Tertiary students with a disability or chronic illness: Stigma and Study

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Abstract

This paper explores ways to support the learning of students with a disability or chronic illness based on preliminary findings of a University of Southern Queensland study, and supporting secondary literature. It argues that for such students the capacity for greater control and management of their 'learning journey' is as important as access to specialised disability support services. This is because reframing support of students with a disability or chronic illness in terms of 'choice' and 'self-management' allows them to maintain their identity as 'able, effective students'. This approach is supported by secondary literature, which affirms that for students with an invisible disability or chronic illness there is often a reluctance to be so – labelled because of the associated stigma. Instead, students often manage their illness by making particular choices about their learning, including their mode of study, and which courses to enrol in. This tendency is echoed by preliminary findings from a University of Southern Queensland (USQ) study based on the learning experiences of students with a chronic illness. These and other findings point to the centrality of the student learning experience and have implications for learning and teaching design within both enabling, and broader university curricula. The paper finishes by examining specific curriculum design responses to the issue of student disability, including the development of learning communities and the potential for more inclusive assessment modes and practices.

Introduction

Disability can play a significant role in individual decision-making in relation to life choices, including the pursuit of education. Studies in the United Kingdom (Fuller et al.2004; Goode 2008) have explored the experiences of students with disabilities in higher education. They identify barriers to success, including aspects of assessment and curriculum, staff attitudes and access to information. Indeed, because students with a disability must, as do other students, negotiate so many variables at the start of their engagement with tertiary education this obliges them to confront their disabilities (Borland & James 1999 pp. 97-98).

The preliminary study outlined in this paper investigated the experiences of students with a disability, including chronic illness, in an Australian tertiary education context. The aim of the study was to examine the influence of disability on a range of choices relating to study, including barriers to participation, utilisation of support services and learning style preferences. However, responses to this preliminary survey also point to the need for students with a disability to negotiate workload, assessment and assessment timetabling requirements. Providing disabled or chronically ill students with choices that enable them to manage their learning journey will have implications for the design of curricula and assessment in both enabling and broader university programs. For this reason, this paper argues, in a USQ context at least, for the provision of more comprehensive learning and teaching support for academic staff, both in terms of resources and professional development, which would enable them to confidently offer students with a disability greater choice in achieving stated learning objectives. The issue of academic capacity in relation to assessment design generally will become increasingly important with the current government placing greater emphasis on specific graduate outcomes, and the capacity for students to demonstrate specified academic standards (Australian Universities Quality Agency 2009). This paper begins by examining the research and institutional context for the study. Next it will outline the study method and findings. Finally, the paper will discuss the findings, and pinpoint particular areas of curriculum and assessment design that may impact on the performance of students with a disability or chronic illness.

Context

Success in tertiary studies for students with a disability has been the subject of much research over the decades (see, for example, Hurst 1998; Konur, 2002; Brown, Borland & James 1999; Goode, 2007; Oakes 2005). This is because of the nature and likely impact of the disability, which may influence the decision to attempt tertiary studies at all, whether to study on-campus or externally, as well as decisions about assessment and other course workload issues.

The introduction of the Disability Discrimination Act (1992) has led to organisational and legislative changes, which have improved access and participation for students with a disability in higher education. In addition, growing awareness amongst education providers of the benefits of inclusive learning and teaching practices has addressed further barriers. However, disability can impact on every aspect of affected students' learning experiences – much of which include core practices such as curriculum design and assessment. Within the Australian context, some institutions have addressed this issue from a broad curriculum design perspective with at least one university offering professional development sessions.

However, at this early stage of our research project it is we believe that there is no consistent approach to addressing this issue across the sector.

Study method and findings

The aim of this pilot study was to explore the experience of students with disabilities, including chronic illness, within the context of higher education. The overarching research question was: how do participants believe their disability has affected their learning experience in tertiary and higher education? This is broken down into more specific questions about the influence of disability on a range of choices relating to study, including barriers to participation and the use of disability support services, but also students' learning style preferences, and the influence of curriculum design on their choices. As such, the study was conducted from a 'social' model of disability, which focuses on the functional context of any given disability rather than seeing disability as a personal attribute (Seale 2006, p. 11).

There were 33 participants recruited for this study who were newly registered with the USQ disability services. Participation was voluntary and targeted students beginning their studies with the aim of following them through the span of their university degree. Because the sample size was small, participant results were analysed using broad categories based on students' primary disability. These included: hearing impairment, vision impairment, learning disability, medical condition, neurological condition, psychological condition, and physical impairment. The most commonly reported disability categories included medical, neurological and psychological, although with such a small sample we cannot yet draw any conclusions about the implications for higher education practices. Participants were interviewed using both a quantitative survey of 16 multiple-choice items, and a qualitative follow-up phone interview, which was designed to supply additional or missing information. This latter stage focused on the impact of students' disabilities on a range of decisions relating to university choice, area of study, workload, success in previous study environments and students' experiences of disclosing their disability. Only results that deal directly with issues related to program and course enrolment and curriculum design will be discussed here.

Disability did appear to have an impact on participants' decisions to cancel their enrolment in both programs and courses. Thirty-two percent of participants reported that they had previously cancelled their enrolment in a particular program of study. Of these, half claimed that their disability had substantially influenced their decision to cancel their enrolment, and 40 percent directly attributed the cancellation of their enrolment to their disability. Sixty-eight percent of participants had previously dropped courses, and of these students, sixty-two percent identified disability as a significant influence on their decision. Thirty-nine percent of

participants reported that their disability had influenced their decision to enrol full or part time.

For a few participants, their disability did have a significant impact on their choice of program, but it did not impact significantly on the majority. One student had tried programs in other tertiary institutions: 'This is my second go at tertiary study. First I tried TAFE and now university and I really, really hope that this will be the right place for me and I have a chance of success this time'. By contrast, another participant was particularly adamant about their ability to choose their preferred program, and claimed: 'It doesn't influence my choice. I just do what I want and suffer the consequences". Thirty two percent of students reported that their disability had a substantial impact on their choice of courses. As one participant explains: 'I have to ask myself: "Can I cope with this subject" about each subject I choose'.

Indeed, issues of choice, management and control surfaced a number of times in participants' responses. One participant's biggest concern was, 'whether I can manage my study, disability and family'. For another a key concern was the impact of study on their condition: 'My greatest concern is taking on the heaving workload and the increased stress to my body. The stress affects the control of my health'. And, finally: 'Not being able to physically undertake the requirement of the lecture or complete the assessments for the course worries me greatly. There are times when I'm not sure that I fit in. Handling the workload and fear of failing are two issues that are constantly on my mind'. Issues of fitting in, and control, also featured in participant comments about their decision to disclose their condition to USQ disability services.

The decision to disclose can be a difficult one for students. We were interested in the impact of this disclosure on participants' personal and educational experiences. Eighty four percent of participants reported positive outcomes as a result of their disclosure. For those who reported negative impacts, some of their responses reflect a sense of embarrassment associated with official acknowledgement of their status:

> I was a little embarrassed to register with Disability Resources as a student with disability. The stigma around disability is very much still there. A lot of people don't understand the severe impact disabilities and mental health issues can have.

Another student initially associated their disclosure with failure:

> "I felt like I was chucking in the towel. I had not long been diagnosed before registering with Disability Resources and I was still in denial".

In this and other responses, there is a repeated theme of managing one's condition, managing one's image, managing the workload or competing life interests.

Physical access and the online environment were the least reported aspects that prevented participants from successful and timely completion of courses. However, it was still a key issue with 50 percent of the sample reporting that their disability had a substantial impact on physical access. It is also worth noting that of the 50 percent of the entire sample who were enrolled externally, 35 percent reported that disability had a substantial impact on their online learning.

For many participants, successful completion of courses and assessment was significantly affected by the unpredictability of their condition. As one participant explains:

> Most of the time my illness is under control, however, when it is not I just can't do anything. The problem is that I can never tell when this is going to happen'. I might have a flare up next week, next month, or possibly not until next year. I just don't know.

Relapses and other critical medical or psychological incidents can have a significant impact on participants' capacity to continue in their studies. One participant had recently experienced this process: 'I fear relapse and subsequent invasive treatment. This would have an extreme impact on my study. I have just returned to study after treatment. I am finding this semester very hard'.

More than 80 percent of participants reported that their disability affected their capacity to successfully complete certain types of assessment. In the following qualitative comment a student explains that their disability may potentially impact on being able 'to complete assignments on time…and understanding all of the tasks'. More than 70 percent of participants identified specific types of assessment such as exams and different forms of *practica* as being particularly difficult. As another student explains: 'At the moment I have concerns about completing assessment on time (mainly essays and other assignments – exams aren't so bad at the moment), but my main concern is my ability to participate in Music productions, such as Opera, choir and solo recitals'. For many participants, as with students more broadly, assessment and assessment practices form a crucial component of their learning journey (Scott 2005).

Participants in this study also reported specific problems in relation to exams. Concentration and fatigue was one issue. For example, one student argued that 'it is difficult for me to sit for long periods of time without moving around, and it is very difficulty to concentrate when I'm in pain'. Another worried about their health would, "tolerate new study and extended sitting'. Anxiety was also cited as a potential barrier to the successful completion of exams. As one participant explains, 'My concentration gets blocked due to my anxiety, and then I'm unhappy about my exam results. I know that I could do better if I was relaxed'.

Discussion and implications

This pilot study has found that USQ participants experienced the impact of disability not just in terms of physical access but also in terms of their ability to enrol in and complete the assessment requirements for specific courses and programs. While this finding has implications for the USQ, and potentially other similarly situated universities, it and other findings of this study also have implications for enabling programs within universities: firstly, because they enrol larger proportions of equity groups and can have higher levels of attrition, and secondly, because of practices they share with universities. For example, the Tertiary Preparation Program at USQ also provides distance education and uses common assessment types, such as exams.

From a more positive angle, this and other studies show that students with a disability or chronic illness use their choice of program, course, and mode of study, as a means of managing the impact of their disability. This can be both in terms of their capacity for study and the way that they are perceived by others. For a few students, managing their image also expressed itself as a reluctance to disclose their status to disability services because of the stigma associated with disability. This is echoed in secondary literature, particularly in relation to students with less visible forms of disability or chronic illness (Rizvi & Lingard 1996; Vickers 2003).

The image of students with a disability or chronic illness who actively choose their own pathways through tertiary education as a means of controlling the effect of their condition echoes a key feature of the social model of disability, which challenges the image of disabled people as 'dependent and in need of care' but at the same time acknowledges the functional impairment that can be associated with an individual's condition (Searle 2006, p.11). From this perspective, more choice for students with a disability or chronic illness may provide them with greater access to higher education.

One choice that the majority of students at USQ make is to study via distance mode. Fifty percent of our study sample had made this choice, and there is evidence to suggest that distance mode provides a level of flexibility that has great potential for addressing the functional requirements of students with a disability or chronic illness. Some positive effects of e-learning for students with a disability include the removal of barriers relating to physical access, preferred learning style and modes of communication – all of which potentially generate a greater parity of learning experience. The online environment also has a greater capacity for integration with Assistive Technologies (software that is designed to assist individuals with particular functional impairments). However, where technology liberates, it can also confine. Software designers who are ignorant of the 'principles of accessible

design' can inadvertently create barriers for people with a disability or chronic illness (Searle 2006, pp. 24-31). Whilst the USQ website ostensibly complies with relevant accessibility standards, results of this pilot study suggest a need for further research into specific e-learning access issues relating to course website interfaces, online resources, course design and assessment design.

Providing greater choice to students with a disability or chronic illness will also impact on higher education practices relating to curriculum design and assessment. Indeed, one implication of this pilot study relates to the finding that participants experienced particular difficulty with assessments that required them to physically attend specific spaces. This finding is echoed in other international studies (Konur 2002; Fuller, Healey, Bradley & Hall 2004). One reason given by participants for this difficulty was the physical effort required for, and the physical and/or mental discomfort experienced as a direct result of, completing the given assessment task. Functional limitations placed on students by their particular disability may be an issue for certain forms of assessment such as laboratory work, field trips, Work Integrated Learning (WIL) and other forms of location—specific learning.

Australian learning and teaching guides reviewed for this paper generally advise academic staff to provide students with different pathways towards meeting stated course objectives; to make accommodations on an individual basis, and to consult with students themselves as part of the process (see, for example, University of Adelaide 2009). The first issue with this approach is that it appears to be based on the assumption that academic staff members possess the level of pedagogical expertise to confidently choose comparable assessment tasks that do not undermine disciplinary and professional standards. The second issue relates to instances where practical assessment tasks are a requirement of professional accreditation. In this case, tertiary teachers may require learning and teaching support to assist them in designing accessible practical assessment tasks (see Doyle & Robson, 2002, for an international example of resource-based learning and teaching support). In the USQ context, there will therefore be a need to reference and/or develop specific learning and teaching resources in consultation with disability service staff.

As well as more specified forms of practical assessment, participants in our study also experienced particular difficulty with examinations. Physical effort, physical and mental discomfort were all cited as issues facing participants during examinations. These findings are echoed in other international studies (Konur 2002, p.133; Fuller *et al*. 2004, p. 312). A British study (Fuller et al. 2004, p. 312) found that relatively high numbers of students with a disability had experienced barriers in relation to forms of assessment. It also found that

specific forms of assessment, such as exams and oral presentations generated significant anxiety in relation to pre-preparation times and stress levels.

Another key factor of our study's participants' perceived ability to complete specific assessment tasks, such as examinations, was related to the sheer unpredictability of their physical or mental condition (see also Vickers 2003). The inability of students with a chronic illness or disability to predict their mental or physical capacity for any given period has significant implications for practice in universities, specifically in relation to assessment type and assessment timing. Current educational practice makes use of assessment 'accommodations', which involves a negotiated adjustment to existing assessment practices to minimise or remove their impact on the learning experience of the individual with a disability or chronic illness. Accommodations can include changes in assessment presentation or format, assignment time extensions, adjustments to support provided, and environmental conditions of examinations, extra time for examinations, access to notes and materials prior to class, allocation of note-takers, sign language interpreters and readers (USQ Student Services 2009; Konur 2002, p. 135). For many students – particularly those with fairly static or physical disabilities – such accommodations may negate any potentially discriminatory effect of established assessment practices. For others, however, particular forms of assessment may be inherently inequitable. This again points to the implication that learning and teaching support be provided to academic staff so they can make informed choices about valid, alternative assessment strategies that do not functionally disadvantage students with a disability or chronic illness.

It is possible to argue that many existing resources do not provide the level of detail required by academic staff. The website of UTAS (2002, p. 8) suggests that this is one Australian university that provides examples of alternative assessment strategies as well as the usual range of environmental and other accommodations. However, these are listed in dot point form only, with no guiding pedagogical rationale. Another resource offers the following comment in relation to alternative assessments and exams: 'The nature and purpose of time limits in academic examinations is currently under examination…another suggestion is that speed of response should not be a primary objective of tertiary assessments, the main aim should be to ensure [that] the critical objectives of the course are met' (Jordan & Rodgers 2005). This last point is also echoed by a different resource, which stresses the importance of providing multiple pathways for students to complete course learning objectives (Doyle & Robson 2002). However, no specific advice about or possible alternatives for specific types of assessment is offered.

Providing staff with clear alternatives for examinations is critical, particularly since this form of assessment is often seen, rightly or wrongly, as a proxy for academic standards. For this reason, the next stage of our project will incorporate further research and informal benchmarking of teaching and learning resources within Australia and elsewhere to find examples of best practice in this area. Whatever the examples of best practice, issues of comparability and academic standards will continue to be an issue for tertiary educators irrespective of which pathways students take through education programs.

One example of this trend is the increasing pressure for high schools, enabling educators and universities to develop and certify specified academic and employability skills or attribute based graduate learning outcomes. The continued emphasis on the development of particular skills will have an impact on students with disabilities or chronic illnesses. This is because while many students with a disability can use alternative methods to acquire skills and knowledge, some generic skills may represent, 'the very skills which, in absence, define their disabilities' (Gosden & Hampton 2001, p. 22). Resolving this type of tension will be ongoing and does not fall within scope of this paper.

Finally, further research with a larger student sample will allow us to more safely generalise from the results of our research although we have attempted, where possible, to support the findings of our own pilot study with other, secondary research. Future research will also potentially allow for finer grained detail within each of the disability categories outlined here.

Conclusion

This paper has examined the results of a pilot study at USQ, which seeks to identify learning and teaching barriers experienced by students with a disability or chronic illness. Initial results highlight a need to consider different ways of improving choices for students with a disability or chronic illness that relate to tertiary program curricula and course assessment. The provision of more choice has the potential to remove learning barriers and better positions such students as active, capable managers of their learning journey. However, the impact on curricula and assessment that this entails also has implications for academic professional development, including the provision of learning and teaching resources that enable teaching staff to balance the minimisation of learning barriers with the maintenance of academic and professional standards.

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