

Society for Research into Higher Education

**Bodies and buildings:
The lived experience of disability, chronic
illness and/or neurodiversity in academia**

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Acknowledgements

The academic year 2019/2020, during which I worked on this dissertation, was extraordinary. I completed my doctoral studies, and we all contended with the global COVID-19 pandemic.

As I am writing these acknowledgements and as I am looking back on this year, I am not quite sure how I have managed to pursue the research, continue data collection, transcribe the interviews, carry out the analysis and deal with writing up. All I seem to remember from the last few months are the guidance I provided to colleagues with their move to online teaching and to my family to maintain normality where there really was none. Yet, here I am with a completed dissertation, and I am sure looking back on these months of turmoil others will remember their many hours of support for me throughout this process.

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Executive summary

This dissertation reports on a research carried out during the academic year 2019/2020 with the support through funding from the *Society of Research into Higher Education*.

The aims of this research project were to uncover how disabled, chronically ill and/or neurodiverse academics experience buildings in higher education, what impact the physical environment may have on their everyday experience and to explore and advance methodological approaches in higher education research.

The overarching research question was: How do disabled, chronically ill and/or neurodiverse members of staff experience academic buildings? Data was collected via a rhythm analysis from one time-lapse video recorded on a Thursday in January 2020, and via interviews with 11 participants, 9 women and 2 men, of whom 5 women are long-established members of academia, whereas the other 6 participants were doctoral students or early careers researchers.

Findings show that despite many improvements and developments over decades, academic buildings still are widely inaccessible, but that inaccessibility is fluid depending on how busy the building is. Ultimately, disabled, chronically ill and/or neurodiverse people are socially and emotionally lonely amongst the masses.

1. Introduction

Research projects are usually borne out of the researchers' personal interests or their professional "hunch" (Trafford and Leshem, 2008, p. 41). The project underpinning this dissertation is no different. In September 2015, I embarked on a doctoral research journey at the University of Kent during which I explored the construction of academic identity under the influence of fibromyalgia (Brown, 2020a). However, very quickly I found myself drawn into the wider debates around disability, chronic illness and/or neurodiversity in higher education. Not only did I uncover a stark underrepresentation of individuals with disabilities, chronic illnesses and/or neurodiversities in higher education (Brown and Leigh, 2018), I also realised how pervasive ableism in academia is and how little discussion there is about that (Brown, 2020b).

Over the course of several years, I sought to explore experiences of academics, researchers, professional services staff and doctoral students with disabilities, chronic illnesses and/or neurodiversities. Through questionnaires, interviews and arts-based workshops I learned about the impact of the contemporary neoliberal academy on individuals with disabilities, chronic illnesses and/or neurodiversities. Higher education publications have also explored the relationship between chronic illness and heightened pressures of marketisation (eg. Tilak, 2008; Gewirtz and Cribb, 2013) and cultural and attitudinal factors impacting academics' personal experiences of health and illness (eg. Opstrup and Phil-Thingvad, 2016; Darabi et al., 2017). The emphasis lies on the academic setting as a culture of perfectionism, over-exertion that does not allow for breaks or holidays (eg. Tytherleigh et al., 2005). However, there is little exploration of how physical spaces in academia could exacerbate or cause health issues amongst those in academia.

Public health research evidences a very clear link between the physical spaces, places of working environments and people's status of health, mental health and illness (e.g. Leaver et al., 2007; Kyle and Dunn, 2008). Buildings, indeed entire cityscapes and landscapes are developed with the end users' mental health and wellbeing in mind (cf. Ige et al., 2018).

Within higher education research buildings are explored as sites of learning (eg. Beard and Dale, 2010; Latimer, 2011), as built environments (eg. Abdul Lateef Olanrewaju, 2012), in the context of green energies and sustainability (eg. Gul and Patidar, 2015; Soares et al., 2015) or within the scope of universal design for learning (Dolmage, 2017) as social and societal barriers to learning and access for those with disabilities and illnesses. University buildings, especially older universities, embody the difference between elitist knowledge communities and the general public through the symbolism of grand staircases and entrance hallways (Dolmage, 2017) with the steps up and into the university posing social and societal barriers to learning and access for those with disabilities and illnesses. However, deeper understanding of the links between buildings and disabled/chronically ill bodies is required to identify means for alleviating some of the difficulties encountered, and to be able to make sense of how people in academia "perform", "act" and "interact".

Findings from my PhD research (Brown, 2020a) show that individuals with disabilities and/or chronic illnesses are required to manage their bodies within the physical space of university buildings. Stairways, heavy doors, lighting fixtures, office sharing, hot desking and open-plan offices all require emotional and physical labour in order to manage symptoms. This insight has led me to raise questions of how disabled, chronically ill and/or neurodiverse academics engage with the buildings and of how the buildings determine the rhythm of everyday academic life? Research and literature are limited in this field and therefore I seek to address this gap. I am responding to the current sociological discourse of bringing the body back into

the focus of research (eg. Bendelow and Williams, 1998; Shilling, 2012). Building on sociological understandings we need to consider bodies not as removed and forgotten or invisible and inexperienced, but as part of who we are and what we do.

The aim of this research project is to uncover how disabled, chronically ill and/or neurodiverse academics experience buildings in higher education. My interest lies in understanding how academic staff with chronic illnesses and disabilities experience and specifically interact with the buildings they frequent and what impact the physical environment has on their everyday experience. I have formulated the following research question:

How do disabled, chronically ill and/or neurodiverse members of staff experience academic buildings?

The sub-questions to answer the research question are:

1. How does a building's lifecycle impact individuals' performance and actions?
2. How do disabled, chronically ill and/or neurodiverse people in academia navigate the building?
3. How do disabled, chronically ill and/or neurodiverse people in academia manage their physical surroundings and working environments in order to manage their bodies?

However, the aim of the research is not limited to merely better understanding the interrelationship of buildings and bodies or to gain a deeper insight into the lived experience and performativity of disability, chronic illness and/or neurodiversity. Given my interest in research approaches, I also wish to tend to exploring and advancing methodological approaches in higher education research.

What follows on from here, is the report on the research carried out during the academic year 2019/2020.

2. Methodology and methods

Research approach

Epistemologically, ontologically and philosophically, I find myself most at home with phenomenology as understood and practised by Max van Manen (2016a, 2016b) and Maurice Merleau-Ponty (2012) combined with the hermeneutic tradition of Heidegger (1996/1953) and Gadamer (2006/1975). These foundations combined build the framework for Embodied Inquiry (Leigh and Brown, forthcoming), which sees the body and embodiment as central to research. To follow the basic principles of Embodied Inquiry means to heed the researchers' and/or the participants' body, to explore the lived experience, and to allow for a variety of methods of data collection and forms of communication. To meet my project aim about advancing methods, whilst at the same time answering the three sub-questions, I planned for an Embodied Inquiry using a two-stage approach combining rhythmanalysis with walking interviews within an interpretive qualitative research framework (Willis et al., 2007).

Due to unforeseen circumstances, I was not able to start data collection for the project "Bodies and Buildings" before the spring term of the academic year 2019/20. I then undertook an initial rhythmanalysis recording and several reconnaissance trips to identify the best locations and times for the recording to ensure interesting and varied data.

Unfortunately, by the beginning of March 2020, the situation around COVID-19 had become so serious in the UK that in the week of the 9th of March the University College London started to ask for provisions to be made to mitigate the COVID-19 impact and prepare for social distancing measures, such as working from home. I was ordered to work from home from the 12th of March onwards.

Under the given circumstances, I needed to rework my approach to research to allow for research to be continued under consideration of the rules and regulations around COVID-19

distancing and prevention strategies. Instead of several time-lapse videos across various buildings I was forced to work with one video that I had taken in January during the reconnaissance phase. The walking interviews were obviously also not possible and had to be replaced by interviews to be carried out online.

Research process

Rhythmanalysis

Due to the changes made, the rhythmanalysis presented in this dissertation is based on one time-lapse video of approximately 3.5 minutes. The time-lapse records the comings and goings from 10:05 am to 10:55 am in the lobby and entrance area of the UCL Institute of Education on a Thursday in January during the spring term of 2020. During this time, I sat next to the camera observing the interactions and making notes in relation to sounds and smells that would not be observable within the film itself.

The space that was filmed (see Figure 1) is a large lobby entrance consisting of both a revolving and an automatic door to an academic building. The lobby is open plan and contains a seated area along the left side of a walking path, a small café across from the entrance, a back entrance to the library when one turns left after entering the building, and a set of stairs to the right of the walking path that goes down to the next level. This next level is the actual main entrance to the building and has its own small square path. Across from the café there is also a reception desk that was not visible, and there is another entrance to the main lobby past the café and reception desk.

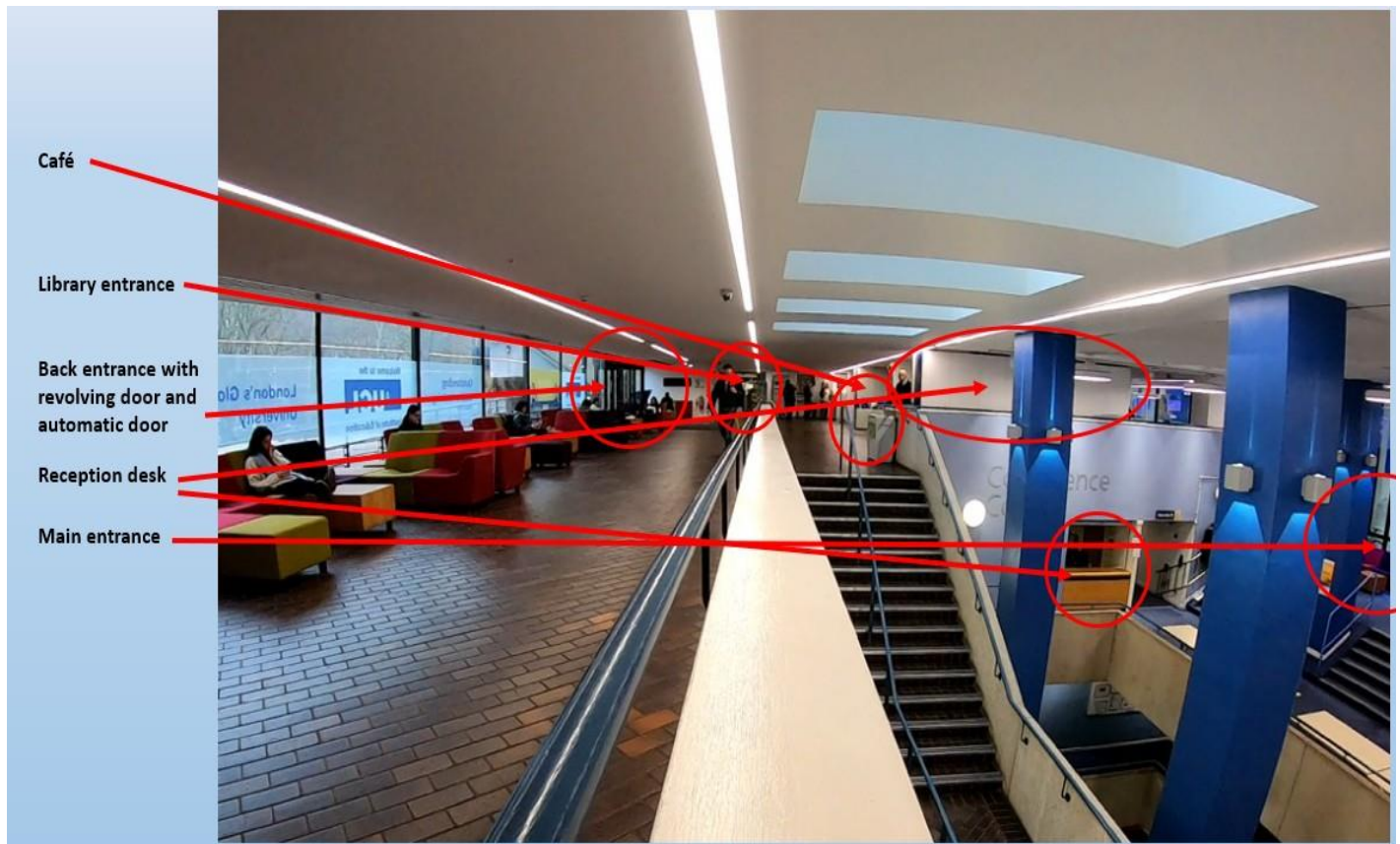


Figure 1: Annotated still image depicting the entrance area of the UCL Institute of Education

Interviews

Having gained ethics approval for the amended approach to interviewing, I recruited academic staff and doctoral students as participants for the research.

I had long debated the eligibility criteria before settling for academic staff and doctoral students as participants eligible for my study. Over the course of the last years I had seen the wealth of literature available regarding the lived experience of disabled students in all educational contexts from primary school through to tertiary education. However, very little has been published regarding the lived experience of disabled staff in academia. In the end, I decided that I would also include doctoral students for two reasons: Firstly, in terms of usage, University buildings are predominantly the work and study place for students from undergraduate through to postgraduate levels. I therefore felt uncomfortable excluding students from this study altogether. Secondly, doctoral students are most often not just

students, but also teach as part of postgraduate teaching assistant schemes. As a consequence, doctoral students find themselves in the liminal space of being a student and an employee and yet, not fully being either.

I recruited 12 participants, 10 of whom were women and 2 men. Unfortunately, due to her fluctuating condition and her significant deterioration in health in connection with COVID-19-like symptoms, one female participant was never interviewed despite four attempts to reschedule the interview. Of the remaining 11 participants, 5 women are long-established members of academia, whereas the other 6 participants are doctoral students or early careers researchers. Across the 11 participants who were interviewed, a wide range of disabilities, chronic illnesses and neurodiversities was covered. This is because many conditions do not exist in isolation but are presenting as comorbid, but also because some illnesses for example may trigger mobility issues, which in turn affects an individual's disability status. One participant is a wheelchair user, and another participant uses a white cane, as commonly used amongst blind or visually impaired people. Three participants have been diagnosed with one or several neurodiversities: autism, Asperger's syndrome, dyslexia, dyspraxia and attention deficit and hyperactivity disorder (ADHD). Several participants have diagnoses related to mental health issues, such as depression and bipolar disorder, either on their own or in conjunction with the psychosomatic condition fibromyalgia. Other conditions and disabilities mentioned were narcolepsy, asthma, chronic migraine, cystitis, irritable bowel syndrome, postural tachycardia syndrome (POTS) and traumatic brain injury following an accident. Most participants also highlighted other ailments, which in their view accompanied their primary conditions, but were severe enough to be disabling in themselves. These ailments were fatigue, sensory overload, headaches and nausea.

The interviews followed Brinkmann and Kvale's (2015) concept of an interview, thus a conversation between two people and lasted between 43 minutes and 1 hour 54 minutes. All conversations took place as recorded Zoom calls, as this platform is my institution's preferred option for online interviews. I commenced all conversations with asking participants if I would be allowed to record the call and starting the recording once that verbal consent had been given. I ended all conversations with participants with an invitation to email me with additional statements or other forms of representations and communications, should they feel they would want to add more information to the interview. Some participants took up this offer and emailed through personal reflections and photographs.

Data analysis

My approach to data analysis is founded on the principle that analysis is a subjective process requiring transparency, reflexivity, and criticality in order to ensure good quality and rigour (Brown, 2019, p. 497). In a project like this one, where there are different sets of data, the analytical process becomes even more organic and dynamic than in traditional interview settings, as the analyses of the two major data sets – the rhythm analysis and the interviews – are interlinked and influence one another. In practice, therefore, the process of analysis is not linear but a consistent to-ing and fro-ing between the separate individual sets of data and the wholistic view of the two sets together.

3. Analysis of results

The contemporary climate of the neoliberal academy disadvantages disabled, chronically ill and/or neurodiverse staff in many ways. There are concerns around job security and stability (see Taylor and Lahad, 2018), there are challenges around the discourses of excellence (Blackmore, 2015; Abouserie, 1996; Watermeyer, 2015) and hyperprofessionalism (Gornall

and Salisbury, 2012), which in turn raise issues regarding health issues as a result of overwork (Taris et al., 2001; Opstrup and Pihl-Thingvad, 2016; Darabi et al., 2017). The interview findings show, however, that these concerns are only part of the story. The physicality of the buildings and the challenges of navigating university campuses are often a far more significant barrier to working in academia.

The behaviours observed in the time-lapse video combined with the stories told in the interviews highlight three key concerns that I would like to discuss further: (1) the impact of the buildings' physicality and materiality, (2) the fluidity of disability experiences and (3) experiences of loneliness.

The physicality and materiality of buildings

Bringing together the findings from the rhythm analysis and the interviews, highlights the discrepancy between experiences: On one level, we can see a group of individuals within a shared space falling into a certain rhythm and understanding about how the space is to be used. At another level, we hear the stories of individuals who are also trying to navigate this same space, but feel that they are too different to belong and are formally excluded by physical barriers. These barriers include doors, but also varying sounds and noise levels, changing smells as well as flickering lights. The impact of light on individuals is a particularly noticeable discussion point, as the effects of lights and glares in buildings have been studied and discussed since the 1950s. Petherbridge and Hopkinson (1950), for example, studied specifically the relationship between brightness and glare in rooms, its impact on comfort amongst people, and its potential levels of disabling effect on individuals. Yet, in the interviews carried out in 2020, some 70 years later, participants still felt they needed to highlight the negative effects light has on them. Similarly, the overall building accessibility itself is a matter that is still of grave concern to those with disabilities, chronic illnesses

and/or neurodiversities. The situation is particularly difficult for people with mobility issues, as despite improvements in wheelchair accessibility and substantive overhauls of legal and regulatory frameworks, a systematic literature review found that no study reviewed was able to report 100% wheelchair accessibility (Welage and Liu, 2011). The matter is further compounded by the historicity of many university buildings, which require different, and often more expensive, architectural approaches in order to ensure disability accessibility (Smith, 2006). In short, despite the many campaigns for accessibility and inclusions, and despite the introduction of the Disability Discrimination Act 1995, the Equality Act 2010 in the UK or the equivalent in other countries, such as the Americans with Disabilities Act in the US, there still remains inequality in access (Gray et al., 2003).

The fluidity of disability experiences

Bearing in mind the discussion from the previous section, it is not surprising that the disabled, chronically ill and/or neurodiverse experience their "otherness" as fluid (Barnartt, 2010). In a space that is shared amongst abled and disabled people and where the rhythm is set by those rushing through, people, whose bodies do not allow them follow that same pattern or rhythm, are made more acutely aware of their differences. This experience, although not formally articulated, is evident in most participants' stories, but most prominently in the statements by Participants 5 and 7, who talk about depending on others in emergency situations or when lifts break. Similarly, in the time-lapse video it is evident that the wheelchair user and the blind person with assistant behave differently to others, in that they stand aside and wait to use the right door, which others are occupying unnecessarily. Although these two situations may have been experienced as minimal at a personal level by the people involved, the incidents do evidence and exacerbate individuals' "special needs" beyond what is "normal" (Deegan, 2010). To some extent, in these

situations, disabled individuals consciously experience their "absent" bodies "dys-appearing" (Leder, 1990) and requiring attention.

In effect, the physicality of the buildings impact individuals' experience of their disabilities and "otherness", which, in turn, leads to individuals needing to adopt different kinds of behaviours (Goffman, 1990/1959, 1990/1963). Disabled, chronically ill and/or neurodiverse participants in this research talked about their ordinary routines to get to and around campuses and university buildings for practical as well as emotional reasons. At a practical level, there are certain routes that are inaccessible, but at an emotional level, there are instances where individuals avoid crossing paths with colleagues or students. These avoidance techniques are common strategies employed by the stigmatised to counter those particular processes of stigmatisation (Goffman, 1990/1963) in order to gain and remain in control over what is known about them (Goffman, 1990/1959). For disabled, chronically ill and/or neurodiverse people, navigating the university buildings therefore simultaneously represents the navigation of their self in their virtual social identity of being an academic and their actual social identity of being disabled (Goffman, 1990/1963). Props and aids, such as backpacks, medications and canes, may well be needed for assistance, but as these are stigma symbols, they will automatically discredit individuals and out them as different and atypical (Goffman, 1990/1963). Conversely, not using particular stigma symbols or only using them in private spaces enables individuals to separate between their public and private personas (Goffman, 1990/1959).

Experiences of loneliness

Considering the statistics and the low numbers of disabled staff in academia, and considering the narratives of using quiet routes and back doors, the overall invisibility of disabled staff in academia is not surprising. Additionally, many conditions and

neurodiversities are not outwardly visible, and individuals may decide to pass (Goffman, 1990/1963) rather than disclose (see Brown, 2020c for more on disclosure in academia). The resultant behaviours to counteract a narrative of "difference" and "otherness" therefore often leads to feelings of isolation and loneliness amongst those who are disabled, chronically ill and/or neurodiverse. Additionally, however, as has been shown in the rhythmanalysis, the materiality of the buildings, their pace, patterns and rhythms cause individuals more generally to be on their own amongst the masses.

Being on one's own and loneliness have long been discussed amongst nursing scholars and medical sociologists in connection with elderly people. In these contexts, loneliness is described as an existential anxiety (Casey and Holmes, 1995), as a state of silent suffering (Moustakas, 2016) or as a sadness and response to pain and desolation (McInnis and White, 2001). On rare occasions, being on one's own is equated with a state of wellbeing that is reached in connection with meditative practices or prayer (de Jong Gierveld, 1998), which would most commonly be described as solitude. The most relevant description for this study and for what is observable in the video and the interviews is the typology of loneliness as a form of emotional and social isolation (Weiss, 1973). The social form of loneliness and isolation is the visible withdrawal from interactions and removal from busy-ness, whereas the emotional form is an internal experience of being on one's own. Unfortunately, the line between solitude and loneliness is thin. Where I may have observed a person on their own in the time-lapse, they may well have been lonely. This is particularly true for the visibly disabled people, the wheelchair user and the blind person, who were invisible to the masses and so were forced to wait their turn. In contrast, participants 2 and 6 talk about withdrawing from given situations to lie down and be on their own. Although, it may be all-too-easy to think that a person who is sick may be needing help, in that moment they not experience loneliness, but seek solitude, instead.

4. Conclusion and outcomes

As mentioned earlier in this report, I had not exactly planned what I ended up doing. Under the circumstances of the global COVID-19 pandemic, it was only natural that my research plans and planned methods for data collection had to change.

How do disabled, chronically ill and/or neurodiverse members of staff experience academic buildings?

The data clearly shows that despite many improvements and developments over decades, academic buildings still are widely inaccessible. However, the inaccessibility is not always due to the buildings themselves, but due to the people within them. Bags that are left on the floor, cables that trail across pathways, even people sitting down and having rest can all become trip hazards, but are even more dangerous for those with mobility issues. Yet, this is still only one part of the story, as individuals are able to navigate buildings in their specific ways and manners and work out a rhythm that suits their bodies within the buildings they frequent.

If there was one way to sum up how disabled, chronically ill and/or neurodiverse people experience academic buildings it would be that they are lonely amongst the masses, with this loneliness being triggered by the inaccessibility of the building and the barriers that represents (Oliver, 1983, 2013) but also triggered by their innermost feelings and experiences of their own dys-appearing bodies (Leder, 1990).

Reflection and evaluation of the research

The rhythmanalysis proved by far more yielding than I had anticipated. Rhythmanalysis is a particular way of looking and by drawing on the researcher's embodied and visceral knowledge, offers insights into social life and interactions (Lyon, 2018; Lefebvre, 2004). In this sense, rhythmanalysis affords an insight into individuals' behaviours, which enable a second, broader layer of analysis. As with any research approach, rhythmanalysis also has its downsides. The role of the rhythmanalyst's experience of embodiment and the body as primary tools for research render rhythmanalysis subjective and dependent on positionality in ways that other forms of research do not. Whether or not we simply consider rhythmanalysis as a sensorial, corporeal (Potts, 2015) version of participant observation (Merrifield, 2006), the approach does help us understand life rhythms and patterns. However, rhythmanalysis used on its own is not sufficient to truly understand interactions and social life. It is possible to observe patterns and rhythms, but the motivations behind particular behaviour patterns require additional exploration. These behaviour patterns are elements of interpretation that have shone through in the interviews, where individuals were specifically focussing on how they personally and individually use and navigate university spaces.

Bearing in mind the circumstances, I am happy with what I have achieved with this dissertation, but I am not entirely satisfied. I do think that walking interviews and the use of several time-lapse videos from different days of the week and various weeks throughout the academic year would have added a layer of knowledge that is currently missing.

Dissemination and agenda for further research

Leading on from the previous section, I am confident about the value and relevance of this research project. Sections I have written as part of a literature review to situate this study

will be published within the scope of introductory overviews in two edited books *Ableism in Academia: Theorising Experiences of Disabilities and Chronic Illnesses in Higher Education* (UCL Press, 2020) and *Lived Experiences of Ableism in Academia: Strategies for Inclusion in Higher Education* (Policy Press, 2021). Regarding the use of rhythmanalysis, I have already contributed a chapter to the book *Temporality in Qualitative Inquiry: Theories, Methods, and Practices* edited by Clift et al. (Routledge, 2021). I am in the process of finalising a traditional research article around the interviews with a view to publish in a higher education journal.

However, as I am somewhat unhappy about the data collection due to the COVID-19 situation, I still aim to record two or three more time-lapse videos and to organise two or three walking interviews. Another avenue that has opened itself through this particular research project is, of course, the consideration of how much COVID-19 has impacted and changed the lived experience of disabled, chronically ill and/or neurodiverse members of academia. Although I have my thoughts around the disability imaginary of the future, it would most certainly be interesting to formally research what COVID-19 has meant and continues to mean. This is because many research participants referred to the situation and differentiated clearly between the "before lockdown" and "after lockdown".

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