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Time to manage: patient strategies for coping with an absence of care coordination and continuity, *Sociology of Health and Illness*, 2016.

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Abstract

This paper examines how people with chronic illnesses respond to absences of continuity and coordination of care. Little work has been done on how the ill person might mitigate flaws in a less than optimal system. Our qualitative research, carried out among ninety-one participants in Australia, reveals that people with chronic illnesses create strategies to facilitate the management of their care. These strategies included efforts to improve communication between themselves and their health care practitioners; keeping personal up-to-date medication lists; and generating their own specific management plans. While we do not submit that it is patients' responsibility to attend to gaps in the health system, our data suggests that chronically ill people can, in and through such strategies, exert a measure of agency over their own care; making it effectively more continuous and coordinated. Participants crafted strategies according to the particular social and bodily rhythms that their ongoing illnesses had lent to their lives. Our analysis advances the view that the ill body itself is capable of enfolding the health system into the rhythms of illness – rather than the ill body always fitting into the overarching structural tempo. This entails an agent-centric view of time in illness experience.

Keywords: chronic illness; continuity of care; coordination; self management; time.

Introduction

Over the last decade the terms 'care coordination' and 'continuity of care' have been increasingly present in health service discourse, representing ideologies of best practice. Coordination of care is, "the provision of a combination of health services and information to meet patients' needs that attends to the connection between, or the rational ordering of, those services" (Shi 2012: 3). Whereas continuity of care occurs when a long-term relationship exists between health care practitioners and their patients beyond specific episodes of illness or disease (thus longitudinal); when the patient's medical information is readily available to any health care practitioners caring for the patient (thus informational); and describes an ongoing relationship between personal care practitioners and patients characterised by high attendance to patient needs and preferences, such as communication and respect (thus relational) (Freeman *et al.* 2001, Freeman *et al.* 2007, Kringos *et al.* 2010, Uijen and Schers 2012).

As Uijen and colleagues (Uijen *et al.* 2012a, Uijen and Schers 2012, Uijen *et al.* 2012b) point out, continuity of care and coordination of care are ideally experienced concurrently by the patient, so that:

1. the care practitioner knows and follows the patient over the course of an illness,
2. patient information is shared between multiple care practitioners, and
3. care practitioners cooperate to ensure that patients experience different kinds of care as seamlessly connected.

Two main conditions are necessary for continuity of care and coordination of care to occur. The first is that the same health care practitioners (practitioners hereafter) will be available to patients for the duration of their illness. The second is that multiple practitioners share information about the patients (see Lingard 2012). However, in respect to the first condition, patients may not be able to access the same (or same group of) practitioners throughout the enduring course of chronic illness. The structural conditions of health care provision in Australia and in many other settings, such as contractions in individual practitioner working hours, and the growth of large practices that employ many practitioners, may mean that patients might see various practitioners and thus may not establish enduring relationships with familiar practitioners.

Second, because most patients with a chronic illness will experience more than one condition at a time (multimorbidity), several practitioners are typically involved in each person's care. Coordination of care is thusly increasingly difficult to assure.

The importance of both continuity and coordination of care in experiences of chronic illness is well established. In a paradigmatic example, Bodenheimer (2008) writes that continuity of care and coordination of care between multiple practitioners is crucial to how well patients can manage their illnesses over time, and so the absence of either is likely to have negative consequences for patients.

Somewhat ironically, because the problem of discontinuous and uncoordinated care is so well researched, and its impacts so evident, information about what chronically ill people actually do when they experience discontinuous and/or uncoordinated care is lacking. Instead, research attention has been given over to addressing the problem on the supply side, an approach initiated in and through close attendance to the negative consequences for patients. Without wishing to engage in problem deflation, this laudable approach has led to the sure and certain classification of patients as passively bearing structural output. As both coordination and continuity of care are concerned with the ongoing ordering of practitioner time relative to the patient 'receiver', patients have come to inhabit the position of victims of unyielding temporal structures that bear down on them with all the weight of late capitalism: the diversification and specialisation of care provision dispensed by numerous practitioners within contracting work hours, the temporal rhythms favoured by large clinics, and so on. While our data suggest that bearing this weight does indeed result in negative consequences for patients, it also suggests that one significant source of agency arises from the capacity enacted by many chronically ill people, to insert the temporal rhythms of their own lives into care provision.

This theme has become evident to us as a result of our deliberate location outside of the tight interconnection of problem genesis and problem manifestation, which has permitted us insight into the space in between; the space in which patients, in effect, speak back to these structuring rhythms to which they are ostensibly wholly subject. In what follows, we advance the view that attending to such a practice, which includes restructuring temporal relations with the health care system from the generative site of the ill body itself, alerts us to another dimension of chronic illness experience obscured by current research. This dimension, inhabited by creative agents propelled by the needs of their own ill bodies, is of value to ensuring continuity and coordination of care, especially in healthcare systems operating

below optimal level. This dimension becomes visible in and through a particular attendance to time.

Time and illness

While aspects of chronic illness itself are well-researched in the clinical and epidemiological literature (Townsend 2012), few social science studies have chosen time as the primary lens for analysing chronic illness (Morris 2008). Those few that have done so usually examine only one aspect of temporal experience (for instance, analysing how much time it takes to manage a chronically ill body, and how much time medical management takes up for the person), and apply this lens to illuminate the passive, restricted, or negative relations the ill person has to and with time (Jowsey 2015).¹ Morris (2008), for example, is concerned primarily with how a person with diabetes fails to break free from the temporal regimes of eating that come with diabetes that he argues mirror childhood experiences, when eating patterns and times were dictated by adults. The person with diabetes, in his analysis, remains an infant, always subject to the temporal rhythms set by external authority – in this case, the constant need to have regular access to insulin.

One immediately evident and relatable temporal structure is a profoundly western, linear progression of time that manifests in calendars and clocks, or ‘calendar and clock time’ (Adam 1995, Postill 2002, Griffiths 1999, Fabian 1983). People with chronic illness may find that scheduling and attending appointments at the right intervals takes up a lot of calendar and clock time, especially if they are seeing many health care practitioners. They may also find that their sense of biographical time changes, as Bury has argued in his well-known work (1982); the onset of chronic illness may lead patients to consider anew the course and direction of their lives, and their goals and aims over time, often in quite different ways than they had prior to diagnosis.

Others such as Ellingsen et al. (2013) have attended to how the chronically ill body itself generates temporal rhythms. Alterations in heartbeat, the drawing in and exhaling of breath, and changes in sleeping and eating patterns all create embodied experiences of time that emerge from the ill body, and intersect – sometimes uncomfortably – with other regimes of time, such as the everyday functioning of a household and its domestic rhythms, and with broader social structures of calendar and clock time such as those governing health care delivery. Such disjuncture between the internal rhythms of time generated by the ill body and existing external temporal structures may mean that the person with chronic illness has to mediate between the two, to get ordinary things done: the shopping, eating with family members, or going to the doctor, for example.

Corbin and Strauss’ (1992) work alerts us as to how different kinds of time associated with different kinds of illnesses might intersect – although their own work does not specifically advance this notion. They describe how chronic illness is experienced by the person in and through their descriptions of distinct phases of illness. They identify nine phases: pre-trajectory, trajectory onset, stable, unstable, acute, crisis, comeback, downward, and dying. In the *unstable* and *acute* phases, symptoms of illness increase or are unrelieved, and are less controlled than in the stable phase. The *comeback* phase “signals a gradual return to an acceptable way of life within the symptoms that the disease imposes” (Lubkin and Larsen 2006: 37). Corbin and Strauss note that these phases do not necessarily occur in a predictable and consistent progression. Nevertheless, their occurrence 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, and is relevant to both the patient, and to their health practitioners in their role of predicting and responding to changes in need.

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, and that allow us to see how different kinds of time are enfolded into each other. Having multiple diseases adds complexity with many illness trajectories, parallel and intersecting according to their separate and combined rhythms. A person who has been in a crisis phase before may enter a crisis phase again at a later point in time, or enter another phase of stability, and each of these might be attended by those bodily-generated rhythms of time that orient the patient to external temporal regimes. In this sense the progression of illness is not only unpredictable but also circular – bringing past into present and anticipated future experience. The impact of each phase in each illness may be amplified or diminished by a co-incident phase in a different illness. 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 ‘progression’ of chronic illness, registered as it is at the level of the patient’s own body, is unique to each patient. It is this unique illness experience that informs patient-generated strategies, designed by them, to ensure coordination and continuity of care when it is not forthcoming from the health care structure.

Crafting one’s own plans to ensure coordination and continuity of care presented a very significant time burden to participants in this study. The notion that a patient effectively ill-served by the health system could be empowered by addressing its shortcomings of their own volition has unsurprisingly been overlooked in studies that have previously examined the absence of continuity and coordination of care. However, for many in our study, so doing nevertheless felt empowering. Our investigation of this feeling suggests that, in order to comprehensively understand patient experiences of a lack of continuity and coordination of care, a patient-centric approach must be taken. Such an approach reveals patients as creative agents who can stitch together discontinuous and uncoordinated care provision, and that the impetus to do so issues from the unique temporal rhythms that illness lends to individual bodies. The crafting of one’s own care strategy thus permits the individual body and its unique experience of time to register at a structural level. It is unsurprising that the patient’s own efforts help to ensure continuity and coordination of care, since these aim to reflect the experience of people living with chronic illness over time (rather than the practitioner’s experience), and aim to centralise the agent in the provision of care (Banfield *et al.* 2013, Haggerty *et al.* 2003, Uijen *et al.* 2012a). Thus, plans for care made direct from the patient’s own temporal experience of her illness are entirely congruent with coordination and continuity of care models.

Methods

The data that inform this study were generated by two qualitative studies; the first was collected by the Serious and Continuing Illness Policy and Practice Study (SCIPPS) in 2007, and the second – an ethnographic dataset – was gathered in the first author’s doctoral fieldwork during 2012. To preserve anonymity pseudonyms were applied to participant data in both studies.

Study 1: SCIPPS

In the first study, 66 participants were recruited by purposive sampling (based on age, area of residence, gender, illness type, and ethnicity) through referrals from primary health care services in the Australian Capital Territory and in Western Sydney, New South Wales (two of eight states and territories of Australia). Eligible participants included people with one or more of three conditions (chronic heart failure (CHF), chronic obstructive pulmonary disease (COPD) and type two diabetes mellitus) and informal (family) carers of people with these conditions, who were aged between 55 and 85 years. The three chronic illnesses listed above were chosen because they are preventable and they represent large, and potentially avoidable, costs to the Australian health system. Semi-structured in-depth interviews were conducted, which each ran for between 60 and 90 minutes. Participants were asked about their experiences of living with a chronic illness, including their experiences of using health services, and their strategies for self-management. A detailed account of the study, including the principal findings, has been reported by Jeon and colleagues (Jeon *et al.* 2010). For the current study, a secondary analysis of the data set was undertaken, using QSR NVivo10 Qualitative Software, to specifically examine the actions people took in relation to health services in order to manage their health.

Study 2: ethnographic interviews and participant observation

Following the SCIPPS analysis, a study of 25 participants was conducted. While not sharing all the hallmarks of a traditional ethnographic work – in which long term access to a well-defined field and ongoing relations with participants over a year or more would be expected – the study nonetheless began from an ethnographic foundation: to acquire a detailed understanding of the daily, lived, bodily and social experiences of chronic illness drawn from the perspective of the ill person. Eligible participants included people with one or more chronic conditions aged between 30 and 85 years, who had no formal diagnosis of cognitive impairment, and who resided in the Canberra region. Participants were recruited through formal support groups and by snowballing, a non-probability technique whereby research participants recommend their peers as participants in the study (Heckathorn 1997). Fieldwork involved participant observation (comprising researcher attendance at monthly chronic illness support group meetings, visiting people in their homes, going walking with people and socialising at local dog parks), as well as both unstructured and semi-structured interviews (with some participants being interviewed multiple times). The semi-structured interviews typically lasted between 45 and 90 minutes; the duration was dictated by participants. Much shorter conversations between participants and with the researcher were also recorded before and after support group meetings. These typically lasted 2-4 minutes and were unstructured. Using an interpretive approach, thematic analysis of ethnographic data was undertaken.

Ethics approval was granted to both studies by the Human Research Ethics Committee, Australian National University (protocol 2007/34 and protocol 2011/656). In addition to providing health and demographic details, participants were asked describe their experiences of chronic illness and their interactions with health care services and practitioners, including any shortcomings in or absences of care and their impact, and what strategies they used to manage same.

Data from all 52 patients and 14 informal carers from the SCIPPS were included; and from the 17 patients and eight informal carers in the fieldwork study, making a total of 91 participants. Forty participants (44%) were male. A wide range of chronic illnesses were represented, with many participants having CHF, COPD and or type two diabetes mellitus (reflecting the inclusion criteria in the SCIPPS study). Illnesses most commonly reported by participants from the fieldwork study were COPD or other lung disease, arthritis, and cancer.

Most participants had multimorbid chronic illness (n=66; 72.5%) and required support from multiple health care practitioners.

Findings

While participants described numerous encounters with practitioners with whom overall they were satisfied, they also described many experiences of poor continuity of care and care coordination when multiple practitioners were involved. Mark, who had chronic heart failure, said,

The issue was poor coordination between departments at the hospital, within the hospital. Poor information was provided. One hand didn't know what the other hand was doing. Tests were uncoordinated. I was sent down from the ward to one diagnosis area, examination area, not everything was quite right so within five minutes I was sent right back again.

They reported that practitioners did not effectively communicate with one another or with the patient; that practitioners frequently lacked current information about the patient's health status, management plan, care needs, and medications (and that reconciling medications was often perceived by patients to be largely left up to themselves). Participants responded to these structurally-informed gaps in care coordination with creative strategies of their own; facilitating communication between themselves and with practitioners, keeping own records of their health information in diaries or folders, creating care plans, and keeping their own very detailed and current medication lists in order to reduce the potential for medication error. Lynette said, "We always have a complete record of Rodger's medical history and his x-rays and take them so that we can always give a very sound basis to his condition for people to start working on, you know, from there. And that's really good. We also have our advanced care plan in place."

Such strategies were creative, in that they depended on 1) patient capacity to recognise a structurally-governed problem in the provision of their care, 2) to imagine their own individually-focused and tailored solution to the problem, and 3) to take actions that they thought would enable their ill bodies to manage over time. This clearly resonates with both historical and current discourses of patient agency. Drawing on Hochbaum (1958), Armstrong (2014) points out that agency is contingent upon patients being subjectively aware and reflexive about their bodily being, their illness and their management behaviours; as well as being capable of synthesising that reflexivity into "promotion of autonomous action" (Armstrong 2014: 165). Participants in our study echoed these observations; identifying that for patients, agency meant that they found themselves engaging subjectively in observation of their own bodily rhythms and capacities, and from that reflexive position identifying creative strategies to act – taking, for example, their ill bodies as the foundation upon which to develop personalised care plans. While such agency resonates with current health system theories and policies of patient-centred care and 'active' or 'engaged' patients, it also meant participants had to take on the time-costs of organising and coordinating their own care or the care of a loved one (including arguing their case with practitioners about what care was needed) – something which occurred in the context of an illness experience they found arduous, strenuous and confronting in a multiply of ways. Claire was heavily involved in care for her husband, Simon, who had dementia and diabetes. She described self-management difficulties emergent from the interaction between dementia and diabetes; that Simon did not recognise the symptoms of low blood sugar and did not remember that he had jelly beans in his pocket and would not eat them. "No, he wouldn't have a jelly bean. 'I'm all right, I'm all right, there's nothing wrong', he'd say." Claire had to manage his daily blood tests; "He

doesn't do the insulin anymore because that's just too confusing for him, and he often gets confused in doing the reading, like putting the little stick into the machine [he] gets that the other way around or whatever then he blames the machine." This meant Claire was constantly needed to care for Simon and felt she could not leave his side. Claire felt that his receiving quality care was dependant on her own memory and attention to Simon's needs:

I don't know where to start planning for that [an exacerbation of Simon's illness]. ... They [family] can't just drop everything all the time ... for a week or more or whatever it may be, you know. And respite care is not easy to get into at all. ... Planning? We've got out name down for the Aged Care Home. So yeah we've got that far. ... I take him to my GP because there were a few issues that I wasn't quite happy with, with the other GP. We moved him, yeah. My GP is very, very thorough, extremely thorough and so I said, 'Well, you know, we won't worry about the other Doctor anymore.' And he was quite happy to do that but, you know, there was things that, like his blood pressure for instance. I went there with him one day and I said to him, 'It seems a long while since Simon's has had his blood pressure taken', and he's on medication for blood pressure. ... okay we take the blood pressure and what is it? A high. So then we have weekly trips about three weeks in a row just to get this blood pressure down and to get him all organized. And then we have to do a blood test, he writes out a blood test thing and I said, 'Well what about his cholesterol and what about something else?' There were four things that I mentioned that he hadn't put on this [pathology form].

While the strategies of participants to manage came at a temporal cost (such as the time it took to create and maintain a medication list), they were intended to reduce the overall temporal and emotional costs that patients faced (such as those faced when medication lists of practitioners were not current). These strategies also meant that patients could have care that 'worked' specifically for their unique circumstances. For many participants the strategies they used to optimise their health management over time felt empowering. This is because they saw their strategies as performing three specific and important functions: they stitched together information from multiple sources to create a whole sense of care that was experienced as temporally continuous; they organised the physical aspects of care – such as medication lists – that worked to temporally align the ill body with medical inputs; and they created plans for the future, that served to comprehensively organise the whole person through phases of care and over time.

Perceptions of poor continuity and care coordination

Specific points in time were identified by participants as having personal and social significance, while also being moments particularly vulnerable to association with poor continuity of care and therefore also requiring patient and informal carer creative strategies. Two such points are the time surrounding diagnosis and transitions between different forms of care. Experiences of time surrounding diagnosis were described by many as a turning point in which they could rule out uncertainty, come to understand the needs of their ill bodies, and feel empowered to change daily practices based on a sense of certainty born of their diagnosis. However, the time surrounding diagnosis was also described in terms of waiting, which signalled possible lapses in care coordination. That is, participants in our study often perceived the care process as dysfunctional, with long waiting periods between appointments and with gaps in communication between practitioners that resulted in poor patient follow up.

They reported that information “got stuck in traffic”, that they “hadn’t heard from anyone” and therefore spent extra time waiting for, or trying to obtain more, information. They reported finding this waiting to be frustrating and, in some cases, anxiety-producing.

Diane, a Finnish woman in her fifties, explained that when her mother Betty was diagnosed with diabetes there were lengthy waits to get in to see care practitioners because the practitioners were not communicating with one another efficiently and no-one had a clear plan on who should see Betty, and in what order. “It [was] quite a while before we actually got to see the diabetes [specialist] there because they had a bit of a mix up there,” she said. When care practitioners established who Diane’s mother needed to see there was more waiting; “the doctor kept saying ‘Have you heard from them?’ And then they did say they had an appointment for us, I think a week later, but we said nobody ever rang us up at all. We left my mobile number there to ring up, I had it on all the time [and nobody called].” Because of the significance of the time surrounding Betty’s diagnosis, being made to wait – to remain inactive or in a state of repose – was experienced as especially frustrating to both Betty and her daughter.

Diane’s account is similar to those of other participants who recounted frustration with what they deemed to be unnecessary waiting periods due to poor communication, between and with care practitioners, during temporally and socially significant points in their lives. Diane’s creative strategy focused on communication, where she provided her mobile phone number to those concerned; kept the phone switched on while she waited; and maintained communication between herself and Betty’s usual General Practitioner.

The second point in time that was deemed by participants as both significant vulnerable to poor continuity of care is transitions between different forms of care such as between primary and secondary health care services, or between hospital and home. Roger was sent home after an exacerbation of illness that had required hospitalisation for several months. Upon returning home, his wife Lynette described it as “a miracle that one of us didn’t kill the other” because Roger was entrusted into her care but with insufficient support offered by health services to assist their transition from hospital to home care. Lynette perceived no continuity of care during this time; “There’s a huge gap between being in hospital and being at home,” she said. “You’re discharged and it’s as if you’ve been set adrift in a boat without oars and an anchor.” Lynette relied on her existing knowledge of Roger’s needs and she learned through trial and error to provide effective care strategies. She maintained close communication with practitioners and she paid close attention to his current medication regimens.

Others also described feeling that insufficient follow-up support had been offered from care providers. Georgina said, “they should follow up people and see how they are coping at least once in a while.” This recommendation, like several others, relied on practitioners to fix the problem. Whereas Frank said:

The trouble is that it’s sort of... the episodes of care are just like that, they are episodic rather than being sort of tied together, I guess, in an overall sort of management strategy. I mean the idea of what [needs] to be achieved is fine, it’s basically keeping the HBA1C [blood sugar level] as low as possible but I think that it would be good to actually have a sort of a health care plan that sort of has goals and that. So I know how often I should attend and that sort of thing. Like, last time I hadn’t heard from my GP about my follow-up. So I had to ring up and find out, well, when does he want me back again? Does he want me to

come back next week to discuss the results of the blood test and I don't know and I ask for a copy of the pathology test and so on.

From this account we see Frank's strategies for managing inadequate co-ordination and continuity include taking an active role in scoping the appropriate next steps in managing his health and taking an active role in communication with practitioners, rather than waiting for practitioners to take that action. These strategies served another function: they reduced the quantity of time patients would spend waiting for communication from and between practitioners and waiting for direction towards the next steps in their care. Frank's desire for a clear plan was one that many participants shared. They wanted to increase their sense of organisation over the role of chronic illness in their daily life and in their future. Many saw care plans as a means of operationalising control over their current and future health. Hugo explained,

The trouble is that the episodes of care are episodic rather than being tied together, I guess, in an overall sort of management strategy. ... part of the care planning is sort of having planned visits for follow up at particular intervals so everyone knows when you're supposed to go and what needs to be done. You know, at twelve months, you need to have your urine test plus liver plus lipid levels or something like that, whereas maybe at three months you just need HBA1C and lipid levels and see the blood glucose or something, you know. ... I'm a great one for planning.

Although several participants in the SCIPPS and two participants in the fieldwork study reported having GP-written care plans, few had applied them. GP-written care plans often contained elements that people said they would find useful, such as instructions for identifying change to the illness phase such as entering a crisis phase (see Corbin and Strauss 1992, Lubkin and Larsen 2006: 37). These plans generally focused on clinical signs and outcomes (for example, weight control, medications) but seldom acknowledged the need for, or mechanisms by which, the patient could adjust their existing practices in terms of social obligations, health management and time use.

As a result, some participants who were active in the management of their health and for whom a GP-care plan was either not provided or was deemed insufficient, created their own plans. People reported developing their own plans for managing phase changes to their illness and the temporally-gauged requirements brought about by such changes. In this sense, such plans were dictated by the tempo of their own ill bodies. Having a plan enabled people to feel a greater sense of certainty and control over their future; it showed them what to expect and gave them capacity to plan for changes to their health that would happen over time. They said:

"I'm on call. Like, I've got my mobile on all the time because she's [care recipient] got the Red Cross Red Call meter there" - Stephanie

"I won't say it's entirely routine, but we both know that this can occur and it may or may not be something that's dangerous, you know. ...if you start feeling the same as you did the day you had a heart attack, what do you do? ... Now we have some idea of what to do, what to look for" - Collin

"I try and get inside and then I just collapse in a chair and if my heart is too [heavy], the angina, I get this heaviness in the chest. I have to take a tablet" – Fernando

These examples demonstrate that people had strategies in place in the event of exacerbation of illness. Plans were developed over time based on the individual's previous experiences of bodily changes in what Corbin and Strauss call 'phases of illness' (Corbin and Strauss 1992) and how such changes played out in their daily lives. In this sense, the care plans that people developed were very much grounded in time. They were developed to mitigate time spent worrying about possible future trajectories of illness (Jowsey 2011), to reduce their sense of risk, and to anticipate change in their health.

People were often faced with managing social elements such as carrying out 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 grandparents who had care responsibilities for their grandchildren. Care plans that were developed by participants frequently incorporated such social rhythms into their plans whereas practitioner-written plans seldom did (care plans are discussed further below).

Chronically ill people in this study typically used a number of strategies to manage daily temporal components of their illness in their own contexts (that is, around the rhythms of work, family and social life, as well as around eating and sleeping rhythms). A third of the participants reported doing this by maintaining their own up-to-date list of their current medications. The lists typically indicated 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 with them at all times so that whenever they saw a practitioner 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. Carers described taking on medication management responsibilities. Diane (previously mentioned) said, "Sometimes she gets things mixed up as well. ... I have to do the medicines these days. She used to do them herself. About a year now I've been doing the medicine because I kept noticing she didn't know what to call the tablets and stuff and now she's got over 20 tablets daily." People reported having had previous experiences of meeting with practitioners only to discover that the practitioner did not have a current medication list. These people reported feeling that the absence of current information negatively informed their quality of care and sense of care coordination. In order to avoid medication errors and to help manage their time, people also kept copies to stick on their kitchen fridge and to help them ensure that they took the correct amount and type of medication at the correct time. Figure 1 shows Pete's medication list.

Figure 1: Pete's medication list, 2012

Medication List

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

In this example 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 is evident. He learned from bodily 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 see the information it contained while on the phone to practitioners. 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 to multiple practitioners and that this could, in turn, inform his medication prescription/consumption that would lead to undesirable changes to his bodily being. Pete's medication list was of average length compared with others that participants spontaneously provided.

Roger (previously mentioned), had lived with severe COPD for several years and when we spoke with him he was using high volumes of supplementary oxygen continuously. Prior to retirement he had been the director of a large scientific 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 other indicators of his health. His own 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 and his life in the context of his illness, developing his own management plan, "putting [his] financial matters in order" and regularly updating his Legal Will. He had a strong desire to maintain control over his body, his life experience and his future, which motivated him to develop his own management plan. The plan had two columns, with a list of symptoms in the first column, matched against 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. When asked 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. If his oxygen saturation dropped below a certain level then he or his wife were to call for an ambulance. 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 essential medication use. Additionally, he could minimise his reliance on multiple care practitioners by taking steps to optimise his chances of staying out of hospital. He said, "I now have a management plan where I know the symptoms of an infection coming on. And when those symptoms get to a certain point, I know what drugs to hit it with."

Standard COPD management care plans such as the COPDX Plan which is commonly used in Australia, 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 the influence of his past practices on current health status) 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. Based on his reflexive observations of his body's needs, Roger created his own care plan, for which he then sought support; rather than having a template supplied and altered to then fit his needs. He illustrated, "in two days I felt I was going down with [infection]. And I hit it with one of those particular family of drugs early on, it was the Prednisolone and I'm still on that. I'm almost finished it. And that stopped it. Otherwise you end up in hospital."

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 what Bury calls ‘biographical disruptions’ (Bury, 1982).

Most people we spoke to about care plans who did not have a GP-written care plan had no idea that care plans were potentially available to them, at no cost, and could possibly help them in their daily health practices. Once people realised what a care plan was, they were often 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 when urgent decision-making was critical, and could empower them to change their socio-temporal practices in times of illness change. Few people reported having a GP-written Management Plan; only two people in the fieldwork dataset reported having one. Fran had used her COPDX 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 practitioners 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. This example demonstrates the importance of having care plans that cater for the needs of the individual and with enough specificity to ensure efficacy. Having those elements present in a care plan increases patient behavioural adherence (as other examples above have demonstrated).

These findings suggest that present systems for maintaining current medication lists across health systems are inadequate to patient needs. Moreover, existing care plan templates do not always attend to socio-temporal elements of people’s lives that, as demonstrated above, critically shape their experience. This may explain why formal care plan uptake in Australia is relatively low.²

Discussion

Throughout this article we have worked to disrupt the notion that patients are merely latent subjects who fall through gaps in continuity and coordination of care. We argue that patients bring multiple strategies to prioritise *their time* and to factor new temporal regimens into existing socially-contextual ones.

In 1985, Corbin and Strauss described different kinds of ‘work’ that patients carry out in the management of chronic illness (Corbin and Strauss 1985). More recently, Townsend and colleagues similarly observed in their 2011 study that chronic illness “requires hard practical, biographical, emotional and moral work” (Townsend 2012: 90, see also Townsend *et al.* 2006). This work can be time consuming (Jowsey *et al.* 2013, Yen *et al.* 2013) and tedious for people with chronic illness; and it requires the person with chronic illness to be reflexive about the needs of their own bodies, and by extension, to have specific knowledge and capacities; to be an ‘expert patient’ (Greenhalgh 2009a, Greenhalgh 2009b) and to be ‘activated’ in illness management (Hibbard *et al.* 2007). We add that it requires people to do hard work on time management too. People in this study, with different chronic illnesses and

at different stages of illness, developed ways of filling perceived gaps in their care coordination. Their creative strategies guided patients in their decision-making and health practices, and their strategies were informed by an acute awareness of temporal factors – both embodied and social.

Participants such as Claire, Diane, Frank, Hugo, Roger and Lynette demonstrated high levels of agency and creative capacity, and a willingness to engage in the ‘work’ of chronic illness. However, not all people living with chronic illness have equal – or possibly even sufficient – capacities to undertake illness work. In such cases where participants lacked resources to manage – energy, knowledge, mobility – they frequently had informal carers (often spouses or their children) helping them (but this too can be seen as the participants mobilising resources (informal carers) to aid them). Our study does not represent the experiences of people who are entirely without agency, creative capacity, or a willingness to undertake illness work. Their absence in this article may be a reflection of our sampling and recruitment strategies (people in palliative care and those with diagnosed cognitive impairments, for example, were not recruited to the study). People without these necessary resources are arguably most in need of quality care and most at risk of poor health outcomes when health systems fail them.

Does the work of chronic illness, and the creative strategies utilised therein, require a pre-existing level of what Nutbeam calls ‘health literacy’ (Nutbeam 2000)? To what extent does such work rely on patient mobility, energy, confidence in self, management skills (of self, of time, of information, and so forth), communicative capacities, informal support and other relevant factors? How does severe depression or pain inform people’s efforts? These influences are not easily disentangled. They are interconnected, and the presence or absence of one certainly informs the other. While this study did not set out to empirically measure their presence, the findings do suggest that even people who demonstrated lower levels of energy, health literacy or skills, and people entering acute or crisis phases of illness, remained engaged with the needs of their ill bodies and creative in their strategies to manage their personal, social and temporal experiences of chronic illness.

Factoring socio-temporal elements into patient-led management plans

Time is an important factor to consider in any care plan. In their controlled trial of a model of care that included the use of care plans, Battersby and colleagues (Battersby *et al.* 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. Patient strategies to manage in the context of inadequate continuity and coordination of care include the development of their own care plans. Drawing on the elements of patient care plans deemed important by participants in this study, as well as those of practitioners, we suggest that effective care plans should go beyond self-management to anticipate changes to the patient's health that will occur over time and inform their time use. 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 amount of time needed to undertake activities and how this relates to the patient's existing social commitments. Time is 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 amount of time needed to engage in health practices has also been shown to increase with multi-morbidity (Jowsey *et al.* 2013). 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 need to cater to multi-morbidity in order to get a better picture of the overall time quantity and time pressure associated with managing different illnesses, which may 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, mainly because of the unique circumstances of each individual patient and the specific management needs associated with each chronic illness. As a beginning, we offer in Figure 2 an example of what the Patient-led Management Plan (PMP) might look like. This Figure was developed by Jowsey as part of her doctoral research (Jowsey 2013).

(metformin) and an endocrinologist is not yet part of Kim's usual care team. Kim is attending cooking classes, which are increasingly becoming available to people with chronic illnesses as part of self-management programs in Australian health care service settings. Kim is undertaking other self-management activities listed under actions. Such details indicate time quantity associated with managing their multiple conditions.

Kim is using a dose administration aid (DOA) pack to manage medications (which reduces the amount of time needed to sort/prepare/take medication). Not all individuals can afford DOAs or need them, and the DOA is not without issues as it has a bias towards no change in illness status, which can cause problems when patients change illness phase and require a change of medications. However, DOAs are helpful in many cases and do reduce time burdens (Jowsey *et al.* 2013).

Medications are listed on the outside (reverse side) of the Patient-led Management Plan. The reason for this is so that a sticker with updated medicinal information can easily be attached to the PMP as needed.

Socio-temporal complications that emerge when changes to a person's health condition occurs (such as moving between phases of illness) are anticipated. For example, the above PMP template example indicates social rhythms and responsibilities that Kim has to pick up her 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 of health services and other people who can provide support.

Chronic illnesses pose monumental burdens to health systems and in Australia chronic illness GP-led care plans have been identified as one mechanism through which patient self-management and patient health outcomes can be improved, thereby reducing the overall burden to the health system. A recent study by Holden *et al.* (2012) found that general practitioners saw chronic illness GP-led care plans as holding important potential for improving patient care, for increasing patient 'compliance' in self-management, increasing monitoring of their health, and as a mechanism through which patients can increase the time they spend with health care practitioners (facilitated by that time being claimable through the Medicare Benefits Schedule). Holden *et al.*'s general practitioner participants also indicated the key barrier to chronic disease management items such as care plans were their own time constraints and that of nurses (2012).

Our findings suggest that patient perceptions of enablers and barriers to the use of care plans are also important. Our study participants suggested that they value and adhere to care plans when (1) they are developed in collaboration with the patient so as to be specific to their needs, (2) they are seen to hold potential for reducing the overall time burden to patients, and (3) they offer the patient effective directive support during exacerbations. When care plans do not meet these criteria and the patient's own objectives, this can result in patients ignoring the GP-led care plan and in some patients investing their own time and effort to develop their own care plan. For patient safety and self-management to be optimal the ideal would be to have one care plan crafted in a collaborative process between all stakeholders to meet the needs and aspirations of the patient. An experience-based and time-focused design approach, such as that offered in the PMP, is recommended. We propose that the PMP could be further

developed with pilot testing and we invite discussion about its potential for use in General Practice.

Conclusion

While different phases and types of chronic illness inform people's capacities to act in ways that hold the potential to improve their bodily experiences, it would be a mistake to assume that even very ill people, or people lacking in 'health literacy' are necessarily without agency. This study demonstrates that patient agency manifests in a multiply of ways to address the immediate and future needs of the ill body. At times the creative strategies that patients employ to address such needs are focused on the daily personal needs of the individual. At other times, they are focused on individual needs within inadequate health system structures of care.

We suggest it is almost impossible for health care practitioners to ensure perfect coordination and continuity of care solely in their own effort for every patient with chronic illness, even in an ideally functioning health care system. Such an effort misses the temporal aspects of illness and its management, including the overall time burdens, moments in time and in sequence, physical rhythms of temporality, biography, and over the period of illness. Out of necessity, and to fill this gap, patients craft their own care plans based on their unique circumstances of socio-temporal aspects, and try to navigate through phases of illness. This crafting is dynamic in nature and may change over the time – as and when required – and often comes as a temporal cost to the patient and/or carer. However, this time-cost required to manage also holds potentially time-saving elements because they are individually tailored. These patient-initiated creative and temporally-bound strategies also empower patients and therefore, have valuable roles to play in any health care system. In poorly functioning settings this role is significant and in optimally functioning settings it is still substantial, and thus such creative strategies and roles should be acknowledged.

Limitations

This paper utilizes two datasets. The first SCIPPS dataset was not collected with time as a theoretical concept of concern. Therefore, opportunities to explore temporal aspects of patient experience were not consciously followed up during interviews. Despite this apparent limitation, secondary analysis of the SCIPPS dataset revealed a wealth of information concerning the temporal aspects with which this paper is concerned. The spontaneously emerging temporal findings suggest that time is important in patient experience.

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Footnotes

¹Typically also, only one type of chronic illness is explored at a time, see for example, Faircloth et al. (2004a), Faircloth et al. (2004b), McKenna et al. (2009), Pound et al. (1998), Rittman et al. (2004), Sanders et al. (2002). However, most people with a chronic illness have multiple illnesses (Britt et al. 2008, Jowsey et al. 2009). This might mean that illnesses impact on experiences of time in multiple ways. This is an important factor that cannot be advanced in whole in this paper but is attended to elsewhere (see Jowsey 2015).

²About 15,000 care plan items were claimed as part of the chronic disease management items on the Medicare Benefits Schedule per month in 2001 (Wilkinson et al. 2002), uptake has remained low with general practitioners suggesting this is informed by their own time constraints, financial viability and the changing eligibility criteria for the items (Blakeman et al. (2002), Bolger-Harris et al. (2008), Holden et al. (2012)).

References

- Adam, B. (1995) *Timewatch: a social analysis of time*, Cambridge, Polity Press
- Armstrong, D. (2014) Actors, patients and agency: a recent history. *Sociology of Health & Illness*, 36, 163-174
- Banfield, M., Gardner, K., McRae, I., Gillespie, J., Wells, R. & Yen, L. (2013) Unlocking information for coordination of care in Australia: a qualitative study of information continuity in four primary health care models. *BMC Family Practice*, 14
- Battersby, M., Harvey, P., Mills, P.D., Kalucy, E., Pols, R.G., Frith, P.A., McDonald, P., Esterman, A., Tsourtos, G., Donato, R., Pearce, R., McGowan, C. (2007) SA HealthPlus: A Controlled Trial of a Statewide Application of a Generic Model of Chronic Illness Care. *Milbank Quarterly*, 85, 37-67
- Blakeman, T.M., Zwar, N.A., Harris, M.F. (2002) Evaluating general practitioners' views on the enhanced primary care items for care planning and case conferencing: a one year follow up. *Australian Family Physician*, 31:582-5
- Bodenheimer, T. (2008) Coordinating care: a perilous journey through the health care system. *New England Journal of Medicine*, 358, 1064-1071
- Bolger-Harris, H., Schattner, P., Saunders, M. (2008) Using computer based templates for chronic disease management. *Australian Family Physician*, 37:285-8
- Britt, H. C., Harrison, C. M., Miller, G. C. and Knox, S. A. (2008) Prevalence and patterns of multimorbidity in Australia. *Medical Journal of Australia*, 189, 72-77
- Bury, M. (1982) Chronic illness as biographical disruption. *Sociology of health and illness*, 4, 167-182
- Corbin, J. and Strauss, A. (1985) Managing Chronic Illness: Three Lines of Work. *Qualitative Sociology*, 8, 224-247
- Corbin, J. and Strauss, A. (1992) The chronic illness trajectory framework: the Corbin and Strauss nursing model. In: WOOG, P. (ed.) *The chronic illness trajectory framework: the Corbin and Strauss nursing model* (p. 9-28). New York: Springer.
- Ellingsen, S., Roxberg, Å., Kristoffersen, K., Rosland, J. H. and Alvsvag, H. (2013) Entering a world with no future: A phenomenological study describing the embodied experience of time when living with severe incurable disease. *Scandinavian Journal of Caring Sciences*, 27, 165-174
- Fabian, J. (1983) *Time and the Other: how anthropology makes its object*, New York, Columbia University Press

- Faircloth, C., Boylstein, C., Rittman, M. and Young, M. E. (2004a) Disrupted bodies: Experiencing the newly limited body in stroke. *Symbolic Interaction*, 27, 71-87
- Faircloth, C., Boylstein, C., Rittman, M., Young, M. E. and Gubrium, J. (2004b) Sudden illness and biographical flow in narratives of stroke recovery. *Sociology of Health & Illness*, 26, 242 - 261
- Freeman, G., Shepperd, S., Robinson, I., Ehrich, K. and Richards, S. (2001) *Continuity of Care: Report of a Scoping Exercise Summer 2000 for the SDO Programme of NHS R&D* [Online]. London: NCCSDO. Available: www.sdo.lshtm.ac.uk [Accessed 4 January 2010]
- Freeman, G. K., Woloshynowych, M., Baker, R., Boulton, M., Guthrie, B., Haggerty, J., Car, J. and Tarrant, C. (2007) Continuity of Care 2006: What have we learned since 2000 and what are policy imperatives now? London: National Institute for Health Research
- Greenhalgh, T. (2009a) Chronic illness: beyond the expert patient. *British Medical Journal*, 338, 629 - 631
- Greenhalgh, T. (2009b) Patient and public involvement in chronic illness: beyond the expert patient. *BMJ Clinical Research Education*, b49
- Griffiths, J. (1999) *Pip Pip: a sideways look at time*, Harper Collins
- Haggerty, J. L., Reid, R. J., Freeman, G. K., Starfield, B. H., Adair, C. E. and McKendry, R. (2003) Continuity of care: a multidisciplinary review. *BMJ*, 327, 1219-1221
- Heckathorn, D. D. (1997) Respondent-Driven Sampling: A New Approach to the Study of Hidden Populations. *Social Problems*, 44, 174-199
- Hibbard, J. H., Mahoney, E. R., Stock, R. and Tusler, M. (2007) Do Increases in Patient Activation Result in Improved Self-Management Behaviors? *Health Services Research*, 42, 1443-1463
- Holden, L., Williams, I. D., Patterson, E., Smith, J., Scuffham, P. A., Cheung, L., Chambers, R., Golenko, X. A. and Weare, R. (2012) Uptake of Medicare chronic disease management incentives: A study into service providers' perspectives. *Australian Family Physician*, 41, 973
- Jeon, Y.-H., Jowsey, T., Yen, L., Glasgow, N. J., Essue, B., Kljakovic, M., Pearce-Brown, C., Mirzaei, M., Usherwood, T., Jan, S., Kraus, S.G. and Aspin, C. (2010) Achieving a balanced life in the face of chronic illness. *Australian Journal of Primary Health*, 66-74
- Jowsey, T. (2011) Perceptions of time and identity: informal family carers of people with chronic illness. *Making Sense of Chronic Disease Series, Interdisciplinary Net. Oxford University*, 1-10
- Jowsey, T. (2013) *Chronic illness time*. Canberra, Australian National University Press
- Jowsey, T. (2015) Time and chronic illness: a narrative review. *Quality of Life Research*, 1-10
- Jowsey, T., Jeon, Y.-H., Dugdale, P., Glasgow, N. J., Kljakovic, M. and Usherwood, T. (2009) Challenges for co-morbid chronic illness care and policy in Australia: a qualitative study. *Australian and New Zealand Health Policy*, 6, 1-8
- Jowsey, T., McRae, I. S., Valderas, J. M., Dugdale, P., Phillips, R., Bunton, R., Gillespie, J., Banfield, M., Jones, L. and Kljakovic, M. (2013) Time's up. Descriptive epidemiology of multi-morbidity and time spent on health related activity by older Australians: a time use survey. *PloS One*, 8, e59379
- Kringos, D. S., Boerma, W. G., Hutchinson, A., Van Der Zee, J. and Groenewegen, P. P. 2010. The breadth of primary care: a systematic literature review of its core dimensions. *BMC Health Services Research*, 10, 65
- Lingard, L. 2012. Rethinking competence in the context of teamwork. in *The question of competence: Reconsidering medical education in the twenty-first century*. Hodges, B.D. and Lingard, L. (ed), ILR Press, London, 42-69

- Lubkin, I. M. and Larsen, P. D. 2006. *Chronic illness: impact and intervention*, Burlington, Jones and Bartlett Learning
- McKenna, K., Liddle, J., Brown, A., Lee, K. and Gustafsson, L. (2009) Comparison of time use, role participation and life satisfaction of older people after stroke with a sample without stroke. *Australian Occupational Therapy Journal*, 56, 177-188
- Morris, D. (2008) Diabetes, chronic illness and the bodily roots of ecstatic temporality. *Human Studies: A Journal for Philosophy and the Social Sciences*, 31, 399 - 421
- Nutbeam, D. (2000) Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. *Health Promotion International*, 15, 259-267
- Postill, J. (2002) Clock and calendar time: a missing anthropological problem. *Time & Society*, 11, 251-270
- Pound, P., Gompertz, P. and Ebrahim, S. (1998) Illness in the context of old age: the case of stroke. *Sociology of Health & Illness*, 20, 489 - 506
- Rittman, M., Faircloth, C., Boystein, C., Tubrium, J. F., Williams, C., Van Puymbroeck, M. and Ellis, C. 2004. The experience of time in the transition from hospital to home following stroke. *Journal of Rehabilitation Research & Development*, 41, 259 - 268
- Sanders, C., Donovan, J. and Dieppe, P. (2002) The significance and consequences of having painful and disabled joints in older age: coexisting accounts of normal and disrupted biographies. *Sociology of Health & Illness*, 24, 227 - 253
- Shi, L. (2012) The Impact of Primary Care: A Focused Review. *Scientifica*
- Townsend, A. (2012) Applying Bourdieu's theory to accounts of living with multimorbidity. *Chronic Illness*, 8, 89-101
- Townsend, A., Wyke, S. and Hunt, K. (2006) Self-managing and managing self: practical and moral dilemmas in accounts of living with chronic illness. *Chronic Illness*, 2, 185-194
- Uijen, A.A., Heinst, C.W., Schellevis, F.G., Van Den Bosch, W.J., Van De Laar, F.A., Terwee, C. B. and Schers, H.J. (2012a) Measurement properties of questionnaires measuring continuity of care: a systematic review. *PloS One*, 7, e42256
- Uijen, A.A. & Schers, H.J. (2012) Which questionnaire to use when measuring continuity of care. *Journal of Clinical Epidemiology*, 65, 577-578
- Uijen, A.A., Schers, H. J., Schellevis, F.G. and Van Den Bosch, W. J. (2012b) How unique is continuity of care? A review of continuity and related concepts. *Family Practice*, 29, 264-271
- Wilkinson, D., McElroy, H., Beilby, J., Mott, K., Price, K., Morey, S. and Best, J. (2002) Uptake of health assessments, care plans and case conferences by general practitioners through the Enhanced Primary Care program between November 1999 and October 2001. *Australian Health Review*, 25, 1-11
- Yen, L., McRae, I.S., Jowsey, T., Gillespie, J., Dugdale, P., Banfield, M., Mathews, P. and Kljakovic, M. (2013) Health work by older people with chronic illness: how much time does it take? *Chronic Illness*, 9, 268-282