Regular Article

Considering Covid-19: Autoethnographic reflections on working practices in a time of crisis by two disabled UK academics

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A B S T R A C T

COVID-19, an infectious disease caused by novel severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2) caused dramatic changes in all aspects of daily life. As the British public was ordered to stay at home, non-essential businesses shut their doors, resulting in an abrupt shift in working practices towards home working. In higher education, university campuses closed to students and staff. In this article, two disabled lecturers working in higher education in the UK reflect on their experiences during this rapid shift in working practices. With a particular focus on how their different impairments intersected with the changes occurring during this time, they employ autoethnography as an emancipatory method to consider the ways in which their working lives were impacted by the decisions made during this period. As well as illuminating their own individual experiences, they use these accounts to consider the wider implications for disabled students and academics. They conclude that, whilst this has been a period of challenge, uncertainty and rapid change, there are also lessons to be learnt regarding accessibility and the possibility for adaptation going forward, for staff and students alike. They suggest that as we emerge from this period of crisis, we need to use these experiences as leverage for positive change; for designing ways of teaching and learning that accommodate everyone, rather than getting swept up in an unthinking pursuit of returning to 'business as usual'.

1. Introduction

The UK higher education Sector's response to the pandemic of COVID-19, an infectious disease caused by novel severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2), led to overnight changes in the working practices of University staff and students, as campuses closed and teaching, and learning moved online. This paper illuminates the experience of this shift, from the perspectives of two disabled academics. We also consider what these experiences mean for disabled staff and students, going forward. We use autoethnography as a 'socially-just and socially-conscious' (Ellis et al., 2011) method, employing personal narratives to explore the impact of these recent events. Both authors are lecturers in Education. Steph is a full-time wheelchair user due to Osteogenesis Imperfecta (also known as Brittle Bones) which is a congenital condition with varying degrees of severity. Steph's is severe. Due to increased risk and consequences of respiratory infection, she is on the UK Government's 'severely vulnerable' list. Steph lives with her mother who is also listed as 'vulnerable'. They are self-isolating for at least 12 weeks as per government advice. Chris is autistic. He lives with his wife and two young children. One of Chris' children was added to the

'vulnerable' list during the early period of the outbreak, meaning he and his family are also self-isolating.

This work builds on a limited amount of research that has been conducted in this area, in relation to disability and the COVID-19 pandemic. In August 2020 a national survey of over 4000 disabled workers was carried out by UNISON. It showed that before the pandemic of COVID-19 only 5% of disabled people were enabled by their employer to work from home on a regular basis. During the COVID-19 pandemic, this rose to approximately half. Of those, 73% felt they were more or equally productive due to reduced impact of pain and fatigue because they no longer had to commute to work alongside increased flexibility of working schedules. 54% of those surveyed want to be able to work from home in the future (UNISON, 2020). However, the negative consequences of isolation must also be highlighted. One study found that during the first month of the first national lockdown in the UK, 9.2% of those who identified as having a Chronic physical illness, also said they were experiencing psychological abuse, 3.5% were experiencing physical abuse, 19.2% had suicidal ideation and 5.3% had self-harmed (Iob et al., 2020).

The above literature is primarily quantitative. In light of this, the accounts that follow here provide a more qualitative reflection on our

experiences of this time. Emancipatory disability research (Oliver & Zarb, 1992) shifts focus away from the consequences of specific impairments towards the everyday structural and attitudinal barriers faced by disabled people (Barnes, 2001). Richards (Richards, 2008) emphasises the emancipatory nature of autoethnography as a means to resist "being colonized by others and subjected to their agendas". Autoethnography amplifies marginalised voices (Ellis et al., 2011), overcoming objectification in relation to disability (Richards, 2008). For instance, autoethnographic narratives have helped complicate reductive understandings of autistic experience (Yergeau, 2018). As autoethnography is sometimes critiqued for a tendency towards self-absorption (Ellis et al., 2011) we acknowledge that we experience this pandemic with considerable privilege; we have relatively secure, non-furloughed jobs, do not work on the 'frontline' and have safe and comfortable home lives. Nevertheless, given the risk of disabled people being forgotten (Langevin & Ruderman, 1616), it is vital that disabled voices are included in discussions regarding this period. Worldwide, approximately one billion people live with some form of impairment (Armitage & Nellums, 2020), which is especially significant considering that disabled people are likely to experience the most negative outcomes from the pandemic, also navigating discriminatory laws and guidelines (Armitage & Nellums, 2020). In writing these accounts, we have considered relational ethics (Ellis et al., 2011), responding by obscuring the detail relating to others. For convenience, we also draw out the main challenges – and some advantages – we faced during this time in a table (appendix 1). We acknowledge that these narratives can only provide partial representations of our experience but hope that our honesty makes them of value.

1.1. Steph's Reflection

I was not initially concerned about the prospect of self-isolating for twelve weeks as I have already experienced extended periods in the house, usually due to fractures, or during recovery from an operation. For me, such periods are usually accompanied by mild depression, although I haven't experienced this during this crisis. When the official 'lockdown' was announced I had already been stuck at home for four weeks due to intermittent strike action, and my adapted car being repaired. My line manager's agreement that I could work from home until my car was fixed meant that I wouldn't have to suffer the anxiety and potential injury that relying on unreliable public transport brings. I hate making requests for 'reasonable adjustments', despite being within my rights to do so, under the Equality Act 2010. It is not uncommon for disabled people to be reluctant to disclose an impairment or to ask for accommodations within the workplace (Lindsay et al., 2018). For me, this reluctance stems from negative experiences of doing so in my previous workplace, and internalised ableism that tells me that I need to be at least as good as, if not better than, my non-disabled workmates to 'make up' for any instances of perceived inconvenience I place on my workplace or colleagues. As Goffman (Goffman, 1963) posits, I, like many disabled people, try to ensure that my impairments (and any resultant needs) are as unobtrusive as possible to reduce the likelihood of workplace discrimination. In a world that relies so heavily on employees meeting increasingly challenging targets, productivity is valued above all else. In a sector where ableism has been described as 'endemic' (Brown & Leigh, 2018), ableism is normalised and ingrained to such an extent that many 'reasonable adjustments' that disabled people seek are seen as unreasonable by employers (e.g. (Inckle, 2018)). Titchkosky (Titchkosky, 2008) calls this a 'sensible say-able', as the denial of the adjustment is positioned as justifiable and ordinary, resulting in disabled people feeling less able to ask for further accommodations. I feel fortunate that, in my current workplace, my line managers and head of department have been supportive. Most of my requested accommodations have been granted, in a way that hasn't made me feel like a burden. I have asked for accommodations gradually, as my confidence in my workplace and management has grown and as my understanding of my needs in my current role has developed. My experience of working from home shifted my

workplace expectations and enabled reasonable adjustments which I hadn't considered before and would never have thought achievable.

The initial couple of weeks of moving to remote working were extremely stressful, a combination of workplace and everyday life uncertainty coming together to make a perfect storm. I love my job, and this was the first time I have felt as though it was all just too much; too much information, too much uncertainty, too many expectations. This wasn't my institution's fault as such: they were having to adjust quickly in response to staff and student's needs, in highly unique circumstances. However, this resulted in a deluge of daily emails, often with conflicting information. Stressed out students also emailed regularly, with valid questions that I couldn't answer. On top of these stressors, The National Institute for Health and Care Excellence (NICE) (NICE, 2020) released guidance for UK intensive care doctors, around how to decide if a patient should be admitted to an intensive care unit (ICU). This guidance suggested that my level of impairment would automatically exempt me from ICU treatment. This has now been updated to instruct doctors not to take long-term, stable impairments into account for decision making. However, the British Medical Association guidelines contradict the updated NICE advice and reintroduced age, co-morbidities and impairment back into the decision-making process (BMJ and COVID-19 Ethical Issues, 2020). This means that although ICU doctors shouldn't specifically take into account my 'frailty' (the fact that I can't live independently), they can still deem me as clinically not viable for ICU treatment due to my impairment and co-morbidities. This left me, along with many other disabled people, feeling extremely distressed and unable to concentrate on work related tasks. Not only am I officially classified as 'extremely vulnerable' to this virus, I may not even get a necessary treatment to help me to recover; staying indoors with no outside contact became imperative.

I quickly noted that the distinction between 'work' and 'home' time getting blurred. I decided to set working hours for myself and stick to these unless I was 'making up' time that I had lost due to impairment/ COVID-19 related stress. One of the main sources of workplace anxiety was learning the new technologies needed to hold lectures and seminars online. Not only did I have to get to grips with new programs, but it soon became clear that the lectures I had prepared were no longer suitable for this medium. Not having any training in teaching remotely meant that redesigning these involved more trial and error than informed choices. Now that we have experienced a few weeks of this online delivery of teaching and communicating with colleagues, I have grown to like it. That isn't to say there aren't issues, particularly for the students who don't have suitable equipment or space to engage in online learning. But on a personal level this new way of working is liberating.

When working face to face with students I have a personal assistant (PA) employed through the government scheme Access to Work (AtW). Although this is a great scheme - without the PA it would be extremely hard for me to hold down my job - it brings another level of additional labour in the form of organisation and paperwork that most people don't have. I now no longer have to contact the care firm and request the hours that I need (which is always more complicated than it seems), nor do I have to order parking passes or fill out the timesheets to send to AtW, or get these timesheets signed by my line manager. These may seem like small tasks, but they take time out of my week, especially when things go wrong between myself and the care company or AtW. Equally working from home enables me to tailor my day around my own medical/care needs, fatigue, student and workplace needs and family life. Not having to factor in the commute to work has meant that I can rest for longer in the morning and I am experiencing significantly less pain and fatigue. During the summer of 2019, where I had time to relax fully and take an extended period of annual leave, I realised that work was increasing my experiences of pain and fatigue, but I wasn't aware to what extent. I had felt that the trade-off was worth it - I didn't want to have to give up a day's work and pay as I felt that this may also reduce my opportunities for progression. Although our department is flexible in that you can work from home on any days that you aren't teaching, it's rare that we get a

completely free day to do this. Before this crisis I would never have considered it a viable option to teach or attend meetings remotely. However, I now feel that, although not unproblematic, online meetings and teaching can be very powerful, useful approaches. Team meetings have felt more constructive, more frequent, and timekeeping has been better. Making most meetings optional has provided the same sense of support as when we are in the office but removed any sense of presentism.

1.2. Chris's Reflection

After years of suspecting I was autistic, I was informally diagnosed during a period in therapy last year, a response to what I now understand as 'autistic burnout' (Raymaker et al., 2020), resulting from a lifetime of masking my differences and failing to communicate my needs. Such 'echopraxia' (Beardon, 2017) leads autistic people to conceal the internalised 'extreme chaos' of their lives, preventing them from seeking support or adaptation. I was referred for a formal National Health Service diagnosis, joining the notoriously long waiting list (McKenzie et al., 2015). I see autism as an 'assemblage' (Deleuze & Guattari, 1987) unavoidably constructed from medicalised definitions (American Psychiatric Association, 2013) but also comprised of wider social and cultural understandings, drawn from the discourse around Neurodiversity (Silberman, 2016) that emphasises difference rather than deficit. My first diagnostic appointment with a psychologist coincided with the commencement of social distancing. Like many autistic people I have a tendency towards anxiety (Swain et al., 2015), a need for routine and a strong dislike of uncertainty (American Psychiatric Association, 2013). Alongside stress about the global crisis and concern for the wellbeing of others, the prospect that my long-awaited diagnosis could be postponed became a major worry. Receiving a text informing me that I could conduct my appointment, but via telephone, was a mixed blessing. Many autistic people find using the telephone challenging (Beardon, 2017). For me, phone calls often result in overwhelm, as my brain feels like it is having to *reach too far* to cope with the process.

My workplace adjustments relate to the 'triad of impairment' (Milton, 2012) said to characterise the autistic experience. For me these translate into difficulties around social contact, sensory processing and routine. Challenge around non-verbal communication is a key feature of autism diagnosis (American Psychiatric Association, 2013). My brain interprets facial expressions, other than a smile, as hostile, making long sessions in front of large groups of students overwhelming. Sensory sensitivity is also a principal attribute of autism (Belek, 2019), with sensory and social overload being the main stimuli for my regular migraines. At work I minimise sensory discomfort by relocating when the office gets too loud, bright or busy, or when small talk is too uncomfortable. Like many autistic people I process sound differently (Davies, 2019), mediating these difficulties with noise-cancelling headphones. I avoid physical discomfort by wearing comfortable clothes of my own choosing. I have also, with my line manager, addressed my anxieties around unexpected change, and my need for 'sameness' (American Psychiatric Association, 2013).

Change is one of my least favourite states and the disintegration of routine, brought about by the COVID-19 response, resulted in overwhelm and an inability to focus on *anything*. Home working was always an option, but I usually worked at university to maintain a routine and to establish spatial and temporal boundaries between home and work. I strongly associate tasks with locations, recognising home working as a privilege I could not fully appreciate. Having young children also often means that home is a busy and noisy environment, which makes it hard for me to focus on work. Whilst people would appreciate not having to commute, I avoid the sensory and social challenges associated with unreliable public transport by cycling or running. Exercise helps my mental health, as does the associated period of time alone. I value my commute for fulfilling these needs, particularly as previous jobs have necessitated delayed, anxious train journeys. Therefore, giving up my beneficial daily

commute hit me hard. The buffer zone of my commute acted as a boundary marker between work and home, helping my brain to readjust. Now working from home, I lost my means of transition.

Also, fueling my anxiety was the rapid change in the nature of work, arising from the abrupt shift to virtual teaching. Many remote pedagogical approaches tend to resemble complex telephone calls. At work I avoid using the phone, choosing instead to communicate via asynchronous methods, primarily email. My dislike of unfinished exchanges means I respond rapidly, making me easily contactable without needing to lift a receiver. While remote audio communication with a single participant is challenging, meetings or teaching involving video and multiple participants multiplies the complexity. Eye contact via webcam and screen is still eye contact and turn taking in virtual meeting spaces is perplexing. Transitioning to remote working also entailed an oversaturation of university policy and guidance on *everything*. The volume of communication from students also increased, many looking for reassurance or certainty in this bewildering new world. An overflowing inbox added to my overwhelm, and my inability to keep up made me feel further out of control. I found it impossible to regulate my emotional responses, and the emotion dysregulation (Swain et al., 2015) during this period was heightened when one of my children began a course of medication that left them immunocompromised. As such, we were forced into isolation for a period of twelve weeks. Again, boundaries were blurred as this isolation initially involved leaving the house for multiple hospital appointments.

Now a few weeks into the global crisis, my personal crisis has settled down. This has involved negotiating routines and adjustments with family, establishing rules for demarcating work commitments from family time to ensure fair participation in both. This also necessitated an acknowledgement of the impossibility of always separating these two commitments, as challenging as this is. I can even tentatively point to some benefits of this new way of working. My choices are restricted and therefore simplified. Exemption from social contexts removes the need for the hypervigilance usually required to pick up on social cues. I have encountered fewer sensory issues, meaning that instances of migraine have reduced - although family life still brings with it a supply of sensory stimuli. The 'complex and often repetitive, embodied movements' used by an individual for self-stimulatory sensory regulation are often called 'stimming' (Yergeau, 2018). For me this involves repetitive hand movements or pacing about a room. Released from social expectations of having to physically *perform* office work, I am more comfortable to enact these movements at home. There are no colleagues to confuse when I find myself perched on my chair, flapping my hands, or laying on the floor under my weighted blanket. I have also established a routine of daily, socially distanced running that replaces my commute, helping to regulate my sensory system. I have not missed the challenging 'social expectations' (Beardon, 2017) of office work and have maintained social contact via text through apps like WhatsApp and Twitter.

Sometimes small changes have had disproportionately positive outcomes. Buying a pinboard was key to demarcating the liminal space at the end of the landing as my 'home office', helping register this as a place of productivity. My aphantasia (Zeman et al., 2016) prevents me from using visual recall. This, coupled with my poor short-term memory, means I benefit from access to concrete information presented clearly, facilitated by my pinboard. I also appreciate not having to pack my bag for work, a daily routine which, due to difficulties with 'executive functioning' (Milton, 2012), often feels like a mammoth task. At home I have everything I need. In terms of teaching, some students are reluctant to attend 'live' virtual sessions, but have reported they appreciate the non-synchronous, screencast approach offered by pre-recorded narration of lecture slides. I have also found students more eager to engage via email than the other options on offer. In terms of assessment, replacing a face-to-face presentation with a pre-recorded video submission has rebalanced power relations that can manifest when nervous students present in front of lecturers. The fact that different pedagogical approaches suit different individuals can be forgotten with moves that seek standardisation and uniformity.

2. Conclusion

Taken together, our personal reflections illuminate the interrelated nature of work, disability and wellbeing. These are, in turn, complex networks of the temporal and spatial, the virtual and physical, the local and the global, the cultural and social, contingent on bodies, circumstance, things, feelings, senses and emotions. Both accounts reveal how work, as a contextualised practice, makes multiple demands on our bodies and minds. These demands are heightened for disabled people. Although this may be most evident at times of crisis, we should remember that this is *always* the case. Lives extend beyond the immediate work environment and, although establishing routine and boundaries are important, lived experience crosses these constructed boundaries on a daily basis. It should not, therefore, only be in the time of global crisis when the needs of disabled people are considered. This should happen as a matter of course.

Choice and flexibility are beneficial for all, and this period could be used as a stimulus for returning to working life post-COVID with a more informed understanding of need, challenge and accommodation. We ask that we do not seek to return to 'normal', rather we use what we have learnt to improve experiences, going forwards. On an immediate level, we need to remember that there will still be those who are unable to return to offline teaching and learning - those who, because of the 'vulnerable' status held by them or their family members, will be unable to attend physical campuses. We must ensure that staff in these situations do not feel pressure to attend, given that they will be able to continue with the 'virtual' teaching and meeting practices that have been established as standard practice during this period. We also need to make online provision for students in these circumstances.

Out of necessity, the recent shift to virtual working has been across the board. We both noted how different aspects of this move have, after initial challenge, been beneficial. This suggests that, rather than seeking to re-establish physical meetings and teaching for all, offering a more hybrid virtual/physical approach is appropriate. Enabling staff to attend meetings physically OR virtually should be an option, given that we have seen that there are affordances of the virtual. Similarly, it will be useful (as well as necessary) to provide some teaching online, rather than considering physical teaching to be the default. This will take careful consideration to ensure that the needs of all are met but let us not pretend that all needs were being catered for *prior* to this period of imposed change! We have proved, during this period, that flexibility, and freedom from the social expectations and surveillance of the office, does not lead to a drop-in commitment, effort or productivity. Rather, it empowers individuals to do their jobs with less discomfort. As we begin to emerge from this period of crisis, a focus needs to be on moving forwards rather than looking backwards; about designing new ways of teaching and learning that work for everyone, rather than an unthinking return to 'business as usual'. We need to use everyone's shared experience of this time, and their enforced experience of challenge and of different ways of working, as leverage for flexibility and understanding going forwards.

Finally, it is important to note that many of the anxieties and challenges caused by the situation we outline above could have been avoided if planning had been put in place and prior warnings about pandemics had been taken seriously by those in power. It is vital that there is not now a blanket assumption, at either governmental or institutional level, that we are fully prepared to endure similar disruptions in the future. Institutions must have workable policies in place, created in consultation with staff, that are ready to be activated. It is clear that more robust planning and anticipatory action is required, at all levels, that takes note of the needs of disabled workers in advance of such situations, rather than relying on a system that puts the burden of adjustment on the individual.

CRediT authorship contribution statement

Stephanie Hannam-Swain: Conceptualization, Methodology, Investigation, Writing – original draft, Writing – review & editing. **Chris Bailey:** Conceptualization, Methodology, Investigation, Writing – original draft, Writing – review & editing.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix 1. Table demonstrating Challenges and Advantages of the move to home working during the COVID-19 Pandemic in March 2021

Challenges (Steph)	Mitigation/recommendations	Advantages
Transition to sudden home working leading to very high stress levels	Make home working more normalised and so the transition wouldn't be as severe	
Sudden transition to digital learning leading to intense pressure to learn new skills quickly and uncertainty that those skills would be valuable as the information would change rapidly	Introduction of digital learning as standard would force digital skill improvements for staff at a more manageable rate.	
Release of public health guidelines which suggests some disabled lives would not be considered for treatment purely due to 'frailty'	Include more disabled people at the table when discussing and developing such plans	
Distinction between 'work' and 'home' becoming blurred	Setting yourself strict boundaries for when you work and how accessible you are to your workplace/colleagues	
Not all students have the equipment and infrastructure for online learning	Funding for students to buy or rent this equipment and have their internet connections upgraded. Alongside this, training into how to make sessions as inclusive as possible (for example	

(*continued*)

Challenges (Steph)	Mitigation/recommendations	Advantages
	which programs and platforms to use that enable the most devices to access the sessions)	
		Reduction of additional labour in terms of having to coordinate my support needs in the workplace. Ability to tailor my working day to accommodate a better work/life balance taking into account impairment effects such as pain and fatigue. Experiencing less pain and fatigue due to not having to commute to work. More frequent, optional, online meetings provide a sense of support but reduce the physical problems of having to be in a room on campus

Challenges (Chris)	Mitigation/Recommendations	Advantages
Disruption of expectation around diagnostic process for Autism leading to anxiety	Focusing on the relief that this process was still going ahead in some form, in spite of the change	
Additional sensitivity resulting from home working in family environment	Use of noise cancelling headphones. Making a separate 'office' space for work at home. Making university work space available later, following lockdown, for staff who needed it was useful	
Overwhelm and anxiety around unexpected change arising from pandemic	Establishing new routines gradually improved anxieties	
The redundancy of previously negotiated workplace accommodations	New rules established with work and family	
The association of particular tasks with locations	Re-establishing associations over time - becoming familiar with my home 'office' space as a place of work, buying a pinboard for key visual information.	
Lack of transition arising from removal of commute leading to anxiety	Establishing time a space boundaries around work and home life. Establishing a routine of daily running	
Anxiety arising from abrupt loss of routine	The negotiation of new rules and routines with family - setting spatial and temporal boundaries around work - improved over time	
Increase in volume of email correspondence from students	Unavoidable in itself at this time, but reduced over time and sharing some of the challenges I faced helped to strengthen relationships with students over this time	
The need for online communication and the challenge of video calls	Communicated challenge around this to line manager - many meetings were made 'optional' and I was able to catch up via minutes. Communicating to colleagues my need for notice before receiving a call. Suggesting alternative forms of communication eg. email	
		Exemption from social contexts leads to less emotionally tiring hypervigilance and reduction in migraines. More opportunities to physically 'be myself' eg. using stimming and other methods of calming down. Less physical discomfort as able to wear even more comfortable clothes than in office. Some challenging organisational tasks no longer necessary - eg. daily packing of bag for work. Choices are restricted and therefore simplified leading to less overwhelm. Non-synchronous (pre-recorded) session avoid the challenging social aspects of the standard lecturing environment

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