top 10% of time use from the COPD sub-sample spent 62.6 hours per month or more on HRA, the top 10% of the Diabetes sub-sample spent 51.4 hours per month or more, and the top 10% of the NSA sub-sample spent at least 34.1 hours per month. Within all sub-samples the time increased with increasing co-morbidity, with estimates of 109.5, 80.1 and 71.5 hours per month for people with five or more conditions in the COPD, Diabetes and NSA sub-samples respectively.

The significantly higher total time for the COPD sub-sample is likely to be due to two factors: 1) that people in this sub-sample had on average more conditions than those in the other sub-samples, and 2) the time demands associated with COPD are higher than many other conditions.

The number of prescribed medications a person takes is also a major and significant determinant of time use, and while numbers of conditions and numbers of medications are clearly correlated they potentially have independent effects on time use. These findings are consistent with our previous qualitative research showing the constraints that multi-morbidity place on the way people spend their time (Jeon et al., 2010).
While the study shows median monthly time use of 5–16 hours per month overall for our three sub-samples, which are not excessive time demands, the demands on those with multi-morbidity become much larger, and people in the top decile of those with five or more conditions face time demands (at the median) equivalent to two to three hours per day. For people with five or more conditions it may be reasonable to assume that exercise is largely ‘health based’ as many of these people will be restricted by their multiple conditions. Under this assumption, the 90th percentile for people with five or more conditions is another 30–40 hours per month – 110.1 hours, 147.5 hours and 118.5 hours for the Diabetes, COPD and NSA sub-samples respectively. These times are equivalent to between 3.5 and almost five hours per day on average. This means that people with the highest number of conditions in the 90th percentile were spending between 5.5 and eight hours each day on HRA.

The study described the median times spent on HRAs either with health services or at home. A gradation of time use for HRA was found with most of the time used for home activities, followed by time used for clinic activities and the least time used for other health activities such as shopping for medicines or attending rehabilitation.

While it is not surprising that the study shows that the factors determining time use relate to health it is interesting that other factors do not seem to be material (in particular whether the person lives in a capital city or elsewhere – where travel time costs might have been expected to be important).
Implications for self-management policy and health service delivery

This first study into time use on HRA undertaken by Australians with chronic conditions has shown that illness management occupies considerable time for those with multi-morbidity. These data cannot identify how much of this time is spent on activities which are unnecessary or inefficient (perhaps due to lack of co-ordination). It is clear, however, that clinicians assisting patients with multi-morbidity need to be aware of the time demands made of patients. Options for reducing this demand may include instigating better co-ordination for booking consultations, identifying methods for reducing waiting times, improving support for self-management activities (Harrison et al., 2012), and using straightforward strategies such as pre-packed blister packs for medications or other dose administration aids (DOA). In Australia, pharmacists can dispense medications in DOA, but at an additional cost to the patient that is not presently covered by the Pharmaceutical Benefits Scheme.

On a larger scale, under the current Australian health system reform, strategies are underway to improve team care and care co-ordination (see for example, Jowsey et al., 2010; National Health and Hospitals Reform Commission, 2009; Black et al., 2012; Anstey et al., 2012). This study provides empirical evidence of the importance of such strategies in terms of decreasing time burdens on people with multi-morbidity. However, as Anstey and colleagues have observed, some approaches to reducing time burdens on both health professionals and patients can have unintentional consequences and the drivers and facilitators of change must be considered carefully. On this matter, Anstey argues that approaches in Australia can learn a lot from those undertaken in other health systems (Anstey et al., 2012).
Finally, for a given level of multi-morbidity, some combinations of illnesses are likely to be associated with higher levels of HRA than others, depending on the concordance or discordance of the illnesses (see Valderas et al., 2009). This issue has not been addressed in this study, and as there are not large differences between time use for particular index illnesses, cluster analysis is likely to be a complex task and will be addressed in a later report.

**Study limitations**

This study had a relatively low response rate, and because of its tripartite structure had relatively small samples in each group. It is possible that people with poor health may have been deterred from responding to the survey and if this is the case then the reported time use may under-estimate the real costs. The Diabetes and COPD sub-samples had lower response rates than the NSA sub-sample. However, as shown in Attachment 2 while response rates varied there were no obvious biases in the non-response, and the usage of the separate samples permitted study of significant numbers of people with diabetes and with COPD.

The study used a recall questionnaire rather than a time use diary to minimise inconvenience to respondents and to extend the period over which the time use could be explored. While there is a known risk of inaccurate recall associated with questionnaires (Dumont et al., 2010) our recent literature review found that they have been utilised in chronic illness research more often than diaries (Jowsey et al., 2012).

This study has demonstrated that the time people spend on HRA is substantial and identified a strong gradient in time demands and levels of illness. However, many questions remain unanswered. An important question is how people prioritise their
health activities against other activities within the fixed amount of time available each day. Deciding how much time a person spends on their health may depend on time scarcity, practical issues and issues of personal prioritisation (Strazdins et al., 2011). Those with multiple conditions or disabilities may also find that they are very slow in performing some of the tasks. Personal prioritisation may also be used to make a conscious decision as to whether a social activity will be attended rather than completing a health activity. Russell and colleagues note that “some tasks are more important for certain patients than others” (2008:55) and this study suggests that further more detailed work is required to understand how these decisions are taken.

The study has not captured fluctuations of time use associated with the trajectory of particular conditions. Nor, as also noted above, did the study capture the opportunity costs; the social time costs that are incurred through the chronic illness time costs (Krueger, 2009). To address these problems qualitative research should be undertaken, exploring which options are available to people concerning their time use, which choices people make, and the motivations behind such choices.

**Conclusion**

Increasing numbers of chronic conditions are significantly associated with increasing time spent on HRA. On average, people in this study who only had one chronic condition spent between three and 13 hours each month on HRA, depending on the sub-sample. However, people with five or more chronic conditions spent on average between 16 and 27 hours each month on HRA, depending on the sub-sample. For those in the top decile of people with five or more chronic conditions in the COPD sub-sample the time spent on HRA was as high as 110 hours. Increasing numbers of
prescribed medications is also significantly associated with increasing time spent on HRA. We suggest that in planning future self-management programs, health care services and health policies, considerations be made in terms of patient time use; the costs and benefits to people with multi-morbidity, who may be experiencing significant constraints on their time and changes to the way they use and value that time.
Attachment 1: The work of chronic illness time use survey

This attachment is presented as Appendix 2 at the end of the thesis.

Attachment 2: Response rates and population comparisons

*National Diabetes Services Scheme*

<table>
<thead>
<tr>
<th>Age</th>
<th>Gender</th>
<th>Response rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>50–59</td>
<td>Male</td>
<td>11.5%</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>18.2%</td>
</tr>
<tr>
<td>60–69</td>
<td>Male</td>
<td>17.3%</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>20.4%</td>
</tr>
<tr>
<td>70–79</td>
<td>Male</td>
<td>18.7%</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>14.9%</td>
</tr>
<tr>
<td>80–89</td>
<td>Male</td>
<td>17.5%</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>8.3%</td>
</tr>
<tr>
<td>All ages</td>
<td>Male</td>
<td>16.7%</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>16.2%</td>
</tr>
<tr>
<td>Total</td>
<td>Total</td>
<td>16.8%</td>
</tr>
</tbody>
</table>

*Australian Lung Foundation*

<table>
<thead>
<tr>
<th>Gender</th>
<th>Response rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>23.7%</td>
</tr>
<tr>
<td>Females</td>
<td>20.4%</td>
</tr>
<tr>
<td>Total</td>
<td>22.0%</td>
</tr>
</tbody>
</table>

*National Seniors Australia*

<table>
<thead>
<tr>
<th>Age group</th>
<th>Response rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>50–64</td>
<td>23.2%</td>
</tr>
<tr>
<td>65–74</td>
<td>33.6%</td>
</tr>
<tr>
<td>75 and over</td>
<td>27.4%</td>
</tr>
<tr>
<td>Total</td>
<td>28.4%</td>
</tr>
</tbody>
</table>
CHAPTER 7  
TIME USE OF INFORMAL CARERS


Abstract

Little is known about the time spent on specific health-related activities by older adult informal carers who assist people with chronic illness. Research has not yet addressed the association between carer health status and their care demands. Such information could inform policy and health system efforts to manage chronic illness.

We conducted an Australia wide survey using recall questionnaires to record time use. The study asked how much time is spent on ‘most days’ for the most common activities like taking medication, self-treatment and testing, and how much time in the last month on less common activities like attending a physician or shopping associated with health needs. The survey was mailed to 5,000 members of National Seniors Australia; 2,500 registrants on the National Diabetes Services Scheme; and 3,100 members of the Australian Lung Foundation. A total of 2,519 people responded, including 330 people who identified as informal carers. Statistical analysis was undertaken using Stata 11. Standard errors and confidence intervals were derived using bootstrapping techniques within Stata 11.

Most carers (96.2%) had chronic illness themselves, and those with greater numbers of chronic illnesses were those who faced the greatest overall time demands. The top decile of carers devoted between 8.5 and 10 hours a day to personal and caring health-related activities. Informal carers with chronic illness spent more time
managing their own health than people with chronic illness who were not informal carers. These carers spent more time on caring for others than on caring for their own health. High levels of caring responsibility were associated with poorer reported carer health. Policy and health care services will need to adapt to recognise and reduce the time burden on carers who themselves have chronic illness. More carefully targeted investment in the social infrastructure of formal care would free up carers for other activities (including their own care) and holds the potential to improve the quality of life as well as the health outcomes of this population.

**Keywords:** carer; informal care; health services; respite; chronic illness; long term condition; chronic disease; time; time use; Australia; health-related activities

**Background**

It is no secret that ageing populations and rapidly increasing rates of chronic illness are creating unprecedented pressure on health and social support systems in all industrialised countries, often exacerbated by health care workforce insufficiencies. Health policy responses have included, among other things, increased discourse and support for patient self-management (Commonwealth of Australia, 2011:7; National Health and Hospitals Reform Commission, 2009); which in practice often implicates family members and friends (‘carers’ hereafter) of people with chronic illness (Essue et al., 2010; Yen et al., 2011; DeJonge et al., 2009). Carers become a key source of care, supported, as the functional ability of the care recipient decreases, by a range of visiting services such as the Home Care Support Program in Canada (Dunbrack, 2003) and the Home and Community Care Program in Australia (Commonwealth of Australia, 2012).
Australian and international studies have suggested that caring activities can be very demanding and can adversely affect carer health (Essue et al., 2010; Knutson et al., 2006). Higher levels of carer burden are matched by lower self-perceived health status than non-carers and increased prevalence of cognitive impairment (Buyck et al., 2011). Informal caring can be stressful (Aranda, 1997; Cain and Newsome Wicks, 2000; Essue et al., 2010) and can lead to deterioration in physical and psychological health (Gallagher et al., 1989; Kenny et al., 2010; Navaie-Waliser et al., 2002; Christakisa and Iwashynab, 2003; Tommis et al., 2009). In the United States, Miller and colleagues have observed that carers “must also cope with their own health problems, typically exacerbated by their caregiving responsibilities” (Miller et al., 2008:2). Nonetheless, carers are relied upon to provide substantial levels of unpaid support including to those with chronic illness.

Creating support strategies for carers relies on understanding the work they do and their areas of need (Candy et al., 2011; Commonwealth of Australia, 2011; McNamara and Rosenwax, 2010). In our earlier qualitative study people living with chronic illness reported the types of care activities undertaken and they suggested that further health service and policy support, including carer respite, would help (Essue et al., 2010). That study did not measure the quantum of caring tasks undertaken. Informal care activities usually include health and personal services, household chores, running errands, and providing emotional, social and psychological support as well as the organisation and transport to formal care appointments (Dumont et al., 2010; Essue et al., 2010).
The components of carers’ work have been studied only in broad terms in Australia and elsewhere (see for example, Australian Bureau of Statistics, 2009b). Such studies have reported that carers spend considerable amounts of time dedicated to caring activities but studies have not sought to differentiate between the care activities provided for care recipients with chronic illness from those with other functional impairments. Australian surveys of informal care have told us little about the component activities of time spent caring, and in particular about time spent on specific health-related activities (HRA). For example, Bittman and Thomson’s (2000) Australian study of informal carer time use (which includes chronic illness care as well as parent care of children with mental and physical impairments), reported that an average of around five hours per week was spent in care-related activities. A subsequent study, which adjusted the estimates from the 1997 Australian Time Use Survey, found that the median time spent by informal carers is around an hour and a half per day (or 10.5 hours per week) (Bittman et al., 2005). Bittman and colleagues also reported that carers of people with a functional impairment (including but not limited to impairments related to chronic illness) spend considerably more time engaging in cooking and cleaning activities than non-carers (Bittman et al., 2004). However, they give no specific information about the time spent on other care-related activities.

As with the Australian studies reported above, time use studies in North America have shown that while some people experienced high time burdens associated with providing care, the median time spent was 78–115 minutes a day (Russell et al., 2007; 2008). However these studies do not report which people might face the greatest time demands nor the magnitude of those time demands. Finally the
literature does not report the health status or the care needs of carers and whether their own chronic illness means they spend more time on caring than carers without this extra burden. We suggest that gaps remain in knowledge about the daily ‘work’ of caring for someone with a chronic illness (Kenny et al., 2010; Corbin and Strauss, 1985), in particular when the carer has their own health problems to manage.

This study addresses some of these gaps. We use survey findings from an Australian study of older adults to explore the time spent on HRA, as distinct from normal household activity, that is associated both with caring for another and with self-management. We suggest that HRA comprises the work of managing illness that is additional to normal activities of daily living; such as navigation and interaction with health care services, managing medications, and maintaining a healthy diet (Corbin and Strauss, 1985). We report how much work carers undertake by both activity type and time.

First, in order to measure the work of caring for people with chronic illness we explore the composition of health-related caring and self-management activity. Second, we examine time spent on HRA by people with chronic illness, both in relation to managing their own health and in relation to managing the health of someone they care for. The relationship between time spent on own health and on caring is detailed. We also examine some of the details of the time spent on specific HRA to observe where the greatest demands lie, and further look at those who spend the most time on caring-HRA to examine how great the demands on these groups of people may be.
Methods

A mail survey was carried out; “How much work is involved in looking after your health?” It built on an earlier qualitative study of people, both patients and carers, living with chronic illness in the western suburbs of Sydney and the Australian Capital Territory (Jeon et al., 2010).

Sample design

The sample was drawn from three sub-populations of older Australians. National Seniors Australia (NSA) is a member organisation of Australians aged 50 and over with 285,000 members from which a sample of 5,000 people was drawn. NSA broadly represents the older Australian community (McRae et al., 2012), and does not contain a large number of people who are seriously ill. To increase the sample of people with more severe chronic illness, older people were oversampled from this population. Further samples were drawn from the National Diabetes Services Scheme (NDSS), a government funded service which provides subsidies for diabetes materials with 280,000 of its registrants aged over 50 years (sample size 2,500) and the Lung Foundation Australia (LFA), a member organisation which supports research into lung conditions and provides member support (sample of all 3,109 persons with chronic obstructive pulmonary disease (COPD) or who supported a person with COPD. Almost all people in this group were aged over 50 years). For ease of reading we use the terms ‘Lung sub-sample’ to reference the LFA sample, and ‘Diabetes sub-sample’ to reference the NDSS sample.

Questionnaire design

Time use was defined as the time reportedly spent on any of three health-related activities:
1. Activities related to use of medical and allied health services in the previous month; such as making appointments, travelling to health services, waiting in waiting rooms, attending appointments and having medical treatments. These activities are referred to as ‘clinic activities’.

2. Activities related to obtaining information, support or products in the previous month; including attending rehabilitation programs, education programs and support groups, shopping for special foods and looking for/reading health information. These activities are referred to as ‘other activities’.

3. Activities undertaken in domestic spaces on most days (such as time spent on exercising, preparing/consuming prescribed medications, and undertaking tests at home such as blood glucose monitoring). These activities are referred to as ‘home activities’.

The questionnaire also collected demographic data (including age, gender, Indigenous status, region of birth, whether speaking English at home, postcode, number in household, household income, marital status, employment status, and highest qualification); and self-reported use of health services. The socio-economic status of each respondent was indicated by the Index of Relative Socio-Economic Disadvantage for the postcode in which they lived, which was drawn from the ABS Census 2006 (Australian Bureau of Statistics, 2006b).

Two standard measures of self-assessed health were included in the survey (the SF12 and EQ5D). Respondents provided information about the time spent on HRA in relation to their own health, and then on HRA related to the health of the person/persons for whom they cared. The two sets of questions were aligned to allow comparison of caring and own health activities.
The measurement of time use in informal care has relied on either diaries (see for example, Bittman et al., 2005) or recall (see for example, Russell et al., 2008; Safford, 2005). While keeping diaries is often regarded as the most accurate data collection method, it is both expensive and potentially intrusive. Recall questionnaires were used in this study to limit the burden of research participation on the respondents, to encourage response, and to provide data which covered longer periods, increasing event numbers and accessing long term rather than daily distribution of time use (Bittman et al., 2005; Safford, 2005; Russell et al., 2008).

Questions on time use (for both own health and caring) asked how much time was spent “on most days” for regular tasks such as managing and taking medication; how much over the last month for less regular activities that included attending rehabilitation programs, shopping for special foods, seeking information; and how much on health service linked activities such as travelling to, waiting for and attending a doctor (see Attachment A1).

The questionnaire drew on questionnaires previously tested by McRae and colleagues (Yen et al., 2011; McRae et al., 2012) and international time use surveys from North America (Russell et al., 2007) and Australia (Bittman et al., 2005). The questionnaire was piloted with 18 members of a local health service consumer network. They suggested changing some terminology, simplifying questions and shortening the survey, which we did. The revised survey was re-tested by 28 older Australians who had taken part in an earlier survey and indicated their willingness to participate in further research. No further changes were made as a result. The revised survey was mailed to selected individuals (as below), with the option to complete it
on line using Survey Monkey®, a proprietary survey tool, or to complete the form
and return it by prepaid post.

Ethics approval for the survey was obtained from the Australian National University

Analysis
Survey responses were computer coded and entered into STATA 11 (Stata Corp L P,
2009). Carers were identified by their completion of the carer section of the survey
form, and their responses analysed. The results are presented in terms of descriptive
statistics addressing various questions, and were estimated using STATA 11 (Stata
Corp L P, 2009). Time use is presented in terms of hours per month on each activity.
As the distribution of time use is highly skewed, results are presented using medians.
To address issues of the highest time demands the 90th percentiles are presented.
To enable comparison with previous studies which address the question of whether
carers with low levels of caring activity are healthier than those who do no caring we
compare the proportions of carers and non-carers with poor or fair health. We use the
carers in the lowest quartile of caring time as those with “low levels of caring”,
following Buyck et als’ use of the lowest quartile.

Respondents were asked how much time they spent on exercise and physical activity
each day. Because exercise time tended to dominate all other reported times, it has
been reported separately to allow the less time consuming activities to emerge. While
the majority of respondents spent some time on HRA, many people did not spend
time on particular health-related activities included in the survey (e.g. attending
rehabilitation, preparing special foods). When looking at the more detailed time
components we therefore report on both the proportion of people undertaking each task, and time spent by those undertaking them. Estimates were weighted to stratum populations for each sub-sample. Given their different structures and different population sizes the results for three samples are reported separately. Standard errors and confidence intervals were derived using bootstrapping techniques within Stata 11.

Results

Response rates differed between the three sub-samples with an overall response of 2,540 (24.0%). Most respondents returned the completed printed survey, with only 75 respondents completing the survey online (uploaded through Survey Monkey). Response rates were highest in the NSA sub-sample (28.6%) which best represents the health status of the overall older population, and lowest in the sub-sample of those registered with NDSS, all diagnosed with diabetes mellitus (17.1%). The response rate for the Lung sub-sample was 24.0%. Broadly the youngest and oldest were least likely to respond, there was little difference in male and female response rates, and while there were differences in response rates by States there were no obvious patterns across the three sub-sample groups.

Structure of the respondent populations

Overall 12.4% (N=313) of respondents identified themselves as caring for other people and provided estimates of time spent on caring. Of those carers, 62% cared for a partner/spouse. All but 12 carer respondents had at least one chronic illness. The carers looking after parents were, on average, almost 3 years younger than those looking after spouses. Those caring for spouses were estimated to spend more time than those caring for parents. However, the differences were not statistically
significant. Thirty of the 313 carers (9.5%) did not report a chronic illness for their care recipient, so the people cared for are assumed to have had a disability derived from some other source.

Table 1 shows the sample size and basic demographics for carers and non-carers with and without their own chronic illness in each sub-sample. Within the NSA sub-sample the most prevalent reported chronic illnesses include arthritis (49.9%), depression/anxiety (32.5%), cancer (23.6%) and chronic pain (21.2%). In addition to diabetes, the most prevalent co-morbid illnesses that respondents in the Diabetes sub-sample reported include chronic pain (48.1%), arthritis (43.4%), and depression/anxiety (42.8%). In addition to COPD, the most prevalent co-morbid illnesses that respondents in the Lung sub-sample reported include depression/anxiety (38.8%), asthma (36.7%), arthritis (33.1%) and chronic pain (32.9%). Chronic pain and depression/anxiety were thus, among the most commonly reported illnesses in all three sub-samples. The illnesses associated with self-reported highest time use include respiratory diseases and diabetes.
Table 2: Sample responses and estimated sample characteristics

<table>
<thead>
<tr>
<th></th>
<th>Diabetes sub-sample</th>
<th>Lung sub-sample</th>
<th>NSA subsample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer with chronic condition</td>
<td>55</td>
<td>117</td>
<td>1,107</td>
</tr>
<tr>
<td>Not a carer with chronic condition</td>
<td>368</td>
<td>559</td>
<td>12</td>
</tr>
<tr>
<td>Carer with chronic condition</td>
<td>130</td>
<td>1,107</td>
<td>183</td>
</tr>
<tr>
<td>Not a carer with chronic condition</td>
<td></td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Carer with no chronic condition</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not a carer with no chronic condition</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not a carer with no chronic condition</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Sample*  

Estimated population structure

<table>
<thead>
<tr>
<th>% Male</th>
<th>Carer with chronic condition</th>
<th>Not a carer with chronic condition</th>
<th>Carer with chronic condition</th>
<th>Not a carer with chronic condition</th>
<th>Carer with chronic condition</th>
<th>Not a carer with chronic condition</th>
<th>Carer with chronic condition</th>
<th>Not a carer with chronic condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>47.3%</td>
<td>57.4%</td>
<td>52.4%</td>
<td>39.4%</td>
<td>35.6%</td>
<td>40.2%</td>
<td>35.0%</td>
<td>41.4%</td>
<td></td>
</tr>
<tr>
<td>% aged &lt;60 years</td>
<td>19.4%</td>
<td>26.1%</td>
<td>9.8%</td>
<td>11.7%</td>
<td>26.3%</td>
<td>25.6%</td>
<td>45.6%</td>
<td>33.3%</td>
</tr>
<tr>
<td>% aged 60–69 years</td>
<td>30.6%</td>
<td>36.5%</td>
<td>33.1%</td>
<td>34.6%</td>
<td>43.4%</td>
<td>49.3%</td>
<td>50.1%</td>
<td>54.6%</td>
</tr>
<tr>
<td>% aged 70 years or older</td>
<td>50.0%</td>
<td>37.4%</td>
<td>57.1%</td>
<td>53.7%</td>
<td>30.4%</td>
<td>25.1%</td>
<td>4.3%</td>
<td>12.1%</td>
</tr>
<tr>
<td>% caring for parent</td>
<td>34.1%</td>
<td>16.8%</td>
<td>21.3%</td>
<td>31.4%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% caring for partner</td>
<td>60.3%</td>
<td>73.6%</td>
<td>62.9%</td>
<td>52.4%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% caring for son/daughter</td>
<td>1.2%</td>
<td>1.2%</td>
<td>5.9%</td>
<td>16.2%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% caring for other</td>
<td>4.5%</td>
<td>8.5%</td>
<td>9.9%</td>
<td>0.0%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note: in theory we expected no respondents from the Diabetes and Lung samples without chronic conditions, but have found 4 and 5 respectively. These may be people who joined the bodies to support their family members.
Health of carers and non-carers

Carers were more likely to report poorer health than non-carers. Table 2 shows the differences between carers and non-carers reporting poor or fair self-assessed health. In all cases the differences between carers and non-carers are significant and material (p=0.000, 0.012, 0.003 for diabetes, lung and NSA sub-samples respectively). Table 2 also shows the differences in self-assessed health status between those in the lowest quartile of caring time (less than 13 hours per month) and those in the highest quartile. None of these differences is significant, and the diabetes and lung sub-samples are in the opposite direction to the NSA sub-sample. The self-assessed health of the least active carers is still worse than that of the non-carers, although the differences are only significant in the case of the diabetes sub-sample. If adjustment is made for the age, gender and social status of the carers, the pattern of those providing low levels of care reporting poorer self-assessed health remains, but is again not significant.

Table 3: Health of carers and non carers

<table>
<thead>
<tr>
<th></th>
<th>Diabetes sub-sample</th>
<th>Lung sub-sample</th>
<th>NSA sub-sample</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Percent with poor or fair self-assessed health (95% CI)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carers in upper three quartiles of caring time</td>
<td>62.3% (47.1–77.5)</td>
<td>80.3% (71.9–88.6)</td>
<td>27.6% (20.0–35.1)</td>
</tr>
<tr>
<td>Carers in lowest quartile of caring time</td>
<td>67.5% (43.9–91.1)</td>
<td>82.87% (70.4–95.2)</td>
<td>18.3% (8.5–28.1)</td>
</tr>
<tr>
<td>Total Carers</td>
<td>63.2% (50.7–75.7)</td>
<td>80.5% (72.9–88.2)</td>
<td>24.8% (18.6–31.0)</td>
</tr>
<tr>
<td>Non-carers</td>
<td>35.0% (30.2–39.8)</td>
<td>70.5% (65.9–75.0)</td>
<td>15.9% (13.9–18.0)</td>
</tr>
</tbody>
</table>
Time spent on own care and on caring

The total time respondents reported spending on their own personal and caring HRA was related to whether the respondent was a carer and whether they had a chronic illness. As shown in Table 3, carers spent more time on their own health than non-carers (consistent with the health status reported in Table 2). For the NSA and Lung sub-samples the differences between carers with chronic illnesses and non-carers with chronic illnesses were significant. In the NSA sub-sample where the differences between those with and without chronic illnesses can be observed, these differences in time spent on their own health were significant for both carer and non-carer groups. Time spent caring, on the other hand, was not significantly different depending on whether carers had chronic illnesses.

Table 4: Median time spent on HRA (hours per month, 95% CI in parentheses)

<table>
<thead>
<tr>
<th></th>
<th>Diabetes sub-sample</th>
<th>Lung sub-sample</th>
<th>NSA sub-sample</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Time spent on own health</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not a carer with chronic condition</td>
<td>10.5 (8.9–12.1)</td>
<td>15.7 (14.1–17.2)</td>
<td>5.9 (5.3–6.5)</td>
</tr>
<tr>
<td>Not a carer with no chronic condition</td>
<td></td>
<td>1.3 (0.6–2.0)</td>
<td></td>
</tr>
<tr>
<td>Carer with chronic condition</td>
<td>22.2 (9.1–35.2)</td>
<td>23.0 (20.1–25.9)</td>
<td>11.8 (8.3–15.3)</td>
</tr>
<tr>
<td>Carer with no chronic condition</td>
<td></td>
<td>3.5 (1.7–5.3)</td>
<td></td>
</tr>
<tr>
<td><strong>Time spent caring</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carer with chronic condition</td>
<td>47.0 (33.1–60.9)</td>
<td>36.0 (24.9–47.1)</td>
<td>30.5 (20.6–40.4)</td>
</tr>
<tr>
<td>Carer with no chronic condition</td>
<td></td>
<td>41.5 (10.4–72.6)</td>
<td></td>
</tr>
<tr>
<td><strong>Time spent on health – self and caring</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carer with chronic condition</td>
<td>87.5 (68.8–106.2)</td>
<td>63.2 (46.1–80.2)</td>
<td>54.75 (38.9–70.6)</td>
</tr>
<tr>
<td>Carer with no chronic condition</td>
<td></td>
<td>76.5 (33.1–119.9)</td>
<td></td>
</tr>
</tbody>
</table>

1 Note: includes all values (i.e includes zeros) but excludes exercise time

2 Cells based on samples of less than 10 observations are not reported
The median time spent on the HRA aspects of caring for another person ranged from around 30 hours per month (an hour per day on average) for the NSA sub-sample to around 47 hours per month (an hour and a half per day) for the Diabetes sub-sample. When combined with the time spent managing their own health the total time spent monthly on HRA by respondents ranged from 55 hours per month to 87.5 hours per month (equivalent to 2–3 hours per day) across the various groups.

**Time use of carer respondents within the highest decile**

The times reported above, of between 2 and 3 hours a day spent on HRA, are not trivial amounts. However, at the 90th percentile, the total of personal and caring HRA time is vastly greater at 248.5 hours per month for the Diabetes sub-sample, 313.0 for the Lung sub-sample and 294.0 for the NSA sub-sample (or between about eight and 10 hours a day).

**Relation of time use and number of chronic illnesses**

The amount of time spent on HRA was associated with increasing number of carer chronic illnesses, reaching a peak with the very high time use by carers with five or more chronic illnesses. As shown in Table 4, the median time spent on HRA by carers with five or more chronic illnesses ranged from 68.3 hours per month in the NSA sub-sample to 113.7 hours per month in the Diabetes sub-sample (or almost 4 hours per day). Table 4 also shows that, as would be expected, the time spent providing care for people with five or more chronic illnesses is also high and is of a similar order to the total time spent by carers with large numbers of illnesses.
<table>
<thead>
<tr>
<th>Respondents with five or more chronic diseases</th>
<th>Diabetes sub-sample</th>
<th>Lung sub-sample</th>
<th>NSA sub-sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers (own time plus caring time)</td>
<td>113.7 (81.7–145.7)</td>
<td>99.5 (69.1–129.8)</td>
<td>68.3 (24.3–112.2)</td>
</tr>
<tr>
<td>Non-carers (own time)</td>
<td>15.7 (9.8–21.6)</td>
<td>23.9 (16.6–31.2)</td>
<td>21.5 (15.6–27.4)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Care recipients with five or more chronic diseases</th>
<th>Diabetes sub-sample</th>
<th>Lung sub-sample</th>
<th>NSA sub-sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers (own time plus caring time)</td>
<td>119 (76.8–161.2)</td>
<td>97.5 (75.0–120.0)</td>
<td>83.2 (23.3–143.0)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Comparative numbers from overall respondents</th>
<th>Diabetes sub-sample</th>
<th>Lung sub-sample</th>
<th>NSA sub-sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer with chronic condition (own time plus caring time)</td>
<td>87.5 (68.8–106.2)</td>
<td>63.2 (46.1–80.2)</td>
<td>54.75 (38.9–70.6)</td>
</tr>
<tr>
<td>Non-Carer with chronic condition (own time)</td>
<td>10.5 (8.9–12.1)</td>
<td>15.7 (14.1–17.2)</td>
<td>5.9 (5.3–6.5)</td>
</tr>
</tbody>
</table>

While our study did not use disability measures we did observe that the number of chronic illnesses a person had was strongly correlated with the time their carer spent on HRA (with correlations 0.58, 0.58, 0.54 for the Diabetes, Lung and NSA sub-samples respectively; p=0.00 in all cases).

Time use for specific activities

As stated above, time use questions were segmented into HRA carried out every day, less frequent non clinical activities, and those related to accessing clinical services. Attachment 1 (in the linked data file) shows details of HRA for each sub-sample and each category of time use. While the estimated time use differs between sub-samples, the overall patterns are very similar. Table 5 show the broad patterns for the Diabetes sub-sample as an example.
Everyday activities took up most time spent on respondents’ own health care and on caring. The largest component of this was preparing special foods in the cases where this was required, which was relatively infrequent for respondents who were not carers (8-16%). However, between 32% and 48% of those caring reported preparing special foods and spent at the median between 30 and 60 hours per month on this activity (varying between the sub-samples). Shopping for health requirements (for example, medicines) is the most common of the non-clinical activities although the overall median time including caring and self-management activities is in the order of two hours per month in all sub-samples. Other activities like attending rehabilitation can be very demanding of time, but only applied to a small number of people. Across all sub-samples the most common clinically-related activity reported was sitting in waiting rooms, and this was the most time consuming or second most time consuming activity after travel depending on the sub-sample.
Table 5: Summary of caring and non-caring time spent on HRA activities for the Diabetes sub-sample only

<table>
<thead>
<tr>
<th>Time component</th>
<th>Non Carer</th>
<th>Carer</th>
<th>Total time caring and on self</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Percent responding</td>
<td>Median response</td>
<td>Percent responding</td>
</tr>
<tr>
<td>Total daily activities excluding exercise</td>
<td>91.9%</td>
<td>7.5</td>
<td>86.7%</td>
</tr>
<tr>
<td>Total daily activities including exercise</td>
<td>93.7%</td>
<td>20.0</td>
<td>90.4%</td>
</tr>
<tr>
<td>Total general activities</td>
<td>81.6%</td>
<td>0.8</td>
<td>75.5%</td>
</tr>
<tr>
<td>Total medical activities</td>
<td>82.4%</td>
<td>2.0</td>
<td>82.8%</td>
</tr>
<tr>
<td>Overall total excluding exercise</td>
<td>95.5%</td>
<td>11.0</td>
<td>92.0%</td>
</tr>
<tr>
<td>Overall total including exercise</td>
<td>95.5%</td>
<td>26.0</td>
<td>95.7%</td>
</tr>
</tbody>
</table>

- Daily activities include sorting/preparing/taking medications, carrying out treatments, testing and monitoring health, preparing special food and exercising or stretching.
- General activities include shopping for health items, shopping for special foods, attending rehabilitation, attending health education, attending support groups, and reading health information.
- Medical activities include organising appointments, organising travel to appointments, time in waiting rooms, attending consultations, blood tests/x-rays etc and attending for other treatments.
Discussion

To our knowledge, our study is the first to measure time spent on specific HRA by informal carers who themselves have a chronic illness. The median time spent on health-related caring activities of between 30.5 and 47.0 hours per month is comparable with median times estimated by Bittman and colleagues (2005) of one hour and 27 minutes of care daily (45 hours per month). Their estimates included all care (including care of people with disabilities) rather than only health-related care. Their study encompassed carers of all ages rather than the older cohort we have studied.

Informal carers did engage in numerous HRA to manage their own health and to assist others in the management of theirs. Some activities were undertaken by most informal carers, for example dealing with medications. More time consuming activities such as preparing special foods and carrying out treatments were carried out by fewer respondents.

The outstanding finding from these results is that informal carers with a chronic illness spent more time on their own HRA than respondents who were not informal carers, and when this was combined with their time caring for others, spent between four and nine times as long on HRA as non-carers. Those in the highest decile spent on average between eight and 10 hours each day on HRA.

We also identified a pattern of increasing time spent on HRA as the carer’s number of chronic illnesses increased. This pattern was also associated with the number of chronic illnesses of the care recipient. While increased morbidity was associated with
increased time use, informal carers with chronic illnesses spent more time caring for others than engaging in activities associated with their own health care. The number of chronic illnesses a person had was strongly correlated with the time their carer spent on HRA. It is likely that the care recipient’s level of disability would also increase with their number of illnesses. Within the Diabetes sub-sample the reported prevalence of chronic pain and depression/anxiety was almost twice as higher for carers (48.1% and 42.8% respectively) than non-carers (25.3% and 20.4% respectively). We have reported the prevalence of chronic illnesses among survey respondents in another article, where self-reported rates of chronic pain and depression/anxiety were lower across the three sub-samples (Yen et al., 2013).

**Implications of findings for carer support strategies: allowances, respite and targeted services**

In most industrialised countries the desire to minimise unnecessary hospital admissions and costly residential care is driving policies to support older people living within their communities, increasing reliance on the ‘unpaid workforce’ of carers (Brodhead, 2003). De Jonge and colleagues (2009), for example, have suggested a model of chronic illness management that reduces costs by shifting care into the community. However, while the model they propose might improve aspects of both the patient and carer experience, it pays no attention to the negative impacts of community-based care on carers.

Sustainable and effective informal care requires “centralised information dissemination, improved care co-ordination, merged funding streams, and expanded consumer direction” (Miller et al., 2008: 8). However, these policy goals also require a more nuanced understanding of the situation and actual capacities of carers. Our
findings suggest that existing faith in the ongoing availability and capacity of informal care may be misplaced. Many carers face time demands which appear manageable, for healthy carers with limited other demands on their time, at between two and three hours a day. However, other carers managing their own chronic illnesses and diminishing functional abilities as well as providing care to another are likely to be struggling. How, though, are policymakers to decide what changes are needed and to whom they should be targeted for best outcomes?

Welfare systems have utilised three key strategies to support informal carers; carer allowances, respite care and targeted service provision. In Australia, for example, carer allowances and respite care are part of the social security system, with home and community care programs generally managed within the health care system. Findings from this study suggest much of the burden of care problem cannot be solved simply by providing income supplements (although these would help) unless these are adequate to buy resources that reduce time demands on carers, and those resources are available. Minor increases in income support are unlikely to assist in better management of medications, transport to health-related appointments, allow access to adequate respite services or improve availability of affordable special foods. Some of the highest pressure points come from level of the carer’s own health, especially those with five or more chronic diseases. There is no simple way to identify this group and target additional resources to assist them.

To what extent should respite services for informal carers be part of future solutions? The Decima report from Canada suggests respite is imperative for caregivers (Decima Research Inc., 2002). Studies, both in Australia and internationally, have
indicated barriers to the short term use of respite services such as carers being unable to access services when they need them, and users feeling guilty about taking respite (Brodaty et al., 2005; Essue et al., 2010). While the cost effectiveness of respite services remains under debate (Keefe and Manning, 2005) the need for informal carers to support people with chronic illness is evident, and as other studies have shown, so too is their need for respite (Essue et al., 2010). The high presence of chronic illness in the informal care population suggests even more urgent attention to addressing barriers of respite use is warranted. Future research to inform design of respite services should explore whether carer chronic illnesses are an additional barrier to respite use.

Furthermore, early work by Valderas and colleagues suggests that some combinations of illnesses may have characteristics in terms of time use and functional impairment that could lead to a better understanding of the needs of both carers and the people they care for (Valderas et al., 2009; Huntley et al., 2012; Glynn et al., 2011). Multi-morbidity research of carer populations could lead to better targeting of respite and other forms of support for people with multiple illnesses.

This study shows that some HRAs lead to the much higher demands on time, providing a focus to improve targeting of services. For example, while not relevant to all carers, preparing special foods and carrying out treatments are tasks associated with large blocks of time. In the case of preparing special foods one obvious option to reduce time burdens seems to be better and more focused utilisation of services of the style of ‘Meals on Wheels’. In Australia, Meals on Wheels (a non-government service run by volunteers) provides affordable meal preparation and delivery services
for people who need it. People eligible for this service include those who are housebound, frail adults, people with a disability or illness and their carers. People with special dietary requirements and chewing or swallowing problems are catered for.

Strategies for enhancing Meals on Wheels-type solutions could move in two directions: expanding the range of meals to meet special dietary needs posed by multi-morbidity; and developing systems which overcome some of the complexities of current temporal arrangements. Regarding this second option, to meet recommended health safety targets meals must be prepared within a particular time and delivered within a particular time, with consumers (and often carers) at home and ready to consume or refrigerate meals when they arrive (Krassie et al., 2000; Jowsey, 2011). While the program currently does free up carers from preparing foods, it cannot offer them complete time flexibility (which has been raised as a point of frustration by carers in our previous qualitative research (Jowsey, 2011)). Strategies that move in these two directions could make significant reductions on time demands of some carers.

Like the preparation of special food, clinical treatments can be extremely time demanding for some groups of patients and carers. While some treatments cannot be safely or easily sped up, advances in ambulatory peritoneal dialysis, ‘satellite’ haemodialysis, and nocturnal dialysis treatments have significantly improved time use experiences of patients and carers by increasing the flexibility of when and where treatments can be undertaken (Agar, 2005; Suri et al., 2006). The value of flexibility that nocturnal treatments offer to patients and carers’ waking lives cannot be over-
stated, and may provide a model for consideration in relation to other time demanding treatments.

There are undoubtedly a wide range of measures available to simplify tasks and reduce time demands on carers. In the Australian context, for example, dose administration aids (DOAs), such as Webster blister packs for the delivery of pharmaceuticals, significantly reduce the amount of time people spend on sorting medications, but are not covered by the publicly funded Pharmaceutical Benefits Scheme. A subsidy would reduce cost barriers to the wider use of DOAs. The survey also found that failure to co-ordinate medical appointments leads to repeated travel and increased waiting times for carers. Virtual appointments and case conferencing have been identified as potential avenues for improving care co-ordination, however in the Australian setting up take has been low and the challenges posed by rural and remote locations have been considerable. Further efforts to better co-ordinate care are required.

Finally, an awareness of this pressing time burden strengthens arguments for constant critical appraisal of the efficacy for standard – often time consuming – self-management tasks. Research by Henderson and colleagues, for example, has identified that for people with diabetes, testing blood glucose levels may not be the most effective use of their time as they do not correlate with improved health outcomes (Henderson et al., 2012).

**Limitations**

This study is based on a relatively small number of survey respondents, from a survey with a 24% response rate. However, while time estimates vary between the
sub-samples, broad patterns are similar. While we have shown that the time allocation to HRA varies according to the number of chronic illnesses experienced by carers, it also likely to depend on the health and functional ability of care recipients, how long carers or their care recipients have had a particular illness, the type of illness (of carer or care recipient), and/or the extent to which a care recipient can access support from others.

While we have discussed the findings in terms of health service options for improving support to carers, we acknowledge that in this survey we did not ask respondents to provide information on what kinds of support they wanted. However, we did ask this of participants in a previous qualitative study (Jeon et al., 2010), and their responses have helped shape the discussion of health service support options.

**Suggestions for future research**

As noted above, we suggest further research is warranted concerning carer multimorbidity and barriers to respite use, including addressing other factors that influence time spent on HRA and the cost of that time to carers. This study has not developed the wider implications of caring, for example the impact of caring on personal health or the quality and duration of sleep (Knutson et al., 2006; Kenny et al., 2010) or ‘weathering’ associated with high physical, emotional and mental demands (Wilkinson and Pickett, 2010). Nor has it addressed other temporalities associated with care such as process time, which references the multiple and interacting processes at play at a given time, that influence for example, the way we perceive and measure time spent caring (Jowsey, 2011; Bittman et al., 2005). The survey did not measure activities forgone due to caring and self-care responsibilities.
Research addressing that would provide insight into the true ‘cost’ of time spent caring. The authors suggest that future research should link time spent on HRA with these kinds of factors to deepen our understanding of the actual ‘work’ of informal care.

**Conclusions**

This paper set out to understand the time use of informal carers who themselves have a chronic illness. Many health policies and service programs assume that the informal carer is healthy and capable of caring for the care recipient. There is also an assumption held in society more generally that family members will be in a position to care for their loved ones and that they will willingly do so. In this study most informal carers were spouses or other nuclear family members. However, in this study most carers also had chronic illness themselves, and those with greater numbers of chronic illnesses were those who faced the greatest overall time demands, of between 8.5 and 10 hours a day devoted to HRA.

If carers are to be able to continue to provide support this suggests that programs focused on reducing the most severe time demands will be needed. Policy and health care services will need to adapt to recognise and reduce the time burden on those carers and their households. More carefully targeted investment in the social infrastructure of formal care would free up carers for other activities (including their own care) and holds the potential to improve the quality of life as well as the health outcomes of this population.
Competing interests
The authors declare no competing interests. The funding organisation (NHMRC) had no role in the study design, data collection, analysis and interpretation, or the writing and publication of this article.

Authors' contributions
All authors made substantial contributions to conception and design, acquisition of data, primary analysis and interpretation of data; and were involved in drafting the manuscript and revising it critically for important intellectual content. Additionally, L Yen conceived of the study; I McRae and M Banfield were heavily involved in primary data analysis; and T Jowsey was heavily involved in drafting and revising the manuscript. All authors read and approved the final version of the manuscript.

Authors’ information
This research was undertaken by three members of the Serious and Continuing Illness Policy and Practice Study (SCIPPS) at the Australian National University. The authors have training in anthropology, psychology and health services research. TJ is undertaking postdoctoral research at the Australian National University concerning experiences of time and chronic illness and this paper forms part of her research.

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CHAPTER 8 PROCESS TIME


Abstract

One of the indicators by which efficacy of care is measured in Australian health care services is time use. Increasing the amount of time that health professionals spend with health service users (HSUs) is associated with better care and better health outcomes. However the health care workforce is struggling to meet the increasing demands of Australia’s ageing population and increasing burden of chronic illness (CI). To alleviate the pressures on the health system, health care policies and programs are placing greater emphasis on self-management and greater reliance on informal care. Little consideration has been given to the implications this has for informal carers in terms of their time use, perceptions of time and connected constructions of identity.

The Serious and Continuing Illness Policy and Practice Study undertook qualitative research, comprising semi-structured in-depth interviews with 10 informal carers and 8 HSU concerning their experiences of complicated CI. Content analysis was undertaken following Morse and Field (1995) and assisted by QSR Nvivo8 qualitative software. Participant stories of chronic illness experiences illustrate complexities that emerge around time and carer identity. Participants suggested that caring is a 24 hour job. Part of this job is measurable through calendar and clock time (CCT), such as how much time a person spends preparing special foods for their care
recipient or assisting them with managing medications. But in understanding temporal experiences there remains a cavity unfilled by measures of CCT. Understanding the 24 caring job entails exploration of the psychological and emotional states associated with process, such as worry time. This paper illustrates how CCT and process time contribute to our understanding of how CI can shape the identity constructions of informal carers. The importance of this topic is rooted not only in our understanding the social dynamics of CI, but also the fiscal components and 'lived costs' of CI care.

Keywords: time; time use; perception; informal care; family carer; identity

Introduction
Chronic illness (CI) is a reality of our time. Western countries including Australia have seen a skyrocketing incidence and prevalence of CI amid increasing workforce pressures and ageing populations (Australian Institute of Health and Welfare, 2008, Britt et al., 2008; Schoen et al., 2008). Seemingly every individual in Australia has been touched by CI either directly or through family and friends. It is a topic of conversation in many health service user (HSU) consultations with health care professionals, as it is around many dining room tables. CI is increasingly weaving its way into the lived experiences of people for much of their lives. Definitions of CI include two key factors: they last for six months or more and require management. CIs that only last six months are in the minority; frequently CI will last many years, most often CI will last for the remainder of the individual’s life. The symptoms can be ongoing, such as with arthritis, or they can occur intermittently, as with epilepsy. While CIs manifest in very different ways they all
share temporal components that create what Bury has coined a 'disruption' to the individual’s biography (Bury, 1982).

The burden of CI in Australia has dramatically increased over the past twenty years and shows no signs of abating (Australian Institute of Health and Welfare, 2008). The Australian health system has implemented several measures to meet this burden, including increased medical workforce (Joyce et al., 2006), increased funding and attention for education and support programs (Nolte et al., 2011), and major health system reform (Commonwealth of Australia Treasury, 2011). Additionally, Australia has seen an increased reliance on informal care in recent Commonwealth policies and initiatives (Australian Government Department of Health and Ageing, 2005; National Health and Hospitals Reform Commission, 2009; Australian Government Department of Health and Ageing, 2006) and State-wide health policies (see for example, ACT Health, 2008). Little consideration has been given to the implications this has for informal carers in terms of their time use, perceptions of time and connected constructions of identity.

This paper is concerned with informal carer temporal experiences of CI, as reported by 18 people. They report numerous facets of temporal experience such as embodied time and shared communities of time, epoch time and imagined biographical futures. However, this paper identifies and briefly explores only two intertwined kinds of time as experienced by carers: Calendar and Clock Time (CCT) and process time. Times that can be identified in carer experience as CCT and process time illustrate the significant and on-going nature of the caring role. I argue that analysis of the way people living with CI experience time furthers our understanding of how CI can
disrupt flows in identity construction. It is not only the chronically ill individual whose identity is disrupted by CI, rather this disruption takes on very real meaning for informal family carers who increasingly dedicate their time to the caring role.

The study
As part of the Serious and Continuing Illness Policy and Practice Study (SCIPPS), semi-structured interviews were held with 78 people living with CI in order to understand their CI experiences. I undertook secondary content analysis of a participant subsample (n=18), some findings from which are reported here.

The SCIPPS project was undertaken in two urban Australian areas: the Australian Capital Territory (ACT) and Western Sydney. Ethics approval was obtained from local Ethics Committees. HSU participants were aged between 45 and 85 years with one or more of diabetes, chronic obstructive airways disease (COAD) or congestive heart failure (CHF) that was deemed to be moderate or severe by their referring clinicians. Eligible HSUs were recruited via general practices, Aboriginal medical services and hospitals. Informal family carers of people with these illnesses were also recruited through general practices and an informal carer support group.

Face-to-face, semi-structured, in-depth interviews each between 45 and 90 minutes duration were conducted by one of six researchers. Time was not a focus of the study so the interview guide included no questions specific to temporality. All interviews were electronically recorded and transcribed verbatim. Qualitative content analysis was performed following Morse & Field (1995) with the aid of qualitative data software (QSR, 2008). The data collection and analysis was guided by Lincoln &
Guba (1985) in terms of the credibility, confirmability, transferability, and dependability to maximise the rigour of the study.

This paper reports secondary analysis that was undertaken from a subset of the initial dataset. The subset (18 interviews) was purposively sampled in terms of geographical location, gender, CI, patient/carer status and immigrant status. A coding scheme was iteratively created to assist the initial stages of secondary analysis. This coding scheme comprised emerging themes concerning perceptions of time and time use. Further in-depth analysis was undertaken following Morse & Field (1995).

The sample included twelve females, nine of whom were informal family carers. Six participants were immigrants whose first language was not English (five participants chose to use an interpreter for the interview). Eight participants lived in the ACT. Six participants were aged under 65 years and twelve participants were aged 65-85 years. The CIs of interest in this study were diabetes (n=10), COAD (n=6), CHF (n=8). Six participants had more than one of these CIs or cared for someone who did.

**Experiences of time: clocks and processes**

Postill (2002) explains that CCT is a standard measure of time in which events are given linear chronological form (2002). In Australia CCT is the salient temporal representational system by which people measure their engagement in activities. CCT is also the system by which time is measured (and by extension, valued) in western health care services (Postill, 2002).
CCT was the system that participants utilised most frequently during interviews. Many participants reported the specific calendar date of their diagnosis: "I had my cardiac arrest on February 12th, 2005. That’s what? 27 months now" (HSU_4). Participants spontaneously reported their time use over previous days and months. For example, they noted how much time they spent managing their care recipient’s medications (5–20 minutes daily) or preparing special foods (up to two hours daily). Carers reported giving up personal planned activities in order to provide care, such as one participant who cancelled her own health appointment because she felt the needs of her husband (who had a sudden exacerbation of COAD) were higher than her own. Participants’ use of CCT to relay their experience partly reflects CCT currency in western thought and also reflects an established discourse of health research with which participants engaged through the semi-structured interviews.

Participants also reported experiencing CI through what Davies (1994) has called process time. Davies writes:

> I would contend that process time is not the same as task-oriented time. The latter tends to stress the task per se and risks separating the activity, at least conceptually, from its context. Process time on the other hand, emphasizes that time is enmeshed in social relations. ... the concept of process time embraces several different times, timings and temporalities. In a simplified manner, one can summarize process time by saying that it refers to letting the task at hand, or the perceived needs of the receivers of care, rather than the clock, determine the temporal relation. Things take the amount of time they need to take and they are invisibly woven into other activities (Davies, 1994: 280–281).

Process time offers insight into the caring dynamics that cannot easily be measured by CCT. This is largely because process time captures the multi-tasking and socially embedded roles of caring. It also captures the aspects of caring that permeate into other activities that are not caring-specific. While Davies’ focus is on activity
processes for paid child nursery workers, I propose that her process time theory can be extended to include the psychological and emotional roles of informal caring. This was nowhere more striking than with the time carers spent ‘worried’, ‘concerned’, ‘stressed’ and ‘anxious’ about their care recipient. These feelings and the psychological processing associated with them were experienced during mundane phases of illness and were more pronounced during acute phases. Carers reported experiencing these feelings during periods of waking care, rest/sleep, and respite. Many felt they were constantly in a caring state of mind. They reported arising during the night to change the sheets and to adjust supplementary oxygen devices. Carers reported feeling that they were completely unable to take formal (CCT) respite from their caring roles because of their feelings of concern and anxiety.

**Caring is a 24 hour job**

CCT and process time are evident in daily experiences of CI. The following 24 hour vignette is based on participant reports and is supported by their voices. It illustrates the interconnected nature of CCT and process time in daily experiences of CI.

Mary's husband Joe was diagnosed with type two diabetes six years ago and CHF two years ago. Yesterday while Mary was searching the internet for information about low salt cooking Joe came inside from the garden at 4pm. He said he was tired and sat in the lounge. Half an hour later Joe asked Mary to get his pills for the angina, which she did.

He learnt after a while, when he could get through a bad angina attack and he wouldn’t go to hospital. That’s always a period of tension for me, because I don’t know whether he’s going or not to hospital, or whether he’s going to get through it. If he decides to stay at home, that again is a very tense time for me until he’s through that period (Carer_4).
Mary found what looked like a good recipe on the internet and joined Joe in the lounge where they watched television together for a while. Mary wasn't really watching it. She was quietly worrying about Joe, looking for signs of change in his condition. Agitated, Mary went into the kitchen to prepare dinner. Joe took three pills, his colour slowly returned. Mary ate dinner. Joe said he wasn't hungry. They went to bed early. Mary propped Joe up on his pillows so he could sleep in his preferred seated position. He said he felt fine. Mary wasn't sure he did. Mary did not sleep well.

This morning Mary awoke at 7am and had breakfast ready for Joe by 7.40am. He took his insulin without her assistance while she prepared his heart medication. They read the newspaper together. At 9am Mary made a doctor appointment for Joe. The doctor was available at 10am, so Mary then called Lucy to let her know Mary wouldn't be attending book club today.

So I said to him, "Better go back to see the doctor because maybe something is wrong for you. Don't stay like that." But my husband doesn’t like to see the doctor. He said, "Oh, it’s okay, it’s okay." (Carer_1).

After some persuasion Joe agreed to go see the doctor, but only if Mary accompanied him.

I’m always with him. But anyway, I’m always with him. He doesn’t go alone by himself. And now I start to say to him, “Look, I know I must go with you but I’m letting my job at home. I cannot do everything, I cannot… Every time I go with you, it’s half a day, sometime all day lost.” My work at home is not done, you see? “Can you try to go by yourself to save me some time?” “Oh, no, no, no. I cannot go. I like better when you are go.” So, anyway, all the time I am with him, all the time (Carer_1).
It was a ten minute drive to the general practice, and a nine minute wait followed by a ten minute consultation. The doctor took Joe's blood pressure and suggested that next time Joe should go to the hospital after taking two tablets and after waiting no more than half an hour. He also reminded Joe to be consistent with his insulin and sugar intake. “The doctor said to him, ‘You must do four blood tests a day: one in the morning, one at lunch, one at night and one before to go to bed’” (Carer_1).

[He's] pretty stubborn, very stubborn actually and he’s never been one to when he’s felt not, not well like, you know, sort of needing sugar he’s never been on to put his hand in his pocket and get his jelly beans and that makes life difficult. (Carer_5).

Mary popped in to the supermarket on the way home while Joe waited in the car.

One service [that] would be good is if you could have somebody that could come and sort of take us shopping. He never gets out. If he could go shopping, but we have a man down here that helps us, but you can’t depend on them all the time (Carer_8).

They arrived home at 11.40am. Mary quickly prepared lunch, keenly aware that Joe's sugar levels were dropping. Joe took his insulin. They ate lunch in the sunlight at 12pm then Joe rested in the lounge while Mary worked on the quilt she is making for their grandson. The quilt is taking longer than she anticipated.

**Chronic illness, caring time and identity**

The story of Mary and Joe illustrates how difficult it can be to measure a process such as preparing special foods. Does seeking the recipe count toward that time? Do we discount the time lost when she retrieved Joe’s medication for him? Does it still count if he doesn’t eat it? And when they sat and watched television, was Mary engaged in leisure (Bittman et al., 2005) or was she caring or was she worrying? In
this way we begin to see the complexities inherent in informal care work and conduct of daily living.

But whatever time is, the commonsense, everyday version of it as linear, regular, absolute, marching from left to right, from the past through the present to the future, is either nonsense or a tiny fraction of the truth. We know this from our experience (McEwan, 1987: 18).

Time is a complex creature. It can be understood through many lenses, each bringing with it a new view of reality. In this paper I have scratched the surface of how carers experience CCT in combination with process time. Measuring the CCT of caring offers us a number, to which can be added value and this is important in health services for financing the training and support of the informal carer workforce. However, CCT only provides us one lens for understanding the carer temporal experience. Further understanding is offered by process time, which points to those aspects of the caring role that are not so easily measured; including the interwoven tasks that form daily living and management of CI, and the on-going nature of emotional and psychological stresses that accompany the carer experience.

People with CI tend to have increasing and multifaceted care needs, which translate into increasing demands on informal carers. Carers juggle demands on their time in their efforts to provide care and in doing so are faced with negotiating or re-evaluating what can be achieved within temporal frames. But does the carer ever have time to stop and question how their time use (which is largely dedicated to someone else) shapes their identity?

Bury has suggested that CI holds the potential to disrupt an individual’s biography and sense of self (Bury, 1982). “Chronic illness”, he writes, “is precisely that kind of experience where the structures of everyday life and the forms of knowledge which
underpin them are disrupted” (Bury, 1982: 169). CI creates such a significant shift in life experience that it alters the way people perceive time in the body and in social activity. Their days are increasingly spent attending different health professionals, spending time collecting and managing medication, shopping for different foods, and so forth. The time spent engaging in these activities both creates and illustrates the shift in identity, the disruption to biography. In this way the conduct through time is perceived of as symbiotic with the disruption.

This paper then, has allowed us to begin to understand the interdependency between conceptions of person, time, and conduct. While none of the key theorists mentioned here have specifically looked at the context of informal carers of people with CI, each offers insights that are translatable into the carer context. They deepen our understanding of those areas of caring that are difficult to measure and difficult to fully comprehend.
CHAPTER 9      SPACES AND TIME USE


Abstract

This paper explores how the structuring of places and time influence Aboriginal and Torres Strait Islander patient and carer experiences of health services. Face-to-face in-depth interviews were conducted with urban Aboriginal and Torres Strait Islander people with diabetes, chronic heart failure or chronic obstructive pulmonary disease as well as family carers (n=19). Content analysis was undertaken. Participants report that each element of the time spent in Aboriginal Medical Services is seen as more valuable and worthwhile than in mainstream health services, from social and health sharing experiences in the waiting room to health care in clinical places; and that users feel they can rely on sufficient time and respectful care in their clinical consultation. Purposeful design of both physical and temporal aspects of health services is called for. We suggest re-introducing opportunities for spatiotemporal design in health care that have been limited by the segmented ‘person as illness’ design features of Australia’s current mainstream health system.

Introduction

Aboriginal and Torres Strait Islander people, the Indigenous people of Australia, have a specific history of colonisation, which has negatively impacted on the health of these populations (Kowal & Paradies, 2005; Paul, 2000). Past experiences of colonisation, health and illness inform Aboriginal and Torres Strait Islander
experiences and choices in the present (Nathan, 1980). The experience of Aboriginal and Torres Strait Islander people in mainstream health services (MHSs) is presently poor, with services often failing to provide a care experience that is seen by Aboriginal and Torres Strait Islander people as respectful, culturally safe, fair and worthwhile (Kowal & Paradies, 2005; Paul, 2000). According to Gracey et al, this is due to MHSs lacking understanding of Indigenous issues and being unwilling to ‘meaningfully engage Indigenous people in their own health’ (Gracey et al., 2006: 332). Personal and community experience of past and present discrimination and racism has also been linked to poor health and further creates a barrier to service use (Harris-Haywood, et al., 2007; Humphery, 2001; Larson, et al., 2007; Paradies, et al., 2008). Indigenous people talking about barriers to the use of Australian MHSs describe the feeling of an alien environment, with no familiar faces or places to link them to the service (Lawrence et al., 2009). Some MHSs have tried to address this by recruiting Indigenous staff as health workers and as ‘front of house’ staff, using local Indigenous artworks in clinic and waiting places, or by providing sessions available only to Indigenous people. These attempts have had limited success and often fade away under the demand pressure of other users (ACT Health, 2011). MHSs continue to be spaces in which ‘primarily middle-class, university-educated and white’ health professionals work (Kowal & Paradies, 2005).

Many MHSs try to optimise patient flow and quality care through the design of health centres such as hospitals (see the Guidelines on Emergency Department Design (Australasian College for Emergency Medicine, 2007)), but do not make significant attempts to make such places welcoming. Nor have they made effort to identify the temporal rhythms that govern health service delivery and how these
rhythms intersect with patient and carer rhythms. In particular, temporalities such as past, present and future (Connerton, 1989), and clocked time (Fabian, 1983; J. Postill, 2002) may operate and be experienced in different ways by health professionals and patients and carers. Aboriginal Community Controlled Health Services (ACCHS) and Aboriginal Medical Services (AMSs), on the other hand, are the service of choice for many Indigenous people, partly because they consistently attempt to make their places (Couzos, 2008) and temporalities welcoming in culturally specific ways. Several AMSs in Australia are ACCHS. They follow a model of comprehensive care that is ‘different to mainstream services and contributes to high quality care, acceptability and accessibility of these [AMSs]’ (Herceg, 2011; National Aboriginal Community Controlled Health Organisation, 2008).

This study is concerned with understanding how space and time are operationalised in different health services, and how this operationalisation contributes to Aboriginal and Torres Strait Islander patient and carer experiences. The lessons from these experiences are of use to all health services.

Places and spaces

This paper uses the term 'place' to refer to defined areas within health service environments and the term 'space' to refer to often abstract meanings, boundaries and uses associated with places (Gans, 2002; Gieryn, 2000). Architects, cultural geographers, sociologists and anthropologists of the built environment continue to explore ways in which health care places reflect and shape behaviour and experiences; as well as ways in which discourses, meanings and imaginings about
places inform how they are used (Gieryn, 2000). Three key analytical areas of place include location, material form, and meaningfulness (Gieryn, 2000). In addition, social spaces or social phenomenon emerge within and in relation to places (Gans, 2002).

In his architecturally-based guide to primary health care design, Purves (2002) examines places in terms of location and material form. He looks specifically at their accessibility, sustainability, convenience to transport, and ease of use or functionality. He also briefly touches on the meanings that people create in response to experiences of places. Williams (2002) further examines meaningfulness in her study of the shift towards informal care giving in the home in addition to formal care provision by health services. She writes:

Places, together with the health care services which characterize them, are increasingly being seen as a context for the development and maintenance of the health of populations. Health geographers are interested in exploring the links between landscape, health and healing as they move away from viewing place as a physical landscape, and towards a relational view in which space is implicated as human activity or vice versa. Meaning is the key to the importance of places, and it is the subjective experiences that people have within places that give them significance (Williams, 2002:154).

Not only are spaces subjectively imbued with meanings, but they also create meanings, invoke responses and shape flows of power (Lawrence, 1990). In a recent study that explored how health professionals experience different clinical settings Nugus and colleagues have identified that the care setting both influenced and reaffirmed flows of power through, for example, the distribution of speaking between health professionals (Nugus et al., 2010: 903). Flows of power in health care settings has also been studied in such terms as patient experiences, patient–doctor communication, patient autonomy and empowerment (see for example, Aujoulat et
disempowerment and empowerment of disadvantaged groups, migrants and Indigenous people (Aujoulat, et al., 2008; Beisecker, 1990; Goodyear-Smith & Buetow, 2001; Jowsey, Gillespie, & Aspin, 2011; Quill & Brody, 1996). Our literature search did not identify any studies concerned equally with flows of power in terms of adult patients and space or place.

**Time**

In comparison with literature about meanings of place and space held by health service users, health service issues pertaining to time use and temporality have been measured and reported in the literature more abundantly. This may be due to the Western understandings of cause-and-effect and measurability of time (Postill, 2002). It may also reflect how time is culturally embedded as a key indicator of efficacy and, by extension, quality in the health industry, and is also the measurable unit equated to finance: that is, time is money (Gell, 1992). Public health research has addressed how health services manage the time use of health professionals and patients, for instance, in terms of waiting times for access to health care such as in emergency departments or other areas within the hospital, in doctor waiting rooms, or on elective surgery waiting lists (see for example, Cohn, 2001; Muntlin et al., 2006; Poissant et al., 2005; Siciliani & Hurst, 2004). The temporality of health service provision has also been researched in relation to embodied concepts of time (Morris, 2008; Rittman et al., 2004) and health professional capacity to 'make time' for providing preventive services in the restricted structure of health services systems (Kottke et al., 1993).
Research that combines sociological analysis of both places and temporality in health research has been minimal. In a rare study by Warin and colleagues (Warin et al., 2000), research concerning patient spatiotemporal experiences of community health centres in South Australia was undertaken. They argue that “experiences associated with space and time had a positive effect on health status by: diminishing barriers to health services, improving quality of care, increasing community participation, providing safe places for social interaction and strengthening people's sense of belonging or attachment to a particular community and place” (Warin, et al., 2000: 1863). In an effort to build on the space-use literature, and to link it with time use in particular, this paper addresses the question: How does the structuring of time and spaces influence Aboriginal and Torres Strait Islander patient experiences of health services? While our use of the term 'structure' can be taken to refer to the way that the physical environment is organised, our particular emphasis is the structuring of space through the interpersonal usages of the physical setting.

Methods
The Serious and Continuing Illness Policy and Practice Study (SCIPPS) aimed to develop policy and health system interventions that are patient-centred and support the provision of optimal care for patients with chronic illness and carers of family members. SCIPPS focused on three serious and long term diseases: complicated type 2 diabetes (‘diabetes’), chronic obstructive pulmonary disease (COPD) and chronic heart failure (CHF). These diseases are common, costly and require ongoing care from multiple providers and services (Jeon et al., 2010). To better understand the experiences of urban Aboriginal and Torres Strait Islander people affected by chronic illness SCIPPS researchers carried out a small qualitative study.
Study approval was obtained from the Australian National University Human Research Ethics Committee, the ACT Health ACT Human Research Ethics Committee, the University of Sydney Human Research Ethics Committee, Sydney West Area Health Service Human Research Ethics Committee and the Aboriginal Health and Medical Research Council of NSW. Consent was obtained from all participants prior to interview. The sub-study of Aboriginal and Torres Strait Islander experiences was planned with and informed by our ACCHS/AMSs collaborators who advised that participant confidentiality was of utmost importance, particularly given the small sample. Accordingly as much identifying data as possible has been removed from this paper and the referencing style 'participant' is used, as advised by the ACCHS/AMSs collaborators. The ACCHS/AMSs collaborators approved this paper prior to its submission for publication.

Recruitment

Data collection occurred during two three-month periods between March 2007 and November 2009. Nineteen Indigenous participants living with diabetes (N=19), COPD (N=3) and CHF (N=11) were recruited by purposive sampling through referrals from two ACCHS AMSs as well as a carer group in the Australian Capital Territory (ACT) and Western Sydney in New South Wales (NSW). Eligible participants included people living with one or more of these three conditions aged between 30 and 85 years. The relatively low age cut-off was chosen to reflect the earlier onset of chronic illness and shorter life expectancy of Indigenous Australians (Council of Australian Governments, 2009).
Percival (2004) and Wagner (1998) argue that family carers of people with chronic illness can provide important insight into the experiences of people living with chronic illness (Percival, 2004; Wagner, 1998). Three family carers of people with the sentinel chronic illnesses, two of whom were related to patient participants, were included in this study, with these people being recruited through an Indigenous informal chronic illness support group in the ACT.

The data collection and analysis was guided by the work of Lincoln & Guba (1985) in terms of the credibility, confirmability, transferability, and dependability to maximise the rigour of the study. We followed the advice of staff of the recruiting AMSs as well as members of the Indigenous Health Interest Group of the Australian National University (ANU) to assure appropriate Indigenous health research methods and community engagement (Humphery, 2001). Interviews continued until saturation of themes occurred (Morse & Field, 1995) at which point the dataset was closed and completed with 19 patients.

**Participant characteristics**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aboriginal and/or Torres Strait Islander</td>
<td>19</td>
</tr>
<tr>
<td>Age (years)</td>
<td>Range: 34–70</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
</tr>
<tr>
<td><em>Chronic heart failure</em></td>
<td>11</td>
</tr>
<tr>
<td><em>Chronic obstructive pulmonary disease</em></td>
<td>3</td>
</tr>
<tr>
<td><em>Type II diabetes mellitus</em></td>
<td>17</td>
</tr>
<tr>
<td>Duration of illness (years)</td>
<td>Range: 1–47</td>
</tr>
</tbody>
</table>
Semi-structured in-depth interviews were conducted with participants by four researchers with experience in multi-cultural research, none of whom were Australian Indigenous researchers. Each interview took between 45 to 90 minutes, following an interview guide. Participants were asked to describe their experience of living with a chronic illness as well as their experiences of interactions with health care professionals including doctors, nurses, health care workers, allied health practitioners in different health service places such as hospitals, general practices, AMSs, palliative care services. The research team judged that sufficient data had been gathered when interviews were no longer providing new insights or ideas central to the experience of having diabetes/COPD/CHF. Participants also completed a 10 minute survey addressing demographics, their health conditions and health care encounters.

**Analysis**

All interviews were electronically recorded and transcribed following assignation of verbatim transcript codes and pseudonyms. The data were analysed using secondary qualitative content and thematic analysis, assisted by QSR NVivo8 (QSR, 2008). The research team modified, by iteration, the coding scheme used in the general cohort. This scheme was used to code all transcripts with each transcript coded by three members of the research team and checked by two other members of the research team to ensure rigour. Following Morse and Field (1995) and Heaton (1998), we used secondary content analysis to identify issues in the data that were commonly raised by participants. The content analysis was assisted by frequency matrix coding in NVivo8. These issues were then further explored thematically. The findings that
are the subject of this paper relate to the interconnected themes listed in Table 2.

Other themes are reported elsewhere.

Table 2: Identified interconnected themes in the health service findings

<table>
<thead>
<tr>
<th>Theme [parent node]</th>
<th>Subtheme [child node]</th>
</tr>
</thead>
</table>
| Experiences of time (and space) | Waiting time  
|                              | Unproductive time  
|                              | Productive time (value)  
|                              | Continuity of care  |
| Space and Meaning (over time)  | Standards of care  
|                              | Cultural safety  
|                              | Flexibility of health services  
|                              | Access to health services  |
| Feelings                     | Feeling cared for (feeling safe)  
|                              | Quality of care  
|                              | Feeling uncared for  |
| Experiences of health service places | Mainstream health services  |
|                              | Aboriginal Medical Services  |

Results

Participants in this study reported spatiotemporal dynamics in their experiences of health care services in MHSs and in AMSs. All participants reported experiences of both MHSs and AMSs. The two AMSs that participants in this study accessed were characterised by small waiting rooms covered in Aboriginal art and health posters, and a door separating the waiting room from private consultation rooms. In the case of MHSs, participant experiences reflected negative encounters with both the clinical and non-clinical aspects of the service. Participants described positive experiences in general in an AMS context, but with experiences in the waiting room being quite different from their experiences with health professionals in the consulting rooms.

Articulations of culture with space: being known in the AMSs waiting room
The AMSs waiting room space contains strong cultural inflections. These track in two key directions, both of which can be understood as adding cultural ‘value’ to the place (see Table 2). The first aspect of value and space we draw attention to is the strong perception that it is a meeting place – a place of easy and enjoyable interaction. “I just, just ah come here on one of my day off and sit out here, have a talk with all my mates [laugh]”, comments participant A. To which he adds “there's always someone you know here [laugh]. So you see it can pass the time away. For me it's a social event too [laugh] coming here [laugh]. … you find out what goes on, yeah”. In the words of participant B “mostly Kooris [Aboriginal people] are coming here ... it’s sort of like a meeting place”. Here the environment of the clinic waiting room is discursively formed into an informal environment within a formal setting where enjoyable interactions are mobilised around community seemingly as much as sickness. Something of the specialness of the space, then, is linked to the quality and tone of interactions between peers. Patient and carer constructions around sociality in the waiting room negate and deflect representation of the space use as one that is solely about sickness. Where MHSs waiting rooms are constructed as quiet and formal sick spaces, AMSs waiting rooms are constructed as meeting and speaking spaces, where people happen to be sick.

This interaction between peers links to the second value, the fact that it creates a space in which the sharing of health information between equals occurs. Participant C said:

We share a lot. You know when we meet people we talk about things. It’s like when you go into [an MHSs] you as a whiter person, you might be lucky if somebody says hello to you. If we go in and I know someone we’ll have a good yarn. 'How you going with yours?' 'You got diabetes yeah. How many tablets are you on?' 'I'm on the needle.' 'Why? How high does yours get?' So there’s always that yarn that we
can pass on that information, ‘What do you do about it?’ and all this stuff, and I think sharing a lot of the things that we do that’s the difference... And not only that, if you’re a bit nervous then it calms you down, a lot of us, so there’s a lot of aspects I suppose we think on a cultural basis.

In this way participant C links the sharing of health information within the space with his culture, suggesting that the sharing is a cultural marker. Socialisation and informal sharing of information in AMSs waiting rooms serves to transform a place within the formal health service delivery environment into one of informality, but also one of increasing knowledge. There is some indication in the above quote that people also have the opportunity to offer and receive what we refer to elsewhere as ‘unsolicited support’ (Ward et al., 2011). Flows of informal and unsolicited support within the space in the waiting room are an important part of how the front of clinic space is constructed by people using it.

Temporal experiences of health service places

Participants reported informally sharing health information with peers in the waiting room, in contrast to the formal sharing of health information with health professionals that took place during consultations. The process of establishing shared knowledge between patients and doctors took place over ‘clock’ time and participants portrayed quality of care in terms of the way they perceived time use. If the participants identified both the immediate and long-term time they spent with health professionals and health services as beneficial, they identified that time use as well spent and reported their health care encounters as quality care. In addition, quality care incorporated the notion that doctors made sufficient time to spend with patients. Participants made comments such as “that’s the thing that AMSs do really well, they take their time. There are not time limits, so they can actually spend a bit
more time with you” (participant D) and “the doctors, they give up their time wherever they are, whether in the surgery, or even the dentist ... they’ve got a lot of things here for people, and they give up their time, and I think [it is] wonderful” (participant E). In this way participant temporal rhythms were synchronized with those of the health professionals. Participants also couched quality of care in terms of timely access to services and what they deemed to be appropriate patient time use in terms of seeing specialists and having tests. A participant with CHF put it this way: “You can appreciate that it’s important to me. If I spend half a day somewhere, it’s half a day of my life gone and I think ‘Well, do I bother?’ For what I’m getting out of it, do I need to go? There are other appointments I’ve got to see but in some of them I wonder if it's worth it” (participant F). In this example the participant's temporal experience of health services is acutely informed by his sense of having limited time to live.

Also of note is the interpretation of time in participant accounts of experiences in the waiting room, which we refer to as the space ‘in front of the door’; the door referencing the doctor's consultation room door and/or the door separating the waiting room from the hallway of consultation rooms. The time spent waiting was not often constructed as being wasted, as it was in the accounts of non-Indigenous participants accessing MHSs (Jeon et al., 2010). Rather it was constructed as creating an opportunity for other valued and important aspects of daily life to take place – sharing health information and spending time with friends and family. Perceptions of time spent in the waiting room were intrinsically linked with the value that Indigenous participants placed on feeling that they had sufficient time with health professionals. This value was often expressed in statements about time spent
‘in front of the door’. Although participants indicated that strong value of using the waiting room as a space for meeting with other members of the community, they said sometimes they did get frustrated with waiting a long time to see the health professional. This was immediately linked with a statement that once the participant got ‘behind the door’ they would have as much time as they needed to consult the health professional, and this was strongly associated with cultural safety, described below, as well as good quality of care (see Table 2). Participant C said “it’s a cultural aspect as well where we get to meet people. We get longer consultations with doctors. We sometimes get cheesed off about that but ... you get plenty of time to explain your problems. So we’ve got a lot of advantages”. Another said “when it’s your turn to go in with a doctor, you look at the time on the wall ... when you come out have a look at the time ... you know you’ve been in there for an hour, like it’s only supposed to be half an hour, but the doctors ... go over thoroughly ... really take their time ... that’s the good thing about here, the doctors” (participant G).

It hinges on the door
While the space in front of the door is one of informal and valued social interaction, the space behind the door is one of formal and professional interface with health carers. In both spaces cultural values and engagement of patients are evident. Behind the door, however, the cultural values are framed slightly differently. In addition to it being a space of sociality and sharing, it is also one of feeling safe and cared for, precisely because there is a perceived recognition of the cultural markers of sharing health information, health services as a meeting space, having a yarn, feeling valued that flow between the informal and formal spaces. Participants felt they had enough time with health care workers and that cultural safety was present in the formal
spaces. Additionally, participant feelings of value and perceptions that they could have a yarn with health care workers further was evidence of the flow of cultural markers between these two spaces.

Continuity of identity and value in the clinical space: behind the door

Participants portrayed AMSs doctors as trusted and valued health professionals because they felt known by them. Participants were known in front of the door and also behind the door, albeit in different ways. Behind the door in the clinical consultation space, part of being known was signalled by a perception of cultural safety – a perception that their identity will not be assaulted, challenged or denied, and that they will be respected and that they shared similar meanings and cultural knowledge with the health care provider (Eckermann et al., 2010). This contrasts with experiences of non-AMSs settings where they were unknown and were treated differently. For example, participant H who had experienced explicit racism from a specialist in MHSs said “so I talk to [my AMSs GP] about anything and everything, you know, and then of course he refers me on to the [MHSs] specialist. He refers me, but he doesn’t know what these specialists are like, you know”. For this participant, the experience of racism was identified as resulting from being unknown by the specialist, thus reinforcing the intrinsic value of being known to their experiences at the AMSs of quality care. This might signal a patient perception that the doctor and specialist are largely unknown to one another and therefore explain that the general practitioner (GP) does not realise the specialist may be treating people inappropriately. Alternatively, it may signal that the patient and the GP have different perceptions of the specialist that reflect their different positions within established hierarchies of power in the biomedical sphere, both of which have
implications for perceptions of continuity and co-ordination of care. We can also understand this participant's description as referencing the valued feelings of safety and feeling cared for that are present behind the door in the AMSs that the participant couches within a cultural safety framework; perceptions and feelings that participants did not often report having experienced behind MHSs doors. However, we also note that in this participant's account there is an implicit criticism of the AMSs in that they are unaware of the cultural insensitivity and danger represented by the specialist to whom they have been referred.

Picking up on the perception of feeling cared for and the importance of communication, participant J compared her experiences of health professionals at the AMSs and MHSs. She said “[AMS’s] Dr 1 helps out a lot. But like I said, Dr 1’s good. She’s very caring. Like the, the heart doctors [at MHSs] they just tell you, 'you got to go here and go there' and it’s up to you to do all that yourself, yeah. I think Dr 1’s very caring”. A carer participant described cultural safety:

There’s already cultural safety in AMSs so people can go in then they’re going to be comfortable to know that their needs are going to be met and that what they say is, if at times it’s not taken serious by the doctor you have other alternatives in an AMSs like the Aboriginal health workers or the registered nurses (participant D).

The importance placed on cultural safety in AMSs needs to be understood in the context of entrenched social and personal memories of not feeling safe in MHSs. This participant also signals a value of the option to interact with other AMSs Health professionals. Unlike the peer socialisation that occurs in the waiting room in front of the door, the formal space behind the door sees the appearance of hierarchies of resort described below, deployed around explicit professional statuses of different AMS staff. This participant, for example, described cultural safety in terms of
patients having options to seek advice from health professionals other than or in addition to their general practitioner. This is different from MHS settings, where there is no invitation to enter other doors and visit other health professionals.

**Discussion**

Indigenous health advocates assert the integrated service offered by ACCHS AMSs exemplify what good primary care truly means (Tongs, 2010). Providing as many services in the one location as possible, with strong links to visiting specialist services, is one of the factors that enable AMSs to claim that they truly look after the whole person. The primary care concept of looking after the whole person is one in which the person experiences continuity of identity, community and value through the whole journey through health services (Dussart, 2010; Herceg, 2011).

Our research suggests that in the Australian context there may be differences in patient satisfaction with services offered by MHSs and ACCHS AMSs. That is, the whole journey through these services and not just health professional encounters contributes to patient satisfaction, empowerment and engagement in managing their health. These findings confirm and support those reported by Nathan in 1980. MHS staff interviewed in Nathan’s study reported their perception that “Aboriginals hate waiting” and that long waiting period prevents their attending health services. In our study people commented on long waiting times when attending health services, however they also noted that the waiting:

- provided an opportunity to share experiences with other members of the community; and
was acceptable on the grounds that once they got through to the consultation they knew they would have adequate time with the health professional.

In addition, our findings suggest that the spatiotemporal experiential characteristics of health care services are different in AMSs and MHSs spaces, and that the meanings of both spaces can be altered. While MHSs may be genuine in their attempts to create an environment of welcome and respect, there is not good evidence of actions that encourage and sustain personal identity, community connectedness and personal value. There is considerable evidence in the literature of how health services are seen by consumers as disempowering, requiring people to follow the established rules and processes of 'good patient' in medical settings (Aujoulat, et al., 2008; Jowsey, et al., 2011). Many of the concerns of health consumer organisations are directed to remedying the failure of respect by health services for the person or to provide patient centred care (Health Care Consumers’ Association of the ACT, 2009).

Participants in this study identified waiting rooms in AMSs as spaces in which they felt the time spent was valued. The significant aspect of valued time in this regard is intrinsically connected to an ability to engage in meaningful interactions with other peers. It is therefore directly linked to issues around relationship. Nathan (1980) reports that urban Aboriginal people rely on community for support in their health management and are consistently likely to seek health information from family and friends before seeking health care from MHS, even though seeking health information from peers is sometimes associated with shame, such as information concerning contraception. People in our study sought and shared health information
from both peers and health professionals in different spaces within the AMS. Much has been written about informal and family support networks for those with chronic conditions outside the places of formal health care delivery (Dussart, 2010; Essue et al., 2010), but perceptions of the informal sociality that occur within these places suggests that the physical settings of the clinic space may have a role to play. This revolves around the question of how interactions in the spaces in front of the door might be used, or capitalised on, to create or enhance networks of support that would then flow out into the non-clinic community spaces or vice versa. Finding ways to address this would be consistent with a whole person or patient centred approach to health service delivery (see Nathan, 1980). People are not their condition; they have different articulations of the self that do not necessarily centre on their just happening to live with a chronic illness (Heil & Macdonald, 2008).

Similarly, participants in this study strongly articulated value in terms of time and connection with health professionals ‘behind the door’. There are resonances here with Atlas and colleagues’ (2009) concept of patient–physician connectedness. They suggest that physicians who foster closer relationships with their patients and identify them as their own may adhere more closely to the guidelines and by extension, secure better patient outcomes. Again, this is a question of relationship, and our findings suggest that the two AMSs in our study are very good at fostering strong relationships with those who attend the clinics. However, Atlas and colleagues (Atlas, et al., 2009: 332) are careful to stress that “a close continuous relationship requires the active participation of both the patient and the physician”. In terms of the findings presented here, there seems to be scope for more than one type of connectedness, which was seen in relation to AMSs attendees having available to
them what Kleinman (1980) referred to as a “hierarchy of resort”: a sense of feeling safe about approaching other health professionals in the clinic (Dussart, 2009; Kleinman, 1980). Kleinman has suggested that people seeking help with their health place health practitioners, specialists, and spiritualists in hierarchies. The person they believe holds the potential to effect the best possible health outcome for the patient is situated at the top of the hierarchy. For example, a hierarchy might have a priest at the top, followed by the general practitioner, and a naturopath at the bottom or it might comprise another ordering. Hierarchies of resort offer patients directional processes in seeking health care. The fostering of these kinds of hierarchies provides opportunities to mitigate situations where there may be break-downs in relationship between different health professionals and patients, as described above. This is especially important in settings where one cannot be guaranteed access to the same doctor on every visit as a consequence of ongoing capacity issues in the health services. In essence, this creates a community style interaction between clinic attendees behind the door that is analogous, although different in scope, to community as it is actualised in the space in front of the door. While this concept offers useful ways of understanding how multidisciplinary teams can work, the atomisation of the team and the places and spaces within which they work in many MHSs prevents the patient having choices about engaging that hierarchy of resort and gaining the benefit it offers.

Similar experiences to those of the ACCHS AMSs occur in other specialised, segregated services, such as some women’s health, HIV health, or migrant health or services where the waiting room offers a community of support, with a clear and specific identity that is carried through to the clinical space (see for example, Warin,
et al., 2000). Our findings suggest that the strength of these and ACCHS experiences lies in the continuous thread of patients feeling valued in and between these spaces. Extending this notion, Nathan (1980) and Heil and MacDonald (2008), note that Aboriginal peoples experience life as 'self-as-social' rather than self-as-individual (cf. Adam, 1988). Understanding the complexities of value intrinsically tied to this notion is imperative to shaping health service behaviour.

The connection between community-oriented specialised health services and improved client-focused culturally or socially appropriate health care is not limited to the GP waiting room or to service provision. The HIV literature was quick to identify that prevention was most effective when it was developed and implemented with broader gay community support. For example, the Australian National Centre in HIV Social Research’s large scale Social Aspects of AIDS study illustrated a positive correlation between a gay community attachment index and the adoption of safer sex practices (Kippax et al., 1993) and in the mid-nineties The Lancet published an article extolling the virtues of a community-based approach in HIV prevention (Coates et al., 1996).

What this paper offers is a snapshot of integration within a primary care service that is not limited to the relationships and communication between the clinical providers but incorporates integration for the patient on their journey through each component of the service. When we think of what characteristics we need to cement into new models of primary health care provision through one stop shops such as advanced medical homes (American College of Physicians, 2006) and multidisciplinary primary health care teams (Usherwood et al., 1997), we could well learn from the
lessons of the AMSs. Health care providers want people using services to see those services positively, to want to attend, to value the contribution that each health professional plays in their good health care and through that make the most of health services and optimise their own health. This is of particular importance in managing chronic illness. The long term relationship between the person and the services they use is crucial to planned and monitored care, and better health outcomes.

However, the quality of what goes on behind the door must match the experience of what goes on in front of the door. Not all people using a health service will want to meet people they know and/or engage in conversation with others while they wait to see a health professional. Indeed, most people in a waiting room in a mainstream practice may not know each other or even see each other as part of one community. Their needs and expectations are equally important and support the notion that there is no ideal one way to meet the diverse needs of people. This diversity notwithstanding, people of all creeds and walks of life hold a desire to feel valued and this paper has indicated some of the ways in which ACCHS AMSs contributes to those feelings and optimises health care.

Limitations

We did not aim for generalisability; rather, we aimed for a small representative sample of people living with the three index conditions, saturation of issues raised in responses from our participants, and coherent interpretations of our data. While the research was conducted across two local sites the findings do not indicate they are site-specific. The study recruited participants through AMSs and as such does not represent the views of people, who for whatever reason, choose not to access AMSs.
The study also only included people living in urban areas and their experiences are likely to differ considerably from those people living in rural and remote areas.

Conclusion

The experience of Indigenous Australians with chronic illness using health services is positive when the time spent by the person at each step of the service journey is worthwhile. Physical and temporal design of services could create this characteristic by going beyond the well-intentioned but superficial gestures of attempting to make a welcoming environment through displaying Indigenous artworks. Purposeful design to make each aspect of the experience meaningful and relevant to the whole person will be challenging, but will reintroduce opportunities for health care that have been limited by the segmented person as illness design features of our current system.

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Competing interests

The funding organisation (NHMRC) had no role in the study design, data collection, analysis and interpretation, or the writing and publication of this article. The authors declare no competing interests.
CHAPTER 10  AGENTS IN TIME


Abstract

Aboriginal and Torres Strait Islander people are the Indigenous people of Australia. The prevalence and burden of chronic disease among them is significantly higher than that of non-Indigenous Australians. This paper describes the chronic illness experiences of 19 Aboriginal and Torres Strait Islander people living in urban areas in terms of their strategic representations of self. Participants in this study used techniques of revealing and concealing chronic illness. These strategies were employed in multiple arenas—among family, among broader community, and in specific spaces including health care services. They highlight tensions that arise through the intersection between the desire to preserve family and community life, and the ways in which the physical body manifests chronic illness. In this paper we bring together notions of time (drawing on Zimbardo’s Time Perspectives theory) and biography (drawing on Bury’s Disrupted Biography theory). Through an analysis of shifting boundaries we conduct an exploratory investigation of the ways in which Aboriginal and Torres Strait Islander people living in urban areas in this study weave together elements of both past and future perspectives to mobilise modes of self-representation and agency in their management of chronic illness. We then consider some options for primary health care.

Keywords: Australia; diabetes; chronic illness; Aboriginal; biographical disruption; health service; Indigenous; primary health care time
Introduction

People experience chronic illness in the context of family (Ward et al., 2011), community (Heil & Macdonald, 2008), society (Bury, 1982); the past, the present and the future. Too often studies of patient experience have focused on individual processes of managing illness or communicating with health care providers to the exclusion of accounts that highlight the impact of chronic disease on personal experience, identity and life trajectory. However, some social scientists have conceptualised chronic illness as biographical (Bury, 1982). Experiences of chronic illness disrupt the way people experience everyday life; leading to disruptions to personal autonomy and senses of identity. Living with chronic illness requires biographical work to adjust and reconfigure personal biographies.

Cross cultural accounts such as Dussart’s (2009, 2010) suggest that living between two cultures creates additional dimensions for the task of biography. She found that people refashion different knowledges which shape their experiences of illness and lead to forms of agency, such as hiding illness, that appear to contradict western medical regimes but allow people to engage in important traditional social roles. Biographical disruptions and processes of reconfiguring identity take place in time, and in relation to past, present and future trajectories. Zimbardo’s work on Time Perspectives explores the role of time in agency, suggesting that individual changes in Time Perspectives can inform future health outcomes (Boniwell & Zimbardo, 2003; D'Alessio et al., 2003; van Beek et al., 2011; Zimbardo, 2002). In this paper we bring together notions of time and biography to illustrate the way the Aboriginal and Torres Strait Islander people who participated in this study shifted boundaries,
priorities and perspectives to mobilise modes of self-representation and agency in their management of chronic illness.

**Background**

Building on the work of Parsons (1967), Bury contends that chronic illness constitutes a major disruption to life and personal identity, disrupting social obligations, requiring people to take on new ways of being that carry with them new social obligations. These changes, according to Bury, fundamentally challenge the individual’s identity (Bury, 1982). He contends that chronic illness holds "precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted" (Bury, 1982: 169). Such disruptions are seen as creating risk insofar as the meanings and cultural categories which are applied to everyday experience and shared by others may be jeopardised.

Accounts of chronic illness from people living in cross cultural contexts suggest a significant additional dimension of biographical work. In relation to Australia’s Indigenous peoples specifically, biographical work is undertaken in multiple arenas; in the family and community context (Griew, et al. 2007; Ward, et al., 2011), in Indigenous and/or non-Indigenous health services (Scrimgeour & Scrimgeour, 2008; Sibthorpe, 2009); and is also informed by specific historical contexts (Aspin et al., 2012; Hoy, 2009; Paradies & Cunningham, 2009). Dussart, (2009, 2010) explored the ways in which the Walpiri people of the Western Desert interpret connections between traditional and western biomedical aetiologies of illness as a means of exploring their experience of chronic illness and understanding illness behaviours. She suggested that the sick role, as defined traditionally by Aboriginal people carries
with it strict rules of social obligation and rules of behaving that conflict with biomedical rules of self-management and geographical location/access to health services. This conflict, she suggests, deters people from revealing their diabetes and from consistently following biomedical paradigms of chronic illness management (Dussart, 2010).

Implicit in this account is the notion of hiding illness which refers to the ways that people employ agency in the present through constructing or representing ‘boundaries' between their lived experience of chronic illness and how they work within existing social conventions of interaction. Such conventions include responsibilities within family and community contexts. They also signal how people with chronic illness act within a western biomedical system and negotiate boundaries within it. Boundaries in the context of this paper include both the sense of how illness itself is hidden from the gaze of others, and also the circumstances and reasons concerned with revealing illness.

**Time and its application to the study of chronic illness**

Time is an important dimension of chronic illness experience. Zimbardo suggests that perception orientations of people towards their past and future structure their agency (Zimbardo, 2002; Zimbardo & Boyd, 1999). That is, people’s decisions and actions are informed by their perspective on their personal and wider societal past, or belief about their personal or wider societal possible future. Zimbardo suggests people can change their Time Perspectives and we contend that this might be a useful way of thinking about how to help people undertake the biographical work of chronic
illness. Such an analysis provides insight into how health services might best support people in this work.

According to Zimbardo and others, the perspectives of individuals concerning the past, present and future inform their present actions and behaviour (Boniwell & Zimbardo, 2003; D'Alessio, et al., 2003; van Beek, et al., 2011; Zimbardo, 2002). The works of Zimbardo and others on Time Perspectives (D'Alessio, et al., 2003; Drake et al., 2008; Stolarski et al., 2011; Zimbardo & Boyd, 1999) suggests that people have both negative and positive perspectives of time in relation to the past, present and future, and these Time Perspectives influence decision-making and behaviour. For Zimbardo and Boyd (1999: 1271), Time Perspectives are: “the often unconscious process whereby the continual flows of personal and social experiences are assigned to temporal categories, or time frames, that help to give order, coherence, and meaning to those events” (Zimbardo & Boyd, 1999). Boniwell and Zimbardo later write “Past Time Perspectives is associated with a focus on family, tradition and history” (2003: 129). A past Time Perspective about familial history of diabetes, for example, might locate diabetes in the blood as a result of colonisation (Dussart, 2010; Heil & Macdonald, 2008) and something beyond control or something to be mindful of in present choices around use of, for example, post-colonial biomedical health services. Alternatively, a Future Time Perspective about the future health of one’s children may invoke revealing and normalising behaviours. An individual’s Time Perspectives informs their agency and manipulation of boundaries.
Boniwell and Zimbardo point out that people’s Time Perspectives can change. Thus, a person’s motivations and behaviours, in this case for managing chronic illness, can also change (Huang, 2005; Jowsey et al., 2011; Nagel et al., 2009). This suggests that with the appropriate support people may be able to change their Time Perspectives and the way they employ agency in regards to their health behaviour and social obligations.

In this small study we aimed to extend these discourses, bringing together notions of time and biography to explore the social nature of chronic illness as experienced by Aboriginal and Torres Strait Islander people living in urban areas, and to examine the implications of this for health services. This paper asks ‘are particular kinds of Time Perspectives associated with the way people experience chronic illness socially and employ agency in managing certain social aspects of chronic illness?’ We argue that at certain times and in particular social situations individuals conceal, reveal or normalise chronic illness. Drawing on Bury’s notion of ‘disrupted biographies’ (1982), and Zimbardo’s Time Perspectives we explore the ways that people in this study mobilise modes of self-representation and agency in their management of chronic illness. While these modes of self-representation sometimes appear to conflict with best practice in western biomedical paradigms, they also reflect traditional ways of being and Time Perspectives that enable people to maintain social norms and obligations.

Design

This research is part of a larger study, The Serious and Continuing Illness Policy and Practice Study (SCIPPS), which aimed to develop policy and health system
interventions that would lead to better outcomes for people with chronic illness.

SCIPPS focused on three serious and long term illnesses – complicated type 2 diabetes (‘diabetes’ hereafter), chronic obstructive pulmonary disease (COPD) and chronic heart failure (CHF) – which are known to be common, costly and require ongoing care from multiple providers and services (Serious and Continuing Illness Policy and Practice Study, 2006). The SCIPPS qualitative study involved semi-structured interviews with participants who had diabetes, COPD and/or CHF; and family carers of people with these conditions. Methods have been described elsewhere in more detail (Jowsey et al., 2012; Ward, et al., 2011). This paper reports key findings from the analysis of nineteen interviews with Indigenous Australian participants who had chronic illness and/or cared for a family member with chronic illness.

Data collection occurred during two three-month periods between March 2007 and November 2009. Nineteen participants with diabetes (N=17), COPD (N=3), and/or CHF (N=11) were recruited. They were recruited by purposive sampling through referrals from Aboriginal Medical Services (AMS) and general practices in the Australian Capital Territory and in Western Sydney, New South Wales. Eligible participants included people with one or more of these three conditions aged between 30 and 85 years. Those included ranged in age from 34 to 70 years. Three family carers of people with the sentinel chronic illnesses (who were not necessarily related to the patient participants) were included in this study (Percival, 2004; Wagner, 1998).
Interview design

In constructing the interview question guideline we followed advice provided through personal communication with staff of the recruiting AMSs as well as members of the Indigenous Health Interest Group of the Australian National University to assure appropriate Indigenous health research questions were included. Semi-structured in-depth interviews were conducted with patients and carers. All interviews were conducted anonymously to ensure their privacy and confidentiality. Each interview ran for between 60 and 120 minutes, following a semi-structured interview guide. A team of four researchers with backgrounds in health and social science research conducted the interviews. Patients and carers also completed a 10 minute demographic survey and provided information about their health conditions and health care encounters. Participants were asked to describe their experience of living with a chronic illness (see Table 1). The research team judged that sufficient data had been gathered when interviews were no longer providing new insights or ideas central to the experience of having Diabetes/COPD/CHF, indicating data saturation.
### Table 1: Interview Guide

<table>
<thead>
<tr>
<th>Key questions</th>
<th>Critical incident / prompting questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Tell me about your experience in living with diabetes/COPD/CHF, OR as a carer.</td>
<td>• Can you tell me exactly what happened? OR Can you walk me through the incident?</td>
</tr>
<tr>
<td>• What concerns you most about your diabetes/COPD/CHF, OR as a carer?</td>
<td>• Why do you think that happened?</td>
</tr>
<tr>
<td>• What is your understanding of diabetes/COPD/CHF?</td>
<td>• How did that affect you/others?</td>
</tr>
<tr>
<td>• What have been the greatest challenges that you have faced as a patient, OR as a carer?</td>
<td>• How did you cope?</td>
</tr>
<tr>
<td>• Tell me about your experience with health professionals in terms of managing your diabetes/COPD/CHF, OR as a carer.</td>
<td>• What do you think would prevent a similar thing happening again?</td>
</tr>
<tr>
<td>• Tell me about your experience with health services in terms of managing your diabetes/COPD/CHF, OR as a carer.</td>
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</tr>
<tr>
<td>• Can you think of anything you would change in health services to improve your experiences or even to prevent negative experiences from happening (again)?</td>
<td></td>
</tr>
<tr>
<td>• Tell me about informal support or help other than health care services you are getting as a patient, OR as a carer</td>
<td></td>
</tr>
<tr>
<td>• Have you ever had any experiences with health services where you did not feel safe?</td>
<td></td>
</tr>
<tr>
<td>• From your experience as in Indigenous person, could you tell me what you think the main issues are for Indigenous people in dealing with the health system?</td>
<td></td>
</tr>
</tbody>
</table>

### Analysis

All interviews were electronically recorded and transcribed verbatim. The data were analysed using qualitative content and thematic analysis, assisted by QSR NVivo8 (QSR, 2008). The research team iteratively established a coding scheme based on analysis of the transcripts and this scheme was used to code all transcripts (each transcript was coded by four members of the research team to ensure rigour).

Following Morse & Field, we used content analysis to identify issues in the data that were commonly raised by participants (Morse & Field, 1995). The content analysis
was assisted by frequency matrix coding in NVivo8. The emerging issues were then further explored thematically to arrive at the findings. Relevant social theory was then identified on the basis of its applicability to deepening our understanding of the findings.

Descriptive analysis (frequencies, means, modes and medians) of the survey data was undertaken using SPSS version 15 (SPSS, 2006). Four key findings emerged from this study, one of which is reported here. The other three key findings concern experiences with health care professionals, experiences of unsolicited informal support, and experiences of spaces and time in health services. These findings have been reported elsewhere (Jowsey, et al., 2012; Ward, et al., 2011, Aspin, et al. 2012). For reporting findings, staff of the AMSs advised us to use the labelling system ‘patient1’ and ‘carer1’ to assure anonymity of participants.

**Ethics**

Study approval was obtained from the Australian National University Human Research Ethics Committee, the ACT Health ACT Human Research Ethics Committee, the University of Sydney Human Research Ethics Committee, Sydney West Area Health Service Human Research Ethics Committee and the Aboriginal Health and Medical and Research Council of NSW. Written consent was obtained from all participants prior to participation.

**Results**

Most participants in the sample were ‘older aged adults’ (45+ years). Thirteen participants had two or more of the three index chronic illnesses. Participants also
had other chronic illnesses including hypertension (n=7), kidney disease or kidney failure (n=3), stroke (n=2), sleep apnoea (n=2), and chronic pain (n=3). Some participants spontaneously raised the issue of smoking: (current smoker n=4; previous smoker n=3; participant’s care recipient smokes n=3). Four participants reported having previously had an alcohol problem.
Table 2: Participant Sample Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male:Female</td>
<td>12:7</td>
<td>63:37</td>
</tr>
<tr>
<td>Torres Strait Islander</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Aboriginal</td>
<td>18</td>
<td>95</td>
</tr>
<tr>
<td>Married</td>
<td>7</td>
<td>37</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;45</td>
<td>3</td>
<td>16</td>
</tr>
<tr>
<td>45–60</td>
<td>6</td>
<td>31</td>
</tr>
<tr>
<td>61–70</td>
<td>10</td>
<td>52</td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working (part or full-time)</td>
<td>6</td>
<td>31</td>
</tr>
<tr>
<td>Disabled/sick</td>
<td>3</td>
<td>16</td>
</tr>
<tr>
<td>Retired</td>
<td>8</td>
<td>42</td>
</tr>
<tr>
<td>Studying/at home</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td>Chronic Condition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>17</td>
<td>89</td>
</tr>
<tr>
<td>COPD</td>
<td>3</td>
<td>16</td>
</tr>
<tr>
<td>Chronic Heart Failure</td>
<td>11</td>
<td>58</td>
</tr>
<tr>
<td>More than one of above</td>
<td>11</td>
<td>58</td>
</tr>
<tr>
<td>Duration of illness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>16.5±16.9</td>
<td></td>
</tr>
<tr>
<td>COPD</td>
<td>16.5±21.9</td>
<td></td>
</tr>
<tr>
<td>Chronic Heart Failure</td>
<td>16.8±17.8</td>
<td></td>
</tr>
<tr>
<td>Other co-morbidities</td>
<td>18</td>
<td>95</td>
</tr>
<tr>
<td>Average number of medications</td>
<td>4±2.5</td>
<td></td>
</tr>
</tbody>
</table>

Experiences of chronic illness

Participants articulated many representations of illness. Illness was seen as something that was steeped in familial history and as such, inevitable. In the words of one participant: “My mum was insulin dependent, my grandmother on my father’s side was also insulin dependent. I mean it was inevitable, you know” (patient2), and in the words of others, “I was born with it…my mother had it and it was hereditary. A lot of my family died before 45[years], in fact” (patient1) and “We seem to think that it’s something that’s hereditary, that we have to get it” (carer2). We use the term ‘in the blood’ to reference this representation of unavoidable ‘hereditary’ illness. The
experience of living with or around others with chronic illness was depicted as an entrenched social reality that referenced both indirect and immediate experiences of chronic illness revealed through family (cf. Thompson & Gifford, 2000). Present experiences of chronic illness were located as arising through this familial past (see Beckett, 1988). People’s Time Perspective on the past, as Zimbardo puts it (Boniwell & Zimbardo, 2003; Stolarski, et al., 2011; Zimbardo, 2002), informed decision-making and actions in the present.

The present and hiding illness

People in this study reported hiding their illness but they also reported circumstances in which illness was revealed and normalised. In one of the interesting ‘concealment’ aspects of illness, participants reported being knowingly complicit in concealing the more mundane self-management aspects of the illness that would signal to others that they or their loved ones were sick. In some cases this was reported as having cultural inflections. That is, the ‘boundary’ centred on an expectation of people behaving in culturally accepted ways even when they knew doing so could lead them to feel physically unwell in the immediate future and could lead to long-term complications of their condition (Boniwell & Zimbardo, 2003). An example of this comes from an Aboriginal woman in her thirties who acted as a carer for her Torres Strait Islander partner who had diabetes. In general she expressed a strong sense of frustration that he decided not to refrain from eating foods that were high in sugar and fat, when he was with his people on the islands. There are linkages here to a sense of shame about being sick; that is, if he were to conspicuously avoid such foods his sickness would be strongly signalled. When asked if people in the community knew that he was ill she commented:
People do know and it [diabetes] is so big up there, but people still have this thing of wanting to keep it quiet, but then when he’s with his own people he eats so much food because the food is very cultural. So he will not stop himself from eating and say ‘oh look I have to watch my sugar mate I’m diabetes, I’ve got diabetes’. He’s just going to sit there and become a part of that social network and eat and be happy, but he will suffer later for that. And there’s normally a point where I’m sitting at the table glaring at him, kind of saying in a way but without verbalising it ‘that’s enough you’re going to get sick (carer3).

This participant supported the concealment of her partner’s illness by refraining from signalling it in an overt way that would shame him in front of his peers. Instead she chose to provide a non-verbal challenge to his behaviour. The motivations behind this concealment may relate to prioritisations of sociality and community over individual bodily needs, and can also be understood in terms of normalisation and discourses of what constitutes normal. Although this participant observed that diabetes was prevalent in the community she also alluded to the taboos of acknowledging and normalising its prevalence, which is itself an example of the ways in which the community hides illness through continuing the traditional ways of eating and sharing food. Members of the community separate their (social) ‘community’ behaviour from their (individual) 'health' behaviour. This participant was equally frustrated by her partner's disregard for effectively managing the diabetes with medication, reporting that he did not take medication while he was on the islands even when this led to him feeling unwell. She explained, “He’s a traditional man and he doesn’t like medications” (carer3). Both of their actions in the present were dictated by a traditional cultural knowledge and prioritisation of cultural ways rather than an anticipated future of his feeling unwell. This is an illustration of what Boniwell and Zimbardo (2003) would identify as an orientation towards the present-hedonistic Time Perspective, also informed by an orientation towards the historical and cultural past.
Other ways that illness can be hidden relate not so much to the kind of cultural nuances noted above, but stem from priority setting in which responsibility to family features as the top concern. Dussart suggests that illness becomes hidden, not through a kind of wilful denial, but through a sense of obligation and protection (2009; see also Dussart 2010). In our study this sometimes appeared to be about responsibilities to children, while at others it was due to looking after family members who were themselves quite ill. A man in his 50s said “I’ve got two kids to get off to school …and after that everything else… and you think ‘oh sugar I should have took my tablets, yeah I will take them later, ... then later comes and you’ve forgot all about them’ ” (patient13). Two participants, each with CHF and diabetes, located the onset of CHF as a result of fulfilling obligations, caring for family members, and concealing by ignoring their exhaustion over a long period to the point where they both experienced a heart attack (patient15, patient9).

One interpretation of what is occurring in these instances is a forgetting or repression of one’s own illness in order to benefit others. A participant who cared for her mother up until the time she died and was still caring for her widowed father said:

I was still in pain but that [was ignored] to care for mum. You don’t worry about your own pain. Since mum died then I fell in a heap and then all my pain and that from my arms and that well then that just shot up, you know. Because well it’s just a power thing ... It’s something that you’ve got to do for your family. It was after mum passed away that all my pain started to sort of come out. I just felt the pain, I suppose. (Patient2).

Not only did she live with the pain, she also indicated that it exacerbated her arm condition by referring to how the pain increased. That is, concealing the illness (by ignoring it) exacerbated her arm condition.
Illness also became hidden through representations of autonomy. Some of these constructions centred on not getting family involved with the illness and keeping to one’s self. There is a boundary thrown into relief here in a double sense. On the one hand it represents a separation between family and the illness, while on the other it is between the individual as independent in the face of a condition that could be constructed as eroding such independence due to deteriorating health. Separation between family and the illness was something that participants engaged in both consciously and unconsciously. A man in his 50s with diabetes and CHF said “I try not to have any of my family around me … you know I mind my own business” (patient13), and “they don’t get involved in it much and I don’t get them involved in it much. ... they don’t know much about me illness, or they know I am a diabetic but they don’t know about me, what it does or tablets or anything like that” (patient13). Similarly, in discussing the connection between independence and their illness a participant said “Yeah, but I, I try to be independent see … I don’t let them know what is wrong with me” (patient11). These experiences concerning independence and illness management were also a feature of experiences reported in the larger SCIPPS qualitative study with the wider Australian population (Jeon et al., 2010).

Empowerment: revealing and normalising the illness

In addition to the ways in which illness became hidden, participants also engaged in processes of empowerment, through revealing and normalising illness. The realities of living with illness were deployed to avert the perceived inevitability of developing chronic illness as a result of its being ‘in the blood.’
Participants reported actively being a ‘role model’ to children or other family members by carrying out their blood sugar testing in front of children. Participants said “I’ve got to set an example so that’s something that motivates me with taking my sugar levels and everything in front of her” (patient8) and “when I’m testing, I’m always saying ‘bloody hell, how can that happen?’ … and I say [to my children], ‘Oi …’this is what you don’t want’ ”(patient4). Here there is the act of being a role model, of setting an example of how to live with illness. There is also a caring dimension by encouraging family members to avert the illness altogether through healthy living. One participant with COPD discussed how he mobilised the affective dimensions of his hospitalisations to provide support and encouragement to his family, and his daughter in particular:

Like I say, [they] get affected by it, you know, when I have to go into hospital, and away from her, like you know, ‘cause I’m very protective of my daughter, I love my daughter. And then they have to travel to come to visit, and like you know, and they see me like with drips hanging out here and there, or something else, you know? That takes effect on them, that’s why like I tell them to be positive and like you know, stick with their like physical things like you know, sport and that …. make them like realise there is more to life than anything else. Your health is more important than anything (patient10).

In addition, the experience of illness confers a type of authority that allows one to comment on the potentially detrimental effects of family members’ lifestyles. A 60 year old man with diabetes, CHF and COPD put it this way: “Well, they’ve all took a note, from what I keep saying to my grand-daughters and grandson and all the grandsons all drink Coca Cola. … I preach to them all the time. I say ‘that’s why I’m a diabetic because of all the sugary drinks’ ” (patient14). What this speaks to is something that is counterintuitive about the lived experience of illness; that there are opportunities for empowerment through drawing on notions of wisdom and knowledge gained through the experience of illness. It creates forms of agency that
are not available if one is of sound health because it relies on first-hand experiential knowledge of living with illness. In this context, therefore participants did not seem to think it problematic to reference the cause of the illness to both family history of illness and lifestyle behaviour (such as drinking Coca Cola); this phenomenon has also been described elsewhere (Dussart, 2010).

Empowerment or agency allows a person to normalise illness internally and within family and community contexts. Not only is normalization played out through being a role model in the immediate family context as in the examples provided above, it also played out in a wider environmental and societal context. One way this occurred was through actively making illness visible to the wider community, that is, beyond just immediate family members. The following example comes from a 65 year old woman who cared for her husband until he died from complications of diabetes. She explains how she and her husband made an informational video about diabetes to educate future generations: “we actually made a video. My husband made … it actually … it was quite funny how it all came about. He used to go and talk to schools about diabetes and explain to kids what the sugar was doing in your blood, and just explaining in real easy terms” (carer1).

Another example of exerting agency through revealing and normalising illness references a community context. A 66 year old man with diabetes and CHF spoke of his granddaughter who had diabetes and lived with her mother in a setting he believed to be detrimental to her ability to develop good self-management strategies: “I just care about what will affect the little girl. And I know for a fact they’re in that town drugs, and drunks and alcohol and everything, but I can’t do nothing about it”
While he expresses frustration at his inability to effect change in the granddaughter’s home environment, which is linked in part to his own poor health, he also attempts to effect a change in the way the granddaughter sees her environment by having her come to stay with him at least 6 weeks a year. “That’s why I bring her down here, every, Christmas”, he remarks, “six weeks at least, that way she’s getting away and she’s seeing the other side of life rather than that side all the time” (patient8). The agency at work here is not just centred on trying to normalise the illness and its management for the grand-daughter, rather we suggest it is also centered around attempts to de-normalise her home environment and show her what Rapport refers to as an “alternative world” (Rapport, 1997). Both environments are ‘family’ based, but one is constructed as ‘unhealthy’ while the other ‘healthy’ through the normalisation of illness and healthy living. Here an irony emerges in that the ‘healthy’ family environment is one where the illness is clearly present and visible. These examples of hiding, revealing and normalising illness all illustrate participant responses to biographical disruption. Additionally, this participant references his efforts to create a temporal rhythm whereby his granddaughter stays with him for six weeks every Christmas. His intention to continue this rhythm signals a balanced future time orientation (Boniwell & Zimbardo, 2003).

Discussion

Participants in this study described processes of concealing, revealing, and normalising their experience of chronic illness to themselves, family and the wider community. In doing so they unveiled the complex nature of relationships and the disruptions to these relationships that can be caused by chronic illness. A Torres Strait Islander man with diabetes concealed his illness from friends in order to (patient8).
privilege the social act of eating ‘cultural foods’ with his community. He knew the ramifications of his actions would likely include increased physical symptoms of sickness (see also, Dussart 2010). Another man with diabetes and kidney disease normalised chronic illness by testing his blood sugar levels in front of children and in doing so not only contributed to their knowledge of health and illness, but allowed himself to imagine better futures for them. These temporally and socially gauged processes, we argue, are intrinsic aspects of Aboriginal and Torres Strait Islander chronic illness experiences. Participants employed processes of restoring order to their identities and their relationships with others through hiding, revealing and normalising chronic illness. The individual’s agency — their ability to manage these relationships — is signalled through the individual’s manipulation and movement of boundaries so that illness is sometimes hidden and sometimes revealed. People hold different motivations for doing so, some problematic such as the relationships between shame and illness (which has been reported in other research contexts (Chae et al., 2010; Werner et al., 2004)), and some empowering such as motivations to protect family, to prioritise culture and community, and to set an example of good self-management behaviour for the next generation. These dynamics reflect social boundaries and historical influences, and point to wider issues of representation and autonomy (Aujoulat et al., 2008; Foucault, 1970; Rapport, 1997).

Our participants indicated that strong connections to family and the wider community were deeply central to their identity as Indigenous Australians and this was inextricably linked to their experiences of living with chronic illness. Chronic illness was sometimes constructed as something that was inevitable through being ‘hereditary’ or in our words, “in the blood”. This perception may signal
disempowerment as family and community did not necessarily 'protect' the individual body from illness. At times, notions of responsibility to family and caring obligations took precedence over some participants' attention to looking after their own health. Alternatively, some family settings carried strong references to normalisation of chronic illness through self-management support and even subverted the inevitability of chronic illness through provision of educational guidance to younger members of the family and to the community.

**Strengths and limitations**

The findings in this small study support and build on the work of Dussart (2009, 2010). We have combined social with temporal theories to understand our findings in a novel way. Our application of Bury’s theory has demonstrated that his notion of disrupted biography remains relevant to understanding present day experiences of chronic illness, and specifically experiences of Aboriginal and Torres Strait Islander people. Our use of Zimbardo’s theory is novel in that we have applied his ideas to qualitative enquiry. We have not emphasised the positive/negative elements of Zimbardo’s Time Perspectives theory here because we find it subjectively problematic; that is, we did not ask people in the study to assign these binary values to their actions and so are not in a position to comment on which choices, perceptions and behaviour reflect, for example, a past negative or a past positive.

We sought to include equal numbers of Aboriginal and Torres Strait Islander people, however only one participant in the study identified as Torres Strait Islander. This paper does not mean to suggest that there are no relevant cultural differences between these two groups. Participants were all recruited through AMSs and as such
the findings may not represent the experiences of Aboriginal and Torres Strait Islander peoples who, for whatever reason, choose not to access an AMS.

**Implications for practice**

One critical aspect of person-centred care is the utilisation of patient voices to inform care (Wagner, 1998). People in this study have strong voices that hold the potential to effect change. If health disparities are to be reduced and patient experiences improved, more focus must be given to understanding the influence of history on present day experience as well as the nuances of patient empowerment through agency in social obligation. In providing patient-centred care the experiences and needs of Indigenous Australians living with chronic illness must be understood and factored into health policy and practice initiatives.

One health policy area that could be pursued is the enhancement of opportunities for those living with chronic illness to engage in activities in which they are able to trade on experiences of living with chronic illness in a productive and empowering space. In terms of our findings, this means following a person, family and culturally-centred model by providing opportunities for Indigenous Australians with chronic illness to exercise forms of agency that are unique to their individual experience of chronic illness. Recent health policy initiatives have attempted to cater for these kinds of cultural aspects of the chronic illness experience through culturally-specific health and self-management programs. One successful example is the NSW Health Aboriginal Vascular Health Program, which supported early detection of illness and risk, and supported self-management following a 'whole of person' approach that catered to Indigenous concepts of health and illness (NSW Health, 2004). This
program has been followed by the Chronic Care for Aboriginal People Program. Another example is the emerging integration of Indigenous definitions of health that include ties to country and community into health policies and programs (Burgess et al., 2005; Ganesharajah, 2009; Social Health Reference Group, 2004), and family centred approaches that recognise the need for longer term relationships with individuals, families and community for addressing chronic illness (Griew, et al., 2007). These kinds of initiatives point to ways in which health services can acknowledge and improve the experiences of Indigenous Australians with chronic illness and contribute to closing the gap in health disparities and experiences of chronic illness (Altman et al., 2008). As Hayman et al. argue, it is essential that these kinds of services have access to continuous funding to improve health outcomes and experiences of Indigenous Australians (Hayman, 2010).

Finally, our study has demonstrated that the individual is empowered through having the opportunity to observe and potentially revise their relationship to the biographical disruptions that arise through the experience of living with chronic illness (Aujoulat, et al., 2008). While Bury's theory of disrupted biography shows that chronic illness has the potential to significantly redirect an individual’s identity, our study suggests that individuals manipulate the way disruptions are experienced by alternately hiding, revealing and normalising their illness. Drawing on Zimbardo’s Time Perspectives theory, we suggest that peoples’ capacity to do so may be informed by shifting focus from the past/present to future Time Perspectives. These aspects of empowerment point to potentially less obvious health policy and service options; that acknowledge the creative capacity of individuals to exercise their ‘will to meaning’ (Rapport, 1997) concerning chronic illness and their past, present and future.
Practitioners should maintain a keen awareness that the cultural kinship ties and rules of obligation that function with Aboriginal and Torres Strait Islander societies hold movable boundaries for individuals that represent additional dimensions in the experience of chronic illness. Supporting people to address these may help individuals to both normalise, hide and reveal their illness in ways that enable them to engage in choices and behaviour that serves their individual health within the wider cultural and community contexts.

Motivational interviewing is a psychological approach widely utilised by health professionals to motivate patients and develop their self-management ability (Zwar et al., 2006). It is a process through which trained professionals elicit arguments for change from clients, and in so doing shift the focus from why the individual cannot achieve change to how they can implement change (Rollnick & Allison, 2004). We suggest there are distinct temporal parallels here between Time Perspectives theory and motivational interviewing. The success of motivational interviewing rests on the way it shifts peoples’ focus in time from past ambivalence to future change. It follows that motivational interviewing may also hold the key to redirecting people’s Time Perspectives. In the case of people living with chronic illness, motivational interviewers should be cognisant of the additional discrepancies that may arise in a client’s lived experience of chronic illness due to living between two cultures.

Motivational counselling may assist clients to identify and reflect on these discrepancies as they join up past and present experiences in a future orientation. For, as the Time Perspective studies have shown, this shift leads to increased health and wellbeing. Thus, motivational interviewing may prove to be a beneficial tool for
empowering Aboriginal and Torres Strait Islander people too, as long as practitioners are strongly grounded in understanding the different influences that cultural kinship ties and rules of obligation hold for moving boundaries in the lived experience of those with chronic illness.

**Conclusion**

The experiences of Aboriginal and Torres Strait Islander people living in urban settings are often overlooked in Indigenous health research. This study highlights the importance of not assuming that people geographically removed from their cultural origins, are completely detached from or have ‘lost’ their cultural ways of being; or indeed, that they place less importance on culture and community. Participants in this study used techniques of revealing and concealing chronic illness. These strategies were employed in multiple arenas—among family, among broader community, and in specific spaces including health care services. They highlight tensions that arise through the intersection between the desire to preserve family and community life, and the ways in which the physical body manifests chronic illness. The strategies also illustrate some of the complex shades of time that underpin people’s experiences of chronic illness. The study points to a need to incorporate into routine health service delivery support for the biographical work of chronic illness articulated by the Aboriginal and Torres Strait Islander people in this study. In providing culturally appropriate care the experiences and needs of Indigenous Australians living with chronic illness must be understood and factored into health policy and practice initiatives.
Acknowledgements

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Competing interests

The funding organisation (NHMRC) had no role in the study design, data collection, analysis and interpretation, or the writing and publication of this article. The authors declare no competing interests.
Throughout the papers that constitute my thesis, I have worked to disrupt the notion that there is a single overarching model of ‘chronic illness’ that would allow us to predict how the future will unfurl for chronically ill people. I have argued that, while Bury’s (1982, 1991) model of disrupted biographies fits very well for some experiences of chronic illness, not all patients will have their future plans and goals permanently ‘disrupted’ by chronic illness. While many people in my study found this to be so, others experienced how chronic illness can enfold itself into the habitual rhythms already undertaken by the person – at work, in sociality amongst friends and family, and so on – as managing the illness becomes, itself, more a part of everyday life than a disruption to it. Indeed, very often when chronic illness is backgrounded in this way, an exacerbation of the illness is experienced as disruptive – indicating just how ordinary some experiences of chronic illness can become over time (cf. Morris, 2008).

One outcome of looking critically at Bury’s work (1982), as well as that of Morris (2008) – both of which have set the scene for how social scientists understand chronic illness – has been to turn attention away from disrupted biographies in which the potentiality of the future is unattainable, and back toward the present, as a point in which agents can powerfully effect change to their experiences of chronic illness. This does not mean that the person dwells solely in present concerns, however; and this is because chronic illness itself brings about a range of considerations about the past, present and future. What it does entail is a focus on changes occurring in the
chronically ill body and the associated needs that follow – needs to adapt to new social and biological limitations born of such changes.

In their 1992 work, Corbin and Strauss alert us to how chronic illness may be experienced by the person in and through their descriptions of distinct phases of illness. They describe nine key phases: pre-trajectory, trajectory onset, crisis, comeback, acute, stable, unstable, downward, and dying. Three of the phases they describe are appropriated into my own model described below. The stable phase is where chronic illness symptoms are under control and the individual with chronic illness is self-managing; the crisis phase is where the illness symptoms are uncontrolled and exacerbated to the point where emergency medical intervention is required; and the dying phase (referred to below as death) is where the illness progresses from the downward phase to death (Corbin and Strauss, 1992; see also, Lubkin and Lasren, 2012), or as Heidegger puts it, the possibility of ‘no-longer-being’ (Heidegger 1962; see also Morris 2008).

Between the stable and crisis phases are the unstable and acute phases, where symptoms of illness increase or are unrelieved, and are less controlled than in the stable phase. There is also a comeback phase, which “signals a gradual return to an acceptable way of life within the symptoms that the disease imposes” (Lubkin and Lasren, 2012: 37). Corbin and Strauss note that these phases do not necessarily occur in linear order. While they may not unfold in a strict temporal order, their occurrence nevertheless reveals the relevance of time in experiences of chronic illness, in the sense that the present and future and how one thinks about time orientations vary in accordance with the phases of illness the person is experiencing.
It is the phases in the middle of the above list – crisis, comeback, acute, stable and unstable – that tend to occur repeatedly and out of linear order. A person who has been in a crisis phase before may enter a crisis phase again at a later point in time and in this sense the progression of the illness is not only unpredictable but also circular – bringing past into present and potentially future experience. The timing of moving between phases is also unpredictable – a person may remain in a particular phase for a long or short duration. The unpredictable and uncertain nature of this relationship between phases and time contributes to the experience of chronic illness as biographically disrupting (Bury 1982) and as creating provisional time (Morris 2008) because it interferes with a habituated management rhythm, and because it may also remind the individual that it is possible that they may be about to enter a final progression of phases into their dying phase. While the phases may not unfold in a strict temporal order, their occurrence nevertheless reveals an immediate relationship between the individual and time; one built on change, uncertainty and a desire to increase certainty. This desire, I argue, is manifest in the habituated rhythms and practices – including social ones – employed to affect the individual’s illness duration, primarily, in the stable phase.

In the Chronic Illness Management Time model I have developed (see figure 1 below), some of this importance is expressed. For instance, in a stable self-management phase (Point D) the individual is able to balance the demands that the chronically ill body makes of a person’s time with those of sociality, incorporating their ordinary social obligations and engagements with managing illness; to both provide and receive social support. It is in this phase that illness might become
habituated, or fall into the background of life, as an unreflected-upon rhythm of life, to the extent that it is like undertaking any other habitual task one might perform in the course of everyday life. Moving into crisis or revised phases may alter this balance – it may trigger not only illness prominence as the illness rushes back into the foreground of experience, but may propel the person into thinking and acting in the present body as it is experienced through pain and even the possibility of death. Such experience might involve quite different actions in and toward time than previously; it may even be a situation in which the future is imagined as a single and critical point of salvation, such as arriving at the hospital in time to preserve life.  

As the individual moves into a crisis phase the balance between the body and sociality is disrupted and the individual’s sociality is largely reduced to receiver mode. For example, they are unable to maintain usual social roles such as preparing communal meals or attending work; instead they are reliant on others to prepare meals for them. Their capacity to undertake health-related activity is also depleted and their reliance on health care professionals is increased. This shift between receiver and giver-capable social modes (changes to the usual rules governing social obligation and reciprocity) is one of the causes of biographical disruption (Bury, 1982; Parsons 1967). Another cause of biographical disruption is the looming possibility of point G in the table given at figure 1 – death – brought sharply into focus when the individual is in point E, the crisis phase. The individual in crisis may

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4 In the table given at figure 1, at points D, E and F the individual is informed by various temporal structures. Points A, B and C reference the multiple layering of time as it is experienced by the individual. As mentioned in the introduction to this thesis, there are many temporal structures that inform people’s lived experiences. Temporal structure A might be, for example, CCT. Temporal structure A may be more influential at point F than at points E, D and G. Likewise, the individual in point D may be more heavily informed by temporal biological relativity or process time, whereas at point E they may be more informed by health service rhythms or by life cycle time (Boxenbaum, 1986). At each point multiple temporal structures inform the individual, some more than others.
become more aware of the possibility of death than when at points D or F, even though death can occur (as a result of or independent of illness) at any time.

**Chronic Illness Management Time Model**

Based on the thesis findings, I propose a model for understanding the complex relationships that arise between time and chronic illness. The model is based on my thesis conclusion, that chronic illness may be experienced as a multiply, rather than as a singular, experience that may itself change quite radically over time, and that may be at times enfolded into everyday experience and at other times radically depart from it. The model I propose thus attends to the importance of the chronic in the experience of the temporal. Additionally, it draws, as stated above, on the notion of temporally-informed illness phases. It is intended to form the basis for improved delivery of care to those with chronic illness.

In keeping with this approach, the model attempts to recognise that chronic illness makes different demands on time during different phases, as described in figure 1, but that time – as obvious as it is in the word ‘chronic’ – is not recognised as lived temporality by those dispensing care advice. Health care is generally operated in Australia in a siloed approach, meaning that a person may have multiple care providers who each provide care with little interaction and communication between themselves and other care providers. Current health care policies and systems (including Medicare Benefit Schedule (MBS) remunerations) are predominantly siloed – they tend to have a single-illness orientation and single health care provider orientation. While well-intentioned, this approach can have unintended impacts on people with severe or multiple illnesses because, as I detailed in Chapter six: time
use of people with multi-morbidity, the time these people spend on health-related activity can already be quite high and, in the case of multiple illnesses, they commonly need to attend multiple appointments with health care professionals. In the qualitative studies I reported on in the introduction and Chapter three (Case studies), participants with severe or multiple illnesses felt that when health care professionals recommended courses of action the recommendations did not consider the patient's existing commitment of time to managing chronic illness, and in the context of other aspects of their lives.

This was important because the new recommendations required an extra commitment of time, additional to that which the patient had already committed to managing chronic illness. Participants, for instance, reported having to prioritise specialist appointments, cancel clashing appointments, and juggle multiple priorities in time-scarce contexts. The model I propose pays especial and direct attention to the time management aspect of chronic illness in order to highlight the importance of the immediate temporal contexts in which people negotiate health-related activity and sociality – a context that is often overlooked, but which has great impact on the ability of the patient to effectively manage illness.
The model I propose gives rise to a care plan – the direct application of the model.

**Current care plans**

There are multiple plans currently in operation throughout health services in Australia and internationally, often called ‘self-management’ or ‘care’ plans. In their controlled trial of a model of care that included the use of care plans, Battersby and colleagues (2007) developed a care plan that they describe in the following way:

The care plan was designed to be a global summary of the patients’ planned care for twelve months, a motivational tool, a measure of outcomes over time, and a communication tool. It provided a record of demographic details, including details about the patients’ partners or community caregivers, health service providers, diagnoses, investigation results, medications, services planned, and services.
received. To break down barriers to co-ordination, all providers had to use a common care plan, which contained a twelve-month overview of the planned care, including the patients’ self-defined problems and goals. The care plan complemented each provider’s detailed management plan. The process of creating the care plan was designed to involve the patients in their own care and to begin the process of behavioral [sic] change to improve their self-management of their chronic condition (Battersby et al., 2007: 41).

In keeping with the overarching intention of all contemporary care plans, this plan was designed to be patient-centered, yet one of the most central elements to patient experience – time – is absent from the plan, as it is absent from those plans in the Australian context.

Presently, there are two types of care plans for which the Australian Government reimburses medical personnel: GP Management Plans (MBS Item 721) and Team Care Arrangements (MBS Item 723). These are written instructions and goals for patient use to enable improved patient self-management and/or improved and co-ordinated care “by providing an organised approach to care” (Department of Health and Ageing, 2012). In 2013, General Practices and Indigenous Health Services were eligible for as much as $250.00 recompense for each registered Indigenous patient for whom they provided a written care plan (Department of Health and Ageing, 2010). This payment incentive was listed as a strategy in the Close the Gap campaign to improve patient health outcomes and thereby reduce the gap in life expectancy between non-Indigenous and Indigenous Australians. Care plans were also available to non-Indigenous persons, for which health care providers can claim reimbursement through the MBS.
An information sheet about care plans, composed by the Department of Health and Ageing, provides an example of “how a GP management plan worked for Joan”:

Joan has returned to her GP to obtain the results of her recent tests. Her GP confirms that she has diabetes. As a newly diagnosed patient, her GP considers she would benefit from a structured approach to her care and suggests a GP Management Plan. Joan agrees to the GPMP and her GP begins documenting her investigations and assessment of Joan’s health and care needs. Joan and the GP agree on the management goals of controlling the diabetes by managing her blood sugar levels and preventing complications. Joan will do regular blood tests at home, exercise more regularly and improve her diet. The GP will organise regular pathology tests. All this is written in the management plan. The GP gives a copy of the GPMP to Joan and makes another appointment in six months’ time to review the plan (Department of Health and Ageing, 2012: 2).

In this example Joan and her doctor agree to activities and goals for the patient as well as for the health system. The patient goals, as reported here, are reasonably vague; whereby Joan will carry out ‘regular’ blood tests and exercise ‘more regularly’ (the point of comparison is not provided so the reader and perhaps even Joan have no idea what kind of temporal component is called upon). Joan is required through use of the term ‘regular’ to take on new health practice rhythms that privilege management of the diabetes. The time cost or time burden of new rhythms may come at a cost to other aspects of Joan’s life, however these are not mentioned in the example.

Official templates for the MBS Item 721 care plans have sections to complete such as those outlined in Table 1.
Table 1. Standard components of a chronic care plan

<table>
<thead>
<tr>
<th>Goals for management</th>
<th>What is my role?</th>
<th>Who will do this?</th>
</tr>
</thead>
<tbody>
<tr>
<td>eg. Blood pressure &lt;130/80 mm Hg</td>
<td>(Management goals with which the patient agrees)</td>
<td>(Treatment and services required, including actions to be taken by the patient)</td>
</tr>
<tr>
<td>eg. Physical activity at least 30 minutes walking (or equivalent) 5 or more days/week</td>
<td></td>
<td>(Arrangements for providing treatment/services (when, who, contact details))</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>If the patient has a previous or existing care plan, when was it prepared and what were the outcomes:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Copy of GPMP offered to patient? YES / NO</td>
</tr>
<tr>
<td>Copy / relevant parts of the GPMP supplied to other providers? YES / NO / NOT REQUIRED</td>
</tr>
<tr>
<td>Review date for this plan: dd/ mm / yy</td>
</tr>
</tbody>
</table>

*Details included in this table can be found at www.health.gov.au/mbsprimarycareitems

Care plans that are completed by health care professionals have been provided to between 11.5 and 29.7% of research participants in this study, depending on the dataset. People with diabetes or lung disease were most likely to report having a written care plan. From the SCIPPS Time Use and Care Co-ordination Survey, 29.7% of respondents from the National Seniors Australia (NSA) sub-sample reported having received a written management plan for their illness, despite the MBS incentives. In this same sample, when asked who was the main person who organised their health care, 37.7% of people listed themselves, compared with 41.3% who listed their GP. More than a third of respondents from that sample considered themselves to be the person who planned and managed their time use and health management. When I asked people in the qualitative studies, including my fieldwork, about care plans they often reported having no idea what a care plan was. When I described what it might include many respondents reported creating their own
strategies for managing both their own care and their interactions with health services. I detail these below.

**Strategies people use to manage gaps in continuity of care and care planning**

Medication and planning

Chronically ill people in my study typically employed multiple strategies to manage daily temporal components of their illness in their own socio-temporal contexts (i.e., around the rhythms of work, family and social life, as well as around eating and sleeping rhythms). One way in which a third of the participants in the qualitative studies reported doing this was by maintaining their own up-to-date list of their current medications. The lists typically followed calendar and clock/ed time (CCT), indicating which medications to take, how much, and when to take them. People followed their list and kept multiple copies of it, often keeping a copy in their wallet. They carried a copy so that whenever they saw a health care professional they could be sure that a current list of medications was available – something they could not guarantee if they did not keep their own record. People reported having had previous experiences of meeting with health care professionals only to discover the professional did not have a current medication list. These people reported feeling that the absence of current information negatively informed their quality of care. In order to avoid medication errors and to help manage their time, people also kept copies to stick on their fridge and to help them ensure that they took the correct amount and type of medication at the correct time. Figure 2 shows Pete’s medication list, which he enthusiastically provided me a copy of.
Figure 2: Pete’s medication list, 2012

<table>
<thead>
<tr>
<th>Medication</th>
<th>Other Names</th>
<th>AM</th>
<th>Mid-day</th>
<th>PM</th>
<th>Bed Time</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fosamax Plus 70 mg</td>
<td></td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>Immediate on arising Friday morning only</td>
</tr>
<tr>
<td>Salbutamol 100mcg</td>
<td>Ventolin, Asmolm Epaq</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Fluticasone 125mcg + Salmeterol 25mcg</td>
<td>Seretide 125/25</td>
<td>2</td>
<td>2</td>
<td></td>
<td>8am &amp; 8pm</td>
<td></td>
</tr>
<tr>
<td>Tiotropium 18mcg capsule</td>
<td>Spiriva</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>AFTER breakfast</td>
</tr>
<tr>
<td>Fusedime 40 mg</td>
<td>Frusehexal, Lasix, Urex, Uremide</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>BEFORE breakfast</td>
</tr>
<tr>
<td>BoneCal</td>
<td></td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>All days except Friday</td>
</tr>
<tr>
<td>Cholecalciferol 1000IU (Vitamin D3)</td>
<td>Ostelin, Ostevit</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>Vitamin D</td>
</tr>
<tr>
<td>Digoxin 62.5 tablets</td>
<td>Lanoxin-PG, Sigmaxin-PG</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td>AFTER breakfast</td>
</tr>
<tr>
<td>Esomeprazole 40 mg</td>
<td>Nexium</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>AFTER breakfast</td>
</tr>
<tr>
<td>Verapamil 40mg</td>
<td>Anpec, Isoplind, Cordilox</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td></td>
<td>AFTER food</td>
</tr>
<tr>
<td>Prednisolone 5mg</td>
<td>Solone, Panafcortelone</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td>AFTER breakfast 10mg per day</td>
</tr>
<tr>
<td>Aspirin 100mg</td>
<td>Astrix, Cartia, Cardiprin</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>AFTER breakfast</td>
</tr>
<tr>
<td>Spiromolactone 25mg</td>
<td>Aldactone</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>AFTER breakfast</td>
</tr>
<tr>
<td>Ferrous Sulphate</td>
<td>Ferro-Grad-C</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>Before breakfast</td>
</tr>
<tr>
<td>Panadol Osteo</td>
<td></td>
<td>2</td>
<td>2</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Omega 3 Fish Oil 1000mg</td>
<td>Nature’s Way, Omega 3, Blackmores, Omega</td>
<td>1</td>
<td></td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nizatidine 150mg</td>
<td>Tazac</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

This particular example demonstrates Pete’s awareness of how his medication management should occur over the course of the day and in relation to his eating and sleeping practices. He learned from experience that certain medications were best consumed before breakfast, for example. Pete kept a copy of this list on the fridge,
which was beside the home telephone so that he could easily identify the information contained therein while on the phone to health care professionals. Additionally he kept a copy in his wallet for the same purpose, and a third copy was kept with his bag of medications so that he could follow it while organising/taking his medications. The three copies were strategically placed to enable Pete’s effective management of his medication consumption as well as his management of risk – of the potential that health services could fail in communicating his current medication needs and practices between multiple care providers. Pete’s medication list was of average length compared with others I saw because many participants had multiple chronic conditions for which medication was prescribed to help manage.

People reported having to learn how to manage their health on a daily basis through a process of trial and error. This process was consciously achieved; indicative of an active will and increasing capacity to enact that will – or agency. Vera (APT029) for example, was keen to minimise the use of prescribed medications to manage her diabetes and was exploring alternative therapies instead. She was in the process of establishing whether her consumption of a particular natural substance affected her experience of diabetes when I interviewed her. She had previously tried other complementary therapies, only to find them ineffective. Her desire to avoid medications drove her to explore alternatives; to spend an unknown potential quantum of her time on finding answers that could empower her to achieve management without medication. Such processes of trial and error could take significant periods of time to establish reliable answers that informed people’s practices, indeed, some such processes took place over a number of years. Other people I spoke with were further down the chronic illness path than Vera and had
already established and habituated practices that worked for particular management situations.

Patient led plans

People in this thesis research reported developing their own plans for managing changes to their illness phase and the temporally-gauged requirements brought about by such changes. Having a written plan enabled people to feel a greater sense of certainty and control over their future – it gave them indications on what to expect and gave them capacity to plan for changes to their health that would happen over time. They were developed over time based on the individual’s previous experiences of changes in phases and how such changes played out in socio-temporal ways. In this sense, the care plans that people developed were very much grounded in time.

Roger had lived with severe chronic obstructive pulmonary disease (COPD) for several years and when I spoke with him he was on eight litres of supplementary oxygen per minute (a very high volume). Prior to retirement he was director of a large genetics research laboratory. His scientific mind created ways of managing his illness; during his visits to hospital he kept a journal of all the medications he was on, how often they were administered, his health status, weight, breathing ability, and so forth. His journal was as extensive as his medical charts and he mentioned that sometimes nurses asked him for details about his management where their records were incomplete. Roger was very active in managing his illness in terms of developing his own management plan, in “putting [his] financial matters in order” and regularly updating his legal Will. He had a strong desire to maintain control over his body, his lived experiences and his future. This is what drove him to develop his
own management plan. The plan he showed me had a list of symptoms in the first column, with a second column stating which action/medication needed to be taken and for how long. He explained that if he had all the symptoms of pneumonia, and it had lasted for more than four hours, then he was to increase his oxygen supply and begin taking particular steroids. If his breathing dropped below a certain level then he or his wife was to call for an ambulance. When I asked him how he would access the steroids he said he had shown the plan to his doctor “who was impressed” and who agreed that it would be worthwhile, given his condition, to keep a stock of particular medications in the cupboard in case of sudden exacerbation. The timeliness of correctly assessing and responding to such exacerbations was paramount given that even a common cold could bring about Roger’s death. Having the care plan and the medications readily available meant that Roger could control certain temporal aspects of his experience – he could anticipate change to his future experiences of health, and more specifically, he could control the timeliness of medication intervention.

Standard COPD management care plans such as the COPDX Plan primarily contain instructions concerning smoking cessation (which are very much couched within a ‘compliance’ discourse), and also include spirometry measures, with limited information concerning management of exacerbations. Although care plans are tailored to benefit individuals, a standard care plan may not have been sufficient to guide Roger in his health practices since he had already ceased smoking (referencing his past) and presently required a high level of care; but also because he was so driven to maintain a sense of control over the management of his illness both in the
present and future. Roger created his own care plan, which he then sought support for; rather than having a template supplied and altered to then fit his needs.

Additionally, having the care plan in place enabled Roger to minimise any sense of disruption born of changes in health phases and of the changes to habituated practices associated with the phases in which he spent most of his time. The care plan reinforced his sense of alertness to change and empowered him to minimise disruptions by minimising the sense of uncertainty so frequently associated with disruptions.

Social plans
For many participants medication was just one element of their health management. In their trial and error strategies to effect optimum management of their health, people were often faced with managing social factors such as catering for non-health related activities in the context of health management needs. For some, this meant relying on family members to take over particular roles for them; sometimes for an hour so they could attend a health appointment and sometimes for an indefinite duration, for example during an exacerbation of illness or as the illness progressed in severity. This was the case for many grandparents who had care responsibilities for their grandchildren.

People also found ways to maximise their time use and their motivation to maintain health-oriented practices by combining their health management with sociality. For some this meant finding people to exercise with them during lunch breaks. For others it meant having shared dining with friends in food venues that catered to the needs
imposed by their illness. In this way people undertook what Bury calls the ‘mobilisation of resources’.

In the following example, Rose mobilised her social and spatial resources to disallow seasonal time to prevent her enjoyment of social rhythms. Rose described her socio-temporal experience of attending her grandson’s birthday dinner, which was held in an upstairs restaurant. It was the middle of a Canberra winter (a time marked by seasonality) and probably about five degrees Celsius outside. Rose, who had severe asthma, was prone to breathlessness with even the smallest level of physical exertion. Additionally, the cold air on her lungs often caused her to have breathing difficulty, which is why she generally stayed home as much as possible during the winter time. On this occasion Rose, who was in her seventies, arrived at the foot of the stairs and began the long climb, in the cold stairway, up to the restaurant. By half way up the stairs she was breathless and dizzy. Her son had to carry Rose the rest of the way up. This experience left Rose completely exhausted and because of her health and the timing of the event in winter she was unable to enjoy the dinner as much as she desired. This experience triggered in Rose a decision not to attend events that would likely cause her such problems. She informed her friends and family of her decision and they accommodated her by holding future events at her home, with take away or catered food. Although her grandson’s birthday still happened during the winter time, Rose was able to change the way she experienced this social time by changing the location. In this way Rose (and others like her) became an agent in her own health care, whereby boundaries of rhythms and routines that were informed by chronic illness were manipulated; disallowing disruption to previously held or desired ways of being.
Summary of people’s experience and care planning

Most people I spoke to about care plans often had no idea that care plans were something that could potentially be available to them, at no cost, and could potentially help them in their daily health practices. Once people realised what a care plan was they were, more often than not, keen to develop or obtain their own. This eagerness was based on a belief that such a plan could aid them in decision-making, particularly at times of illness exacerbation, and could empower them to change their socio-temporal practices in times of illness change. Few people reported having their own written GP management plan; only two people in my fieldwork reported having one. Fran had used her care plan to determine how to proceed when she had an exacerbation of COPD. She followed the instructions laid out, which were, according to her symptoms, to attend the hospital emergency centre. When Fran arrived at the hospital the staff told her that she did not need to come in, that she should go home and rest. She explained that she had followed the care plan, which she showed them, and although she had correctly followed the plan the staff maintained that her attendance “was a waste of time”. Fran was frustrated that the plan, as she perceived it, had wasted her time. She decided not to follow it again. The other woman who reported having a care plan was Belinda, who had diabetes. When I asked Belinda for details of the plan she could not remember them and said she wasn’t sure if it was really all that useful, or even if it was an actual care plan. She had not used it but had filed it along with all her other health service paperwork.

It seems that there is a genuine desire held by people living with chronic illness to have guidance that can enable them to make decisions and take actions that will enhance not only their health and wellbeing but also their capacity to balance socio-temporal needs that emerge through changes to their health. These people would like
care plans to fill that role. Presently existing care plan templates do not attend to
socio-temporal elements of people’s lives that, as demonstrated above, critically
shape their experience. This may explain why the care plan uptake is low. Evidence
presented here suggests that people are using other strategies to guide their decision-
making and health practices, and that these strategies are informed by an acute
awareness of temporal factors – both embodied and social. I suggest that future care
plan templates will benefit from tailoring to social and temporal factors so that
people with chronic illness can not only anticipate changes in their health but can
also plan for how such changes will impact on their socio-temporal rhythms and
practices. Enacting changes to care plans that factor in patient time more
comprehensively may increase uptake and effective use of care plans.

A new plan
Based on the thesis findings and proposed model, I suggest that current plans should
go beyond self-management to anticipate changes to the patient’s health that will
occur over time and inform their time use. Care plans should also assist people to
plan for transition into and between phases. This means that care plans should have
both present and future time orientations. Additionally, the evidence suggests that
care plans should tailor to social and temporal components of health such as the
quantum of time needed to undertake activities and how this relates to existing social
commitments. Participants in this research have made it clear that they value things
that remind/enable them to take prescribed medications at the correct time.
Medication details are currently present on most care plan templates and they should
remain there to assist people to manage. The more specific the temporal information
is the more effective it can be. I therefore suggest that care plans contain details of
timing of medication consumption and time quantum of self-management tasks.

People in this thesis research have also made it clear that social factors as well as
time quantum spent on health practices are influential to their daily health
management. Most care plan templates do not currently account for social factors,
timeliness and scheduling, or time quantum associated with tasks. Time is, however,
critical to shaping people’s capacity to engage in both health-related activity and
existing social commitments. As such, time must feature in care plans if they are to
have high uptake and high use by people with chronic illness for whom they are
intended to assist.

The quantum of time needed to engage in health practices has also been shown to
increase with multi-morbidity. People with multiple illnesses have more
appointments and tasks to juggle in the context of their existing lives and in the
context of finite time. Therefore care plans should cater to multi-morbidity in order
to get a better picture of the overall time quantum and time pressure associated with
managing different illnesses, which may be in different phases and therefore bring
about specific socio-temporal strains and requirements.

Designing a care plan that addresses these socio-temporal issues as well as
previously established self-management ones is a difficult task. As a beginning, I
offer in Figure 3 an example of what the Patient-led Management Plan (PMP) might
look like. I propose that the PMP could be further developed with pilot testing.
**Figure 3: example of Patient-led Management Plan on a pocket card**

<table>
<thead>
<tr>
<th>When I am self-managing my health is under my control</th>
<th>When I am in a health crisis I may need urgent help I might need to be hospitalised or need to access more health services</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Aims</strong></td>
<td><strong>Aims</strong></td>
</tr>
<tr>
<td>To prevent complications and maintain stable sugars. To only drink wine on the weekends (max. one glass daily).</td>
<td>To minimise complications, to get better as quickly as possible and return to self-management capacity</td>
</tr>
<tr>
<td><strong>Strategies</strong></td>
<td><strong>Strategies</strong></td>
</tr>
</tbody>
</table>
| • 30mins walking daily  
• Avoid salty foods, low fat diet  
• Regular self-testing blood sugar levels  
• Test blood pressure at pharmacy  
• Eye check every two years  
• Check micro albumin every year | • Rest - no walking  
• Hospital - low salt, low fat meals |
| **Resources**  | **Resources**  |
| Diabetes cooking class, Tuesday mornings 10-12pm.  
GP monthly checkup  
Podiatrist (Ray Evans) every three months | Cancel Diabetes cooking class temporarily.  
Ph. xx xxxx |
| **Medications**  | **Medications**  |
| • pick up DOA pack beginning of each month.  
• Medications are listed on reverse side of this card  
• **Allergies:** none | Call Cook County Pharmacy (check if medications have changed)  
Ph. xx xxxx |
| **Social factors**  | **Social factors**  |
| Pick up Tim and Yuni (grandchildren) from school 3pm, Wednesdays and Thursdays | Suzie (their mother) will pick them up.  
Ph. xx xxxx |
| **Signs of trouble** **(I might be becoming unwell)**  | **Signs of trouble** **(I might be becoming unwell)**  |
| If swollen ankles, breathlessness, or cold/flu then go to  
doctor - Kisha Williams,  
Cook County Health Clinic Ph. xx xxxx  
GP emergency appointment call at 8.45am for same day appointment | If chest pain or trouble breathing/walking then go to hospital  
Preferred hospital: The Canberra Hospital  
Preferred doctor: Dr Felix Fletcher  
Guss and Beccy can make decisions on my behalf, including calling an ambulance |
| **People who can help me**  | **People who can help me**  |
| Family: Guss (husband) Ph. xx xxxx  
Family: Beccy (sister in law) Ph. xx xxxx  
Friend: Aroha Ph. xx xxxx  
Neighbour: Peter Ph. xx xxxx | emergency contact person:  
Guss. Ph. xx xxxx  
Neighbour: Peter Ph. xx xxxx (water garden and feed fish if I’m in hospital) |
| Medicare item: 721 (GPMP) □ or 723 (TCA) □  | Review of 721 or 723: item 732 □ |
In this example the individual has two common chronic illnesses (multi-morbidity). We can tell that the person is in a phase of the diabetes where the illness can be managed by their GP with tablet medication (metformin) and an endocrinologist is not yet part of the individual’s usual care team. The individual is attending cooking classes, which are increasingly becoming available to people with chronic illnesses as part of self-management programs in health care services. The individual in this case is undertaking other self-management activities listed under actions. Such details indicate time quantum associated with managing their (multiple) conditions.

The individual is using a dose administration aids (DOA) pack to manage medications (which reduces the quantum of time needed to sort/prepare/take medication). Not all individuals can afford DOAs or need them, and the DOA is not without trouble as it has a bias towards no change, which can cause problems when patients change phase and change medications. However, DOAs are helpful in many cases and do reduce time burdens. Medications are listed on the outside (reverse side) of the PMP. The reason for this is so that a sticker with updated information can easily be attached to the PMP as needed.

Socio-temporal complications associated with change that occurs with changes to health (such as moving between phases) are anticipated. For example, the above example indicates social rhythms and responsibilities that the individual has to pick up their grandchildren from school twice a week at a specific time. It also indicates social support they can utilise when they are unable to meet this commitment. Similarly, the fish need to be fed each day (a regular temporal interval) to sustain their health and wellbeing. When the individual moves into a crisis phase they may
become unable to meet these existing temporal commitments, and so can call upon their social network to offer assistance. Both columns of the PMP include contact phone numbers for health services and other people who can provide support.

**PMP practical application and utilisation issues**

In this thesis I have demonstrated how time features in chronic illness practices and in this chapter I have presented a case for developing a new kind of care plan that can assist people with chronic illness to manage socio-temporal components as well as medical ones, and in the context of fluctuating bodily and social needs that emerge with changes to phase of illness. I now briefly outline some practical considerations for the actual use of the PMP in terms of health service delivery.

Change is something that can only happen with time. If time does not pass change does not occur; they are therefore linked. Most examples of management plan templates in Australia currently available do not anticipate change (beyond requiring a review of the plan at three-monthly intervals). The Medicare COPD self-management plan (Item 721) is an exception to this; it provides information on page two for “manag[ing] crises” and “exacerbations” (see sections D and X) (Medicare Local ACT, 2012). Its attention to social factors is limited. It is also highly medicalised, with a section focused on health measures such as spirometry readings, which are helpful to people in their endeavours to understand and evaluate changes to their health.

Like the doctor-led management plans that are presently covered on the MBS under Items 721 and 725, I propose that a new format of management plan also be covered.
I propose that health care professionals can work with patients to create a chronic illness time management plan that accounts for at least two phases: stable and crisis. The PMP can be patient-led in that the patient can provide most of the information for the card and can have the capacity to change details on the card. The health care professionals can make the patient aware of the PMP template and help them complete it and upload it onto electronic devices (see below). As with the present management plans the PMP can be reviewed at regular intervals with health care professionals. It contains the same core components as current MBS chronic care items, such as aims of care, goals, and management strategies (and thus it can potentially be claimable under Item 725).

It can be printed onto an A4 size piece of paper, and when folded up can have ‘emergency health information’ visible on the outside of the paper. The management aspects of the stable phase (day to day) are presented in the left hand column; the management aspects of the crisis phase are presented in the right hand column. If the plan was kept short, as in this example, the individual with chronic illness could keep a copy in their purse/wallet. They could provide a copy to other people mentioned on the plan, which would improve vital communications between those involved.

If the individual has chronic illness that is managed with oxygen or other kinds of treatment, those details can be listed under the ‘medication’ section. If the individual requires the use of an Epipen, instructions for finding/using it can be included. Similarly, if the individual has allergies they should also be listed on the PMP. The ‘signs of trouble’ section might look quite different if the individual has chronic illnesses that require immediate change to dose or medication, such as people with
lung disease. In which case, instead of saying ‘go to hospital’ the care might contain treatment options such as ‘increase supplementary oxygen from 1 litre to 2 litres, increase puffer use, take emergency medication: antibiotic X and steroid Y. If no relief within six hours go to hospital. Call 000 for ambulance’.

If relevant, under people ‘who can help me’ the details of the individual’s Public Trustee or Power of Attorney can be listed. Also, if the contact people in any of the sections have multiple phone numbers, these can all be listed.

**Electronic applications of the PMP**

As we move increasingly into an age of technology we should consider the electronic applications of the PMP. The PMP could be made freely available as a phone application and copies could be shared with other people listed on the PMP (for example, Beccy in Figure 3). Phone applications are becoming increasingly popular in health, with self-management applications now available to assist in smoking cessation, weight management and exercise (see for example, Australian Government Quitline, 2012). The PMP could also be made available as a part of the patient electronic health record. There could be a space on the patient electronic health record that is accessible and changeable by patients, where the PMP is located. If the PMP was made available as part of the record that would mean that health care professionals would have access to information they would not otherwise be necessarily privy to; such as the social factors evident in figure 3. Having a copy of the PMP on the electronic health record may also increase patient engagement with the record and with their health more generally. The present electronic health record is currently very frustrating for patients as it contains very little useful information
for the patient and the process of adding information to the record is cumbersome. The inclusion of a PMP template will improve this. It should have an easily identifiable print function so that patients can update their PMP online and print off the updated copy.

**PMP testing**

The PMP pocket plan was developed over three months (November 2012 – January 2013) in collaboration with GPs and consumers from the ACT. It was refined with the help of people from my fieldwork study as well as members of Health Care Consumers ACT, who indicated that time is a major aspect of the chronic illness experience, one that if factored into a care plan could serve to help those afflicted. Minor adjustments to the PMP were made after a focus group with members of the Canberra Lung Life Support Group to reflect the patient experiences, and the refined version is presented here in figure 3.

For their help in refining this proposed PMP card, I wish particularly to thank Suzanne Eastwood of Health Care Consumers ACT, Dr Paresh Dawda and Jane Desborough of the Australian Primary Health Care Research Institute, Helen Cotter of the Canberra Lung Life Support Group, and Dr Christine Phillips of the ANU Medical School.
Conclusion

The evidence suggests that people find practical ways to manage disruptions posed by chronic illness. They do this in terms of their habited rhythms and routines, their biographical work, and their social interactions and obligations. They also do this when they engage with health services – they find ways to manage chronic illness with and without effective health care delivery from health services, and they find ways to manage the multiple appointments and tasks associated with each illness. For people in this study, efforts to manage socio-temporal components such as those brought about by changes to health status have included processes of trial and error, and keeping personal records and management plans. The management plans people have described have included social elements and temporal ones. They have included anticipation for change between stable and crisis phases of illness, and what that means in terms of their social obligations, health management practices and time use. The experiences and efforts of people in this study informed the development of the Chronic Illness Management Time Model, which identifies relationships between chronic illness and time, and how such relationships inform the individual’s attention to bodily and social factors. People’s experiences additionally informed the development of a Patient-led Management Plan (PMP). The PMP could be utilised by people with chronic illness/es to support their health practices in the context of other aspects of their lives, and in the context of bodily change occurring over – and in relation to – time.
CHAPTER 12     DISCUSSION

This thesis set out to examine how a wide range of chronic illnesses brings ideas about, and relationships to, time into the foreground of life – at least for a while. Anthropological literature is replete with material detailing the relationships people have to time in varying circumstances, from the ways in which the seasons provide a rhythm into which quicker and more intimate beats – those of the workday, those of familial life, those of the body itself – might be organised. My aim has been to bring such richness and everydayness to health services literature, which I have shown in this thesis to be wanting in these areas.

In particular, I have shown that chronic illness brings about new relationships to time; daily practices and rhythms alter, and the individual’s future imports new meanings. Such changes are experienced with immediacy as the individual comes to habituate new ways of being. They are also experienced over long duration, as new rhythms, practices and patterns develop and solidify. The once-imagined future becomes increasingly unreachable and new imaginings develop in the context of chronic illness. In this way the individual can have their biography disrupted by chronic illness, but they can also experience durations of time where the new practices and rhythms forged from illness become habituated and familiar.

Addressing the research aims

In chapter one several aims were listed, which have each been addressed throughout this thesis. I have researched and provided information on:
a. how relationships to time change with chronic illness; and

b. how much time people spend on managing chronic illness.

In order to address issues a and b above, the following steps were taken:

1. a review of the literature relating to time use in managing chronic illness was conducted and published. The review maintained specific focus on people with chronic illness and informal carers;

2. I collected data and undertook both primary and secondary analysis (quantitative and qualitative) in order to describe how people’s relationships to particular temporal structures inform their practices associated with chronic illness. I focused on three temporal structures: calendar and clock/ed time (CCT); past, present and future time, and biographical work;

3. I analysed the extent to which Bury’s theory of biographical disruption is useful for understanding present-day experiences of chronic illness; and

4. I contributed to academic knowledge by providing ethnographic point-in-time data about chronic illness as it is experienced by people living in Australia.

Additionally, I created a model for understanding the relationship between time and chronic illness, and I developed a chronic care plan (the Patient-led Management Plan) to assist people in negotiating this relationship over time.

Throughout this thesis I have detailed relationships to time that change with chronic illness. In particular, the thesis has focused on:

1. the CCT time spent on health-related practices in order to manage chronic illness in the context of existing life worlds;
2. the associations between chronic illness and *disruptions to biography*; and
3. how chronic illness informs the individual’s ideas about the *past, present and future*.

Although interconnected, these three temporal focal points will be discussed here in turn.

**Calendar and Clocked Time**

A chronic illness diagnosis brings with it changes to the ways in which time is experienced and used, consumed, spent, gobbled up. While the international literature on time use is extensive, very little has previously been known about how chronic illness informs time use. Building on the works of Bittman (Bittman, 2005; Bittman and Thomson, 2000), Russell (Russell et al., 2007; 2008) and De Vaus (De Vaus, 2004), the thesis has addressed this gap, presenting detailed information concerning the CCT people living with chronic illness spend on particular health-related practices.

As an initial enquiry into this specific time use arena, the thesis began with a literature review (Chapter four), which outlined previous research efforts that map time use of people living with chronic illness. Most studies included in the review provided details about time spent on general management rather than on specific tasks. Two studies provided overall estimated time spent by people with chronic illness on health-related activities. Both studies concerned people with diabetes; with Russell et al. (2005) reporting that people spent on average 120 minutes each day on health practices, and Safford et al. (2005) reporting that people spent on average 58 minutes each day. The review identified several limitations in existing literature,
including those imposed by particular methods undertaken to measure time expenditure. Three holes in the literature that were identified were addressed in Chapters five, six and seven of the thesis. These holes were:

1. a dearth in literature concerning measured time use of people with specific chronic illnesses were identified;
2. no studies concerning time use of people with multi-morbidity were identified; and
3. few studies distinguishing between care recipients with chronic illness and care recipients with disabilities.

The need to address these issues was based on a health policy and health service rationale; that specific chronic illnesses (such as COPD and chronic heart failure) and multi-morbidity require substantial resources from the health system to manage and they may also require significant resources – including time – from people living with those illnesses to manage. Also, that the tasks undertaken by carers of people with chronic illness may differ significantly – in terms of type of activity undertaken or time required to undertake the activity – from those of carers of people with disabilities, and that identifying these factors could point to policy and services areas of need.

The thesis included three Chapters (five, six and seven) where the quantity of time spent on particular health practices was reported. I established various factors that influence CCT time use and the ‘work’ of chronic illness; including type of illness, multi-morbidity and carer status. People with multiple chronic illnesses and people with COPD were found to spend more time managing their health than people with other chronic illnesses or just one illness. Chapter five therefore presented time use
of people who had a formal diagnosis of COPD. I established that although people with COPD spend high amounts of time on health practices, this is not strongly related to how much time has passed since they were diagnosed. I also framed the findings in terms of time use as an indicator of biographical disruption.

This was followed by Chapter six, concerning the effect that multi-morbidity has on people’s time use. Higher number of chronic illnesses was strongly associated with higher amounts of time spent on health practices. As demonstrated in the literature review (Chapter six), its focus – and indeed, this thesis focus – on time use of people with multi-morbid chronic illness is the first of its kind. The policy and health service implications of Chapter six are manifold, particularly because knowing the quantity of time required to manage multi-morbidity can inform health policies and services on where to direct their attention in providing more effective support.

Informal carers were found, in Chapter seven, to spend more total CCT time on health-related activity than people with chronic illness who were not caring for others. Almost all the carers in this study had chronic illness themselves, meaning they spent time on their own health and the health of others, which combined could be substantial. Although previous studies have reported the time use of informal carers in Australia, Chapter seven presents the first study to explore the time use implications of informal carers who themselves have chronic illness. The import of this is based on an assumption in many health policies that informal carers will willingly assist those with chronic illness and be in a position to do so. My findings suggest that informal carers may, however, not be any better off than those they care for and that the overall time they spend on health practices may leave little room for
other activities such as participating in the paid workforce. Additionally, Chapter nine contains the first article to break down time components of chronic illness care into specific health practices. Again, knowledge of these components can inform health care services in their provision of support. The considerable quantity of time that informal carers spend on health practices, as presented in Chapter seven, effectively illustrates how biographical disruption can be informed by daily time use.

**Biographical disruption**

I have argued that time use may be an appropriate measurable indicator of what Bury has called disruptions to biography – that high amounts of time spent on health practices may indicate disruption. The time use articles identified COPD and diabetes as generally requiring more time to manage than other illnesses. And indeed, the qualitative research found that people with these conditions (and others) experienced disruptions to their biography. In Bury’s original study of people with rheumatoid arthritis (1982) he identified chronic illness as disruptive. In my own research, the CCT time use associated with managing arthritis was approximately 7.8 hours (median) per month (Yen et al., 2013). I identified other illnesses that required much more time to manage, such as COPD, diabetes and even heart conditions. Bury’s findings of disruption were for people with arthritis, who had a comparatively small time use requirement. It follows that people who had illnesses requiring even more time use would also experience disruptions to biography. I propose that the CCT time use reported in this thesis supports that, as does the qualitative data.

Around the time a person is diagnosed with chronic illness they need to ‘mobilise resources’ as Bury (1982) has alerted us to. One such resource is time. The amount
of time required during the diagnosis phase to establish new rhythms and practices, to fit in multiple medical appointments, and to rearrange social relationships and orders of reciprocity, can be substantial. This time burden was established in Chapter five (time use of people with COPD), although the patterns of increased time use in the years immediately following diagnosis did not reach statistical significance. Further research with a larger cohort may allow for significance to be reached, in which case we would have stronger quantitative evidence to support Bury’s theory.

Chapter six (time use of people with multi-morbidity) established considerable time burdens associated with higher numbers of chronic illness. The patterns here were strong, suggesting that the more chronic illnesses an individual has, the more time they spend on health practices. This is indicative of biographical disruption, particularly when we look at individuals in the 90th percentiles of time expenditure on health practices. The complication that really arises in associating high time use with biographical disruption is that high time use does not always and necessarily mean that the individual will consider that their biography has been disrupted. So although I maintain that time use is a useful indicator of biographical disruption, this indicator – like so many indicators – is not without fault. To establish biographical disruption, time use data should be supported by qualitative data that can enrich and validate time use findings.

The relationship between time use and disruption to biography is not a simple one. Turning to the qualitative component of this thesis, I have identified that whether the individual considers chronic illness to be biographically disruptive is informed by the timing of illness onset and the individual’s thoughts about their biography. As I
outlined in Chapter one (Introduction), people like Pete – who became ill late in life, and who believed that chronic illness was a natural part of later life – did not necessarily view chronic illness as disruptive, even when the time burden associated with managing their health was high.

I have also identified in this thesis spaces in which the individual with biographical disruption can and does manifest agency to habituate new rhythms and practices and thereby reduce the impact of chronic illness to their daily life and biography. The habituation of new practices over sustained periods of time can minimise a sense of disruption; they come to experience chronic illness management as merely one aspect of their daily living. I have established that this is particularly the case when the individual maintains long periods in mundane or stable phases of managed illness. Moving from these phases into critical, crisis or dying phases of illness can, however, reinforce a sense of disruption. One of the strengths of this thesis, then, is the identification of temporally-related aspects of chronic illness experiences, which inform the applicability of Bury’s theory. His theory that chronic illness is experienced as biographically disrupting is applicable – my research shows – to most individuals living with chronic illness at one time or another, but the habituation of practices and the maintaining of stable periods can serve to reduce the sense of disruption.

Just as disruptions play out in the body, so too do they play out in work and social contexts. My research shows that even people who had disruptions to their biography were able to manipulate the boundaries born of chronic illness by, at certain times, changing their health-related rhythms and practices to accommodate social needs.
This important finding has been illustrated with the experiences of people such as Bill, who ceased taking his blood glucose levels (BGLs) and keeping a close eye on his diabetes management while visiting his friends in Melbourne. When he was at home in Canberra his management of the diabetes was a top priority and he had developed and habituated over the years home-based health rhythms, such as synchronising the timing of food consumption and use of prescribed medication, to manage his BGLs and reduce the risk of diabetes exacerbations. The immediacy of such time use habituation reduced his daily sense of biographical disruption (although his anxieties about his future mitigated this to some extent). However, when Bill was visiting his friends, something he did for 4–5 days each year, he abandoned those habituated practices and instead privileged sociality over his health – disallowing the illness to control particular points in time along his biography. For other participants such abandonments took place in smaller immediate temporal allotments, such as for those who allowed themselves one day of the week when they would eat or drink what they desired, rather than abstaining entirely every day of every week. My research has identified that the extent to which an illness was experienced as biographically disruptive could be manipulated by the individual through changes to their bodily and social practices when in stable phases of illness.

The transition from a stable phase of illness into a phase that requires medical intervention severely reduces the individual’s ability to maintain certain rhythms and practices. It is at these junctures that chronic illness can be experienced most profoundly as disruptive – not only in the immediate sense of disturbance to daily cycles – but also to larger scale epochs of time such as the individual’s overall biography. This is nowhere more vivid than in instances, such as in the case of Ben
who had cancer, when one’s mortality is brought into focus, during a critical phase, by the possibility of chronic illness ending a person’s life.

In contrast, the thesis research has additionally identified a limited number of individuals who reported not experiencing disruption, but instead experiencing reinforcement of their biography through chronic illness. This was the case, for example, with Ray who had post-polio syndrome; an illness that he framed as linking him to a particular socio-historical time and place, upon which his sense of identity and belonging grew. This finding, while limited to the minority of participants, supports previous research findings of Carricaburu and Pierret (1995:80) and Pound et al. (1998). This is an important caveat to acknowledge because it suggests that biographical disruption is not unanimously part of the chronic illness experience.

In summary, having mobilised their resources, the individual in a mundane or stable phase of illness solidifies new routines, practices, and imaginings of their biography, to accommodate a future where chronic illness can have its place. For potentially many years the individual can affect the extent to which chronic illness is experienced as disruptive – they can habituate practices, minimise chronic illness as merely one aspect of their daily life, and at times they can give priority to aspects of their life other than those concerned with chronic illness. The limits of this are, however, radically shaped by exacerbations and associated medical intervention. Finally, and in contrast to these main findings, chronic illnesses can become a defining aspect of the individual’s identity construction. Chronic illness can reconfirm the individual’s relationship to their past actions and associations, and by so doing be experienced not disrupting but as reinforcing their biography.
Past, present and future time

In Chapter three (Case studies) and Chapter 10 (Agents in time) I have focused on past, present and future time, as a salient temporal structure that takes on new meaning with chronic illness, and as a structure referenced in Bury’s (1982) theory of biographical disruption. These Chapters, as well as Chapter eight (Process time) utilise ethnographic observations that, in a similar fashion to Adam (1995), point to the ways in which multiple temporal structures are experienced by the ageing and chronically ill individual and by their carer. These chapters have described some of the complex shades of time that cannot be understood if we analyse people’s experiences only through the lens and measurement of CCT. They also demonstrate that measuring CCT alone as an indicator of biographical disruption may be insufficient. Part of the reason why people experience biographical disruptions with chronic illness is because of the capacity chronic illness has to affect their time use in present and future practices.

It is not only the individual’s time use in present and future time that is altered by chronic illness, but also their ideas about, and their relationship to, the past, present and future. In particular, shifting into critical and dying phases of chronic illness can bring into sharp relief the practices an individual has had throughout their life and the actions they have yet to take. The future, then, takes on particular significance with chronic illness as it seemingly runs out or dissipates, taking with it the concrete individual (Chernus, 2011; Geertz, 1966).

The individual’s orientation toward past, present or future time informs their action. Drawing on Time Perspectives theory, this thesis has demonstrated that people’s
orientations toward the relationship between their chronic illness and past, present or future time can their self-management practices. Time Perspectives theory essentially proposes that people have different orientations to the past, present and future, which inform decision making and behaviour (Zimbardo, 2002; Zimbardo and Boyd, 1999). I have argued in Chapter 10 (Agents in time) that activating people with chronic illness to engage in particular rhythms and practices may be usefully informed by initiating a shift in their orientation from past to future time. This shift is again echoed in Chapter 11 (Practical application of findings) with the PPMP, where anticipation of a changing future (brought about by changes in illness phase) is addressed.

**Time value**

Finally, the thesis has addressed the aspect of time value in Chapter nine. I propose that in order to understand the temporal structures and their interaction with chronic illness, we must consider the value that an individual places on both their health and their time. Chapter nine identified that people with chronic illness spend a large amount of time waiting to see health care professionals, but that several factors inform the way this time is experienced, not least of which being the value that is created or lost through the process of waiting. This finding echoes that of my close analysis of whether chronic illness is experienced as biographically disrupting; whereby the quantity of time spent on health practices is much more meaningful when combined with the individual’s thoughts about that CCT time (and indeed, in relation to other times as well). To understand the relationship between time and chronic illness all of the factors mentioned in this discussion must be considered.
CONCLUSION

Time permeates all aspects of lived experience, but with chronic illness comes new relationships to time. The chronically ill body is one that establishes new rhythms and practices, which become habituated over time and which alter to accommodate changes in the body and in social life. Such establishments and habituations usually bring with them experiences of disruption to biography as well as to the way the individual experiences past, present and future time. The time required to take on new practices and manage chronic illness in the context of an existing life can be substantial and while this is usually associated with biographical disruptions it is not always so. This is informed: by time; by the age of the individual and the stage of life they are in when they become ill; by the trajectory of the illness – how it manifests in the individual’s life over time; by the individual’s ideas about their life course; and by the values they attribute to time and health. Time, in its many forms, must be considered in order for us to better comprehend the complexities inherent in people’s experiences of chronic illness.

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APPENDICES

Appendix 1  Statement of authors’ contributions to articles


Authors' contributions: TJ made substantial contributions to conception and design, acquisition of data, primary analysis and interpretation of data; and was heavily involved in drafting the manuscript and revising it critically for important intellectual content. LY conceived of the study; made substantial contributions to conception and design; undertook primary analysis and interpretation of data; and was heavily involved in revising the manuscript critically for important intellectual content. PM contributed to acquisition of data, analysis and interpretation of data; and was involved in initial drafting stages of the manuscript. All authors read and approved the final version of the manuscript.

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Extent to which research is my own: I used data from the Serious and Continuing Illness Policy and Practice Study (SCIPPS) for this thesis. I undertook systematic database and hand-searching for the review articles. I assessed abstracts and then articles for inclusion/exclusion criteria. I analysed the included articles. My contribution to writing the paper: I undertook primary analysis and interpretation of data; and drafted the manuscript. I revised the manuscript critically for important intellectual content. I undertook revisions to the manuscript as requested by journal reviewers. I also managed the writing, revision and submission process.
All authors made substantial contributions to conception and design, acquisition of data, primary analysis and interpretation of data; and were involved in drafting the manuscript and revising it critically for important intellectual content. TJ, IM and NB conducted statistical analyses. TJ wrote the initial draft of the manuscript, supported in the findings by IM and NB, and supported in the introduction and discussion by LY.

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Extent to which research is my own: I used data from the Serious and Continuing Illness Policy and Practice Study (SCIPPS). I contributed to designing the survey. I conducted a focus group to pilot the survey, analyzed data and played a major role in writing the paper.

My contribution to writing the paper: I analysed and interpreted data. I drafted the manuscript and revised it critically for important intellectual content. I undertook revisions to the manuscript as requested by journal reviewers. I also managed the writing, revision and submission process.

Author contributions

TJ made substantial contributions to survey conception and design, acquisition of data, primary analysis and interpretation of data; and was heavily involved in drafting the manuscript and revising it critically for important intellectual content. IM made substantial contributions to survey conception and design, acquisition of data, primary analysis and interpretation of data; and was involved in drafting the manuscript and revising it critically for important intellectual content. MK, PD, JG, LY made substantial contributions to survey conception and design, and also contributed to early interpretation of data, as well as revising the manuscript critically for important intellectual content. LY also conceived of the study. JV, RB, LJ, RT and MB made substantial contributions to early interpretation of data, as well as revising the manuscript critically for important intellectual content. All authors read and approved the final version of the manuscript, except MK who was critically ill at the time of submission (and died shortly thereafter). MK had indicated approval on the previous draft.

<table>
<thead>
<tr>
<th>Name and signature</th>
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<td>Tanisha Jowsey (TJ)</td>
<td>29.11.2012</td>
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<tr>
<td>Ian S. McRae (IM)</td>
<td>05.02.2013</td>
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<tr>
<td>Jose M Valderas (JV)</td>
<td>05.02.2013</td>
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<tr>
<td>Paul Dugdale (PD)</td>
<td>05.02.2013</td>
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<tr>
<td>Rebecca Taylor (RT)</td>
<td>06.02.2013</td>
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<tr>
<td>Robin Bunton (RB)</td>
<td>13.02.2013</td>
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<tr>
<td>James Gillespie (JG)</td>
<td>05.02.2013</td>
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</tbody>
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On the PLOSone author contributions (manuscript submission) page the following information was entered:

<table>
<thead>
<tr>
<th>Conceived and designed the experiments</th>
<th>TJ IM MK PD JG LY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Performed the experiments</td>
<td>TJ IM MK PD JG LY MB</td>
</tr>
<tr>
<td>Analyzed the data</td>
<td>TJ IM MK JV PD RT RB JG MB LJ LY</td>
</tr>
<tr>
<td>Wrote the manuscript</td>
<td>TJ IM</td>
</tr>
<tr>
<td>Critically revised the manuscript</td>
<td>TJ IM MK JV PD RT RB JG MB LJ LY</td>
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</table>

Extent to which research is my own: I work with the Serious and Continuing Illness Policy and Practice Study (SCIPPS) and draw on their data for this thesis. I contributed to designing the survey, conducting focus group piloting of the survey, analyzing data and writing the paper.

My contribution to writing the paper: I analysed and interpreted statistical data (the statistical analyses were undertaken by IM and MB). I drafted the manuscript and revised it critically for important intellectual content. I undertook revisions to the manuscript as requested by journal reviewers (with assistance from IM and LY). I also managed the writing, revision and submission process.

All authors made substantial contributions to conception and design, acquisition of data, primary analysis and interpretation of data; and were involved in drafting the manuscript and revising it critically for important intellectual content. Additionally, LY conceived of the study; IM and MB were heavily involved in primary data analysis; and TJ was heavily involved in drafting and revising the manuscript. All authors read and approved the final version of the manuscript.

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<td>Michelle Banfield (MB)</td>
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<td>James Gillespie (JG)</td>
<td>05.02.2013</td>
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<tr>
<td>Laurann Yen (LY)</td>
<td>29.11.2012</td>
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Extent to which research is my own: I used data from the Serious and Continuing Illness Policy and Practice Study (SCIPPS). I played a major role in designing the interview questions. I recruited participants, conducted most interviews, managed multiple SCIPPS datasets, and analyzed data. I also used data from her thesis Chronic Illness Time project. I conceived of the Chronic Illness Time project, designed the project, obtained ethics approval, recruited participants, undertook interviews, undertook fieldwork and analysed the data.

My contribution to writing the paper: I undertook all tasks required to write and publish the paper.

Comments: Interdisciplinary net is not a journal as such. It is an online resource as well as an institute for fostering international academic collaboration. It is housed at Oxford University. TJ presented a paper at a conference in September 2011 and this is a published conference proceedings paper, which was peer reviewed prior to publication.

TJ, LY and CA developed the research tools. TJ, CA and NM conducted qualitative interviews with participants. TJ and NJW coded the data reported in this manuscript. TJ and LY analysed the data reported in this manuscript. TJ prepared the first draft of the manuscript. TJ and LY reworked the theoretical components of the manuscript. All authors provided advice and input to prepare the manuscript for journal submission. TJ drafted the responses to reviewers’ comments, with assistance from LY, and prepared the final draft of the manuscript for publication.

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<tr>
<td>Laurann Yen (LY)</td>
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<tr>
<td>Nathaniel John Ward (NJW)</td>
<td>05.06.2012</td>
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<tr>
<td>Justin McNab (JM)</td>
<td>30.06.2013</td>
</tr>
<tr>
<td>Clive Aspin (CA) – signature not provided as out of contact</td>
<td></td>
</tr>
<tr>
<td>Tim Usherwood (TU)</td>
<td>30.06.2013</td>
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My contribution to writing the paper: I made substantial contributions to conception and design, acquisition of data, primary analysis and interpretation of data; and was heavily involved in drafting the manuscript and revising it critically for important intellectual content. With LY, I undertook the early analysis and wrote findings for the first draft. With LY, I undertook substantial revisions to the manuscript as requested by journal reviewers. I also managed the writing, revision and submission process.

TJ developed the research tools and conducted qualitative interviews with participants. TJ and NJW coded the data reported in this manuscript. TJ and NJW analysed the data reported in this manuscript. TJ prepared the first draft of the manuscript. TJ and KLG reworked the theoretical components of the manuscript. All authors provided advice and input to prepare the manuscript for journal submission. TJ drafted the responses to reviewers’ comments, with assistance from KLG, and prepared the final draft of the manuscript for publication.

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<tr>
<td>Nathaniel John Ward (NJW)</td>
<td>05.06.2012</td>
</tr>
<tr>
<td>Karen Louise Gardner (KLG)</td>
<td>31.01.2013</td>
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My contribution to writing the paper: I made substantial contributions to conception and design, acquisition of data, primary analysis and interpretation of data; and was heavily involved in drafting the manuscript and revising it critically for important intellectual content. With NW, I undertook the early analysis and wrote findings for the first draft. KG contributed to revising the final draft. I undertook substantial revisions to the manuscript as requested by journal reviewers. I also managed the writing, revision and submission process.
Appendix 2  Time use questions and categories from SCIPPS time use survey

Cover page to the SCIPPS time use survey:

---

Thank you for participating in this study. Your answers will provide important information about how much time and effort people spend on looking after their health or the health of someone they care for. It will take about 20 minutes to complete the questionnaire. You can complete the questionnaire here, using this paper copy, or you can complete it online at the website listed on the covering letter. If you complete this paper copy, could you return it within 2 weeks using the addressed postage paid envelope provided. Please complete Part A and Part B of the questionnaire. If you look after someone else, please also complete Part C.

Please feel free to ask a friend or a family member to help you with the questionnaire if you want.

---

How to fill in the questionnaire

- Use a pencil or a blue/black pen
- Do not use a red or felt tip pen
- Do not use liquid paper
- Please put an X in appropriate boxes, do not use ticks.

Some questions ask you to write an answer in a box.

Example: What type of cancer? 

How many people altogether live in your household? 0 4

Some questions have a combination of written answers and response boxes. Please ensure you answer each relevant row or part of the question.

Example:

How old were you when you were first told? Yes

Do you have cancer? 5 7

If you make a mistake in pencil, please erase fully. If in pen, block out the incorrect answer like this. 8 1 and put an X in the correct box, like this: X.
The following is an excerpt from pages eight and nine of the SCIPPS time use survey. Pages 10 and 11 of the survey were for carers to complete and included the same time use categories as reported here.

**Q46: Daily time use**

**On most days how much time do you generally spend on the following?**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Hours</th>
<th>Minutes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sorting your medications</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preparing your medications</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Taking your medications</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carrying out treatments</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Testing or monitoring your health</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preparing special foods</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Taking exercise/stretching</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Q47: Other time use**

**In the last month how much time did you spend on each of the following?**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Hours</th>
<th>Minutes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shopping for medicines, equipment or disposables, other necessary health items for yourself</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shopping for special foods you may need for yourself?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attending rehabilitation programs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attending health education of self management programs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attending support groups, such as cancer or diabetes groups</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Looking for and reading health information</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Q48: Attending clinics**

In the last month how much time did you spend on each of the following?

<table>
<thead>
<tr>
<th>Activity</th>
<th>Hours</th>
<th>Minutes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organising appointments for yourself</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Organising travel to and from health-related appointments</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Travelling to and from health-related appointments including support groups</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sitting in waiting rooms</td>
<td></td>
<td></td>
</tr>
<tr>
<td>With the doctor or other health professional for consultation, advice or treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having blood tests, x-rays or other tests</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having other medical treatments (e.g. dialysis, chemotherapy, radiotherapy)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 3  Information sheet

Study: Chronic illness time

Tanisha Jowsey is a PhD candidate undertaking research about how people experience time and chronic illness. How much time do people spend on health-related activity? How does chronic illness influence other aspects of life? How much time is wasted? How do people juggle different time commitments? How are people’s thoughts about their future informed by chronic illness? These are the kinds of questions that Tanisha is interested in exploring. The temporal elements of people’s lived chronic illness experiences have health policy implications, which will also be explored in this study.

Tanisha is interested in speaking to people living with chronic illnesses such as diabetes, arthritis, chronic heart failure and chronic obstructive pulmonary disease. The research includes participant observation and interviews with people who have chronic illness and people who provide informal care for them. Participant observation will involve Tanisha being involved in or observing the day-to-day activities of the people being studied and possibly taking photos of study participants. Interviews will involve participants discussing pre-determined subjects with the researcher and this will be audio-taped.

To be eligible to take part in this study, you will:

- Be aged 20-84 years
- Be a resident of the Australian Capital Territory or surrounding region
- Have a formal diagnosis of chronic illness or care for someone who does
- Be willing to discuss your experiences and perceptions of chronic illness and time.

Interviews are being held on Wednesday 6th June and Tuesday 12 June 2012.

Contact

Should you wish to know more about this project or would like to participate you can contact Ms Jowsey directly;

Ms Tanisha Jowsey
Australian Primary Health Care Research Institute
College of Medicine and Biological Environment
The Australian National University
ACT, 0200, Australia
Phone: (61) 2 6125 7599
Email: Tanisha.Jowsey@anu.edu.au
Appendix 4  Fieldwork interview guide

Chronic Illness Time. Jowsey 4823

Semi-structured interview guide

1. What was life like before you were diagnosed with chronic illness? (how has it changed?)
2. I'm interested in your experiences of chronic illness and time. How do you experience time in and through your body?
3. Do you experience illness in relation to different times of the day? for example, how do you experience illness at night or during the day?
4. As a person living with chronic illness how do you experience social time?
5. When it comes to living with chronic illness, what daily activities are valuable to you?
6. When it comes to living with chronic illness, what activities do you avoid in relation to time? for example, what activities do you consider to be a waste of time?
7. Thinking back to the last time you were in hospital, can you tell me what happened? How did you perceive that time?
8. Thinking back to the last time you were with your GP, can you tell me what happened? How did you perceive that time?
9. What sort of self-management activities do you engage in and how often? What are the most difficult aspects of engaging in self-management? What are your thoughts about self-management and time?
10. What worries you about living with chronic illness? How much time do you spend worrying? are there times when you worry more? (tell me about that).
## Appendix 5  Chronic illness time - fieldwork data 2012

<table>
<thead>
<tr>
<th>Participant</th>
<th>Details</th>
<th>N=25  (including informal carers, n=8)</th>
</tr>
</thead>
</table>
| Ray         | 66 yrs, male  
Post-polio syndrome  
Notes: migrant. Polio as a baby. Walks with pronounced limp. Interviewed in person at Lung Life August meeting 2012. Low SES | |
| Dawn        | 80 yrs, female  
Osteoarthritis 30 years (multiple hand operations)  
Epilepsy 12 months  
Notes: Interviewed by phone July 2012 and at her home August 2012 | |
| Jadzia      | 45 yrs, female  
Cancer (brain) 3 years  
Facebook/ blogspot  
Notes: prayers to god recorded on her blog, worried about whether she will see her children grow up. Multiple cycles of treatment. Profound biographical disruption | |
| Jill        | 71 yrs, female  
Arthritis in hands >10 yrs. Uses gloves, cream, asprin to manage Bronchiectasis >20yrs. Lots of breathing exercises and occasional puffer. Coughs ‘a lot in the morning and in spring time’ Padgets disease - 8 yrs bone growth in cranium, headaches,  
Notes: always worried of Padgets reoccurrence  
wife of Max | |
| Max         | 69 yrs, male  
Atrial fibrilation (CHF) 2 years.  
Notes: Beats too slowly = blackouts. Pacemaker. Avoids too much physical activity. If BP falls below 65 pacemaker ‘kicks in’ (often while sleeping) Lifelong fear of getting diabetes has informed behaviour  
Husband of Jill | |
| Ben         | 34 yrs, male  
Cancer (lymphoma around lungs and heart) 6 months  
Notes: Facebook and interview at his home July2012 | |
| Kate        | 32 yrs, female  
Wife of Ben carer 6 months  
Notes: Facebook and multiple conversations at her home July2012. Profound biographical disruption during Ben’s treatment. ‘Those daydreams about the future, I couldn’t bare to think of them. We just had to focus on the present.’ | |
| Lucy        | 70 yrs, female  
Bowel knots – since surgery 6 months ago problems  
Underactive thyroid 10yrs+ (managed by pills only), HBP10yrs+ (managed by pills only, once daily – but she does check blood pressure often)  
Notes: Parents lived to 86, 91 – Lucy doesn’t want to live that long due to health deteriorating.  Wife of Felix | |
<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Gender</th>
<th>Diagnosis/Conditions</th>
<th>Notes/Remarks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Felix</td>
<td>70 yrs</td>
<td>male</td>
<td>Atrial fibrillation. Noted: Used to take meds at night. BP falls to 42 while sleeping. Awakes feeling ‘sluggish.’ Now takes meds in morning to avoid this. Father died at 68yrs. Felix was very worried at that age. Husband of Lucy.</td>
<td></td>
</tr>
<tr>
<td>Bill</td>
<td>68 yrs</td>
<td>male</td>
<td>Diabetes – insulin 12 yrs. Depression – medicated 20 yrs. Mother diabetes amputee, he was carer. Interviewed at his home July 2012.</td>
<td>Notes: Single. Low SES. ‘worry makes your BGLs go up’.</td>
</tr>
<tr>
<td>Richard</td>
<td>65 yrs (approx.)</td>
<td>male</td>
<td>COPD. Diabetes.</td>
<td>Notes: Low SES. In and out of hospital a lot for COPD exacerbation.</td>
</tr>
<tr>
<td>Meryl</td>
<td>65 yrs (approx.)</td>
<td>female</td>
<td>COPD.</td>
<td>Notes: on supplementary o2. Prefers ventolin nodules to puffers. Prefers portable oxygen to home concentrator – lungs feel different, expand more.</td>
</tr>
<tr>
<td>Dale</td>
<td>70 yrs</td>
<td>male</td>
<td>Ripple’s disease (rare disease, affecting organs, brain, eyes – he now has a false eye that he likes to remove to shock people). Emphysema since 1990. No supplementary o2.</td>
<td>Notes: Smoker 30 years. Stopped 20 yrs ago – still misses it.</td>
</tr>
<tr>
<td>Frank</td>
<td>72 yrs</td>
<td>male</td>
<td>COPD + possible lung cancer (bleeding in lungs 12 months). Recurring pneumonia. Notes: Recent hospitalisation. Smoker 52 yrs. Quit 2yrs ago upon diagnosis. Migrant from Europe.</td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td>Age</td>
<td>Gender</td>
<td>Diagnosis</td>
<td>Carer Details</td>
</tr>
<tr>
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<td>--------</td>
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<td>---------------</td>
</tr>
<tr>
<td>Lola</td>
<td>40 yrs</td>
<td>female</td>
<td>Carer to brother with COPD and mental disabilities</td>
<td>Notes: difficulty in knowing when to hospitalise brother and is concerned with not knowing how much time he has left to live. Profound disruption to biography, brother calls at all hours of the day/night. Interviewed twice at cafe July 2012</td>
</tr>
<tr>
<td>Doreen</td>
<td>75 yrs</td>
<td>female</td>
<td>Muscular Sclerosis since age 35</td>
<td>Hepatitis 12 months</td>
</tr>
<tr>
<td>Pete</td>
<td>80 yrs</td>
<td>male</td>
<td>Pulmonary fibrosis</td>
<td>Asthma</td>
</tr>
<tr>
<td>Jim</td>
<td>49 yrs</td>
<td>male</td>
<td>No own illness</td>
<td>Carer of mother with cancer 12 months</td>
</tr>
<tr>
<td>Rebeka</td>
<td>51 yrs</td>
<td>female</td>
<td>Cancer 12 months</td>
<td>Carer of parents (mother with cancer, grandparents with dementia) for 35 years. Interviewed at my home July 2012</td>
</tr>
<tr>
<td>Jane</td>
<td>49 yrs</td>
<td>female</td>
<td>Sleep apnoea</td>
<td>Notes: undiagnosed for ten years, sleep mask in 2011 ‘changed my life’ now has energy, feels ‘ten years younger’</td>
</tr>
<tr>
<td>Daisy</td>
<td>70yrs (approx.)</td>
<td>female</td>
<td>COPD, arthritis</td>
<td>Notes: on portable supplementary oxygen. Difficulty to manage the o2 paraphernalia due to arthritis in hands. Low SES Impromptu short interview at Lung Life meeting August 2012</td>
</tr>
<tr>
<td>Tim</td>
<td>28 yrs</td>
<td>male</td>
<td>Myasthenia gravis (severe auto-immune disease)</td>
<td>Notes: previous to illness was very strong and enjoyed the gym. Illness onset ‘I just wanted to die.’ Heavily dependent on partner/carer. Profound disruption to biography. Underwent ‘risky’ surgery to remove thyroid (successful) – although highly medicated, strength returning. ‘now I am happy again’</td>
</tr>
</tbody>
</table>