Shifting narratives of the Self – students' experiences of chronicity and multiplicity in the management of chronic illness at university

#### Abstract

Drawing on the chronic illness scholarship and identity theories, this paper aims to deepen the understanding of the biographical disruptions experienced by undergraduate students living with a long-term health condition. Data are drawn from in-depth interviews with six undergraduate (female) students attending university in England. The analysis highlights the ways chronicity *and* multiplicity come together to shape students' health and social identities. The findings reveal three narratives of the Self: the *ill Self*, the *determined Self*, and the *authentic Self*. These distinct, yet interconnected, narratives highlight the complex shifts in the Self as students sought ways to 'push through' multiple (academic, health, social) pressures. Maintaining academic and social engagement met with significant challenge, ultimately shaping the emotional and social lives of these students. The paper offers a novel contribution to how undergraduate students navigate multiple identities in the face of ongoing illness.

**Key words:** Chronic health conditions; health identities; biographical disruption; students; university.

## Introduction

Prioritisation of student wellbeing reflects deepening concerns about the physical and mental health of university students (Public Health England 2015, Universities UK 2015). Yet the unique challenges faced by students with a chronic health condition have been relatively overlooked in research to date – despite evidence of growing numbers of young adults

affected by chronic illness (Grimes et al. 2019, Shah et al. 2019). Students in higher education are increasingly faced with a range of academic, social and financial pressures, and what it means to be a student today has shifted in the context of a changing higher education landscape (Alsubaie et al. 2019, Brooks et al. 2021). The marketization of higher education, including (increasing) student tuition fees across the sector (in the UK and many other countries), has exacerbated financial pressures for students, with impacts on their identities as 'powerful' consumers of education, but also their emotional and mental wellbeing (Alsubaie et al. 2019, Raaper 2021, Silverio et al. 2021). The pressures for students with long-term health conditions are likely to be intensified in this changing higher education landscape as they navigate both illness identities and student identities. Yet, sociologically, there has been limited work examining the experiences of students' with chronic health conditions (some exceptions are discussed shortly) including how (ill)health may shape these students' identities and university experiences.

This paper draws on a study that sought to advance the understanding of undergraduate students' experiences of living with a chronic health condition – illustrating the complex ways chronicity *and* multiplicity work together to shape three narratives of the Self. These distinct narratives illustrate the varying ways different health and social identities were (sometimes inconsistently) privileged by students, with significant impacts on their everyday academic and social lives. The paper commences with an account of some of the seminal contributions to the chronic illness scholarship and social identity theories before considering the specific work undertaken with university students. We conclude by highlighting some possible implications for universities, along with suggestions to advance research and scholarship in this field.

#### Chronic illness as biographical disruption and continuity

Contributions to the sociological understanding of chronic illness have been influenced by Bury's (1982) notion of biographical disruption, with much of the related research documenting the unsettling impacts of illness on the individual's everyday lives and future biographies (Corbin and Strauss 1985, Charmaz 1995). This includes the chronically ill facing new uncertainties in the context of ongoing ill health, demanding lifestyle adjustments and new forms of coping. Yet, other evidence offers a counter perspective and suggests possibilities for biographical continuity (Williams et al. 2009), biographical contingency (Monaghan and Gabe 2015), or biographical suspension (Saunders et al. 2018). Possibilities for both recurrent disruption and continuity highlight how health and illness identities are not static and can frequently shift over time and in differing contexts (Brown et al. 2017). Indeed, social identity theories highlights how an individual's self-concept is developed in relation to others – including the felt pressures to conform to group or social norms (Turner 1975, Stryker 2004, Stets and Burke 2014) and how this triggers or motivates action (or lack of). Following Tajfel and Turner (1979), an individual's self-categorisation or understanding of the Self is thus made-up of both personal and social identities. Understanding how both the university experience and a chronic health condition impacts on students' identities is crucial for ensuring these students are supported in the higher education environment.

## Students with long-term health conditions

The shifting and temporal aspects of chronic illness may be particularly relevant in the context of students' health and wellbeing, including how they navigate multiple identities in different social contexts.

Heaton et al. (2016), for example, examined the ways in which young adults actively manage the medical aspects of their conditions to 'fit' with preferred everyday activities and navigate a 'normal' life. Evidence of this kind draws attention to the complex ways young people navigate a range of 'shifting normalities' (Sanderson et al. 2011), within ever changing bodily experiences and social conditions (Saunders 2011, Spencer et al. 2018). These socially located and dynamic experiences of (ill) health are known influences on young people's health and social identities and forms of illness management (Bray et al. 2014, Saunders 2014, Spencer et al. 2018). However, an exploration of university students' identities in relation to chronic illness have been relatively underexplored (exceptions include Balfe 2007, 2009, Spencer et al. 2018, 2019) — despite increasing recognition of the impacts of university on students' identities (Brooks et al. 2021, Raaper 2021).

The presence of a long-term condition may well shape students' university experiences, including the forms of illness management they engage in (or not) whilst attending university. An Australian study (Spencer et al., 2018) revealed the difficulties students experienced with managing conflicting health and academic demands at university. The relative invisibility and fluctuating nature of symptoms was especially challenging and not well accommodated by rigid university processes and structures. Similarly, research with UK-based students has focused on how illness shapes students' identities and practices. In a study of students with Type 1 Diabetes Mellitus (T1DM), Balfe (2007, 2009) revealed the importance these students attached to the idea of being seen as normal by their peers – and perhaps as evidence of their engagement with ableist discourses and a desire to 'fit in'. Drawing on Shilling's (2003) 'body projects', Balfe unpacked the ways students differentially privileged varying health and student identities in order to minimise any negative impacts on their social identities.

Concealing their illness and related health practices (e.g. injecting insulin in private spaces) and consuming alcohol with peers offered 'positive' ways for these students to maintain their preferred 'normal' student identity (see also Saunders 2011, Spencer et al. 2019). The active manipulation of symptoms in an effort to conceal illness was done so in full knowledge of the risks to their immediate and longer-term health. Taking such risks and 'trading' their health for more immediate academic and social gains (Spencer et al. 2019) were deemed necessary as part of students' ongoing negotiations of different social and healthy body projects (Saunders 2011) – again illustrating evidence of the powerful effects ableist discourses have on shaping the perceived legitimacy of (ill) health identities, particularly in the context of hidden disabilities (Calder-Dawe et al. 2019).

In this paper, we extend these contributions through introducing the concept of multiplicity to unpack how students with long-term health conditions construct and navigate their health and social identities at university. Multiplicity has been differentially theorised to reflect 'the many possible ways of seeing, feeling, doing or being a particular thing' (Setchell et al. 2018, p. 166). Although different theoretical perspectives exist (see for example Deleuze and Guattari 1987, Mol 2002) they share the common idea of the singular being made up of multiple elements. The individual is thus constituted of multiple identities and practices that come together in different (often contradictory) ways and at different times. In this study, multiplicity emerged from our collective and reflexive analysis of our findings and in particular, how participants described how they constantly juggled competing demands and managed the cumulative and unpredictable effects of ongoing ill health. In this context, our analysis shows how multiplicity gave way to competing and contradictory narratives of the Self. Although identity theories remind us of the presence of multiple identities, the concept of multiplicity has yet to be fully developed in the chronic illness literature. Here, we

highlight the utility of the term for understanding the differing ways students navigate numerous, often competing demands, and the subsequent impacts such multiplicities have on illness identities. As our analysis reveals, chronicity *and* multiplicity do not operate in contradiction but rather, work together to shape three new narratives of the Self.

#### Materials and methods

This paper draws on interview data generated as part of a qualitative study with six undergraduate students (all female) attending one large university in the south of England. The main aim was to elicit the narratives of students with a chronic physical health condition. A convenience sampling strategy was used to recruit undergraduates from different degree programmes and who self-reported a medically diagnosed chronic physical health condition (e.g. diabetes, epilepsy, asthma). Mental health conditions were not included in the absence of a physical health condition. However, many participants also had mental health conditions (anxiety, depression), which they attributed to the impacts and stresses of having a physical health condition – reflecting the inter-relationship between physical and mental health. Participants were recruited via posters displayed around campus and electronic bulletins circulated via email. Recruitment materials included information about the study and its aims, along with details about the interview and how students might get involved. The limitations of our sampling strategy are discussed later in the paper.

#### [Insert table one].

Four interviews were conducted in a quiet meeting room on campus; one interview was conducted via Skype and another via telephone at the request of participants. Interviews lasted from 1 to 2.5 hours in length and were conducted by the first author – an experienced female qualitative health researcher. Drawing on the extant literature and previous research

by the first author, a discussion guide was developed to explore participants' experiences of health and chronic illness, their transition to university, and how they manage (or not) their health at university. The guide was sufficiently flexible to enable participants to tell their own stories and identify the areas they saw as being most important to their health and university experiences and piloted with a group of students attending a different university. Interviews were audio-recorded and transcribed verbatim by a professional transcription service.

Interviews were analysed thematically and narratively. Thematic analysis enabled the development of topical categories emerging from the data itself. For example, data were analysed inductively via an emic approach to identify the key terms and expressions participants' used. These terms were coded and then grouped into categories to begin the identification and interpretation of salient ideas emerging from the data. These categories were discussed by the authors to identify core thematic areas that captured key features of the narratives, as well as comparing points of departure in our interpretations.

In contrast, narrative analysis enabled a more nuanced examination of each participant's whole story, including how they positioned themselves within their narrative (and in relation to the researcher) and the temporal construction of these stories (Riessman 2008). Narrative analysis allows us to 'to see different and sometimes contradictory layers of meaning, to bring them into useful dialogue with each other, and to understand more about individual and social change' (Andrews et al. 2008, p.1). In keeping with this analytical approach, attention was paid to not only what participants said, but also how they described and (re)presented their experiences and Self during the discussions. Narratives are thus understood as co-constructed between the participant and researcher and reflect a particular representation of

the Self at a given time point (Riessman 2008). This analytical approach enabled us to better unpack how students engaged in different identity work (and in relation to the interviewer) and by paying attention to consistencies and shifts in participants' narratives of being a university student with a long-term health condition. By combining thematic and narrative analysis, we were better able to scrutinize the synergies and differences in core themes within and across individual narratives – offering a deeper appreciation of participants' experiences of ill health at university. The relative strengths and co-construction of narratives are considered in our final discussion.

The study received ethics approval from a University Research Ethics Committee. All participants were provided with a study information sheet. Written informed consent was taken at the start of each interview. Participants were offered opportunity to ask questions and were free to withdraw at any point. All data were pseudo-anonymised and stored securely in line with data protection requirements. Participants were advised that they could stop the interview at any time and were made aware of available support services. Some participants took up these services after sharing the difficulties they were experiencing. For example, a number of participants were visibly upset during interviews as they described the difficulties they encountered. During these moments, the participant was asked if they would like to proceed, take a break, or terminate the interview. The participant was then guided to the university support services.

#### **Results**

Findings revealed the complex, and sometimes contradictory, ways students sought to manage their (ill)health and uphold their preferred student identities. Our analysis revealed how multiplicity and chronicity worked together to produce three key narratives of the Self:

the ill Self, the determined Self, and the authentic Self – reflecting the ways these students continuously juggled multiple identities, as the following analysis reveals.

## Multiplicity and chronicity – the ill Self

Despite clear differences in their programmes of study, health conditions, social and family backgrounds, distinct commonalities were evident across the six interviews (some contrasting views are highlighted). All participants talked at length about the ongoing, sometimes unrelenting, adverse features of their conditions – particularly the experiences of chronic pain and debilitating fatigue. Managing the latter was a central preoccupation, often with significant disruptive impacts on participants' academic studies and personal lives. The experience of being (constantly) ill was reported as a significant stressor, which exacerbated their symptoms. Imogen, for example, described how she would frequently battle with fatigue and unanticipated dizziness – often brought about during moments of stress, which in turn intensified her symptoms.

Interviewer: Can you say more about how stress affects you?

Imogen: Stress [...] makes me dizzy, which often makes me more stressed, which makes me more dizzy. So that's probably the most difficult one for me to manage, because stress is part of uni.

For Imogen, the spiralling effects of stress triggered a cascade of other symptoms as she described her vulnerability to 'almost anything'. Likewise, Jude hinted at the cumulative effects of multiple symptoms and how she would become caught in a 'vicious circle' of ill health. The culmination of being in constant pain, side-effects of medication, and dietary restrictions often challenged her perseverance to 'keep going'. Coupled with academic and

clinical placement demands from her nursing degree, Jude's narrative revealed how multiplicity and chronicity ultimately took its toll on her wellbeing.

I get really tired. It feels like if I close my eyes, I'll fall asleep no matter where I am [...]. I don't know if it's the medication, or if it's because I'm using more energy up to do what I was doing and it causes pain. [I]t's like a vicious circle [...]. It's the impact of placement and the assignment all due on the same day, it takes its toll (Jude).

From the beginning of the interview, Renee shared the multiple demands on her as a wife, mother and nursing student with numerous health conditions. Frequent hospital admissions, ongoing medical procedures and a cocktail of different medications (all with their own side-effects) were increasingly difficult for Renee to manage.

[W]hen I'm so stressed, fatigue sets in, so I start to break-down and I feel so exhausted. But the thought of assignments, I can't sleep [...]. I went to work and I was like, 'Oh God, I need to get my formative [assessment] done because we are submitting it on Monday [...] I need to get home, shower, and get on with my work, [...] and I have kids too' (Renee).

The impacts on students' emotional wellbeing were clearly evident as they outlined the intensity of managing numerous demands arising from their conditions, whilst simultaneously trying to preserve their academic and social engagement. The latter often suffering as a consequence. The experience of chronic fatigue was particularly difficult because of its effects on concentration, but also because of its unpredictable nature and

relative invisibility to others – a point we return to later in our analysis. Students described how they would need to 'pace themselves' to ensure they could avoid triggering fatigue and 'successfully' minimise any possible disruption to their studies. Yet pacing themselves could further intensify the effects of multiplicity as the pressures would simply build-up.

You go to lie down, you want to rest. Then you start thinking of having to submit so much assignments, I actually don't sleep so I get up [...]. It's like that anxiety of everything (Renee).

The ongoing, recurrent symptoms described by participants resulted in significant disruptions to their academic studies and personal lives. Shannon, Imogen, and Beth all described how they had either changed their degree programme, had fallen behind, or had taken time off from their studies. Indeed, the disruptive effects of their conditions seemed to be a constant feature of their narratives as they talked about their earlier experiences of being ill. Shannon, for example, described how her first term at university was characterised by frequent hospital admissions brought about by unexplained pain and fatigue.

I was in and out of hospital. I had intense stomach pains, I'd just be in loads of pain all the time [...]. My attendance got even worse and I was getting really bad (Shannon).

Imogen reported suspending her studies during a 'bad time' of ill health. She had been at university for four years but was in her third year of her degree, and (in her view) had fallen behind her peers. Beth expressed her desire to graduate later in the year, alongside an awareness of the possibility for a 'flare-up' of her oral allergy syndrome. Comparing herself

to others and 'getting behind' exacerbated the stress she felt, along with the constant risk of experiencing a life-threatening emergency such as anaphylaxis – reflecting her ongoing identity negotiations in order to align with her peers, albeit with a risk to her health. The unpredictability of illness was particularly disruptive and difficult to manage. Imogen shared how the dizziness brought on by her chronic vestibulitis could present sudden safety issues. Similarly, Jude provided examples of times when she would fall over without obvious reason.

I was at work and I suddenly came across really dizzy and felt like I was going to pass out [...]. It was like the room was spinning all the time, and I went back to uni and then suddenly it got a lot worse, and I ended up falling down some stairs because I was so dizzy (Imogen).

Of significance here is the way in which such difficulties and disruptions were evaluated by participants for their impacts on who they were as students – or more often, how they were viewed by others. Despite emphasising the unpredictable nature of their conditions, ill health was also described as being ever constant. Beth, for example, reported that she faced a constant risk of a severe allergic reaction, resulting in her self-exclusion from social events involving food. This uncertainty appeared to trigger shifts in how students presented themselves during the interview (c.f. Balfe 2007, Spencer et al. 2018). For example, participants' often displayed evidence of resistance to the idea that they were ill or different from others, all the while describing the significant and debilitating aspects of their conditions. Joyce presented herself as 'fine', yet also talked about the frequent dizzy spells, poor mobility and extreme fatigue she experienced. She used humour to dismiss the severity of her condition (to others), or divert unwanted attention towards her illness – despite, at times, clearly struggling with symptoms. Others talked in the third person and in doing so,

discursively distanced themselves from the difficulties they personally encountered (c.f. Spencer et al. 2019) – and in many ways can be seen as part of the complex negotiation of different versions of the Self.

Renee also indicated signs of downplaying the severity of her condition and its impacts, albeit in a different way. As evidenced, her earlier account of multiplicity and chronicity revealed significant impacts on her mental wellbeing as she described the ways she would actively try to 'block-out' the emotional impacts of her condition. Downplaying her symptoms offered one way to minimise their significance – despite being acutely aware of the lasting impacts on her psychological wellbeing.

I always try to block certain things from my mind, just to move on. But when you try to block so many things, even though you are going through pain, you try and block a lot of things [...]. It can bring you down [...]. So in a way, it's not helpful to block things from your mind. Like when sometimes you have a lot of pain [...]. Like you are trying to avoid certain things, which can lead to depression, to anxiety. You think about it, you're anxious, but you don't want to show it. Then as times goes on, it surfaces (Renee).

#### Pushing through and faking it – the determined Self and authentic Self

Despite clearly articulating the struggles they experienced, participants frequently described the ways they sought to 'push through' and not give into their illness or reveal the ill Self – often providing examples of their tenacity and determination to 'keep going'. Students

presented themselves as being strong, determined and capable of 'powering through' and as they sought to uphold a diligent, hard-working student identity (c.f. Spencer et al. 2019).

I can do this. So that was basically my mind, I was like, you know what, I'm going to do this. I got into a really determined state (Joyce).

It's not as though I can't do something. I will do it. It might take me longer or a different way around it, but I will find a way around it. [I]t doesn't mean I can't do things (Jude).

Like others, Renee appeared incredibly stoic throughout the interview. 'Retuning her mind' enabled her to push through periods of intense pain and fatigue and avoid taking any analgesia. Indeed, taking medication was a sign of 'giving in' to her condition – something she fiercely resisted. She articulated a reluctance to seek out help for her academic work, despite the severity of her symptoms. Here, pushing through was preferable than deferring the (academic) pressures to a later time.

Renee: I don't take pain killers.

Interviewer: So how do you manage to get through the day?

Renee: Sometimes I have to rest [...]. I've tuned my mind, it's something I have to deal with, mentally [...]. So, even though when I go for placement, sometimes it can be excruciating, but I just have to tune my mind. So it was how I got it done, I just kept on. Sometimes I'd be walking in the room with my laptop in one hand because I couldn't sit. I'd get in pain. It disrupted my sleep because I was

in pain. And I just asked myself, 'If I don't get it done, I'm just piling a lot of things'. I think I put too much stress on myself.

Renee and Jude both described how they avoided extensions for their academic work – often suggesting that their health conditions were not serious enough to warrant any special privileges. Failing assessments was preferable to showing any 'weakness' or inability to cope. When probed further as to why they would not seek an extension, the importance of being seen, and treated, like a normal student came through strongly. Indeed, pushing through offered one way to uphold their preferred normal student identity.

I've never [had an academic extension] because in December when I was not well and I was given a medical certificate, I didn't give it to the uni' [...]. I just asked myself, 'if I don't get it done, I have another assignment coming. When am I gonna get it done?' [...]. And I just want to be like any other student. That's another reason I didn't given my medical certificate. I don't want to be like, 'Oh, I have an issue'. I just want to be normal, like any other person (Renee).

Determination to push through, irrespective of the consequences, was also strongly motivated by a desire to conceal their illness from others. Throughout the interview, Joyce was very reluctant to acknowledge that her condition could hold her back in any way. Pushing through was made possible by little adjustments and 'planning ahead a little'. Attending the gym to improve muscle strength or eating salty foods when her blood pressure was low aided Joyce to continue as 'normal'. She described how she would restrict her fluid intake whilst on clinical placement fluids to avoid frequent trips to the bathroom or, at worse, be incontinent.

Yet perversely, restricting fluids made it more likely that she would pass out in the clinical area – often necessitating an explanation to others.

I'm in the loo every 5 minutes, and they must look at me and think, 'she's having us on'. I've passed out and somebody's said, 'are you okay?' And I went, 'yeah, I'm fine' [...]. I think everybody's like, 'what's wrong with you' [...]. But I'm certain, you know, even if I told them about the EDS [...]. Oh, by the way I've got a massive this and that. It just sounds like attention seeking (Joyce).

When asked about why she was reluctant to disclose her condition and symptoms to others, Joyce expressed her concerns about being seen as a fraud or being labelled as disabled.

They'd think you're putting it on, you're mad, it just feels a little as if you're being a fraud [...]. I'm just so worried that I'm going to end up with this label of, 'Oh, look at her, she's milking this so-called thing that we can't see'. And I'm desperate not to have that label. I don't want to be that student. That scares the life out of me (Joyce).

Whilst pushing through enabled participants to keep going and foreground their determined Self, such perseverance not only held undesirable health and academic consequences, but also gave way to the idea that they could be seen as faking their illness. Concerns about not being seen as authentically ill often strengthened participants' attempts to keep going. Shannon, for example, described her reluctance to seek out an academic extension because of concerns about being labelled as a 'wayward' student who had been over socialising. The idea of 'faking it' tied to her earlier experiences of ill health and the difficulties of reaching a

diagnosis for her symptoms. For Shannon, pushing through and concealing her symptoms offered one way she could affirm a legitimate healthy identity and thereby counter common comments she received such as, 'you're always ill'. Yet perversely in doing so, she ran the risk of not being seen as legitimately ill.

For a year I didn't do PE because my knees hurt too much. It got to the point where a lot of other students just thought I was faking it [...]. And I just kind of like, I'm just ill (Shannon).

Imogen too described her concerns about authenticity. Lack of visibility of her condition and not being believed resulted in the felt need to frequently justify herself to others – reflecting the impacts of 'disability scepticism' on her actions and interactions and the need to have her condition legitimated by normative ableist privilege (c.f. Calder-Dawe et al. 2019). Yet she also described a reluctance to talk about her health and its impacts because of her fears about not being believed. She was particularly concerned that her symptoms may be explained away as evidence of anxiety and thus, not to be taken seriously. Despite immediate safety concerns arising from the sudden onset of dizziness, Imogen described how other people (including doctors) were largely dismissive about her symptoms.

It's quite difficult sometimes to get through to some of them. You do get a lot of, 'Oh well, you don't look sick', and my tutors although they're understanding every now and then they'll say, 'You know, extensions don't help, you'll just get more behind'. And it's a like, well I didn't want to be ill [...]. I feel like I have to justify myself a lot (Imogen).

The idea of not being authentically ill complicated participants' reflections on the Self as they constantly wrestled with a strong desire not to be defined by their illness, whilst simultaneously describing the need for others to understand the impacts of their lives. Yet in order to reconcile this tension, perversely, participants often demonstrated evidence of faking being well – rather than faking ill health.

# Shifting narratives of the Self – preparing for the (uncertain) future

Despite presenting themselves as being determined and resisting a position of ill health, participants also talked about how they had come to adjust to their conditions, albeit with a degree of reluctance. Within these discussions, continuous shifts in the Self were evident as they talked through, on the one hand, accepting their ill health, whilst simultaneously trying to uphold a determined Self. These struggles posed a threat to their authentic Self (identified by participants as 'who they really are') as participants engaged in frequent comparisons between their old (healthy) Self and their new future (ill) Self.

Imogen, for example, described how the ongoing fatigue she experienced forced her to rethink and reflect on her future, as well as find new ways of prioritising her studies and social life. She talked about feelings of frustration as she compared herself to the person she used to be – an energetic, social person 'who never stops'. She described how she had reluctantly come to adjust to the limitations posed by her condition.

I used to be one of those people who never stops and it's been really difficult to learn to have to stop and I can't do things that I want to do. I have to manage my

energy levels. That was really tough. I've had it for three years now so I'm beginning to come to terms with it, but it still gets quite frustrating (Imogen).

Yet for others, the idea of facing an uncertain future remained difficult. For Joyce, she realised that her dream to work as an independent midwife may remain a dream. Shannon reported how she was 'really depressed and really upset' following her diagnosis. She expressed her determination to keep going, albeit with help but then reluctantly accepted how managing constant pain and fatigue (coupled with limits to her mobility and low blood pressure) meant that she would struggle with most careers and, because of this, faced a less certain future. Constantly questioning the (limits of) the ill Self reflected the ongoing tensions she experienced when faced with a different version of herself – and one that ultimately could not be changed.

I think the biggest thing is questioning if I can do something or not. Like, can I do this job? [I]f I'm lucky, I'll manage to get a job in the industry it'll be amazing, but I might just have to go into retail or something [...]. Because I don't have enough energy [...] and I'm scared that I'm not gonna be able [...]. Like, can I do these things? (Shannon).

It does alter your life. My life now is completely different [...]. It is hard, it is very hard. And there are times you think, 'actually, I just can't do it.' Then once you've had your sleep and had a moment to feel sorry for oneself, you get back up and you carry on because you can't change it (Jude).

These and other accounts highlight how negotiating and comparing different versions of the Self met with significant personal challenge. These difficulties, and the dangers of reflecting on who they use to be with who they might be in future, extended to comparisons made between themselves and others. Whilst frequently expressing a desire to be seen as 'just like any other student', participants also recognised how their lives differed significantly from peers and why, at times, they may not, or could not, achieve what they saw as being their full (academic) potential. Despite some resistance to the latter, participants acknowledged that they 'needed to be kind' to themselves and in doing so, accept that their lives are not, and will not be, the same as others.

I think a message for myself would be to remember that if I'm not feeling well, not to push myself because then I'll just get more ill (Imogen).

In a way it has affected me, knowing very well that it's not everything you can't do [...]. Because certain things are not the same as someone who is not having a long-term condition. You can't compare (Renee).

Here, being kind of themselves, was part of acknowledging their illness (and its limits) were part of accepting their authentic Self and a reworking of what it means to be a 'normal' student

#### **Discussion**

The narratives presented in this paper offer new understandings of how biographical disruptions can shape differing (sometimes competing) narratives of the Self. Significantly,

multiplicity, including how such pressures shaped students' reflections on the Self and their management of ill health at university. Our analysis of multiplicity revealed the impacts of multiple pressures from their health conditions, academic studies, and broader social and family lives. Multiplicity was thus compounded by chronicity, which worked together to shape the ongoing and uncertain nature of ill health. Because of this, we can better understand students' reluctance to seek out help for academic work since extensions for assessments, for example, only delayed the stresses to a later time point – thereby exacerbating the effects of multiplicity in the (near) future.

These findings point to the complex ways in which university students narrate and navigate multiple identities in the face of ongoing illness including how they categorise themselves in relation to the social world (Billig et al.1988) and specifically, the normative assumptions about (dis)abled bodies (Calder-Dawe et al. 2019). For these students, the lack of visual clues to their ill health served to govern their actions and practices and legitimate (or not) their (ill) health identities. Here, we can see how the identity work undertaken by these students is interwoven with academic and social pressures and shapes the differential privileging of different versions of the Self and at different times. Further, these different versions are constantly in flux depending on, and in relation to, the social context. The student Self is thus, constituted of multiple identities, which are themselves distinctly constituted in relation to others – and how others see them (Burke 2003, Stets and Burke 2014). These students' concerns about the perceived legitimacy of their different identities reflect the daily struggles they experience when attempting to present their preferred student identity, all the while striving to retain the authentic version of their Self – and one that acknowledges their everyday experiences of ongoing ill health.

Identity theory suggests that when individuals feel good about themselves, they take on more identities (Stets and Burke 2014). However, our data suggests a different perspective and highlights the difficulties and contradictions that emerge from multiple identities and the (negative) impacts on the Self. Our analysis of these students' ongoing identity negotiations often resulted in the privileging of the determined Self in an effort to uphold a 'normal' student identity – often to the detriment of their health and academic studies.

The analysis presented here reflects the ways in which participants constantly wrestled with differing, multiple versions of their authentic Self. The latter often shifting in response to the disruptive and fluctuating demands of their health conditions, but also the degree to which these students wanted to reveal their ill Self to others. In contrast to reflecting temporary biographical suspension where the individual neither aligns with an ill or healthy Self (Saunders et al. 2018), our analysis shows how multiplicity can give way to differing, yet coexisting identities (Balfe 2009). By highlighting the co-existence of multiple Selves, we can better understand the apparent contradictions in participants' accounts and practices, including how and why students responded to such pressures. Their willingness to disclose their conditions to others and seek out help, for example, was closely tied to normative assumptions about aligning with a healthy student identity. Yet, in this context, multiplicity reminds us of how different versions of the Self co-exist, which are differentially prioritised at different moments in response to varying social conditions (Setchell et al. 2018).

Participants thus shifted to and from different versions of the Self in response to how they perceived the reactions of others.

Research with university students has highlighted how students draw on (competing) frames of reference in their management of chronic illness and how these are underpinned by concerns about 'normalcy' (Balfe 2007, 2009, Spencer et al. 2018). Indeed, social pressures and concerns about being seen as normal have been found to guide young adults' decisions about disclosing their conditions to others (Saunders 2014, Spencer et al. 2018). Here, concerns about being seen as fake or different to others not only shaped participants' (un)willingness to come forward for help, but may explain the tendency to foreground the determined Self and thus, uphold their preferred outward healthy (read *normal*) identity (Balfe 2009, Saunders 2014).

Our analysis extends these insights by revealing the significance of authenticity to students' preferred identities. Concerns about being seen as legitimately ill, or at worse faking illness, not only prompted students to hide their symptoms or avoid seeking help, but often resulted in participants shifting back and forth between multiple Selves in an effort to be authentic both to themselves and others. Reminding us too of how social structure can impact on the complex workings of the Self (Tajfel and Turner 1979, Stryker 2004). Whilst such shifting may be read as evidence of ongoing biographical adjustments (Charmaz 1995), concerns for authenticity also reflect the powerful effects of socially sanctioned identities on these students' practices (c.f. Saunders 2014). Indeed, upholding a preferred healthy student identity was, at times, prioritised over academic or health concerns – irrespective of the consequences (e.g. failing assignments) (Spencer et al. 2018, 2019).

These shifting narratives of the Self reflect the complexity, and effects, of multiplicity *and* chronicity on students' lives. The analysis reported here is based on the accounts of six (female) undergraduate students from one university context and thus a note of caution is

offered with respect to their broader significance. Inevitably, findings may not reflect the experiences of students studying in different contexts or those of postgraduates, but they do highlight some of the difficulties encountered by students and support findings from other similar research (Balfe 2009, Spencer et al. 2018, 2019), and thus, may have transferability across higher education institutions.

Despite our intention to recruit both male and female students, the all-female sample and absence of men's perspectives and experiences warrants consideration. Men's 'hesitancy' to talk about health-related concerns is widely reported (Gast and Peak 2011) as part of the workings of gender and how dominant masculinity impacts on men's willingness to discuss areas that may identify them as 'weak', such as ill health. These gendered processes may have influenced our sample and highlight the need to develop ways to encourage men to come forward in future research. As noted, the narratives presented here are co-constructed and the accounts offered inevitably reflect how participants wished to present themselves to the female interviewer (an academic) at that particular moment in time. Further, the interpretation of participants' accounts may have been guided by the authors' own experiences of balancing university and personal lives. Our own academic identities and how we navigate multiple (work, health, family) pressures inevitably influence how we come to read and interpret students' narratives. Yet, our reflexivity on these impacts help us to deepen our thinking on the issues, all the while acknowledging that in qualitative enquiry meanings are co-constructed during data collection and analysis.

Despite the homogeneity in terms of gender, the sample did reflect considerable diversity in terms of participants' ages, programmes or study and family lives. Again, some caution is needed with respect to the comparability of the data, particularly with respect to the differing

ages of participants. Despite such differences, our analysis has revealed distinct similarities across the narratives suggesting important commonalities in these students' experiences. These similarities may offer new starting points for the development of appropriate forms of support for students with long-term conditions and through a focus on the impacts of common ongoing, multiple symptoms such as chronic pain and fatigue. For example, universities may need to offer more flexibility for those students juggling the competing demands placed on them because of their health condition. This may include tailored study plans that address the fluctuating impacts of symptoms, but also developing support services that enable these students to connect with others that are also grappling with the pressures of being a student with a long-term health condition. Developing shared understandings and support may mean these students feel less alone and more included in university life and may help them to come forward for help when they need it most. By understanding how multiplicity and chronicity come together to shape these students' narratives of the Self and experiences of ill health at university, our findings help to account for the apparent selective engagement in various forms of illness management, but also their willingness to come forward for help. The reported reluctance to seek out help and related impacts on their emotional and mental wellbeing highlights the urgency with which to develop deeper understandings of, and support for, students with long-term conditions.

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## **Table one: Study participants**

**Shannon** was a 22-year-old film studies student in her final year of her degree. She was diagnosed with Ehler-Danlos syndrome (a connective tissue disorder causing pain, fatigue and mobility restrictions) in her first year at university, which promoted her to change her degree programme and extend her time at university. She lived alone in adjusted accommodation on-campus.

**Joyce** was 44 years old and in her second year of her midwifery degree. She had a large family with five children who also had multiple health conditions. Joyce was diagnosed with Ehler-Danlos syndrome in 2008 and came late to her studies after having her children.

Renee was a 33-year-old adult second year nursing student. She lived with her husband and two young children and commuted daily to attend university. She worked part-time as a health care assistant. She came to the UK 10 years ago from Ghana. Renee was diagnosed with synthesis pelvic dysfunction after the birth of her children, which left her in chronic pain. She had arthritis and was recently diagnosed with thalassemia.

**Imogen** was 22 years old and in year three of her model design degree, but had been at university for four years due to her ill health. Imogen was diagnosed with chronic vestibular neuritis in year two of her studies – an infection of the vestibular nerve in the inner ear causing severe dizziness, vertigo, nausea and vomiting. She lived with fellow students close to the university.

**Beth** was a 23-year-old third year midwifery student. She had been diagnosed with oral allergy syndrome in her first year of university and needed to take a year off from her studies. She had been recently diagnosed with polycystic ovary syndrome and endometriosis. She lived off-campus in a shared house with other students.

**Jude** was a 48-year-old nursing student. She worked part-time in a children's respite centre. Jude lived with her three children and husband. Jude was diagnosed with vitamin B12 deficiency after an extended period of ill health. Her initial diagnosis triggered a cascade of medical investigations resulting in other diagnoses, including pernicious anaemia, arthritis, Raynaud's syndrome, fibromyalgia and ulcerative colitis.