

ORIGINAL ARTICLE

'I am just a shadow of who I used to be'—Exploring existential loss of identity among people living with chronic conditions of Long COVID

Chao Fang¹  | Sarah Akhtar Baz² | Laura Sheard² | JD Carpentieri¹

¹Department of Education, Practice and Society, Institute of Education, University College London, London, UK

²Department of Health Sciences, University of York, York, UK

Correspondence

Chao Fang, Institute of Education, 20 Bedford Way, London WC1H 0AL, UK.
Email: chao.fang@ucl.ac.uk

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Abstract

Identity loss and (re)construction forms a central debate in sociology of chronic illness. Living with chronic/persistent health conditions may raise questions about how disruptions can touch upon and further threaten the very roots of existence, by which people reflexively perceive a coherent and stable sense of 'being-in-the-world'. Whilst medical sociologists have shown interest in 'existential loss' in chronic illness, this question remains largely underexplored. Adopting a qualitative study on Long COVID (LC) as an example, this article illuminates existential identity loss as a deeply painful experience of losing body as a fundamental medium to retain continuity and consistency of one's narratively constructed identity. Interviews with 80 LC sufferers in the UK revealed that living with persistent and often uncertain symptoms and disruptions can cause the loss of biographical resources and resilience, making it difficult to reflexively understand their own being within the world. Their dynamic responses to LC also highlighted how sufferers' longing for a narratively coherent self

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can profoundly shape the ongoing construction of their identity in chronic health conditions. These insights into the complicated and often hard-to-express existential pain of identity loss can also nurture more holistic understandings of and support for LC and chronic illness more broadly.

KEYWORDS

chronic illness, existentialism, Long COVID, narrative identity, temporality

INTRODUCTION

Sociology of chronic illness has long been interested in identity issues (e.g., Bury, 1991; Charmaz, 1983). Living with chronic or persistent health conditions is often seen as a ‘critical point’ that can risk disrupting people’s identity as a coherent narrative thread linking their past, present and expected future (Bury, 1982). Such disruptions can raise ‘existential questions’ about how chronic illness can touch upon and further threaten the very roots of existence by which people reflexively perceive a coherent and stable sense of ‘being-in-the-world’ (Giddens, 1991). Medical sociologists thus far have paid attention to the existential experiences of chronic illness, often contextualising patients’ identity within the broad parameters of body, biography, time and uncertainties across different health conditions (e.g., Adamson, 1997; Bury, 1982; Charmaz, 1983; Williams, 2000). The sociological literature on chronic illness is yet to have provided explicit theoretical explanations for these often deeply painful but hard-to-articulate experiences, particularly why existential loss may arise in lived experiences of chronic illness and how it is experienced and responded to in everyday life. We argue that it is useful to approach existential loss through a temporal and biographical lens of identity in which the coherence and integrity of self-narratives are interrupted as a result of losing the body as a social medium to perform themselves in relation to others and the world (Scheper-Hughes & Lock, 1987; William, 2000).

Long COVID (LC) as an emergent long-term health condition can provide a unique example to closely examine the existential aspects of identity issues in sociology of chronic illness. Resulting from infection of Coronavirus (COVID-19), LC can lead to a protracted (over 4 weeks but often much longer) and turbulent course of illness that involves but is not restricted to respiratory, cognitive and cardiovascular symptoms. Common symptoms include fatigue, dyspnoea, brain fog and pain issues, while patients also report a myriad of other symptoms such as hair loss, skin rashes, insomnia and sensory dysfunction (Sivan et al., 2021). Living with LC can be both distressing and limiting as patients may suffer from one or more challenging symptoms, often facing uncertainties as a result of the persistence and fluctuation of such symptoms (Ladds et al., 2021; Rushforth et al., 2021). The loss of the coherence of ongoing lives and identity lies at the heart of the lived experiences of LC, with increasingly common narratives reported by patients about the loss of their ‘old self’ and expected life trajectories (e.g., Burton et al., 2022; Ladds et al., 2020).

Unique to LC is the ‘unknown’ nature of many of its mechanisms, courses, treatments and support (Sivan et al., 2021). Little information has been available (at least at the time of writing) in medical and societal discourses for people to draw upon to manage their symptoms and to

further make sense of the everyday impacts of these disruptions (Rushforth et al., 2021). Without sufficient references to confront their struggles, people with LC are at particular risk of ‘ontological insecurity’, a painful realisation of the alienness of their ‘broken’ body and disrupted self-narratives within the external world (Giddens, 1991). In other words, the ‘unknowns’ about the impacts of LC may jeopardise people’s self-identity of ‘being’ and ‘ongoing’ as meaningful in the world. A growing body of literature has illuminated the detrimental impacts of LC on patients’ identity, such as in terms of generalised traits of being an active and independent person (Burton et al., 2022; Callan et al., 2022) or roles within specified professional, familial (parental), age and social contexts (Humphreys et al., 2021; Ladds et al., 2021; Spence et al., 2023). While this focus on particular identity traits and roles is valuable, little in-depth analysis has been offered to capture the existential dimension of identity loss and (re)construction in LC in sociology of chronic illness.

To address this gap, this article draws upon a qualitative study on LC to enrich sociological understandings about existential loss of identity in chronic health conditions. By analysing in-depth interview data from 80 self-identified LC sufferers in the UK, we investigate identity as a narratively constructed and coherent entity that encompasses a reflexive process of interpreting and retaining a sense of self-sameness and continuity over time (Ezzy, 1998; Ricoeur, 2002). To capture the complexity around existential loss in LC experience, we also employ a generalised framework developed by Ettema et al. (2010) for organising nuanced subjective experiences. That is, we seek to explore ‘circumstance’ for, ‘experiences’ of and ‘responses’ to existential loss of identity. These understandings can further illustrate the significance of retaining and restoring a deeper sense of identity in facing ongoing health issues. The insights into the complicated and often hard-to-express pains of identity loss can also facilitate more holistic understandings of and support for LC and chronic illness more broadly.

MAPPING EXISTENTIAL QUESTIONS OF IDENTITY IN CHRONIC ILLNESS

Identity loss and (re)construction form a central debate in sociology of chronic illness (Bury, 1991; Charmaz, 1983). Key to this debate is the narrative construction of identity, an ongoing process where one constructs narratives to achieve a sense of continuity to reflexively understand themselves and their place in the world (Ricoeur, 1980, 2002). Living with persistent health issues can strongly discredit this process of identity construction. Bury’s canonical concept of ‘biographical disruption’ (1982) has captured a profoundly temporal dimension of identity loss by arguing that chronic illness can disrupt the coherence of one’s narrative time connecting their perceived past, present and future. It thus requires fundamental rethinking of one’s biography to mobilise resources to narratively reconstruct a ‘new’ self, updating their plans and expectations accordingly for altered situations moving forward (Williams, 1984). The temporal dimension of identity loss is also closely intertwined with an embodied direction in which disruptions are not only caused by illness per se but also ‘the ways that illness impinges on one’s physical ability to engage with daily life’ and the unique socio-historical contexts they are situated in (Engman, 2019, p. 120). That is to say, the dynamics and complexity around identity loss and (re)construction in chronic illness need to be understood within the intersections between time, body and biography. Particularly, it is crucial to recognise how the body significantly shapes people’s ability to (re)construct their identity as a biographically coherent entity, over time before and following the onset of illness.

Existential meanings in identity are not an unfamiliar topic to medical sociologists. Williams (2000) pointed out that 'existential meanings' are negotiated within both existing social arrangements and individual circumstances to interpret biographically troubling issues about chronic illness (e.g., 'why me?'). These existential meanings lie in what Orona (1990) coined 'existential coordinates' in her study on Alzheimer's patients, highlighting how the onset of illness can cause significant uncertainties and further initiate a highly reflexive process of reconstructing their once taken-for-granted narratives about the past and future (Adamson, 1997). These reconstructions are both temporal and existential as Williams (1984) argued that 'chronic illness is a rupture in our relationship with that world... [n]arrative reconstruction is an attempt to reconstitute and repair ruptures between body, self, and world by linking-up and interpreting different aspects of biography in order to realign present and past and self with society' (Williams, 1984, p. 197). In this vein, chronic illness may further become 'chronicity' (Smith-Morris, 2010) in which life per se turns to a series of disruptions and people's reflexivity about their illness, body and self is routinely merged into the continuum of their life. The ongoing reflections of living and managing symptoms may also lead to adaption and even growth that can help people to accommodate their illness and life rhythms (Manderson & Wahlberg, 2020). The chronicity of living with chronic illness can be particularly useful to understand Williams (2000) 'existential meanings' in late-modernity. Living in a society where shared norms are becoming increasingly individualised and fluid, people with chronic illness may continue to problematise both the social and individual basis to regain the harmony between their inner temporal coherence of self and the flow of the external world (Bury, 2002). In other words, people may be more acutely and frequently aware of existential meanings and struggles in facing chronic illness in contemporary society.

Despite broadly acknowledging the deeply painful and reflexive nature of living with chronic illness, medical sociologists have tended to approach existential loss largely at face value, such as simply a profound sense of discontinuity and meaninglessness. They however have rarely posed in-depth inquiries into what existential loss means to people's identity and everyday lives in sociology of chronic illness. Useful lessons can be learnt from empirical/psychological studies on health-related existential losses. In a thorough review of empirical research on existential loneliness, Bolmsjö et al. (2019) elucidated that people with terminal/severe illness and those living with extreme frailty in old age can experience 'immediate awareness of being fundamentally separated from other people and from the universe, and typically, because of this awareness, experiencing negative feelings, that is, moods and emotions' (Bolmsjö et al., 2019, p. 1314). Studies also extended existential loneliness beyond extreme health conditions of death and dying, such as chronic pain and ageing-related physical decline. For instance, Andersen et al. (2021) and Carr and Fang (2023) argued that existential struggles with loss (e.g., health, bonds and self-worth) can gradually emerge from varied health challenges across old age and even lifespan. Indeed, the above empirical findings have indicated that existential loss may occur despite age and severity of health conditions, but the evidence so far has largely focused on the experiential aspects of existential loss, such as loneliness, uncertainties, emptiness and abandonment, but not loss itself. As such, in-depth analyses are needed to more systematically explore the social construction of existential loss in chronic health conditions.

The answer to enriching understandings about existential loss of identity in chronic illness can be rooted in sociological theories on 'crisis'. By examining major and critical life transitions (e.g., the realisation of one's own death and bereavement), Berger and Luckmann (1967) argued that humans are at risk of confronting 'marginal situations' in which the taken-for-granted realities that encompass one's everyday lives become problematised. Such risks highlight the frailty

of identity as a coherently constructed entity (Ezzy, 1998; Giddens, 1991). This fragile nature of self-identity is further demonstrated in the tempo-spatial construction of 'life-world'; that is, humans can only experience the external world and feel being 'real' and 'meaningful' in it, if they achieve a sense of coherence in self-identity both over time and in their interactions with others (Schutz & Luckmann, 1973). In other words, by directly and indirectly (learning from others) interacting with society, they accumulate 'a stock of knowledge' of past experience to guide present actions and to project future lives, thus presuming the continuity of experience and meaning to form a sense of identity across time and space (Ricoeur, 1980). When such continuity is disrupted by crises, people may be called into what Giddens termed 'existential questions', where their present existence becomes disconnected from both the past and future (Giddens, 1991). As such, they may find the once familiar external world, with which they were closely engaged, becomes distant causing them to fall into a status of 'non-being'. We already know chronic illness can be highly disruptive. What remains implicit, however, is how living with such ongoing bodily and other subsequent disruptions is likely connected to existential questions of losing one's self-continuity.

LONG COVID AS A UNIQUE EXISTENTIAL CHALLENGE

LC as a complex and yet largely unknown long-term health condition is likely to give rise to existential challenges (as discussed above) and thus provide an ideal example to examine the existential aspect of identity loss and (re)construction in chronic illness. Existing research has captured that LC can disrupt people's meaning, resources and resilience that have long helped them discern 'who they are' (Callan et al., 2022; Humphreys et al., 2021). This disruptive impact on identity lies in both the vastly heterogeneous symptomology and the ongoing 'unknowns' about the long-term effects of LC (Spence et al., 2023). Unlike other well-researched chronic illnesses such as arthritis, which have a relatively clearer symptomology and management methods, the onset and development of LC related symptoms can be extremely diverse, individualised and even somewhat random, ranging from physical damages to neurological and sensory dysfunction and, for some an amalgamation of these (e.g., Sapkota & Nune, 2022). Even compared to other chronic illnesses of unknown aetiology/treatment, the vagueness and apparent randomness regarding the mechanisms, development, length and treatment for LC remain particularly profound (Burton et al., 2022; Rushforth et al., 2021). Being trapped in a lingering process of disjunct oscillation between fears about endless ongoing struggles and hopes for a smooth recovery, LC sufferers may have little to refer to from external resources (others) to recover the 'disrupted chronology' of their unexpectedly turbulent illness trajectory and their narratives about the present and future (Rushforth et al., 2021).

The lived experience of LC not only shows generalised features of prolonged disruptions as experienced in other chronic conditions but also entails unique uncertainties and randomness. As such, it allows us to closely examine the existential dimension of sufferers' identity as a coherent entity temporally and biographically constructed by narratives. That is, their identity may be repeatedly challenged, restored (alongside the fluctuations between symptoms and recovery, as well as between desperation and hope) and ultimately discontinued in the prolonged battle with LC. The existential nature of the identity challenges can also be evidenced by LC sufferers' determination, if not desperation, to seek to fix the disrupted narratives about themselves (Callard & Perego., 2021; Rushforth et al., 2021). Often being neglected and disbelieved in the early stage of the COVID-19 outbreaks, many frustrated sufferers turned to both societal and personal means

(e.g., social media, academic research, personal experience and support network) to understand their ‘fragmented inner monolog’ and further to re-position themselves into the world (Callan et al., 2022; Rushforth et al., 2021). In light of the broken narratives that LC sufferers have to carry about themselves and their connection with the external world (e.g., treatment, public awareness) in their ongoing lives, their experiences provide an excellent case to sociologically scrutinise the existential aspects of their identity loss and (re)construction.

DATA AND METHODS

Participants

We draw upon a qualitative study with 80 people who self-identified as experiencing LC symptoms. The study was conducted between November 2021 and March 2022 in the UK. We recruited LC sufferers from representative samples, including 59 participants from six national and regional cohort studies¹ and the remaining 21 from wider society (e.g., snowballing, social media). This sampling strategy allowed us to gain insights into both the prevalence and diversity of existential loss of identity in the lived experiences of LC sufferers from different socio-demographical circumstances. We approached LC sufferers who reported having COVID-19-related symptoms for over 4 weeks and particularly focused on those who indicated having persistent symptoms for over 8 weeks. The majority of our participants had had symptoms for over 6 months, with the longest sufferers being around 20 months at the time of the interviews. Their symptoms also varied from mild to severe. As such, 80 interviews were collected, including 56 females and 24 males. The age range of the participants was 18–75. The majority of 53 participants were aged 30–59, whilst eight and 19 participants were respectively in the 18–29 and 60–75 age groups. We also ensured ethnic diversity in our sample, engaging with 45 White British and 35 ethnic minority participants.

This study was ethically reviewed and approved by the University College London Institute of Education Research Ethics Committee and University of York Health Sciences Research Governance Committee. We also received permission from the participating cohort studies.

Interviews

We adopted a narrative interviewing approach to enable our participants to take the lead to tell stories about their lived experiences of LC. Given patients were among the first to report LC symptoms and thus have collectively ‘made’ LC as a medically and socially recognised condition (Callard & Perego., 2021), we regarded our participants as ‘experts’ to help us gain in-depth understandings about the impacts of LC. This ‘bottom-up’ approach thus gave the agency to freely construct narratives about their illness trajectories by not only reporting disruptions caused by LC but also reflecting on their experiences within their biographies. Thanks to this approach, the existential dimension of their experiences ‘unexpectedly’ emerged throughout their narratives, providing ideal data to explore existential loss of identity in chronic/persistent health conditions.

The interviews were guided by semi-structured questions, which focus on the lived experiences of LC in the following areas (not necessarily in a strictly chronological order): (1) initial experiences of COVID-19, (2) lasting symptoms and their impacts on day-to-day lives, (3) experiences of health care, (4) coping strategies, (5) support resources and networks and (6)

reflections on losses and changes. These in-depth interviews captured both the participants' big stories (major events such as life-changing symptoms, hospitalisation) and small stories that are lived and enriched in everyday settings (e.g., altered daily routines and social activities) (Phoenix & Sparkes, 2009). These narratives highlighted existential loss of identity, not only resulting from multifaceted disruptions but also as everyday encounters that can cast a subtle and lingering shadow on people's sense of meaning and being in their ongoing lives with LC.

Data analysis

Based on existing sociological research on chronic illness and crises, we analysed LC as an embodied experience that can disrupt the temporal construction of identity as a narratively coherent entity (Berger & Luckmann, 1967; Williams, 1984). To more systematically capture the complexity around existential loss (that can give rise to LC suffers questioning their day-to-day identity), we adopted an organising framework from Ettema et al. (2010) to contextualise our findings in three dimensions: (1) *circumstances* from which existential identity loss arises, (2) *experiences* of deeper loss of identity (3) *responses* to retain/resume the authenticity of self as a narratively coherent being. This categorisation also mirrors our social constructionist ontological standpoint and interpretivist epistemological approach, allowing us to engage with our participants' accounts to capture how the narratives about their lived experiences and identity are interpreted and constantly constructed by LC and the broader social contexts in which they are situated.

Figure 1 shows our coding process. Step 1 captures an illustration of an early iteration of codes under the dimensions of 'circumstances', 'experiences' and 'responses'. Step 2 shows a

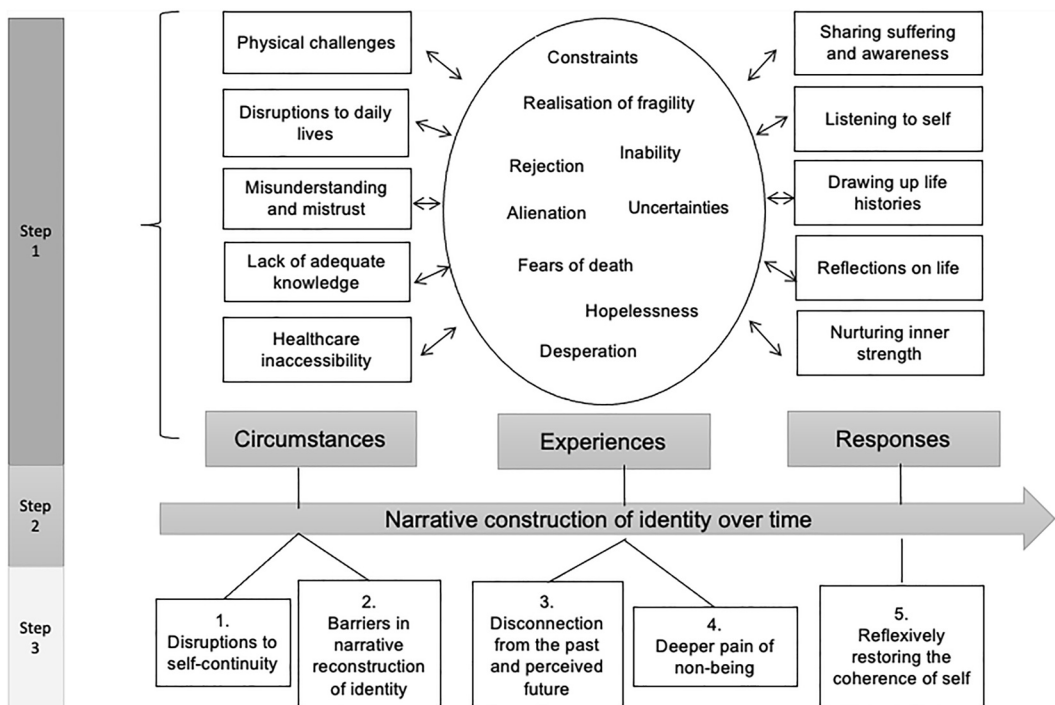


FIGURE 1 An illustration of the coding process.

temporal process of identity construction by which we further examined the initial codes and their categorisation to explore what existential loss means to our participants and how such loss disrupted the ongoing construction of their narrative identity. This step has two layers: first, we sought to understand the 'experience' of existential loss of identity and how it was experienced as a status of non-being biographically disconnected with both one's past and future; second, we contextualised the 'experience' into a fuller picture of the social construction of existential loss by clarifying circumstances for, experiences of and responses to it in the temporal process. In doing so, as shown in step 3, we further developed the codes into five analytical themes.

FINDINGS

The existential aspects of identity loss and (re)construction have so far been largely approached from an experiential angle, for example, focusing on existential loneliness or existential uncertainties (e.g., Adamson, 1997; Carr & Fang, 2023). We make further steps to use the lived experiences of people with LC to unfold the construction of existential loss, through narrative time that organises one's life stories into a meaningful order and thus give them a sense of coherence regarding who they are as their lives move on (Ricoeur, 1980). The interviews have revealed a complex and highly existential picture of living with LC. Challenges facing our participants were closely connected to losses resulting from a wide range of persisting and fluctuating self-reported symptoms. The most common symptoms they encountered included fatigue, brain fog, breathlessness, muscular/joint pains, loss of smell, taste and sight. Some also reported internal organ damage (e.g., lung, heart and kidney) that is often (or as perceived) interconnected with other health conditions. While facing these bodily disruptions, many participants had to encounter ongoing uncertainties in many ways that create multifaceted losses to their macro life plans and everyday living.

Five themes are illustrated below. As shown in Figure 1, themes 1 and 2 underline the *circumstances* of how existential loss of identity may arise from bodily and social ruptures to the continuity and consistency of one's narrative identity. Themes 3 and 4 capture the lived *experiences* of existential loss through a lens of narrative time and its impact on the sense of 'being-in-the-world'. The final theme focuses on agentic dimension of our participants' *responses* to reflexively restore the coherence of self. By presenting our findings in this manner, we did not intend to outline living through and recovering from the existential loss of identity as a linear process. Rather, by using LC as an example, we sought to highlight the interconnectedness of these experiences. We found that chronic health conditions are imbued with oscillating confrontations between existential identity loss and restoration. These findings helped us better appreciate the disrupted narrative time facing our participants and how this was deeply embedded in their fundamental sense of meaning and being in their ongoing lives. To protect our participants' confidentiality, pseudonyms are used.

Theme 1: Disruptions to self-continuity

The loss of self-continuity can create *circumstances* that give rise to existential loss of identity. Lives are constructed and made coherent by narratives that provide a plot of stories to integrate one's past, present and anticipated future into a meaningful whole (Ricoeur, 2002). This sense of self-continuity plays a central role in retaining identity as a narratively coherent entity in

facing life's changes over time (Ezzy, 1998). This continual (re)interpretation of self-narratives is deeply rooted in one's routines and life history that are sedimented through the past and thus can provide references to rectify present and future changes/challenges. Health issues can present significant and often persistent challenges to one's self-continuity in which the body is a social artifact, both physically and socially shaping sufferers' (in)ability to continue their routines (Scheper-Hughes & Lock, 1987).

In facing one but more often multiple symptoms, our participants reported living with LC as a significant *circumstance* in which the rhythm of ongoing life became disrupted (White, 2022). This temporal disruption was starkly evident in our participants' accounts about their physically and/or cognitively debilitating LC symptoms. For example, the bodily deterioration facing Sam profoundly restricted his capacity to resume commitments that are central to the narratives about his 'past' self:

I can't do things at the same pace or energy level as before. I get breathless now quicker than I used to do. I used to take my daughter running, she's an aspiring athlete. And now I can't do that, I missed that and she misses that... my life and my social scene revolved around friends through cycling or running. And now I don't see those people as much because I don't do those activities. You know my whole lifestyles changed and my whole social scene has changed because of it.

(Sam, 51, male, white British)

Significant in LC (and other chronic conditions) is that the disruptions to one's life routines are often so prolonged that the sense of self-continuity could no longer encompass their ongoing lives as consistent and meaningful. As a result, sufferers such as Patricia may find their once taken-for-granted self-narratives becoming increasingly irrelevant and ultimately invalid:

Because you see no end to it! I think like all illness there comes a point when you can't remember what it was like to be well, you just can't, because you used to do something. I used to go out dancing twice a week or whatever, and you look at it and you think, well, I couldn't even get up, let alone go dancing twice a week... You reach a point where you don't actually remember being well.

(Patricia, 63, female, white British)

A unique aspect of the disruption to self-continuity in LC is the diverse impacts of the ongoing bodily deterioration and its resultant constraints on sufferers from extremely wide age groups. Drawing upon reported experiences from a sample aged between 18 and 75, it was clear that our participants, each with their unique life stories, encountered varied interpretations and consequences when it came to the disruption of routines throughout their lives. For example, self-discontinuity could mean an earlier end to active healthy ageing lives for those in old age, but young people and those in middle age found that living with LC-elicited disruptions may lead to an unexpected closure/pause to their youthful and busy social or educational lives.

Theme 2: Barriers in narrative reconstruction of identity

The *circumstances* eliciting existential loss may not only result from temporal disruptions to self-continuity but can also be rooted in social environments. The narrative construction of

identity is by no means an inner process but are a constant performance to others to ensure a sense of self-continuity guiding one's narratives as consistent and meaningful (Schutz & Luckmann, 1973). Living with chronic and particularly emergent health conditions like LC, however, may be closely connected to unique *circumstances* that undermine sufferers' attempts to restore their self-continuity. These barriers are profoundly social as it can be hard to present their often physically invisible symptoms and/or widely under-recognised struggles to others as a means of conforming to their previously consistent self-narratives.

Whilst there is an increasing awareness of chronic health conditions, sufferers' painful experiences have not always been well received by others. This was particularly prevalent among our participants who frequently felt their novel LC conditions and their 'broken' body were not taken seriously and were rejected by others, including family members, friends and health-care professionals. This could be highly challenging as the sufferers may fail to gain approval from their significant social circles to affirm and further integrate their ill-stricken narratives into the ongoing construction of self-continuity:

With my family I didn't want to talk about it too much with them... but then, on the odd occasion I talked about it, I could tell that it's upsetting for people to hear, so I just wouldn't. But then there was a point when they'd say, "Oh you know, you're just being really silly, you just have to not think about it, you know, move on." I think they genuinely did think that I was just traumatised from having Covid because I was really terrified when I had it. It's really difficult to explain but then I think I've had a really difficult experience, I have this chest pain that I have all the time. I don't think they understood exactly how bad it was.

(Zara, 31, female, British Pakistani)

The 'failed' narrative construction of identity could be even more prevalent for those without 'physically visible' symptoms. John, for example, called LC a 'hidden disability', which he felt may impede others' ability to empathise with his self-narratives about illness and suffering:

If somebody sees me outside, they assume, oh, you're out, you're well. Because it's a hidden disability. I'm not in a wheelchair. I haven't got a plaster cast on my hand. And people find it very difficult to accept and understand.

(John, 63, male, white British)

These barriers may give rise to both 'failed' and contradictory narratives about living with debilitating and persisting health challenges. Due to the lack of sufficient discourses available in society to understand and justify the painful disruptions caused by LC, some sufferers may express different self-narratives to others, despite these being contradictory to their actual illness experiences. A good example is Paul who carried competing narratives about himself with LC. As a result, he struggled to unify his ill-stricken narratives and the 'superficial' narratives that he had long performed to others:

Interviewee: My mental health I believe is good. I'm not depressed at all. I'm quite a strong person, you know, positive person.

Interviewer: Did you experience any kind of frustrations after you had these COVID-related symptoms such as the vision difficulties and memory problems?

Interviewee: Well, I find it is frustrating [pause]... Well, I mean, I can't drive. I used to love driving, go for the shopping, and cook. So I can't do anything. I'm just, you know, quite – I feel quite useless!

(Paul, 75, male, white British)

Theme 3: Disconnection from the past and perceived future

Persistent health conditions like LC, as illustrated above, can create significant circumstances that may give rise to *experiences* rupturing one's identity. Identity is constructed and enacted both vertically within a temporal flow and horizontally with others (Berger & Luckmann, 1967). The time that the construction of identity is situated within, however, is not merely a linear process segmented by natural measurements such as hours, days and years. Instead, the time one engages with is a succession of intersubjective representations that originate from events in the external world and are governed by a plot, narratively making these events into a coherent and meaningful story (Ricoeur, 1980). When facing chronic health conditions, one's narratives about 'who they used to be' (prior to their illness) would become less relevant to continuing to interpret and integrate their experiences in their illness-stricken lives. Despite this, the inertia of the 'old self' may be so persistent that sufferers' self-narratives become fixed in the past.

The disconnection between the past and present can be experienced as a highly reflexive but painful encounter in which sufferers feel unable to accept their 'new' self-narratives:

This isn't who I am I. No, that's exactly right. I don't recognise myself... At some point, I was like crying every day, it was absolutely heart-breaking, I just could not get over the fact I wasn't getting better, I could just see myself as an ill person. I just could not accept it...

(Lucy, 51, female, white British)

Such experiences are inherently existential as they question sufferers' sense of being-in-the-world by trapping their identity as a real and legitimate being in the past (that is no longer relevant). The existential confrontation with temporal disconnections in identity may also lean towards the future. Whilst many chronic health conditions involve uncertainties in sufferers' illness trajectories, LC could uniquely encapsulate what we termed 'random openness' of greatly complex symptomology and management. Without clear pathways to recover from and/or manage the largely unknown trajectories moving forward, sufferers' ability to envisage narratives about their future may be shattered:

It became very lonely to be in that position and to not understand when, or if you're ever going to get better. I try not to think that way, but I do worry that this will never go and this will be a permanent thing... And then it did make me think that planning for the future, it's a big thought thinking that, you know what, can I do it with this kind of pain, can I or can I not?

(Emily, 31, female, white British)

The experience of feeling disconnected from both the past and future could further disrupt sufferers' narrative time as a whole, creating ruptures in the ongoing process of their identity

construction. As such, their narratives about the present (in the shadow of illness) may have to stand alone in their deep reflections on time. After suffering from debilitating LC symptoms of weakened muscle strength and mobility, as well as partial sight and hearing loss, Paul felt he and his wife could only live for ‘today’:

The biggest worry that I have is that if anything happened to me and my wife – if I was left on my own and I couldn’t support myself, function with cooking or dressing... we’re living today, and trying not to dwell.

(Paul, 75, male, white British)

Theme 4: Deeper pain of non-being

The existential pains of losing one’s identity in chronic health conditions can be further confronted as a deeply painful *experience* of non-being. Human existence can only be felt as real and made meaningful if people can understand themselves within a coherent plot that interprets and integrates their experiences both in time and over time (Ricoeur, 1980). In time, one’s long accumulated life routines can afford a sense of everydayness to help guide their present experience. Over time, this everydayness can further afford self-continuity to provide an ongoing framework of biographical references to contextualise their everyday lives with meaningful and coherent narratives. This temporal consistency in self-narratives is by its nature oriented towards an existential status of being-in-the-world in which one can feel that their engagements with others and the world are justified and can stand the test of narrative time. Much of this existence however is not reflected in the awareness of being-in-the-world but taken for granted (Ezzy, 1998). The existential struggles to affirm a sense of being-in-the-world would only become apparent when the everydayness in time and the self-continuity over time are lost due to significant disruptions (Giddens, 1991). This existential identity loss is often rooted in one’s biography and thus can be experienced in diverse ways.

Prolonged and often life-changing conditions, as can be seen from our LC sample, are likely to cause such *experience* of existential loss by risking losing sufferers’ identity propelling them towards the deeply painful status of non-being. John was one of our participants who departed on an existential journey to question the meaning in his ongoing life:

Before I had it [LC], I was working as a social worker, two young children, physically active, I was involved with various groups and, and suddenly I could do nothing. None of that. So everything, everything by which I defined myself was taken away. So that all the external things were taken away. So I was left with who am I, what is the meaning of life? You know those big questions ...

(John, 63, male, white British)

Existential loss could also entail an extra layer of struggles for sufferers who are already faced with previously accumulated insecurity about their being in the external world, such as those in socioeconomic disadvantaged positions. This double existential loss was captured in Ahmad’s minoritised experience as an immigrant in the UK. He experienced both the sense of non-being as mentioned above and the struggles of surviving in a world in which he felt he

did not belong to, as was reiterated to him by a denied visa extension to stay in the UK in the aftermath of his LC:

I am not a British citizen I am dependent upon a visa in the UK... I did not have family that could support me to keep myself alive, to keep myself going.

(Ahmad, 37, male, Pakistani)

The status of non-being and the experience of feeling not-being-in-the world may run deeper to undermine sufferers' ability to maintain the everydayness and their identity–continuity to cope with challenges alongside their ongoing lives. For example, Susan felt she had become 'a shadow' of herself because of suffering from fatigue, brain fog and organ dysfunction:

I always was a fairly confident person, always had big responsible jobs which I sort of thrived on stress and all the rest of it. Now, I just feel like I'm a little old lady. I don't have any confidence at all. I would much prefer not to go out the house at all, I'll stay at home and cuddle up and when I'm tired go to sleep and things like that. I'm just a shadow of who I used to be, I've gone very withdrawn.

(Susan, 63, female, white British)

Such declined resilience could give rise to painful ontological realisations of frailty and limitation inherent in their existence, something that sufferers once felt was distant but has become more imminent than ever. These realisations could be particularly existential, reminding them of their vulnerability and even the inevitability of finitude and mortality:

It knocks the stuffing out of you. You don't feel the same. I know I'm getting older. I'm seventy-five, it has made me feel vulnerable and susceptible to illnesses, I'm aware more of... I was afraid. Well, we all know we've got to die, don't we?

(Iris, 75, female, white British)

This sense of vulnerability was even evident among those younger and perceived as 'healthy', revealing the prevalence of such existential loss facing LC sufferers:

The narrative that I was fed, and a lot of people my age were fed, at the start of the pandemic that, "oh, you're young, you're basically invincible," this experience has made me realise I'm actually not invincible, and I get sick quite a lot now because of Long COVID So yeah, people are much more vulnerable than we think.

(Kate, 21, female, mixed race)

Theme 5: Reflexively restoring the coherence of self

The analysis conducted thus far has indicated that people with chronic health conditions may experience existential loss. This loss can manifest as a painful realisation of non-being, where they feel isolated from both their past and future within the narratives of their lives. As life moves on, many sufferers, as captured by our study, also showed their diverse *responses* to these deeper pains by seeking to fix their broken self-narratives and further to restore their fundamental sense of being-in-the-world. This process is often highly reflexive as sufferers need to re-approach their

self-narratives to experience the world in time and further to retain self-continuity over time (Manderson & Wahlberg, 2020). The strategies to do so also entail a social dimension in which sufferers could negotiate with broader society to pursue a coherence both within their identity and with the external world, despite complex disruptions and barriers (Berger & Luckmann, 1967).

A key step to resume sufferers' narrative construction of identity is to develop new self-narratives about their illness-stricken life. This was important and even symbolic to our LC participants, particularly to those who were not officially diagnosed with COVID-19 and/or LC (due to health-care barriers). How to further make sense of and justify the mysteries about LC disruptions became a priority for many as a means of starting adjustment to re-integrate the broken self-narratives into their ongoing lives. For instance, Lucy was determined to 'validate' her suffering after having to be extremely persistent to access specialist care:

It's always felt a bit fraudulent, but as I've met more and more people who were in that first wave [of COVID-19 outbreaks], we're all pretty much in a similar boat that we were ill, but there was no testing. But when I first got to the Long COVID clinic at {HOSPITAL1} they gave me a kind of diagnosis of COVID even without the test, so it made me feel a bit more, I think the official word is "validated".

(Lucy, 51, female, white British)

The attempts to find new grounds to legitimise their broken self-narratives could also be closely interwoven with their reflections, allowing them to reconnect their new self with their pre-illness narratives:

I think for me, if I hadn't had this time of reflection, I just would have carried on, we all would have just carried on working... and I think I'm probably in a better place because I haven't worked. I've had time to share with my family, cos they've all been here. I think I've got a greater understanding of myself and of everybody.

(Susan, 63, female, white British)

This retrospective lens may further provide a unique opportunity in which sufferers could combine their experiences of reviewing life histories and confronting new self-narratives to resume their self-continuity. As evidenced in Kate's accounts, central to this narrative, reconstruction of identity was existential growth that can integrate her new narratives into their overarching biographical framework to reconnect the past, present and future:

It's definitely made me slow down about life a lot more. I think there's a lot of pressure these days on young people to do lots of things and do it in a certain order, and sometimes you need to adjust your life so that you can do it in the way that you can. Even though I've been forced to do that, it's really given me a different perspective on life, in that I would much rather thrive in it than just sort of exist, like most young people do... In a sense, living my life to the fullest is kind of my outlook on it now.

(Kate, 21, female, mixed race)

Given that the new self-narratives about disruptions and reflections can play an integral part in gaining self-continuity, the existential impact of this identity reconstruction could be long-lasting, even beyond the illness trajectories. Reflecting on recovery from LC, some participants found the renewed perspectives about themselves and life useful for retaining self-integrity in facing other

changes/challenges moving forward. Despite sufferers' diverse strategies to restore the narratives of self-consistency in their ongoing lives, it is also clear that this process is never linear but often turbulent and prolonged. When facing a condition like LC, with its greatly complex disruptions and the underdeveloped support pathways, sufferers' attempts to reconstruct their identity as a narratively coherent being may be obstructed. John, whom we mentioned above, had to face almost a seemingly endless journey to seek answers for the 'big questions':

I went on an internal journey which still continues cos you peel away the layers and there's still more layers underneath. You never get to the bottom of it...

(John, 63, male, white British)

DISCUSSION AND CONCLUSION

Our study provided insights into an underexplored issue of existential loss of identity and (re) construction in sociology of chronic illness. We found that existential questions facing people with chronic health conditions are often foreign and hard to understand and articulate, despite the complex and overwhelmingly painful experiences. This dilemma lies in the very nature of existential loss, not simply as an experience of losing particular identity roles and traits but more broadly connected to the fundamental longing for being-in-the-world (Giddens, 1991).

By approaching identity as a narratively constructed entity to unite one's past, present and perceived future as a meaningful whole, we drew on a qualitative study on LC to explore how chronic health conditions can challenge sufferers' identity and why/how such experiences can be existential. It became evident to us that living with persistent and often uncertain symptoms and disruptions can give rise to nuanced *circumstances* in which sufferers may lose biographical resources and resilience to reflexively understand one's own being within the world (Berger & Luckmann, 1967). Central to such existential loss, as clearly captured by our data, is the *experience* of disrupted narrative time in which sufferers' present lives and the narratives they have reconstructed about these experiences become disconnected from both their past life history and perceived future life trajectories (Ricoeur, 2002; Rushforth et al., 2021). Such existential loss is not restricted to chronic illness but can be observed in other experiences such as bereavement and migration (e.g., Carr & Fang, 2023; Madison, 2006). Unique to chronic illness, however, is its embodied dimension, where both time and the world are chronically disrupted, lived and adjusted through the body (Engman, 2019; White, 2022). Therefore, existential loss of identity in chronic illness can be experienced as a struggle to retain temporal connectedness and the unity of self-narratives in the present and over time (of which the body is a significant aspect). Ultimately, such experiences may fall into a deeply painful status of 'non-being' in which people's routinely created and sustained reality becomes fractured, disabled and paused in the ongoing flow of their lives.

These struggles with existential loss are also profoundly social. As argued by both Williams (2000) and Bury (2002), chronic illness sufferers may more frequently and acutely confront the existential parameters of body, health and life in postmodern society, as a result of increasingly losing universally taken-for-granted social discourses to legitimise their broken self-narratives. Our study of 80 people with LC provided an ideal example to shed light on this highly reflexive nature of chronic illness in the intersections between the illness-stricken individual life and available social discourses. The insightful picture about the 'random openness' associated with living with complexities and unknowns around LC highlights that existential loss is

closely connected to deprivation of inclusive and enabling discourses to support LC sufferers in wider society (e.g., biomedical knowledge and social awareness). The deprivation was particularly evident when LC sufferers confronted (repeatedly) failed and contradictory self-narratives as a consequence of having nowhere to turn to for support and understanding. This existential loss can also be intertwined with social dynamics in a broader sense in which the struggles with 'non-being' could exist even before the onset of chronic illness (such as the marginalised experiences facing Ahmad) and further intensify during their illness trajectory. The social construction of existential loss was also vividly captured by our participants' dynamic and highly individualised *responses* to adopt, revise and even reject the status quo, to re-contextualise their broken self-narratives into the temporal cohesion of their narrative identity (Ricoeur, 2002).

Our study further contributed to the 'existential questions' in sociology of chronic illness by providing a more systematic picture of not only the experiential dimension of existential identity loss (Adamson, 1997; Orona, 1990; Williams, 1984) but also its holistic construction, including circumstances, experiences and responses (Ettema et al., 2010). These extended understandings allowed us to more comprehensively capture the fluidity and diversity of existential loss in this construction process. As our participants reflected during their prolonged journey to confront LC, the deeper pain of existential loss did not arise from changes/challenges at one point of time but were accumulated from persistent and repeated disruptions/failures over time (alongside their illness trajectories and their life history). This fluidity is also demonstrated in the non-linear and often oscillating process of confronting existential loss and restoration of identity. Moreover, the fuller picture of this social construction revealed the diversity of sufferers' existential loss. Based on a sample from socio-demographically distinctive backgrounds, our findings affirmed the arguments of Engman (2019) and Williams (2000) about the significance of understanding the impact of chronic illness both in the context of illness experiences per se and as part of sufferers' biography. We also furthered their arguments by illuminating an existential aspect to better understand the deeply painful and biographically reflexive experiences in chronic illness. Only by appreciating the whole construction process of such complex, fluid and highly individualised experiences, can we nurture more holistic understandings of and support for the existential loss of identity in LC and chronic illness more broadly.

By situating existential loss of identity as a highly disruptive and reflexive part of the lived experience of LC, our in-depth findings highlighted the complex nature of such experiences in both a conceptual and 'lived' sense. Despite many of our participants voicing the deeper pain of living with an alienated self and facing the broken promises of their once taken-for-granted life-plot, they frequently lacked the vernacular to clearly make sense of their existential loss. This lack of literacy points to the inadequacy of social structures to enable sufferers and those supporting them (including family, health-care professionals and others in wider society) to recognise and subsequently deal with existential loss. This issue is not only relevant for LC but can also be observed in other chronic health conditions (e.g., Andersen et al., 2021; Carr & Fang, 2023). While there may be no immediate cure for existential pain of identity loss, we found that understanding from others is important. Furthering education for families and care professionals will allow for a more sympathetic and understanding environment to help sufferers to better make sense of, justify and adapt to ruptures in the continuity of their narrative time. Although existential loss of identity may not be universal/apparent among people with LC and other chronic illnesses, it should not be overlooked. Instead, this existential dimension should be considered and supported based on individual needs, values and life histories. In addition to the implications for external support, our study provided insightful knowledge to further shape existing self-support discourses for sufferers with LC and other chronic conditions. It can enable them to

more holistically and deeply understand their distressing and often 'foreign' illness experiences and thus help further integrate their 'new' self into their narratively constructed and coherent identity.

AUTHOR CONTRIBUTIONS

Chao Fang: Conceptualization (Lead); Data curation (Lead); Formal analysis (Lead); Investigation (Lead); Methodology (Equal); Project administration (Lead); Writing – original draft (Lead); Writing – review & editing (Lead). **Sarah Akhtar Baz:** Data curation (Lead); Formal analysis (Supporting); Investigation (Supporting); Methodology (Equal); Project administration (Supporting); Writing – review & editing (Supporting). **Laura Sheard:** Data curation (Supporting); Formal analysis (Supporting); Funding acquisition (Lead); Investigation (Supporting); Methodology (Equal); Validation (Supporting); Writing – review & editing (Supporting). **JD Carpentieri:** Conceptualisation (Supporting); Data curation (Supporting); Funding acquisition (Lead); Investigation (Supporting); Methodology (Equal); Supervision (Lead); Validation (Lead); Writing – review & editing (Supporting).

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CONFLICT OF INTEREST STATEMENT

The authors declare none.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data will be submitted to the UK Data Service following the completion of the CONVALESCENCE study.

ETHICS STATEMENT

This study has been ethically reviewed and approved by the University College London Institute of Education Research Ethics Committee (ref: REC 1554) and University of York Health Sciences Research Governance Committee (ref: HSRGC/2021/466/B). We have also received permission from the following cohort studies to conduct this study with their cohort members: National Survey of Health and Development, National Child Development Study, 1970 British Cohort Study, Next Steps, Millennium Cohort Study and Born in Bradford Cohort Study.

PATIENT CONSENT STATEMENT

All participants provided their informed consent prior to data collection and were informed that their anonymised data will be used in publications.

ORCID

Chao Fang  <https://orcid.org/0000-0002-7072-6072>

ENDNOTE

¹ There are six participating UK cohort studies. The five national studies are National Survey of Health and Development (born in 1946), National Child Development Study (born in 1958), British Cohort Study (born in 1970), Next Steps (born in 1989–1990) and Millennium Cohort Study (born in 2000–2002). The one regional study is Born in Bradford Cohort Study, where we identified 21 participants (parents of children born in Bradford Royal Infirmary between March 2007 and December 2010).

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