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Episodic disability and adjustments for work: the 'rehabilitative work' of returning to employment with Long Covid

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ABSTRACT

Long Covid is an activity-limiting condition that causes significant long-term impairment that can last up to one year or longer and impacts labour participation. 'Episodic disability' is an apt conceptual framework to comprehend the fluctuating impairments of those with Long Covid and the barriers they encounter when returning to employment. Drawing on 65 narrative interviews, conducted between 2021 and 2022, from three UK studies involving adults with Long Covid, this article demonstrates how participants experienced a 'spoiled identity', had their 'disability' status challenged due to existing in-between (dis)ability classifications and experienced their 'bodies-at-odds' with their working environment. The additional 'adjustment' and 'administrative' work of navigating disabling systems required participants to balance workloads to avoid relapse. Utilising 'episodic disability' demonstrates that current sickness absence, return to work and welfare policies are disabling and unfit for purpose, requiring participants to take sole responsibility for the additional 'rehabilitative work' involved in returning to employment.

Points of interest

- There is very little advice for people with Long Covid on how best to return to work. Long Covid is not yet officially classified as a 'disability' in the UK.
- People with Long Covid may have symptoms others cannot see and symptoms that vary. One day symptoms may be very severe and debilitating and other times they are less severe.

- People with Long Covid report sadness, guilt and fear about being unable to work as well as they had done before.
- Because Long Covid symptoms can be invisible to others and their severity is unpredictable, some people said they felt disbelieved about how serious their symptoms were and said that people at work did not realise they needed workplace adaptations.
- Sickness absence policies that classify employees simply as either 'able' or 'disabled' do not work for people with unpredictable illnesses that vary in their severity, like Long Covid.

Introduction

In March 2023, the Office for National Statistics (ONS 2023) estimated that 1.7 million people in the United Kingdom (UK) were experiencing ongoing symptoms for at least one year following a Covid-19 infection and 762,000 were experiencing symptoms for at least two years. Ongoing symptoms following a Covid-19 infection have been labelled 'Long Covid' and can involve over 200 symptoms (e.g. fatigue, post-exertional malaise, and cognitive dysfunction) that span across 10 organ systems and include unpredictable fluctuations, often triggered by physical or cognitive exertion in the majority (87%) of sufferers (Davis et al. 2021). People with Long Covid report that symptoms, such as fatigue, severely impact their ability to perform activities of daily living, including showering, cooking, and even watching television (Nielsen and Yarker 2023). With many people with Long Covid experiencing substantial, fluctuating impairment over 12 months, aligning with the Equality Act's (UK Government 2010) definition of disability, this article will use the Episodic Disability Framework (O'Brien et al. 2008) to illustrate the challenges of returning to employment in the UK with the undocumented disability of Long Covid.

Initial evidence showing how those with Long Covid tried to cope with disability at work found substantial shifts in their labour participation. According to the ONS (2022), economic inactivity has risen ten times among people with self-reported Long Covid in the UK, compared to those without Long Covid. Furthermore, a survey of those with Long Covid ($N=3,762$) across 56 countries found that of those able to return to work, nearly half of respondents (45%) had reduced their work schedules, compared to the period prior to disability (Davis et al. 2021).

Surveys with people with Long Covid conducted by the Work Advocacy Group, Trade Union Congress (TUC) in June 2021 ($n=3,296$) and March 2023 ($n=3,097$) suggest that reductions in labour participation are driven by discrimination and disadvantage. TUC (2023, 9) concluded that 'comparisons between the two surveys reveal how starkly [the treatment and support for employees with Long Covid] has deteriorated'. Comparing the 2021 and 2023

surveys, discrimination and disadvantage increased from 52% to 66% and the number of those not getting all or any workplace adaptations they requested, rose from 39% to 48% respectively.

Some qualitative studies have documented reduced employment capacity among those with Long Covid, while exploring the impact of cognitive impairment (Callan et al. 2022) and doctors' experiences of Long Covid (Taylor et al. 2021). However, few published qualitative studies on Long Covid have focused on return to employment. One such study (Lunt et al. 2022) using an online mixed-method survey analysed the work ability ratings of participants with Long Covid in the UK (n=145), finding that only 15% of respondents managed a full return to work and reported barriers included symptom unpredictability, managing symptoms alongside workplace demands and unhelpful workplace attitudes. Another UK-based qualitative study (Nielsen and Yarker 2023) exploring the return to work journeys of 12 workers with Long Covid found that participants undertook identity work to align their occupational identity with an emerging Long Covid identity. This alignment allowed participants to accept a new identity as a worker with limited working capacity. Despite drawing on sources of support from colleagues and managers to generate a sense of workplace belonging, participants had not achieved a sustainable return to work but were cycling between attempts to return and recurring sickness absence.

Additionally, an analysis of interviews and online forum discussions conducted as part of a mixed-method study with participants with Long Covid in Belgium, found that those with Long Covid experienced scepticism from employers and colleagues, resulting in a lack of workplace and welfare support (Kohn et al. 2022). More recently, Belgium, like more than 50 countries (though not the UK), has classified Covid-19 an 'occupational disease', providing workers with long-term disability associated with Covid-19 infection additional financial protection and compensation, as well as strengthening their claims for welfare and workplace support under the Equality Act 2010 (TUC 2023). The TUC (2023) assert an urgent need to investigate the experiences of returning to employment with Long Covid in the UK.

To address this call for research, we analysed narrative interviews conducted in the UK between March 2021 and July 2022 with people coping with continuing disability associated with Long Covid. Before detailing the methods used, we first outline two concepts used to frame the analysis and interpretation of the data: O'Brien et al. (2008, 2023) 'Episodic Disability Framework' and Cooper et al. (2023) 'rehabilitative-related work' undertaken by those with disabilities and chronic illnesses.

Episodic disability

O'Brien et al. (2008) derived the Episodic Disability Framework to capture the multidimensional, episodic experience of living with HIV, a condition

characterised by fluctuating periods of illness and wellness. As rationale for its development, they argued that existing disability frameworks did not capture 'the complex disability experience specific to HIV' and that 'a framework is important for adults living with HIV, health providers and policy makers to be able to adequately measure and address the disablement needs of this population' (O'Brien et al. 2009, 2). The Episodic Disability Framework includes: (1) dimensions of episodic disability (e.g. symptoms, daily activities, social inclusion, uncertainty); (2) contextual factors that influence disability, including extrinsic (e.g. social support, environment) and intrinsic (e.g. living strategies, personal attributes); and (3) triggers that exacerbate disability (e.g. changing medication, experiencing serious illness) (Boyd 2012; O'Brien et al. 2008).

The concept of 'episodic disability' has been used to understand experiences of other illnesses which fluctuate between periods of relative wellness and debilitating illness, such as multiple sclerosis (MS) (Vick 2012), chronic pain (Campbell et al. 2022), rheumatic diseases (e.g. arthritis, lupus), Crohn's, migraine, epilepsy, and mental health disorders (e.g. depression and anxiety) (Gignac et al. 2021). O'Brien et al. (2023, 1) argued that Long Covid can be described as an 'episodic disability' given participants experience their symptoms fluctuating along a continuum of impairment that involves 'ups and downs', 'flare-ups' and 'peaks' followed by 'crashes'. Analysing a mixed-method global internet survey ($n = 510$) of people returning to work with Long Covid, Stelson et al. (2023) identified 'episodic disability' as a 'comprehensive framework' for conceptualising barriers to returning to work within and outside the working environment. Intersecting barriers such as episodic symptoms, disbelief at work and household responsibilities were identified as preventing employees' return to work. Further qualitative research is required to investigate such barriers in more detail.

Amongst literature on episodic disabilities, Vick (2012) argued that while those who are able-bodied experience a unity of body and self, people with episodic disabilities experience an 'unsettled embodiment'. They are neither considered able nor disabled and live in a 'body-at-odds' which disrupts dominant understanding of disability as the binary opposite to being able-bodied. The concept of 'multiple subjectivities' originates from interpretive sociological theory and queer scholarship, where bodies have fluctuating ways of being and do not fit neat categories (Vick 2012). Since people with episodic disabilities move between (almost) wellness and (disabling) illness, they 'fall out of culture' because they challenge homogenised constructions of ability, disability, health, and illness (Vick 2012). Research with people with CFS/ME (Brown, Huszar, and Chapman 2017), also characterised by relapsing-remitting symptoms, found that participants were 'betwixt and between spaces' and in a position of 'liminality', where even those who considered themselves recovered, described being in the world of illness and wellness. For people with

Long Covid, the persistent unpredictability of their symptoms meant they were unable to make plans regarding their readiness to return to employment, and so also occupied a liminal space (O'Brien et al. 2023).

Research demonstrates how those with episodic (Vick 2013; Lightman et al. 2009) and invisible disabilities (Gemma 2021; Williams et al. 2023) are positioned as unworthy candidates for workplace and welfare support because their disabilities challenge dominant assumptions of disability as visible and static. Those with episodic disabilities rarely disclosed their disability and when they did, they reported having their disability cast as a performance problem with long-term consequences for employability (Gignac et al. 2021). Similarly, those with invisible disabilities (Olsen 2022), reported weighing up the benefits of reasonable workplace adaptations with the potential harms of disability disclosure, including evaluating the additional work of coping with disbelief.

'Administrative' and 'adjustment' work

Cooper et al. (2023) argue that the emphasis placed on returning to employment among those with long-term physical or sensory impairments demonstrates the high social value attached to economic activity. However, rather than focusing exclusively on employment as the primary form of work, sociologists Corbin and Strauss (1985) theorised work beyond paid employment, by describing the 'three lines of work' (illness, everyday life, and biographical work) involved in chronic illness. By drawing on theories from disability studies and medical sociology, disciplines historically at conflict with one another due to conflicting ontologies of 'illness' and 'impairment', Cooper et al. (2023) suggest that 'rehabilitation-related work' is an underexplored area within both disciplines, despite being 'a facet of disabled people's lives…in which they invest time, energy and expectation' (11). Therefore, by reconceptualising rehabilitation through 'administrative work' (including arranging and attending rehabilitation appointments) and 'adjustment work' (including adjusting to new ways of living and working), the time and energy used to return to employment can be conceptualised as another form of work.

This article explores the significance of Long Covid as an episodic disability and draws on Cooper et al. (2023) concepts of 'administrative' and 'adjustment' work to illuminate the invisible forms of work involved in attempting to return to paid employment while living with a disability.

Methodology

This analysis includes narrative interviews which were undertaken for three complementary UK studies between March 2021 and July 2022, using identical methods. The first two studies included adults with Long Covid. The third

study investigated experiences of Covid-19 recovery from a diverse range of ethnic groups and included interviews with participants who reported ongoing symptoms for 12 or more weeks after infection. Participants ($n=65$) ranged in age from 20 to 65 years, the majority ($n=52$) aged between 30 and 60 years. The sample was comprised of a majority female ($n=49$) and white population ($n=45$ white British/other white; 14 Asian/Asian British). Half the participants (33/65) were employed in public sector jobs; nine worked in the private sector, three were self-employed, one worked in the charity sector, one in a mix of the public and private sector. It was not possible to classify some participants (18/65) by employment sector because they were in caring roles ($n=4$), unemployed due to illness or on long term sick leave ($n=8$), still in full-time further/higher education ($n=5$), or their occupation was unknown ($n=1$). A range of occupations were represented in the sample, with the highest participant numbers being in healthcare ($n=9$), education ($n=9$) and academia ($n=8$). Ethical approval was granted to the University of Oxford by Berkshire Ethics Committee (12/SC/0495).

Sampling across the three 'parent' studies aimed for maximum variation (Coyne 1997), including diversity by geographical location, occupational social class, ethnicity, gender, and age. Recruitment was through various routes, including social media, clinicians, support groups and snowballing to facilitate diversity in experiences and perspectives. Verbal consent was recorded at the start of the interview. Narrative interviews were conducted by one of six experienced and trained qualitative social scientists by video call or telephone and audio-and/or video-recorded, according to participant preference. Participants were offered a £30 voucher to thank them for sharing their time and experiences. Interviews typically lasted 60–90 min, although some were shorter and/or conducted over multiple sessions if the participant preferred (e.g. due to fatigue); the longest totalled 3.5 hours. The first part of the interview invited participants to relate their narrative about how they became ill and how Long Covid had affected their lives. The second part drew on semi-structured topic guides with various prompts, including questions about the impact of Long Covid on employment and ability to work.

Interviews were transcribed verbatim and checked for accuracy. Subsequently, after participants were given the opportunity to review and redact the transcript of their interview, they were invited to sign a copyright form so that the recordings and transcripts could be used in research, teaching, broadcasting and on public facing online platforms with free access to topic summaries and clips. Transcripts were further de-identified (e.g. removal of place names) and imported into Nvivo20 (released in March 2020) for organising textual data for coding/analysis. Our multistage analytical approach was as follows. Data relevant to the impact of Long Covid on participants' employment experiences were analysed (by AM) using the mind-mapping 'one sheet of paper' (OSOP) technique (Ziebland and McPherson 2006). The

descriptive themes generated by this process were then further examined (by EA) using framework analysis (Gale et al. 2013). This analytical approach meant that themes were identified inductively from the data before being applied deductively to the analytical framework of episodic disability (O'Brien et al. 2023), 'administrative work' and 'adjustment work' (Cooper et al. 2023) to help organise the findings. Refinements to the approach and the line of argument were shaped by discussions within the author team and informed by existing literature on episodic disability and experiences of Long Covid. Interview extracts have been selected to illustrate the range of views relating to the themes generated.

In preparing this article, additional steps were taken to protect the anonymity of participants because of the potentially sensitive nature of their narratives concerning paid employment. For this reason, in relation to their discussion of impacts of Long Covid on work, participants are referred to using distinct gender-neutral pseudonyms and pronouns, and professions and/or job titles are not disclosed alongside specific quotes. The only exception to this approach was for one participant (Robert, a chef whose main Long Covid symptom concerned his lost or distorted sense of smell and taste) whose whole Long Covid experience centred on his ability to do and enjoy his job. Robert gave permission for his name and job title to be used.

Findings and discussion

In this section, we present the four themes generated by our analysis which was informed by medical sociology and disability studies. The themes include: a spoiled identity; existing in-between illness classifications; the workplace as disabling and enabling; and the adjustment and administrative work of returning to employment with Long Covid.

A spoiled identity

Like previous research on Long Covid (Kohn et al. 2022; Nielsen and Yarker 2023; Stelson et al. 2023), most participants were eager to return to work; they described missing *'social contact'*, having a *'purpose'* and feeling that returning to work represented progress towards regaining some *'normality'*. By comparing themselves to their pre-Covid, more able-bodies selves, participants presented themselves as having a 'spoiled identity' (Goffman 1963). They described themselves as reliable and hard-working before developing Long Covid, asserting their high attendance rates *('I've never taken time off work before'* [Pat]) and strong work ethic *('I've worked all my life […] forty-two years […] left school on the Thursday, and I started at the local [industry] on the Monday'* [Billie]).

In contrast, when discussing experiences of illness after developing Long Covid, participants described themselves as being a '*shadow of [their] former self*' [Alex], '*losing that sense of yourself*' [Rowan] or feeling like a '*failure*' [Nicky]. Oli also felt like a '*failure*' for being unable to return to work, whereas Drew, who was made redundant after a period of long-term sickness absence and a failed phased return, experienced an altered sense of self.

> *I'm suffering tremendously mentally, [...] because I'm not working, I feel like a failure and every time I think about going back to work, I can't even imagine myself going back to what I was doing ever.* [Oli]

> *[Long Covid] was suddenly a big part of my identity. A big part of my life. A substantial part of my earning capacity all gone overnight and that was really hard. [...] [When] my boss was telling [me about my redundancy], I was just crying [...] because it felt like such a solid and...an unmoving and permanent loss because of illness.* [Drew]

Some participants, such as Wynn, experienced a role reversal, where instead of providing care, they were being cared for: '*I used to finish a full-time job [and] do this community work...it breaks my heart to know it's reversed on me now where I need help.*'

Accounts of a spoiled identity were also prevalent among participants who had managed to return to work. Ellis felt frustrated at not being as '*sharp*' as normal because '*that side of me is impaired*', whereas Robert, a chef who experienced distortion of his sense of smell and taste over a year after infection, described his spoiled identity as '*being [like] a marathon runner and getting old...you can't do it anymore*'. Rowan described how cognitive impairment left them doubting their professional capabilities: '*It makes you really question every memory you have [...]. You think, "Did I come up with that?" It strips you of your ability to make a decision.*'

These findings echo other research in which participants with Long Covid reported feeling that the non-specific symptoms and current lack of biomedical validation for Long Covid threatened their occupational identity as strong, healthy workers (Ladds et al. 2020; Nielsen and Yarker 2023). Narratives of a 'spoiled identity' are common in research on other episodic disabilities, such as multiple sclerosis (MS), where participants described themselves as 'unreliable' or 'risky' employees due to being unable to predict the occurrence or duration of their symptom relapses (Vick and Lightman 2010, 73).

Existing in-between illness classifications

The fluctuating, intermittent nature of episodic disability meant that participants existed in-between the boundaries of (almost) 'able' and 'disabled', thus challenging their ability to distinguish when to return to work (Vick 2013). Participants spoke about preparing or attempting to return to work too soon and experiencing relapses, extending sickness absence.

It took me a really long time before I accepted that I wasn't well enough to work. I probably drove my managers mad, because I would email every couple of weeks and say 'Right, I think I'm better, I'll be back on Monday', and then lo and behold, I would be ill again. [Nicky]

Participants, such as Evan, were alleviated from the uncertainty of when to return to work by accepting clear medical advice: *'When the doctor said I should go off work, I was so relieved because I didn't have to keep trying every day to do my work and do all my things at home'.* Brooklyn negotiated a shorter return to work with their general practitioner (GP) but found that returning too soon caused their symptoms to worsen.

My GP actually advised me to take two months off work and I thought this was ridiculous because I've never had two months off work even though I trust my GP and I negotiated that, 'Could I just have a month off?' and he said, 'Well, okay' reluctantly but, 'You need to come back to me before you return to work.' So, when I had my relapse, I understood that I should have listened to my GP.

After two failed attempts to return to work, Wynn accepted their nurse's advice to take long-term sick leave to prevent further symptom flare-ups.

[The nurse] says, 'You're gonna have to stop. […] you're damaging yourself because every time you get to a certain stage and you try and work, your body is fighting against it and [causing] more damage…' So, I ended up being off work again.

Like those with the episodic disability MS (Vick 2013), who had to substantiate sickness absence with medical documentation due to existing in-between classificatory systems of (dis)ability, people found the process of needing to repeatedly renew their sick line certification dispiriting. Bobbie, for example, described the process of needing to repeatedly prove to their employer that they (still) had a 'legitimate' illness, as *'soul destroying'*.

Having to repeatedly renew sickness absence paperwork brought uncertainty for employers and participants, making it challenging for both to plan the return to work. After a period of rolling sick leave certificates, Riley said their employer had to hire a replacement due to uncertainty about when they would return.

I think [my employer and I] were both in denial about how long [Long Covid] would go on for. It was only after I put my fourth, fifth or sixth sick notes in that [my employer] said Right…I think we realise that you're not going to be back anytime soon…and we're going to hire in a bit of support to cover some elements of what you do.

Participants such as Cam faced uncertainty about how to convey their fluctuating capacity to their employer, when they themselves could not assess their capacity. *'I don't know what I can do and what I can't do […], but as an employer they need to know […] it's incredibly, incredibly difficult'.*

For some, intermittent and fluctuating impairments meant that they were neither considered fully fit to work, nor classed as disabled or unable to work. Rae felt that existing *'in-between'* sickness classifications posed challenges for employers because absence policies used binaries such as 'healthy' or 'ill', 'able' or 'disabled' to assess employees' workability.

> *It's very difficult again with employers […] do we say we're 10 per cent sick, you're sick, you're not sick? […] What does the policy say where you are slightly not well?… [at work they] record you as either ill or you're well, nothing in between.*

As others have demonstrated (Boyd 2012; Stelson et al. 2023) there is limited acceptance of disability as a varying phenomenon, resulting in those with episodic disabilities contending with disbelief. In the current study, some participants felt that their employer or line manager suspected that they were avoiding work and just taking time out for no reason. Similar stigmatising cultural narratives that cast those with invisible impairments as 'lazy' have been reported as used by employers of those with chronic pain (Grant et al. 2019).

Despite disability carrying no 'particular look', it is often presumed that (dis)ability is a category that can be judged through visual cues (Lightman et al. 2009). For this reason, many people with episodic disabilities (Gignac et al. 2021), described their impairments as 'hidden' or 'invisible' disabilities, like Ellis in the current study: *'There is still a complete lack of understanding […] from the management [at work], and colleagues and it's the hidden disability thing, completely […] the fact that…I don't look like I need support'.*

Those with invisible impairments have been described as unworthy candidates for workplace accommodations due to not being visibly or permanently disabled in the same way from day to day (Gemma 2021; Williams et al. 2023). Participants in the current study also attributed their lack of workplace support to the invisibility of their impairment. Robin described the challenge of passing as 'impaired' or less able to work when they looked 'able-bodied'.

> *At the start [of the pandemic] folk were saying 'Covid isn't real' …and then […] 'Long Covid it's a lot of nonsense!' […] and that would get me down [and] I wouldn't speak about how rubbish I felt, because of that […] It's not like you've got a broken leg.*

The ability to pass as 'able-bodied' using existing disability measurements meant that some participants were forced to return to work due to, for example, visa requirements, running out of sick leave or the financial pressures of being unable to live on statutory sick pay: *'Financially I need to get back [to work] I'm only on statutory sick pay now [and it's] a huge pay cut'* [Flynn].

Some participants received workplace occupational health support to return to employment. Wynn felt occupational health had supported them to

make their disability more visible after struggling to convey the severity of Long Covid while working remotely.

> [O]nce the occupational therapist at work mentioned that I was disabled and the report went back, it made [my employer] realise how ill I was […]. They're not seeing me face-to-face [or] how far I can walk and can't walk [or] that some days I can't get to the bathroom.

The uncertainty of how Long Covid would be treated in the workplace and whether participants would experience disbelief, contributed to a reluctance to disclose disability. Jesse described being unable to disclose their Long Covid to Human Resource (HR) managers who Jesse felt believed Covid-19 infections did not cause long-term impairment and only lasted the duration of self-isolation after infection, as recommended at the time.

> There's parts of health that you couldn't discuss but I think that, in our HR Department, 'Oh have you […] finished your ten-day isolation?' Nobody thinks, even occupational health, […] they think it's just ten days and then that's it.

Indeed, Blair revealed they would rather request holidays than disclose disability and take sick leave due to the fear of appearing *'weak'* or different in their workplace.

Like those with other episodic disabilities (Gignac et al. 2021), who frequently have their disability cast as a performance problem and rarely disclose impairment due to fear of employment termination, participants in the current study were fearful that disclosing the severity of their disability would result in unfair dismissal: *'I was probably a bit worried that if my employer found out just exactly how bad I am they would say, "Bye, bye"'* [Flynn].

Participants who had been unable to return to employment described the challenges of living with continued uncertainty about whether they would ever be able to return to work and how unemployment would impact them financially: *'I was really worried about the future, how was I going to have an income, what was I going to do with myself, what was I going to be able to do'* [Nicky]. Those who had just started their careers anticipated having to retrain and navigate a labour market where some job requirements automatically excluded them from applying: *'If a role is full-time, I already know…I'm not going to apply. […] I guess in a weird way you are somewhat shut off from the job market'* [Jude].

The workplace as disabling and enabling

Participants who returned to work, described navigating a working environment designed for able-bodied employees and, like those with other episodic disabilities (Vick 2013), were expected to maintain the same pace and rigorous demands as their able-bodied colleagues: *'I remember mentioning to one*

of my managers that I couldn't do the report […] because I couldn't remember the names of [people] and her response was, 'Oh well doing the report will help with your brain fog' [Jesse].

Garland-Thomson (2011) claims that those unable to mould their bodies and minds to fit the shape and function of their working environment are rendered 'misfits' by the social environment. Participants in the current study highlighted a 'misfit' between occupational policies and practices and the episodic nature of Long Covid. Taylor expressed frustration that there were no policies or practices *'that fit'* with Long Covid and described the inadequacies of a four-week phased return for a new, medically unexplained condition: *'I asked [my employer] about [a phased return] early on and I was told it would be a four-week thing […]. I know that's normal for other conditions, but this is an unknown condition'.*

Previous research (Nielsen and Yarker 2023, 17), among people with Long Covid also found that current return to work policies are 'inflexible and unfit for purpose'. More specifically, despite phased returns being the most requested and implemented workplace adaptation, most (92%) of respondents with Long Covid reported that phased returns are unsuitable for fluctuating impairments (Trade Union Congress (TUC) 2021, 20). Furthermore, a one-size-fits-all approach to returning to work homogenises bodies as always ready, willing, and able to work, further marginalising those with episodic disabilities who are ruled by fluctuating impairments (Vick and Lightman 2010).

It has been argued that those with episodic disabilities experience a 'body-at-odds' with their working environment and 'fall out of culture' due to challenging homogenised constructions of illness and disability (Lightman et al. 2009; Vick and Lightman 2010). In the current study, Kit experienced a tension between demands for a reliable, productive body and their episodically disabled body, causing them to withdraw from employment.

> *The thing with [my job] is you can't be there one week and then not be there the next, that's why I'm having to stop that job […] and my [clients] are suffering because I'm there and then I'm not…and that's like the number one […] thing that you don't do [in my job].*

Some participants were offered adjustments that helped them manage symptoms while working, including teleworking, flexible hours, adapted roles, and frequent breaks. For these participants, the working environment moulded to the shape and function of their bodies, becoming enabling rather than disabling (Garland-Thomson 2011). Pat said their employer adapted their role to fit their changed capacity, allowing them to add value, despite fluctuating capabilities.

> *As soon as it became clear that I couldn't function in the role, [my employer] worked with me to look at how the role could be reduced, and it became clear that it wasn't*

going to work and then they created a new role that allowed me, to still add value. They reduced hours, they gave me complete control and flexibility of my diary.

Participants who described the workplace as accommodating mentioned managers who took account of their fluctuating disability. Chris highlighted ways in which their manager treated them as an equal and gave them autonomy to shape their workload around fluctuating impairment: *'My direct manager was incredibly understanding and told me… 'I [will] behave as everything's normal […], we're not looking when you're out [of office], do what you can.', and this was great support'.* Robin felt that their relaxed workplace atmosphere and ability to disclose impairment to their manager supported them to stay in employment.

> *I'm lucky, the place that I work, it isn't a hard-pushed place, it's a very relaxed atmosphere …If I had to go and speak to my boss and say, 'I'm struggling now, is it alright if I sit down for a [little] while' … [they would] be totally fine with that.*

Colleagues who understood Long Covid, including those who had suffered from Covid-19 or Long Covid themselves, helped establish an accommodating workplace culture. While Morgan attributed their *'sympathetic'* workplace to a senior colleague who had *'struggled'* with Covid-19 symptoms, Marley revealed that having colleagues who experienced cognitive impairment helped them disclose disability at work.

> *Most of [my colleagues] have had Covid so far. Everyone's got symptoms, but they've got different [symptoms], […] when we talk, it's always the same. 'Yes, I've got that', 'I've got that', 'I understand. I know you lose your words. I'm losing my words as well'.*

Administrative and adjustment work

The uncertain guidance and lack of workplace support when returning to employment with Long Covid meant participants often had to undertake the 'administrative work' and 'adjustment work' (Cooper et al. 2023) of returning to employment with a new impairment for themselves. Taylor described being left alone to find answers: *'Nobody [at work] can actually offer support, because nobody actually knows, and I've gone with questions, and it's usually 'No, don't know anything about that', and it's me that's had to go and find things out'.* Taylor tried to involve HR in the 'administrative work' of returning to employment, by offering to share their symptom diary, but their offer was initially declined before being accepted later: *'Even my HR meetings, when I talked about this [symptom] diary and sending it, they didn't want to know, they said, 'No, it's fine we don't need to see it, that's for your benefit''.*

As previously demonstrated among other disabled employees, participants had to endure 'exhausting and largely invisible…work' to achieve an acceptable employment status and adjustments (Dollinger et al. 2023, 8). In our study, the 'adjustment work' of returning to employment took various forms

including education, negotiation, and identity work. For instance, Ash had to 'educate' their line manager that their debilitating fatigue was not the same as the tiredness one would expect when returning to employment after other illnesses. Similarly, Casey recounted the education work involved in explaining their energy impairment and defending workplace adaptations to colleagues: *'[It's] having to explain to people 'I'm sorry, I can't come to your all-day meeting' or 'If we have this meeting, I'm going to need a break' and all these new things'.*

'Adjustment work' also involved the labour of negotiation, where participants negotiated personal and professional workload priorities to strike a 'relative equilibrium' between workloads involved in chronic illness (Corbin and Strauss 1985). Rae negotiated with their manager to balance full-time employment, alongside coping with an energy impairment and everyday life work.

> *I've had instances where I've called my boss like, 'Oh please can I just start…two hours later with work because I'm just so tired' […]. She said, 'It's fine you can start two hours later', but [then] I have to […] finish two hours later and then start rushing with the evening chores and then you continue getting tireder and tireder.*

Participants' ability to engage in 'negotiation work' was dependent on whether the workplace was enabling or disabling. For example, Lee said their ability to take frequent breaks throughout the working day was reliant on their employers' willingness to negotiate with them around their working practices: *'I'll have a nap for a half an hour during the day and the employer will allow [me] to do that.'* Previous research (Dollinger et al. 2023) shows that employers' lack of awareness of how to support disability at work resulted in employees being regarded as solely responsible for managing their impairments.

The conflict between competing work forms often disrupted participants' illness trajectories resulting in a re-evaluation of their distribution of labour and prioritisation of one workload over another (Corbin and Strauss 1985). The challenge of negotiating between various workloads is conveyed by Lou, who describes taking 'sick days' to manage their return to employment alongside parenting.

> *I still take a lot of sick days where I mostly just sleep because I've overexerted and this is where it […] gets into the parenting sphere as well, work is more restful for me than being at home.*

For some participants like Nicky the internal negotiation between different workloads resulted in prioritising returning to full-time employment which resulted in a trade-off with leisure activities: *'In terms of interests, doing things, seeing people […]. I often just don't have the energy to do it, if I've been working'.* Achieving a 'relative equilibrium' between workloads required a careful balance like walking along a 'tightrope' (Corbin and Strauss 1985).

The 'negotiation work' of finding a 'relative equilibrium' between competing workloads, when even the smallest of physical or mental tasks could be exhausting, often resulted in repeated failed attempts to return to employment caused by setbacks in recovery that participants, such as Cam and Kit, called *'relapses'* and *'crashes'.* Drew pushed themselves at work because they *'wanted to see a progression'* but described stretching themself like a piece of *'elastic'* or *'bungy cord'* only to be pulled *'right the way back'* by symptoms. It has been argued that people with episodic disabilities experience their bodies as having 'indeterminate liquid borders that expand and contract' depending on the extent of any recent physical or mental exertion (Vick 2013, 179). Previous research with those with Long Covid (Kohn et al. 2022; Nielsen and Yarker 2023) report similar recurring cycles of returning to work, overdoing it and then being on sick leave once again.

When there were no grounds within which to engage in negotiation work with managers or when the various forms of 'adjustment work' were perceived to be too extensive due to disabling workplace structures, participants were forced to prioritise workloads (Corbin and Strauss 1985). In some instances, this meant that participants decided to stop working to *'concentrate on…recovery'* [Pat]. After feeling *'abandoned'* by their employer, Ali felt too ill to fight for workplace adaptations: *'It's sad but there's no point fighting because I'm just so ill, I'm just sick and tired. I just want to get well, put myself first [instead of] trying to reason with people who are unreasonable.'* Similarly, while Drew described their redundancy as upsetting, stopping work allowed them to start a long process towards recovery.

> *I don't think that there was very much else that I could've done because me stopping work was a good stage in my recovery, and being able to do less helped me do more rather than me just trying to like muddle through without knowing the rules of myself properly… I wasn't in any rush to get a new [job]. I kind of understood that I would have to be unemployed for a bit.*

For some, withdrawing from the labour market brought about another form of 'administrative work', namely applying for benefits (Cooper et al. 2023). Billie who had taken early retirement, recalled the 'administrative work' of navigating a benefits system with a cognitive impairment, where they were further disadvantaged by having their benefits taxed off their pension.

> *I lost £114 that month […] without receiving any benefit […]. So obviously, […]in this brain fog, kind of tired…this is right in the middle of Covid as you might imagine, […] you're waiting fifty minutes on the phone to get an answer.*

As previous research (Chawrun 2023; Sang, Calvard, and Remnant 2022) demonstrates among disabled employees and caregivers, systems of support established to 'accommodate' disability often inadvertently construct and shape disability, burdening people with disabilities with additional 'administrative work'.

In contrast, participants who had returned to employment, such as Jude and Nicky described how 'adjustment work' encompassed the identity work of having to accept a *'new self'* or *'post-Covid me'* which involved careful monitoring of symptoms to (hopefully) avoid relapse. Rowan, who had been able to return to work, found that four hours was the maximum they could manage.

> *I've now returned to work again in consultation with the occupational health on a four hours per day basis and I am still balancing that with managing a lot of my symptoms [...]. I am able to manage my symptoms [so] that I can do four hours of work, but that is very much the maximum amount I can do.*

In coming to terms with their new (in)capacity, participants found new ways of working including relying on other senses, note-taking and working from coloured paper. Drew discovered that their fatigue could be managed by limiting the time they spent sitting or standing.

> *I've realised that being able to lie down or recline is the way for me to be able to get more out of myself because my fatigue is driven by being upright by sitting, standing, working, it doesn't really matter what I'm doing, as long as I'm upright a clock starts ticking in my head.*

For participants, such as Charley, returning to employment brought with it the identity work of attempting to pass as 'able-bodied' due to fears that disclosing Long Covid at work would mean that they would be judged as less capable.

> *I'm very aware that there are some circumstances where I'm trying to play down my symptoms [...] it might be at work where I want them to be confident that I'm still able to do a good job [...]. I want obviously to come across as professional [...]. I don't want people to think that my symptoms are stopping me doing a good job.*

This form of 'impression management' is common among others with invisible disabilities (Sapir and Banai 2023), who employ discursive identity work of concealing and revealing their disabilities to manage the costs and benefits of disability disclosure for accommodations.

Conclusions

Despite our participants working prior to their Long Covid illness in a wide range of occupations (mostly full-time) across the public, private, charity and other sectors, 'episodic disability' has proved to be an apt conceptual framework to make sense of the unpredictable, non-linear trajectories that people with Long Covid experience as they attempt to return to employment with relapsing-remitting disabilities (O'Brien et al. 2023). The concept of 'adjustment' and 'administrative' work (Cooper et al. 2023), captures the time and effort of navigating disabling workplace and welfare structures that fail to

recognise participants with Long Covid as suffering from a 'disability' or temporary 'impairment' and do not provide them with the support required to return to employment without adversely impacting their health. The 'Rehab, Research and Recognition' demanded by people with Long Covid online (Schermuly, Petersen, and Anderson 2021), like 'rehabilitative work', is in keeping with neoliberal governance and captured by the concept of 'responsibilisation', where patients are deemed responsible for matters previously the domain and responsibility of the state.

Our study has strengths and limitations. It is one of the first qualitative studies to use narrative interviews to investigate attempts to return to employment by people with Long Covid in the UK. Another strength is its amalgamation of theories from medical sociology (e.g. illness work) and disability studies (e.g. episodic disability), two disciplines with a long-standing tension, due to opposing ontologies of illness and disability (Cooper et al. 2023). Using recently developed and novel theories of 'episodic disability,' 'administrative' and 'adjustment work', this article further substantiates theories and applies them to the emergent illness of Long Covid. Another significant strength is our use of data from three complementary studies that provide a substantial number of robustly collected and analysed qualitative interviews ($n=65$) from an ethnically diverse sample. Despite this, people who choose to participate in research are not always representative of the wider population and various intersectional factors (e.g. gender, class, ethnicity) not discussed in detail in this article may impact the security of participants' employment and their initial risk of exposure to Covid-19 infection. We acknowledge too that, whilst our study is large for a qualitative study, the numbers interviewed do not allow the full spectrum of work and working environments to be included, and we found it difficult to recruit people working in some jobs (e.g. supermarket workers, transport operators) where they are likely to have had high levels of exposure to Covid-19 during early phases of the pandemic. Another potential limitation is that our participants' accounts were conducted between March 2021 to July 2022, when the UK had lifted its third national lockdown and was following a four-stage roadmap towards lifting Covid-19 restrictions (Cabinet Office 2021). Consequently, our participants' accounts may not fully represent the experiences of people with Long Covid returning to work during the first or second national lockdowns in the UK or in other countries, nor when no Covid-19 restrictions are in place.

This article shows how, despite participants expressing eagerness to return to employment, the inability to accrue social value by participating in traditional paid labour resulted in some participants navigating a 'spoiled identity' (Cooper et al. 2023; Goffman 1963; Ladds et al. 2020). The uncertainty of existing in-between illness classifications or in a position of 'liminality' (Brown, Huszar, and Chapman 2017), compounded participants' rehabilitative work, resulting in many having to 'prove' their impairments to doctors and colleagues,

in the face of obvious disbelief about the severity and longevity of their symptoms. Just as people with Long Covid struggle to validate their candidacy in encounters with medical professionals (MacLean et al. 2023), these struggles extend to the workplace where some participants battled to validate their candidacy as 'disabled' or 'impaired' employees and to access disability benefits or workplace or welfare support. The inability to qualify as 'disabled' meant some participants, such as those not afforded workplace adaptations, were forced to adapt to able-bodied norms in the workplace and were rendered 'misfits' or 'bodies-at-odds' with their working environment. In contrast, those given support and autonomy to shape their workload and circumstances around fluctuating symptoms were able to maintain employment. In turn, such organisations became 'sites of care and compassion' (Lawrence and Maitlis 2012), facilitating the disclosure and management of Long Covid at work.

The participants returning to an unaccommodating workplace were burdened with additional forms of 'adjustment work', whereby it was their responsibility to reintegrate themselves into the workplace by advocating for and defending workplace accommodations. The labour of returning to employment required careful balancing of various forms of work to strive for a 'relative equilibrium' (Cooper et al. 2023; Corbin and Strauss 1985). Failure to strike a balance resulted in relapses which some participants deemed too detrimental to their health and recovery. Thus, like Nielsen and Yarker (2023) found, participants stopped attempting to return, prioritising recovery over their return to work and withdrew (at least temporarily) from the labour market. However, leaving employment did not signify an end to their 'working status', but brought additional forms of work, such as the 'administrative work' of applying for benefits. Lunt et al. (2022) also found that participants with Long Covid felt that returning to work would jeopardise recovery but argued that these beliefs run counter to the belief that 'work can contribute to the rehabilitative process [and is] good for well-being' (371). As Lunt et al. (2022) indicated, and as this article further demonstrates, returning to work can be a disabling and often harmful experience for participants with Long Covid if workplaces are unwilling or unable to adapt to their fluctuating impairments.

While some disabled groups are said to have experienced the Covid-19 pandemic as an 'equalising mechanism' due to the creation of 'new, shared, virtual space' (Sapir and Banai 2023), flexible online spaces have dwindled since the beginning of the pandemic (Brown 2023). For low-paid employees, the disabling distinction at work is more prominent as they are generally afforded less flexibility to manage their disability at work. For instance, over 75% of high-paying jobs in educational, professional, scientific, technical and management services can be conducted remotely, whereas this is the case for fewer than 15% of low-paying jobs in retail, agricultural, accommodation and food services (Dingel and Neiman 2020). The abundance of Long Covid cases among key occupations that require in-person participation at

non-negotiable times, alongside the continued inflexibility of these occupations, risks exacerbating inequalities and absences in already understaffed workplaces (Reuschke and Houston 2022).

Moreover, the UK has one of the lowest unemployment benefit rates in Europe and disability claimants are subject to stringent conditionality rules, including medical assessments that are described as more 'punitive' than supportive, even in pre-pandemic times (Wright, Fletcher, and Stewart 2020). However, the Covid-19 pandemic has revealed gaps in social security demonstrating the need to develop appropriate welfare support and rehabilitative pathways to prevent 'disabling' those with Long Covid with additional forms of 'rehabilitative work' and facilitate employers to retain those with Long Covid in the workplace.

Currently, those with Long Covid, like other episodic disabilities, are often falling through the institutional cracks as not 'disabled enough' to qualify for welfare and workplace support (Vick 2013). The challenge of recognising Long Covid as a 'disability' or temporary 'impairment' arises from the inability of existing disability measurements to capture 'uncertain' fluctuations in Long Covid symptoms (O'Brien et al. 2023). Unlike long-standing episodic disabilities, such as HIV and MS that are classified as disabilities under the Equality Act 2010 that protects against unlawful discrimination and facilitates welfare and workplace support, a diagnosis of Long Covid does not necessarily grant the label 'disabled' or the protections that accompany this classification (Trade Union Congress (TUC) 2021). Furthermore, Long Covid differs from other illnesses because as yet its recovery trajectory is unknown, diagnostic tests and treatments are unavailable and researchers are still learning about what the consequences of returning to work may be for people with Long Covid.

Nevertheless, to accommodate this widespread, fluctuating disability there must be acknowledgement and means of addressing diverse workplace needs. While a few participants in this study felt that some of their impairments were beginning to improve, meaning that they required temporary workplace adjustments, many had been suffering from significant impairments for a year or more by the time they were interviewed. For these participants the extent of their symptoms still meant that they either required substantial changes to their employment status, including retraining, redeployment, or they faced periods of unemployment, accompanied by uncertainty about when, how and in what capacity they would be able to return to full- or even part-time employment. If workplace and welfare support systems continue to be inadequate, those with Long Covid and other episodic disabilities will continue to miss out on the well-documented health benefits of sustained employment (Lunt et al. 2022). Moreover, they will continue to face the unknown risks, to their overall health and longer-term recovery, incurred by feeling forced to manage disability in ways that accommodate their working environment rather than moulding employment around their disability needs.

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