**Citation:** Cluley, V., Martin, G., Radnor, Z. & Banerjee, J. (2021). Frailty as biographical disruption. Sociology of Health and Illness: a journal of medical sociology, 43(4), pp. 948-965. doi: 10.1111/1467-9566.13269

This is the accepted version of the paper.

This version of the publication may differ from the final published version.

**Permanent repository link:** https://openaccess.city.ac.uk/id/eprint/25802/

**Link to published version:** https://doi.org/10.1111/1467-9566.13269

# Frailty as biographical disruption

Dr Victoria Cluley (Corresponding author), Post-doctoral Research Fellow, Cardiovascular Sciences, University of Leicester.

Professor Graham Martin, Director of Research, THIS Institute, University of Cambridge.

Professor Zoe Radnor, Professor of Service Operations Management, Cass Business School. City, University of London.

Dr Jay Banerjee, Consultant in Emergency Medicine and Honorary Professor of Emergency Care, University Hospitals of Leicester, NHS Trust.

## Abstract

Biographical disruption positions the onset of chronic illness as a major life disruption in which changes to body, self and resources occur (Bury 1982). The concept has been used widely in medical sociology. It has also been subject to critique and development by numerous scholars. In this paper, we build on recent developments of the concept, particularly those taking a phenomenological approach, to argue that it can also help in understanding other disruptive health-related experiences across the lifecourse, in this case the onset of frailty. We draw on the findings of 30 situated interviews with frail older people, relating their experiences of frailty to the concept of biographical disruption. We show that frailty shares many similarities with the experience of chronic illness. Using the lens of biographical disruption to understand frailty also offers insights relevant to recent debates around both concepts, and on the continued relevance of the idea of biographical disruption given changing experiences of health and illness, including the circumstances in which biographical disruption is more and less likely to be experienced. Finally, we reflect on the potentials and limitations of applying the concept to a health-related condition that cannot be categorised as a disease.

Abstract: 197 words

Main text: 8.271 words

**Key words:** biographical disruption, frailty, embodiment, ageing, old age, qualitative, UK.

**Data sharing:** The data that support the findings of this study are available from the corresponding author upon reasonable request.

## Introduction

Over the last few decades, the idea of ‘frailty’ has gained traction in the care of older people in many healthcare systems with ageing populations. Used in general parlance to convey some form of physical or mental weakness (Cluley et al 2020), in clinical circles it is used to refer to “a multi-system reduction in physiological capacity,” resulting in decline of resilience so that an individual’s function and wellbeing may be compromised by minor challenges (Campbell and Buchner 1997: 317). While often linked to the ageing process, frailty and ageing are distinct concepts. Frailty is not an inevitable consequence of the arrival of old age. Frailty has a multifactorial aetiology that can overlap with the ageing process (Rogans-Watson *et al.* 2020). Those experiencing frailty will likely also experience a variety of chronic illnesses such as arthritis, diabetes and Parkinson’s disease (Rahman 2018). Besides older people, frailty has been described in homeless people (Rogans-Watson *et al.* 2020), middle-aged adults (Petermann-Rocha *et al.* 2021), and younger people with HIV (Montaño-Castellón *et al.* 2020). While not unique to the ‘very old’ or even the old, its incidence and prevalence increase with age, as people accumulate more deficits that can render them susceptible to frailty (Rockwood and Mitnitski 2007).

As clinical use of the term frailty has increased, so scores, measures and indexes have proliferated to define frailty more precisely, identify those experiencing it, and aid decision-making (e.g. Fried *et al.* 2001; Rockwood *et al.* 2005). Though they vary in exactly how they define frailty, as Grenier (2020: 71) notes, such approaches “treat frailty as the purview of biomedical and health care specialists.” Frailty does not constitute a disease; however, it is usually associated with multi-morbidity, and through this process of medicalisation, ‘the frail’ are constituted as a clinical population group, constructed through clinical understandings and classification systems (Grenier 2007).

The medicalisation of frailty is subject to growing interest among social scientists, who have attended to both the implications of the adoption of the term by clinicians, and the experience of frailty among older people. Studies have suggested that whatever the clinical utility of the term, a ‘diagnosis’ of frailty may have negative consequences for older people (Grenier 2007; Grenier *et al.* 2017a; Grenier and Hanley 2007; Torres and Hammarström 2006; Warmoth *et al.* 2016; Authors forthcoming). More broadly, Grenier et al. (2017a) and Pickard et al. (2019) highlight the social function of the term as a counterpoint to discourses of successful ageing: a means of connoting what older people should avoid. Frailty has been associated with the negative discourse of the ‘fourth age’ (Gilleard and Higgs 2011; Pickard 2014), with older people failed or ‘frailed’ by society’s stigmatisation of deep old age and frail bodies (Grenier *et al.* 2017a). A growing number of studies offer insight into the experience of frailty as a disruptive life experience with profound consequences for both sense of identity and day-to-day functioning (Grenier 2007; Nicholson *et al.* 2012; Torres and Hammarström 2006)—what writers in the sociology of chronic illness have long referred to as a ‘biographical disruption’.

First conceptualised by Bury (1982) in his analysis of interviews with people affected by rheumatoid arthritis, biographical disruption positions the emergence of “chronic illness as a major kind of disruptive experience” (Bury 1982: 169). The idea is premised on Giddens’ (1979: 124) concept of the ‘critical situation’: “a set of circumstances which—for whatever reason—radically disrupt accustomed routines of daily life.” For Bury (1982), the onset of a chronic illness represents this very disruption to biographical continuity: “illness, and especially chronic illness, is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted” (Bury 1982: 169).

In the near four decades since Bury introduced the term, it has become one of the best-known concepts in medical sociology (Locock and Ziebland 2015). It has been applied to a wide range of long-term conditions, and has been subject to critique, revision and reorientation in the process. Engman (2019) recently sought to expand the theoretical basis of the concept, proposing embodiment as a lens through which to view the experience of biographical disruption. In this paper, we seek to build on this proposition to advance the debate around the applicability of biographical disruption, by applying the concept to the experience of frailty among older people. In so doing, we extend biographical disruption to a health-related status that is subject to ongoing contestation and development (Rockwood and Howlett 2018)—and one where the existing literature would make conflicting predictions about whether biographical disruption has conceptual purchase. This allows us to offer theoretical propositions about the circumstances in which biographical disruption is most likely to be experienced, which might be tested in other conditions, including health-related experiences that fall outside disease categories, at the frontiers of medicalisation.

The focus here is on frailty in older age. This focus allows us to extend the concept of biographical disruption to the furthest reaches of the lifecourse. We acknowledge that frailty and ageing are not synonymous, and frailty can be experienced by those who are not old; moreover, the ageing process itself, distinct from frailty, can be disruptive (Taghizadeh Larsson and Jeppsson Grassman 2012).

## Biographical disruption: a biography

Biographical disruption has been applied to a great variety of chronic illnesses. We examine this literature selectively to show how the concept has developed since its introduction, and highlight key points of debate (see Locock and Ziebland 2015 for a more comprehensive literature review).

Bury (1982) identified three forms of biographical disruption: disruption to the ‘normal’ way of being, including bodily performance and help-seeking behaviour; disruption to self-identity, involving change to the individual’s sense of self and position within society; and disruption of the social and material resources that people rely on for everyday life. The majority of subsequent studies have focused on the first two elements (Ciambrone 2001; Gisquet 2008). In applying the concept to a wide range of conditions, researchers since Bury have tested the ‘boundary conditions’ under which biographical disruption might apply. Several studies have suggested that the concept’s usefulness can depend on the chronic illness in question, its timing, and the circumstances of the person affected (Engman 2019; Faircloth *et al.* 2004; Williams 2000). Most recently, Wedgwood et al. (2020) highlight the problematic nature of heterogeneous samples used in many studies to explore biographical disruption, which, they argue, has resulted in the neglect of influences such as age, gender and class on the experience of chronic illness.

Perhaps most notably, studies have found that the diagnosis of a chronic disease can be much less impactful for people whose lives are already characterised by challenge and disruption. Pound et al.’s (1998) study of the experience of stroke among older, working-class people found that the concept had limited resonance. This was seemingly not just a matter of superficial stoicism: given wider experiences of poverty and hardship, Pound et al. (1998: 502) argue, “chronic illness may be anticipated and experienced by some older people as normal.”

Faircloth et al. (2004) similarly found that for participants who had suffered stroke, biographical disruption did not always occur. Depending on their stage in life and wider health experiences, some considered it part of their ongoing life course trajectory rather than a distinct disruption: "when the stroke is associated with ageing and other health conditions the stroke survivor may simply be resigned to their current experience of physical decline" (Faircloth *et al.* 2004: 258). The majority of Harris's (2009: 1031) participants recalled their diagnosis with hepatitis C as "no big deal": something that was almost expected given their previous status, in most cases, as injecting drug users. In some circumstances, a diagnosis may represent less a biographical disruption, and more another trial to contend with—one that may be less challenging than other events that fill their day-to-day lives (Ciambrone 2001).

Moreover, the experience of chronic illness has itself changed considerably since Bury developed the concept. Bury (1982) notes that the ambiguity associated with the diagnosis of rheumatoid arthritis contributed to the disruption his participants experienced, including uncertainty about both cause and treatment. Changes in the state of knowledge about many chronic conditions, and the rise of evidence-based medicine and shared decision-making, mean that a diagnosis now may have somewhat different practical and symbolic implications (Shostak and Fox 2012; Wouters and De Wet 2016).

As well as offering insight into the breadth of experiences of chronic illness, studies since Bury's have spawned a range of variants of the concept of biographical disruption. Notions such as biographical continuity (Williams 2000) and biographical flow (Faircloth *et al.* 2004) suggest that for many people, chronic illnesses are not abrupt disruptions but inescapable elements of "the 'normal chaos' […] of everyday life and existence" (Williams 2000: 51). For Bell et al. (2016), illness experiences may be best characterised through the idea of 'biographical oscillation'. Rather than a "one-off biographical 'disruption' that steers us off an 'illusory' linear or predictable life trajectory," for Bell et al. (2016: 184), the onset of chronic illness might “be usefully reframed as one of many ‘biographical oscillations’ encountered in the life course that re-route us between continually shifting, often ‘messy’ and unanticipated life trajectories.”

Some of the evidence from existing studies suggests that these limits to the applicability of biographical disruption may be especially pertinent in relation to the experiences of older people. Pound et al. (1998: 501) assert that older people “may anticipate illness as inevitable in old age,” while Bury himself suggests that expectation, rather than disruption, may typify the experience of chronic illness among the ‘very old old’ (Bury and Holme 2002). Yet other studies suggest that this is not universal. Sanders et al.’s (2002) participants simultaneously viewed osteoarthritis as normal (in that it was an expected aspect of the ageing process) and highly disruptive to identity and to day-to-day life. Similarly, combining two longitudinal studies of ageing with chronic illnesses and disabilities, Taghizadeh Larsson and Jeppsson Grassman (2012: 1167) find “that illness changes do not necessarily have to be wholly unexpected to be experienced as disruptive.”

Given such diversity of findings in both different and seemingly similar groups (see also Locock and Ziebland 2015 for a more comprehensive review), it is difficult to draw conclusions about the transferability of the concept of biographical disruption, or to make firm predictions about the circumstances in which it is more likely to occur. Characteristics such as age, prior experience of adversity and socio-economic background seem to be at best inconsistent predictors of biographical disruption. In consequence, the literature on biographical disruption can appear rather idiographic and descriptive, providing insight into a wide range of experiences but offering little predictive or explanatory purchase that cuts across them.

The recent contribution of Engman (2019) seeks to move beyond this impasse. Drawing on the work of Merleau-Ponty (1964), she argues that “embodiment constitutes a mechanism whose contours explain whether or not biographical disruption becomes a meaningful feature of the illness experience” (Engman 2019: 120). Positioned phenomenologically, bodies are our site of experience, and it is through our bodies that we come to know the world. Merleau-Ponty’s (1964) ‘sentient-body-subject’ positions bodies as the sites of meaning via individual perception and experience within a shared world (Williams and Bendelow 1998). Our knowledge of the world, and of our bodies, is accumulated over time and is drawn upon to make sense of things. Echoing calls for greater attention to the role of the body in chronic illness (e.g. Kelly and Field 1996; Williams 1996), Engman (2019) posits that since embodiment is central to both the *biological* and the *social* dimensions of the experience of disease, it is key in determining the occurrence (or not) of biographical disruption. “Biographical disruption does not,” she argues, “result from illness as such, but from the ways that illness impinges on one’s physical ability to engage with everyday life” (Engman 2019: 120). The participants in Engman’s study, organ transplant recipients with a variety of conditions, varied in the extent to which they experienced biographical disruption: she attributes this to differences in the degree to which the transplant introduced “novel physical limitations that make familiar behaviours and habits inaccessible” (Engman 2019: 124).

From this perspective, one might expect the onset of frailty—defined clinically as a “multi-system reduction in reserve capacity” that leaves the frail person “at increased risk of disability and death from minor external stresses” (Campbell and Buchner 1997: 315)—to be an axiomatic example of biographical disruption. Such a fundamental change in one’s relationship with the world, mediated through a body whose capacities have previously been taken-for-granted (Williams 1996), presents a significant break in experience. Whereas the experience of at least some long-term conditions might be sidelined or compartmentalised by people who are otherwise able to continue as normal, frailty is all-encompassing: the accumulation of multiple deficits that, together, leave an individual’s capability and experience of the world fundamentally altered. As noted above, however, frailty is not a disease. Some approaches to frailty tend to conceptualise frailty as synonymous with the ageing process, and see frailty as invariably associated with increasing chronological age (Bergman *et al.* 2007). Here, we take the alternative standpoint, associated with various geriatricians and social gerontologists, that although age is a strong predictor of frailty, the aetiology of frailty is more complex, to be found in the "accumulation of deficits" (Rockwood and Mitnitski 2007: 722) over time from long-term conditions and other "behavioural, environmental and social risk factors" (Bergman *et al.* 2007: 732). Frailty, in this conception, is the cumulative impact of "a diverse range of deficits including functional limitations, morbidity, psychosocial status, and cognitive ability" (Bergman *et al.* 2007: 732). Correspondingly, the consequences of frailty for older people are not readily grouped into a common, delimited set of symptoms and bodily impacts, as is arguably the case for most chronic diseases. Moreover, a 'diagnosis' of frailty has important social as well as clinical implications. As Grenier (2020: 71) puts it, frailty "is not only a marker of illness, decline or a period of the life course where one is 'closer to death'. Frailty is also a set of discourses and practices that have emerged in tandem with contemporary ideas of autonomy and individual responsibility." Frailty is experienced as a mix of healthcare needs, bodily incapacities, and economic, cultural and social norms regarding independence and the idea of 'good ageing'.

Together, arguably, this combination of clinical and socio-cultural influences make the consequences for the embodied experience of the frail individual all the more profound in the way they "rupture […] the ability to enact habits and routines" (Engman 2019: 124). On the other hand,  this supposition would appear to contradict the notion that biographical disruption is contextually contingent, and less forceful for those who might anticipate decline and disruption (Bury and Holme 2002; Faircloth *et al.* 2004; Pound *et al.* 1998; Sanders *et al.* 2002).

With these debates in mind, therefore, we consider the relevance of the concept to a cohort of older patients who—according to one clinical assessment tool at least—fall into the category ‘frail’. We examine the applicability of the concept to this group, the degree to which it appeared to characterise their experiences accurately, and the implications of our findings for Engman’s proposition that phenomenological understandings of embodiment hold the key to explaining the presence or absence of biographical disruption. Finally, we reflect on the validity of our approach, and the extent to which applying a concept developed in relation to chronic conditions to a much wider and more loosely defined status is viable and produces useful insights.

## **The study**

The findings drawn on to show the use of biographical disruption as a tool for making sense of experiences of frailty are taken from a wider project, *Understanding frailty: patient, carer and health care professional perspectives*. This qualitative study was undertaken in a busy emergency department (ED) in an NHS hospital in the English Midlands. We aimed to explore how key stakeholders in emergency care, including clinicians, patients and carers, make sense of frailty. Situated interviews (Gale and Sidhu 2019) were conducted within the ED with 100 participants including patients (30), carers (30) and healthcare professionals (40). Twenty-two interviews took place with patients and one or more carers and eight with patients alone. The interviews were conducted over the summer of 2018 and the project was granted NHS ethics approval by the London – Brighton and Sussex Research Ethics Committee. This paper draws on these 30 interviews with patients and/or carers.

Situated interviews seek to combine the open and situated approach of ethnographic research with the flexible focus of semi-structured interviews (Gale and Sidhu 2019). Situated interviews take place within the setting of interest. Like semi-structured interviews, they are based on a relatively flexible approach to conversation. They also account for the goings on of the research setting such as environmental, sensory and emotional aspects. In this way, they seek to capture “situated sense-making practices” (Housley and Smith 2011: 704). The author responsible for data collection was situated within the ED over a three-month period and identified participants opportunistically. The interviews took place at bedsides, in empty bays, in ambulances, at workstations and in the waiting room.

Both our study design and our sampling frame were opportunistic. The study was conducted in a local ED because of our prior interest in the increase in admissions of patients considered frail nationally. To work towards efficient and effective decision-making, the hospital had recently implemented the voluntary use of a frailty screening tool for people aged 65 and over attending the ED. This formed the basis for our sampling frame: patients identified as frail by clinicians using the Clinical Frailty Scale. This tool, originally developed by Rockwood *et al.* (2005) and extended into its current nine-point form in 2008, involves scoring patients on a scale from 1 (very fit) to 9 (terminally ill) on the basis of their reported functioning and ability two weeks before. Patients who had a frailty score of 5 (mild frailty) and over were given information sheets about the study; informed, written consent was obtained prior to beginning interviews. Patients may or may not have been made aware of their frailty score following this assessment (see Cluley et al 2020 for an in-depth discussion of this), and therefore some were likely aware that they had been ‘diagnosed’ as frail, while others were not. However, given the nature of the assessment process (particularly its focus on the status of the individual two week previously, rather than in the moment of crisis that precipitated the ED attendance) and the threshold score of 5 used for recruitment (implying that individuals needed, at a minimum, “help with high order instrumental activities of daily living,” such as “finances, transportation and heavy housework”), it is reasonable to surmise that participants were experiencing frailty, whether or not they had been told about the label. Thus, while we took this clinical assessment of frailty as a convenient means of identifying potentially eligible participants, we acknowledge the limitations in such clinical categorisations. Our aim was to explore the experience of frailty more broadly for people who, the assessment suggested, were affected by it. The study's focus, accordingly, was not the specific episodes that had prompted the current attendance or admission, but the lived experience of this cohort, including the full breadth of health, wellbeing and sociocultural influences of the condition identified by authors such as Grenier (2020) and Pickard (2014). We understood the disruptive effects of the experience of frailty as occurring as much through these wider influences as through its direct manifestation in their health, reduced resilience, and increased susceptibility to disease (Campbell and Buchner 1997).

Interviews were audio recorded and transcribed verbatim. To ensure confidentiality, names and personal details were not recorded. For patients, only frailty score and gender were recorded. Transcripts were analysed using discourse analysis. We followed Potter and Wetherell's (1987) flexible ten-step guide, focusing particularly on the identification of interpretive repertoires. Potter and Wetherell (1987: 149) define interpretive repertoires as "recurrently used systems of terms used for characterising and evaluating actions, events and other phenomena" that are "constituted through a limited range of terms used in particular stylistic and grammatical constructions." We followed Potter and Wetherell's (1987) approach closely to identify six repertoires used by patient participants to make sense of frailty.  Given limits of space, here we offer detail mainly on our approach to coding (step six) and analysis (step seven).

Unlike thematic analysis, coding in Potter and Wetherell's approach to discourse analysis seeks actively to identify anomalies and inconsistencies, owing to the range of linguistic resources available to speakers and the acceptance that speakers may shift between compatible and incompatible repertoires to construct meaning. With this in mind, we first organised the interview talk into broad codes using qualitative data analysis software (NVivo 12). Coding was an iterative process that involved re-reading transcripts to identify specific topics discussed in similar and different ways.

The analysis process in Potter and Wetherell's approach to discourse analysis has two aims: to highlight patterns and to establish functions of the discourse. [First author] re-read codes and transcripts many times, searching for patterns across the talk, particularly instances of similarity and contradiction where participants used similar patterns of words and phrases to make sense of what they were talking about, consistent with the characteristics of interpretive repertoires. We identified three repertoire pairs that were used consistently throughout participants' talk:

- Frailty is a bodily issue / frailty is about mind-set
- Frailty is a negative experience / frailty is an inevitable experience
- I'm not frail / I feel frail

We then recoded data according to these repertoire pairs, again using NVivo. Organising the data in this way allowed comparison within and across the data coded to each repertoire, to interrogate how the repertoires related to participants shared social and cultural worlds (see Authors forthcoming), and to wider themes in the sociological literature—including the concept of biographical disruption.

## **Findings**

This paper draws on the talk shared in the interviews with the 60 patient and carer participants. Overall, they constructed frailty as a bodily state that is seen and felt but can also be resisted. Participants' descriptions of frail older people included reference to mobility issues such as walking with a frame or "doddering around," physical weakness, thin bodies without "much on their bones," and the need for support with day-to-day activities. This embodied experience was overwhelmingly described in negative terms. However, even though all patients interviewed alluded to personal experiences of frailty, most did not identify as frail. At once, therefore, participants acknowledged the disruptive impact of frailty in terms of its bodily consequences on them personally, and disavowed the label, playing down its impact. Quite apart from their categorisation as frail in the eyes of clinicians in the ED, they recognised the applicability of the term to their lived experience—and yet they declined to identify themselves as 'frail people'. In exploring this apparent contradiction, and its implications for our understanding of the circumstances in which biographical disruption is experienced, we present our findings using the three constituent components identified by Bury (1982) as a structuring device.

### *Frailty and the disruption of a 'normal' way of being*

The first aspect of biographical disruption involves "the disruption of taken-for-granted assumptions and behaviours," "the breaching of common-sense boundaries" and "attention to bodily states not usually brought into consciousness" (Bury 1982: 169). This disruption to a previous or 'normal' way of being and a new awareness of bodily and existential issues was evident throughout our participants' talk about frailty. Generally speaking, participants tended towards the idea of frailty as a normal part of the ageing process, rather than as a syndrome arising from ill-health. When asked to describe a frail person, participants were readily able to do so, invoking familiar tropes about physical weakness and vulnerability, and often suggesting a sense of inevitability or even fatalism:

> "Well it's a damned nuisance. It's typical old age, I suppose; we've got to accept these things, haven't we?" (Participant 2)

> "You always meet these kinds of people, frail and that, it's just one of those things in life as you get older" (Participant 25).

To this extent, frailty differed from the unexpected and untimely disruption experienced by Bury's (1982: 171) participants, for whom rheumatoid arthritis in middle age "marked a biographical shift from a perceived normal trajectory through relatively predictable chronological steps to one fundamentally abnormal and inwardly damaging." Rather, it was naturalised as part of the lifecourse in later life, more in line with the participants in Pound et al. (1998) and Bury and Holme's (2002) studies. Indeed, normalising frailty as an expected phase towards the end of a lifecourse fits with Bury's (1991) notion of 'coping' that allows those experiencing chronic illness to make sense of it.

This is not to say, however, that frailty did not disrupt. Indeed, for some participants, the onset of frailty represented a noticeable break from their prior experiences of ageing, or at least a marked acceleration in decline. Participants highlighted the challenges wrought by physical decline to their everyday lives:

> Participant 12: "Well I think it has come on gradually but then all of a sudden, you know, so I sort of expected it, it's sort of been more frequent. I used to be able to do that and now I can't do it."

Whether a more sudden challenge brought on by a fall or other acute episode, or a matter of gradual decline, participants offered plentiful descriptions of the difficulties posed by frailty. They described daily activities that previously they had taken for granted, and profound changes and disruptions to their normal way of being. Such accounts were in line with Engman's (2019) focus on the importance of changes to embodied experience in prompting biographical disruption, because of the way it disturbs taken-for-granted capacities of the body.

> Interviewer: "Is the garden something you once enjoyed?"
> Participant 21: "Yes I did. I enjoyed doing the garden. I could cut anything down and fiddle around, get all the weeds out, but my son don't—he thinks the flowering weeds are flowers and it's annoying."
> Interviewer: "That does sound annoying."
> Participant 21: "It's so frustrating because I can't do it now so he has to."

> "Not being able to do things sometimes, you know, or reach things off high shelves. […] Yes, you want to get something and you can't but you struggle and try and it's maddening sometimes." (Participant 12)

The participants' negative descriptions of their experiences of frailty also highlight the severity of disruption that their frailty had brought to their lives. Their talk pertained to loss, pain, inability and frustration.

> Participant 24's carer: "Quite scary, it's a loss of independence."
> Participant 24: "You lose everything."

> "Oh, I get frustrated naturally because when you live on your own, you've just got to be able try, even if you don't make a very good job of things." (Participant 2)

> "Frustrating, so frustrating. And then it's, you know, silly little things that you can't do, that we all take for granted." (Participant 29)

In all, participants suggested that the experience of frailty in old age is very disruptive to normality: to what Bury (1982: 169) refers to as "taken-for-granted assumptions and behaviours." Although some participants drew little distinction between old age and frailty—reflecting broader ambiguities in general usage of the term (Authors under review), as well as clinical debates around the nature of frailty alluded to earlier (Bergman *et al.* 2007)—for others, frailty represented something quite distinct. That they anticipated gradual decline as part of old age did not make the additional deficits associated with frailty less troublesome. Just as "the body in pain emerges as an estranged, alien presence" (Williams 1996: 25), with the onset of frailty, the participants' bodies were rendered visible to them through their changed appearance and the things they could no longer do.

### *Frailty and the challenge to identity*

Bury (1982: 169) describes this component of biographical disruption as necessitating "a fundamental re-thinking of the person's biography and self-concept." Changes in the way they felt about themselves and their personal abilities were seen in our participants' talk about their experiences of frailty.

> "I've struggled with my legs for two years, why I don't know. Because we have been abroad for 50 years and we used to do a hell of a lot of walking. And we used to always walk, we never stayed around the hotel sort of thing. And I thought my legs should be good, you know. They just went funny, they just did.I don't know, they just went weak." (Participant 6)

They described feeling scared of hurting themselves, feeling embarrassed and feeling reluctant to ask for help. Adaptations to their day-to-day lives left some feeling dependent. For others, attempts to resist dependency, fear and embarrassment, and instead to carry on as 'normal', had produced their own problems. Participant 29 discussed how, in trying to maintain his garden, he fell and had to wait for help.

> Participant 29: "I was painting the fence and I found myself on the floor. As you can see, I banged my head, and somebody found me on the floor and fetched my wife."
> Interviewer: "Gosh, that must have been a shock."
> Participant 29: "Yeah, I wanted to get it done and I felt fine but I don't know what happened."

Here participant 29 had attempted to resist the increasing impediments frailty was placing on his body.

More broadly, despite the personal experiences recounted in the previous section, most participants contested the label of frailty. Much of their talk was performative: it served to maintain their sense of self, and to distance themselves from an image of frailty that was both negative and stigmatising. For example, even as they acknowledged their reduced bodily abilities, participants sought to affirm what they could still do, emphasising continuity with their earlier selves. In so doing, and despite their inherently bodied experiences of frailty, participants set up a separation between their bodies and their sense of self.

> Interviewer: "So if someone said to you, "You're a bit frail," how would that make you feel?"
>
> Participant 3: "Not very good. I would say I was strong. Like I say, I'd not be very good for a punch-up. But I like to think I can hold my own."

> "If somebody told me I was frail, I couldn't do anything for myself, I'd feel a bit upset, you know. Can you dress yourself? I said of course I can. I can't do washing, I mean, which is a big job, or cook dinners, a dangerous job, you know, using the gas and that. But otherwise I can do pretty well everything, I can do shopping and I know how much money is, you know, I can count money." (Participant 12)

In these excerpts, participants draw a distinction between the increasing problems posed by their bodies, and their continued competence as individuals. Again, this talk is evidence of Bury's (1991) concept of 'coping'. While she may not be "good for a punch-up," participant 3 says that she remains "strong." Participant 12 draws a distinction between "big" or "dangerous" jobs, including the kind of "heavy housework" identified in the Clinical Frailty Scale as symptomatic of mild frailty, and things that she can still do, such as shopping and counting money. In both cases, the participants note their continued *cognitive* capability even in the face of physical decline: they are keen to assert that their bodily limitations have not compromised the essence of their selves. Perhaps paradoxically, the all-encompassing nature of frailty as a generalised reduction in capacity seems to make it all the more important for these participants to retain their non-frail identity. Rather than being overwhelmed, they emphasise what they retain.

### *Frailty and the mobilisation of resources*

The third component in Bury's (1982) original construction of biographical disruption pertains to the social resources on which individuals draw, and to which they contribute, through participation in familial and community networks. Bury's participants described disruption to such resources due to their own sense of embarrassment and separation from wider society; this resulted in the contraction of their social worlds.

Similar disruption was evident in the interviews with patients and carers in this study. It was particularly pronounced for those who still lived independently. Their increasing need for support conflicted with their desire for independence and their need to maintain their sense of identity. Many tried to continue with their everyday lives without support and were reluctant to ask for help.

> Participant 6: "Yes, yes. I always have this feeling I don't like putting on people, if I can do anything for myself, I'd do it, you know."
> Participant 6's son in law: "They don't accept, they're not accepting that they can't do things."
> Participant 6's daughter: "They can't do it, they're still, yeah. I understand to a certain extent she feels like, 'I don't want to just sit there and everybody do everything for me, I want to try and do some bits', but there's some things we don't really want her to do, like cooking."

In many cases, participants benefitted from strong social networks that could compensate for the restrictions that frailty presented. Several were accompanied by relatives in the emergency department. Their responses, however, emphasised the importance of independence to their identity: the importance of continuing to be seen as competent adults, capable of performing everyday tasks by themselves.

> Participant 6: "I went up [the stairs] on my own all the while before. Up 'til then, we were doing pretty well. I cooked what we needed, we did the shop, bit of gardening."
> Participant 6's daughter: "Yeah, you were still doing your cooking, weren't you, mum?"
> Participant 6: "Yeah. So they all told me in the hospital when I was here the other week, last week: I'm too independent."

> "I don't like people looking after me, you know what I mean? I wouldn't like someone to come and give me a bath, or anything like that, you know? Or if they come and look after your, you know, body functions and all, I'd feel very, very embarrassed about that." (Participant 11)

Seemingly simple tasks could thus become, as Bury (1982: 176) describes, "a burden of conscious and deliberate action."

Following Goffman (1968), Bury (1982: 176) argues that this burden can lead people with a chronic condition to deliberately limit their social circles, and "restrict their terrain to local and familiar territory where they are least likely to be exposed to the gaze and questions of acquaintances and strangers." The declared response of our participants was somewhat different. As noted in the previous section, participants sought to emphasise their ongoing cognitive ability and show that the physical challenges they were facing did not define them. Similarly, they adjusted their day-to-day routines with a view to achieving continuity, managing the impacts of frailty and avoiding the sense that this was an all-encompassing, all-changing challenge to their routines, resources and identities.

> Participant 21: "It's so frustrating because I can't do it now so he has to. I can't do like I used to do and now I can't change a duvet cover."
> Interviewer: "Right, yeah, OK, so day-to-day tasks like that have become a bit harder? Sure. Duvets are heavy sometimes, aren't they?"
> Participant 21: "Yeah, they are and especially the one I bought from Marks and Spencer. I can't think of anything else. I can't go shopping, not on my own. If I go with my son, we go in the car and we walk, and I push the trolley round but I daren't go out on my own."

> "It's a big step back for people if you've got to ask, can you do so-and-so for me? Can you do so-and-so? That's if you feel, 'oh I can do that for myself', you know, 'I'll manage that'." (Participant 11)

Where possible, participants described maintaining routines in adapted form, acknowledging the limitations that frailty brought, but resisting the notion that this was a matter of life-changing decline. Again, the far-reaching scope of frailty made it all the more important for participants to delimit its impact. This meant *emphasising* the separation between body and disease, between body and mind, and between body and self.

> "To me, it's for older people, I don't count myself old. We don't, I think it's all in your head, if you think you're old, you will be old, won't you? But we don't think ourselves old, do we?" (Participant 27)

## Discussion

Our findings suggest that the concept of biographical disruption has strong resonance with the experiences of people discussing their experiences of frailty in older age. The themes resonate with other studies of the experiences of frail older people (e.g. Grenier 2007; Grenier and Hanley 2007; Nicholson *et al.* 2012; Puts *et al.* 2009; Torres and Hammarström 2006; Warmoth *et al.* 2016). We show that that their experiences reflect the challenges to everyday life, sense of self and resources that Bury (1982) identified in his original exposition. While frailty is not a disease, its wide-ranging impact on individuals and their activities means that it is perhaps even more disruptive than chronic conditions whose effects are narrower, and more readily contained. This can be attributed to the profound effects of frailty on the body, and thus on embodied experience and sense of self (Engman 2019). However, our findings also challenge the notion that the physical and social consequences of change to one's bodily abilities alone, as Engman (2019) suggests, offers the key to understanding the circumstances in which biographical disruption applies. Rather, we suggest, a broader understanding of embodiment, encompassing the cognitive response to physical decline, is critical to identifying the circumstances in which biographical disruption is likely to be experienced.

In contrast to some of the long-term conditions that have been viewed through the lens of biographical disruption in past studies, the impacts of frailty were pervasive. As Grenier (2020) shows, while frailty may be physically felt, it is also politically, socially and culturally constructed. This leaves frail older people with the task of managing a stigmatised identity as well as physical implications. While the impact of diseases such as Ménière's Disease (Bell *et al.* 2016) is undoubtedly profound, they are perhaps not as existentially consequential as an experience that leaves people "at increased risk of disability and death from minor external stresses" (Campbell and Buchner 1997: 315). Yet for the patients we spoke to, this appeared to render a response that contained the impacts of frailty all the more important. This manifested in particular in allusions to activities that participants could still undertake, and in participants' work to distinguish between the physical impacts of frailty and its cognitive impacts.

Participants thus drew a line between their identities and biographies, and the impact of frailty, casting it as an "outside force" even as they felt "its invasion of all aspects of life" (Bury 1982: 173). While embodied experience is "central to the social process" of the impact of disease on lives (Kelly and Field 1996: 246), constructing a duality between self and body was functionally helpful to our participants (cf. Williams 1996). It enabled them to preserve a sense of their selves and their capacities that was safe from the tendrils of frailty—at least as long as they could demonstrate their continued cognitive competence, or their ability to undertake some tasks with a degree of independence.

More than this, however, our findings suggest a need for a more thoroughgoing conceptualisation of embodiment that goes beyond Engman's (2019: 124) primary focus on the way in which "a breakdown at the level of the physical body […] impinges on one's ability to enact one's embodied orientation towards the world." Engman (2019: 124) argues that "biographical disruption begins with a breakdown at the level of embodiment (specifically, the introduction of novel physical limitations that make familiar behaviours and habits inaccessible)," such that people's "identities have been thrown into question due to their inability to enact the roles that they associate with those identities". Certainly, the direct impact of frailty on the everyday lives of participants in our study was profound and consequential. However, our findings suggest that physical changes alone, and the changes in embodied orientation to the world, are not sufficient to explain the presence or otherwise of biographical disruption. Rather, an expanded understanding of embodiment, incorporating an understanding of its cognitive components, is required.

Williams (1996) notes that the onset of chronic illness renders the body apparent to the individual, disrupting the taken-for-granted relationship between self and body. The body "dys-appears" (Williams 1996: 38): it becomes visible through its failure, and individuals become estranged from their bodies. In response, they seek a reconciliation—a "re-embodiment" in response to "dys-embodiment"—that adapts to and makes sense of the new bodily state (Williams 1996: 38; cf. Bury 1991). Yet such "negotiated settlements" with the body are often transient and fragile. Thus, Williams (1996) argues, chronic illness is experienced as a series of oscillations between embodied, dys-embodied and re-embodied states.

Our findings show how frailty causes biographical disruption not just through its direct impact on one's physical and social capacities, but also through the threat it poses to an imagined (future) personal narrative, particularly through its association with cognitive decline. In seeking reconciliation with their changed bodily reality, participants focused on what remained of their previous embodiment. They emphasised what they still could do over what they could not, focusing on their cognitive ability, separating the mind from the body. They adopted what, following Williams (1996), might be termed a 'strategic dualism', distinguishing between their cognitive and physical capacities in seeking to achieve reconciliation with their new bodily realities. The participants' construction of and resistance to frailty was framed as much in terms of the ways it did not (yet) affect them bodily: it was the wider connotations of frailty as much as its material bodily impact that was disruptive.

Relatedly, the participants' awareness of the stigmatised status of frailty was evident throughout the interviews. Other writers have noted the construction of frailty as an undesirable other to discourses of 'active ageing' (Marhánkova 2011): a 'fourth age' or 'failed old age' through which positive images of a successful and healthy 'third age' are constructed (Grenier *et al.* 2017a; Pickard *et al.* 2019). Participants' eagerness to disavow the impacts of frailty on their bodies, and to emphasise their continued cognitive ability and capacity for independent living, should be read in this wider socio-cultural context. Even as they constructed frailty as an epidemiological inevitability at the population level—i.e. something that would affect a significant portion of people in their age group—they viewed it as a failure at the personal level, and emphasised what they were doing to resist it. The valorisation of independence is a strong and persistent feature of late-modern liberal society (Aronson 2002; Cluley *et al.* 2020; Giddens 1991; Martin *et al.* 2005), and the efforts of participants to salvage their identities and resist the stigmatising connotations of frailty should be understood accordingly.

Thus, participants resisted a sense of biographical disruption by rethinking their relationships with their bodies in a way that allowed them to adapt to their changing circumstances. Thus it is not just the impact of a condition on an individual's "ability to enact an embodied orientation towards the world" (Engman 2019: 120) that determines the likelihood of the experience of biographical disruption: it is the extent to which individuals are able to reconcile themselves with their new corporeal reality, and achieve 're-embodiment'. Yet even successful reconciliations are contingent and precarious, particularly when trajectories are unknown. Therefore the oscillation between embodiment, dys-embodiment and re-embodiment is likely to require an ongoing process of negotiation (Williams 1996). Mirroring Bell et al.'s (2016) view of biographies as oscillating processes (rather than fixed ideals) that impel ongoing adaptation, the experience of disease, impairment, disruption and resolution too will oscillate. For an experience like frailty, therefore, and perhaps for progressive diseases too, the experience of biographical disruption is likely to unfold through time, as individuals oscillate between successful re-embodiments and further challenges posed by new developments in their condition.

Our paper has strengths, including its application of the notion of biographical disruption to an emergent clinical classification not previously viewed through this lens, and also some limitations. Most notably, while the presence (and sometimes the contribution) of informal carers in interviews sometimes added richness to the conversations, it may also have resulted in a form of social-desirability bias, perhaps encouraging patient participants to ‘talk up’ their desire for independence. The setting for the interviews may also have had an important bearing on their content. While there are some methodological advantages to situated interviews of this kind (Gale and Sidhu 2019), the emergency department environment is likely to have influenced the discussions in difficult-to-predict ways. The ED attendance and frailty screening process was not the focus of our study; nevertheless, this setting could have affected patients’ accounts, given the uncertainty brought about by emergency situations. Certainly, our dataset falls short of the longitudinal approach taken by some writers in this field, which permits the development of biographical disruption to be examined as it unfolds (e.g. Taghizadeh Larsson and Jeppsson Grassman 2012). Our findings, however, do echo those of similar studies not conducted in hospital settings (Warmoth *et al.* 2016).

Finally, our work to apply the concept of biographical disruption to a health-related state other than a long-term condition deserves some further reflection. It could be objected that this constitutes an over-extension of a concept that was developed, and to date has been applied, in relation to long-term conditions. Whether understood as a corollary of the normal ageing process or as a collection of symptoms arising from illnesses and other behavioural, social and environmental influences (Bergman *et al.* 2007), frailty is rather different: it does not present in a uniform fashion, and as our participants discussed, it was seen not as abnormal but as something to be anticipated in later life. To this extent, one might question whether it has potential to disrupt at all. We defend the application of biographical disruption to frailty on three counts.

First, the degree of disruption to biographies likely to arise from different long-term conditions is also likely to vary. Contrast, for example, the onset of rheumatoid arthritis in middle age (Bury 1982) with the experience of stroke in later life, an event “anticipated by some as being an event along the trajectory of old age" (Pound *et al.* 1998: 503). The experiences described by participants in our study resonated strongly with all three components of biographical disruption set out by Bury (1982): as we note, just because frailty can be seen as an epidemiological inevitability for a wider population does not mean it is not disruptive for the individual, especially given the discourses that construct frailty as a personal failing (Grenier *et al.* 2017b; Pickard *et al.* 2019).

Second, alongside this face validity, applying the concept of biographical disruption to frailty generates analytically useful insights, with potential relevance to other applications. Our analysis identifies the disruptive capacity of the social as well as the physical features of frailty: the way in which stigmatisation and individualisation of blame for frailty themselves disrupt, and demand a response from those affected. Such a finding has clear relevance to long-term conditions whose effects are also constituted socially, and indeed has resonance with Bury's (1982) own identification of embarrassment and stigma as important aspects of rheumatoid arthritis's disruptive impact. Similarly, our finding regarding the 'strategic dualism' deployed by participants—their separation of bodily and cognitive impacts—also has relevance for the response to disruption posed by both long-term conditions and other health-related experiences.

Third, as we noted in the introduction, the increasing concern with frailty of healthcare systems and biomedical researchers places the term, and the people experiencing it, at the frontier of medicalisation. By definition, medicalisation is not beholden to conditions that fall easily into accepted categories of health and illness. If medical sociology is to provide critical insights into its impacts that remain current and relevant, we must apply our conceptual tools in ways that are responsive to these shifting boundaries. The resonance of biographical disruption with experiences of a non-disease category is perhaps testament to the impact that medicalisation *itself* has on the subjects of medical discourse, categorisation and intervention.

## Conclusion

In applying the concept to a health status encompassing a wide range of bodily consequences, we argue that biographical disruption presents a useful concept for understanding experiences of frailty. Moreover, we suggest, considering frailty through the lens of biographical disruption offers insights that help to explain the mixed findings of others with regard to the applicability of the concept of biographical disruption. Since frailty represents a condition that is to some extent an expected part of the lifecourse but is also thoroughgoing in its impact on people who experience it, the existing literature offers conflicting predictions about the relevance of the concept.

In line with the proposition put forward by Engman (2019), our findings indicate the importance of a condition's impact on individuals' embodied relationship with the world as a determinant of biographical disruption. But beyond this, drawing on Williams (1996), we also highlight how a 'negotiated settlement' between individuals and their new bodily reality leads them to resist the label of frailty, achieve reconciliation (albeit provisional), and minimise biographical disruption. For other conditions, our findings suggest that both the disruption of day-to-day embodied existence, and the reconfiguration of the relationship between self and body it precipitates, are important in influencing the presence of biographical disruption.

## Acknowledgements

Graham Martin is based in The Healthcare Improvement Studies Institute (THIS Institute), University of Cambridge. THIS Institute is supported by the Health Foundation, an independent charity committed to bringing about better health and healthcare for people in the UK.

## Address and email for correspondence

Victoria Cluley, Cardiovascular Sciences, University of Leicester, Room 210, Maurice Shock Building, University Road, Leicester, LE1 7RH.

vc139@leiecster.ac.uk

## References

Aronson, J. (2002) Elderly people’s accounts of home care rationing: missing voices in long-term care policy debates, *Ageing & Society*. **22**, 4, 399–418.

Bell, S.L., Tyrrell, J. and Phoenix, C. (2016) Ménière’s disease and biographical disruption: where family transitions collide, *Social Science & Medicine*. **166**,177–85.

Bergman, H., Ferrucci, L., Guralnik, J., Hogan, D.B., et al. (2007) Frailty: an emerging research and clinical paradigm—issues and controversies, *The Journals of Gerontology: Series A*. **62**, 7, 731–7.

Bowker, N. and Tuffin, K. (2002) Disability discourses for online identities, *Disability & Society*. **17**, 3, 327–44.

Bury, M. (1982) Chronic illness as biographical disruption, *Sociology of Health & Illness*. **4**, 2, 167–82.

Bury, M. (1991) The sociology of chronic illness: a review of research and prospects, *Sociology of Health & Illness*. **13**, 4, 451–68.

Bury, M. and Holme, A. (2002) *Life after ninety*. [Online]. London: Routledge.

Campbell, A.J. and Buchner, D.M. (1997) Unstable disability and the fluctuations of frailty, *Age and Ageing*. **26**, 4, 315–8.

Carricaburu, D. and Pierret, J. (1995) From biographical disruption to biographical reinforcement: the case of HIV-positive men, *Sociology of Health & Illness*. **17**, 1, 65–88.

Ciambrone, D. (2001) Illness and other assaults on self: the relative impact of HIV/AIDS on women’s lives, *Sociology of Health & Illness*. **23**, 4, 517–40.

Cluley, V., Fyson, R. and Pilnick, A. (2020) Theorising disability: a practical and representative ontology of learning disability, *Disability & Society*. **in press**,.

Cluley, V., Martin, G., Radnor, Z. and Banerjee, J., 2020. Talking about frailty: Health professional perspectives and an ideological dilemma. *Ageing and Society*. Online available at: https://www.cambridge.org/core/journals/ageing-and-society/article/talking-about-frailty-health-professional-perspectives-and-an-ideological-dilemma/7E6D71BEF364F9F989940E3F3514349F

Engman, A. (2019) Embodiment and the foundation of biographical disruption, *Social Science & Medicine*. **225**,120–7.

Faircloth, C., Boylstein, C., Rittman, M., Young, M., et al. (2004) Sudden illness and biographical flow in narratives of stroke recovery, *Sociology of Health & Illness*. **26**, 2, 242–61.

Fried, L.P., Tangen, C.M., Walston, J., Newman, A.B., et al. (2001) Frailty in older adults: evidence for a phenotype, *The Journals of Gerontology: Series A*. **56**, 3, M146–57.

Gale, N.K. and Sidhu, M.S. (2019) Risk work or resilience work? A qualitative study with community health workers negotiating the tensions between biomedical and community-based forms of health promotion in the United Kingdom, *PLoS ONE*. **14**, 7.

Giddens, A. (1979) *Central problems in social theory: action, structure, and contradiction in social analysis*. Los Angeles, CA: University of California Press.

Giddens, A. (1991) *Modernity and self-identity: self and society in the late modern age*. Cambridge: Polity Press.

Gilleard, C. and Higgs, P. (2011) Ageing abjection and embodiment in the fourth age, *Journal of Aging Studies*. **25**, 2, 135–42.

Gisquet, E. (2008) Cerebral implants and Parkinson's disease: a unique form of biographical disruption?, *Social Science & Medicine*. **67**, 11, 1847–51.

Goffman, E. (1968) *Stigma: notes on the management of a spoiled identity*. Harmondsworth: Penguin.

Grenier, A. (2007) Constructions of frailty in the English language, care practice and the lived experience, *Ageing & Society*. **27**, 3, 425–45.

Grenier, A. (2020) Rereading frailty through a lens of precarity: an explication of politics and the human condition of vulnerability. In Grenier, A., Phillipson, C., and Settersten, R.A. (eds.) *Precarity and ageing: understanding insecurity and risk in later life*. Bristol: Policy Press. pp. 69–90.

Grenier, A. and Hanley, J. (2007) Older women and 'frailty': aged, gendered and embodied resistance, *Current Sociology*. **55**, 2, 211–28.

Grenier, A., Lloyd, L. and Phillipson, C. (2017a) Precarity in late life: rethinking dementia as a 'frailed' old age, *Sociology of Health & Illness*. **39**, 2, 318–30.

Grenier, A.M., Phillipson, C. and Lloyd, E. (2017b) Precarity in late life: rethinking dementia as a frailed old age, *Innovation in Aging*. **1**, Suppl 1, 671.

Harris, M. (2009) Troubling biographical disruption: narratives of unconcern about hepatitis C diagnosis, *Sociology of Health & Illness*. **31**, 7, 1028–42.

Harwood, R.H. (2019) Editor's view, *Age and Ageing*. **48**,465.

Housley, W. and Smith, R.J. (2011) Mundane reason, membership categorization practices and the everyday ontology of space and place in interview talk, *Qualitative Research*. **11**, 6, 698–715.

Kelly, M.P. and Field, D. (1996) Medical sociology, chronic illness and the body, *Sociology of Health & Illness*. **18**, 2, 241–57.

Locock, L. and Ziebland, S. (2015) Mike Bury: biographical disruption and long-term and other health conditions. In Collyer, F. (ed.) *The Palgrave Handbook of Social Theory in Health, Illness and Medicine*. [Online]. London: Palgrave Macmillan. pp. 582–98.

Marhánkova, J.H. (2011) Leisure in old age: disciplinary practices surrounding the discourse of active ageing, *International Journal of Ageing and Later Life*. **6**, 1, 5–32.

Martin, G.P., Nancarrow, S.A., Parker, H., Phelps, K., et al. (2005) Place, policy and practitioners: on rehabilitation, independence and the therapeutic landscape in the changing geography of care provision to older people in the UK, *Social Science & Medicine*. **61**, 9, 1893–904.

Merleau-Ponty, M. (1964) *The primacy of perception*. Evanston, IL: Northwestern University Press.

Montaño-Castellón, I., Zeballos, D., Gutiérrez-Peredo, G., Netto, E., et al. (2020) High prevalence of frailty and prefrailty status in Brazilian patients living with HIV, *AIDS Research and Human Retroviruses*.

Nicholson, C., Meyer, J., Flatley, M., Holman, C., et al. (2012) Living on the margin: understanding the experience of living and dying with frailty in old age, *Social Science & Medicine*. **75**, 8, 1426–32.

Petermann-Rocha, F., Pell, J.P., Celis-Morales, C. and Ho, F.K. (2021) Frailty, sarcopenia, cachexia and malnutrition as comorbid conditions and their associations with mortality: a prospective study from UK Biobank, *Journal of Public Health*. fdaa226.

Pickard, S. (2014) Frail bodies: geriatric medicine and the constitution of the fourth age, *Sociology of Health & Illness*. **36**, 4, 549–63.

Pickard, S., Cluley, V., Danely, J., Laceulle, H., et al. (2019) New horizons in frailty: the contingent, the existential and the clinical, *Age and Ageing*. **48**, 4, 466–71.

Potter, J. and Wetherell, M. (1987) *Discourse and social psychology: beyond attitudes and behaviour*. London: Sage.

Pound, P., Gompertz, P. and Ebrahim, S. (1998) Illness in the context of older age: the case of stroke, *Sociology of Health & Illness*. **20**, 4, 489–506.

Puts, M.T.E., Shekary, N., Widdershoven, G., Heldens, J., et al. (2009) The meaning of frailty according to Dutch older frail and non-frail persons, *Journal of Aging Studies*. **23**, 4, 258–66.

Rahman, S. (2018) *Living with frailty: from assets and deficits to resilience*. London: Routledge.

Rockwood, K. and Howlett, S.E. (2018) Fifteen years of progress in understanding frailty and health in aging, *BMC Medicine*. **16**, 1, 220.

Rockwood, K. and Mitnitski, A. (2007) Frailty in relation to the accumulation of deficits, *The Journals of Gerontology: Series A*. **62**, 7, 722–7.

Rockwood, K., Song, X., MacKnight, C., Bergman, H., et al. (2005) A global clinical measure of fitness and frailty in elderly people, *CMAJ*. **173**, 5, 489–95.

Rogans-Watson, R., Shulman, C., Lewer, D., Armstrong, M., et al. (2020) Premature frailty, geriatric conditions and multimorbidity among people experiencing homelessness: a cross-sectional observational study in a London hostel, *Housing, Care and Support*. **23**, 3/4, 77–91.

Sanders, C., Donovan, J. and Dieppe, P. (2002) The significance and consequences of having painful and disabled joints in older age: co-existing accounts of normal and disrupted biographies, *Sociology of Health & Illness*. **24**, 2, 227–53.

Shostak, S. and Fox, N.S. (2012) Forgetting and remembering epilepsy: collective memory and the experience of illness, *Sociology of Health & Illness*. **34**, 3, 362–78.

Taghizadeh Larsson, A. and Jeppsson Grassman, E. (2012) Bodily changes among people living with physical impairments and chronic illnesses: biographical disruption or normal illness?, *Sociology of Health & Illness*. **34**, 8, 1156–69.

Torres, S. and Hammarström, G. (2006) Speaking of 'limitations' while trying to disregard them: A qualitative study of how diminished everyday competence and aging can be regarded, *Journal of Aging Studies*. **20**, 4, 291–302.

Warmoth, K., Lang, I.A., Phoenix, C., Abraham, C., et al. (2016) 'Thinking you're old and frail': a qualitative study of frailty in older adults, *Ageing & Society*. **36**, 7, 1483–500.

Wedgwood, N., Smith, L., Hendl, T. and Shuttleworth, R. (2020) Boy interrupted: biographical disruption during the transition to adulthood, *Sociology of Health & Illness*. **42**, 1, 20–34.

Williams, S.J. (1996) The vicissitudes of embodiment across the chronic illness trajectory, *Body & Society*. **2**, 2, 23–47.

Williams, S.J. (2000) Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept, *Sociology of Health & Illness*. **22**, 1, 40–67.

Williams, S.J. and Bendelow, G. (1998) *The lived body: sociological themes, embodied issues*. London: Routledge.

Wouters, E. and De Wet, K. (2016) Women's experience of HIV as a chronic illness in South Africa: hard-earned lives, biographical disruption and moral career, *Sociology of Health & Illness*. **38**, 4, 521–42.