Received: 1 September 2023 | Revised: 30 October 2023 | Accepted: 30 October 2023 | Published online: 2 November 2023

International Journal of Changes in Education
2024, Vol. 1(1) 4–10
DOI: 10.47852/bonviewIJCE32021657
BON VIEW PUBLISHING

RESEARCH ARTICLE

Pain, No Gain? A Joint-Autoethnography of Our Working Lives as Academics with Chronic Illnesses

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Abstract: This paper adopts a joint-autoethnographic approach to explore our lived experiences of working in academia while living with chronic illness, specifically ankylosing spondylitis, at two "new" public universities in the North of England, UK. Use of the novel methodological approach of joint-autoethnography enables us to provide a snapshot into what it means to be "othered" in contemporary neoliberal academia. We contribute to existing debates, which seek to disrupt perceptions of academia as an elitist, ableist, and privileged ivory tower. Through data captured in personal research diaries, we shed light on the emotional and embodied experiences of living with chronic illness while navigating academia, and how we perform our (un)spoiled academic identities. This is important because women with chronic illnesses and disabilities are significantly under-represented in senior roles within universities. This paper will interest an international readership because chronic illnesses are widespread in the workforce, and these individuals offer a unique perspective within higher education and have an awareness of the barriers faced by other academics and students with chronic illnesses.

Keywords: chronic illness, higher education, performance

1. Introduction

Traditionally, academia has been seen as an ivory tower, that is, elitist, ableist, and privileged (Brown & Leigh, 2020). In a bid to shed light on the lived realities of contemporary academics, recent literature has explored a range of individual academic experiences, for instance, the experiences of LGBTQ faculty members of being "out" in an academic setting (Prock et al., 2019) and working-class academic narratives (Warnock, 2016). Indeed, in the pages of the *Journal of Diversity in Higher Education*, work has focused on challenging gendered microaggressions in the academy (Haynes-Baratz et al., 2022); barriers institutionally to academic success for women of color (Domingo et al., 2022); and more broadly experiences of otherness (Pifer & Baker, 2014). This important work highlights that navigating academia is a personal and political endeavor requiring intense emotion work (Brown & Leigh, 2020). Yet, in comparison to work on disability, race, ethnicity, gender and class, relatively little has been written on chronic illness in the academy. This is an important area in need of further investigation, particularly considering the push for universities in the United Kingdom to support equality, diversity, and inclusion (Advance HE, 2020). The context of higher education is significant, given the unique combination of having to perform excellence in the competing areas of teaching, administration, and research (Wilkinson, 2019). This paper therefore makes an important contribution to existing work focused on diversity, equity, and inclusion in higher education, focusing explicitly on experiences relating to chronic illness as young women in academia.

The term "chronic illness" refers to a health condition or disease that is long-lasting in its effects, requires ongoing medical attention, and/or limits or restricts an individual's everyday activities. It is often applied when the course of the disease lasts for more than 1 year. A chronic illness means having to adjust to the demands of the illness and the medication or intervention used to treat the condition. Diagnosis of a chronic illness can change the way an individual lives their life, as well as their self-perception. Examples of chronic illnesses include arthritis, fibromyalgia, Crohn's disease, ulcerative colitis, other inflammatory bowel diseases, cancer, and heart disease.

Our own experiences of trying to juggle living with chronic illness, specifically ankylosing spondylitis (AS), and work as academics at higher education institutions in the Northwest of England, UK, motivated us to undertake this joint-autoethnography. AS is a long-term, degenerative condition, in which areas of the body, including the spine, are subject to inflammation. Symptoms include back pain and stiffness, pain and swelling in peripheral joints, caused by inflammation, and fatigue. It is a type of inflammatory arthritis, as well as an autoimmune disease. While there is no cure for AS, treatment attempts to keep the condition under control, yet those treatments may have limited success and often come with their own unpleasant side effects. While this paper focuses on us, and our experiences, experiences like ours are not uncommon, with chronic illnesses affecting 15 million people in England (Department of Health, 2012).

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Through this paper, we explore the emotional and embodied impact of living with chronic illness, while working as academics, and bring to the fore how we perform our identities as academics while living and working with chronic illness. This paper is of interest to an international readership because chronic illnesses are widespread in the workforce, and those living with chronic illness are able to offer a unique perspective within higher education and have an awareness of the barriers faced by other academics and students with chronic illnesses (Wilkinson & Pickard-Smith, 2023). Therefore, understanding the lived experiences of those living with chronic illnesses can enable a more supportive workplace culture to be fostered.

This paper is structured as follows: firstly, we cohere literature surrounding chronic illness and higher education. We then highlight our theoretical framework, working at the intersection of theory on performance of identity (Butler, 2020; Goffman, 1959) and literature on emotion and embodiment. After this, we detail the methodology of a joint-autoethnographic approach, before presenting data on the theme of performing (un)spoiled academic identities. Finally, we conclude. In this concluding section, we signpost recommendations for how academics living and working with chronic illness(es) can be better supported in academia.

2. Literature Review

It has been contended that academic ecosystems attempt to homogenize and normalize ways of being a scholar (Brown & Leigh, 2018). Consequently, academics with chronic illnesses are unseen and under-represented, leading Brown and Leigh (2018) to question "where are the disabled and ill academics?".

To redress this, Brown (2020) explores lived experiences of ableism in academic, through an account of how academic identity is constructed when living with fibromyalgia. The author highlights that fibromyalgia is a contested condition, as symptoms (such as chronic widespread pain, fatigue, sleep disturbances, and cognitive dysfunctions) wax and wane, and change over time, making the condition difficult to comprehend. Brown (2020) contends that, as a hidden or invisible condition, individuals can choose whether to disclose, pass, or conceal (Goffman, 1963) and therefore have an element of control over their identity. Moreover, Janssen (2021) has explores experiences as a full-time academic of living with the disabling disease of collagenous colitis, a condition that affects the large intestine and leads of episodes of watery diarrhea and stomach pain. Janssen (2021) proposes practical recommendations for higher education institutions. For instance, that the academy promotes awareness of colitis, and funds research into the condition, and that university estates increase the provision of accessible toilet facilities (Janssen, 2021).

Intersectional identity markers exacerbate the experiences of being a chronically ill or disabled person in academia. This is highlighted through Wilkinson and Pickard-Smith's (2023) honest article on what it is like to be women, who identify as having a disability to not only remain but also to progress and indeed thrive in academia. The intersectional dimensions are also brought to the fore from the perspective of Andrews (2020): someone who identifies as an ill, white, cis female mother, and academic who passes as able-bodied and middle class. Andrews (2020) discusses her experiences of living with an over-active immune system in the ablest academy. Andrews (2020) highlights that it can be isolating to work with energy and pain levels that fluctuate, and a future riddled with uncertainty. Additionally, Stone et al. (2013) contend that chronically ill academics are unexpected workers in what is conventionally viewed as an able-bodied work environment. The authors, in the context of Canada, explore the lived experiences of academics with multiple sclerosis (MS), who are seeking to have their needs accommodated, showing that getting these needs met is a complex process for many academics with MS. The paper finds that having their needs accommodated is dependent on whether having MS has been disclosed to others, and the institutional support available to support disabled faculty members (Stone et al., 2013).

Having brought together literature on chronic illness and higher education, we now explain how our joint-autoethnography will be theoretically framed through the lens of performance.

2.1. Theoretical framework

We mobilize the theoretical framework introduced in this section to address the following aim and research questions:
Aim:

- To provide insight into the lived experiences of working in academia with chronic illnesses.

To address this aim, we proposed the following research questions:

(1) What are the emotional and embodied experiences of living with chronic illnesses while working as academics?
(2) What coping strategies did we adopt while living with chronic illnesses and working as academics?
(3) How did we perform our identities as academics while living with chronic illnesses?

2.1.1. Performing identity

According to Goffman (1963), stigma is an attribute that can cast discredit on the individual possessing it. Goffman (1963) identifies three types: abominations of the body (for instance, physical disfigurements), blemishes of individual character (for example, alcoholism, fascism), and tribal stigma (including nationality, religion). This paper is interested in first of these types of stigma: abominations of the body. Having a chronic illness, and the associated stigmatization, can affect an individual's self-concept; capacity to adapt to the illness; and the quality of their social networks (Millen & Walker, 2001). Millen and Walker (2001) contend that social stigma is a delegitimizing social process which is derived from popular and medical views of chronic illness. "Stigma" in this sense refers to an individual who is disqualified from social acceptance (Goffman, 1963).

Stigmatization occurs at a variety of levels and is influenced by the degree to which the body is blemished or disfigured, and the character of the individual being discredited (Goffman, 1963). Goffman (1963) asserts that many "blemished" individuals are subject to being devalued due to their reduced participation in the "normal" world, and their own reflections on a poor body image. Stigmatized individuals typically adhere to the same ideas about identity as non-stigmatized individuals. Consequently, they tend to downplay the "visibility" of their stigma (Goffman, 1963). Chrisler (2011) focuses on stigma in the context of women's bodies, with an interest in "leaks, lumps, and lines." The author proposes means of resisting, reframing, and coping with stigma. However, existing research reveals that camouflage, in the context of issues of identity, can also be problematic, leading to questions such as: "are people responding to the real me?"; an over-reliance on the camouflaged image in social interactions; and worries that the "truth" will be brought to light (Coughlan & Clarke, 2002).

We are interested in the ways in which we performed our (spoiled) identities (Goffman, 1963) in the academic workplace while living with chronic illness, and engage with performance theory from Goffman (1959) and Butler (2020) to frame our analysis. According to Goffman (1959), an identity is “spoiled” when it departs from approved standards of behavior or appearance. In this paper, we use the term “(un)spoiled” to highlight the invisibility of chronic illness and that the departing of standards of behavior or appearance may not be visible to others.

Goffman (1959) engages with the perspective of dramaturgical performance, that is, the activity of an individual which serves to influence other individuals. Goffman (1959) makes a distinction between a “front region” and a “back region”. “Front region” is the space where the performance occurs, while the “back region” is where performers openly construct illusions and impressions, and where the performer can step out of character, relax, and drop their front (Goffman, 1959). Goffman (1959) has a third region, including all places that do not fall into the front and backstage, called “the outside region,” with individuals on the outside of the establishment called “outsiders.” Goffman (1959) recognizes that individuals conceal evidence of “dirty work” from the audience, undertaking this work in private. Goffman (1959) also advances the idea of “audience segregation,” in which individuals ensure that those in which they play one of their parts in front of are different to the individuals they play a different part in front of in another setting. Goffman (1959) highlights the fragility of a performance, in that minor mishaps can shatter the impression of reality it attempts to foster. The theorist talks about “defensive practices,” which are strategies an individual employs to protect their projected identity.

From a Goffmanian perspective then, identity is performed; it is acted, and role play is crucial to the performance of identity that we present to others. Instead, Butler (2011), with a focus on gendered identity, argues that gendered identity is performative; it is not fixed. How people act, walk, speak, and talk combine to form an impression of being a man or a woman (Butler, 2011). The body thus becomes its gender through corporeal gestures and movements, a “stylized repetition of acts,” which are subject to be revised and consolidated as time goes on (Butler, 2020). Being a man/woman is not internal – gender is not innate or natural; it is continually (re)produced and crafted through behavior (Butler, 2011). In this paper, we argue that chronic illness, like gender and sexuality in Butler’s (2020) writing, is always in the process of becoming, and thus chronic illness is something an individual “does,” rather than something they are, as Henderson and Noam Ostrander (2008) argued of disability.

Having outlined the academic context and theoretical framework for this study, we now detail our methodology.

3. Research Methodology

3.1. Reflections on positionality

Influenced by feminist thinking, it is important for researchers to critically reflect on their positionality, and the impact this has the research process and outcome (Berger, 2015). This is particularly important for autoethnography where the researcher is both the tool and subject of the research. It is for this reason that both authors of this paper, the source of the joint-autoethnographic reflections, now provide reflections on our positionalities.

3.1.1. Samantha

I am a female academic in my early thirties and have worked at my current institution for seven years. Following the birth of my first son, I developed two new auto-immune issues, including AS. AS has caused me so much pain and stiffness in my peripheral joints to the extent where, at times, I cannot even straighten my arms, and it has made previously simple tasks like getting out of bed in the morning a real struggle. It has left me exhausted with no energy, particularly in the mornings and evenings. It has also left me inundated with hospital appointments.

3.1.2. Catherine

I am also a female academic in my early thirties and have worked at my current place of work for 4 years. I had experienced back pain as well as pain in my peripheral joints over a number of years. Working at my previous institution the pain was so bad that sometimes colleagues had to assist me to my car in the car park. When I began my role as Senior Lecturer at my current institution, I was always making apologies for my back and neck pain and stiffness, which often makes me look awkward and uncomfortable. My AS also leaves me with chronic fatigue which sometimes makes everyday tasks difficult to fulfill, for instance extended periods of standing and attending long meetings.

3.2. A joint-autoethnographic approach

Autoethnography “requires vulnerability, fosters empathy, embodies creativity and innovation, eliminates boundaries, honours subjectivity, and provides therapeutic benefits” (Custer, 2014). We considered that an autoethnographic approach was well suited to “get at” the often vulnerable and embodied experience of living with chronic illness. More specifically, we used a joint-autoethnographic approach where we, the two authors of this paper, recorded our own experiences. This approach is simultaneously autobiographical, collaborative, and ethnographic (Gates et al., 2020). Joint-autoethnographies are much less present in the literature, compared to autoethnographies.

Autoethnography, as Allen-Collinson and Hockey (2008) make apparent, has not gone without criticism. It has been critiqued for being “self-indulgent, akin to ‘navel-gazing’.” We argue that a joint-autoethnographic approach can help to overcome some of the critiques heralded at autoethnography. That is, rather than focusing on individual personal narratives, there is a shift to collective agency (Lapadat, 2017; Wilkinson & Wilkinson, 2020). The difference between auto-ethnography and joint-ethnography is the mutual corroborative role of joint-autoethnography. In this paper, we co-construct a narrative by collaboratively writing about a common experience, which captures how we experience working with a chronic illness in academia both similarly and differently (Cann & DeMeulenaere, 2012).

Our research meets the criteria of transferability, credibility, and dependability, used to measure the validity and reliability of data in qualitative research. Our literature review section clearly describes the background and context of the research so that the reader can judge the applicability of the findings in other situations. To ensure our research is dependable, we now document and explain all stages of research, including data collection by sharing the practicalities of undertaking this joint-autoethnography.

Over a period of 7 months for Samantha (September 2021–April 2022) and 6 months for Catherine (January 2021–July 2021) we recorded in individual A5 sized written diaries our embodied observations, feelings, and interactions of our everyday experiences of working in higher education while living with a chronic illness. We wrote in our diaries approximately three times a week, and additionally when a specific event or feelings occurred that warranted a reflection. Sometimes the observation would be a brief paragraph, while at other times we may have individually written a page of reflective notes, depending on the thoughts and feelings the moment or day had generated. We tried to write as close to the moment warranting observation as possible, while it was fresh in our minds. We each had approximately 75 journal entries, and around 30 pages of autoethnographic notes. We did not set any strict criteria about what our notes would be reflecting on, as we recognized we were interested in the banal everydayness of our experiences. Travers (2011) discusses that diaries are useful for documenting a narrative of events, thoughts, and emotions. Our diaries contained subjective accounts that we reflected upon periodically, both individually and together. For us, the process of writing reflexively about the experiences of working in academia while living with a chronic illness was cathartic, and we encourage others in higher education to use diary writing as a tool to think through their experiences.

Autoethnography makes apparent the researcher's thoughts and feelings (Méndez, 2013) and can lead to the "vulnerability of revealing yourself" (Ellis & Bochner, 2000). This gives autoethnography a unique position ethically (Tolich, 2010). Lapadat (2017) notes that a strength of a joint-autoethnographic approach is a shift to shared vulnerability. While this research was focused on ourselves, our feelings, and our experiences, others may be present in our self-narratives. Autoethnographic ethics departs from the necessity for informed consent in traditional research ethics (Israel & Hay, 2006). We did not gain consent from others for the story we tell in this paper, yet we do ensure that no other individuals are identifiable in our narrative.

3.3. Reflexive thematic analysis

We utilized Braun and Clarke's (2019) reflexive thematic analysis, where we view qualitative data analysis as being about telling "stories" and actively generating themes from the data. Our role in knowledge production was central to this inductive, data-driven approach (Braun & Clarke, 2019). Our analysis approach meets the criteria of credibility, involving repeated reading, comparing data, and summarizing and categorizing information without making changes to the data. To expand, the first stage of Braun and Clarke's (2019) reflective thematic analysis approach involved re-familiarizing ourselves with the data by reading our field diary excerpts critically and analytically – we did this individually. We then individually undertook the creative labor process of coding. Following this, we generated initial themes. We then reviewed and developed these together before moving on to a process of refining, defining, and naming the themes. The process was conducted knowingly and reflexively.

We now move on to discuss how we performed (un)spoiled academic identities.

4. Performing (Un)Spoiled Academic Identities

Through reflecting on our experiences of navigating academia while living with a chronic illness, we agree with Goffman (1959; 1963) that whether one decides to disclose or to conceal a condition it is an act of self-preservation, information control, and impression. The below excerpts reveal our reservations about disclosing our conditions to colleagues:

> *It is now a few months since my return from maternity leave and I have sought to disclose my chronic illness, AS, to my place of employment, but I was very worried that as I had returned to work full-time following maternity leave, it may just be perceived that I was struggling to cope with the competing demands or motherhood and academia, and that my illness may not be taken seriously.*
>
> (Samantha, 9th October 2021)

> *Today, were due to move into our new building and had to make decisions about the orientation of our desks in our new office. We had to come to an agreement with our 'office buddy'. I immediately had a strong opinion about my preference for desk orientation, as I experience fusion, pain and stiffness in my neck which makes turning it (for instance to see who is entering a door behind me) very difficult and painful. As such, I preferred to be forward facing. I did not tell my office buddy the extent of my reasoning, only that I have 'trouble with my neck'. I prefer colleagues to consider my issue as something that is temporary and fleeting and not something that is permanent.*
>
> (Catherine, 6th May 2021)

In the above, Samantha was concerned that the disclosure of her condition, AS, may be misinterpreted as her struggling to adapt to working in higher education full-time as a new mother. This concern that her AS would be dismissed as fabrication, or as an overwhelmed worker seeking validation, was compounded by the fact that AS is a largely invisible and less known condition (Brown & Leigh, 2018). Interestingly, Catherine notes that she disclosed part of her symptoms, but not her full diagnosis, preferring colleagues to see her illness as something temporary and fleeting and not permanent, believing this permanence holds greater stigma regarding a spoiled identity (Goffman, 1963).

Rather than "coming out" about our chronic illnesses (Defenbaugh, 2011), a commonality noted across our diaries is that for several months, we both decided to "pass" (Goffman, 1963), worrying that knowledge of our chronic illness may categorize us as a deviant within the normed and normalized academy, which in turn may lead us to be stigmatized (Goffman, 1963). This is particularly significant when returning to Brown and Leigh's (2018) question "where are the disabled and ill academics?". For us, a key concern was that if others knew the full extent of our illnesses, we may be prevented from accessing opportunities which would support our career progression. However, as we reflect below, this identity work requires significant "emotional labor" (Hochschild, 1983):

> *I am in a lot of pain today, and my joints are stiff to the extent where I cannot turn my neck around and feel in a slouched position. I am trying to look 'well', as I am not ready to 'come out' about my condition as I am wanting to progress to Reader and worry that being 'ill' may restrict me from being given opportunities as it may be perceived that I could go off sick and therefore be unreliable, but it is emotionally exhausting pretending to be well.*
>
> (Samantha, 3rd September, 2021)

> *Today I delivered a four hour block lecture and workshop, followed by a quick dash across campus to deliver another workshop. I am experiencing a flare up of my AS currently, which means both my levels of pain and fatigue are particularly high. I try to ensure this does not come across though, both to students and colleagues. In particular, I don't want to sound tired and monotonous to students as I worry about this being reported back in module evaluations and student surveys.* (Catherine, 22nd March 2021)

Above, we reflect that because our bodies do not outwardly display their issues and are not inscribed with any noticeable stigmatizing features (Goffman, 1963), we were able to "pass" and be treated as "normal"; this was positive in terms of us not feeling like we are being restricted from career progression opportunities due to being ill, or through being negatively graded by students in module evaluations. Afifi and Steuber (2009) note that it is risky and can make an individual feel vulnerable when they reveal sensitive information about the self. However, the alternative to this is information control and performance of wellness, which is also emotionally laborious (Brown, 2020; Werth 2011). From this performativity of concealing illness, it can be seen, to adapt Butler's (2020) work on gender and sexuality into the context of chronic illness, that chronic illness is something we *do,* rather than something we are.

In both our diary entries, we discuss how we crafted our identities in the backstage (Goffman, 1959), in terms of taking medication and applying makeup in such regions to craft an appearance of "wellness":

> *When I first started taking my CIMZIA*[1] *a nurse was supposed to be coming to campus to show me how to do my injection, but I share an office and CIMZIA has to be injected subcutaneously in either the stomach or the top and outer part of your thighs, which are areas I naturally would not have on show to colleagues. I managed to make arrangements with my colleague that she would make herself scarce, and I locked the door from the inside so that students could not enter.*
>
> (Catherine, 7th January 2021)

> *I woke up this the morning feeling extremely fatigued and in pain and this was written all over my face, but I made a conscious effort to apply my make up to make it look as if I was well and healthy as I am not ready to talk about my illness with colleagues.*
>
> (Samantha, 28th November 2021)

In the first excerpt above, Catherine discusses how a nurse visited her in her work office to show her how to administer an injection used to treat her AS. However, Catherine can be seen to have to struggle with juggling the logistics of administering this injection in the workplace, which had the additional complication that the medication must be stored in the fridge. For Catherine, administering this medication in a shared office put her in a position where she would have to expose parts of her body deemed not acceptable in this place. Interestingly, while an individual's office space may be considered a back region, where a performance can openly construct illusions and impressions, step out of character, relax, and drop their front (Goffman, 1959), the shared nature of this office prohibited Catherine from using this space in this way. As such, this made it difficult for Catherine to conceal the "dirty work" (Hughes, 1962) of injecting herself from the audience. In the second excerpt above, Samantha discusses "putting on her face" in the backstage arena of her home, in order for her illness to remain invisible. Goffman (1959) may thus consider the application of makeup a "defensive practice" deployed by Samantha to protect her identity. There are parallels here with Defenbaugh's (2013) experience of concealing her inflammatory bowel disease diagnosis from others. Defenbaugh (2013) reflects that while her illness is primarily invisible, on days where her immune system takes over her body, she looks morbid: pale, gaunt, tired, and drained of energy and color. Consequently, she conceals her ill features and attempts to hide her ill identity underneath a mask of cosmetics. Like Defenbaugh (2013), for Samantha, this ritualistic transformation was for the appearance of health and vitality and to look less outwardly sick.

Also evident in our research diaries were instances of embodiment in relation to what Longhurst (2001) and Chrisler (2011) may term our "leaky" and "messy" bodies:

> *I injected my CIMZIA injection into my thigh this morning before setting off for work. What I didn't realise was that the blood from the injection site had stained my light coloured trousers, leaving a visible patch of blood. I know that anything to do with blood and women's bodies is a little taboo, so I was on guard all day about people noticing this, and tried to conceal it with props, such as a cup of coffee rested on my thigh in meetings, or hand gestures.*
>
> (Catherine, 11th May 2021)

> *Because I have now been taking steroids for a number of months in a bid to control my AS, I have developed 'moon face'*[2]*. This makes me feel really self-conscious, not only when I am meeting staff and students in person, but primarily when I am having Zoom conversations – because on Zoom/Teams calls I can also see my face and the size and shape of it. Today I pushed my laptop further away from me so as to make my face appear smaller. I worry whether people will think the change in my face shape is from weight gain, pregnancy, illness or the truth – as a result of medication.*
>
> (Samantha, 8th March 2022)

Our experiences above build on the work of Longhurst (2001) who seeks to bring to the fore "leaky" "messy" zones between inside and outside of bodies and their resulting spatial relationships. Catherine recounts how the blood leaking through her trousers is what Longhurst (2001): (i) would call "matter out of place", and so she attempts to conceal it. No one discussed the blood mark with Catherine, perhaps reflective of how discourses of bodily fluids can be difficult to talk about (Longhurst, 2001). Samantha discusses the moon face she has developed due to long-term steroid use, to treat her AS. This reflects existing literature (Hale et al., 2015) which finds that treatments for certain chronic illnesses, with specific reference to steroid use, can have a significant impact on the body and self-image. Interestingly, while AS is considered an invisible illness, the side effects of the medication produce visible bodily changes.

Having discussed our performances of our (un)spoiled academic identities, we now conclude this paper.

5. Conclusions

This paper has sought to further disrupt perceptions of academia as an elitist, privileged, and ablest ivory tower (Brown & Leigh, 2020), by bringing to the fore our embodied lived experiences as contemporary academics navigating academia while living and working with chronic illnesses. Through the novel method of a joint-autoethnographic approach, we have provided an insightful snapshot of what it means to be "othered" in contemporary neoliberal academia (Brown & Leigh, 2020), through the specific example of chronic illness, therefore building on an existing body of work exploring diversity, equity, and inclusion in higher education. Our paper is theoretically framed at the intersection of literature on performing identities and emotion and embodiment to explore living and working as academics with AS. We found that we attempted to "pass" (Goffman, 1963) as "normal," worrying that knowledge of our chronic illness may categorize us as a deviant within the normed and normalized (academic) society, which in turn may lead us to be stigmatized (Goffman, 1963). However, this identity work required a significant amount of emotional labor. Further, we found that there was a lot tied up in the decision about whether to disclose or to hide our conditions. This itself is act of self-preservation, information control, and impression management (Goffman, 1959; Goffman, 1963). On occasions, we did not reveal the full extent of our illnesses, and on other occasions we attempted to conceal our illnesses through

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[1] A prescription medicine called a Tumor Necrosis Factor (TNF) blocker.

[2] 'Moon face' is a term used to describe facial swelling caused by steroid use.

crafting or performing an appearance of wellness. Disabled and chronically ill academics are widespread in the workforce, and we agree with Wilkinson and Pickard-Smith (2023) that our lived experiences of juggling chronic illnesses with academia have given us a unique perspective within higher education, and that we have an awareness of the barriers faced by other academics and students with chronic illnesses, which is something that should be harnessed.

6. Recommendations

In concluding this paper, we propose the following practical recommendations:

(1) We recommend higher education students and academics join or create – with institutional support – a network for students and academics with in/visible illnesses for the sharing of practices and experiences which can help students and academics with chronic illnesses to feel less alone.

(2) We encourage higher education academics to use reflective diaries to reflect on their own experiences of managing their chronic illnesses, recognizing that the process of writing itself can be cathartic, and to share these if they feel comfortable doing so. The more voices we hear, the more the unique experiences and challenges faced by chronically ill academics can be recognized.

(3) We recommend institutions adopt inclusive and supportive processes to support progression opportunities (e.g., opportunities for leadership roles) for those with chronic illnesses and other identity markers (such as gender or ethnicity) that may intersect to create barriers in academia.

Through implementing these recommendations, academics can become more reflexively aware of the ways in which they manage their chronic illnesses while working as academics, and a more supportive culture can be fostered for academics and students with chronic illness(es) in higher education, and more awareness of the barriers faced by other academics and students with chronic illnesses can be brought to light (Wilkinson & Pickard-Smith, 2023).

7. Limitations

This research was limited to on our own auto-ethnographic experiences as academics in two higher education institutions in the UK. Further research could build on the experiences we presented herein, using in-depth interviews with students and academics with intersecting identity markers living and working with a range of chronic illnesses in higher education institutions internationally. This would enable a better understanding of the diverse lived experiences and manifestations of chronic illnesses within the academy.

Ethical Statement

This study does not contain any studies with human or animal subjects performed by any of the authors.

Conflicts of Interest

The authors declare that they have no conflicts of interest to this work.

Data Availability Statement

The data that supports the finding of this study are not publicly available due to privacy concerns of the participants. However, anonymized data are available from the author on reasonable request. Requests should be made to Samantha.wilkinson@mmu.ac.uk and should include a brief description of the intended use of the data.

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How to Cite: Wilkinson, S., & Wilkinson, C. (2024). Pain, No Gain? A Joint-Autoethnography of Our Working Lives as Academics with Chronic Illnesses. *International Journal of Changes in Education*, *1*(1), 4–10. https://doi.org/10.47852/bonviewIJCE32021657