



Narratives of continuity among older people with late stage chronic kidney disease who decline dialysis



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ABSTRACT

Chronic and life-threatening conditions are widely thought to shatter the lives of those affected. In this article, we examine the accounts of 19 older people diagnosed with late stage chronic kidney disease who declined dialysis. Accounts were collected through in-depth interview in the United Kingdom (March–November, 2010). Drawing on a phenomenological approach, we focus particularly on the embodied and lived experience of the condition and on how participants constructed treatment modalities and approached treatment choice. We look toward contemporary elaborations of the conceptual framework of biographical disruption to illustrate how participants managed to contain the intrusion of illness and maintain continuity in their lives. We argue that three interactive phenomena mitigated the potential for disruption and allowed participants to maintain continuity: (a) the framing of illness as “old age”; (b) the prior experience of serious illness; and (c) the choice of the treatment with the least potential for disruption. We conclude that a diagnosis of chronic illness in late life does not inevitably shatter lives or engender biographical disruption. Instead, people are able to construct continuity owing to complex narrative interpretations of diagnosis, sensation and treatment choices.

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1. Introduction

The potential for chronic illness to dramatically disrupt the ordinary flow of life has received much research attention and continues to dominate lay, academic and health professional perspectives of the chronic illness experience. Michael Bury's (1982) biographical disruption has gained significant currency in articulating this idea (Lawton, 2003). However, Bury has been criticised for excluding contextual factors, notably age and other illnesses. Here, we examine the narratives of older people (those aged over 70-years) diagnosed with late stage chronic kidney disease (CKD) from a phenomenological perspective and look toward contemporary elaborations of biographical disruption to illustrate how they managed to contain the intrusion of illness and maintain

continuity in their lives. We focus on the lived experience of the condition and how participants constructed treatment modalities and approached treatment choice. We situate the treatment decision in the context of participants' attempts to maintain continuity to understand the reasons why people choose treatments which might, to some, seem counterintuitive or contradict what is presumed to be in their “best interest”.

1.1. Biographical disruption: basic tenets and elaborations

Based on his study in rheumatoid arthritis, Bury highlighted the complex and multifaceted ways in which chronic illness can lead to a fundamental rethinking of a person's biography and self-concept. He drew attention to how pain and discomfort provoke new consciousness of the body, the contingent and fragile nature of (embodied) existence, and the possibility of death, normally only seen as distant possibilities or the plight of others. He also underscored how illness brings individuals, their families, and wider

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social networks face-to-face with the character of their relationships, where normal rules of reciprocity and mutual support might be altered through new types of dependency. Bury posited that expectations and future plans are de-stabilised and must be re-examined within the constraints of illness. These experiences culminate in “marking a biographical shift from a perceived normal trajectory through relatively predictable chronological steps, to one fundamentally abnormal and inwardly damaging” (Bury, 1982, p. 171).

Despite its wide use as an analytic framework in social science research on chronic illness, biographical disruption faces major challenges from recent empirical and conceptual work. The importance of age and stage in the life-course at which a person becomes ill has been a central theme of redress (Lawton, 2003). Timing was originally underlined by Bury (1982) when he drew attention to the common cultural image of arthritis as a disease of the elderly. For his participants, most of whom were comparatively young, diagnosis represented premature aging and hence marked a shift from a perceived normal aging trajectory. Age as a factor mediating how individuals experience and respond to chronic illness was further illustrated by Pound et al. (1998). Their study revealed how for older adults stroke, while constituting a considerable impact on their lives, was not typically reported as extraordinary, or biographically disruptive. Similar findings have been described elsewhere (e.g., Faircloth et al., 2004; Sinding and Wiernikowski, 2008) and hence the idea that chronologically-framed expectations govern experience has gained wide acceptability. As Bury and Holme (1991) suggest: “It seems clear that most of us operate within a definite ‘social clock’ which guides our expectations of events within the biographical context. Such expectations influence whether events are anticipated or unanticipated, the latter having more negative implications for quality of life than the former” (p. 94).

A second challenge comes from studies inferring prior illness experience to mediate whether chronic illness is perceived as biographically disruptive. Faircloth et al. (2004) observed how stroke survivors already marked by other illness did not typically report stroke as biographically disruptive but rather one event in an on-going life. Similar ideas were presented by Williams (2000) and Pound et al. (1998) who reported how lives were not biographically disrupted by stroke if they were already restricted by other illnesses. Others have suggested illness might actually reinforce aspects of biography if considered consistent with particular lifestyles or cultural norms. Olsen et al. (2013), for example, observed how hepatitis C was a symbol of shared identity among the drug-using communities they studied.

A third challenge comes in recognition that people who have lived with general adversity and material deprivation more readily maintain continuity throughout illness (Ciambrone, 2001; Pound et al., 1998). These studies reinforce the appraisal of illness according to particular points of reference within a person's biography and habituation to particular crises.

These ideas represent an important corrective to biographical disruption by challenging the implicit assumption that illness always enters lives hitherto untouched by crisis or struggle (Lawton, 2003) and underscore the importance of acknowledging contextual factors. They reveal an underlying “will to continuity” – that is, a fundamental drive to maintain aspects of previous life – which shapes how people construct narratives to manage the intrusion of illness.

1.2. *The case of chronic kidney disease*

CKD has emerged as a global health challenge, affecting mainly older people (Stevens et al., 2010). From a biomedical perspective,

those affected experience gradual deterioration in kidney function which might progress to CKD stage 5 (CKD5), clinically defined by a glomerular filtration rate <15 ml/min/1.73 m². Symptoms include swelling, especially around the face, forearms, elbows and ankles caused by the build-up of toxic fluids, fatigue, cramps, nausea and excessive itching. CKD is associated with multiple morbidities including diabetes, hypertension and cardiovascular disease. The patient experience is particular and complex, characterised by long-term medical interventions and renal replacement therapies, such as dialysis and transplantation. There is currently no cure for CKD and without renal replacement therapy people with CKD5 will inevitably die.

Within renal care, advances in biotechnology have seen improvements in how dialysis is delivered, changing assumptions about the status of the older renal patient. When the first kidney dialysis outpatient unit was opened in 1963 in Seattle, USA, dialysis was rationed to people of working age (Blagg, 2007). Now dialysis is available to those previously regarded as too old and appears to have become normalised for older patients in more economically developed countries. Transplant is usually not a choice for older people because of physical frailty and the likely extent of co-morbid conditions.

Despite these advances, dialysis remains physically demanding and invasive. In replacing human biologies with an external machine it alters the margins of embodiment, where the edges between body and “other” become blurred (Kierans, 2005). In so doing, it produces new sets of ontological categories which present the body as a hybrid composition of spare parts: a “machine-organism” (Haraway, 2004, p. 297) or “cyborg entity” (Kierans, 2005, p. 344). These descriptions underline patients' dependencies on biotechnology and the radical transformations in body and self which accompany dialysis (Russ et al., 2007). They highlight how medical interventions like dialysis are not mere peripheries in the lived experience of CKD but its very substance (Kierans, 2005), a point echoed in suggestions that the perceived intrusiveness of CKD is judged essentially by the intrusiveness of its medical management (Karamanidou et al., 2013). For older people, the intrusion of dialysis might be greater because of increased physical frailty, difficultly managing complex technology if undertaken at home, or the burden of frequent travel if undertaken in hospital (Burns and Carson, 2007). Additionally, it might not significantly improve survival (Hussain et al., 2013). Hence, the benefit of dialysis to the frail older person has been profoundly challenged. Developments in care and a shift from life-extending toward life-enhancing treatments have enabled the emergence of a new treatment alternative: conservative kidney management (CKM).

Unlike dialysis, CKM is not renal replacement therapy and focuses on maintaining residual renal function. It manages CKD using regular outpatient appointments offering supportive treatments to treat symptoms, with access to psychological services. End-of-life issues might be discussed, possibly with input from palliative care specialists. CKM is advocated in several developed countries and data from the United Kingdom and Australia suggest that 14% of people with CKD5 receive CKM (Carson et al., 2009; Morton et al., 2012b).

1.3. *The present article*

Here, we present qualitative data from a study which aimed to examine the lived experiences of older people with CKD receiving CKM. We focus on one major theme, “continuity and disruption”, and discuss this relative to the debates around biographical disruption and continuity. In so doing, we aim to outline how older people with CKD attempt to deal with illness by containing its intrusion into their lives at both symbolic and behavioural levels;

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