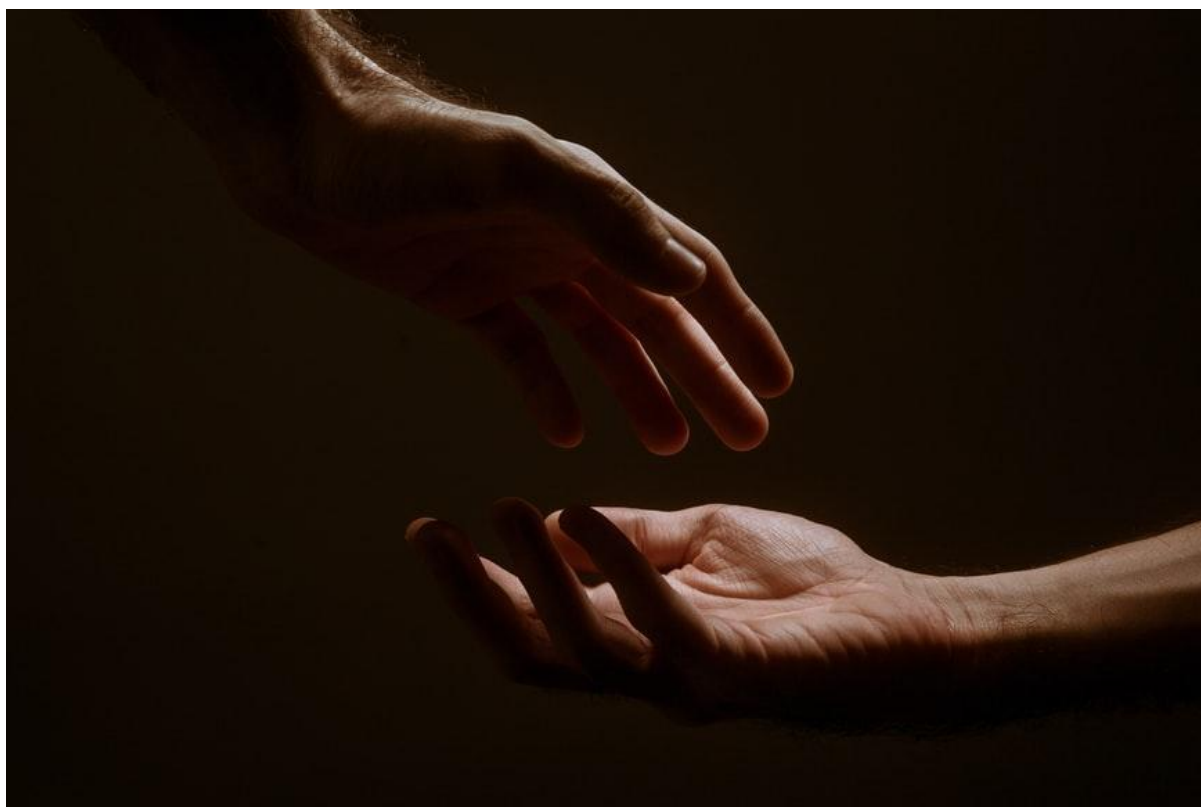




An exploration of loss and identity among people living with Long COVID



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Abstract

Identity loss and (re)construction forms a central debate in sociology of chronic illness. People living with chronic/persistent health conditions are often faced with both a 'broken' body and a disrupted self-narrative. The loss of the coherence of ongoing life and identity also lies at the heart of the lived experiences of people living with Long COVID (LC). Drawing upon a qualitative study of 80 people with self-identified LC symptoms in the UK, this paper unveils an insightful picture of how our participants lost and also sought to restore their identity as a multi-dimensional, narratively constructed and embodied entity. We found that, as a complex and still largely underexplored health condition, LC could lead to the compounded loss of not only the physical self but also a profound sense of meaning and self-worth. As reported by our participants, identity loss around LC may arise from ongoing bodily disruptions to daily routines and the lack of support and understanding to legitimise their suffering. They often experienced LC as suppressing and existential loss of meaning and being. Their dynamic responses to LC also highlighted how their longing for a narratively coherent self profoundly shaped the ongoing construction of their identity.

Key words: Long COVID, identity, loss, grief, embodiment, chronic illness

Introduction

Long COVID (LC) as an emergent health condition can be both physically daunting and emotionally laden (Rushforth, et al., 2021). Resulting from infection of SARS-CoV-2 (COVID-19), LC can lead to a protracted (more than 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 (shortness of breath), brain fog and pain issues, while patients also report a myriad of other symptoms such as hair loss, skin rashes, insomnia and sensory dysfunction impacting smell, taste and hearing (Lopez-Leon, et al., 2021). Living with LC can be both distressing and limiting as patients may suffer from one or more challenging symptoms and have to face uncertainties as a result of the persistence and fluctuation of such symptoms (Ladds, et al., 2021; Rushforth, et al., 2021).

Whilst the knowledge about this new health condition is fast-evolving, the definitions of LC and its treatments however still remain largely underdeveloped, due to the multisystemic and often fluctuating symptomologies and its multidimensional impacts on patients (authors reference). Varied chronic illnesses (e.g., myalgic encephalomyelitis and chronic fatigue syndrome) have been drawn upon by researchers and practitioners to navigate explorations and development of support for people living with LC (Newman, 2021). There are also increasing calls for LC to be understood and supported within the paradigm of chronic illness, to shed further light on the complex and pervasive impacts of LC (O'Rourke, 2022; Alwan, 2022).

As medical and social discourses on LC advance, there are increasingly common narratives reported by patients about the loss of their 'old self', future plans and identity more generally (e.g., BBC, 2021; Ladds, et al., 2020). A growing body of literature has focused on the detrimental impacts of LC on patients' identity (Humphreys, et al., 2021). These studies have predominantly approached identity either in terms of generalised traits (e.g., active, independent) (Burton, et al., 2022; Callan, et al., 2022) or within specified contexts (e.g., professional roles, parenthood) (Ladds, et al., 2021; Humphreys, et al., 2021). While this focus on particular identity traits and roles is valuable, it is also important to acknowledge that the impact of LC can penetrate one's lives across various aspects and may even run deeper to give rise to a sense of grief about losing fundamental meaning and being (Ireson, et al., 2022). To extend the current literature to better understand the impact of LC on identity, this article reports on a qualitative study exploring 80 self-reported LC sufferers' identity loss and reconstruction. In particular, we investigate identity as a multi-dimensional, narratively constructed and embodied entity including but not limited to individuals' traits and roles (authors reference; Engman, 2019). In this investigation, we aim to capture why and how LC, as a persisting and often unpredictable condition, can elicit patients' identity loss/challenges in a multitude of ways and how the experience of living with LC influences the complex and ongoing (re)construction of identity.

Our focus on the complexity and depth around identity can shed light on LC as a compounded loss of not only the physical self but also a profound sense of meaning, self-worth and consistency (Bury, 1991). As such, we seek to provide unique evidence to further sociological understandings about the disruptive impacts of long-term illness conditions on people's identity construction both at an everyday and more existential level (William, 2000; Engman, 2019). These insights can also enrich official definitions and understandings about what LC means to patients, shaping the relevant healthcare and social support provisions in a more holistic manner.

Chronic illness, loss and identity (re)construction

LC can be considered as a chronic health condition in the absence of effective treatments and time limits on its duration. There are increasing debates on "reimagining chronic illness" to better contextualise and understand the complexity around LC (O'Rourke, 2022). Like many other chronic conditions, such as arthritis and chronic fatigue syndrome, the long-term effects of COVID-19 symptoms can persist and fluctuate over time, routinely causing multifaceted losses to challenge the continuity of patients' everyday lives and further the coherence of their identity (Rushford, et al., 2021; Bury, 1991). This disruptive nature of identity losses is also closely connected to a process of 'grieving'. That is, patients often experience their chronic illness as an embodied transition in which they learn to adapt to their bodily changes/deteriorations to revise and reintegrate their 'former self' in ongoing lives (Stephenson & Murphy, 1986).

Sociologically speaking, living with chronic illness can be closely connected to a sense of 'spoiled identity' (Goffman, 1963). Such experiences can deeply discredit people's experiences as a patient due to losing formerly constructed meaning and strength to make sense of and justify different aspects of their ongoing lives. Bury's canonical concept of "biographical disruption" (1982) has famously captured this temporal dimension of chronic illness as a "critical point" that can risk breaking patients' identity as a coherent narrative thread linking their past, present and expected future. As such, the struggle to resume once taken-for-granted life routines and the inability to continue one's narratively coherent identity are central to the experience of living with chronic illness (Ricoeur, 2002). To understand such disruptions is, hence, to not only understand illness *per se* but also appreciate the relationship between the "effects of illness and a subject's pre-existing embodied orientation towards the world and of the considerations of identity that those effects give rise to" (Engman, 2019: 126). In other words, chronic illness needs to be understood within the ongoing (temporal) construction of patients' biography. When chronic illness reaches the very root of patients' connection with the familiar self, relationships and the external world, they will inevitably confront what Giddens calls 'ontological insecurity' (Giddens, 1991). By living in a broken body and an altered life world (Wurz, et al., 2022), they

may experience existential anxieties of losing identity as a fundamental ground for integrity and continuity of meaning to make sense of their lives and being moving forward.

The impact of chronic illness on patients' identity also lies in a powerful sense of grief in response to multifaceted and even deeply painful losses of temporal and narrative coherence of self (Ireson, et al., 2022; Roos, 2017). Similar to grief following death of a loved one, the grief as a result of living with chronic illness may involve loss and thus disruptions to meaning but also entail agentic dimensions of reconstructing/adjusting one's identity moving forward (Stephenson & Murphy, 1986). Meanwhile, unique in chronic illness related grief is the presence of the 'broken' body may become a (ir)regular reminder of the multifaceted losses and pains related to illness. That is, the suffering from chronic illness may face an unavoidable and deeply pervasive experience of losing perceived control of their body as the fundamental basis of everyday lives (e.g., unable to cook, walk or meet responsibilities) (Engman, 2019; Stephenson & Murphy, 1986). Furthermore, the process of reconstructing chronic illness patients' identity may only be temporary (at least as perceived by patients) rather than permanent, as the patient may still retain the hope of recovery (Brooks, et al., 2015). As such, living with chronic illness may be closely connected to embodied experiences of loss and thus could require rigorous emotional labour to make sense of and re-integrate it in one's ongoing lives (William, 2000).

The complexity around the impact of chronic illness is further rooted in postmodernity (such as in the UK), in which shared social norms continue to break down and diversify while individual experiences become increasingly heterogeneous (Giddens, 1991). As such, the interplay between socio-cultural structures and the construction of individual identity may be more fluid (Bury, 2002). This post-modernist perspective can thus illuminate the significance of employing a person-centred approach to understand the lived experiences of losing and reconstructing meaning and identity in chronic illness (Bell, et al., 2016). To do so, it is important to incorporate patients' biographical, relational and socio-cultural contexts to understand the unique experience of living and coping with chronic health conditions from their own perspectives.

Long COVID and mysteries about broken self-narratives

In alignment with the existing literature on chronic illness, LC can give rise to varied disruptions to meaning, resources and resilience that have long helped patients discern 'who they are' (Humphreys, et al., 2021; Callan, et al., 2022). Unique to LC is the emergent and 'unknown' nature of many of its mechanisms, courses and treatments (Sivan, et al., 2021). Little information has been available in medical and societal discourses for patients to draw upon to make sense of the narratives about their body, everyday lives and their sense of identity more generally (Rushford, et al., 2021; authors reference). Living with such a novel condition may also involve an ongoing process of disjunct oscillation between fears about

endless ongoing struggles and hopes for a smooth recovery (Rushford, et al., 2021; Burton, et al., 2021). As such, the ongoing ‘unknowns’ about the long-term impacts of LC may continue to impact patients’ ongoing lives, interrupting or even disabling the “chronology” of patients’ illness trajectories (Rushford, et al., 2021). These uncertainties around the chronology of recovery may entail wider impacts on patients’ biography as a consistent entity, disrupting their capability to act upon the ‘old’ self to justify their present experiences and envisage their future lives. In other words, patients’ 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.

Despite the lingering and still largely emergent impacts of LC, patients have demonstrated their agency to seek to fix the disrupted narratives about themselves. Patients are claimed to have collectively constructed LC; they were among the first to report and shape the medical and societal discourses about LC as a physically challenging and socio-emotionally laden experience (Callard & Perego, 2021). Often being neglected and disbelieved in the early stage of the Covid-19 outbreaks, many frustrated patients turned to advocating online and/or participating in research as means of revealing their illness narratives, their struggles in accessing support and to further shape scientific understandings about LC (Rushford, et al., 2021; Callan, et al., 2022). In addition to the above collective endeavours, patients also exercised their individual agency to actively search for understanding and support from their personal experiences and in the rich matrix of their relationships (often from their family, friends and/or informal carers, and healthcare professionals) (Humphreys et al., 2021). All these attempts have illustrated LC sufferers’ determination, if not desperation, to fix what is ‘wrong’ with them, and further to understand their “fragmented inner monologue” to seek to justify their suffering as a LC patient and further reconstruct their broken self-narratives (Rushford, et al., 2021).

While both formal and individual understandings about LC continue to evolve, some mysteries remain underexplored due to the vastly varying nature of sufferers’ lived experiences. Research has revealed a myriad of multisystemic and often changing symptoms (presumably) related to LC, ranging from physical damages to neurological and sensory dysfunction and, for some an amalgamation of these (Sivan, et al., 2021). 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 (e.g., Sapkota & Nune, 2022). The vagueness and apparent randomness about the mechanisms, development and treatment for LC may powerfully challenge patients’ ability to comprehend what LC really means to them and their lives. Whilst it is useful to focus on specific aspects of individual experiences, such as particular symptoms and loss of certain identity traits and roles, we argue it is also important to examine the impacts of LC in the broader context of biographical development (of coherent self). As such, we seek to conceptualise LC within the paradigm of *identity as an ongoing social*

construction, informing more holistic understandings to acknowledge and mitigate the pervasive and deep impacts of LC.

The study

To more holistically understand what LC means to people, we draw upon in-depth interviews with 80 people with self-identified LC symptoms collected from six national and regional cohort studies in the UK between November 2021–March 2022. The study has received ethical approval from the authors' institutions and the participating cohort studies.

Sampling: the average person with LC

Our study focuses on the social construction of identity of people living with LC and particularly how their everyday experiences are intersected with wider socio-cultural discourses to make sense of and deal with the impacts of such a complex and uncertain condition (Engman, 2019). As such, we are keen to capture a fuller picture of the lived experiences of 'the average people with LC' - we recruited participants not from healthcare systems and social media but from nationally and regionally representative cohort studies in the UK. Existing qualitative studies on LC have largely draw upon samples from members of self-selecting groups (e.g., LC support groups) and/or patients from healthcare systems (e.g., Rushford, et al., 2021; Ladds, et al., 2020; Reay, et al., 2021). While valuable, these samples may exclude people who do not join support groups and those who have not been formally diagnosed with COVID and LC; thus, their voices may remain largely unheard. Furthermore, given the lack of universal and accessible definitions about LC, some people may not recognise or even know 'LC' despite their persistent symptoms resulting from COVID infection.

To embrace a more inclusive approach, we recruited our sample via the following two routes. Firstly, we recruited 40 participants from five nationally representative cohort studies based in the UK: 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 1989-90) and Millennium Cohort Study (born in 2000-02). Specific COVID-19 surveys from the above cohort studies were used to identify cohort members who reported having COVID-19 related symptoms for over 4 weeks. We particularly approached those who indicated having persistent symptoms for over 8 weeks and the recruitment was terminated when the target of 40 interviews was reached. Secondly, given that it is widely understood that socio-economic and racial inequalities can disproportionately contribute to COVID-19 related challenges, we also collected interviews from 40 participants in Bradford, a region in the North of England with high levels of deprivation, poverty and health inequalities (Lockyer, et al., 2021). We adopted a similar selection approach with the Born in Bradford Cohort Study, where we identified 21 participants (parents of children born in Bradford Royal Infirmary between March 2007 and December 2010). The remaining 19 participants were recruited in wider Bradford society through community workers and snowball sampling, to gain samples

from more diverse demographical backgrounds. Both the national and Bradford-specific recruitment oversampled individuals with higher socioeconomic deprivation and from ethnic minorities to reach people who may be underrepresented in other LC studies. In so doing, 80 interviews were collected from socially and ethnically diverse participants across varied age groups (see table 1).

Table 1: social and demographical characteristics of interview samples	
	Sample (N=80)
Gender	
Female	56
Male	24
Age	
18-19	2
20-29	6
30-39	20
40-49	18
50-59	15
60-69	14
70-79	5
Ethnicity	
White British	43
South Asian	30
Southeast Asian	2
White other	3
Mixed	2

Interviews: constructing illness narratives

Humans are natural storytellers, who can draw upon their past experiences and socially mediated knowledge to present themselves to others and to retain their sense of identity (Rushford, et al., 2021). By adopting a semi-structured interviewing style, we encouraged our participants to freely relay their stories about living and coping with LC. Questions we asked focus on the lived experiences of LC in 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 healthcare, (4) coping strategies, (5) support resources and networks, (6) reflections on losses and changes. These in-depth interviews captured both the participants' big stories (major events such as life-changing symptoms,

hospitalisation, loss of employment) and small stories that are lived and enriched in everyday settings (e.g., altered daily routines and social encounters) (Phoenix & Sparkes, 2009). As such, we generated 80 in-depth interviews totalling over 3,500 minutes with an average length of 44 minutes. All these interviews were remotely and independently conducted by the four authors (apart from one face-to-face interview with a participant with hearing difficulties) and then transcribed verbatim by professional transcribers.

Our interview strategy to give voice to the participants has closely resonated with the ongoing calls for further integrating patients' views into LC research (Alwan, 2022). We adopted a bottom-up approach to enable the people with LC, especially those from disadvantaged and underrepresented groups, to share their individual experiences to shape broader societal understandings of LC. Many participants in our study are 'wounded storytellers', who demonstrated their motivation to join other peers "in their shared vulnerability" to transform their broken individual stories into collective narratives of suffering to call for further changes (Frank, 1995).

Data analysis

We adopted a reflexive thematic analysis method with an inductive approach to interpret the pervasive and often nuanced impacts of LC on the participants' lives and identity from their own perspectives (Braun & Clarke, 2021). The first and second authors coded the interviews independently and then compared the codes and findings. A combination of NVivo 12, a qualitative analysis software package, and more traditional analogue reading and coding was used to manage and analyse the data. The codes were further discussed and refined by the research team (all authors) in frequent meetings.

To more systematically capture the complex and sometimes even deeply painful impacts of LC on the participants' sense of identity, we adopted an organising framework from Ettema et al. (2010), to contextualise our findings in three dimensions: (1) *circumstances* from which identity losses and challenges arise, (2) *experiences* of multifaceted identity losses (3) *responses* to retain/resume the authenticity of self. This categorisation also mirrors our social constructionist ontological standpoint and interpretivist epistemological approach, allowing us to engage with our participants' accounts to capture how their lived experiences and identity are interpreted and constantly constructed by LC and their situated broader social contexts. 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 further captures how these codes were further developed to five analytical themes under the three dimensions.

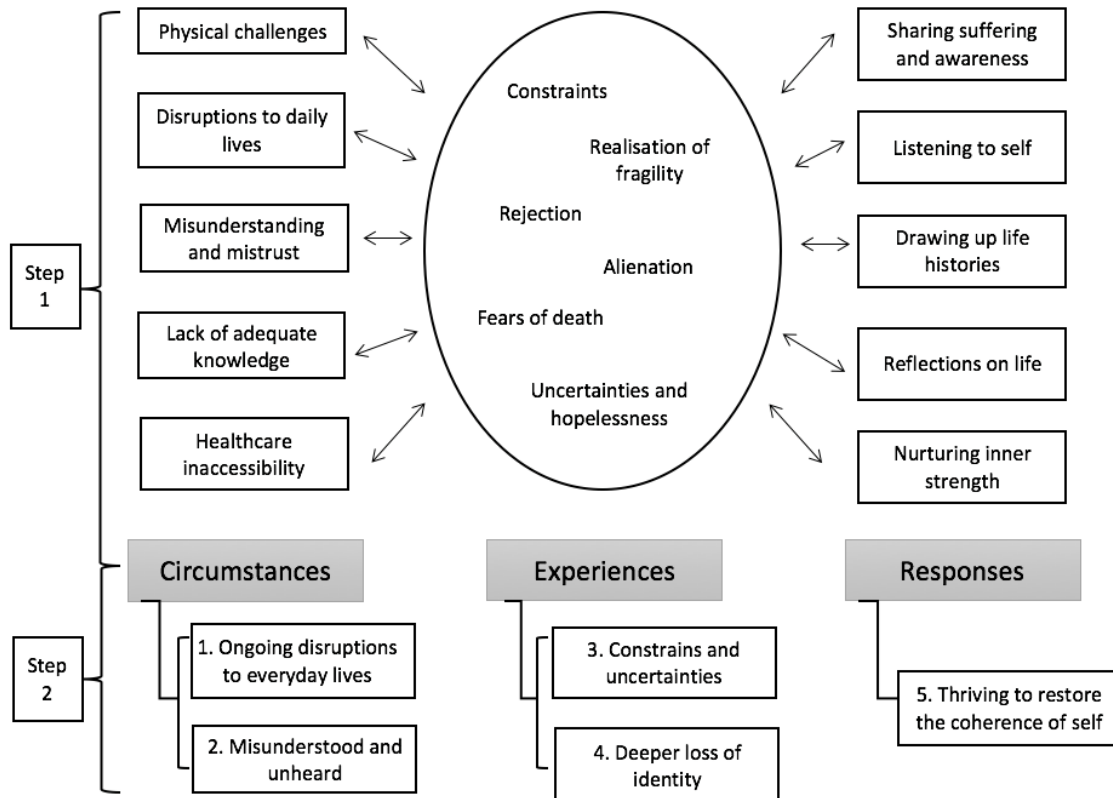


Figure 1: An illustration of the coding process

Findings

The 80 interviews have revealed a complex picture of living with LC. Challenges facing our participants were closely connected to a myriad of losses resulting from a wide range of persisting and fluctuating self-reported symptoms. The most common symptoms we 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 often (or as perceived) interconnected with other health conditions. Ambiguity was often attached to LC symptoms as many participants had been never been formally diagnosed with COVID or LC. Some believed they had COVID-19 at the very beginning of the pandemic (Spring 2020) when testing was not widely available in the UK. The lack of official confirmation of COVID-19 infections and symptoms was further amplified by difficulties in accessing healthcare (authors reference). The duration of their symptoms ranged from 6 weeks to around 20 months at the time of the interview.

All five themes capture a rich picture of how our participants lost and also sought to restore their identity as a multi-dimensional, narratively constructed and embodied entity alongside living with LC. Theme 1 and 2 underline individual and socio-cultural *circumstances* of living with LC that could disrupt and discredit the authenticity of one's identity. Theme 3 and 4 capture how our participants *experienced* (and often also grieved) pervasive and deeper loss

of identity in their ongoing lives. Theme 5 focuses on the agentic dimension of people's responses to identity loss whilst living with ongoing challenge of LC. By presenting our findings in this manner, we did not intend to outline living through and recovering from LC as a linear process. Rather, we sought to highlight the interconnectedness of these experiences, in which living with LC may involve changing circumstances for self-identity but also an oscillating confrontation with identity loss and restoration. These findings helped us better appreciate the disrupted temporality of lives facing our participants and how this is deeply embedded in their identity as an ongoing social construction. To protect our participants' confidentiality, pseudonyms were used below.

Theme 1: Disruptions to ongoing lives

Most evident in our participants' accounts of LC was the physically and/or cognitive debilitating symptoms they encountered. In facing one but more often multiple symptoms, these people reported living with LC as a significant circumstance in which they felt impaired and sometimes even unable to carry out daily activities and responsibilities (e.g. walking, cooking, working and parental duties). To varied extents, they lost their body/brain as a fundamental medium to fully experience and engage with the once taken-for-granted world (Engman, 2019). Such disruptions to their continuing performance could challenge their routines that have long helped them to maintain their everyday lives and reaffirm their identity.

These changes might be significant but also 'small' and 'subtle', they could persist, fluctuate and accumulate to gradually challenge what our participants perceived as 'normality':

"Like the out of breath thing is – it's really difficult for me to manage my stairs, I get very out of breath. I'm very limited [in] what shopping I can do, I quite often have to get shopping brought in. The brain fog, it's a nightmare, I have to have everything written down 'cos I can't remember things. You know, alarms on my phone and everything and yeah, it's affected every aspect of my life, it really has." (Susan, 63, female, white British)

Life post COVID-19 infection could also be disrupted in a more profound sense due to failing to resume commitments that are central to their core identity. Ahmad expressed his frustration at not being able to fulfil what he felt was his role as a father at a key stage of his young son's development due to fatigue:

"I feel bad for my little son because he's five and he's just started school this year and, you know, sometimes I can't take him to his swimming now if I don't feel up to it or take him to his football classes or gymnastics. So just those extra activities that we've got for him and I feel like as a father figure, it's my duty and sometimes my wife has to do it now." (Ahmad, mid-30s, male, British Pakistani)

The disruptions may not only lie in inability to enact their responsibilities and roles in the present time but could also be connected to struggles to continue their long-held priorities in their ongoing lives. Ahmad continued to talk about the disruptive nature of living with LC by highlighting that his family-centred values may be threatened, by being unable to support his son for the foreseeable future:

“So mostly I would say stuff [LC] just to do with family because I don’t know, family has always been important to me like even with my actual brothers and sisters, so you know, having my own child is definitely going to have that impact. Yeah, I’d mostly say it’s linked into him.” (Ahmad, mid-30s, male, British Pakistani)

Theme 2: Misunderstood and unheard

For our participants, living with LC involved ongoing disruptions to everyday life; it was also closely connected to the societal and emotional barriers of addressing these challenges (Rushford, et al., 2021). Many of our participants felt the disruptive nature of LC symptoms and felt their resultant struggles were often misunderstood, unheard and even disbelieved. These barriers could give rise to a unique circumstance, in which people might have to question the authenticity of themselves due to the lack of resources that legitimise their experiences.

Our participants frequently felt they were not being taken seriously and were being rejected by others, including family members, friends and healthcare professionals. This could be particularly painful if their close contacts failed to listen to and trust their illness narratives. Emily felt so disappointed about the lack of empathy from her family that she decided to face the distress alone:

“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. So yeah, 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 above account reflected a broader context in which discourses about LC symptoms and impacts were still largely missing both in formal/medical and everyday paradigms. The lack of knowledge about understanding to support those with LC could be even more prevalent for those without ‘physically visible’ symptoms. John for example called LC a ‘hidden disability’, which he felt may impeded others’ ability to empathise with his suffering:

“If somebody sees me outside, they assume that, 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)

This struggle to access accepting and supportive networks could be rooted in individual circumstances. That is, formerly embedded cultural, generational or familial values developed in earlier life could smother individuals’ ability to express their emotions, confirm their suffering and ultimately enhance the legitimacy of their ‘new’ body and self. Paul is one of the participants who had little emotional language to embrace what LC really meant to him before being offered a platform for reflection, despite having suffered from the tremendous pains of losing his taken-for-granted routines and confidence:

“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, you know, 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, you know, 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: Constraints and uncertainties

Integral to living with LC was the complexity of disruptions and the lack of understandings to support those experiencing it. These compounded challenges could be experienced in our participants’ everyday lives as a profound sense of constraint and uncertainty, suppressing their capacity to act upon their identity (who they used to be) to perceive the present and envisage the future regarding their illness trajectories and lives (Williams, 2000).

Due to the physically and/or cognitively debilitating nature of LC, our participants’ daily activities and life rhythms were often constrained by and constructed around their symptoms. Steve elaborated how his symptoms limited what he could do and more fundamentally who he wanted to be:

“I was struggling to do things that before I would do easily. Without a thought. I think, yeah, it’s a constraint on what you can do... Even if the symptoms have passed off, there’s a bit at the back of your mind that says maybe, maybe something else is gonna happen. So I think it’s kind of a two part thing. There’s the actuality of what happens to you. My legs ache, I don’t want to go for a walk. And if I go for a walk, I’ll get really

bad leg aches and I don't want them. So you don't go for the walk." (Steve, 63, male, white British)

Experiences of constraint might not be temporary but could also have more enduring impacts, leaving LC sufferers' future lives uncertain and vulnerable. For many, their illness trajectories involved a unique 'random openness' of greatly complex and fluctuating symptoms (compared to many other health conditions), which could shatter people's ability to plan and envisage their lives moving forwards:

"The symptoms are so random and crazy, they don't fall into any set of anything, the whole relapse cycle. You know, because you can feel better for a few days, later on you know your heart lifts, you feel fantastic, and then you crash again and it's like a kind of false dawn every few days, 'yes, finally I've cracked it' and then 'oh no, you're ill again'." (Lucy, 51, female, white British)

Those of a younger age could be particularly vulnerable to the numbing impact of uncertainties on envisaging their future self:

"I know for a fact that if I stay the way [of losing mobility] I am at the moment, I probably won't be able to be in a normal job. And I've come to terms with that quite a bit. Because I just wouldn't be able to keep up at all." (Kate, 21, female, mixed race)

The vulnerability of uncertainty could be further exacerbated by lacking or delayed access to healthcare (which was very prevalent among our participants, see authors reference). This would raise further random openness about their already puzzled body and embodied identity. Christine had to face a long wait before seeing her doctor, all the while facing anxieties about what would happen to her:

"I'm concerned, I'm still waiting to see if actually I've got long-term problems with my lungs. So I suppose there is always niggling in the background that fear of thinking that 'well, I've still got symptoms almost two years on, so what does that mean, is there something horrible that's gonna come and we're gonna find that everybody suddenly getting early dementia?'" (Christine, 51, female, white British)

Theme 4: deeper loss of identity

The painful experiences as a LC sufferer could run deeper than health issues, questioning their being (or not being) on a more ontological level. Fundamental in these deeply painful confrontations was an insurmountable discrepancy between body and mind, as a result of losing their body/brain as a primary device to embrace their existence in the world (Ettema, et al., 2010).

One powerful embodied experience of loss widely shared by our participants was being trapped in a frail and deteriorating body that may result in them feeling disconnected to one's taken-for-granted self, others and the external world. Susan felt she had become "a shadow" of herself due to losing her confidence to fatigue, brain fog and organ dysfunction:

I always was a fairly confident person, always had, you know, big responsible jobs which I sort of thrived on stress and all the rest of it. Now, I just feel like I'm like a little old lady. I don't have any confidence at all. I would rather not go out the house if I don't – I would much prefer not to go out the house at all, you know, 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 deep pains of becoming "withdrawn" could be connected to a sense of 'grief' about losing the integrity of self:

"Before I had it [LC], I was working as a social worker, two young children, physically active, you know, 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 and had to face that. Uh, which was very profound and gave me a huge insight to suffering and loss." (John, 63, male, white British)

The impact of living with a broken body and a withdrawn self was also likely to give rise to painful ontological realisations of vulnerability and finitude. For those of an older age, these realisations could be particularly existential, reminding them of their ageing and even the inevitability of mortality:

I don't know if you've heard the expression, 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 deeper pains 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', and you know, this experience has made me realise I'm actually not invincible, and I get sick quite a lot now because of LC.... So yeah, people are much more vulnerable than we think." (Kate, 21, female, mixed race)

Theme 5: thriving to restore the coherence of self

While living with an identity suppressed and even deeply discredited by LC, our participants also demonstrated their dynamic responses to draw upon resources to fix their broken self-narratives. Underpinning such endeavours was their longing to reconstruct a coherent narrative, a thread of identity to better understand themselves moving forwards (Ricoeur, 2002).

For our participants, developing persistent COVID-19 symptoms was often a dividing line that discontinues their formerly constructed narratives about who they are. 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. This need was particularly evident among patients who were not officially diagnosed with COVID-19 and/or LC. 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, to be honest, but as I’ve met more and more people who were in that first wave, 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 LC 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)

Their attempts not only focused on finding new grounds to legitimise their broken self-narratives but also involved actively drawing upon their earlier life experiences as a pool of reference to retain the continuity with their prior bodily experiences and narratives:

I suppose for me, maybe compared to other people, it’s been a bit easier in that I’m used to having a long-term health condition that gives you fatigue and muscle aches... I’ve had Graves and I’ve got rheumatoid arthritis, so I’m an autoimmune type person, so it’s sort of in that way, so it made sense to me, OK, this is an immune function gone awry, and I know I’m that kind of person. (Christine, 51, female, white British)

The retrospective lens afforded by LC also provided a unique opportunity for people to reflect on their lives. Such reflection facilitated a growing appreciation of the meaningfulness about themselves and life more generally. This reflection was particularly valuable for Susan who was off from work for months due to LC:

“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)

For some participants, the combined experiences of reviewing their own life histories and confronting new disruptions could enable them to develop a new frame of meaning and purposes to re-define their identity moving forward:

"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 people young people do... In a sense, living my life to the fullest is kind of, yeah, my outlook on it now." (Kate, 21, female, mixed race)

Discussion

Our paper provided insights into the pervasive and often deeply painful impacts that living with LC can have on people's identity. By drawing upon in-depth interviews with 80 LC sufferers from different demographical and symptomatologic circumstances, we found that LC as a novel long-term health condition can cause a multitude of losses in the physical, emotional, social and existential aspects of their ongoing lives. These losses are often fluid and frequently intersect, further challenging their taken-for-granted resources (e.g., health, routines and social connections) and capability (e.g., physical strength and mental resilience) to retain their identity as a coherent entity moving forward. Evident in our findings are the 'biographical disruptions' facing people with LC and their desire to 'mobilise resources' to cope with these disruptions (Bury, 1982; 1991). As such, the LC sufferers sought to legitimise and re-contextualise their altered life circumstances within the ongoing construction of biography. By capturing diverse lived experiences of LC (e.g., experiences of people in different age groups, with distinct health histories and support networks), our study has also resonated with Engman's (2019) argument about the embodied nature of biographical disruptions. That is, the impacts of chronic conditions should be understood not only in the context of illness *per se* but also as part of patients' biography, imbued with socio-cultural norms and self-narratives from earlier life. This has furthered this discussion on disrupted temporality by using LC as a unique example to clarify how life histories are carried forward, confronted and adapted to deal with the discontinuity and unpredictability of the ongoing construction of self-narratives (Rushford, et al., 2021; White, 2022).

The temporal dimension of living with LC also reaffirmed the narrative construction of identity, highlighting the significance of "coherence of the narrative plot with a beginning, a middle, and an end" in facing multifaceted identity challenges and losses (authors reference). By conducting in-depth interviews with 80 participants, we captured both their 'big' LC stories

of major life changes/challenges (e.g., loss of mobility) and ‘small’ stories of everyday encounters with multifaceted disruptions. These combined stories depicted an insightful picture of the ‘random openness’ associated with living with complexities and unknowns around LC symptoms, illness trajectories and treatments (as captured in the findings). As such, we were afforded further insights into ‘disrupted narrative time’. That is, the ongoing constraints and uncertainties associated with LC could penetrate across various moments of our participants’ lives interrupting their life rhythms (White, 2022); these could also suppress their capability to re-integrate their lived lives to inform present and future (Ricoeur, 2002). Our focus on temporality offered deeper insights into the impacts of LC on people’s identity by highlighting a more fundamental fear of losing their long taken-for-granted self in the past and facing a shattered future (Ettema, et al., 2000). The deeply painful impacts of LC were also evident in our participants’ dynamic responses when aiming to legitimise and contextualise their broken self-narratives within their broader biography. Such endeavours helped to restore the temporal cohesion of selfhood so that their lives moving forward can stand ongoing tests of time (Ricoeur, 2002).

Our findings on the deeper pains of living with LC furthered the value of exploring ‘existential questions’ in the sociology of chronic illness (Giddens, 1991; William, 2000). While we found that our participants’ lived experiences of LC could be rooted in the painful ontological awareness of their frailty, mortality and finitude, they often found it difficult to perceive and justify their existential struggles. Some had never questioned nor articulated these largely foreign and overwhelming experiences before the interview. This dilemma opened up further grounds to explore existential crisis in the paradigm of sociology of health and illness. So far existential experiences have been documented (often as spirituality) in sociological studies on terminal illness and extreme frailty (Exley, 2004). Our paper provides a powerful example to demonstrate that existential loss needs not be restricted to the above extreme conditions but can also be observable in long-term/chronic health conditions. At the heart of such experiences is a status of ‘non-being’, in which people’s routinely created and sustained reality becomes fractured and disabled (Berger & Luckmann, 1967). This can be particularly true when living with ongoing health challenges and the loss of biographical resources and resilience to reflexively understand their own being within the world (Giddens, 1991). The existential concerns reported by our participants across different age groups and from varied backgrounds also highlighted the prevalence of the experience and the significance of support for such deeply painful experiences in the context of chronic illness.

Finally, the profound sense of loss captured by our study advanced the understandings of non-death related grief and how these understandings can be interwoven within the sociology of chronic illness. Particularly stark in our participants’ lived experiences with LC was a myriad of multifaceted and often interconnected losses, ranging from the loss of health, social/familial lives and further to identity and their fundamental sense of being. While non-death related grief has been closely examined in different chronic conditions (e.g., dementia,

disability), research of this kind often pays attention to the ‘living sorrow’ of caregivers and family members rather than suffers themselves (e.g., Harris, 2019). Stephenson and Murph (1986) compared the ‘existential grief’ of those experiencing chronic illness and the disabled with bereaved people who had lost their loved one. They found that for people with chronic illness or disabilities, ‘existential grief’ may be felt more constantly and somewhat more directly because “the reality of death, disease, and the randomness of existence are ever-present and unavoidable” (p.144). Sociology can offer a valuable lens to capture such embodied encounters in chronic illness by explaining the profound loss of the body (physically and/or cognitively) as a primary device to experience self and form bonds with others and the world (Engman, 2019). Only by appreciating the meaning of such embodied loss, can we nurture more holistic understandings of and support for chronic conditions, including LC.

Implications and limitations

On a practical level, our study revealed the pervasive and even deeply painful experiences of living with identity losses and challenges presented by LC. These findings highlighted the significance and urgency of providing holistic and person-centred support for LC in both professional and everyday settings. Given the largely unknown and complex nature of LC, medical care for those living with this novel condition remains largely fragmented and often insufficient (although fast developing), whilst their psychosocial needs also remain inadequately addressed (Ireson, et al, 2022). Therefore, future support needs to not only improve the accessibility and consistency of medical care for people living with LC (as demonstrated in Ireson, et al., 2022; authors reference), but also further acknowledge and support their emotional, social and existential needs in facing the disruptive and restrictive impacts of loss.

Understanding is key among healthcare professionals, family members and communities. The sense of empathy and support can alleviate LC sufferers’ multifaceted distresses and also help them to better make sense of, justify and adapt to their loss, changed body/brain and ultimately ‘different’ self. Support should also reflect the extremely diverse symptoms and needs facing sufferers; thus, a more person-centred approach is key to informing and delivering future practice. For example, existential loss of identity may not be universal among people with LC, it should however 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 the external support, our study provided insightful knowledge to further shape existing self-support discourses for people with LC. It can enable them to more holistically and deeply understand their distressing and often ‘foreign’ LC experiences and thus further to adapt to the identity challenges they face alongside their illness trajectories and disrupted ongoing lives.

The study presented in this article also has limitations. Firstly, despite having captured a temporal dimension of the impact of LC (e.g., how it may disrupt people’s identity coherence

over time), we acknowledge that future research is needed to further examine the ongoing experiences of and the fast-evolving support for LC. This gap will be addressed in our continuing work as part of a larger longitudinal qualitative study, which include three rounds of interviews with same 80 participants, where possible apart from attrition, between 2021-2023 (this article reports findings from the first round). Secondly, whilst a diverse sample of participants were included in our study, people with LC from Black backgrounds (the largest minority ethnic group in the UK) and many other ethnic minorities were missing. Therefore, future research should seek to capture experiences from these underrepresented groups and/or incorporate a more inclusive sampling approach.

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