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# Accepted Manuscript

Complex and dynamic times of being chronically ill: Beyond disease trajectories of patients with ulcerative colitis

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**Abstract:** This article contributes to health research literature by problematizing the linear, sequential and intelligible understanding of time in the studies of illness. Drawing on the work of Martin Heidegger, it attempts to overcome the problem of considering the time of illness as either a framework controlling patients' experiences or a mind-dependent feature of their lives. The paper offers a conceptual analysis of the stories of ulcerative colitis patients from a recent clinical trial to present temporalities of illness as both objective and subjective, relational and dynamic. We attend to a combination of temporalities related to the ambiguous unfolding of illness and patients' relationships with such an unpredictable world of changing bodies, medical practices and temporal norms. Furthermore, our analysis reveals openness of times and considers ulcerative colitis patients as constantly evolving beings, with multiple possibilities brought about by illness. The paper highlights co-existence of times and considers patients' lives as incorporating a multiplicity of futures, presents and pasts. It concludes with conceptual observations about the consequences of developing complex approaches to illness in health research, which can better highlight the situatedness of patients and their multi-dimensional temporal foundations.

**Keywords:** United Kingdom, Time, Chronic illness, Temporality, Heidegger, ulcerative colitis

to address a number of important limitations in the interpretation of time that the current health services literature reveals in its presentation of patients' health concerns, and their views on healthcare professionals' practices in the supportive role. In order to achieve this, the paper uses interview data collected during a recent clinical trial (CONSTRUCT) with ulcerative colitis patients discussing their health and illness stories, in order to respond to the following limitations in the health and illness literature.

Firstly, researchers often present patient's life trajectories, or changes to their health and wellbeing over the course of an illness linearly, as a succession of instants along an imaginary line (which we shall call in this paper a patient's 'career', Murray et al., 2005; Robinson, 1990). In so doing they tend to focus on static medical outcomes such as functioning and treatment adherence, and on temporal sequences of interventions that fail to express the very movement of time (Gergel, 2013). Within such flat temporalities, priority is often accorded to synchronising individuals' activities in a healthcare context with externally imposed temporal frameworks (such as a patient's history taking, medical progression, or the "controllable time" of consultation reporting, cf. Richardson et al., 2008) to the exclusion of a patient's surprisingly divergent experiences, as described by them. As a result, temporal experience is often explored within a binary framework that is pre-defined by the healthcare professional – such as temporary or permanent illness, available or ideal treatment options, "reclaimed" or "consumed" time (Seymour, 2002). These are perceived to be logically distinct, clearly separate dimensions, that relate to a patient's past, present and future whereas we would argue for a more nuanced, overlapping, and less distinct approach to understanding the complex dimensions of health and illness.

goals such as planned drug treatments (Grant et al., 2005; Hjemblink and Holmstrom, 2006). In so doing it focuses on “turning points” – moments of substantial change in the direction of patients’ lives – and becomes preoccupied with defining the developmental stages in a patients’ career, rather than examining issues of instability or unpredictability that influence patient judgement (Karp, 1994). The approaches emphasising chronological time as sequences of experiences, which presented illness as a temporary disruption (Charmaz, 1991; Kelly, 1992), also fail to fully explain the changes caused by illness to the character of lived time, patients’ feelings of timelessness and insecurity leading to uncertainty. In the case of chronic illness, constant uncertainty about interventions (failure of another “new” forms of treatment, cf. Davies, 1997), experiences of temporal disorientation and “liminal” time, question the expectations about clear and successive phases of wellness and sickness present in the health services discourse (Coventry et al., 2014). While some scholars acknowledge repeated disruptions as part of chronic illness and temporal behaviour of the body in disease as being outside of patients’ control (Larsson and Grassman, 2012), others still stress orderability of health experiences, assume patients’ ability to deliberately manipulate time as a part of self-management and emphasise the importance of “time work” in adjustment to disease (Flaherty, 2003). Recent criticisms of these approaches challenged the understanding of time as a resource and highlighted that self-management has so far failed to improve the health of people living with chronic disease (Coventry et al., 2014). They further emphasised the need to adopt phenomenological approaches and explore inter-subjective temporal experiences such as feelings of loss of routines, felt “slowness” of drug treatments, maladaptive coping rhythms, and disrupted temporal orientation, which contribute to the complexity of chronic illness.

to the temporal meaning of being, which he posits as a central focus of his writings. Earlier deployment of Heidegger's ideas to explore illness recognised the importance of relational understanding of disease as an unfolding of links between patients, other people and things and challenged perceptions of patients as mainly coherent and rational actors (Borrett, 2013; Papadimitriou and Stone, 2011). These approaches questioned health economic and self-management narratives of illness, which often do not account for contracted temporal lifeworlds of patients and fail to help patients in adjusting to emotional consequences of chronic disease (Coventry et al., 2014). Furthermore, engagement with Heidegger's phenomenology also helped to identify potential mechanisms mediating stress of patients with chronic illness, which account for both objective and subjective temporal experiences (Carel, 2012).

Building upon this relational and dynamic understanding of time, this paper engages with Heidegger's ideas in the context of the study of ulcerative colitis (UC), a chronic condition that causes inflammation and ulceration of the inner lining of the rectum and colon (the large bowel). We use this specific example as an opportunity to contribute to a broader critical discussion about different ways of understanding the process of living with chronic illness, bringing attention to patients' engagement with the world unfolding beyond the stereotypes of "doctors" time (Ortendahl, 2008) and categorisation of "neatly mappable" trajectories of illness. We begin by briefly presenting CONSTRUCT, the clinical trial we used as our case study, before discussing some of Heidegger's theoretical ideas about time and how they relate to the interview data derived from the trial.

## **2. Context and Methods: The CONSTRUCT Study**

effectiveness of two drugs (infliximab and ciclosporin) in treating patients with steroid resistant UC (Seagrove et al., 2014). The Research Ethics Committee for Wales has given ethical approval (Ref. 08/MRE09/42) for CONSTRUCT clinical trial; each participating Trust or Health Board has given NHS Research & Development approval. Patients admitted to hospital with acute severe ulcerative colitis were recruited between March 2010 and February 2013 and randomised to receive one of the trial drugs for up to 12 weeks. To understand their experiences and perceptions of treatment for UC, one of the authors conducted 35 semi-structured recurring interviews with 20 participants (by telephone, lasting, on average, 30 minutes), selected using purposeful quota sampling, at about three and 12 months after recruitment. The number of three-month interviews was split evenly between those randomised to infliximab and those to ciclosporin, with ten participants in each group, of which three in each group also had a colectomy.

Ulcerative Colitis is a chronic condition estimated to affect 1 in 420 people in the UK (Crohn's and Colitis UK, 2013). It is believed that genetic, immune and environmental factors play a role in its causation (Ford et al., 2013). UC is often debilitating for patients as expressed in terms of the emotive and deeply-felt impact it has on their life choices. As a complex illness, UC can bring about unexpected changes to a patient's health trajectory, with worsening symptoms, requiring a change in medication and possibly hospitalisation leading to unexpected changes to their perceptions of self, treatment regimes and healthcare plans.

UC is considered an 'individual' disease (Crohn's and Colitis UK, 2013) because symptoms vary from person to person according to the extent of the colon affected, ranging from slight bleeding to the urge to pass a stool 20-30 times over the day and night, cramping pains in the



all because of extreme fatigue and the need for ready access to a toilet (Rubin et al., 2010). It is this latter group of patients who were recruited to CONSTRUCT when they were hospitalised acutely ill with UC. They live with the constant unpredictability related to the timing of flare ups, ability to control them (Casati and Toner, 2000) or the need to have a surgery, something that happens in 40% of UC sufferers (Dinesen et al., 2010). This unpredictability of the disease makes it particularly difficult for patients and healthcare professionals to manage their health (Ford et al., 2013). Although the CONSTRUCT trial was not originally concerned with patients' temporal experiences, the issues of time, rhythms and durations of healthcare actions have dominated both doctors' and patients' responses to the trial and called for our attention. Temporal orientations were behind the decisions about the efficiency of two drugs and progress of the trial, which encouraged continuous adjustments of rhythms and schedules of medical interventions. In this process, patients developed their own temporal symbols and sensibilities about time, which prompted us to reflect on the continuity and discontinuity of treatments, challenges to established procedures and uncertainty among doctors about the temporal flow of this chronic illness.

In particular, the trial exposed that patients re-evaluated their temporal routines and habits, as well as challenged their taken-for-granted belonging to the world and questioned their relations to objects and emotions. Development of patients' familiarity with chronic disease, blurring of the boundaries between normality and pathology (74% of UC patients consider it 'normal' to have flares, Rubin et al., 2010), and conflicting information about the effects of 'healthy' diet on UC raised issues about uncertainty and complexity of illness, which we address in this paper. The possibility of having surgery, removal of part of the colon and creation of a stoma for extremely ill patients also highlighted conflicting potentialities of UC:

### 3. Heidegger: dynamic ‘being’ and temporal openness

Drawing on the results of the CONSTRUCT study, the paper uses Heideggerian ideas to develop conceptual understanding of health practices and the situated being of UC patients. For Heidegger, ‘being’ is always relational – it is about being-with others in the world which is, most fundamentally, temporal. On the one hand, this approach stresses *experiential and dynamic* nature of time, which challenges the conventional picture that fails to account for its passage and assumes its linear progression. Heidegger says that: “We ourselves *are* time” (Heidegger, 2002, 169), insisting that time cannot be seen as an external framework, within which life can be placed into constantly available and calculable fragments. Time is not limited to an objective phenomenon, which frames patients’ presence in quantifiable terms such as measurable times of recovery. Rather, time is best expressed in relation to the verbal sense of an act of being human (*tim-ing*), which is not limited to a simplified depiction within a measurable and objective world.

In the study of illness, attention to such subjective or “felt time” is particularly important, as it highlights an oft-overlooked, fleeting and temporal set of emotions and experiences that relate to shortened or extended flow of time or the reversal of a sequence of events (Livneh, 2007). This approach presents a shift in our understanding of human beings, from describing them as objects to seeing them as creatures whose lives are constantly developing and in flux. This helps to further explore patients’ process of becoming who they are (beyond the stereotypes of UC patients) and what is meaningful to them.

From a Heideggerian standpoint, a patient's life is always happening in relation to other people, objects, and emotions (which he would describe as 'worldliness'). Thus, whilst patients are involved with the dominant spatio-temporal structures framing their lives in terms of objective, orderable and useable entities (such as treatment schedules), they are also involved in the very happening of being – a temporal coming-into-presence of things. In this case, as Elden's (2002, 17) reading of Heidegger suggests, patients' means of engaging with the world "are not primarily determined by geometry and measurable distance, but by the more prosaic notions of closeness and nearness". Such engagement with the world means that patients themselves are always in the process of developing, and their existence is futural and projective, rather than one that simply emerges in the present. Their future expectations and possibilities arise out of a 'living' past (health interventions, medicines and diagnoses), which is still effective in the present and orients their ability to operate with others. Similarly, patients' ability to draw on what has come before depends on how they are developing and projecting themselves into specific ways of life.

There are several implications of this conceptual thinking, but in this paper we will concentrate on three key consequences that are particularly interesting in relation to patients in CONSTRUCT: 1) inter-subjective being ill, 2) projective being, and 3) multiple temporalities of being ill.

### ***3.1. Inter-subjective being ill***

Firstly, the paper examines Heidegger's (1996) argument that temporality is not a faculty of consciousness. Time is not private as it is dependent on others' decisions and actions. For example, the consultation can lead to temporal changes to treatments or drug regimes. It

to reveal the everyday fact of the constant and ongoing encounter that is the world ... an encounter in which things, persons and our own selves come to light” (Malpas, 2008, 306). In Heidegger’s terms, time of UC is more than subjective as it involves unpredictable coming to presence of a combination of things, experiences and people. It cannot come solely from the acts of patients since the very nature of this illness involves negotiation of the very identity of “patients” in response to changing public medical practices and temporal norms (Kelly, 1991). Illness for the UC patient could be defined as “a constellation of experiences instead of a cohesive process” (Brown et al., 2006, 125), unfolding in the world which patients can never master, so time of illness cannot be seen as internal to consciousness. Taking this on board, this paper studies the interrelationship between measured objective time and patients’ temporalities, and challenges the assumption about an orderability to one’s health experiences.

### ***3.2. Projective being***

Secondly, this paper examines life in terms of possibilities and futural being, rather than in terms of pre-defined orderings of stages, phases or health careers. In the medical discourse, lives of UC patients are often considered in terms of “healthy” possibilities, according to standard medical notions of wellbeing (such as lack of pain or biological dysfunction). In this context, progression of illness is often seen as moving from past to present and then prescribing the future, not as a patient’s own possibility, but as a series of predetermined external events (Borrett, 2013). However, Heidegger (1996, 343) gives priority to future, which is a necessary dimension of any sense of past or present. In his terms, human existence is characterised by ‘being towards death’ and this acknowledgement of future mortality and projective orientation is integral to how human beings see current and past actions as

different possibilities of being. For Heidegger, such projection is something a human being is, rather than something s/he does. Taking this perspective on board, this paper explores patients' projective being and opening of possibilities for patients, which are not end-states, but potentialities realised through temporal re-evaluation of personal goals and purposes, choices and self-understandings.

### ***3.3. Multiple temporalities of being ill***

Thirdly, the paper follows Heidegger in considering temporalities of human life as complex, unified and non-sequential. Heidegger (1996) suggests that instead of considering past, present and future as separate entities, we should understand them as linked and open to one another. This challenges the conventional picture of time, where illness remains framed within present experience, and the present takes over the whole of time (Mattingly, 1998), the past is reduced to merely a present that has passed and the future is the present prefigured in the now. In conventional accounts of time, surgery has been portrayed as "biographical disruption" (Kelly, 1992; Kelly, 1991), which assumed a clear separation between patients' past and present through 'bodily alienation' and 'betrayal' of previous emotional experiences (Williams, 1996). In Heideggerian terms, the past is not a collection of antiquated presents and the future something "yet to come", but co-existent conditions of the present and the movement of time. If we follow Heidegger's (1992, 19) rationale, experiences of UC patients' past pain and discomfort are "anything but bygone". Instead of interpreting illness as a temporary disruption to the body, with clear temporal markers that signify start- and end-points of health crises or health recovery, there is a transformative notion of blurring of temporal dimensions and limitations. This approach shifts focus from the "now" to the moments of existential openness bringing together past, present and future. Such "moments

## 4. Results

### *4.1 Inter-subjective being ill*

Following Heidegger, this paper draws on the CONSTRUCT clinical trial to explore patients' encounters with objective time and suggests the impossibility of its deliberate ownership. UC represents a combination of issues that may include: patients' health experiences, tests, treatments and drug use, relationships with others, emotions and knowledge of service provision. In Heidegger's (2002) terms, the time of illness can be expressed as a dynamic happening which reveals the gathering together of things and subjects, not limited to human experience. CONSTRUCT participants stress their inability to manage such complex time:

*"In my body, it was like there was a fight going on forever, even when I think it's under control, there's still this sort of underlying ... that's what I think of it as a fight, because it's not settled" (KLM0010)*

*"You didn't know until about 30 seconds before that you needed to sort it out and you could have been anywhere at the time. You could have been driving up a motorway and you aren't going to get anywhere in 30 seconds" (QRS0028)*

As these quotations intimate, time is not a faculty of consciousness, but something which emerges out of the process of being ill (a fight which is not settled). From Heidegger's perspective, the patient needs to be seen not as an object in time, but as a constantly developing creature, whose illness progresses as a result of a life immersed in things and situated in relation to the lives of others. This account is supported by Morse's (2000, 99)

medical explanations about time, experience and judgement, which focus on the rate of the passing of time as expressed by patients, and their perceptions of time as a collection of purely psychological acts (Flaherty, 2003).

Narratives from CONSTRUCT present the time of illness as not only created by patients, but also as shared with fellow human beings. When illness is considered as a combination of human beings and material things, the question shifts from exploring the ownership of time (i.e. who controls the waiting time for treatment) to an understanding of ‘illness time’ that might appear unfamiliar or strange. One of the patients explains:

*“I came out at the end of August, within a couple of weeks of my being discharged I started to notice, my sugars were up a little bit [...] I don’t feel well and I know it sounds awful but I weed myself one day and I touched my leg and it was sticky and I thought this isn’t right [...] I’ve been on insulin and everything, just coming down of that now and then this happens, the vomiting. So it’s just a conglomeration of things” (TUV0001)*

Time here does not refer only to the anticipated duration of a particular treatment or the expected progression of a set of symptoms. Rather, the pace and modality of illness is constituted out of the “gathering” of things and the way they come together (Heidegger, 1996). The patient specifically refers to being ill as a “conglomeration of things”, which exceeds recognisable symptoms and exists beyond discharge from hospital. Time is revealed through how things such as insulin, vomiting, and high blood sugar relate to one another, which cannot be entirely determined.

Due to its emergent and complex nature, UC carries ambiguity. In Canguilhem’s terms (1973, cited in Philo, 2007,88), disease such as UC is yet another form of life, that continuously

combination of different elements (such as symptoms and medications), and is itself a part of a gathering of other things such as therapies, drug treatments, and rehabilitation strategies. As Carel (2012, 99) stresses, “there is no coherent unified experience of illness”, and we would suggest, no singular temporality of illness. While UC presents itself as a chronic physical disorder, it also appears to represent certain properties and experiences that contain biomedical elements and are dependent on therapeutic intervention. Many study participants described this temporal ambiguity in relation to being hospitalised:

*“If you’re going for surgery you’re going to have drugs, you’re going to get side effects, hallucinations or whatever they give you so you’ve got the same risks either way... [after] surgery I got an infection and 6 weeks later I went back into hospital and I was more in danger of dying at that stage than I was originally from the surgery.” (QRS0028)*

As this quote demonstrates, coming to know what it means to have UC is not something that is disclosed in one particular mode of the physical condition which can be improved by surgery. The illness provides possibilities for other modes that are continuously opened up (Heidegger, 1992), and which give particular salience to the resulting side effects, infections or traumas. Here the temporality of UC is not reduced to clearly identifiable periods of surgery and rehabilitation, but involves indeterminate and ambiguous temporal transitions in and out of hospital, which can pose more danger than the initial effects associated with the illness. Another patient also expresses this ambiguity of UC, referring to living with it as a “metabolic thing”:

*“I just don’t know, something is causing this [illness]. It’s almost like a metabolic thing because I can go literally probably 12 hours and then have an hour or two of really bile, vomiting and then that is it again.” (TUV0001)*



for healthcare professionals to promote clear strategies for patients to cope with time (i.e. suggesting that they let time pass without pain by counting to 100) (Hellstrom and Carlsson, 1996). Accepting the ambiguity and indeterminacy of UC, challenges both medical and social attitudes to the temporality of illness and its expected development. It demands that attention is paid not only to the periods of medical care for medical problems, but also to the uncertain opening up of the illness, as a gathering together of bodily capacities (such as energy levels), objects (such as drugs prescribed), perceptions (such as unidentified risks) and emotions (such as fear of dying).

#### ***4.2 Projective being of patients***

Taking on board Heidegger's view of human existence as always projective, the paper considers patients' lives as open-ended and future-oriented. Several participants in this study expressed their sense of the future as structuring their sense of the present, and configuring possibilities about living with illness:

*“It is coping, you just get by, get through the days really, it will settle down for a while and then it's not so bad. It's always looming ... Sometimes I would go to the loo 10 times a day and that was just normal, but when you think about it, it is not normal at all (laughs), it's something you always have to think about, you're always thinking about having to go to the loo” (KLM0010)*

This vision of temporality of an illness as something “looming” and coming from the future, challenges a vision of time as static and divided into three different stages. The notion that a patient's history is one-directional does not satisfactorily explain the process of being with illness. As Livneh and Martz (2007, 129) state, in living with chronic illness: “expected life-

environment (Hennstrom and Carlsson, 1996). In this case, the future is a necessary part of the present, which makes explicit the conditions of “normal” living. Another patient explains the importance of the future in grasping present activities:

*“You are going to have to change your clothes once maybe twice a day and be prepared for that even though you are prepared for it because you know it is going to happen, but actually you are fighting it every minute of the day” (QRS0028)*

The future here is not a moment that will come about and then pass away. Rather, as Heidegger (1996) would stress, it configures patients’ current understandings and their engagement (‘being-with’) with the world. Thus a UC patient is not someone who is limited to the present as unchanging and ahistorical. Rather, there is a clear projection towards the future. Such an approach presupposes an openness to time that would help patients re-evaluate their goals and purposes. Patients develop their understanding of themselves by projecting themselves into a way of life or a particular “possibility of being” (Heidegger, 1996, 193). In the context of this study, a patient living with UC can project their thoughts towards a “healthy” way of life, and thus set about doing what healthy people do:

*“Just living a normal life. Making sure that I ... you know, to keep my health stable I will try controlling my diet so I have specific foods, I’ll do activities, I’ll go swimming.” (HIJ0002)*

This quote illustrates the futural existence of a patient who is applying himself to the activity of being what he understands himself to be. Projection here is a way of pressing ahead into a possibility of living a “normal” life. This involves not just imaginative achievements, but specific forms of conduct (controlling diet, swimming), doing what a “healthy” person does. Heidegger (1996) terms such conduct an “existential” possibility, which does not bring about

not perceived as end-states that determine one's status as 'unhealthy'. Another patient

explains:

*“I would visit the toilet between at least, well not at least but anywhere between 18 and 23 times a day. I was self-employed, I couldn't take on full time employment [...] there were many things that I would have liked to have done that I couldn't do and even things that I originally did like holidays that were a nightmare because like just going to an airport or flying became a major chore. I couldn't be around my kid [...]. (QRS0028)*

**Interviewer:** *So can you describe what difference the operation has made to your daily life?*

*On a daily basis it means that now if my wife says to me we're going to the shops, I can go with her and I don't think about anything, I just get in the car and go. I can be more prepared probably than my wife or child because I can get up and go.” (QRS0028)*

Using Heidegger's logic in the context of the above quote, it is possible to recognise differences between the factual possibility of having surgery and an existential possibility of devotion to taking care of the family and developing as an independent person. For the patient, an opportunity to be healthy and do things one “would have liked to have done” is not about bringing some possible future state into play. Even after surgery, as the patient explains, his ability to be a healthy husband or father involves continuously doing what a family person does (accompanying his wife on shopping trips and sharing childcare activities). There can be specific targets effected and activities organised in becoming a healthy person in the future, but the project of being healthy is not exhausted by a specific set of goals (getting ready quickly, being more mobile). Nor does it stop after some achievements have been accomplished. Being healthy is always futural in relation to what a

making at the existential level within healthcare practices, we should avoid limited provision of future contexts for patients (such as explaining future pay-offs and achievements), which currently prevail (Papadimitriou and Stone, 2011).

### **4.3 Multiple temporalities of being ill**

Following Heidegger's insistence on the unitary character of being, this paper suggests complex interpretations of living with UC as a process of being present that is stretched between the past and the future. This challenges more traditional, health professional accounts that tend to "place chronic illness and chronically ill bodies in time" (Driedger et al., 2004, 123) and divide their temporal experiences into logically distinct domains.

However, for many patients in this study such separation does not make sense and their past, present and future are experienced at one and the same time. For example, a man in his 50s stated that the colon surgery did not provide a clear break from the past and previously experienced issues continued to influence his life:

*"[After the surgery] I'm getting all the side lines of colitis without actually having err you know the bowel problems I'm getting all the stiff joints and erm me knuckles and me elbows and me knees are all stiff and err normally at this point I would be having steroids ... to make the colitis die down but I'm erm I'm not because I've not got any bowel there as such but the remaining bowel is giving me problems as well."* (DEF0016)

In his words, the past and present are intertwined as illness and its symptoms continue to develop and unsettle him after the surgery. He is not expressing the time that has passed as time that once was and is no longer. As Hoy (2009, 106) argues, in such a situation, "the past is still working itself out" and an individual develops his relation to past-present in a way that

his grounding in specific ways of life that reflect a past that was never present. Such

immersion in the world in relation to specific 'past' gatherings of things defines possibilities upon which patients can act:

*“Because I had had it [UC] 30 years, mentally I was prepared for the surgery so to a degree maybe we could have carried on with the drug but I had had enough by then... My family has a history, my dad had a history, he had it removed, large sections of his intestine and bowel so there was a hereditary route as well of bowel cancer so there were other pressures really.... If it [the drug] had been available 15 years ago and I had found it, and it would have just made it 50% more bearable, then I would probably not got round to surgery .”*

(QRS0028)

In this excerpt, this 50-year-old male describes the past as a relational combination of illness and drug strategies showing up as significant, or not showing up at all. Unlike some studies in evidence-based medicine, which draw on fragmented versions of the past (Ortendahl, 2008), a Heidegger-inspired approach helps to account for complex interrelations between past and present. As the quote above suggests, previous availability of effective UC drugs indicates the unfolding of different pasts which never materialised, but continued to affect the patient's life and his decisions about trying new treatments or accepting surgery. In seeing his life with UC as challenging and stretched between past and present, the patient remains open to the past (removal of the intestine similar to the one experienced by his father) and recognises the situated character of his being ill.

The unity of time can also be revealed in what Heidegger (1995, 294) describes as a “moment of vision”, when patients can get a grasp on the resources available in relation to their individual realities and where past, present and future come together. Such moment of vision

one out of the 'everydayness' of existence (Collins and Shubin, 2015; Shubin, 2015). As a middle-aged woman in our study suggests, different moments of intensity in illness provide opportunities to stand outside oneself and reconnect past, present and future:

*It also made me rethink my whole life. What I wanted to do, I don't want waste it doing silly jobs I just want it to do my job, work for myself you know it was really quite an experience, eye opening. ORH0053*

**Interviewer:** *The mere fact of having the disease?*

*Yes. I think I got it because I was really stressed working really hard for a lovely boss but for not much money, being slightly used, you know [...] That made me realise I'd rather work for myself than bust my bottom for somebody else. ORH0053*

**Interviewer:** *You you've started working for yourself?*

*Yeh, I've got my little tiny yard and I just ride out for people and look after their ponies... it's nice, because the people are nice, you know, and that's what I really like. ORH0053*

As this fragment highlights, UC prompted this woman to take action and created an opportunity ("moment of vision") to question the banality of her existence caught up in an unwanted job, which she linked to her deteriorating health. Such an "eye-opening" moment influenced the patient to act for the sake of her future and helped her discover new possibilities by doing things she loves. By facing her fragility and vulnerability caused by UC, her moment of vision revealed the past not as a closed structure (inescapable process of "busting bottom" for not much money), but as a particular set of activities continuing to resonate with "where her heart is". In Heidegger's terms, encountering UC calls the patient to

## 5 Conclusions

Drawing on Heidegger's work, this article has contributed to the health research literature by problematizing the linear, sequential and intelligible understanding of time in studies of illness. Firstly, the paper challenged existing approaches to the time of being chronically ill that assumed agency-centred accounts of temporal health experiences as either controlled by medical frameworks structuring disease or simply enacted out of a patient's conscious choice. The Heidegger-inspired approach has indicated that the time of illness is both objective, since it relates to a patient's being with others in the world, and subjective, since time is what patients are. In so doing, the paper has challenged binary accounts of temporary and permanent times of illness. Drawing on examples from the CONSTRUCT study, this work has stressed the importance of attending to the uncertainty permeating the awareness of UC patients, and revealing the complexity of their dynamic interaction with symptoms of illness and drugs. In addition, it has attempted to express their being ill beyond the estimation of probabilities, or the evaluation of disease trajectories. In this respect, the article has contributed to the development of a more complex understanding of "chronicity" that moves beyond the "objective and universal measurement" of time oversimplifying the temporal course of a chronic illness (Schinnar et al., 1990). We have provided a conceptual framework, which can help to develop important practical implications. Our findings suggest that the formal healthcare focus on supporting temporal self-determination of chronically ill patients may misinterpret their temporal orientations. As in our data, the situations of "lostness" reveal that times of illness are not solely mind-dependant, include mental consequences of disease and call for complex interventions (such as mindfulness-based psychotherapeutic

Secondly, the paper explored time for the UC patients as constantly evolving beings, whose lives are always futural. It expressed potentialities of such projective being and argued against restricting being ill to particular present mode in which it occurs (such as stereotypes of disease or “healthiness”). In this respect, the paper resonated with the broader arguments in health research that warn against prioritising the present dimensions of illness and call for increased attention to potentialities within patient’s lives to improve their health recovery (Papadimitriou and Stone, 2011). In so doing, it challenged practical responses to chronic illness, which support patients’ coping with future life lost and portray the future as simply present yet-to-come (Little et al., 1998). As our findings suggest, present-focused healthcare interventions (adaptation to living with specific diagnosis and its current temporal norms, i.e. Future Time Perspective, cf. Coventry et al., 2014) that define patients’ expectations in some temporal field called “the future”, are prone to dashing their hopes with the failure of yet “another trial”. Instead, we would argue for health treatments, which are supportive of the uncertainty linked to changing symptoms of disease and often contradictory life orientations of chronically ill people. Patients’ projective activities call for techniques that offer opportunities to explore a multiplicity of futures, support positive, if secondary, consequences of illness such as negotiating obstacles and creative adaptability to a changing illness context. (Carel, 2012)

Thirdly, the article has adopted Heidegger’s thinking on the unity and complexity of time to develop transformative understandings of UC, which blur temporal dimensions between past, present and future. It did so by focussing on the multiplicity of UC patients’ futures, created along with the past and present. Thus the paper contributed to the debates in health research



covered up by its calculative ordering in healthcare systems. As our findings demonstrate, adopting such multiple visions of time helps to recognise experiences of “living” past, which are often overlooked in conventional medical histories, but still interact, collide and inform temporal developments in UC. As Davies (1997) suggests, this recognition of the different pasts can help chronically ill people to reduce their psychological vulnerability, appreciate new meaning in living with disease without allowing anxiety to overwhelm them. Our findings also speak to Carel’s (2012) argument that appreciation of complexity of times can improve patient-physician communication, help patients to maintain an inner sense of continuity and narrow the gap between objective assessment of patients’ well-being and subjective experiences of illness. By drawing attention to “eye-opening” moments, the paper has revealed the importance of things that already matter to patients in getting to grips with their individual realities and helping them to explore new potentialities in their lives. This final point has significance beyond the scope of this paper as it illustrates broader challenges in healthcare research. There is a clear need for a more nuanced understanding of time, which can explain the effects of illness on patients and highlight differences between their temporal experiences and perceptions in relation to the “objective” conception of time used by health professionals (Gergel, 2013). Our analysis of relational, dynamic and open temporal experiences of UC patients, which do not follow orderly patterns, suggests that Heidegger-inspired ideas might appeal to those seeking to explain the messiness and unpredictability of chronic illness in order to offer richer accounts of patients’ lives.

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ACCEPTED MANUSCRIPT

- Many studies of chronic illness use linear and intelligible view of time
- Results of the recent clinical trial highlight uncertain and disruptive flow of illness
- Illness has its own temporalities that come to patients at unexpected times
- Time of illness comes to patients from the future and “living past”
- Therapeutic benefits of novel time approach address patients’ emotional disruptions

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