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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.

1. Introduction

This paper presents a new perspective on the concept of 'time' in health and illness. It aims 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.

Secondly, the existing literature often presents time as an entity both consciously intelligible and easily manipulated by patients and healthcare professionals, in order to achieve specific goals such as 'planned' drug treatments (Grant et al., 2003; Hjelmblink and

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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 address these limitations, this paper attempts to develop a broader interpretation of time, drawing on phenomenological work of Heidegger (1977, 1982, 1992, 1995, 2002) in relation 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

CONSTRUCT (Comparison Of iNfliximab and ciclosporin in STeroid Resistant Ulcerative Colitis: a Trial) was a randomised controlled trial comparing the clinical and cost 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 min), 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 abdomen, anaemia and dramatic weight loss (Sajadinejad et al., 2012; Srinath et al., 2012). UC is extremely disruptive for patients with severe symptoms as they often do not go out at 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