

Time and chronic illness: a narrative review

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Abstract

Purpose This narrative review is concerned with the ways in which the relationships between time and chronic illnesses have been chartered in recent literature. It aims to identify types of time (referred to here as temporal structures) most commonly reported in chronic illness literature and to assess their bearing on people's lived experiences.

Methods Literature searches of three electronic databases (Google Scholar, MEDLINE, and PubMed) were carried out in November 2014 of articles published between 1970 and 2013 using the following search terms (and derivatives): chronic illness AND time AND (patient OR carer). The review followed four procedural steps: (a) comprehensive search, (b) temporal structure appraisal, (c) synthesis of findings, and (d) critical appraisal.

Results Forty studies met the inclusion criteria and were included for review. Four types of called temporal structures had a strong presence in the literature: calendar and clocked time, biographical time, past–present–future time, and inner time and rhythms. The first three temporal structures are largely understood socially, and the fourth is predominantly understood in and through the body. Several studies reported more than one temporal structure as informing people's chronic illness experiences. A wide array of chronic illnesses were represented in these studies.

Few studies reported on the experiences of people with multi-morbid chronic illnesses.

Conclusion Chronic illness induces new relationships to time. Drawing on Hyden (Sociol Health Illn 19(1):48–69, 1997), it is suggested that “narrative” storytelling—as a temporally informed analytic device—might prove effective for reconciling the tensions emergent from new and multiple relationships to time that chronic and multiple illnesses create. Opportunities exist for healthcare practitioners and health services to offer patients illness support that is cognisant of their relationships to time.

Keywords Narrative · Chronic illness · Time · Qualitative · Literature review · Biographical

Introduction

Chronic illnesses are “health problems that require ongoing management over a period of years or decades” [1]. Although chronic illnesses have different physiological, biological, and pathological properties, they share a common thread—time. Severe chronic illnesses induce different temporal rhythms and different relationships to time than are experienced by the healthy person, or even the person with acute illness. New practices may be developed and routines established to manage chronic illness in personal and social contexts. As rhythms of bodily life alter, a person's expectations for the future might change, and their relationships with other people (who have their own temporal rhythms) might also adjust. Meanings attributed to past and present experiences and practices, as well as future plans and imaginings, acquire new significance with chronic illness. As the time spent on health-related practices increases, meaning attributed to time expenditure may also take on new valence.

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This narrative review is concerned with the myriad ways in which the relationships between time and chronic illnesses have been chartered in the literature since 1970. The review question is: In what ways does time feature in empirical literature concerning chronic illness? Following Baumeister and Leary [2], this review scopes and evaluates common temporal theories in the chronic illness literature, in terms of their relevance and application to understanding chronic illness experiences [2]. Four temporal structures are identified in the literature—by theorists and/or study participants—as critically informing people’s chronic illness experiences. They are calendar and clocked time, biographical time, past–present–future time, and inner time and rhythms. These structures are appraised here in terms of their contribution to understanding the impacts of chronic illness on people’s lived experiences and meaning-making processes. The implications of understanding time’s bearing on those living with chronic illness are then discussed, with attention to strategies for improving people’s experiences and well-being.

Methods

Literature searches of three electronic databases (Google Scholar, MEDLINE, and PubMed) were carried out in November 2014 of articles published between 1970 and 2013 using the following search terms (and derivatives): chronic illness AND time AND (patient OR informal carer). The search was aimed at finding empirical studies that focused on time as a constitutive dimension of chronic illness experience. Inclusion criteria were studies concerned primarily with people’s temporal experiences (all genders and ages) of chronic illness, and publications written in English. Literature was excluded if either chronic illness or time was not a core feature of the article’s analytical or theoretical application.

A review of identified literature was undertaken. The review followed four procedural steps: (a) comprehensive search, (b) temporal theoretical/structure appraisal, (c) synthesis of findings, and (d) critical appraisal. The critical appraisal included identification of which temporal structures were evident in each included article, appraising the extent to which the identified structures were explored, and identifying strengths and weaknesses in the resulting arguments.

Findings

Forty studies met the inclusion criteria and were included in this review [2–41]. Ten temporal structures were presented in the literature, with several studies concerning more than one structure. Calendar and clocked time was the most commonly reported temporal structure [3–25].

Other identified structures included biographical time [3–5, 25–39]; inner time and rhythms [29, 40, 41]; outer time [40, 41], social time [40, 41], ecstatic temporality [33]; past–present–future [3, 5, 29, 33, 36, 38, 42]; process time [4]; and experiential knowledge over time, which references time in memory [38, 43].

While chronic illness itself is well researched [44], few studies have centralised time as a key lens through which chronic illness experiences can be understood [33]. Many of those that have done so, only centralise one main temporal structure, and explore one type of chronic illness [9, 26, 28, 29, 37]. The studies included in this review presented a wide range of chronic illnesses as well as a range in severity of illness, with many studies attending to experiences of people with severe illness and/or high illness-management needs.

Review of the included literature identified four key interconnected temporal structures that significantly contribute to our understanding of how chronic illnesses are experienced:

1. Calendar and clocked time (socially understood construct);
2. biographical time (individually held temporal construct, understood more completely as the individual ages and in relation to society);
3. past–present–future time (socially understood temporal construct); and
4. inner time and rhythms (individually held temporal construct, uniquely tied to inner rhythms and processes).

Overlap between these four structures was noted, primarily between biographical time and past–present–future time. The first three temporal structures are largely understood socially, and the fourth is predominantly understood in and through the body. These structures—as they are presented in the chronic illness literature—are explored in turn (see Fig. 1).

Calendar and clocked time: time use

The most salient temporal structure that people in Western societies perceive and utilise is calendar and clocked time—a linear motion upon which calendars and clocks operate [45, 46]. It has been understood both socially and analytically as a key temporal structure underpinning Western societies [46–48]. Calendar and clocked time 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. Calendar and clocked

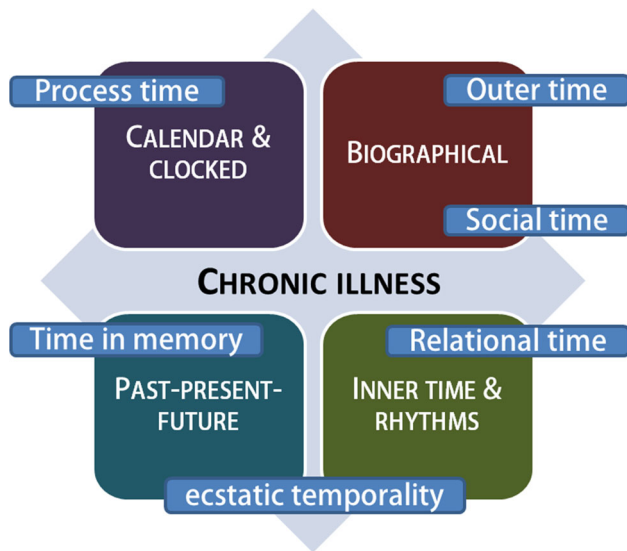


Fig. 1 Temporal structures that feature in chronic illness experiences

time is the most dominant temporal structure underpinning health service delivery in Western societies. Not surprisingly then, it features in many studies included in this review.

These studies looked specifically at how much time people with chronic illness spend on different aspects of self-care and health. In their literature review, Jowsey et al. [7] identify 22 articles concerning recordings of clocked time by studies internationally. They observe that according to the combined findings of studies included in their review, a person with a chronic illness that is associated with high time use demands (such as diabetes or chronic obstructive pulmonary disease [10]), who exercises and who is an informal carer of someone else who also has high time demands, could spend 2 to 7 h daily on health-related activities [7]. However, they note several methodological issues in the studies that prevent an accurate calculation of such time expenditure. Certain activities such as travelling to attend a clinical appointment or undertaking diabetes foot care may be associated with immediate higher time commitments than other tasks such as taking medication. However, tasks that may only take 5 min daily—such as taking medication—amount to two and a half hours over the course of a standard month [10]. Higher number of chronic illnesses is associated with higher overall time spent on health practices [6]. The management of chronic illnesses, and diabetes in particular, is interpreted in several studies as equating to a “full-time job” [10, 12, 13, 15, 31, 49, 50]. While the complexities of addressing the measurement of time use are attended to in these articles, little is said of other temporal structures or how such time expenditure is experienced. An exception is Jowsey’s [4] application of Davies’ notion of “process time” [51] to

understanding chronic illness experiences. According to Davies, process time “emphasises that *time is enmeshed in social relations*. Several processes may intertwine simultaneously and the fabric of life is patterned by the multiple criss-crossing chains of these processes” [51: 280]. Jowsey writes that “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” [4: 4].

Another exception, again from Jowsey et al. [5], is a study concerning the experiences of Aboriginal and Torres Strait Islanders in mainstream and culturally specific health services, whereby Jowsey et al. report that a large amount of time is spent in the waiting room at Aboriginal Medical Services—which could be several hours—was not seen as a “waste of time”; rather it offered patients an opportunity to socialise and share health information with one another. The perception of value concerning time use was a critical focal point in their study. They write,

“A participant with CHF [chronic heart failure] 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” [18: 201].

While the study is concerned with calendar and clocked time, quotes such as this one also reference participants’ wider biographical (temporal) concerns that take on new meaning with life-threatening chronic illness.

Biographical time

Biographical time references the summative period of time allotted to an individual during the course of their life. Several studies indicated that because of the ongoing nature of chronic illness, people with chronic illness tend to locate its meaning in relation to their overall biographies [27, 30, 37, 39, 52–54]. The development of biographical specific literature began with Bury in [30]. He suggested that 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 [30]. In work that focused closely on experiences of people with rheumatoid arthritis, Bury 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 (see also [8, 26–28, 34, 37, 52, 53]).

In response to Bury, Pound and colleagues note that in their qualitative study of elderly people who had survived strokes, stroke was not seen by participants as causal of disrupted biography. Rather, participants reported that in the context of their lives, chronic illness was “not that bad” [26]. The authors suggest that the reason for this may be age related and that stroke was perceived by some participants as a part of normal ageing [26]. 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 [30: 171]. The *timing* of the illness onset was therefore identified as influential in whether or not a chronic illness was perceived of as disrupting to the individual’s biography (see also, [27]). Similarly, in their study of homosexual men with human immunodeficiency virus (HIV), and in response to Bury’s notion of biographical disruption, Carricaburu and Pierret develop the idea of biographical reinforcement. Their study showed that a diagnosis of HIV reinforced people’s biographical expectations of the outcomes of their homosexual relations [52].

Like Bury, Corbin and Strauss also describe chronic illness as having a significant impact on the individual’s biography. Their study participants with chronic illnesses (primarily cardiac diseases, cancer and stroke) and with paraplegic and quadriplegic injuries are described as undertaking three kinds of work: biographical, illness, and everyday life work [31, 32]. Illness work and everyday life work are couched within a framework of calendar and clocked time; “to be performed daily, weekly, monthly” [31: 225–256]. The links between these two temporal structures, they suggest, are keenly felt by the individual with chronic illness. Corbin and Strauss write,

While changes of [illness] trajectory often have strong impacts on biography, biographical changes can also strongly affect the trajectory management and so an illness itself. For instance, pregnancy in a woman, diabetic since childhood, may provide just the incentive to keep her blood sugar within acceptable limits, something she had found difficult to do while growing up because of her fierce competitive desires. How it is important to do so not only to safeguard the health of her foetus, but so that she might live long enough to see the child grow up [31: 231].

The motivation driving daily management of chronic illness, in this example, is framed by biographical concerns.

While Charmaz is well known for her work on chronic illness as informative to self-identity construction, her early work identifies time as critical to informing such constructions [3, 55]. Charmaz writes “the struggle for control over illness and for control over time is a struggle to control the defining images of self” [3: viii]. Charmaz attends to time in terms of biographical and past–present–future orientations, and to a lesser extent: calendar and clocked time, and routines (interpreted here as part of rhythms and inner time).

Several studies chiefly concerned with respiratory conditions (asthma, chronic obstructive pulmonary disease) focused on biographical time [8, 38, 39, 56]. People with chronic obstructive pulmonary disease in Pinnock and colleague’s study described “acceptance of the situation as a ‘way of life’ rather than an ‘illness’” [39], thusly referencing both duration of illness and biographical time (‘life’). These participants “struggled to tell a coherent illness story distinct from their life story” [39]. Morgan and Thomas report an added temporal tension created by the nature of asthma: “parents’ views of asthma as a long-term and potentially serious illness often co-existed with a view that asthma was not a constant condition and something their child had ‘all the time’, but rather an intermittent illness that ‘came and went’” [38: 561]. The chronicity of asthma was here called into question in terms of duration and relentlessness.

Past, present and future

In Charmaz’ [3] work, she reports on the experiences of people with chronic illness based on longitudinal qualitative data, which by its nature privileges a past–present–future orientation. By extension, this orientation also brings into focus the biographical implications of chronic illness, as discussed above. Charmaz frames chronic illness experiences in terms of “interruption, intrusive illness, and immersion in illness”, with interruption having clear temporal overtones [3: ix].

Paterson’s [43] study of adults with type 1 diabetes followed people over a 2-year period, using audio-recorded think-aloud and post-think-aloud data as well as interviews and focus groups [43]. Past–present–future time is referenced through the research methods of gathering both present tense and past tense (recall) data. One of Paterson’s central findings was that patients formed bodily and experiential knowledge over time (referencing biographical and inner temporal structures), but that this knowledge of

how illness was experienced over time was seldom valued by healthcare practitioners in decision-making contexts.

Morris [33] applies a phenomenological analysis to understanding how diabetes informs people's relationships to time. Morris first summarizes the implications of Heidegger's notion of "ecstatic temporality" for people's freedom. Ecstatic temporality refers to the interconnected nature of past–present–future time as informing bodily presence and potentiality (which Heidegger describes in terms of "being" and "in-order-to" [57: 365]; requiring that the individual be "improvisational" in the way that past–present–future orientations inform the individual's self-identification and action). Morris then explores how the individual's improvisational and ecstatic relationships to time can be seen to change through the experience of managing diabetes. People with diabetes, Morris argues, are 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 restricted by necessarily being in what Morris calls "provisional time" [33].

Drawing on the past–present–future theoretical positioning of Zimbardo and colleagues, and building on the ethnographic work of Dussart, Jowsey et al. report on the influence that significant, and often negative, past experiences have for Aboriginal and Torres Strait Islander people's engagement with health services and self-management practices [42]. Because of the influence of past experiences on people's ideas and practices, Jowsey and colleagues call for increased support for patient biographical work in health services.

Inner time and rhythms

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 lunar cycles. Rhythm has been described elsewhere in terms of cycles and cyclicity [58, 59], with emphasis on epoch time—whereby sociocultural and environmental events become markers of points in time [47, 60]—and external rhythms. Rhythms of the body and of individual practices take on salience in chronic illness experiences:

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 [45: 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 at play at any given moment in the functioning body. For example, the process of sleeping is undertaken after approximately 15 h of waking time. Certain processes occur at different speeds [48] 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 [61]. 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 climatic changes [45: 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 has noted, it is the body that posits around us a biological world through which we come to experience external phenomena, and develop perception and representation. Extending on Heidegger's [57] hermeneutical device (and unfinished work) that "being in time" is a context with which the individual cannot be separated, Merleau-Ponty [62] notes that time as a dimension of being is observable through bodily experience and practice. While neither Merleau-Ponty nor Heidegger is concerned specifically with chronic illness, their ontologies are applied by Morris, as well as Ellingsen et al., in their studies of chronic illness [33, 40, 41]. Ellingsen et al. write "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" [41: 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.

Ellingsen et al.'s [40] phenomenological study concerns 23 people with chronic illness (22 had cancer) who were in palliative care. In their attention to embodied time and rhythms, they 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. Ellingsen et al. explore how these times intersect and are experienced by the palliative person. Their three temporal structures are similar to the four key scales of time identified in this literature review, whereby we might understand outer and relational time to be more broadly socially understood structures that overlap with biographical, past–present–future, and calendar and clocked time. 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 (see also, [40]).

McCoy’s study of people with HIV and their adherence to antiretroviral drug regimens also draws phenomenological conclusions about the tensions emergent for the individual with HIV between “self work” (which is similar to Corbin and Strauss’ theoretical position) and two kinds of time: inner time and calendar and clocked time. McCoy explains that antiretroviral drugs require strict attention to clocked time in order to maintain drug levels in the body (for example the dose is to be consumed every 8 or 12 h) [20]. However, adherence also requires that the dose be consumed on an empty stomach, or with food. And because the clocked timing of dose consumption is not negotiable, the individual must align their inner time with it, even if their body tells them that food is or is not required at that time [20].

Discussion

Four key temporal structures featured in this review: calendar and clocked time, biographical time, past–present–future time, and inner time and rhythms. At first glance, it would seem that because calendar and clocked time is the most commonly reported temporal structure in the chronic illness literature, it may have greater bearing on the individual’s experience. For some people, this may certainly be the case. They do report their concern over the time they spend waiting to see a doctor, travelling to appointments, and checking their blood pressure. However, the presence of calendar and clocked time in the literature may demonstrate more than its public salience. It may reflect the relative ease with which it might be engaged with in quantitative research. Biographical time was also frequently cited, again indicating its salience. However, people’s orientations to time—in its many forms—are subject to change. At times, the individual is oriented toward calendar and clocked time, and at other times, they are more concerned with their past, the present, or how their future might unfold. During such orientations, they remain informed by a constant biographical ageing process

and inner rhythms of the body. At other times, such as during clinical examinations and tests, the individual may be chiefly oriented toward inner time. It is equally likely that they could be chiefly oriented toward any number of temporal structures (which may not even be accounted for in this review). Figure 1 privileges the four temporal structures that form the central findings of this narrative review, while also listing other temporal structures that were present but not focal points. For numerous other temporal structures not attended to in this literature review, see Boxenbaum’s list [63] and articles in the *Time and Society Journal*.

An amalgamation of the literature concerning time and chronic illness experiences immediately evidences the complexity in the way that time and chronic illness collide in people’s experiences and accounts. This evidence is almost entirely lost in articles where single temporal structures are explored. Rather, a unilateral relationship between time (singular) and illness (also often singular) is taken, implying simplicity where none exists. Chronic illness is not only experienced temporally in terms of time use—as much of the literature would suggest. Nor is it experienced merely in terms of biography [64, 65].

Few studies were identified that addressed multiple temporal structures [5, 8, 20, 31, 33, 41, 42]. These few studies begin to unravel the complex relationships that time and chronic illness hold for the individual whose task it is to somehow function. Such functioning entails not only getting on with every day affairs but also constantly renegotiating the self and identity in relation to each illness and its bearing on how time is experienced.

Similarly, few studies addressed multi-morbidity [4, 6, 10, 66]. This was surprising given that the prevalence of multi-morbidity has increased in Western countries so much that it is now the norm for people with chronic illness to have more than one condition [6, 67–69]. The individual with multiple illnesses may think about and engage with time differently from the individual with just one illness. To illustrate, the individual could have diabetes, which necessitates an active engagement with both calendar and clocked time and inner time in order to regulate insulin within the body. The temporal scape associated with diabetes or HIV involves close attention to bodily rhythms and the timing (and type, and amount) of food and liquid consumption, whereas other illnesses (such as epilepsy, cancer, or chronic pain) require different relationships to time.

Most of the studies included in this review provided examples that would seem to indicate that their study participants had severe chronic illness or illness that required significant management needs, rather than illness that had very little bearing on their overall lived experiences and little calendar and clocked time to manage.

Jowsey et al. and Yen et al.'s research indicates that time spent managing chronic illness may be informed by the specific type and number of illnesses, the severity of illness and the self-rated health of the individual, duration of illness, as well as informal support such as having a partner to help manage tasks [6, 8, 10].

How might these complexities in understanding the intersection between time and chronic illness be addressed in a practical sense? In his review of social science's attention to people's narrative stories as discursive devices to inform self-identity, Hyden attends to the temporal components of narrative stories [70]. Please note the present article is a "narrative review", which is a structured form of literature review and quite different from a narrative—or story—as a communication device. The term "narrative story" is used here to reference the latter. Labov's seminal work concerning narrative story structure [71] was among the first to identify that a classic seven-stage narrative story is pinned to past–present–future orientations at various stages [71, 72, 73]. Such temporal orientations, Hyden suggests, help both the narrator and listener to identify where the meaning-making in the narrative story should occur [70].

At first, chronic illness may seem to lack all connection with earlier events, and thus, it ruptures our sense of temporal continuity—and if the rupture is not mended, the fabric of our lives may be ripped to shreds [30]. It is in this context that narrative stories become particularly interesting. They offer people an opportunity to knit together the split ends of time. For people living with chronic illness, narrative stories may be applied toward fitting the illness disruption into a temporal framework. That is, narrative stories can provide a context that encompass both the illness event and surrounding life events and recreate a state of interrelatedness. The French philosopher Paul Ricoeur expresses this sentiment when he says that "time becomes human to the extent that it is articulated through a narrative mode, and the narrative attains its full meaning when it becomes a condition of temporal existence" [74: 52]. In other words, narratives recreate a temporal context that had been lost, thereby taking on meaning as part of a life process (see also [75, 76]).

Narration and intersubjective storytelling are mechanisms through which people create meaning of illness over, and in relation to, time. This is particularly evident in their stories about the time surrounding illness diagnosis or severe exacerbations of illness, and in their stories of how chronic illness features in terms of their overall biographies.

This review has established that time features in different ways in accounts of chronic illness and that often multiple temporal structures are called upon in a single narrative story by a person living with chronic illness, to

aid them in their sense-making. Understanding the implications that chronic illness hold for someone's time use creates one layer of understanding. Add to that the implications that the illness holds for their previous, present, and future actions and a more complex understanding begins to take shape. Finally, add in attention to inner time and rhythms, and the richness of people's experiences become more evident. By identifying commonly reported temporal structures in chronic illness experiences, this narrative review concludes that the different ways of conceptualising time offer unique richness to understanding chronic illness experiences.

How might this enriched understanding inform health-care practitioners, service providers, and even policy-makers? How might we seek to improve people's quality of life and well-being? Past–present–future time, as well as biographical time, are attended to in chronic illness narrative and storytelling workshops, which are starting to appear in different forms and catering to the needs of people in different age groups and with different illnesses [77–79]. In their evaluation of a storytelling workshop for people living with cancer, Chelf and colleagues report that 97 % of participants agreed that "storytelling was a helpful way to cope with cancer" and that most participants saw therapeutic benefits of the storytelling [80: 1].

Digital storytelling is also becoming more common. Workshops offer people living with illnesses such as dementia a structured way to create a digital story about their experience [79]. Through the course of the workshop, participants upload their digital photographs into software that allows for collage and slideshow and overlay this with their own narrated story (audio recorded) to create a short (usually 3–5 min) montage film called a "digital story". The digital story enables the creator to make biographical sense of their experiences and also serves as a reminder for the person with dementia of their history, relationships, and of their being valued. Digital stories have also been applied to fields other than chronic illness, such as human rights [79].

Other research, included in this review, calls for attending to biographical work in health service settings [42]. Studies provide suggestions that attend to calendar and clocked temporal concerns of patients and informal carers. Suggestions are made for reducing waiting times and time spent on health-related practices such as sorting medications, and for healthcare practitioners to review their expectations of patient self-management with respect to the patient's capacity and existing time burdens [10, 14, 15, 43]. Paterson points out that patient capacity can be increased through "empowerment" toward patients being actively involved in decision-making concerning their illness management [what others have discussed in terms of enablement and activation (see, for example, [81])], but

that such strategies come (ironically) at a clocked time cost to healthcare practitioners and act as a barrier to their initiating empowerment strategies [43]. Inner time is also relevant to patient–practitioner interactions, where patients may describe how they negotiate processes of trial and error in aligning their inner time with calendar and clocked time. Such accounts demonstrate to the healthcare practitioner the complexities that patients are negotiating. It may be that simply being aware of, and appreciating, these complexities can direct healthcare practitioners toward offering patients more tailored suggestions for enhancing their self-management strategies.

On a macro-scale, some studies included in this review suggest that social welfare supportive services and policy drivers could help patients and informal carers by increasing financial assistance, appropriate and accessible respite services, and other forms of support to informal carers [14, 15]. While macro-scale suggestions do tend to be very much calendar and clocked time specific (and not directly attentive to other temporal structures), the impacts of suggested changes could potentially be far reaching and have significant implications for how people living with chronic illness experience time more broadly.

Conclusion

Literature concerning people's experiences of living with chronic illness privileges four key temporal structures: calendar and clocked time, biographical time, past–present–future time, and inner time and rhythms. Each structure has a unique bearing on the way people experience chronic illness, which becomes evident not only in people's self-management practices, but also in the way they talk about chronic illness in their lives. Managing chronic illness is a time-consuming task, and it is also seen to inform the way people make sense of their overall biographies: of their past actions, present situations, and future opportunities. This bearing that time has on people's experiences of chronic illness is currently acknowledged in health service delivery through micro-level initiatives that offer to support the individual in their personal sense-making (such as through digital storytelling workshops) and self-management strategies (such as respite services), as well as macro-level initiatives directed toward reducing time burden on patients and informal carers at a population level (such as through increasing welfare support, improving transport, or coordinating healthcare services). Offering support strategies to patients and informal carers that cater to every kind of temporal structure they perceive as influential over their chronic illness experiences, is, arguably, an impossible task. The author suggests however, that strategies which attend to one of the four key temporal

structures identified here, or attend to more than one temporal structure, may hold more benefits for people living with chronic illness than those strategies that are not cognisant of time.

Compliance with ethical standards

Conflict of interest Tanisha Jowsey declares that she has no conflict of interest.

Ethical approval This article does not contain any studies with human participants or animals performed by any of the authors.

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