

Young adults' experiences of biographical retrogression whilst living with long COVID

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Abstract

During the early years (2020–2021) of the COVID-19 pandemic, relatively little attention focused on experiences of people with long-lasting symptoms, particularly young adults who were commonly understood to be invulnerable to serious effects of the virus. Drawing on narrative interviews with 15 adults in their twenties and living in the UK when they became ill with long COVID, we explore contextual factors which made their long COVID illness experience, and the whole-scale disruption to their lives, challenging. We propose that existing adaptations of the concept of biographical disruption are problematic for this group, and instead suggest that 'biographical retrogression' may more accurately reflect these young adults' experiences. For many of these young adults, their illness occurred at a crucial stage in forming or solidifying (presumed) adult trajectories. Secondly, the recency of long COVID did not allow for comparison with an existing 'grand narrative' of recovery, so the future course of their illness was not just unknown for them as individuals; there was no prognostic map against which to assess their symptoms. Thirdly, the lives of people with long

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COVID have been disrupted in the context of global *societal disruption* by the same virus, rendering their experiences both topical yet invisible.

KEYWORDS

biographical disruption, biographical retrogression, experience of illness, long COVID, young people

INTRODUCTION

Within weeks of the first reports of SARS COVID-19, the potential for profound disruption to daily life was apparent. Early predictions (Walker et al., 2020) warned of ‘a severe and acute public health emergency’ and, in the absence of mitigation and suppression strategies, 7 billion infections and 40 million deaths globally in 2020. Such models raised concerns that health-care systems would be overwhelmed without effective vaccines and public health measures to restrict social contact and limit contagion, and measures were widely introduced during 2020–2021. Journalists, social and political commentators and policymakers, alongside public health specialists, contributed to daily reportage of numbers of cases and deaths and widespread societal disruption. Schipper et al. (2021) noted ‘major upheavals in life as we know it in every corner of the planet’ with ‘deep and far-reaching’ impacts, speculating that the ‘turbulent transformation’ and ‘abrupt social disruption’ globally may set precedents for social change in other areas, such as climate change. Alongside this societal disruption, the rhythm of people’s lives was profoundly altered whilst infection rates, and public health measures to halt the virus’ spread, were at their height. Whether or not infected themselves, the disruptive influence of COVID-19 pervaded people’s lives, and discussion of the waxing and waning of cases and new variants, pressure on intensive care units and deaths dominated public and private discourse in 2020 and 2021. Wood et al. (2022) note that: ‘Citizens may tolerate temporary restrictions on rights and privileges in the face of emerging threats, which may give way to animosity and resistance if the policy persists... As the threat subsides, the public may demand the termination of restrictions’ (p. 14). Indeed, as the pandemic moved beyond its initial crisis stages, some politicians and population groups became increasingly invested in downplaying the continuing threat of COVID-19; by March 2023, <20% of UK adults reportedly thought the ‘coronavirus pandemic [was] an important issue facing the UK today’ (Office for National Statistics, 2023).

Whilst public health messaging initially focused on the heightened risk of serious illness and death amongst the most vulnerable (the elderly/people with serious health conditions), reports of people with multifarious longer-lasting symptoms began to coalesce. The collective ‘making’ of the condition commonly called ‘Long COVID’ by those first affected (Callard & Perego, 2021), emerged from shared stories, often through social media, as people struggled to make sense of myriad bizarre unpredictable, relapsing, remitting and diverse symptoms which transformed daily life. Unsurprisingly, researchers (e.g. Callan et al., 2022, Kingstone et al., 2020, Rushforth et al., 2021) have highlighted the pertinence of the concept of chronic illness as biographical disruption (Bury, 1982) in understanding the experiences of people with long COVID, though seldom considering young adults specifically.

Bury's exposition of illness as biographical disruption drew on clinic observations and conversations and interviews with rheumatoid arthritis patients. His construction of chronic illness as a major disruptive experience drew on Giddens' 'critical situations' in which 'day-to-day situations in routine settings ... are radically disturbed ... (e.g.) disruptions of the social fabric brought about by major events such as war' (Bury, 1982, p. 169). Key elements of Bury's original conception of biographical disruption have obvious relevance for people with long COVID. Chronic illness, he suggests, replaces the taken for grantedness of everyday life, with 'a burden of conscious and deliberative action', leading people to impose restrictions on their lives and withdraw from social relationships.

Bury's concept of biographical disruption has been extensively utilised in health and illness research. By 2013, around 900 papers referenced his key articles (Bury, 1982, 1991), variously supporting, challenging and extending his original conception (Locock & Ziebland, 2015). Some applications moved beyond chronic illness. For example, Owens et al. (2008) framed the 'shattered biographies and repair damage to their moral identities' following young men's deaths by suicide as 'tales of *biographical disintegration*' (p. 239), both for the deceased men and parents who needed to perform a 'two-fold reconstructive task' to make sense of their son's death and the 'destruction of their life's work as a parent' (p. 239) against a backdrop of 'moral accountability' (p. 241). Locock et al. (2009) examined biographical disruption in relation to motor neurone disease (MND), a condition 'at the boundary between chronic and terminal illness' (p. 1043). Their analysis focused not just on biographical disruption, repair, reconstruction and flow/continuity but also on '*biographical abruption*', which they described as encapsulating a common feeling that the diagnosis was a 'death sentence'; 'disruption implies disturbance and unwelcome changes, and "abruption" is intended to convey a sudden ending, literally a "breaking off"' (p. 1047). When chronic illness is remitting rather than terminal, people may experience '*biographical suspension*' (experienced as 'suspended "wellness," suspended self or suspended futures') whilst their lives are 'on hold' or paused when symptoms such as pain prevent life 'as normal' (Bunzli et al., 2013). In relation to young people with mild to moderate asthma, Monaghan and Gabe discuss the concept of 'biological contingency', when chronic illness is an "'only sometimes" problem' (Monaghan & Gabe, 2015), and Saunders (2017) introduced the concept of '*normal recurrent disruption*' for young adults with inflammatory bowel disease.

Other authors have considered illness at different life course stages. For example, Williams (2000) discussed the notion of 'normal illness' as '*biographical continuity*' in older adults and Sanders et al. (2002) reported older people's accounts of painful and disabled joints as both a 'normal and integrated part of their biography' (p. 247) and a source of biographical disruption. In relation to adult-onset asthma or arthritis in young people, Kirkpatrick et al. (2018) framed illness as a '*biographical paradox*' and an 'untimely breach' when the onset of chronic illness was perceived as an 'age-dissonant life event' (p. 732), whereas Williams et al. (2009) questioned the relevance of the concept of biographical disruption for children and young adults who had had cystic fibrosis all their lives. In understanding why some people who had had solid organ transplants at various ages construct this experience as biographically disruptive whilst others do not, Engman considered embodiment to be the foundation of biographical disruption, arguing that illness experience inevitably includes the '*impact* that illness has on people's ability to participate and enact the life that they were immersed in prior to becoming ill'. Physical impairment from an early age, she argues, 'is always already part of [people's] embodied sense of the world', whereas gradual, previously unnoticed bodily changes that reach a threshold or sudden onset of symptoms, 'pierce a subject's flow of activity [and...]

manifest as biographical disruption' which prompts people to re-evaluate their future which is rendered 'necessarily uncertain' (Engman, 2019, p. 126). She suggests that this may be experienced differently if people's lives are 'already in flux', such as at the beginning of retirement when the impact of illness may be lessened. By contrast, others argue that the experience of chronic illness may be particularly challenging during young adulthood. As Saunders (2017) notes, this life stage often involves significant life transitions and periods of substantial change—such as leaving the parental home and starting college, university or new jobs or careers—which present particular challenges in managing a chronic illness. Yet, despite recent studies of biographical disruption at the 'younger end' of the age spectrum (e.g. Monaghan & Gabe, 2015), few have explored young adults' experiences of chronic illness through the lens of biographical disruption (Saunders, 2017).

Here, we question whether existing developments of the concept of biographical disruption fully encapsulate the experience of young adults who were living with long COVID between 2020 and 2022. Whilst the scientific understanding of long COVID continues to develop, the young adults featured here acquired long COVID at a time when its natural history, optimal treatment and likely prognosis were poorly understood, and the very existence of the illness was often contested, in medical contexts and wider society (Maclean et al., 2023). We also note the uniqueness of experiencing this illness during the historical emergence of a novel virus whose societal and economic impact was documented globally as a *collective* disruption through news and social media. Thus, the paper seeks to extend the concept of biographical disruption in two main ways. First, it focuses specifically on young adults with long COVID in the early years of the pandemic (2020–2022), most of whom were previously healthy, showing the changes and challenges long COVID inflicted not just on their daily lives and identities but also on their (presumed) futures at a life stage when adult biographies are forming. Second, although there have been appeals to consider biographical disruption in its *social* context, most studies have focused on individualised biographies largely divorced from the broader social context. For the young adults in this study, the societal context was inescapable; their own experience of this novel illness occurred at a time of global focus on COVID-19 and disruption to people's lives, yet when there was no evidence base on the likely natural history of long COVID.

METHODS

Participants were young adults, who became ill with long COVID aged 18–30 years, sub-sampled from two linked UK studies—one on long COVID in adults (CSO—COV/LTE/20/04) and the other on the impact of long COVID on families (NIHR COV-LT2-0005). Whilst definitions of 'young' adulthood are somewhat arbitrary and vary, culturally and historically, here, we have broadly followed the definition used in recent UK studies of chronic illness at this life stage (Polidano et al., 2020; Saunders, 2017).

Data collection and sampling

Ethics approval was granted by Berkshire Ethics Committee (Ref 12/SC/0495). Interviews ($n = 15$) contributing to this analysis were undertaken online between May 2021 and July 2022. Sampling within the 'parent' studies aimed for maximum variation (Coyne, 1997), including diversity by region, occupational social class, ethnicity, gender and age. Table 1 shows their

TABLE 1 Participant characteristics.

Name/ pseudonym	Age at interview (month/year)	Gender	Self- described ethnicity	When developed COVID	Employment status prior to COVID	Living circumstances at interview
Ben	28 (May 2021)	Male	White	March 2020	Employed	Living with partner
Charles	30 (May 2022)	Male	White	March 2020	Employed	Living with parent(s)
Charlotte	29 (November 2021)	Female	White	October 2020	Employed	Living with partner
Christian	28 (March 2022)	Male	White	March 2020	Employed	Living with partner
Esther	26 (October 2021)	Female	Jewish	January 2021	Employed	Living with parent(s)
Faatimah	20 (June 2022)	Female	Black	March 2020	Student	Living with and supported by friends
Felix	22 (June 2022)	Male	White	December 2021	Student	Living with parent(s)
Hannah	21 (June 2022)	Female	White	July 2021	Student	Living with parent(s)
Jessica	23 (June 2022)	Female	White	December 2021	Student	Living with parent(s)
Kathryn	22 (May 2022)	Female	White	October 2021	Employed	Living with parent(s)
Lucy	32 (May 2022)	Female	White	March 2020	Employed	Living with parent(s)
Megan	26 (November 2021)	Female	White	July 2021	Employed	Living with parent(s)
Michael	22 (May 2022)	Male	White	Early 2020	Student	Living with parent(s)
Xanthe	26 (May 2022)	Female	Greek Cypriot	December 2020	Student	Living with parent(s)
Zoya	23 (July 2022)	Female	Pakistani	Late 2020	Student	Living with parent(s)

ethnicity and employment status and their age at (and date of) interview and when first ill with COVID-19. Six identified first being ill with COVID-19 in the first quarter of 2020 and three in the last quarter of 2021. Participants all discussed their experiences from the time they first identified as having COVID-19 up to the time of their interview. Some remained incapacitated by their symptoms, and none had returned to their state of health pre-COVID, although a minority detected some potential signs of improvement. All interviews were conducted by health social scientists with extensive experience of qualitative research.

Recruitment routes included social media, clinicians, support groups and snowballing. Interviews were audio/video-recorded according to participant preference and typically lasted 60–90 min (range 50 min to 3.5 h); some were conducted over multiple sessions if the participant preferred (e.g. due to fatigue). The first part invited participants to relate their narrative about how they became ill and how long COVID had affected their lives. The second part used semi-structured topic guides. Recordings were transcribed verbatim. Participants could review their transcript and indicate any sections they wished to be removed and choose whether they wished to be referred to by a pseudonym or their own name in study outputs.

Data analysis

Transcripts were checked for accuracy, further de-identified (e.g. removing place names) and imported into specialist computer software (NVivo) for organising textual data for coding/analysis. Discussion amongst the authorship team continued throughout data collection and analysis. In a multistage analytical approach, the interviews were first independently analysed and coded by experienced qualitative researchers using a thematic approach for each study. Predominant themes which structured participant experiences were identified and discussed amongst the authorship team and the advisory groups of the constituent studies (which included people with lived experience of long COVID) (see www.hexi.ox.ac.uk/Long-Covid-in-Adults and www.hexi.ox.ac.uk/Family-experiences-of-Long-Covid for details on predominant themes).

Second, iterative author discussions around biographical disruption led to a decision to focus on young adulthood, as young adults had received little attention in articles on long COVID. The transcripts for the young adults were repeatedly revisited and recoded (by KH) using the theoretical lens of biographical disruption. Refinements to the approach and the line of argument were informed by further discussions amongst the authorship team, which included qualitative sociologists of health and illness who were familiar with the evolution of the concept of biographical disruption and a lived experience co-author; emerging literature on experiences of long COVID; and relevant papers on various manifestations of the concept of biographical disruption. Interview extracts were selected to illustrate key themes.

RESULTS

Participants ($n = 15$) were aged 18–30 years when they first reported COVID-19 symptoms (in 2020 or 2021) (Table 1) and aged 20–32 years when interviewed with ongoing long COVID symptoms. At the time of the interview (in 2021/2022), participants all self-identified as having long COVID or indicated that they had had ongoing symptoms for more than 3 months following COVID-19 infection; several had been infected before tests were readily available outside clinical settings to confirm exposure and before vaccination was first offered to healthy people in their twenties. The minimum time between infection with COVID-19 and interview was 4 months, but several described their experience of symptoms over a period of 1–2 years. Most participants were female ($n = 10$); four reported their ethnicity as non-white; seven were studying and eight were employed when they first became unwell with long COVID. Participants lived in different parts of England and Scotland during their illness; one had returned to his parents' home elsewhere in Europe by the time of the interview.

We consider the impacts of long COVID on these young adults' lives in relation to two themes which pervaded in their interviews: the changes and challenges long COVID had brought to their day-to-day lives and identities; and the suspension and disruption of their presumed futures. We also illustrate how their experiences are recounted against the oscillation of COVID-19's wider societal disruption which they felt sometimes rendered their illness invisible or disputed.

Moving back—Changes and challenges to young adults' lives and identities due to long COVID

Most of these young adults reported being very healthy before contracting COVID-19. Ben was *'fit and well and healthy... playing rugby... active... living a normal life'*. Charlotte described her family's lifestyle as *'really outdoorsy'* and active. She said *'I wasn't ever poorly before. I've never been ill...'*. Felix described himself as *'a 22 year old with no prior illness, who is fit and has really a healthy life'* and said doctors he had seen were *'pretty shocked'* by his illness, because of his youth, gender and prior fitness. One had reportedly voiced preconceptions about who might be a 'candidate' for long COVID:

it will go away eventually because I'm, like, a young, fit guy ...like, I'm not [a] depressed housewife. And, like, he basically implied that Long COVID you only get if your character is weak or, like, more emotional, which I think is pretty shocking.
(Felix)

The few participants who had previously experienced mental or physical illness had largely been able to continue with their lives despite their prior conditions, except Christian who was *'just like sick all the time'* with Lyme's disease in 2018, although *'not so bad that you couldn't carry on'*. Charles' 'mild' asthma had not stopped him from being *'fairly fit and fairly active'* and in 2018 he had taken to running *'like a duck to water'*. Similarly, Lucy previously did gymnastics and danced competitively despite having asthma and, before long COVID, Jessica had *'managed to get to a place'* where she *'knew how to deal with'* the anxiety and depression she *'struggled with'* earlier in life.

Participants' narratives conveyed the 'normality' of their lives before having COVID-19. For example, Zoya said she would:

go out with friends, meet friends, just go out in general...I'd like to go to different places, eat out... that kind of stuff... normal like just meeting up... socialising... this was a huge thing that before Covid I would, you know, I would socialize quite a fair bit... a normal amount as people would.
(Zoya)

Their narratives portrayed them as motivated (*'always been a motivated person and wanted to achieve well and stuff'* [Faatimah]), active, engaged (*'I studied and enjoyed it... it made up a huge part of myself'* [Felix]) and even driven. For example, Hannah related how *'the other person I was before... would do everything... I'd push myself so much, "if I'm tired I don't care, you're still doing it"'*, Charles described his 'high octane' pre-COVID lifestyle, and Michael listed activities he previously enjoyed but could no longer do:

[I] tried to pack as much into my life as physically possible. Was very active, very much liked having lots of different things going on... there was very rarely an evening where I wasn't doing something. And I loved it... I thrived off of busyness... that kind of high octane ... doing all these things all at once and the thrill of just, just doing, doing, doing.

(Charles)

I used to like, for example, go paddle-boarding... with my friends. I couldn't do that now. Playing tennis with my friends. I can't do that. Going for a run with them. Going for a walk with them. Anything like that, can't do it. So, all I can really do I guess with my friends is sit in the garden and distance from them.

(Michael)

Michael's narrative not only included this itemisation of lost, previously shared physical pursuits with friends, but illustrates well how these young adults' long COVID symptoms profoundly disrupted their ability to continue with their lives. Despite saying he was 'a bit lucky' to not be younger when he developed long COVID, Michael described its 'really extreme' impact on his life and medical training:

the impact it's had on me it's really extreme. I used to do a lot of exercise and really enjoyed it. I obviously can't do that. I haven't been for a walk for a year. Yeah, so, it's pretty extreme impact and the PoTS¹ is a big impact as even sitting up for too long can really cause exacerbation and symptoms and tachycardia [rapid heart rate] for the rest of the day and difficulty sleeping and palpitations and boredom... I haven't been under financial pressures... I'm really grateful and lucky for that. I don't really have stress in terms of I don't have any responsibility really... In some ways, the fact that it's happened at this stage of life could be, you know, could be considered a bit lucky... But the loss of my [University] course and the vision of what life kind of should be like for me; that, that's the most difficult thing.

(Michael)

Others provided similar narratives of being physically and/or mentally unable to carry on with even the most mundane aspects of daily life, sometimes being bed-ridden, wheelchair-bound or confined to the sofa for months, in pain or physical distress and unable to concentrate or think clearly because of 'brain fog'. Their symptoms' severity, unpredictability and all-pervasiveness rendered huge changes to their lives. Charles described his 'shock' when 'everything had to stop... it's been a huge shift in my lifestyle'. Hannah said, 'I want normality, I want my old life back where I can... just like be able to have fun and not sit there worrying I'm going to throw up... [or] get poorly... I want that part of my life back, like I miss that part of me a lot; it was fun'.

Their constellations of long COVID symptoms thus disrupted these young adults' lives, destroying their prior 'normality' and identities. Faatimah recounted the 'whole challenge' to her sense of self of not being able to do everything she could do before her illness ('My normal self wouldn't have lain in bed all day... You'd still get up or go for a walk'). She, like others, struggled to come to terms with her changed capacity:

it's a struggle with feeling also the mental struggle of just knowing... your old capacity and not just being able to fulfil that, and it's still hard... I mean, obviously now, I'm accepting my new self more, but it's still hard sometimes... [For example] doing an exam... I just don't have the capacity or brain space to really effectively answer.

(Faatimah)

Participants described every aspect of their lives as affected. Those who were students had had to suspend or extend their studies, falling behind peers. Those who were working had to give up, amend or take long absences from their work, threatening their identity and financial security. Felix said, *'my whole image of myself [is] basically destroyed'* and Zoya described feeling *'older than I am'*. She previously saw herself as *'a big person... into sort of decorating, interiors, art, that sort of thing...that requires a lot of sort of... that kind of energy'*. She said it was *'honestly... quite devastating'* that she could no longer do these things. Participants' limited energy or capacity for their social life opened a gulf between them and their friends:

it's been quite difficult... I was very much the instigator and the organiser of my friendship group and now I'm not because I just don't have the capacity. So, it's really hard because our lives are so different now... they've all got their own homes and some of them have children, whereas I've been back home. So, the gap is just so huge. They've tried very hard and been very supportive. But I've also had them get very upset when they see me and say, "I miss my friend." And that's hard because I'm here, I'm still here. "You are talking to me, but you're telling me you miss me." So, they've had to get their head around it and kind of change the things that we can do... it's just a lot of learning and adjusting for everybody.

(Lucy)

Participants who had been studying and some who had been working often returned to their parental home. Whilst they expressed gratitude that they were lucky enough to have a family to care for and house them, their narratives suggest this was a difficult, 'backwards' step, reflecting both their own expectations about the biographical direction of travel (transition) towards full independence, alongside perceived societal expectations about life course trajectories, which often failed to keep pace with increasing trends for young people to live at home for longer. Charles said, *'I would joke at the start, as if I'd **regressed back** to being 12 years old again, in terms of what my parents were doing for me'*. Lucy had been *'fiercely independent'* and *'travelled quite a lot'* by herself but moved back after struggling for months, unable to shop or cook for herself, *'stuck in'* her upstairs flat with *'one thing after the other because my immune system was just so weak'*. She described this as *'a really difficult decision because I tried that whole year for my flat'* but she had needed considerable help with frequent hospital appointments and day-to-day care, such as bathing. She said the physical contents of her life were stored away, in the hope she could use them in future:

...all of my stuff moved back in and once I had my own kitchenware, things like that... all kind of went into the loft in the storage for we hoped one day when I can be independent again... so I have to kind of move my whole life back in again and that was a big task... such a huge change going from... running my own home to really relying on all of them... it's just been quite a shock and quite difficult to adapt to...

you don't expect to kind of be **put back** into your childhood home all over again. And so, there was a lot of emotions attached to that... not only moving home, but not being able to do anything for yourself as well.

(Lucy)

Charles also was *'very reluctant to **move back** in [with parents] because I had just left. I'd just flown the nest and I didn't really wanna be boomerang kid and come back, again'*. For Kathryn, losing her independence was the *'biggest thing'*, Michael described almost returning to his adolescence and Felix related the shock of needing his parents' care again:

I've gone from living by myself, working by myself, travelling by myself to literally needing help to like get into a shower... you lose like that spontaneity of just being able to do things... I don't know how to word it. It's just, yeah, just a part of you kind of like dies a bit.

(Kathryn)

I don't want to be at home. I want to be at university and progressing... [it's] difficult to see those around you progress and you're kind of static, almost kind of living like you did when you didn't, like secondary school you know, at home with your parents.

(Michael)

...pretty shocking at first. Like, I come back sick and need care... before I lived basically on my own. I got a scholarship and I worked to finance my studies... it's stressful for both of us because for them [parents], emotionally, they don't know [what'll happen]... they want to see me succeed and now I'm here, can't finish my studies, no idea what the future is going to look like.

(Felix)

Lucy also referred to implicit cultural repertoires of (irreversible) progress to independence in adult life as she described the impact of her illness and return home on her mother who she said was *'grieving for me even though I'm still here, because it's the loss of the person that I was. She didn't expect to see a 30-year-old coming home and caring for her, and seeing me in a wheelchair for the first time. It's all been a lot to process'*.

As well as the loss of self and this violation of a presumed path to adult independence, the extent of people's symptoms had practical implications, for example, on family finances or space, as Lucy described:

We've been lucky that an OT [occupational therapist] fitted the adaptations around the house. But I still haven't been given a referral for a wheelchair service, so I pay for the wheelchair hire... I'm on PIP [Personal Independence Payment], which has been a huge help because that money just goes directly to the chair. And without the chair, I was literally stuck in the house because I couldn't get out on my own. So, it's created such independence... I've just given up my car. I couldn't get out of a contract, so I had to keep paying for it. I'm very lucky I've had savings 'cos I was working full-time. It was the same with my flat, I couldn't get out of flat for so long as that had to be paid for even though I wasn't there. So, a lot of my savings that I'd worked

hard for has gone on living. I say living, but I'm not using these things, the flat I wasn't living in, a car that I can't drive... But now we're looking at a hoist but that will cost more money and getting the wheelchair in and out of the house, I can't do that on my own.

(Lucy)

In this sample, the young adults who were already living with their partner before getting COVID (Ben, Charlotte and Christian) had remained in their homes, although the two who had children faced the loss of their working identity alongside their identity as the kind of parent they wanted to be. Christian said there was '*no easy fix*' in choices to prioritise '*what you can do and still survive*':

...you strip away all non-essentials, whether that means social interactions or type of work activities... you've really got to work out what is most important to you and how to prioritise that. For me, that was being able to spend quality time with my wife and daughter but that's meant that my professional life has had to suffer. You know, I used to have a career; now I'd say I have a job. It's a good job, but it's not a career... less pay, quality of life, that sort of thing...you've got to decide for yourself and try and make it work, right, within what's realistic.

(Christian)

Charlotte, who remained very unwell since contracting Covid, described '*really tough times*' as her family life changed and her symptoms were too severe to continue working. She encapsulated these multiple identity losses by saying, '*I don't feel like I am that me who I was before anymore*'. Her husband had taken on almost all her parenting roles; she described how her role as a '*normal mum*' and her close connection with her children's lives had changed:

If they need somebody in the night, they don't shout 'mummy' anymore, they shout 'daddy'. They don't rely on me the same, which is really sad... It's for everyday things... The school run has really bothered me because you don't realise how much you're just in the know because you go to school... You know who they're playing with. Such things like, if they've had a bump, bumped their head at school, they tell the parent, the person who picks them up. I don't know these things anymore about them... We can't go to any family gatherings because I can't stand noise and lights... I've got to be sat down or in the wheelchair, which I find hard mentally... when I'm in the house I don't notice as much that I can't do the normal, I'm not a normal mum. If I go somewhere in the wheelchair and I realise how much I can't do so we can't, like, go to the zoo or the park. So, their dad does a lot of that bit, that sort of stuff with them now without me.

(Charlotte)

Such poignant descriptions of these young adults' changed lives illustrate both implicit cultural narratives about life course progression in young adulthood and how the 'normal' course of their daily lives had been profoundly disrupted. Their core identities, not just their sense of who they were but who they hoped or expected to become, had been fractured. They felt 'out of step' with peers and out of time, simultaneously both older than their peers (in their reduced physical capacity), yet also younger (in their need for basic care from parents and others). They found

themselves in an unexpected place in their adult lives: not progressing; dependent; unable to work, study, be physically active and have a ‘normal’ social life; and unable to care for themselves or others. As Ben said, *‘I now have a long-term health condition that’s impacting me every day. For a twenty-eight-year-old active man, that’s not something I’ve ever had’*. Faatimah suggested an extra toll of being a young adult with long COVID: *‘even when you’re healthy you compare yourself to people all the time. You’re at a stage of life where people are doing so many different things and you just think everyone’s better than you’*.

Thus, these young adults’ narratives showed how all but one of those who were not already living with a partner had had to return to their parental home, and whilst grateful for family support, in life terms they felt they were taking a step backwards, returning home in a decade of life when they, their peers and wider society expected continuing progression to full independence. Whilst these experiences share some similarities with the biographical suspension described in literature about people with other illnesses, the language used (*‘moving back’*, *‘regressing back’*, *‘putting back’*) conveyed a strong sense of **reverting** to earlier life stages which could be characterised as *‘biographical retrogression’*. In the next section, we discuss the additional uncertainty about whether these unwanted changes might resolve, allowing them to regain not only their former young adult lives, both in terms of where—and who—they had previously been but also their hoped-for (or presumed) future before long COVID.

Disrupted futures in the context of a nascent condition with no established natural history

Because so little was known about the natural history of long COVID, given its recent emergence, these young adults had to find ways to manage the shattering of their previous lives without knowing what the likelihood was of a full recovery. Scientific uncertainty about the realistic course and extent of recovery left participants in a liminal state, beset with worries about their future. This could pervade every aspect of life:

I worry that I’m not gonna get better and it’s gonna be some sort of autoimmune condition and I’m not gonna be here for [my children]... I worry that I’m gonna stay as I am and never be able to be part of their lives. I worry me husband’ll want somebody else because you know, I’m poorly and not bringing a lot to his life, but stress. So, yeah, lots of worries. Worries financially. What am I gonna do when my pay stops and I worry I’ll lose my nursing qualification if I can’t get back soon... I’ve done coming up 18 months [sick leave]. So, lots of worries.

(Charlotte)

Christian, another parent, reflected on how his family aspirations had been affected:

if we hadn’t got pregnant [before he became ill], we probably would have stopped trying for a child... if we had aspirations to having a larger family, that’s you know, completely untenable, well it is, it can’t happen.

(Christian)

He said there was *‘no way’* he and his wife could *‘deal, as in, like, look after’* another child. He spoke about how *‘of course’* he would *‘like to be who I was before I had long Covid, very much be*

the father I envisioned I would be... To be honest, I try not to think about it because I don't know how hopeful I am'.

Others voiced concerns that *'it's never going to get better'* (Hannah). Michael described pervasive uncertainty in his life since becoming ill: *'once Long Covid hits... nothing is certain. I wasn't expecting this to happen, happen to me. Imagine what could happen next'*. Jessica had not had an *'exact plan'* for her future before long COVID but had been planning to work part time and *'take some time out'* to travel before applying for jobs to start the following year. Now she felt *'everything'* had *'gone out the window'* and she could only plan a *'month at a time... see how, where I am there then'*. Whilst Ben was *'finally somewhere that... I can see the light at the end of the tunnel'*, Felix summarised the depths of his concerns for his—and his parents'—future:

...to be honest my whole world view like just broke after I got Long Covid. You know, you get an illness and like the health system, most of the doctors don't take it seriously... I have no idea how my future will be. Maybe it will go away eventually, I don't know.... like the insecurity. My parents don't know if they have to care for me... they have saved enough money for both of them... They don't know if I'm able to work or do anything in the future... They may need to care for me... the long-term issue, it's like the big elephant in the room.

(Felix)

Michael expressed hope he would *'one day'* complete his medical training and use his experience of a lengthy, poorly understood illness to *'help and believe people, basically'*, but was unsure whether he would be well enough to resume his studies. Like others, he implied taken for granted possibilities had gone: *'I don't really look too far in the future anymore... as I would've done. I would've been like what specialty am I gonna go into? Where am I gonna live? I can go to Australia, you know, all these kind of things'*. Similarly, Faatimah explained being unable to apply for jobs she had wanted because of the interruption to her study. Her comment that she was *'not the same person... [nor] any other person'* suggests her experience of long COVID was dehumanising:

some grad roles want to see that you've graduated... the grade and the degree certificate, and I'm not going to have that. And so there's some roles I can't apply for... it is frustrating... obviously, as a young person, you feel like ...part of your life is lost, like I didn't really get a normal university experience and I might not get the job I want... And I would also just say that just being realistic in ...remembering my capacity and not comparing myself to a version of myself that doesn't exist... like that person doesn't exist, and so I have to be realistic... I think just not comparing yourself to other people is just really important because you'll drive yourself crazy – you're not that same person that you were and you're also not any other person as well.

(Faatimah)

Others conveyed the difficulty of feeling they lagged behind peers. Jessica said her friends were *'living their best life'* whilst her future had stalled:

...obviously for my future... it's setting me back quite a way, like lots of my friends are moving out... I can't see myself being in a position that I'd be able to do that ... it's

a bit sad... I'm seeing everyone like live their best life like in apartments with friends and I just don't know at what point I'll be able to do that.

(Jessica)

Xanthe too *'would have moved out [of parents' house] by now'*, without long COVID. She considered it *'a unique position'* to develop a chronic illness *'out of the blue'* in one's mid-twenties (*'you're just ready to leave the nest and you're stuck'*). She elaborated on her disrupted plans and dreams:

I had savings... a really great job. Like the starting salary was phenomenal... I was [just] 25 when I first caught it... I was ready to move out. I was financially ready. I was mentally ready. I was physically ready.

(Xanthe)

When thinking about her future, she said *'most of the time I feel terrified [not knowing where I'll be] health-wise, financially, career-wise.'* Nonetheless, like Michael, she described feeling 'lucky' she was not younger when she developed Long Covid: *'I'm lucky I've been able to get my qualification, so I'm not sort of a child suffering trying to even get through school... I'm sort of stuck...[but] I can't possibly be like this forever... that's what I try to remember'*.

Kathryn thought, having had to give up her previous career, she *'probably'* would not have a job in the coming months and Hannah worried whether she would be well enough to take up a valued opportunity (*'I'm a 21-year-old girl who has just finished a neuroscience degree and has landed a really good job... that could potentially like change my future'*).

Whilst these young adults' experiences of shattered daily lives and disrupted (presumed) futures may have commonalities with people developing other disruptive health conditions in early adulthood, acquiring their illness early in a new global pandemic added to their intense state of liminality due to a unique set of factors. First, the recent emergence of COVID-19, and in particular, the absence of any scientific understanding about who might develop long COVID and the extent and timeframe for recovery, left these young adults unable to realistically assess whether their biography was 'just' suspended or stagnant, or more profoundly and permanently altered. Secondly, in the initial stages of the pandemic, whilst COVID-19 was high on the societal agenda in an unprecedented global context, long COVID (especially in young adults) was not. During the first months of the pandemic, discussion of the virus and a pervasive discourse of the seemingly 'random' risk of death or hospitalisation meant the vast majority of the general population accepted profound societal and personal disruption for a while at least. As Esther said:

...throughout lockdowns... you've watched the news at any given hour and they would have the most up to date statistics on who, how many people had Covid... [or] died that day from Covid. And seeing those numbers increase and increase and increase and increase, I think showed the severity... it wasn't just statistics on a screen. You know, it wasn't like it was something that was happening on the other side of the world. You know, everybody knows somebody or everybody knows somebody who knows somebody ... who's died because of Covid or who's been in intensive care... you actually have the personal stories to go along with that and which is why I think that those statistics on the screen were actually really impactful... it was just happening to everyone and anyone and people who were really

healthy and had always looked after themselves and had never smoked and had never had any health problems or whatever. It, it just seemed to be happening to lots of random people from lots of different random walks of life.

(Esther)

Yet, whilst COVID-19 had seemed omnipresent in the public consciousness, their own illness felt invisible, because healthy young adults (and also children (Wild et al., 2024)) were persistently portrayed as very low risk for any lasting consequences of infection. Charles recalled, how months after first contracting COVID,

...it was just a shock and a horrible feeling that I was still unwell that we didn't even [know], the, there is no such [thing] as Long Covid. There, there, there was no real popular perception. I remember being at a party in February [2020] and speaking to my friend who is a doctor and said I was worried about catching it. And she said, "Oh, don't worry, you'll be fine. You, you're a young guy. You're not getting up on a ventilator. Don't worry about it."

(Charles)

Thirdly, during the disruption to social interaction consequent on various lockdown measures, most people with long COVID were not visible to, or visited by, others outside their household, as they might have been when ill in non-pandemic conditions. Jessica said, *'it's all behind closed doors. People haven't seen how unwell I've been. I think a lot of people were in shock when they heard, you know what 2020 looked like for me'*, and Faatimah said in lockdown *'it was really kind of easy to disguise my symptoms because everyone was at home or sleeping the whole day'*.

At times the concurrent societal disruption and widespread discussion of COVID-19 could normalise or downgrade the consequences of their illness or alternatively heighten its impact. For example, Christian acknowledged it was a *'weird time'* because *'lockdowns were... going on for ages, so part of me I was like "Ah well, it's probably the situation getting me down or making me feel weird"'*, but also said it was *'really hard'* to be so *'tired and fatigued... particularly in the lockdowns when people haven't been able to help because they've literally, you know, not been allowed to come round; that's been very difficult emotionally'*.

However, as the months passed and lockdowns eased, people with long COVID could feel not only poorly understood but even wilfully marginalised as people in general were perceived to want to *'live their lives'*, whilst those with long COVID struggled with a (*n* often disputed) consequence of an otherwise highly visible novel virus. Xanthe said:

there's no understanding.... in the general public's mind, Covid is over, unless you have been affected by Long Covid, or you know someone who even died from (Long) Covid, or was very close to dying... [E]ven my siblings... most of my friends, they don't wear masks on the Tubes anymore... they just don't care. Because the Government hasn't said, 'We need to protect people with Long Covid,' when the Government was saying, 'You need to wear a mask,' ...most people followed the rules, generally speaking... [And now] the Government have said that 'Covid is over', essentially the, the general public... I get it, you know, they want to live their lives.

(Xanthe)

Similarly, Ben described it as ‘*very challenging*’ and ‘*quite disheartening*’ to see young people in the media disputing the need for preventive measures, ‘*saying... it’s not needed, this is just a cold. It was very hard when you’re on the side-lines with Long Covid ... I could never think that this would happen to me or to anybody that I would know, like it’s that much of a change in their daily life you wouldn’t think this was possible*’. He too recognised the strength of people’s desire to return to pre-COVID times:

... people want normal back, whatever, whatever normal will be, people are craving that kind of... people want contact with people ...to go for a meal together without it being masks to walk around with, glass barriers between tables... everyone just wants to get back to, to not having to shout through glass to order a coffee.

(Ben)

DISCUSSION

These narratives of young adults living with long COVID in the early 2020s show profound disruption to their daily lives, identities and (presumed) futures. They are redolent with descriptions of the suspension of life as they knew it before contracting COVID-19, alongside deep uncertainty about when or to what extent they will recover. Their narratives of living with long COVID resonate with key elements of Bury’s original description of chronic illness as biographical disruption. Perhaps most pertinent are that (i) the uncertainty underlying ‘most forms of disablement’ (p. 168) involves fluctuating symptoms and uncertain outcomes; (ii) the structure of daily life is disrupted and common sense boundaries are breached; (iii) attention to bodily states becomes heightened and conscious; (iv) there is a ‘biographical shift’ from perceived normal trajectories and ‘relatively predictable chronological steps’ (p. 171); and (v) access to medical knowledge can be double-edged, offering knowledge of their physical state and its causes but an understanding of the limits of medical intervention. For many, the restrictions on daily life imposed by their symptoms led to a bewildering loss of self (*‘my whole image of myself is basically destroyed’*; *‘a part of you dies a bit’*; *‘I don’t feel like I am that me who I was before’*, *‘the other person I was before’*) reflecting the ‘fundamental form of suffering’ Charmaz describes as people ‘observe their former self-images crumbling away’ (Charmaz, 1983, p. 168), as chronic illness restricts their lives and social interaction, and may lead to a sense of being discredited and a burden. Because of the recency of long COVID as an illness category, the lack (as yet) of any reasonable expectations about recovery, grounded in the experience of others, left these young adults in a heightened state of liminality (*‘you’re not that same person that you were and you’re also not any other person as well’*).

A key strength of our study is its focus on an understudied group experiencing a novel condition, interviewed relatively soon after the emergence of a new virus globally. To our knowledge, this is the first study to examine experiences of young adults with long COVID specifically, and one of the first studies to examine chronic illness as biographical disruption in young adulthood (Saunders, 2017). Another strength is the use of rigorous methods of data collection and analysis. As acknowledged elsewhere (Maclean et al., 2023), the nature of illness narratives is that they are ‘honed’ (Rushforth et al., 2021) as people repeatedly ‘rehearse’ their illness, for both medical and non-medical audiences, as they try to make sense of their illness and the support they need. We also acknowledge that people who choose to take part in

qualitative interview studies may not be representative of the wider population in various ways, and their narratives may differ from those told in other contexts. We also acknowledge elsewhere (Maclean et al., 2023) that interview accounts are to some extent co-created by the narrator and interviewer at a particular ‘moment in time’. Our own interests will also have influenced our reading of the data; most of the authors who led the analysis have a longstanding interest in how people experience illness and the evolution of the concept of biographical disruption. However, another strength is having a lived experience co-author who was able to validate the presentation of the analysis, recognising its authentic feel for him and his peers.

The fact that these are the stories of ‘vanguard patients’ (Maclean et al., 2023), who developed long COVID within the first 2 years of a pandemic caused by a novel virus, inevitably means their imagined futures and lifetime trajectories following long COVID are not just unknown to them but unknown to science and collective human experience. In these early stages of the pandemic, almost all potential pathways to recovery were untrodden or at best truncated; the prospect and timeframe for recovery was unknown to them as individuals and to science. This may in part explain why their illness experiences do not fully conform, we argue, to other reconceptualisations of biographical disruption. Too few had experienced sufficient recovery for *biographical flow* or *continuity* (Williams, 2000) to be salient. Evidence of strategies used by people with neurological conditions—avoidance and denial, cognitive reframing and strategies to ‘reconnect to identity in the past’ (Roger et al., 2014, p. 1)—were largely absent. Whilst our participants’ narratives clearly suggested that experiencing an extended period of debilitating illness in their twenties and early thirties was an ‘untimely breach’, their illness was not simply a *‘biographical paradox’* as conceived by Kirkpatrick et al. (2018) (a childhood disease in adulthood or a disease common in older adults in early adulthood) but had echoes of the ‘liminality of being ... once again children’ as experienced by young men with traumatic brain injury who returned to their parental home for basic care (Webb, 1998). They also differed from the young adults living with a stoma in Polidano et al.’s (2020) study who experienced *‘biographical renewal’* following the ‘liberating effects’ (p. 342) of surgery and studies of people with chronic illness in adolescence and very early adult years, such as Monaghan & Gabe’s (2015) study of young people with mild to moderate asthma or Sanders et al.’s (2019) research on young people with type 1 diabetes. Both these studies involve young people who have illnesses which have a strong scientific evidence base underpinning clear treatment and symptom management pathways; in some senses, therefore, they can be characterised as ‘normal’ illnesses (Williams, 2000) whilst long COVID in 2020–2022 absolutely could not. Also, these two studies mainly involve young people who have had several years since diagnosis (in childhood or adolescence) to learn ways to accommodate their illness, albeit whilst navigating changes and challenges that accompany the transition to adult life. Our participants by contrast had had only months, at most 2 years, to navigate ways of living with the profound and often sudden changes brought about by their long COVID. Yet, whilst in many ways their former lives had come to ‘a sudden ending’ (p. 1047), their experiences were also very different from people with a progressive, terminal condition (MND) and the associated *‘biographical abruption’* described by Locock et al. (2009), although participants’ experiences arguably share some similarities with the *‘biographical suspension’* described by Bunzli et al. (2013), entailing ‘suspended wellness’, ‘suspended self’ and ‘suspended future’. However, most of our participants have not yet experienced any real sense of recovery, and their future with a previously unknown disease remained suffused with uncertainty. Thus, they did not just describe the impact of long COVID as suspension or stagnation but also as a *backward* step in a decade of life dominated by a cultural script emphasising the expected passage from dependence to independence and

childhood towards parenthood, progression at work or towards a 'career', and a oneway 'flight' from the parental 'nest'. The reluctance that several described in their move *back* to their parental home, often even to the bedroom they occupied as a child or adolescent, leads us to suggest the term '*biographical retrogression*' may be more appropriate. The circumstances of the pandemic, which limited social interaction and increased social isolation, perhaps intensified this sense of stepping back into a more constrained environment. We acknowledge that, as young adulthood as defined here spans a decade when people make many changes to their lives, the form of *biographical retrogression* may differ in some respects for the minority of our participants who were living with a partner, with or without children. Whilst none of these three people returned to their parental home, they nonetheless conveyed a sense of a backwards step in their careers or as parents, but this potential distinction warrants further examination in future studies. Faatimah is perhaps the clearest anomaly because she managed to continue her studies thanks to living with very supportive friends who provided practical support, although she did speak about the impact on her course and future career prospects.

Another characteristic of being amongst long COVID's 'vanguard' patients is the unparalleled juxtaposition of the underlying cause of their own illness (infection by COVID-19) and a constant, pervasive media focus on humanity's global, imminent vulnerability to exposure to COVID-19 and its potentially fatal consequences. Hence, our participants, like others with long COVID, were negotiating their own individual biographical disruption caused by COVID-19 against the 'grand narratives' of the virus (as either fatal or 'serious' enough to require inpatient [intensive] care, or short, self-limiting and 'mild' [*like a cold*]). This juxtaposition is unlike other potentially fatal viruses, which were more geographically confined (e.g. Ebola) or had a socially differentiated transmission in the earliest stages of their emergence before the natural history, prognosis and effective treatments were established (e.g. HIV) or occurred before real time global news reporting was all pervasive (e.g. the twentieth century outbreak of 'Spanish' influenza).

Thus, during much of 2020 and 2021, their *own* disrupted lives occurred alongside whole-scale *societal* disruption stemming from 'lockdown' measures to contain COVID-19's spread; as the pandemic apparently ebbed, people with long COVID navigated their illness against an increasing public voice asserting that the pandemic was 'over'. In both contexts, albeit in different ways, their experience as young adults with long-lasting debilitating symptoms following COVID-19 infection was challenging and sometimes contested, as reported in other studies of adults with long COVID (e.g. Roth and Gadebusch-Bondio, 2022). Their narratives were more characteristic of the 'chaos' narrative genre described by Frank (1997) as less well received than the culturally preferred 'restitution' (in which illness is transitory and overcome) or 'quest' (in which 'gains' from illness are emphasised) genres. Whilst restitution and quest narratives may become more prevalent as more people recover from long COVID in future, in the early 2020s, the societal and political eagerness to 'return to normal' as quickly as possible (conceivably a *collective* restitution narrative in response to the negative experiences of the pandemic) or 'build back better' (conceivably a collective quest narrative, albeit short-lived) have perhaps intensified societal discomfort and unwillingness to accommodate the unresolved illness and severe disruption experienced by people with long COVID.

AUTHOR CONTRIBUTIONS

Kate Hunt: Conceptualization (lead); data curation (equal); formal analysis (lead); funding acquisition (lead); investigation (equal); methodology (equal); project administration (equal); supervision (equal); validation (equal); writing – original draft (lead); writing – review & editing

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CONFLICT OF INTEREST STATEMENT

The authors have no competing interests to declare.

DATA AVAILABILITY STATEMENT

All data available for secondary analysis are subject to appropriate permissions.

PATIENT CONSENT STATEMENT

All participants provided informed consent prior to the commencement of the interviews.

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ENDNOTE

¹ Postural orthostatic tachycardia syndrome, a condition that causes an abnormal increase in heart rate after sitting up or standing up, has been reported in some people with long COVID.

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