Ableism in Academia

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Disclosure in academia: A sensitive issue

Nicole Brown

In an age where social activist movements for increased awareness and tolerance are commonplace, it is interesting to observe that there are still huge gaps in our knowledge and experience. The social model of disability (Oliver 2013) has certainly helped develop the understanding that disabilities are not ‘a person’s fault’ but a matter of and for society and societal values. In the last decade there has been an increased interest in making public life more accessible. In the United Kingdom this is evidenced in initiatives such as the ‘offer me a seat’ campaign (Transport for London n.d.), the Accessible Travel Policy (Office of Rail and Road 2019) and the widening of the blue badges system (BBC News, 15 June 2019). Conversations on social media, however, highlight that despite the increased awareness relating to the experiences of the disabled, chronically ill and/or neurodiverse, misconceptions and misunderstandings still prevail, leading to fundamental crises for individuals (BBC News, 15 January, 7 August, 19 November 2018; Coleman 2018; Rimmer 2019).

In this chapter, I draw on my research into academics’ lived experience of illness to consider individuals’ sensitivities and the sensibility required in communicating with disabled, chronically ill and/or neurodiverse academics. I commence this chapter with a brief introduction to the research upon which this chapter is based. Subsequently, drawing on the research data analysis and using specific examples from the research, I focus on sensitivity demanded of all of us. I discuss sensitivity around our use of language and individuals’ experiences of illness that may directly impact conversations and or processes, such as
the research on hand. Further, I highlight how sensitivity helps deepen understanding when considering the situation of those needing to disclose a disability or illness, or more specifically an invisible, potentially contested condition. Finally, I emphasise the need for sensitivity in relation to the emotional labour involved in being ill and/or disabled.

The construction of academic identity under the influence of fibromyalgia

The premise of this research project was the understanding that illness and/or disability as a lived experience impacts a person’s understanding of self and thus will influence their construction of their academic identity. The focus on fibromyalgia is particularly pertinent, as fibromyalgia as a condition is contested. Fibromyalgia is characterised by chronic, widespread pain, fatigue, sleep disturbances, cognitive dysfunctions (often described as ‘brain fog’ or ‘fibro fog’), increased sensitivity and psychological disorders (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. Moreover, 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 hours. A person with fibromyalgia may get up early in the morning struggling to move for the pain, but then several hours later may be well enough to engage in exercise programmes, work routines or other everyday activities, only for the body to then crash under the strain, to the point where the person will experience debilitating fatigue and pain, sometimes for several days before getting better again. Therein lies the main problem for individuals diagnosed with fibromyalgia. The lack of a definite process for diagnosis and the variability of the condition make it a doubtful and contested condition within the medical professions, too (Ehrlich 2003; Wolfe 2009; Mengshoel et al. 2018; Häuser and Fitzcharles 2018).

For this research, I recruited 28 academics from all career stages who had been diagnosed with fibromyalgia. Academic roles ranged from early-career researchers currently undertaking their PhD studies, via 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 and those in part- and full-time employment in further education and higher
education contexts. 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. Participation varied among and across participants, with some starting the research and dropping out and others temporarily withdrawing from the research tasks but then returning to them in order to complete them. Of the 28 academics signed up, eight participants can be considered as having dropped out entirely.

The research approach has been published elsewhere (Brown 2018a; 2018b; 2019). Suffice it to say, data was generated through arts-based approaches combined with interviews conceptualised as conversations between the researcher and participants (Brinkmann and Kvale 2015). Data analysis drew on artistic approaches as well as on traditional coding processes through an iterative process of sense-making through employing hermeneutics (Smith et al. 2009) and thematic analysis (Braun and Clarke 2006; 2019). For the following sections, I have extrapolated some data from the research that referred to the themes of interruptions, correct language, disclosure and emotional labour in order to highlight the broader topics of sensibility and sensitivity. Participants’ names used in the following are pseudonyms.

**Interruptions and disruptions**

Throughout the process I encountered interruptions and disruptions to the data generation and analysis stages. Due to the variability of fibromyalgia, academics drifted in and out of participating in the research. They were keen to tell their stories, share their experiences and be heard; but the reality of life with fibromyalgia and pressures of academic work led to flare-ups and complications, which in turn resulted in the increased need for pacing. Within the hierarchy of academics’ priorities, participation in my research was often the first thing to be abandoned or cut back on. During the course of my study two participants interrupted their PhD
studies, one participant decided not to continue her PhD studies and forfeited her scholarship, and three further participants contemplated reducing working hours and workloads, accepting diminished salary. Out-of-office messages were a constant reminder of the fluctuation of illness and long-term absences.

![Figure 3.1: Screenshot of an email sent to Nicole Brown.](image)

But as someone with fibromyalgia myself, I too encountered flare-ups and periods of increased pain. Mostly I was able to maintain composure and it would not impact the conversations with the participants so that they specifically asked about my health status:

And so, what about you? Do you have it as well? And is that why you started to look into it?
   Jackie

Nicole
I never asked but, if I may know (don’t worry if you can’t answer) do you yourself suffer from fibromyalgia?
   Carmen

In all honesty, being able to maintain public face and composure was only possible because many of the conversations happened by email. Indeed, my participant Carmen’s query started a whole conversation around my being ill, carrying out research and balancing work with the doctorate and family commitments:

From Nicole to Carmen:
Dear Carmen,
I saw your message earlier, but was rushed, so didn’t want to reply straight away. The short answer is yes, I do. The full story is somewhat longer, but I was initially diagnosed in 2003. However,
I didn’t accept the diagnosis and so continued the journey from doctor to doctor, until in 2012 I was diagnosed again. This was the point where I started accepting the diagnosis. But with hindsight I showed the first signs of fibromyalgia when I was a teenager, so probably around 1990. So, yes, I have a long story myself. Feel free to ask away… [smile emoji].

From Carmen to Nicole:
Hi Nicole, thank you so much for sharing your stories
I appreciate it
And well done to you that you have worked hard so far for your phd and other things in your career
I just....... I’ve been finding the phd hard as I’m ill a lot
I have constant headaches, sore throat, fatigue and fever
And it’s just..... people around me start to adapt with my pain I think as I’m always ill
And like with panels and examinations etc. it’s done after 8 months, 1 year etc. and it’s just that my 8 months seem to be different than a healthy student’s
As I am not capable of 8 hours a day of work, for example
And in the end my PhD is assessed by my thesis
And not say my thesis and the situation where I’m working on my thesis with this illness
Sometimes I feel like it’s a huge struggle cause I can’t work as much as other people in the way that I have limited time and energy
That’s why I asked.

From Nicole to Carmen:
I fully understand. And it doesn’t come easy for me either. I am usually asleep by 10 pm, and don’t do much after 8 pm actually. For me the worst thing is the brain fog, which really upsets me. But I am ill a lot, too.

From Carmen to Nicole:
I’m just worried that I won’t finish my PhD, I think.

This conversation disrupted the natural flow of the interview and we ended the conversation on a leisurely note, only to take up the interview on another occasion. However, these interruptions demonstrate the reality of being a researcher and trying to work through an illness. Similarly, there is ample evidence throughout all interviews of how
individuals, including myself, started struggling after a certain amount of time, finding it difficult to focus thoughts, not being able to prevent brain fog from setting in:

[Pause]. Right. I tell you, tell you what Alison, I'm starting to struggle now. Umm, umm, I mean, I think it's been roughly an hour anyway, that we've been talking. If it's okay with you, I'd, I'd like to ask you back for another chat, cos I, I've actually written down a, a few questions, and I've got a few questions that I want to, to ask, but I really, I'm starting, I know that I'm starting to, yeah, not be able to focus.

Nicole

Sorry Nicole, I'm fucked, I'm really tired. Lost my train of thought, going to lie down for a second, yes.

Hanna

Thank you for changing it this afternoon, but I, I slept for 12 hours when I got, because I got back yesterday [from an international conference]. I was, I was so behind and, I appreciate you being able to adjust it.

Jackie

Once I had coded all the data and had gone over all of the interviews, I realised that one particular conversation between Angela and myself epitomises the severity and immensity of the task of balancing work and life with an illness, of carrying out research and maintaining a relatively normal work schedule while having fibromyalgia:

Nicole: And at the same time to be very, very honest, I'm finding myself, that I'm now starting to struggle to make the connections that I need to make [laughs].

Angela: Oh no. Okay, yeah, it's hard when you're focusing.

Nicole: I'm coming to the limits of my concentration span, I think.

Angela: I understand, yeah. I totally get it. I do. Believe me.

Nicole: It's really frustrating cos, yeah, it's lovely to hear you talk, and, and it kind of makes a lot of sense, of the things that you say in it, and I, I get the drift of, you know, like, some jobs being more, sort of, related to status and reputation,
and therefore not as welcoming or accommodating to people like ourselves basically.

Some of the interruptions were also signs of minds drifting off, but at the same time a way for the participants to engage me in their personal environments:

I don’t mind [wearing a headset and standing out from other colleagues]. [Waves]. Sorry, I’m just waving to some, my neighbours. [Laughter]. But I don’t mind wearing a headset, in fact I think it’s great.
Jackie

There was a couple of years really of doing sort of small courses. I did a Spanish course, I did a course in soft furnishings in curtain making. I made these curtains, I’ll show you my curtains. They are pretty good curtains. See? Look, those curtains there [moves the screen round to show curtains].
Hanna

It was situations like these that made the research process particularly difficult. Sensitivity and sensibility were required in order to respond appropriately to the needs of individuals. I was constantly trying to distance myself from my own experience as an academic with fibromyalgia in order not to become known as ‘the fibromyalgia patient’, not to be leading in my questioning and to maintain objectivity regarding the thoughts and experiences of others. However, through engaging with the participants on such a personal level, being shown around their houses, meeting colleagues, friends, husbands and partners, I felt drawn into the participants’ world in a way that I feared would disrupt my analysis and my understanding of what was happening. For some participants, like Hanna, the conversations through the research process would constitute their only social contact for a week, sometimes two. In this sense, dismissing individuals’ stories, even if they would not necessarily be the focus of the research, would have been detrimental to the individuals and consequently to my relationship with them.
The correct language and terminology

The research showed how the academic participants in this research made sense of academic identity and their work in academia, but also their experiences with the fibromyalgia diagnosis. Throughout this sense-making process academics engaged in a scholarly debate and considered their experiences on a personal level but through a somewhat academic lens. It is this scholarly and academic endeavour to reach understanding that has led to the all-important debate around terminology and language. The importance of language and terminology was highlighted in an informal conversation at a very early stage of this research project, when I spoke to a participant about being a fibromyalgia patient, but corrected myself to say a person diagnosed with fibromyalgia:

Nicole: So, one of the questions relates to how you feel as a fibromyalgia patient, I mean, a person diagnosed with fibromyalgia.

Patricia: I’m not a person diagnosed with fibromyalgia, or a patient. I am a sufferer.

Within the wider discourse around illness, disability and neurodiversity, language and terminology are a hotly debated topic. There are advocates who would like to see language to reflect that the person is more important than the person’s disability, for example. Then again, there are specific groups advocating terminologies used to reflect the person’s identity that is encapsulated in language. According to this debate, it should therefore be unthinkable to say ‘the disabled’ or ‘the handicapped’, but would be desirable to use ‘the Deaf’ or ‘the Autistic’ (Sinclair 2013). Language here is seen as a powerful tool to convey thought processes. A person using a wheelchair, for example, would primarily want to be seen as the person rather than the disabled person (Ward and Meyer 1999). This interpretation is closely aligned with the social model of disability (Oliver 2013) that sees disability as a barrier imposed by society and its members. In contrast to this, proponents of the use of ‘the Deaf’ or ‘the Autistic’ are generally advocates of the affirmation model (Swain and French 2000). For them, being ill, disabled or neurodiverse is not a negative, non-normal experience. Instead, they embrace their illness, disability or neurodiversity as part of their identity. In this sense, offering a hearing aid to those who are deaf is an affront to their identity: the inherent experience of being deaf is taken away from them (Leigh 2009).
Similarly, the term ‘patient’ is charged with connotations and reminders of a person’s passivity and victimisation within the medical realm, as patients are objects within doctor–patient relationships, whose experiences are validated by doctors and who are supposed to endure treatments prescribed to them. Most participants in this research were very precise regarding the terminology they used and they wanted to be used. Even if most participants did not express their preferences as clearly as Patricia had done, the most widely used terminology around fibromyalgia was to do with suffering:

I go through phases of this, and so therefore, I must be lucky, that I’m not one of those people that suffers all the time but, no it comes and goes.
Jackie

I have just seen [a tweet] which reminded me that I had not responded to your DM [direct message]. Please accept my apologies. This is the way it is with FM sufferers, or at least me. I have been going through a very bad patch for about the last 8 months or so.
Patricia

One of the, my colleagues, she was talking about fibromyalgia, she was talking about how she was suffering […] I said I feel the same.
Kate

Did we really need to talk to pain sufferers? Like, yes, also pain sufferers is a really problematic term [thumbs up sign]. So there has been a fair amount of political juggling.
Alison

The language that participants and I have used throughout the project was therefore largely agreed upon on an individual basis. After all, not only are these terms politically and culturally charged and as such represent signs of oppression and victimisation, they also encapsulate personal experiences and feelings in relation to being ill. The conversation quoted above highlights very clearly how politically correct language may sometimes be inappropriate exactly because it takes away that charged connotation. With fibromyalgia the concern around the right use of language and terminology is even more complex, as fibromyalgia is badly understood and therefore not clearly classifiable as an illness,
disease or disability. Overall, all participants described fibromyalgia as a disabling condition, although most were reluctant to refer to themselves as disabled. Sensitivity regarding which language to use and how to approach individuals was key for the development of a long-lasting relationship with individuals.

**Considerations of disclosing fibromyalgia in academia**

Where hidden or invisible conditions like fibromyalgia are concerned, individuals have a choice to disclose, pass or conceal (Goffman 1990/1963) and therefore more control over their identity (Kundrat and Nussbaum 2003). The decision on whether or not to disclose fibromyalgia is closely linked to academics’ personal attitude towards the condition, and as such rests on a number of factors. Age plays a particularly important role in this connection. Individuals who are older or who have more experience with illnesses tend to cope better with managing issues around their conditions and the broader concerns of disclosure (Kundrat and Nussbaum 2003). Before being able to publicly announce and stand by an illness, the person needs to have come to terms with the condition at a very personal level. For some participants, being ill with fibromyalgia was very strongly connected with the feeling of being held back and slowed down. This emotional response also determines how participants act and react towards others knowing about their condition. Participants generally consider fibromyalgia as disabling and are not shy ing away from considering themselves as being disabled or referring to fibromyalgia as a disability.

> For me a disability is something except for which you would be able to perform at full capacity and participate fully, in your, in your life, however you want that to be. […] Mine is a thing that reduces my potential performance and that needs accommodations to bring me up, to the level of everybody else. No, I think, I think mine’s a disability.

Sian

And yet, having lived with fibromyalgia for a long time and attempting to make sense of the condition does not necessarily mean that one has accepted and fully come to terms with it to such an extent that a public disclosure is acceptable. To be confident enough to tick the ‘I am disabled’ box means that this person would have accepted his/her dysfunction,
disability or illness, a rather advanced stage in the moral career of a discredited person (Goffman 1990/1963), as it means learning to accept chronic illness, neurodiversity or disability as a normal experience of life or even as an asset, an outlook on disability that is at odds with internalised ableism:

I think I would disclose if I needed any reasonable adjustments, or if I could put those in place I would not disclose maybe, it depends, it depends. I know now that I couldn’t go for a full-time teaching post, lecturing post, because I wouldn’t have the stamina. Unfortunately. And that’s very sad to have to say that or admit that.
Kate

In addition to this very personal interpretation and understanding of disability, a public disclosure brings further risks. Academics, specifically early-career academics, worry about the consequences of being identified as someone dealing with health issues and conditions. In an environment where temporary, as-and-when contracts are more prevalent than permanent, tenured positions, employees are concerned about job insecurity. Individuals fear that by admitting to health conditions or disabilities they may be worsening their chances for employment. For them, the rewards of passing (Goffman 1990/1963) are greater than the consequences of disclosing. Some participants told of occasions when they had shared their diagnosis with colleagues whose lack of understanding had led participants to change their views on disclosing and to generally hold back:

What I’ve found interesting this year is, I’ve had three students come to me telling me they’ve got it [fibromyalgia]. And it was really interesting, when I said I understood because I had it, and they said, but you’re so full of energy, how do you keep going? Because they’ll sit in lectures and then say, I’ve got to leave, and I’ll go home, and they won’t see me go ooh [does flopping exhausted action].
Jackie

I’ve told four people at work that I have fibromyalgia and I think, two of them kind of understand.
Yasmin
Whether or not academics choose to disclose their disabilities and illnesses is, in practice, a risk-benefit analysis of consequences associated with the specific concern or issue. In order to access support, workplace adjustments, potential financial benefits and allowances, academics do need to disclose their conditions. Another potential benefit of disclosing a condition is the opportunity to have an ally and companion, someone to share the same identity with (Defenbaugh 2013). However, disclosing more commonly means being categorised as a deviant within the normed and normalised society, which in turn leads to being stigmatised (Goffman 1990/1963). Within academia it is this stigmatisation that causes particular concerns. Invisible, lesser-known or contested conditions are dismissed as a fabrication, malingering and the act of a fundamentally lazy or overwhelmed worker seeking validation. Considering such strong views, the act of disclosing automatically links the personal and private to the public. Participants talk about how disclosing fibromyalgia as an illness or potentially as a disability could result in an increased risk of being stigmatised and discriminated against, particularly as fibromyalgia itself is a contested condition and not widely understood or accepted. At the same time, this risk is weighed up against the potential support and help they would receive.

I now do put in that I have a disability, because, well, I mean with, with that sort of thing it’s because I might need access to some form of service.

Bernie

Well I’m always honest about it, so for example I submitted a grant application on Monday and there was the equalities disabilities monitoring form and so in a box it said, you know, ‘do you have any special concerns’ and I’m always honest, and I put on there, you know, multiple chronic medical conditions that require accommodations, so I don’t hide it in terms of submitting my work.

Sian

The decision about whether to disclose or to hide a condition is therefore an act of self-preservation, information control and impression management (Goffman 1990/1959; 1990/1963) – thus it is identity work. For most participants, disclosing to colleagues and immediate line managers did not equate to disclosing to the university at institutional level; and they felt more comfortable with completing the monitoring and disability review forms than with explaining themselves to colleagues:
They [colleagues] can’t help me, you know, so it’s basically, like, why would I want a pity party. There’s nothing they can do, they can’t take my work from me, they can’t give me any less work, they can’t do my work for me, they can’t give me the career progression that I want, erm, with the record I have, without it there is no such thing as a mitigating circumstances form, for career progression, erm, and people don’t have an ability to forget what you tell them. They will just constantly be asking me how am I feeling, and, you know, how are you doing and I don’t want to talk about it with them if they can’t help me.

Sian

Sian’s words in relation to what colleagues can and cannot give her exemplify this cost-benefit analysis. She does not want her colleagues to feel pity, commiserate with her or focus on her illness more than on practical work and solutions. A ‘pity party’ would have a serious impact on her academic identity: not only how she sees herself, but also how others within academia see her.

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, disclosing fibromyalgia would be seen as 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 workplace politics, so I think it is, I’m not at all talking about the lived experience, but I think it is easier, say, you’d get a better reaction if you’re a woman and you say ‘I have breast cancer’ than if you say ‘I am a woman and I have’, I don’t know, ‘borderline personality issues’.
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. […] It wasn’t a conscious hiding of it, but it might have been unconscious. And also remember, it also goes with the research because before that research was ‘fibromyalgia’s a psychosomatic disorder’, so did you want people to think it’s in your head, and things like that; or is it the influence of research then in the last four or five years talking about, you know, neurological conditions or sort of, sort of biochemical sort of aspects of it. So,
I don’t know whether it’s the, having that professor identity, or something, or if it is to do with the research [that] is now, if you like, validating my experience as not just being in my head, but having a physical cause. [...] 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. Her moral career has taken a turn towards being a professional within her group of the ‘discredited’ (Goffman 1990/1963, 38). For her, fibromyalgia is now no longer merely an illness she has to deal with, but also the focus of her research and public engagement activities. In her own words, she is now in a position where she can indulge in more freedom and flexibility:

If I don’t have a class, and if I’m not well, if I decide I’m going, not going to start work at nine o’clock, I’ll start at 12 o’clock and I’ll carry on for my, whatever number of hours I want to work, or I can work from my bed, so I’m in pain, but my brain’s working, so I’ll work from my bed. I can do that.

Dana

Other participants, especially those in the early stages of their career, find being ill in academia taxing and demanding. In their view, 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 (Charmaz 1991; Frank 2013). 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. Participants express their experiences and feelings of isolation and having to work through their needs by themselves, especially if they have not disclosed their condition to those
around them, and so they have to deal with their illness on their own and thus become even more isolated:

At the moment I just feel like I'm just a, a mess. I feel like, like, people are avoiding me from my course, maybe not deliberately but they're just, they're so busy and involved with what they are doing. And I think extended illness of this type makes people very uncomfortable. They, they don't know what to say, they don't know what they can do. It's not like an acute illness where they can come and visit you with a bunch of flowers and, you know, you're in bed looking all poorly and then next week you're not so bad and then the following week you're back in the office. I think it's very confusing for other people and, and, yeah, I think it makes them feel uncomfortable, and I feel like people who were very supportive, say, six months ago, the last, this last spell of illness since March, I've hardly heard from them at all, not seen them, so I do feel a bit abandoned. And, and, you know, I, I have made an effort to keep in touch with people, it's not that I've put myself off, I understand that they're really, I mean, they are insanely busy, they could, you know, they're in the midst of their PhDs, but it's, I do feel a bit hurt.

Hanna

You know, and then the really annoying part is that when I do want any social interaction or I want to go and see people or talk about ideas nobody has any time for me, right.

Sian

Thought processes around disclosure therefore relate to physical, material manifestations as well as emotion work. In effect, individuals analyse and calculate whether disclosing the condition is a risk worth taking. Individuals are more likely to disclose their health concerns if they feel that disclosure facilitates continued employment and explains absences or conditions (Butler and Modaff 2016). Women with fibromyalgia have also been found to be more likely to disclose when fluctuating work commitments or changes in work relationships occur (Oldfield et al. 2016). The difference between the general public and academics is manifested in the dimension of disclosure. Non-academics choose to disclose illness and impairments to provide information about the contested illness or to selectively reveal invisible impairments (Oldfield et al. 2016).
‘Disclosure dances’ in academia

In order to understand what it means to be disabled or ill in academia, higher education must be seen in the context of the processes towards increased marketisation, internationalisation and bureaucratisation (Hussey and Smith 2002; Tilak 2008; Gewirtz and Cribb 2013). Through their ability to critically reflect and analyse, academics identify the working conditions as a contemporary academic in the neoliberal university as a source of aggravation for their symptoms. However, academics do not interpret the academy as a source or cause for the condition. Instead, working in academia continues to be romanticised (Lovin 2018) and is still seen as worth striving for, and so the participants’ focus lies on managing their emotions and bodies in an attempt to compete with non-disabled colleagues.

In an environment where, as discussed, the culture of overwork is endemic, the academic who becomes ill or disabled faces the decision on whether they disclose their ‘weaknesses’. This choice around disclosure is open to anyone who has a so-called ‘invisible’ disability, and even individuals who have more obvious physical disabilities can often choose the extent to which they disclose their effects. For example, they may have no option but to disclose that they are in a wheelchair or use a mobility aid, but could decide whether to disclose the fact they also have a diagnosis of fibromyalgia and the additional pain, fatigue and brain fog they suffer. At the same time, disclosure is a form of information management and controlling what kind of information is shared (Goffman 1990/1963). Openly admitting to having brain fog – a cognitive dysfunction – in an employment that prides itself for cerebral work is not the same as openly admitting to having pain. The selection of what is shared at which point, under which circumstances and with whom, and the subsequent sharing of details are ‘dances rather than declarations’ (Oldfield et al. 2016, 1451), as, like dancers, individuals respond to circumstances and persons when they share particular experiences or details. This is because disability or illness are often not interpreted or felt as fixed states, but as fluid, liminal spaces or continua. Within the lived experience of a disabled or chronically ill body individuals go through phases of ‘feeling normal’ and ‘feeling disabled’ within their bodies (Deegan 2010, 30ff.). Apart from the fact that conditions often fluctuate and therefore disability or chronic illness does not take on permanency, the narratives of individuals with disabilities and chronic illnesses highlight that personal circumstances, external
factors and environments impact the conception of whether or not the body is experienced as ‘normal’. Disability is not dichotomous, but a fluid state (Barnartt 2010), where one’s experience of cognitive dysfunction, pain and fatigue is more or less pronounced. With this in mind it is not surprising that disclosure is complex.

Ultimately, within academia three core conditions need to be met for a person to be able to disclose their ‘otherness’. First, the person with the diagnosis needs to have reached a state of personal acceptance. For example, if we use the example of an individual academic with fibromyalgia, they would first need to learn to accept that there is something ‘wrong’. It is perhaps easier to accept an illness than to accept disability, but then it is not so easy to accept an illness that does not have an outcome – unlike cancer, for example, where the narrative is one of heroism (Frank 2013) for those who fight and survive, but also for those who are brave knowing that they cannot survive. Second, those with a fibromyalgia diagnosis need to experience acceptance at their workplaces. The culture at the workplace must be such that individual differences are accepted and understood. Medically unexplained or contested conditions like fibromyalgia and chronic fatigue syndrome, in particular, are not met with the right levels of understanding. For example, a visible disability requiring wheelchairs, walking canes and guide dogs is more easily understood than disabilities that cannot actually be seen. ‘But you don’t look sick’ is commonly heard. Finally, in order to be able to fully disclose the fibromyalgia diagnosis, an academic needs to be sure that there will not be any repercussions. In reality, many academics, especially those with hidden disabilities and illnesses, experience discrimination in one form or another – not necessarily as a malicious act, but because of lack of understanding (Brown and Leigh 2018). As society is discriminating in that sense, academics with illnesses worry that their workplace will be equally discriminating if it becomes clear that they have health needs, and so they end up not disclosing their condition. With this in mind, the disclosure issue is really about how comfortable academics are within their own skins. Disclosure therefore needs to be discussed as a personal, private event as much as it needs to be considered as a public event.

When disclosure is considered within the public realm, it tends to be discussed in the context of stigma. Many academics with invisible conditions or disabilities have got an opportunity to navigate their image and control if and how much they would like to divulge of their condition, and hence their ‘otherness’. Their bodies do not openly display their issues and are not inscribed with any stigmatising features (Goffman 1990/1963). This is obviously a concern because they may be 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. At the same time, not disclosing a condition does mean that academics may pass and not be subjected to stigma (Goffman 1990/1963). General awareness and understanding of the lived experiences are so limited that individual symptoms do not tend to come up within everyday interactions with others. Academics may struggle with brain fog, lack of concentration and focus, but these are personal experiences, not public ones. In the case of conditions like fibromyalgia that are contested and medically unexplained, individuals are often doubted and indeed start doubting themselves. But even conditions that are visible or disclosed through stigma symbols (Goffman 1990/1963) such as back rests, wheelchairs and hearing aids lead individuals to question themselves. Sensitivity is therefore the key component in an empathetic approach to communicating with disabled and chronically ill academics.

The emotional labour of disclosure

In the previous sections I have shown how negotiating fibromyalgia in the academy is not only a public but also a private endeavour. I have also highlighted how the research process as a whole and individual conversations in particular have been shaped by the condition and external factors surrounding it. In this final section, I would like to return to the theme of disclosure as a sensitive issue. Ultimately, any work relationship with others but also with oneself requires the negotiation of emotions.

For example, the choice of whether or not to disclose a condition is as much emotional as it is logical and rational. On the one hand, there are benefits to disclosing illness, in that as the person disclosing a condition, you can share your experiences and explore a support network of others with the same identity. Disclosing therefore leads to having an ally and companion through illness (Defenbaugh 2013). On the other hand, trying to contain the important information around one’s illness results in individuals needing to manage their conditions, but also trying to ‘hide’ key components of who they are. This information control (Goffman 1990/1963) is fraught with the potential risk of being exposed involuntarily or of being blackmailed into disclosing a condition one may not necessarily be ready to share publicly. The most recent examples of such journeys relate to the Welsh rugby player (Davies 2019) and Queer Eye presenter Jonathan Van Ness (BBC News, 22 September 2019), whose HIV diagnoses suddenly entered the public domain. With hidden
or invisible conditions individuals normally have a choice to conceal or disclose and therefore have more control over their identity. Age is often thought to be relevant for how individuals deal with illness and disabilities, as older people are more experienced in dealing with illness. Age here is not understood as the chronology of life and time; it is rather the space, state of mind and mindset within one's lifespan that relates to whether an individual has had more or less experience with being ill (Kundrat and Nussbaum 2003). However, in reality, coming to terms with a condition on one's personal level and subsequently managing the information about oneself in social networks are detailed processes of knowing who to tell what and ensuring that different groups of peers do not necessarily meet each other in order to be able to maintain the chosen secrecy in the workplace, for example. As this information management requires careful staging of one's identity as well as the containment of emotions, information control needs to be seen as a form of emotional labour (Goffman 1990/1959; 1990/1963).

Although emotional labour and emotion work within academia are still poorly researched (Constanti and Gibbs 2004), several strategies and factors for emotion management have been identified (Archer 2008; Morris and Feldman 1996; Frost 2003). The strategies range from ‘playing the game’ and speaking out about what is wrong through to lowering one’s own expectations or, in the worst case, ‘quitting the game’ (Archer 2008). The emphasis in all these works lies on the fact that the requirement to manage and control information about oneself leads to emotional pain. If no active countermeasures are taken to alleviate this emotional pain, it has the potential to become toxic ‘to the point that it can be contained no longer and finally erupts’ (Ward and McMurray 2016, 88). This eruption may then manifest itself as an aggravation of symptoms, stress or worsening mental health, which in turn will increase the emotional impact on individuals. Knowing that these are the experiences of individuals with disabilities or chronic conditions, we return to sensitivity. In an ableist society such as academia, this kind of sensitivity and empathy is often foregone – not necessarily because of malicious intent, but because of lack of understanding and awareness of different ways of living and working.
References


