Experiences of Higher Education for Students with Chronic Illnesses

Abstract

This paper explores the experiences of students with chronic illnesses in UK universities. Sixty-seven students with chronic illnesses completed an online survey with open-ended questions about their experiences in higher education. Questions covered four main topics: academic work; university staff; social and extracurricular activities; and participants' miscellaneous opinions. Using thematic analysis, the data were analysed with references to the social model of disability and social representations of chronic illness. Participants wrote of misconceptions surrounding chronic illnesses, a sense of inequality, and feeling undervalued. Many staff members seemed to lack understanding and so 'policed' academic regulations rather than accommodating for their chronic illnesses. However, some participants wrote of social and academic 'allies' who offered understanding and proactive support. The findings add substance to the chronic illness literature with the focus on students at university, and we offer recommendations to universities for improving inclusivity for students with chronic illnesses.

Keywords: students; chronic illness; fatigue; higher education; myalgic encephalomyelitis; university

Points of Interest

- Disabled students with energy-limiting chronic illnesses are frustrated by a lack of support and feel that they have fewer opportunities than non-disabled students.
- Some university staff may hold negative views of disabled individuals, and so provide inadequate support. This can lead to students' reluctance to disclose chronic illnesses.
- Students with chronic illnesses felt that some staff and peers did not class chronic illnesses as 'real' disabilities and felt that they were perceived lesser than those with visible disabilities.
- Some students proudly owned the label of 'disabled' to educate others, including staff, who sometimes used university regulations inappropriately to excuse not

adjusting support for disabled students. Some staff and students were perceived as supportive allies.

- Universities must listen to disabled students and those with chronic illnesses to ensure they fulfil their legal and moral obligations of providing equality of opportunity, enabling all students to succeed.

Introduction

In 2017/18, approximately 13% of higher education students reported having a known disability (HESA 2019), but there is little research into the university experiences of students with chronic illnesses. Medically, a chronic illness is defined as a condition that lasts a year or more, which may require ongoing medical attention, and/or limits daily activities (Warshaw 2006). However, Hale (2018, 2020) investigated the use of the term within online chronic illness communities, and observed that these communities refer to chronic illnesses as those necessitating the rationing of energy expenditure due to symptoms of fatigue, pain, and malaise, such as myalgic encephalomyelitis (ME). Of 153 individuals identifying as having chronic illness, Hale found that 95% agreed that this definition represented their experience. Furthermore, Hale (2020) identifies chronic illness as a type of disability, in accordance with the UK Equality Act's legal definition of disability, as a condition affecting one's ability to function from day-to-day (GOV.UK 2020). Hale (2020) proposed that such chronic illnesses may also be referred to as 'energy-limiting chronic illnesses' or 'energy impairments'. Hale's work presented a mutual understanding of the term chronic illness, giving a shared voice to a distinct online community of disabled individuals who categorised themselves as having an illness that was previously poorly understood or disbelieved. Therefore, this article will adopt Hale's definition of 'chronic illness' throughout.

Within compulsory education, pupils with chronic health issues may be less likely to gain academic qualifications than healthy pupils (Champaloux and Young 2015). Adolescents with chronic illnesses may be academically disadvantaged and less

likely to continue onto higher education. Research with individuals who have progressed from school into higher education is minimal, and little is known about whether there are differences in experiences, graduation rates, or attainment between students with and without chronic illnesses.

Models of disability

There are several theoretical models of disability, one of which is the medical model. This claims that disability is purely a medical phenomenon that causes impairment in the body's functioning or structures (Haegele and Hodge 2016). Any limitations arising from the disability are assigned to the impairment; thus, to improve their situation, the assumption is that the disabled individual must be treated (Bingham et al. 2013). Consequently, the belief is that a disabled student with a chronic illness would have a diminished experience of higher education due to their physical symptoms. However, this model fails to consider the social and environmental context in which the disabled individual is situated.

Subsequently, others have adopted a social model of disability (Oliver 1983, 1990), which describes disability in more complex terms, rather than as a purely medical phenomenon. The social model separates 'impairment' from 'disability', where the former is a physically-derived bodily or psychological difference or affection, such as a chronic illness, whilst the latter occurs when society fails to accommodate for impairments. For example, enabling students to attend classes online (rather than requiring physical attendance) for a person with an energy-limiting condition may facilitate access to education without the need to travel to and sit through a class, which might be exhausting. Environmental issues (such as living off campus) can provide a barrier to inclusion, regardless of any physical impairment. A lack of provision for a

disabled person's impairment needs can result in environmental barriers, which can prevent them from doing something, thus leading to the label of 'disabled'. With these barriers in place, disabled individuals are often excluded from full societal participation (Anastasiou and Kauffman 2013). Hence, the social model proposes that 'disability' is socially constructed through society's attitudes towards disability and its inaction and unwillingness to accommodate for impairments (Hodkinson 2016), rather than being a result of the impairment itself.

The social model of disability has been criticised for its over-emphasis on social constructionism, with critics suggesting that quality of life may not be improved even if societal barriers are removed (Anastasiou and Kauffman 2013). Those with chronic illnesses can experience debilitating symptoms of pain and fatigue, which would remain challenging regardless of social barriers. Oliver (1996) reiterated that the social model did not intend to reduce disability to societal issues, but rather to explain how disabled individuals are restricted within a society designed for non-disabled individuals. Proponents of the theory stress it has been influential in important societal change (Thomas 2004).

Alternatively, an affirmation model of disability ~~has been proposed~~ (Swain and French 2000)~~; this includes~~ focuses on positive social identities ~~and adopts a more hopeful view of disability whilst recognising impairment.~~; the paper references that individuals can be excluded because of physical and social constraints arising from a disability or impairment, but primarily focuses on positive self-identification for disabled people.

~~It acknowledges that individuals can be excluded because of physical *and* social constraints arising from a disability or impairment.~~ From the perspective of chronic illness, the understanding that a disability brings genuine physical limitations alongside

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a need for accommodations to facilitate engagement may be important when attempting to understand and improve students' experiences of inclusion in higher education. Integrating different facets of disability theories enables a more holistic interpretation. According to the World Health Organisation (2017): disability is the interaction between an individual's body and the society in which they live. Qualitative research into the social construction of disability (Bê 2016) showed that many participants with chronic illnesses lacked support and accommodations due to perceived institutionalised discrimination. Not only were they limited due to discrimination, but the discrimination often worsened their fatigue and mental health. This may be due to the attitudes surrounding disability; if a disability is perceived as stigmatised or its validity is questioned, individuals and society may be reluctant to remove the barriers that disabled individuals face. Therefore, society's perception of disability and chronic illness is fundamental (Levitt 2017).

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Social representation of chronic illness in higher education

Social Representation Theory (Moscovici 1961) proposes that social groups use systems of social representations to communicate and navigate the world with mutual understanding. Social representations are groups' collective values, ideas, and practices. These may be developed through discourse, behaviour, social interactions, or policy. For example, when new social stimuli are presented, individuals may use anchoring; anchoring involves consulting existing social representations and attributing meaning to the stimuli, which gains a collective objectified definition. Through objectification, the stimuli may become immune to questioning as the discourse of the majority retains the objective social representation. Social representations may affect how we treat certain social groups (Lorenzi-Cioldi and Clemence 2001); if a group has become stigmatised,

there may be negative consequences from outsiders (Howarth 2006).

There are many stigmatising social representations of disabled individuals and those with chronic illnesses. Examples include laziness (Whittle et al. 2017) or disbelief (Edwards, Thompson, and Blair 2007; Mullins and Preyde 2013), both of which may lead others to doubt people's capacity to succeed at work (Beatty 2012). Disabled individuals can also be represented as objects of 'pity' (Kaushansky et al. 2017). These misguided views may seriously impact students' experiences of higher education whilst living with chronic illnesses. For example, staff have been found to lack empathy towards disabled students and showed reluctance to make adaptations (Moriña, Cortés-Vega, and Molina 2015), perhaps because they perceive students as lazy or lying. Such negative social representations may deter students from disclosing their disability due to fear of stigma (Hughes, Corcoran, and Slee 2016; Kendall 2016), which then limits their access to disability support (Brown and Leigh 2018).

The reluctance to disclose disability or illness may extend to peers. Kaushansky et al. (2017) found that young people with chronic illnesses often withheld disclosure to their peers through fear of rejection, being pitied, or being 'othered'. One longitudinal study found that peer support was significantly predictive of academic outcomes in higher education for minoritized groups, which may be mediated through emotional and academic support (Dennis, Phinney, and Chuateco 2005). Likewise, Gibson (2012) reported that peer support and friendship were vital in facilitating good higher educational experiences amongst disabled students. These studies stress the importance of social support and inclusion and suggest that outcomes may be poorer if students are rejected or disbelieved regarding disability or chronic illness.

Higher education is an important catalyst for improving social mobility and employability amongst marginalised groups (Haveman and Smeeding 2006), including

those with chronic illnesses, who tend to have poorer chances than other students (Nørup 2019). Research surrounding student disability in higher education exemplifies accessibility issues, stigmatisation from staff, and lack of accommodations (Moriña 2017). However, research concerning the subgroup of disabled students with chronic illnesses is minimal. This may relate to known difficulties in disclosing a disability to UK universities during application and enrolment processes, because option categories tend to be limited and medicalised (Hughes et al. 2016). A lack of validation of chronic illness on entering university may reflect Hale's (2018) finding that individuals with chronic illnesses feel unrepresented. The paucity of research exploring the higher educational experiences of students with chronic illness, coupled with the knowledge that individuals identifying with the chronic illness label may be misunderstood, rejected, othered, or carry an otherwise negative social representation, indicates a need to investigate further.

Aims of the Study

This study aimed to explore the individual experiences of students with chronic illnesses within the social context of a university, whilst considering social representation theory and models of disability. It further aimed to gain insight into experiences that helped or hindered students' progression through higher education to inform universities of best practice regarding this subset of students. In light of this, we utilised a qualitative approach to data analysis, thematic analysis (Braun and Clarke 2006, 2013), allowing us to capture the voices of individual students, and to identify key themes (based on meaningful representations in the data) relating to our aims.

Research process

Participants

Participants were 67 students (60 female, 5 male, 1 self-described as non-binary, and 1 self-described as gender queer) aged 18 to 55 (M = 25.76, SD = 7.95) with a diagnosed chronic illness (see Appendix A for a list of participants' self-reported diagnoses). Participants were current students (in 2018/2019) or had attended a UK university (excluding the Open University) within the past 12 months, so experiences were reflective of current university life. There were 38 undergraduates, 19 postgraduates, six recent graduates, and four indicated an 'other' status.

Research Instrument

An anonymous open-ended survey was designed for this study. Eligible participants were required to have lived with chronic illness as per Hale's (2018) encapsulation during their time at university (involving fatigue, pain, or malaise). The survey was hosted on the web platform, Qualtrics. An initial set of eligibility questions were followed by demographic questions (age, gender, university level), and questions regarding diagnoses; the amount of demographic information requested was limited, to ensure that participants were sufficiently confident of anonymity to be honest about their experiences.

Next, participants answered 12 open-ended questions concerning experiences of higher education. These questions were written by the first author, who has personal experience of chronic illness, with the aim of gathering participants' lived experiences of navigating university. The questions were assessed for face validity, readability, and objectivity with the second author and another student with chronic illness. They related

to: (1) academic work; (2) university staff; (3) social and extracurricular activities, and (4) opinions of experiences in higher education.

An open-ended survey design was chosen as the most practical way of gaining qualitative data from the target population. Participants could fill in the survey when they felt well, could take as much time as needed, and were able to have breaks and return to the survey.

Procedure

Ethical approval was granted from the Keele University School of Psychology Ethics Committee. The survey was advertised via social media; participants were encouraged to share the survey with other students with chronic illnesses. This was a suitable recruitment method as those with chronic illnesses are known to join social media groups for social support they may not receive elsewhere (Brigden et al. 2018; Lian and Grue 2017).

Interested participants were directed to an online information and consent page, which they had to read and check before continuing. Participants then answered the survey questions using as much time as required. They were asked to write as much as they wanted and could miss any question. A final question provided the opportunity to add anything that was not included in the main survey. Participants were thanked for taking part and debriefed.

Data analysis and reflection

Thematic analysis was chosen for analysing the data (Braun and Clarke 2006, 2013) as this offered the flexibility to explore in a data-driven and theoretically informed way. The lack of previous research within the area of chronic illness and higher education

meant unexpected themes were likely, but there was also value in socially constructing participants' responses by consulting theory, such as the disability theories and social representation theory.

The first author familiarised themselves with the data and adopted an inductive, data-driven approach. Data were coded allowing for new or unexplored concepts and short descriptions of each code were noted; concepts directly matching earlier codes were given the same code. After coding, the data were grouped into similar themes, considering relevant theories. The validity and finalisation of themes was discussed within the research team.

Although the data were analysed inductively, it is acknowledged that true objectivity is unlikely. The first author has experienced chronic illness and student life at a UK university. Therefore, they were able to contribute a sensitivity to existing issues and themes, and notice novel findings in comparison to the existing theories and literature, alongside experiences and conceptualisations that were similar or dissimilar to their own lived experience of having chronic illness at university. They acknowledged that with the range of positive and negative experiences of being a disabled student at university, they approached the research as a participant as well as a researcher and were likely to have focused on key themes that resonated with themselves. The first author's personal experiences allowed nuanced understanding of the students' voices as they approached the questions from similar frames of reference. Importantly, vastly different experiences and opinions than those of the first author were noticed and considered, demonstrating the first author's ability to relate to participants' experience that contrasted with her own. As recommended by Nowell et al. (2017), to strengthen the trustworthiness and credibility of data analysis, the second and third authors examined the first author's analysis to ensure that the findings were clear,

coherent, and representative of the data. The second author is a current university lecturer with expertise in higher education research; when collaboratively checking the first author's analysis, this allowed the themes to be strengthened and understood from a different but related perspective, through discussions to clarify meanings.

Results

Three main themes (with subthemes) were identified using Braun and Clarke's (2006) thematic analysis.

Perceptions of chronic illness and disability

The first theme identified was perceptions of chronic illness and disability. Subthemes included: perceptions of chronic illness compared with other disabilities; negative perceptions of adopting this identity; and positive perceptions from those who identify as having a chronic illness and use the label to educate others.

Perceptions of chronic illness compared with other disabilities

Some participants said that they thought they were perceived more negatively than those with a visible disability:

> …some thought it was an excuse not to turn up to lectures… I felt that people seemed to view invisible and visible illnesses completely differently. Those with clear disabilities were treated with more understanding than those with invisible from my point of view.

This participant felt that because their disability was not visible, they were being judged as though they had a choice about attending lectures, rather than being limited by their disability. It was as though others did not categorise their impairment as

legitimate. Another participant felt similarly invalidated when they wrote: ‘The finance department told me that they couldn’t help students who chose to go part time, and that the government will only help those with “actual disabilities”’. This suggests that the experience of chronic illness is negated because it is invisible, even by a member of staff. Staff may not realise there may be no choice but to study part time, as other participants also claimed similar experiences: ‘I’ve had to do my degree part time. My first year I became so unwell that I only ended up doing 25% of a full-time course’. Thus, serious chronic illness does not manifest in an overtly visible way, and staff may not accept it as a legitimate disability, increasing the likelihood of discrimination towards students with chronic illness.

‘Disabled’ as a negative identity

Whereas some participants express their frustration at not being identified as disabled whilst having chronic illness, others seemed reluctant to self-identify with the disability label. Participants who refused to adopt the label thought it might alter their own self-perceptions and work as a self-fulling prophecy. For example, one student said: ‘I think that if I start to think of myself as a disabled person, I will truly become a disabled person and lose my ability to achieve my dreams and goals independently.’ Notably, to participate in the survey, the participant would have self-identified as having a chronic illness causing significant daily energy impairment (which conforms to the UK’s legal definition of disability; GOV.UK 2020), whilst denying that chronic illness is a disability, resonating with the first subtheme. This quote also suggests that self-identifying as disabled can have negative consequences, whereby adopting a disabled label may change self-perceptions and inhibit potential. Another participant said: ‘I just want to be judged as me and not as disabled’, suggesting they do not want to be defined

by the label, even if they do identify with the term.

When chronic illness affects the individual in a manner that is visibly apparent, for example, using a wheelchair, this may lead to negative perceptions from others. One participant stated: 'Some people have been embarrassed to walk with me whilst I am in my wheelchair', suggesting that non-disabled people are uncomfortable being associated with someone who has a noticeable disability. Fear of being perceived negatively or causing embarrassment may deter some participants from assimilating 'disabled' into their identity.

'Owning' the chronic illness identity to educate others

Some participants talked about embracing the chronic illness identity in a bid to educate others. When asked about their feelings towards disclosing chronic illness to staff, one student said: 'Apprehensive, mostly because fibromyalgia isn't seen as a legitimate illness, even though it is... I recently decided I was going to start telling people in hopes of educating them on the importance of recognising invisible illnesses'. Even though they felt hesitant to discuss their illness, they owned the legitimacy of their illness and made a conscious effort to educate others. They took a proactive role in representing people with the illness. This was apparent in many participants' views, for example:

> I would train the lecturers on chronic and invisible illness. I would set up a system for all course notes to be available for students who cannot attend due to chronic illness so they do not miss anything. I would make a standardized system for informing about health with centralised accessible info for lecturers so you don't have to have a repeated conversation.

This quote shows the persistent efforts made by this student to represent people with chronic illnesses and ensure they are treated fairly. They identified some of the issues students with chronic illnesses face and actively educated staff to ensure these issues were addressed in the future. It seems that many students with chronic illnesses feel empowered by being given the opportunity to educate others on the topic, for example, one student praised the research study: 'This is such an important subject to investigate. Thank you so much for giving us a voice, it means so much.' It is important for those who actively adopt the chronic illness label to raise awareness, have their voice heard, and improve the student experience. Additionally, it shows that students felt this education was needed, perceiving that the existing level of chronic illness education provision was unsatisfactory. This lack of education may partly explain the misconceptions of chronic illness in the previous subtheme.

In summary, perceptions held by staff and students may have a negative impact on those with visible and invisible chronic illnesses. Those with invisible chronic illnesses may feel invalidated as others do not acknowledge their chronic illness as a disability, whereas those with visible chronic illnesses may be targets of outsiders' negative perceptions. Although there are some students who resist defining themselves as disabled due to the belief it will damage or limit their outcomes, others wish to champion their chronic illness identity to help educate those with inaccurate assumptions or beliefs.

Students with chronic illnesses are under-prioritised and undervalued at university

Some students felt undervalued in comparison to peers, because their university did not prioritise their disability-related needs. Participants explained that their universities failed to prioritise accessibility and that some disabilities were not supported optimally.

The perception that their disability was not prioritised by their institution fed into their feelings of inequality and being worth less than other students.

Universities not prioritising disability accessibility

A lack of physical accessibility was deemed an issue for disabled students at university. One participant wrote:

> I can't access the SU because the nearest disabled parking bays are hundreds of metres away... It may make the uni more aesthetically pleasing, but it presents a huge accessibility challenge and basic provisions like gentle slopes and disabled bays are completely ignored.

This participant felt that the university had prioritised building appearance above the accessibility needs of students. Not only is prioritising image above student access likely to lead to resentment, it is also discriminative, resulting in a lack of equality and inclusivity for disabled students. Another participant expressed frustration at the lack of accessibility provision: 'The university has the budget to pay him [Head of Department] a salary so he can buy a Porsche, but they won't provide wheelchair accessible desks because apparently we don't have the budget.' The comparison between their basic needs not being met and the Head of Department's luxury purchases reveals a deep sense of injustice aimed towards the wider university and unfairly distributed finances, contributing to feelings of being undervalued and under prioritised.

Chronic illness not prioritised for disability support

As mentioned in the first theme, there are perceptions that chronic illness is not a valid disability due to its invisibility. This may have led to some disability support services

not prioritising chronic illness as a disability and not giving the support required. For example, one student said:

> I have noticed that there is a disparity between different types of disability/illness - for example blind students, students with a learning difficulty… are offered more support… it can contribute to a feeling that you are less important - there should be the same level of general support offered to all with chronic illnesses/disabilities according to their needs.

This student suggested that universities ought to prioritise services on a needs-basis, rather than segregating and allocating services based on the type or classification of disability, which leads to feelings of inequity. Participants commonly suggested that individuals with visible disabilities were provided with most support from disability services, but also that some invisible disabilities like learning difficulties are given high priority. This suggests that it is not the invisibility of chronic illness that causes issues with disability support, but the chronic illness itself.

Students' worth prescribed by graduate employability

The theme of undervalue and inequity appeared to weave throughout the data, especially in terms of university admissions and prospective employability. One student said:

> I feel as though I am looked at as less than the other students even if this isn't true… Only 3% of qualified English lawyers have a disability as the profession is so inaccessible so that is also over my head.

Participants felt that they were treated as lesser than other students. The presentation of a statistic of inaccessibility for one career pathway suggests their frustration at job prospects being limited. Another student described discrimination during an admissions interview: 'staff openly discriminated, at interview I was told "we don't want to give a place to someone with your type of disability because you might not be able to do the work post qualification"'. Both participants suggested that their chronic illness affected their graduate employability, in a systemic manner regarding the inaccessibility of a law career, and on an individual discriminatory level where they were told directly that their chronic illness may impact their ability to do a job.

Awareness of the lack of career opportunities for those with chronic illnesses may accumulate throughout their time at university, as one student wrote: 'The further into uni I got the less I believed I had potential to get a good job'. It seems that university support for students with chronic illnesses was inadequate to facilitate their belief that they could achieve a satisfactory graduate job. Another student emphasised this: 'I'm going through this with no guarantee I'll be able to even undertake full-time employment (like most grad jobs are) upon graduation'. The lack of information, support, or encouragement may lead those with chronic illnesses to feel apathetic and discouraged around completing university, as their worth has been decided by how employable they feel they are, reflected by the university's lack of support.

It is evident that participants do not feel they are treated equally on many levels. They do not feel accessibility to facilities is prioritised, nor do they feel that chronic illness is allocated parity of disability support compared to other disabilities. Furthermore, the data show that students' feelings of being undervalued are bolstered by the university basing their worth on graduate employability. Universities may be

inadequately supporting those with chronic illnesses to pursue their desired career, alongside openly discriminating in interviews.

'Police' versus 'allies'

Participants tended to describe staff members as either 'police' or 'allies'. Some staff ('police') would show a severe lack of understanding of chronic illness and vehemently enforce regulations set for the general student body, without reasonable adjustment. 'Allies' were staff and students who were supportive and understanding towards those with chronic illnesses.

Staff as 'police' who lacked understanding

Some students commented that staff's policing of the usual rules for the general student population could have adverse effects on disabled students. This suggests a lack of understanding of chronic illness from those staff members and a reluctance to accommodate for students' disability requirements. One student said:

> My department refused to record lectures despite having the equipment installed in all the department teaching rooms. They said they did so to encourage attendance but in my opinion it's not fair on people who can't come in for health reasons.

Instead of supporting students who were unable to attend lectures due to chronic illness, these staff members would prioritise policing poor attendance from students who *were* able to attend the lectures. This had adverse consequences for those students with chronic illnesses who could not attend lectures, as their learning was affected due to restricted access to lecture material; they felt they were being punished for something

they could not control. The disallowing of accommodations had detrimental impacts on the students' academic outcomes. One participant wrote: 'I feel like I have so much potential but the unwillingness of my uni to help make adjustments and the judgements of my lecturers are holding me back from actually what I could achieve.' Participants' aspirations were quelled and participants felt the lack of accommodations limited their academic achievements.

The unaccommodating nature of some staff members' attitudes towards students with disabilities is further shown by this participant: 'If I need something in a lecture or seminar I have to bug people to get it.' Other students talked about the challenges and frustrations of gaining coursework extensions when their illness was affecting their ability to work:

> I got extensions sometimes and was allowed these if I had a flare up but apparently there was a limit… I was told I wouldn't be allowed anymore – not sure how this is right as it's not my fault when I have a flare up and can't do my work as quickly as someone else… Then to catch up I worked hard and then subsequently relapsed because of this.

The implication here is that the staff member believes that the student is somehow accountable for and able to control their illness, and that they perceive their role as to enforce deadlines, and to 'police' strict rules about limiting extensions. Furthermore, the rigid policing of extension allowances had exacerbated this student's illness; attempting to compensate for their inability to gain an extension caused further distress and relapse.

The 'policing' attitude was sometimes explained by a lack of understanding of chronic illness impairments rather than an intent to cause harm: 'There is not enough

flexibility for those with chronic conditions - administration doesn't understand the concept of a flare'. Additionally, 'policing' may stem from scepticism about the validity of chronic illness, with many participants using the word 'excuse': 'People assume it's fake or an excuse'; 'Some tried to understand but I think some thought it was an excuse not to turn up to lectures'; 'Some tutors thought it was an excuse I think, and didn't understand properly.' These quotes link to the earlier theme regarding perceptions of chronic illness; negative misconceptions can result in reluctance to allow accommodations, and inappropriate 'policing' of regulations towards disabled students.

Allies who understand chronic illness

Alongside negative experiences with staff, some students have found supportive allies who understand chronic illness and want to help: 'I am always nervous about telling anyone about my chronic illness, but all the staff I have talked to at [redacted] have been really supportive. They are happy to adapt to my needs'. This student talked of their anxiety about telling staff they have a chronic illness but was pleased to find supportive outlets. Allies were particularly common within university disability departments: 'The disability team is extremely helpful and liaises on my behalf with my department so that I do not have to explain my condition whenever a problem occurs', and; 'My disability adviser is really understanding and does his best to put support in place'. The allies seemed to have a thorough understanding of chronic illness, which was lacking amongst 'police'. Consequently, allies may need to liaise with 'police' when requesting disability accommodations to which students are entitled.

Allies tended to be staff working within disability departments, which may be expected, as they are extensively trained to do their job in supporting disabled students. Allies were also found in other students with disabilities, suggesting that staff and

student allies both understood chronic illness. One participant noted the importance of a disability society for accessible socialising: ‘A society for disabled students where they can talk with no pressure to turn up and arrange meetups and off campus activities to encourage socialising with people who understand.’ Other disabled students fulfilled the role of allies because they offered a level of mutual understanding. Some participants mentioned that they felt socially excluded due to their non-disabled peers’ lack of understanding: ‘I do think it’s difficult to maintain friendships when chronically ill because some people do not understand the need to cancel or for them to come to you rather than the pub some days’. A lack of chronic illness knowledge may lead to misunderstandings when those with chronic illnesses have flare ups.

To summarise, the role adopted by staff and students towards students with chronic illnesses may depend on the level of understanding they have surrounding chronic illness. Those with little understanding or scepticism about the validity of chronic illness may attempt to police the students rather than accommodate their disabilities. Allies may be found in those who work within university disability departments and other students with chronic illnesses or disabilities, as they better grasp chronic illness and the associated impairments.

Discussion

This research explored students’ personal experiences of chronic illness within the social context of higher education. A main finding from the data is that students felt that their illness was often misperceived and misunderstood, leading to strict policing of academic regulations by some members of staff rather than accommodations for their disability needs. This could be explained partially by the often invisible nature of chronic illness. Consequently, some students felt that identifying with chronic illness

resulted in a negative identity, but others openly owned their disability and educated others, championing equal rights for disabled students.

Many participants reported feeling undervalued by their university, which is exemplified by universities prioritising building aesthetics rather than accessibility, and with open discrimination in interviews. Some also felt their worth was represented by how employable they were, and that universities did little to help them realise their academic and graduate potential.

In contrast to 'police', who refused adjustments and enforced general rules, some staff showed understanding and provided support to disabled students; these staff members were labelled as allies and were often found in the university disability support department. Furthermore, other disabled students provided a sense of inclusion and understanding within places such as societies, where disabled students found allies in similar others.

Perceptions of chronic illness and disability

Participants described their experiences of scepticism from others about the validity of chronic illness, demonstrating how chronic illness may have developed a negative social representation (Moscovici 1961; Howarth 2006) and therefore impacted people's opinions of this subgroup. This scepticism and the subsequent negative social representations may also result in a reluctance of those experiencing chronic illness to accept it as a valid diagnosis or label. A small number of participants identified disability and chronic illness as representing a negative identity; the constant minimisation of chronic illness by others could have been internalised so that they reject the concept of chronic illness as a disability (Waugh, Byrne, and Nicholas 2014). Alternatively, they may not identify with the word disability and perhaps feel like

having a chronic illness is more of a limitation on certain occasions rather than being persistently unable to do something. Those who accept the disabled label may not want this to be their defining feature, as one qualitative US study found the theme of 'needing to be normal' amongst student nurses with chronic illnesses (Dailey 2010). Dissociating from the label using denial may be protective; one study found that using denial was linked to better adaptation and adjustment to disability amongst a sample identifying as having psychiatric conditions or learning disabilities (Livneh, Martz, and Wilson 2001).

Regardless of why some students do not identify as disabled, it seems that they may be disadvantaged for not doing so. Only by identifying as disabled and disclosing a disability are students able to apply for equity allowances or disability support (Brown and Leigh 2018), and consequently those with a visible disability may be more likely to get accommodations. However, when disability is visible, students may be at risk of negative responses from others, such as embarrassment, which also reinforces a negative self-identity as a disabled student. In contrast, if a disability is invisible, students may be less likely to be believed, be less likely to get accommodations, and may be disbelieved if they *do* disclose. The social representations that others hold of disability may be influenced by the visibility and nature of a specific disability, with direct consequences for the accommodations available to students.

In accordance with the affirmations model, ~~Some~~ participants attempted to reduce the stigmatisation of chronic illness by adopting ~~a disabled identity~~disability ~~and using it~~ as a positive part of their identity and using it to educate those with misconceptions. This often involved making recommendations to their university about supporting disabled students. This also supports a study by Hutcheon and Wolbring (2012) who found that some participants claimed their self-voice by assertion and spoke of the importance of increasing awareness of disabilities at university. Adopting the

disabled identity and using it for empowerment to educate others may be key in reducing negative social representations of the subgroup, whether in higher education or wider society. Workshops with children in secondary schools have been shown to increase positive perceptions of people with disabilities (Pinfold et al. 2003), suggesting similar educational interventions could be useful in higher education. However, the onus should not be on students with disabilities to ensure their own educational equity. Nevertheless, if self-motivated, disabled students should be given a platform to educate others and have their voices heard.

Students with chronic illness are under-prioritised and undervalued at university

The presence of positive and empowered students with chronic illnesses who want to educate reflects the lack of existing knowledge and training coming from the universities themselves. This exemplifies how far behind society is in recognising, acknowledging, understanding, and providing adequate help for students with chronic illnesses. It may be this lack of support and understanding that leads to students with chronic illnesses feeling under-prioritised and undervalued. Participants provided examples of how the physical university environment can disable impaired individuals; for example, universities have failed to provide wheelchair accessibility to certain buildings, which may prevent the inclusion in activities of students with chronic illnesses (Anastasiou and Kauffman 2013).

Our participants felt that university support provided to those with chronic illnesses was not equally spread across the range of disabilities; that is, they report that universities assume needs based on disability type, providing more help to those with visible disabilities. The participants felt that visible disabilities were better understood and therefore received the most appropriate support. Having others disbelieve chronic

illness and having no way to evidence it may feed further into the negative social representation of chronic illness and perpetuate the lack of university support by illegitimating and undervaluing students' needs. Matthews (2009) argues that the emphasis on disability type confirms the university's focus on the medical model of disability, which categorises disability into diagnoses. However, the categories on student support forms do not always represent diverse students' impairments, limit availability of support to certain diagnosable disabilities.

Some students felt undervalued regarding graduate employability because of their chronic illness. Oliver (1990) suggested that low employment of disabled people has continued to contribute to their marginalisation in society as a graduate's worth is often dependent on their employment situation; graduate employability is directly linked to UK university rankings (e.g. the Teaching Excellence Framework; Office for Students 2020). Nario-Redmond (2010) suggested that low employment rates of disabled individuals could have contributed to a negative social representation of disabled individuals as incompetent. This social inequality may be reflected within higher education institutions and could perpetuate the low employment rates for disabled graduates and non-graduates. Transitioning into the workforce and finding a job is very important for disabled students, whether to prove their 'normality', to combat discrimination and oppression, or for taking control of their lives (Vlachou and Papananou 2018). Higher education could help improve the employability of marginalised groups, yet the opportunity is wasted if staff and students uphold these negative stereotypes and social representations of disabled students (Beatty 2012).

'Police' versus 'allies'

Staff, as well as university systems, seemed to lack understanding towards students with

chronic illnesses. This lack of understanding often resulted in staff members policing academic regulations at the expense of accommodating for chronic illnesses. Previous findings suggest that a lack of empathy towards disabled students produces resistance to adapt to their needs (Moriña, Cortés-Vega, and Molina 2015). Furthermore, these staff members may be infringing upon the Equality Act (2010) by illegally discriminating due to a disability and failing to anticipate the need for reasonable adjustments. Accommodations must be made so that disabled students have equal opportunities with non-disabled students. One student spoke of staff limiting the number of extensions based on how many they have already had; this fails to account for the unpredictable and blameless nature of chronic illness, and rather, indicates that staff may feel they have given too many allowances when they have merely equalised the assessment opportunities between disabled and non-disabled students.

One participant believed that rigid policing had prevented them from fulfilling their potential, which exemplifies the barriers for disabled students created by society within the social model of disability (Hodkinson 2016). Accommodations may help students with chronic illnesses reach their potential, but excessively policing regulations, sometimes illegally, is likely to hinder their progress, or even exacerbate their illness (Bê 2016). Royster and Marshall (2008) highlight that universities do not understand how to accommodate for students with chronic illnesses and recommended that a staff member with adequate knowledge of chronic illness be allocated to each student with a chronic illness as an ally. They could then liaise with other staff on behalf of the student to enforce accommodations. Students within this study praised some supportive staff as being allies, usually those within the disability support department, who stood out as supportive in contrast to the 'police'. It may be that some staff allies have greater understanding of students' illness because they experience them

themselves, although Brown and Leigh (2018) claim that there is a lack of staff identifying as disabled or who have disclosed disability or chronic illness in higher education.

It is also important for other students to understand chronic illness, as good peer support can be predictive of academic outcomes (Dennis et al. 2005). Many participants reported a lack of understanding from their peers, which resulted in feelings of social isolation. Establishing disability societies may offer students with chronic illnesses a chance to socially identify with similar and empathetic peers. Strong self-identity within a social group can help improve collective and individual self-esteem (Tajfel et al. 1979; Nario-Redmond, Noel, and Fern 2013), and can improve student outcomes in higher education (Thomas et al. 2017). However, the idea of joining a disability society for some students may be unappealing due to the stigmatised social representations society holds of the subgroup of disabled individuals (Nario-Redmond et al. 2013). This may be especially likely for those who appraise 'disabled' as a negative identity, refuse to label themselves as such, or deny they have a disability at all.

Recommendations

These findings lead to several practical recommendations for universities. With the recurrences of misconception and stigmatisation towards both chronic illness and disability, it is suggested that universities implement education for staff and students about chronic illness, invisible illnesses, and disabilities, rather than relying on disabled students to effect change (Jung 2003). Staff training around the need for and appropriateness of anticipatory adjustments is essential to inform genuinely inclusive approaches to education and assessment (Waterfield and West 2006). It is acknowledged that social representations of chronic illness are not limited to

universities but are the issues of wider society. Nevertheless, an educational establishment is an ideal environment to implement interventions aiming to tackle these issues where students, on graduating, can take this knowledge with them.

Further, it is recommended that university disability support should be based on needs, rather than diagnoses. This could involve an open-ended response box rather than discrete medicalised categories on a student support form, which would allow students to communicate their issues in their own words and open a dialogue between students and support services. On reading this, staff could then find out how best to accommodate for the student's needs, in negotiation with the student, without requiring the student to adopt a 'disabled' identity.

Finally, staff and universities should value and support students with chronic illnesses to increase their chances of social mobility, rather than perpetuating marginalisation of this group. Staff must accommodate for students' needs rather than policing academic regulations rigidly across the entire student cohort. Staff education and training, as discussed earlier, would facilitate this, increasing empathy and understanding, enabling them to provide for the needs of students with chronic illnesses, rather than mistakenly believing they would be giving them advantages over other students.

Strengths and Limitations of the Study

This study is one of the first to explore the experiences of students identifying as having chronic illness at university. The researchers were mindful of the marginalised groups' accessibility needs and how these might limit them from taking part. Therefore, the study was in the form of an online questionnaire using an open-ended response format to gather rich data. The questionnaire allowed respondents to take breaks and return

later, and aimed to record a broad range of experiences from students who may have had little opportunity to talk about this previously. The insights gained are therefore novel and support the literature and theory into social representations of disabled individuals, and misconceptions of invisible illnesses.

Although the format of the study allowed participation by a range of individuals across UK universities, there were only five male participants. This may show a bias in recruitment, or it may be due to the higher prevalence of females suffering from certain chronic illnesses, such as myalgic encephalomyelitis (Faro et al. 2016) and fibromyalgia (Fairweather, Frisancho-Kiss, and Rose 2008). Consequently, future research could attempt to recruit a more balanced sample to explore any gendered issues, perhaps by consulting male health websites or contacting male disability researchers.

The study only gathers perceptions from students rather than from the university staff. Although these participants talk of their frustrations surrounding university inaccessibility or staff policing, there may be alternative explanations for these issues, which would only be uncovered by asking all involved parties. Future research may therefore wish to gain staff perceptions (e.g. Abu-Hamour 2013; Zhang et al. 2018) alongside students', to investigate similarities, differences, and to provide additional context to this research.

Conclusions

Although there has been much research on disabled students within higher education, students with invisible chronic illness, stamina, or energy impairments were rarely included. These findings suggest that students with chronic illnesses share similar higher educational experiences to students with other disabilities, such as barriers to accessibility, stigmatisations, and resistance from staff. However, more specific insight

is provided into how the social representations of students with chronic illnesses are negative; for example, students with chronic illnesses feel not only disadvantaged in comparison with fully able students, but they also feel students with other disabilities receive more support. The research therefore demonstrates how universities may exclude and disable students rather than including and enabling them. ~~Our findings also support the disability affirmation model, in that our participants report exclusion as a result of both their physical impairments *and* the social environment in which they are studying.~~

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Appendices

Appendix A – List of Participants' Chronic Illness/es

- Fibromyalgia
- ME
- Joint Hypermobility Syndrome
- Fibromyalgia
- M.E
- ME and fibromyalgia
- Rheumatoid Arthritis
- Ehlers Danlos Syndrome, Dysautonomia
- POTS, Fibromyalgia, chronic fatigue, MCAS
- ME/CFS
- ME/CFS
- Ehlers-Danlos Syndrome and gastroparesis
- Crohn's Disease
- ME
- Coeliac Disease
- Rheumatoid Arthritis
- Interstitial Cystitis
- Current working diagnosis is borderline lupus
- Ehlers Danlos Hypermobility Type and Chronic Migraine
- Ehlers Danlos, Chronic Fatigue Syndrome, Ulcerative Colitis
- Joint hypermobility syndrome (now known as HSD, but I have symptoms of hEDS which I'm getting checked for soon)
- Chronic Fatigue Syndrome
- POTS
- ME, fibromyalgia and hEDS
- POTS
- POTS, chronic migraine
- Chronic fatigue syndrome
- Ehlers-Danlos type 3
- Joint Hypermobility Syndrome / Hypermobility Spectrum Disorder
- Chronic Fatigue Syndrome (ME)
- Lupus
- Postural Orthostatic Tachycardia Syndrome
- POTS, CFS/ME, b12 & vit D deficiency
- Ehlers Danlos Syndrome Coeliac
- Hypermobility Spectrum Disorder/ hypermobile Ehlers Danlos syndrome
- Chronic fatigue syndrome
- Ehlers-Danlos Syndrome and Mixed Connective Tissue Disease
- Hypermobile Ehlers Danlos Syndrome, M.E/ Chronic Fatigue syndrome, Intestinal Dysmotility
- Chronic Fatigue Syndrome/M.E
- ME/CFS, Fibromyalgia, Ehlers-Danlos Syndrome
- Nephrotic syndrome, thoracic outlet syndrome
- Myalgia encephalomyelitis
- Fibromyalgia and myalgic encephalomyelitis (ME or CFS)
- Chronic Fatigue Syndrome
- Chronic fatigue syndrome, dysautonomia (maybe some others)

- Myalgic Encephalomyelitis
- Chronic Fatigue Syndrome
- Chronic migraine, ME/CFS, dysautonomia
- CFS/ME
- ME
- Cfs
- M.E. and Fibromyalgia
- Chronic Fatigue Syndrome
- Lupus as part of a connective tissue disorder diagnosis
- Chronic migraine
- Me/cfs
- Chronic fatigue syndrome, suspected Ehlers-Danlos syndrome
- MS
- Auto Immune Haemolytic Anaemia
- Crohn’s disease
- POTS, ME/CFS
- Epilepsy
- Type 1 diabetes
- Fibromyalgia
- Sciatica caused by a herniated disc
- Chronic Kidney disease, Chronic pain disorder.
- I have over 18. The main diagnosis is Ehlers Danlos Syndrome and 2 bulging discs in my spine