

**Abstract**

In this article, I draw on my research regarding the lived experiences of 28 academics with fibromyalgia, whose academic roles ranged from early careers researchers undertaking their PhD studies, to mid-career academic practitioners and lecturers to professors in later career stages. I present the active work academics undertake on their bodies to navigate the working environment in higher education. I commence with an overview of the lived experience of fibromyalgia before providing an insight into being ill and/or disabled in higher education. I outline the context and details of the fibromyalgia study before discussing the participants' experiences of managing their fibromyalgia symptoms, managing their public and private selves and of being ill in academia. In the conclusion I return to the key issues of the ill and disabled body in academia, where I outline how managing the fibromyalgia body in academia represents a specific form of bodywork on the part of the individuals.

**Keywords:**

bodywork, fibromyalgia, academic identity, public self, being ill, higher education, academia

## **Managing fibromyalgia in higher education**

### **Introduction**

Over the past two decades the body has re-entered the social sciences as object and subject of research, and is an explicit focus in research in relation to the concept of identity formation, where scholars recognise the interconnected relationship between body and mind (Beck et al., 1994). The body is no longer seen as a mere vessel containing the human being, it forms identity and as such is a project involving development and improvement. However, often the body only comes into our conscious experience when it fails us (e.g. Leder, 1990; Shilling, 2012). With few exceptions (Freedman and Stoddard Holmes, 2012; Leigh, 2019; Brown and Leigh, 2020; Brown, 2021), embodiment is not commonly discussed in the context of academia, and so the body in education or higher education still remains largely absent.

In this article, I draw on my research regarding the lived experiences of academics with fibromyalgia. The focus on this demographic stems from the complicated relationship between fibromyalgia symptoms, academics' personality and the working conditions in contemporary academia. This article therefore discusses academics as embodied workers in general and more specifically which role a contested chronic condition like fibromyalgia, plays for individuals within academia as a workplace. I explore the research participants' lived experiences of working in academia and how academics view the interrelationship between working in academia and fibromyalgia. I argue that despite the academics' cerebral understanding of disabilities as social justice and social issues, their dealing with and experience of fibromyalgia are deeply embedded within a strongly internalised medical positioning. My contribution lies in the exploration of the higher education context and the active work academics undertake on their bodies to navigate their working environment.

### **Literature review**

#### ***The lived experience of fibromyalgia***

Fibromyalgia is a complex condition characterised by persistent wide-spread pain, chronic fatigue, sleep disturbances, increased sensitivity, psychological disorders and cognitive dysfunctions, often described as "brain fog" or "fibro fog" (White and Harth, 2001) and it is associated with a wide range of somatic symptoms (Wolfe et al., 2010). The range of symptoms on its own makes the condition difficult to grasp, but in addition, fibromyalgia symptoms typically wax and wane, change and move. These shifts of kinds of symptoms, their distribution and their severity happen over the space of longer periods such as months

and weeks, but often occur within days or even within hours. Added to that, there is no specific test to diagnose fibromyalgia, and so it is diagnosed by excluding other conditions. The lack of a definite process for diagnosis and the variability of the condition make fibromyalgia a doubtful and contested condition even within the medical professions (Ehrlich, 2003; Wolfe, 2009; Häuser and Fitzcharles, 2018).

Numerous studies relating to the lived experience of fibromyalgia and what it means to live with a fibromyalgia diagnosis report on the relative difficulty of coming to terms with the condition (e.g. Råheim and Håland, 2006; Sallinen et al., 2011; McMahon et al., 2012a, 2012b; Diviney and Dowling, 2015). Receiving a fibromyalgia diagnosis may be a welcome relief from anxiety around more severe and life-threatening diseases. For the individual, an accurate and unambiguous categorisation also means gaining access to treatments, healthcare and insurance entitlements (Briones-Vozmediano et al., 2013; Mengshoel et al., 2018). For others, the relatively vague status of fibromyalgia between psychological disorders and physiological causes leads to doctor-shopping, rejecting the diagnosis and refusing treatment (Sturge-Jacobs, 2002; Mengshoel et al., 2018). It appears that because of its contentious and mysterious nature, fibromyalgia does not allow for imbuing or making meaning of the condition (Madden and Sim, 2006). As a consequence, individuals with fibromyalgia perpetuate a medical view of their illness by focussing on normalising life (Juuso et al., 2011, 2013), staying healthy (Grape et al., 2015) or finding treatments to fix their "dysfunctional" bodies (Eik et al., 2020). Fibromyalgia prevalence studies confirm a male to female ratio of 1:9 (Grodman et al., 2011), with the large majority of women diagnosed with fibromyalgia aged from 30 to 40 years and older. Although there is no typical fibromyalgia personality as such (Malin and Littlejohn, 2012), fibromyalgia is more likely amongst people who are action-prone and tend to over-exert themselves (Van Houdenhove et al., 2001), amongst people who show high levels of neuroticism-anxiety and low sociability (Albiol et al., 2014), amongst people who display high levels of harm avoidance, persistence and self-transcendence combined with low levels of self-directedness (Lundberg et al., 2009; Glazer et al., 2010), amongst people with high levels of neuroticism and psychoticism (Montoro and del Paso, 2015), and amongst type D personalities, who experience negative emotions but do not express those to avoid disapproval or rejection (van Middendorp et al., 2016). These are all traits that are often ascribed to women and academics.

### ***Being disabled/ill in higher education***

The contemporary environment of higher education is one where overwork, productivity and effectivity are praised (Taylor and Lahad, 2019). Demands of the universities mean that academics are continuously required to carry out high quality research, acquire relevant research funding and produce reputable research publications (Abouserie, 1996; Watermeyer, 2015). The pursuit of excellence is crucial if an institution is to gain higher status and a better reputation across the higher education market, which in turn attract more students, more staff and more funding. Excellence therefore leads to prestige, a relational value against which institutions measure themselves (Blackmore, 2015).

For individuals, working in a prestigious institution is motivation to increase productivity and quality of their own work to input and contribute to the institution's collective prestige (Blackmore, 2015). In addition, the common fallacy that working in academia is a privilege prevails. Academia, it is felt, offers freedom, flexibility and autonomy in ways that other workplaces do not (Ylijoki and Ursin, 2013; Sutton, 2015). Freedom and flexibility do represent a major advantage of working in academia, but at the same time are an equally major drawback, as they embody a form of control (Henkel, 2005a). Belonging to the academic community means to be amongst like-minded individuals and as such offers a sense of security and safety, but there is "a price to be paid for the privilege" (Bauman, 2008:4). Being part of a community means individuals lose freedom, autonomy, the right to assert themselves and to be themselves. In this sense, flexibility of work is not enabling but a means to maximise labour contributions as cheaply as possible (Lovin, 2018). The work flexibility offered at academic institutions results in the need to demonstrate "heroic stamina" (Beretz, 2003:52) to work at all times. In effect, academics conform to and have internalised values of workaholism (Fassel, 2000), which is an "addiction that [Western societies] praise, value and brag about" (Gini, 1998:18).

For academics who are disabled, chronically ill and/or neurodivergent, this already dire picture of a pressurised working environment is further compounded. Explorations of academics' lived experiences of disabilities, chronic illnesses and/or neurodivergence have started to emerge over the past few years (e.g. Inckle, 2018; Waterfield et al., 2018; Brown and Leigh, 2018, 2020; Olsen et al., 2020; Brown, 2021). The most recent discourses and research reports specifically focus on the value, skills and knowledge disabled academics bring to an institution (e.g. Hansen, 2020; Lourens, 2021). Despite these influential publications, however, academia continues to be experienced as an ableist environment with significant barriers to work. In the following I show what happens to and for individuals

who may have been diagnosed with fluctuating and contested conditions, such as fibromyalgia, that are experienced as disabling, within such an environment.

### ***A gap in the literature***

From my personal experience of working in academia and having been involved in fibromyalgia support groups, I had gained anecdotal evidence that fibromyalgia was more prevalent in academia than may have been acknowledged formally. The above literature review demonstrates the complexity of fibromyalgia as a contested condition as well as the contextualised issues of illness and disability in higher education. Additionally, studies highlighted that students, teachers, medical staff and doctors were overrepresented amongst the patient groups for chronic fatigue syndrome or myalgic encephalomyelitis (Wessely, 1990, 1994), a condition that is closely related to fibromyalgia. Yet, there is a clear gap in the literature that connects fibromyalgia with academia.

### **Methodology and methods**

#### ***Research aims and questions***

The aim of the research reported here was to offer insights into academia as a workplace and to explore how this particular workplace may foster or potentially cause distress that becomes physically manifested in the disabling condition that is fibromyalgia. To this end, I formulated the following overarching research question (highlighted in bold) and three subsidiary questions:

#### **What is the relationship between fibromyalgia and academic identity?**

1. What is the role of academia for an academic?
2. What does fibromyalgia mean for an academic?
3. How is fibromyalgia experienced in academia?

In order to fill the gaps raised by previous research into fibromyalgia and illness within higher education, I designed an Embodied Inquiry (Leigh and Brown, 2021). Embodied Inquiry is an approach to research that centralises the role of the body, that of the researcher and that of the participant, throughout the entire research process. Philosophically, Embodied Inquiry is situated within hermeneutics and phenomenology, so that research is a meaning-making process between the researcher and their participants, with the relationship between the researcher and their participants seen as dynamic and collaborative. As a consequence, ethics was also dealt with in a relational way as a process

beyond the institutional ethical approval, which was successfully obtained at the beginning of the research.

### ***Recruitment and sampling***

Having received ethical approval, I recruited participants for the study via calls for participants on social media and mailing lists. For individuals to be included in the study the participants needed to have been diagnosed with fibromyalgia and they needed to self-identify as academics. Individuals would then email me to ask to be included in the study, following which I provided the full information sheet and consent form.

This recruitment process led to the sample size being varied in terms of the academic positions, roles and workplaces represented. I recruited 28 academic participants, of whom 2 were male and 26 were female. All participants identified as British, with 26 participants identifying as white, one person identifying as Black and one identifying as Asian. Academic roles ranged from early careers researchers currently undertaking their PhD studies, to mid-career academic practitioners and lecturers to professors in later career stages. Participants' working conditions ranged from independent research positions and self-employment, to hourly paid lecturers, part- and full-time employments at pre- and post-1992 institutions.

The fibromyalgia diagnosis as inclusion criterion was more clearly defined and led to fewer variabilities. All participants had received a formal diagnosis at some point in their lives, with the time lived with a formal fibromyalgia diagnosis between 3 and 10 years. During the course of my research and work with participants, two participants' fibromyalgia diagnoses were re-evaluated and refined. The fibromyalgia diagnosis was not entirely revoked but reframed within the context of Ehlers-Danlos Syndrome and Central Sensitisation Disorder, respectively. As the fibromyalgia diagnosis continued to be relevant and both participants' treatments for fibromyalgia were also continued, the participants' contributions to the research were not excluded.

### ***Data collection***

In the spirit of participatory research and collaborative sense-making the process of data generation in this Embodied Inquiry combined interviews with creative and arts-based forms of communication. Interviews were held via Skype, recorded using the additional software application Evaer and lasted for one hour. All recordings were transcribed verbatim.

Participants were also encouraged to provide additional materials to illustrate, exemplify and further explain their experiences. As a consequence, the final data sets consisted of transcribed interviews, photographs, poetry, narratives, mind-maps and collages.

### ***The analytic process***

Analysis followed the principles of the reflexive thematic analysis (Braun and Clarke, 2006, 2019) in an iterative, spiralling process. The interview data was input into NVivo and coded according to the principles of good quality research being critical, reflexive and transparent (Brown, 2019) as determined in Embodied Inquiry.

The data was considered and reconsidered at regular intervals consisting of several cycles of coding. At first, I familiarised myself with all transcripts, then I began the coding process by highlighting large categories such as "academic contract", "academic identity", "disclosure", "experience with fibromyalgia" "symptoms of fibromyalgia", "managing symptoms" or "feeling ill" and "being well" in separate transcripts. Once I had identified a code in one transcript, I then reread and recoded all other transcripts for the same codes to ensure they were all relevant.

The analytic process then moved to the visual materials, such as the collages, the mind-maps and the photographs, which the participants shared with me. I analysed the visual materials according to the first and second levels of interpretation as outlined in the systematic visuo-textual analysis (Brown and Collins, 2021). The first level is noticing and describing, where the use of perspective, colour, space and composition are noted. The second level of interpretation is conceptualising, where elements are identified that unite all artefacts. The analysis therefore moved from one participant's submissions to all other participants' materials. The key elements that united the artefacts related to the depiction of the public and the private as two separate entities. I then returned to the NVivo files to specifically search for connections between the artefacts and the codes.

The next stage was to redefine and review all codes and categories from the textual and the visual materials to generate themes. To this end, some codes were combined, whilst others were excluded, so that ultimately three key themes relevant to academic identity and work, and the impact of fibromyalgia on academic work and career were identified: (1) managing fibromyalgia symptoms, (2) managing the public and private self and (3) being ill in academia.

Finally, the codes and themes generated from the codes were shared with participants for member-checking. At the same time, the quotes providing evidence for the codes and themes were also shared and specific consent was sought for the quotes to be included in the final write-up with the proviso that pseudonyms would be used instead of actual names.

## **Findings**

In the following, I present the key themes I identified: (1) managing fibromyalgia symptoms, (2) managing the public and private self and (3) being ill in academia.

### ***Managing fibromyalgia symptoms***

Having fibromyalgia means to consciously counteract pain, mental health issues and cognitive dysfunctions. Throughout their illness experience, most participants have learnt to manage their bodies and have developed strategies to better cope with the fibromyalgia symptoms. This is achieved through medication (Baker and Barkhuizen, 2005), but also through alternative means, such as massages and homeopathy (Ashe et al., 2017). The general message regarding fibromyalgia was to seek to alleviate pain early on. One participant created a series of photographs demonstrating this active management of the body. Strategies for pain management included medication, the application of heat or ice packs, support structures, such as height increases on laptops or lumbar support for chairs, or support stockings and wrist support:





**Figure 1: Photographs demonstrating strategies to manage fibromyalgia symptoms**

The above photographs represent a specific kind of bodywork academics undertake to manage symptoms. By applying heat packs, creams and the like, academics with fibromyalgia effectively do work on and to their own bodies in order to manage and control what are perceived as deviant bodies. Individuals become experts in listening to their bodies (Bates, 2019), recognising their limitations (Juuso et al., 2011) and developing a routine around the failing body (Charmaz, 1997). Participants talked about avoiding pain wherever they could, for example, through getting up and stretching or varying activities from sitting down to moving around. In Charmaz's (1997) terms they have developed a way of life that incorporates the illness routine into their everyday activities. This is further exemplified in the strategies academics use to deal with as cognitive dysfunctions. For participants, the issue with brain fog is that they cannot actively work towards avoiding it and therefore they need to employ strategies to deal with potential situations of brain fog occurring suddenly. The strategies for brain fog are largely employed on a private level through taking copious notes, maintaining detailed records or through alternating more difficult with some lighter, mundane tasks:

I've just adapted to learning to do other kinds of work tasks. So, I get brain fog but then I do things like file my expenses, or plan my, plan my next research trip, or change my syllabus for the fall term, or, erm, you know, tidy up my papers and my references system or do a, awful lot of email and conference planning and stuff. I just do other low-level tasks

Sian

I wouldn't manage without it [keeping records], so we're insisting.

Kate

Employing such illness routines has two purposes for the academics: they manipulate their bodies to promote physical wellbeing as well as to reinforce their academic identity. In effect, academics engage in conscious manipulation and management of self (Goffman, 1990/1959) through information control (Goffman, 1990/1963). Naturally, dealing with symptoms includes the emotion work needed to come to terms with a failing body, and as such is part of identity work more generally, as the body represents the event of becoming (Budgeon, 2003). When participants look after themselves and employ strategies towards avoiding or pain and brain fog, they make clear decisions on what they do in the public or the private realm.

Additional support materials, such as ergonomic chairs and stands, use of dictation software products and the like require careful consideration. The participants talked about how such tools and implements were helpful, and how they used them in their own homes. And yet, they did not use them within the public sphere of the academic office, specifically within those that are designed as shared or open-plan spaces. Where academics are using specific tools, gadgets and support materials, they do so, expecting that their colleagues will feel differently about them and that they will stand out.

I get up from meetings a lot and I need a desk near the bathroom. [...] I have physical accommodations at my desk. I have working practice accommodations with Flex-time and flexible location.

Sian

Managing the fibromyalgia body is therefore closely interlinked with the management of the academic body as a public and private identity.

### ***Managing the public and private self***

For many participants, continuing their roles in academia is intrinsically linked to who they are and how they see themselves. Within higher education the public self, the person who is

represented on university profiles and who presents at conferences, for example, is kept quite separate from the more private self, which emerges in familiar surroundings among friends and family, but also in everyday settings. The public picture academics present is heavily edited, in order to protect others from the realities of their experiences, but also to protect themselves from becoming even more vulnerable:

My Instagram is just cakes and gardening and cats and, and, you know, knitting and it's just nice stuff. [...] I think that's really common [...] it's a very, very narrow version of what's happening.

Hanna

It is quite understandable that individuals would not want to upset friends and family by highlighting how badly ill they are; or that they would not want to open themselves up to criticism.

Returning to work after a prolonged absence also requires additional bodywork and emotion work. Jackie, for example, was required to adjust to having had her work tasks and responsibilities changed in her absence:

I felt like I was just being pushed to one side. [...] It's almost like I wasn't there and therefore I didn't have a value. It's so bizarre.

Jackie

Jackie expresses very clearly the emotional upheaval and isolation she experienced on the basis of the alternative provisions that were put in place during her absence. In addition to emotional isolation, participants often feel physically and literally isolated. Being moved into a specific part of a building, or being assigned particular work spaces or offices can mean that individuals are quite literally removed from the majority of their peers. Managing the body is therefore not merely a social or personal matter, it actually is materially spatial, too, resulting in physical isolation, as well as emotional.

### ***Being ill in academia***

Being an academic means more to individuals than a mere profession or role. For the participants, being an academic is a lifestyle choice that allows them to indulge in their personal curiosity and thirst for knowledge. In this sense, fibromyalgia represents an admission of weakness. It is this element of weakness that also determines the tendency towards not disclosing fibromyalgia. For some participants, considering themselves as ill or disabled is a self-fulfilling prophecy and the beginning of a downward spiral of failure that will be more difficult to escape. Therefore, instead of admitting defeat the academics push themselves through episodes of illness, pretending that everything is fine:

Some days I have no idea how I've got to the end of a lecture because you put so much energy into it, especially on those days, when you've got more and more tired [...] I do sometimes get to the end and think, I don't actually remember the last part of the lecture, but we got there.

Jackie

People see me as being able, and yeah, they see the image I portray; they see me as being able and energetic and mostly on and up.

Yasmin

In the conversations, participants highlighted that even once they have personally come to terms with being ill, the disclosure of that illness in academia is still contentious. Attitudes and expectations in relation to productivity and ways of working are such that deviation from that norm is practically impossible, especially in an environment where precarious contracts and job insecurity are rife:

I don't think you can, you can like openly disclose.

Kate

You're breaking protocol because you're being vulnerable, personal and interpersonal, and intrapersonal; and you're asking for something different, you're asking to be assisted, you're asking for help, you're actually displaying the need for assistance, which is really not welcomed all the time, and actually it's irritating.

Angela

There are kinds of disabilities that are easier to disclose, that have different kinds of stigma that do affect work place politics

Alison

Many participants discussed disclosing to colleagues and the university in relation to and connection with their contractual conditions. Participants on fixed-term contracts or on support staff or teaching fellow contracts were less likely to disclose their fibromyalgia diagnosis. The question around when people were told of, found out or knew about her life with fibromyalgia prompted Dana to contemplate her privileged professorial position:

Most people only know about me having Fibromyalgia once I became a professor. [...] I remember when I, or we had HR paperwork being reviewed and we were renewed and we were being asked to update them, and I put about Fibromyalgia and one of my colleagues, I don't know why he knew that, said "Are you sure? Are you sure you want people to know that?"

Dana

Dana goes on to explain that she had eventually come to terms with the diagnosis on a personal level and is now using her privileged position as a professor to advocate for and

support others with fibromyalgia. For her, fibromyalgia is now no longer an illness she has to deal with, but also the focus of her research and public engagement activities. Generally, participants, especially those in early career stages, find being ill in academia taxing and demanding. In their views, getting the balance right between work and private life is often difficult because academia is experienced and interpreted as an all-encompassing lifestyle choice and identity. Participants therefore regularly refer to their emotional experiences, and managing their self-worth and feelings of isolation. Being diagnosed with a chronic illness is in itself life-changing and isolating. But then, the feeling of not being able to be completely open, honest and transparent about the body's needs and therefore the adjustments required also leads to a wide range of emotional responses.

## **Discussion**

### ***The ill, academic body***

The findings highlight that through the experience of fibromyalgia, the otherwise absent body regularly and consistently edges its way into academics' consciousness (Leder, 1990). Living with fibromyalgia therefore is a conscious act of managing a body that is often considered as failing or disturbing. For those working in academia, this is particularly pertinent, as weakness and vulnerability are not welcome within the scientifically rational, emotionally detached environment of self-control (Bellas, 1999).

### ***Image control and information management***

Academics with fibromyalgia have got an opportunity to navigate their image and control if and how much they would like to divulge of their condition, thus their "otherness" (Goffman, 1990/1963). Their bodies do not openly display their issues and are not inscribed with any stigmatising features. As a consequence, academics with fibromyalgia are treated as "normal" in relation to productivity and effectiveness although they may not be able to meet these high expectations due to their bodily limitations. The stigma comes in through the use of gadgets and gimmicks to make life easier. Signs of adjustments, such as different kinds of chairs, lamps, specialist equipment, computer software programmes, prove difference in treatment of those who are ill compared with those who are not. In times when most academic staff owned their personal offices these differences may not have played out as openly as they do now in open-plan environments and hot-desking suites. In today's set-up in many institutions joint offices and open-plan constructions result in increased contact amongst colleagues so that direct comparisons between one another's work, conditions and adjustments are possible more easily. By being granted the extra office in order to prevent sensory overload and at the same time to allow for the personal

management of breaks during the working day, the individual is quite obviously treated differently, and in the eyes of colleagues "better". This is particularly relevant in instances, where individuals may not necessarily have full knowledge of an individual's special needs due to a complex condition.

### ***Managing symptoms***

Managing one's personal needs in relation to the bodily experience of fibromyalgia ultimately leads to having to deal with one's own and others' emotions. Managing the body and the body's dysfunctions therefore cannot be seen as isolated and separated from managing emotions. The introduction of a backrest to ease back and neck pain, for example, coincides with experiences of shame, embarrassment and guilt. It is shameful and embarrassing that someone much younger than others would need a backrest. In the event of individuals being granted special working spaces, and potentially even separated and own offices, the feelings of shame and embarrassment extend to guilt, in particular as institutions generally are struggling for desks and office spaces. By using wrist support or lumbar support, by getting up in a meeting to do stretches or by taking medication in that public sphere, the participants will make it known to others that they are physically struggling with something. Colleagues who do not necessarily understand the difference in treatments may become jealous. The answer for many is to largely avoid social interactions in order to evade situations, where they may have to explain themselves (Armentor, 2017).

As a consequence, individuals engage in front-stage and back-stage behaviours (Goffman, 1990/1959) with many academics' ensuring that their public persona, on social media but also at work, is such that it conceals (Goffman, 1990/1963) the impact fibromyalgia has on them. They actively produce a public, front-stage persona, they "manage" their bodies in the sense that they are "working on their bodies" or "working their bodies". In that sense, disclosing or controlling the information around a condition can become a bargaining chip within that competitive environment of academic status and impact. The public-facing managing strategies are around restructuring workdays, reorganising workload or merely pushing through. By contrast, the strategies academics with fibromyalgia use to manage symptoms are largely hidden and invisible: pain medication, hot baths, Epsom salts, the use of massage and Tens machines. In the private sphere, they immerse themselves in their illness (Charmaz, 1997), whilst in the public realm of academia they use their bodies to enact the academic they aim to be (Goffman, 1990/1959).

### ***Having fibromyalgia in academia is bodywork***

The bodywork here reminds of the emotion work describing the balancing act between "feeling and feigning" (Hochschild, 1983:90) with the body here being used as a tool to bridge that gap. It is this particular element of bodywork that leads to feelings of isolation, in that individuals experience a distance between themselves and others (Råheim and Håland, 2006). The process of immersion in illness itself leads to individuals withdrawing into themselves in order to make sense of and deal with their illness experience (Charmaz, 1997:99).

## **Critical reflections**

### ***Limitations***

Qualitative research is often critiqued for its small sample size and the resulting lack of generalisability. As a consequence, qualitative researchers tend to focus on concepts such as transferability (Lincoln and Guba, 1985), applicability (Lincoln and Guba, 1990), credibility (Creswell and Miller, 2000) or fuzzy generalisation (Bassegy, 2000, 2001) to ensure robustness and high quality of data, which in turn ensures comparability. This study is not different in this regard. Given the relatively low statistical prevalence of fibromyalgia, combined with the difficulty of obtaining a diagnosis and the fact that many people do not wish it to be known that they have fibromyalgia, a smaller sample size is to be expected. As fibromyalgia is more commonly diagnosed among women than men, the perceived gender imbalance in this study is also anticipated. Validity and robustness were achieved through the detailed engagement with the data and the member-checking process in the analytic stage of the research.

### ***Significance***

The study's significance lies with the conceptualisation of bodywork within higher education and the increased understanding developed through the use of an Embodied Inquiry design. As a result, the main implication for the higher education sector is to engage in a much more body-centred approach to policy-making. Institutions and the sector need to consciously transcend the body-mind duality. Currently, the emphasis within higher education lies with cerebral effectiveness and productivity at the expense of the intricate interplay between body and mind as exemplified in the experience with fibromyalgia. Institutions are called to create an environment that more actively fosters bodily and physical well-being to *en-able* rather than *dis-able*.

### ***Further studies***

This research was undertaken from a multi-disciplinary viewpoint, specifically embracing educational and sociological theories, whilst accounting for disability studies and medical lenses. The lack of engagement with language surrounding disability conceptualisations may therefore be seen as another potential limitation. The reason for this apparent shortcoming was that many of the participants with fibromyalgia themselves struggled to identify with a particular philosophical outlook with many calling themselves ill or sick, but very clearly rejecting the term disability for their experiences. Also, these ways of dealing with fibromyalgia, the image control and information management, as well as the managing of symptoms, are probably similar among the general population with fibromyalgia. With this in mind, there is scope to delve deeper into the sense-making processes of academics and non-academics with fibromyalgia to explore how personal outlooks on disability shape the acceptance of fibromyalgia as well as the management of the public and private self.

### **Conclusion**

With this study I sought to explore the relationship between fibromyalgia symptoms and the context of higher education. Through rationalising and interpreting their experiences, individuals have highlighted the role the somatic and psychological play in fibromyalgia, for example, when they refer to the deterioration of symptoms at particular life or career stages. Research provides evidence for a link between action-prone, over-active behaviours (Van Houdenhove et al., 2001) and fibromyalgia, and perfectionist tendencies and health concerns, more generally (Flett and Hewitt, 2002; Sirois and Molnar, 2016). The connection between academic identity and fibromyalgia can therefore not be denied.

Through managing their bodies to deal with fibromyalgia symptoms academics also undertake active bodywork to create a coherent version of self (Goffman, 1990/1959) for the public. In the context of this research, bodywork has been identified as (a) the management of the fibromyalgia body, the deviant body, thus the management strategies employed in order to be able to fulfil the role as an academic and embody academic identity; (b) the management of the academic body as a public and private identity; and (c) the individual's work on and with the fibromyalgia body to make sense of one's self.

### **Declaration of interest statement**

The author reports there are no competing interests to declare.

### **Ethics**



This study was undertaken under the ethical approval as obtained from the University of Kent. No approval number was allocated.

## References

- Abouserie, R. (1996). Stress, coping strategies and job satisfaction in university academic staff. *Educational Psychology*, 16(1), 49-56.
- Albiol, S., Goma-i-Freixanet, M., Valero, S., Vega, D. & Muro, A. (2014). Personality traits (ZKPQ) of patients with fibromyalgia: A case-control study. *Anales de Psicología*, 30(3), 937-943.
- Armentor, J.L. (2017). Living with a contested, stigmatized illness: experiences of managing relationships among women with fibromyalgia. *Qualitative Health Research*, 27(4), 462-473.
- Ashe, S.C., Furness, J., Taylor, S.J., Haywood-Small, S. & Lawson, K. (2017). A qualitative exploration of the experiences of living with and being treated for fibromyalgia. *Health Psychology Open*, 4(2).
- Baker, K. & Barkhuizen, A. (2005). Pharmacologic treatment of fibromyalgia. *Current Pain and Headache Reports*, 9(5), 301-306.
- Bassey, M. (2000). *Case study research in educational settings*. Buckingham: Open University Press. Retrieved from <http://www.gbv.de/dms/bowker/toc/9780335199853.pdf>.
- Bassey, M. (2001). A solution to the problem of generalization in educational research: empirical findings and fuzzy predictions. *Oxford Review of Education*, 27(1), 5-22.
- Bates, C. (2019). *Vital Bodies: Living with Illness*. Bristol: Policy Press.
- Bauman, Z. (2008). *Community: Seeking Safety in an Insecure World*. Cambridge: Polity Press.
- Beck, U., Giddens, A., & Lash, S. (1994). *Reflexive Modernization: Politics, Tradition and Aesthetics in the Modern Social Order*. Stanford University Press.
- Bellas, M.L. (1999) Emotional Labour in Academia: The Case of Professors, *The ANNALS of the American Academy of Political and Social Science*, 561(1): 96-110.
- Beretz, E.M. (2003). Hidden disability and an academic career. *Academe*, 89(4, July-August), 50-55.
- Blackmore, P. (2015). *Prestige in Academic Life: Excellence and Exclusion*. Routledge.
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3:2, 77-101
- Braun, V. & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, 1-9.

- Briones-Vozmediano, E., Vives-Cases, C., Ronda-Pérez, E., & Gil-González, D. (2013). Patients' and professionals' views on managing fibromyalgia. *Pain Research and Management*, 18(1), 19-24.
- Brown, N. & Collins, J. (2021). Systematic visuo-textual analysis: A framework for analysing visual and textual data. *The Qualitative Report*, 26(4), 1275-1290.
- Brown, N. & Leigh, J. (2018). Ableism in academia: where are the disabled and ill academics?. *Disability and Society*, 33(6), 985-989.
- Brown, N. & Leigh, J. S. (eds.) (2020). *Ableism in Academia: Theorising Experiences of Disabilities and Chronic Illnesses in Higher Education*. London: UCL Press. DOI: [10.2307/j.ctv13xprij](https://doi.org/10.2307/j.ctv13xprij)
- Brown, N. (2019). Identity boxes: using materials and metaphors to elicit experiences. *International Journal of Social Research Methodology*, 22(5), 487-501. DOI: [10.1080/13645579.2019.1590894](https://doi.org/10.1080/13645579.2019.1590894).
- Brown, N. (ed.). (2021). *Lived Experiences of Ableism in Academia: Strategies for Inclusion in Higher Education*. Bristol: Policy Press.
- Charmaz, K. (1997). *Good Days, Bad Days: The Self in Chronic Illness and Time*. Rutgers University Press.
- Chinn, S., Caldwell, W. & Gritsenko, K. (2016). Fibromyalgia pathogenesis and treatment options update. *Current Pain and Headache Reports*, 20(4), 25.
- Creswell, J.W., & Miller, D.L. (2000). Determining validity in qualitative inquiry. *Theory into Practice*, 39(3), 124-130.
- Diviney, M. & Dowling, M. (2015). Lived experiences of fibromyalgia. *Primary Health Care*, 25(9).
- Ehrlich, G.E. (2003). Fibromyalgia is not a diagnosis. *Arthritis and Rheumatism*, 48(1), 276.
- Eik, H., Kirkevold, M., Solbrække, K. N., & Mengshoel, A. M. (2020). Rebuilding a tolerable life: narratives of women recovered from fibromyalgia. *Physiotherapy Theory and Practice*, 1-10.
- Fassel, D. (2000). *Working Ourselves to Death: The High Cost of Workaholism and the Rewards of Recovery*. Lincoln, NE: Backinprint.com.
- Flett, G.L. & Hewitt, L. (2002). *Perfectionism: Theory, Research, and Treatment*. American Psychological Association.
- Freedman, D. P. & Stoddard Holmes, M. (eds.) (2003). *The Teacher's Body: Embodiment, Authority, and Identity in the Academy*. Albany NY: State University of New York Press.
- Gerald, A. S., Freedman, D., & Stoddard Holmes, M. (2012). Teaching pregnant: A case for holistic pedagogy. In: Freedman, D. P., & Stoddard Holmes M. (eds.). *The Teacher's Body: Embodiment, Authority, and Identity in the Academy*. SUNY Press. 179-86.

- Gini, A. (1998). Work, identity and self: How we are formed by the work we do. *Journal of Business Ethics*, 17(7), 707-714.
- Glazer, Y., Buskila, D., Cohen, H., Ebstein, R.P. & Neumann, L. (2010). Differences in the personality profile of fibromyalgia patients and their relatives with and without fibromyalgia. *Clinical and Experimental Rheumatology*, 28(6), 27.
- Goffman, E. (1990/1959). *The Presentation of Self in Everyday Life*. London: Penguin Books.
- Goffman, E. (1990/1963). *Stigma: Notes on the Management of Spoiled Identity*. London: Penguin Books.
- Goldenberg, D.L. (1999). Fibromyalgia syndrome a decade later: what have we learned?. *Archives of Internal Medicine*, 159(8), 777-785.
- Grape, H. E., Solbrække, K. N., Kirkevold, M., & Mengshoel, A. M. (2015). Staying healthy from fibromyalgia is ongoing hard work. *Qualitative Health Research*, 25(5), 679-688.
- Grodman, I., Buskila, D., Arnsion, Y., Altaman, A., Amital, D. & Amital, H. (2011). Understanding fibromyalgia and its resultant disability. *The Israel Medical Association Journal*, 13, 769-772.
- Hansen, N. (2020). Disabled women academics reshaping the landscape of the academy. In *Routledge Handbook of Gender and Feminist Geographies* (pp. 61-69). Routledge.
- Harris, S. (2005). Rethinking academic identities in neo-liberal times. *Teaching in Higher Education*, 10(4), 421-433.
- Häuser, W. & Fitzcharles, M.A. (2018). Facts and myths pertaining to fibromyalgia. *Dialogues in Clinical Neuroscience*, 20(1), 53.
- Henkel, M. (2005a). Academic identity and autonomy in a changing policy environment. *Higher Education*, 48(1/2), 155-76.
- Hochschild, A. (1983). *The Managed Heart: The Commercialization of Human Feelings*. Berkeley, CA: University of California Press.
- Inckle, K. (2018). Unreasonable adjustments: the additional unpaid labour of academics with disabilities. *Disability and Society*, 33(8), 1372-1376.
- Juuso, P., Skär, L., Olsson, M. & Söderberg, S. (2011). Living with a double burden: Meanings of pain for women with fibromyalgia. *International Journal of Qualitative Studies on Health and Well-being*, 6(3), 71-84.
- Juuso, P., Skär, L., Olsson, M., & Söderberg, S. (2011). Living with a double burden: Meanings of pain for women with fibromyalgia. *International Journal of Qualitative Studies on Health and Well-being*, 6(3), 7184.
- Juuso, P., Skär, L., Olsson, M., & Söderberg, S. (2013). Meanings of feeling well for women with fibromyalgia. *Health Care for Women International*, 34(8), 694-706.
- Leder, D. (1990). *The Absent Body*. Chicago: University of Chicago Press.

- Leigh, J. (ed.). (2019). *Conversations on Embodiment Across Higher Education: Teaching, Practice and Research*. Routledge.
- Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic Inquiry*. Beverly Hills, CA: Sage.
- Lincoln, Y.S., & Guba, E.G. (1990). Judging the quality of case study reports. *International Journal of Qualitative Studies in Education*, 3(1), 53-59.
- Lourens, H. (2021). Supercrapping the academy: the difference narrative of a disabled academic. *Disability and Society*, 36(8), 1205-1220.
- Lovin, L. (2018). Feelings of change: Alternative feminist professional trajectories. In Taylor, Y. & Lahad, K. (eds.). (2018). *Feeling Academic in the Neoliberal University: Feminist Flights, Fights and Failures*. Palgrave Macmillan. 137-162.
- Lundberg, G., Anderberg, U.M. & Gerdle, B. (2009). Personality features in female fibromyalgia syndrome. *Journal of Musculoskeletal Pain*, 17(2), 117-130.
- Malin, K. & Littlejohn, G.O. (2012). Personality and fibromyalgia syndrome. *The Open Rheumatology Journal*, 6, 273–285.
- McMahon, L., Murray, C. & Simpson, J. (2012a). The potential benefits of applying a narrative analytic approach for understanding the experience of fibromyalgia: a review. *Disability and Rehabilitation*, 34(13), 1121-1130.
- McMahon, L., Murray, C., Sanderson, J. & Daiches, A. (2012b). "Governed by the pain": narratives of fibromyalgia. *Disability and Rehabilitation*, 34(16), 1358-1366.
- Mengshoel, A. M., Sim, J., Ahlsen, B., & Madden, S. (2018). Diagnostic experience of patients with fibromyalgia—A meta-ethnography. *Chronic Illness*, 14(3), 194-211.
- Montoro, C.I. & del Paso, G.A.R. (2015). Personality and fibromyalgia: Relationships with clinical, emotional, and functional variables. *Personality and Individual Differences*, 85, 236-244.
- Olsen, J., Griffiths, M., Soorenian, A., & Porter, R. (2020). Reporting from the Margins: Disabled Academics' Reflections on Higher Education. *Scandinavian Journal of Disability Research*, 22(1), 265-274.
- Råheim, M. & Håland, W. (2006). Lived experience of chronic pain and fibromyalgia: Women's stories from daily life. *Qualitative Health Research*, 16(6), 741-761.
- Råheim, M., & Håland, W. (2006). Lived experience of chronic pain and fibromyalgia: Women's stories from daily life. *Qualitative Health Research*, 16(6), 741-761.
- Sallinen, M., Kukkurainen, M.L. & Peltokallio, L. (2011). Finally heard, believed and accepted—Peer support in the narratives of women with fibromyalgia. *Patient Education and Counseling*, 85(2), 126-130.
- Shilling, C. (2012). *The Body and Social Theory*. (3rd ed.). London: Sage.

- Sirois, F.M. & Molnar, D.S. (eds.). (2016). *Perfectionism, Health, and Well-being*. Cham: Springer International Publishing.
- Sturge-Jacobs, M. (2002). The experience of living with fibromyalgia: confronting an invisible disability. *Research and Theory for Nursing Practice*, 16(1), 19.
- Sutton, P. (2015). A paradoxical academic identity: Fate, utopia and critical hope. *Teaching in Higher Education*, 20(1), 37-47.
- Taylor, Y. & Lahad, K. (eds.). (2018). *Feeling Academic in the Neoliberal University: Feminist Flights, Fights and Failures*. Palgrave Macmillan.
- Van Houdenhove, B., Neerinckx, E., Onghena, P., Lysens, R. & Vertommen, H. (2001). Premorbid "overactive" lifestyle in chronic fatigue syndrome and fibromyalgia: An etiological factor or proof of good citizenship? *Journal of Psychosomatic Research*, 51, 571–576.
- van Middendorp, H., Kool, M.B., van Beugen, S., Denollet, J., Lumley, M.A. & Geenen, R. (2016). Prevalence and relevance of Type D personality in fibromyalgia. *General Hospital Psychiatry*, 39, 66-72.
- Waterfield, B., Beagan, B. B., & Weinberg, M. (2018). Disabled academics: a case study in Canadian universities. *Disability and Society*, 33(3), 327-348.
- Watermeyer, R. (2015). Lost in the 'third space': the impact of public engagement in higher education on academic identity, research practice and career progression. *European Journal of Higher Education*, 5(3), 331-347.
- Wessely, S. (1990). Old wine in new bottles. *Psychological Medicine*, 20, 35-53.
- Wessely, S. (1994). Neurasthenia and chronic fatigue. *Transcultural Psychiatric Research Review*, 31, 173-209.
- White, K. & Harth, M. (2001). Classification, epidemiology, and natural history of fibromyalgia. *Current Pain and Headache Reports*, 5, 320–329.
- Williams, S. J. & Bendelow, G. A. (1998). *The Lived Body: Sociological Themes, Embodied Issues*. Routledge.
- Wolfe, F. (2009). Fibromyalgia wars. *The Journal of Rheumatology*, 36, 671-678.
- Wolfe, F., Clauw, D.J., Fitzcharles, M.A., Goldenberg, D.L., Katz, R.S., Mease, P., Russell, A.S., Russell, I. J., Winfield, J.B. & Yunus, M.B. (2010). The American College of Rheumatology preliminary diagnostic criteria for fibromyalgia and measurement of symptom severity. *Arthritis Care and Research*, 62(5), 600-610.
- Ylijoki, O.H. & Ursin, J. (2013). The construction of academic identity in the changes of Finnish higher education. *Studies in Higher Education*, 38(8), 1135-1149.