

The lived experience of students with an invisible disability at a Canadian university

Michèle Preyde

47-60 minutes

Points of interest

- Students with various disabilities attend higher education; however, an often under-examined group are those with disabilities that are invisible, such as dyslexia, attention-deficit hyperactivity disorder, and/or mental illness.
- In this study the perceptions of students with invisible disabilities experience at university were examined.
- Although the university was accommodating to the needs of students with invisible disabilities, the participants reported the presence of social and organizational barriers that makes the university experiences difficult for these students.
- Having a disability that is invisible can make it easier for these students to be treated normally; it also means, however, that the validity of the disability can be questioned and that others may not understand the full extent of their limitations.

Introduction

An estimated 4.4 million people in Canada have a disability; approximately half a million of these disabilities are non-visible (Statistics Canada 2007 Statistics Canada. 2007. *Participation and activity limitation survey 2006: Analytical report*. Catalogue No. 89–628-XIE. Ottawa, ON: Social and Aboriginal Statistics Division. [Google Scholar]). Exact prevalence rates are difficult to obtain given the differences in terminology used in the literature (Matthews and Harrington 2000). According to Matthews and Harrington, using terms such as 'non-visible' or 'hidden' leads to the implication that the disabilities can become visible if one merely looks for it; conversely, invisible implies that the disability cannot be seen at all. Invisible disabilities can be considered an umbrella term to refer to disabilities that interfere with day-to-day functioning but do not have a physical manifestation. Although some of the symptoms of the disabilities may be exhibited behaviourally, the cause of the disability cannot be seen. The types of invisible disabilities included in this research include dyslexia, mental health disorders, and attention-deficit hyperactivity disorders as these disabilities have been treated as a distinct group with respect to education (Wolf 2001 2001. College students with ADHD and other hidden disabilities. *Annals of the New York Academy of Sciences*, 931: 385–395. [Crossref], [PubMed], [Web of Science ®], [Google Scholar]).

Within Canada, post-secondary education is provided by two types of institutions: universities, which traditionally grant degrees; and colleges, which typically offer vocationally oriented programmes and grant diplomas and certificates. Services for students with disabilities within post-secondary education are governed by the Canadian Charter of Rights and Freedoms (1982) and provincial human rights statutes (Ontario Human Rights Commission 2006 Ontario Human Rights Commission. 2006. *Education and disability: Human rights issues in Ontario's education system*. Toronto: Education Consultation: Policy and Education Branch, Ontario Human Rights Commission. [Google Scholar]). According to the Ontario Human Rights Commission (2002 Ontario Human Rights Commission. 2002. Policy and guidelines on disability and duty to accommodate. <http://www.ohrc.on.ca/en/resources/factsheets/disability2> (accessed February 2010). [Google Scholar]), providers must take the needs of persons with disabilities into consideration; barriers that limit participation must be removed. If the removal of these barriers would pose undue hardship for the service provider, then accommodations must be put in place, which means that reasonable adjustments must be made that promote

dignity, independence, integration, and equal opportunity (Ontario Human Rights Commission 2002 Ontario Human Rights Commission. 2002. Policy and guidelines on disability and duty to accommodate. <http://www.ohrc.on.ca/en/resources/factsheets/disability2> (accessed February 2010). [Google Scholar]). In 2005 the Government of Ontario passed the Accessibility for Ontarians with Disabilities Act with the aim of making Ontario barrier free for individuals with disabilities (Ontario Ministry of Community and Social Services 2011). Ontario universities are continually attempting to align themselves with these accessibility standards.

Starting in the mid-1980s, Canadian post-secondary institutions established centres to support the needs of students with disabilities (Cox and Klas 1996Cox, D. and Klas, L. 1996. Students with learning disabilities in Canadian colleges and universities: A primer for service provision. *Journal of Learning Disabilities*, 29(1): 93–97. [Crossref], [PubMed], [Web of Science ®], [Google Scholar]). Since then, the rates of students with disabilities enrolled in higher education have been on the rise (Hill 1992Hill, J. 1992. Accessibility: Students with disabilities in universities in Canada. *The Canadian Journal of Higher Education*, 22(1): 48–83. [Google Scholar]). Hill provided the first comprehensive evaluation of the accessibility of Canadian universities. Based on reports from service providers within universities, Hill found that although several accommodation services are available, several barriers to accessing services were still present, which included a lack of funds, staff, and resources, the accessibility of campus, procedures for identifying individuals with disabilities, and the attitudes of faculty and staff towards individuals with disabilities. Since 1992 few authors have continued to evaluate the university experience for students with disabilities within the Canadian context (Fichten et al. 2003Fichten, C., Asuncion, J., Barile, M., Robillard, C., Fossey, M. and Lamb, D. 2003. Canadian postsecondary students with disabilities: Where are they?. *The Canadian Journal of Higher Education*, 33(3): 71–114. [Google Scholar]; Hill 1994 Hill, J. 1994. Speaking out: Perceptions of students with disabilities at Canadian universities regarding institutional policies. *Journal on Postsecondary Education and Disability* 11, no. 1: 1–14. [Google Scholar]; Cox and Klas 1996Cox, D. and Klas, L. 1996. Students with learning disabilities in Canadian colleges and universities: A primer for service provision. *Journal of Learning Disabilities*, 29(1): 93–97. [Crossref], [PubMed], [Web of Science ®], [Google Scholar]; Duquette 2000Duquette, C. 2000. Experiences at university: Perceptions of students with disabilities. *The Canadian Journal of Higher Education*, 30(2): 123–141. [Google Scholar]). Based on international research that examined the experience of students with disabilities within higher education, areas that have been found to be difficult for students with various types of disabilities include the transition to university; physical barriers within the university environment; accessing course information, including the lecturing environment; accessing information within the library system; the process of disclosure; how knowledge is assessed within the university; and attitudinal barriers, including lack of awareness about disabilities; and additional financial cost (Baron, Philips, and Stalker 1996Baron, S., Philips, R. and Stalker, K. 1996. Barriers to training for disabled social work students. *Disability and Society*, 11: 361–377. [Taylor & Francis Online], [Web of Science ®], [Google Scholar]; Borland and James 1999Borland, J. and James, S. 1999. The learning experience of students with disabilities in higher education. A case study of a UK university. *Disability and Society*, 14(1): 85–101. [Taylor & Francis Online], [Web of Science ®], [Google Scholar]; Fuller et al. 2004Fuller, M., Healey, M., Bradley, A. and Hall, T. 2004. Barriers to learning: A systematic study of the experience of disabled students in one university. *Studies in Higher Education*, 29(3): 303–318. [Taylor & Francis Online], [Web of Science ®], [Google Scholar]; Goode 2007Goode, J. 2007. 'Managing' disability: Early experiences of university students with disabilities. *Disability and Society*, 22(1): 35–48. [Taylor & Francis Online], [Web of Science ®], [Google Scholar]; Holloway 2001Holloway, S. 2001. The experience of higher education from the perspective of disabled students. *Disability and Society*, 16(4): 597–615. [Taylor & Francis Online], [Web of Science ®], [Google Scholar]; Madriaga 2007Madriaga, M. 2007. Enduring disablism: Students with dyslexia and their pathways into UK higher education and beyond. *Disability and Society*, 22(4): 399–412. [Taylor & Francis Online], [Web of Science ®], [Google Scholar]; Tinklin and Hall 1999Tinklin, T. and Hall, J. 1999. Getting round obstacles: Disabled students' experiences in higher education in Scotland. *Studies in Higher Education*, 24(2): 183–194. [Taylor & Francis Online], [Web of Science ®], [Google Scholar]; Vickerman and Blundell 2010Vickerman, P. and Blundell, M. 2010. Hearing the voices of disabled students in higher education. *Disability and Society*, 25(1): 21–32. [Taylor & Francis Online], [Web of Science ®], [Google Scholar]). It has also been reported that students put forth additional effort to have appropriate adjustments implemented (Borland and James 1999Borland, J. and James, S. 1999. The learning experience of students with disabilities in higher education. A case study of a UK university. *Disability and Society*, 14(1): 85–101. [Taylor & Francis Online], [Web of Science ®], [Google Scholar]; Goode 2007Goode, J. 2007. 'Managing' disability: Early experiences of university students with disabilities. *Disability and Society*, 22(1): 35–48. [Taylor & Francis Online], [Web of Science ®], [Google Scholar]; Holloway 2001Holloway, S. 2001. The experience of higher education from the perspective of disabled students.

Disability and Society, 16(4): 597–615. [Taylor & Francis Online], [Web of Science @], [Google Scholar]. These additional challenges reflect the ways in which the university context may be seen to marginalize and dis-empower students with disabilities (Holloway 2001Holloway, S. 2001. The experience of higher education from the perspective of disabled students. *Disability and Society*, 16(4): 597–615. [Taylor & Francis Online], [Web of Science @], [Google Scholar]). This is the essential argument found in the Social Model of Disability (Oliver 1990Oliver, M. 1990. *The politics of disablement*. London: Macmillan. [Crossref], [Google Scholar]; 1996Oliver, M. 1996. *Understanding disability: From theory to practice*. London: Macmillan. [Crossref], [Google Scholar]), in which it is stated that individuals with impairments are disabled by environments from which they are systematically excluded. Accordingly, students with disabilities have to make the system work for them (Holloway 2001Holloway, S. 2001. The experience of higher education from the perspective of disabled students. *Disability and Society*, 16(4): 597–615. [Taylor & Francis Online], [Web of Science @], [Google Scholar]).

The experiences of students with various types of disabilities are different, and these students thus face unique challenges and require different services depending on the type of disability (Hill 1992Hill, J. 1992. Accessibility: Students with disabilities in universities in Canada. *The Canadian Journal of Higher Education*, 22(1): 48–83. [Google Scholar]). Wiener and Siegel (1992Wiener, J. and Siegel, L. 1992. A Canadian perspective on learning disabilities. *Journal of Learning Disabilities*, 25(6): 340–350. [Crossref], [PubMed], [Web of Science @], [Google Scholar]) suggest that Canadian institutions have done well to attend to physical access for students with disabilities, and the focus of the twenty-first century is to address the needs of students with dyslexia and mental health issues. According to two national surveys, the two largest categories of disabilities reported included dyslexia (23.9%) and mental health disorders (17.8%) (Holmes 2005Holmes, D. 2005. *Embracing differences: Post-secondary education among aboriginal students, students with children and students with disabilities*. Montreal: The Canada Millennium Scholarship Foundation. [Google Scholar]). Differences in the type and level of social integration have been found between students with physical disabilities and those with dyslexia (Association of Canadian Community Colleges 2008 Association of Canadian Community Colleges. 2008. *Pan-Canadian study of first year college students: Report 2 the characteristics and experience of aboriginal, disabled, immigrant and visible minority students*. Catalogue No. HS28-119/2-2009E. Québec: Learning Policy Directorate, Strategic Policy and Research. [Google Scholar]). When compared with students with physical disabilities, students with dyslexia were less likely to report positive attitudes toward their institution and that their institutions demonstrated less positive responses toward them as students. Also, fewer students with dyslexia expressed a positive relationship with their faculty and they indicated that few of their faculty established an interest in helping them as students (Association of Canadian Community Colleges 2008 Association of Canadian Community Colleges. 2008. *Pan-Canadian study of first year college students: Report 2 the characteristics and experience of aboriginal, disabled, immigrant and visible minority students*. Catalogue No. HS28-119/2-2009E. Québec: Learning Policy Directorate, Strategic Policy and Research. [Google Scholar]). Thus, it is important to determine why the experiences of students with invisible disabilities are perceived negatively.

It has been indicated that the lack of a visible sign of disability presents students with unique challenges for their education (Longo 1988Longo, J.A. 1988. The learning disabled: Challenge to postsecondary institutions. *Journal of Developmental Education*, 11(3): 10–14. [Google Scholar]). It has been found that students with disabilities often want to be treated as normal students, and they will often not disclose their disability in order to appear normal (Tinklin and Hall 1999Tinklin, T. and Hall, J. 1999. Getting round obstacles: Disabled students' experiences in higher education in Scotland. *Studies in Higher Education*, 24(2): 183–194. [Taylor & Francis Online], [Web of Science @], [Google Scholar]). Passing as normal, however, does not eliminate the disability. Furthermore, questions begin to unfold when we attempt to understand what it means to live with an invisible disability. Specifically, what are the implications of continually attempting to conceal one's disability? No study has been located that examines the experience of having an invisible disability within a university setting. Without such direct consultation, accessibility may be limited given that we do not know what elements of the university experience are most alienating (Tinklin, Riddell, and Wilson 2004Tinklin, T., Riddell, S. and Wilson, A. 2004. Policy and provision for disabled students in higher education in Scotland and England: The current state of play. *Studies in Higher Education*, 29(5): 637–657. [Taylor & Francis Online], [Web of Science @], [Google Scholar]). Therefore, the purpose of this phenomenological study was to reveal the perceptions of the experiences of students with an invisible disability in the university context.

Method

Context

This research was conducted within a university located in south-central Ontario. The university consists of seven faculties, including natural and physical sciences, social sciences, and humanities. The university has a long-standing commitment to supporting the needs of students with disabilities, and it has established a Center for Students with Disabilities. In addition, the university has gone to great lengths to ensure its standards are in accordance with legislation by developing an Accessibility for Persons with Disabilities Advisory Committee and hosting an annual Accessibility conference. Furthermore, faculty members, instructors, and teaching assistants are required to complete a course on Accessibility Service Provision.

Recruitment

Following ethical approval, a convenience sample of university students was recruited through posters distributed across the university in areas often used by students with disabilities. Interested students emailed the researcher and an interview was arranged. Participants were not required to provide documentation for their disability for inclusion in the study; however, they had reported registering with the Centre for Students with Disabilities (CSD), which requires documentation to support their disability. The interviews were conducted in a private office at the university, recorded, and later transcribed verbatim.

Interviews

In-depth interviews were conducted that were semi-structured in format (Daly 2007Daly, K. 2007. *Qualitative methods for family studies & human development*. Thousand Oaks, CA: Sage Publications. [Google Scholar]). Participants were asked to focus on their university experience as a student with an invisible disability. Participants were asked to provide specific examples of when they felt that their disability had impacted their life as a university student. Some of the prompts used related to issues of disclosure, self-identification, and whether they experienced any supports, accommodations, and/or barriers.

Data analysis

An interpretative phenomenological (Heidegger 1962Heidegger, M. 1962. *Being and time*. New York: Harper and Row. (Orig. pub. 1927.) [Google Scholar]) approach to the analysis was undertaken to gain insight into participants' lived experience. In order to respect the individual differences and the unique context from which the sample was drawn, an approach that provides an idiographic interpretation was also required. Thus, an interpretative phenomenological analysis (Smith and Osborn 2003Smith, J. and Osborn, M. 2003. "Interpretative phenomenological analysis". In *Qualitative psychology: A practical guide to methods*, Edited by: Smith, J.A. 53–80. London: Sage. [Google Scholar]) was conducted as it combines these two approaches. According to Smith (2004Smith, J. 2004. Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative research in psychology*, 1: 39–54. [Taylor & Francis Online], [Web of Science @], [Google Scholar]), interpretative phenomenological analysis provides an understanding of the participants' experiences through an analysis that is idiographic, inductive, and interrogative. Within this approach, themes are developed that are idiographic in that they provide an in-depth and rich description of the lived experience. This analysis also includes the use of inductive techniques that are flexible to account for unanticipated concepts and notions. The approach, however, also requires that the researcher interrogate the existing literature to ensure that the themes can provide a comprehensive understanding of the phenomenon of interest (Smith 2004Smith, J. 2004. Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative research in psychology*, 1: 39–54. [Taylor & Francis Online], [Web of Science @], [Google Scholar]). The themes developed relate to both the subjective experience of the students' impairment and the social factors influencing the experience.

Results

Participants

Ten female students with a self-reported invisible disability participated in the study. In

general, however, the types of disabilities reported by the participants included: dyslexia ($n = 4$), attention-deficit hyperactivity disorder ($n = 3$; one co-morbid with dyslexia and another with a mental health-related disorder), and mental health disorders ($n = 3$), including major depressive disorder, obsessive compulsive disorder (OCD) and bipolar disorder. The level of study of the participants included second-year undergraduate students ($n = 1$), undergraduate students in their third or greater year of study ($n = 7$), and graduate students ($n = 3$). Participants' programmes of studies varied from the natural sciences to the social and applied sciences.

Nature of the disability

Based on the participants' reports, the fluctuating nature of the disabilities was apparent. Participants reported that they varied as to the onset of their disability, when their disability was diagnosed, and how it has affected their university experience. Based on this variability, participants indicated that they were at different stages regarding their experience with and understanding of their disabilities. Some of the participants with dyslexia reported being at a place of acceptance towards their disability, noting the benefits of knowing their individuals strengths and weaknesses. Two participants with mental health disabilities reflected on how they were able to excel in their education prior to the onset of their disability, and that now they were struggling. These participants were frustrated by the barriers associated with having a disability and reflected on what they have lost:

So like somebody who had a disability all their life could hypothesize what life would be without that barrier, but I know because I've had, I didn't have that barrier before. I know what my life was like when I was the top of my class and when I was able to study and there was people struggling, but it wasn't me. So I can really see the contrast and I know what it would be like if all those barriers were down for me. (P2)

Based on this participant's interview, it was apparent that these barriers related to both the impairment of her disability and other barriers constructed within the university environment.

In addition, the type of disability and the influence that it has had on the participants' lives has also been variable. For some participants, their disability predominantly influenced them academically. For others, their disability was reported as 'always interacting' (P3). In addition, some of the participants discussed how the impact of their disability fluctuated over the course of the semester and that this impact was unpredictable. This fluctuating nature of the disability influenced the participants' ability to accomplish academic requirements. One participant described this experience as follows:

[rid[ing] the wave, where if you're having a few good days you get lots of work done; if you're having a few bad days you don't get any work done and you hope that the bad days don't all clump together at important points. (P2)

These participants indicated that although organization was important, sometimes they were just not able to complete their assignments by their due dates, which required them to request extensions at the last minute. Participants' reported that they could not predict or overcome the impact of their disability.

Another important consideration about the nature of the disability, reported by participants, was the additional effort required because of the disability itself. This additional effort related to trying to concentrate, complete assignments, and complete course readings: 'Well in my case it takes me twice as long to read anything than it would take anyone else or twice as long to write anything' (P3). They expressed frustration when they compared themselves with other students and their ability to succeed without the enormous amount of effort that the participants have to expend. This additional time commitment means that students with disabilities have to be organized and utilize good time-management skills, an area that the students with attention-deficit hyperactivity disorders indicated was particularly difficult for them. Several participants indicated that despite the amount of effort they put into their academics, their performance was rarely a true reflection of their abilities and intellect. Maintaining this continual level of effort was reported as exhausting for the participants, as one participant said:

I just feel like all I'm ever doing is try to focus on my studying, being stress out because of school work or actually trying to study or do my school work and everyone else I see is able to go out, have fun, actually enjoy themselves. (P8)

The accessibility of the university context

Most of the participants reported that the university in general was accommodating and promoted a general feeling of acceptance. One participant stated that she chose this university because of the positive reputation of the CSD. Concerning the CSD, most

participants indicated that the staff were helpful and provided students with good services. Participants indicated that the benefits of the CSD extend beyond the accommodations they provide for the students. Specifically, participants said that 'the CSD is a pretty safe place for people' (P6), where students can discuss issues that they are struggling with and develop unique bonds with people in administrative roles within the university.

Types of accommodations

The entire participant sample reported utilizing, at some point during their university experience, accommodations to assist them with limitations related to their disabilities. Accommodations included the ability to write examinations with the CSD with additional accommodations; the use of an adaptive computer program that converts text to speech for assistance with course readings; the use of note-takers for lectures; and the receipt of medication for their disability. For some, medication is important to assist in maintaining focus and function within the university context. Establishing an appropriate drug regime, however, was reported to be difficult and can take a long time.

Several of the participants also reported using the counselling services through the CSD, either for therapy related to their disability or to provide support following difficult social experiences. A final service reported by the participants was the Library Centre for Students with Disabilities, which includes a private location in the university library where students have access to adaptive technologies and a librarian devoted to coordinating these services. Participants valued their access to this reserved location because it promotes a sense of acceptance, community, and safety.

Participants reported that the accommodations used were imperative for their success at university. Unfortunately, participants felt that utilizing these services identified them as a student with a disability. For example, one of the drawbacks – reported by the students about writing their examinations in the CSD – was that it can be awkward for some students to explain to their peers why they did not write the examinations with the rest of the class. Also, participants reported feeling a certain level of stigma related to using the Library Centre for Students with Disabilities. For example, one participant said: 'I feel kind of embarrassed sometimes to go in that section of the library because it's very visible' (P1). As described by Goode (2007Goode, J. 2007. 'Managing' disability: Early experiences of university students with disabilities. *Disability and Society*, 22(1): 35–48. [Taylor & Francis Online], [Web of Science ®], [Google Scholar]), the need for accommodations involves a process that can make students with disabilities 'extra-visible' in a negative way, which has reduced students' desire to request them.

Finally, participants indicated that they were required to complete extra steps in order to receive these accommodations. As one participant said: 'I've probably filled out 100% more paperwork than anybody here. Like it is, the bureaucracy behind being a student with [dyslexia] is like, holy cow, the system is crazy' (P6). This 'bureaucracy' included registering with the CSD every semester, and the complex system of paperwork, meetings, and organization involved in obtaining accommodations for examinations, note-takers, and automated texts. The extra effort involved in navigating the bureaucracy of this system was reported as an additional source of frustration for the participants. Although accommodations are designed to provide support for the students, they were perceived to actually exasperate the difference between the students with and without disabilities.

Social and organizational barriers

Most of the participants reported that they felt that their university experience was different from the 'typical' university experience because of the additional barriers, challenges, and struggles that they endured. Some of the reported additional challenges related to having to implement and utilize different accommodations for their learning, as noted previously. Participants also reported social and organizational barriers within the university context, which create unnecessary burdens and thus have the potential to marginalize students with invisible disabilities.

Social barriers

Participants reported that they experienced social barriers related to negative social attitudes, which were manifested in negative perceptions and comments about disabilities. Based on the participants' reports, it was inferred that the negative perceptions related to the invisible nature of the disability. Participants reported that there is a general lack of understanding about disabilities, which they felt was heightened as the disability is invisible and can be attributed to a psychological component. One of the participants, with mental illness and nerve damage in her hand, described how she perceived a difference in others' understanding when she disclosed her different disabilities:

I think people understand surgery. You know, it's a very concrete concept, you know. People can understand that, you know, if a knife nicks a tendon it can cause nerve damage and that's why my hand shakes and that's why it's hard to hold a pen. These things are all logical and they all follow. Bipolar is not completely understood. (P11)

This lack of understanding was perceived as an underlying influence for many of the negative perceptions. Participants reported receiving negative comments about their disability, such as comments that belittle the severity of the disability, comments that people with disabilities are 'bad' or unstable, or comments that students with their disabilities did not belong at university. Participants reported that other students would make such negative comments in front of the participants; they inferred that these comments were probably made because these individuals did not know they had a disability. In addition, all of the participants reported that they felt that other people, including professors and other students, questioned the validity of their invisible disabilities.

Since the disabilities are invisible, participants indicated that they needed to provide documentation for their disability. Participants noted that having to provide documentation is emotionally difficult and made them feel less legitimate. Moreover, when considering the effects of stigma, Corrigan and Watson (2002) Corrigan, P. and Watson, A. 2002. Understanding the impact of stigma on people with mental illness. *World Psychiatry*, 1: 16–20. [PubMed], [Google Scholar] indicated that public stigma can sometimes be internalized, called self-stigma, which can lower levels of self-esteem and self-efficacy. This process appeared to be occurring for some participants:

Because I'm not the most confident student in the world and I always have this tendency to believe that everyone else is right and I'm wrong, it started making me question myself. [...] I felt like maybe I don't belong here. I guess it always boils back down to that whole imposter thing. Maybe I don't belong here and that's not really a very pleasant feeling. (P4)

Furthermore, this perceived lack of understanding was also reported to limit participants' willingness to disclose their disability. Participants indicated that their disability is a 'private and personal' (P6) matter. Many participants said that they will only disclose in close relationships or when necessary, such as in an attempt to receive understanding for their specific challenges or to be able to receive certain accommodations. When requesting accommodations, participants indicated that within the university sometimes requests for accommodations were met with resistance from their professors. This resistance mostly related to the misconception that accommodations provide the student with an unfair advantage as opposed to levelling the educational field. Similarly, participants reported that sometimes other students were perceived as resentful of their ability to use accommodations, as one participant noted: 'You could hear it in little, little comments like, "Oh aren't you lucky?"' (P3). According to Corrigan and Watson (2002) Corrigan, P. and Watson, A. 2002. Understanding the impact of stigma on people with mental illness. *World Psychiatry*, 1: 16–20. [PubMed], [Google Scholar], public stigma also negatively influences the types of supports that individuals with disabilities receive. For some participants, these public perceptions appeared to be negatively influencing the participants' choice to seek accommodations. A few participants indicated a resistance to seek accommodations for fear that utilizing accommodation could be perceived as a disappointment:

I also didn't want to be a disappointment to myself and to some extent I think sometimes I just want it to go away and I just want to be normal and by not getting the accommodations I thought that perhaps that might make me a bit more normal. (P3)

This notion of normalcy was discussed by other participants. Some participants indicated that they wanted to be above the need for accommodations. Most of the graduate students indicated that they had the impression that 'usually students don't need accommodations anymore when they're in graduate school' (P3).

Marker of disability or passing as normal?

Since the disabilities were invisible and 'you don't get a handicapped sign because you have an invisible disability' (P2), participants discussed the notion of a physical marker of their disability. Some participants indicated that a marker or a signal of their disability might help to validate others understanding of their disability: 'Well it would certainly be easier if I had like a blue spot on my hand so I could say here, see. You know, this is my disability' (P3). These participants, however, wanted the mark to be concealable. Several participants reported that they would choose to hide their disability in an attempt to limit public perceptions. As one participant said: 'at the same time it's also easier to become normal because it's invisible. So people don't really treat you any differently unless they, unless you say I have a disability' (P6). Thus, although some participants reported a desire to have a visible manifestation of their disability, most participants held strong

notions about their ability to maintain a nondisabled status when necessary.

Organizational barriers

In addition to the social barriers, participants revealed several aspects of the organizational structure of the educational system that were perceived to marginalize students with invisible disabilities. Participants reported experiencing challenges within the classroom because of the structure of this environment (such as the way lectures were structured). Specifically, participants noted that the size of the lecture halls, other noises, speech of professors, and the number of students in the class present them with difficulties. As a result, participants indicated that they are often not able to retain key points during the lecture.

Participants also indicated that procedures for having accommodations in place presented additional barriers. Specifically, although most accommodations are facilitated through the CSD, professors are often responsible for implementing some of the accommodations that students with disabilities require; the discretion of their professors regarding the implementation was perceived to be subjective. Although some participants reported that they had largely positive experiences with their professors implementing appropriate accommodations, many participants indicated that their experience with professors has been mixed:

A lot of professors are very accepting, but I do. I do feel like sometimes they feel like you're trying to get away with something. And I also think that, that the act of asking them is a bit degrading where, you know, because it should be your right. (P2)

The receptiveness of the professors was perceived to vary based on the personality of the professor and the types of accommodations that the students were requesting. For example, participants reported that sometimes they were met with resistance from their professors when the students requested additional accommodations that lacked formal procedures for implementation (e.g. mid-term examinations, in class pop-quizzes, and extensions on assignments). Participants reported that one reason they are given regarding the resistance to provide these types of accommodations is the perceived fairness to other students, as described earlier. Participants reported being frustrated about having to rely on the professors' discretion for accommodations.

Additionally, many participants reported that they perceived their education to be 'one-dimensional' (P6). The students reported that they believed that university is set up for one type of learner, from which they felt systematically oppressed:

Schooling's very one dimensional. It's very – you know, testing is all the same, how they test knowledge, how they, how they structure the classrooms. Like it's for every, [...] every situation is usually the same. So it's not like they branch out and try and figure out how best people learn. So you know, a person with an [invisible disability] has to fit in that, in that environment. (P6)

Participants said that they were frustrated and even felt stigmatized by the education system:

The system is built for people who are quote-unquote normal and when you're not that normal person, that normal way of learning or that normal way of functioning in the world then you can face additional challenges on top of the regular challenges that are part of university. (P3)

Students with dyslexia are often disadvantaged because of the privilege given to the written word (Baron, Philips, and Stalker 1996) Baron, S., Philips, R. and Stalker, K. 1996. Barriers to training for disabled social work students. *Disability and Society*, 11: 361–377. [Taylor & Francis Online], [Web of Science ®], [Google Scholar]. According to Tinklin and Hall (1999) Tinklin, T. and Hall, J. 1999. Getting round obstacles: Disabled students' experiences in higher education in Scotland. *Studies in Higher Education*, 24(2): 183–194. [Taylor & Francis Online], [Web of Science ®], [Google Scholar], this preference for written language poses additional challenges for the traditional modes of assessment used in universities, indicating that these forms of assessment may not reflect the students' true abilities. Participants reported feeling discriminated against by the way the educational system evaluates performance. Furthermore, participants acknowledged the need to change the system to 'provide people the opportunity to learn different ways' (P1) and that a new approach could benefit all students, even those without disabilities. Based on the participants' reports, participants not only face challenges related to limitations inherent in the disability itself but feel further disabled because of the educational system.

Recommendations for change

Participants made several recommendations to improve their educational experience.

They reported a desire for increased consideration for the limitations related to their disabilities. Participants also wanted more information about their disabilities and to learn about different coping skills. These students would also like more finances devoted to providing computers with adaptive technology and personnel to support the students. Lastly, participants reported that one way to facilitate a better understanding would be to develop more education and awareness programmes about different disabilities for staff and faculty at the university. It was suggested that these awareness programmes could help to break down their perceived stigma related to the social attitudinal barriers.

Discussion

The findings of this research provided a unique insight into the experience of having an invisible disability at university from the perspective of students. In accordance with the idiographic understanding, the themes developed suggest that the university experience of individuals with invisible disabilities is dynamic and multifaceted. Specifically, the students' experiences with their impairment varied in its impact on their education. The participants reported that overall the university was supportive and provided accommodations to meet their needs. At the same time, they reported the presence of barriers that made the university experience difficult. Consideration for these variances and providing flexibility is essential to promote an accessible environment for students with invisible disabilities. Confirmation of the students' experiences can be supported by the existing, yet relatively small, literature related to the experiences of students with disabilities in general (Borland and James 1999; Borland, J. and James, S. 1999. The learning experience of students with disabilities in higher education. A case study of a UK university. *Disability and Society*, 14(1): 85–101. [Taylor & Francis Online], [Web of Science ®], [Google Scholar]; Tinklin and Hall 1999; Tinklin, T. and Hall, J. 1999. Getting round obstacles: Disabled students' experiences in higher education in Scotland. *Studies in Higher Education*, 24(2): 183–194. [Taylor & Francis Online], [Web of Science ®], [Google Scholar]; Holloway 2001; Holloway, S. 2001. The experience of higher education from the perspective of disabled students. *Disability and Society*, 16(4): 597–615. [Taylor & Francis Online], [Web of Science ®], [Google Scholar]; Fuller et al. 2004; Fuller, M., Healey, M., Bradley, A. and Hall, T. 2004. Barriers to learning: A systematic study of the experience of disabled students in one university. *Studies in Higher Education*, 29(3): 303–318. [Taylor & Francis Online], [Web of Science ®], [Google Scholar]; Madriaga 2007; Madriaga, M. 2007. Enduring disablism: Students with dyslexia and their pathways into UK higher education and beyond. *Disability and Society*, 22(4): 399–412. [Taylor & Francis Online], [Web of Science ®], [Google Scholar]). In addition, the results revealed important findings regarding the unique experience of living with an invisible disability within higher education.

A notable paradox was found regarding the participants feelings about the invisible nature of their disability, which has implications for disclosure unique to this population. Specifically, since their disabilities were invisible, participants reported a desire to have a visible manifestation of their disability, which could reduce public questions about the validity of their disability. In order to implement accommodations, students with invisible disabilities must disclose their disability, a process that was often perceived negatively due to the lack of understanding and questions of validity that were assumed to be related to the lack of a physical manifestation of their disability. Although disclosure and seeking accommodations has been reported as a difficult process faced by individuals with a variety of disabilities, disabilities such as dyslexia and attention-deficit hyperactivity disorders have been contested in the literature (Brinckerhoff, Shaw, and McGuire 1992); diagnosis requires highly trained professionals (Proctor and Prevatt 2003; Proctor, B. and Prevatt, F. 2003. Agreement among four models used for diagnosing learning disabilities. *Journal of Learning Disabilities*, 36(5): 459–466. [Crossref], [PubMed], [Web of Science ®], [Google Scholar]) and misdiagnoses are common (Rosso 2004; Rosso, J.A. 2004. *Misdiagnosis and dual diagnoses of gifted children and adults: ADHD, bipolar, OCD, Asperger's, and other disorders*, Scottsdale, AZ: Great Potential Press. [Google Scholar]). Having a visual marker of the disability was perceived as having the potential to facilitate understanding. However, participants wanted to be able to choose when to disclose their disability. The students preferred the marker be concealable in an attempt to limit public perceptions in times when they did not want their disability to be apparent. The stigma associated with their disability has reduced some students' desire to request accommodations. Thus, it is recommended that universities continue to promote awareness about various forms of disabilities.

In addition, it was also found that participants perceived that the implementation of some forms of accommodations were contingent on the subjective preferences of their professors. Although some procedures for accommodations are formalized through the university's disability services, other accommodations may need to be negotiated with the professors. In an attempt to reduce the need for students to request individual accommodations, and in light of the issues of disclosure stated above, it is recommended

that universities continue to pursue universal instructional design (UID; Silver, Bourke, and Strehorn 1998; Silver, P., Bourke, A. and Strehorn, K.C. 1998. Universal instructional design in higher education: An approach for inclusion. *Equity & Excellence in Education*, 31: 47–51. [Taylor & Francis Online], [Google Scholar]), which promotes an environment that can be adaptable to different kinds of learners. Adopted from architecture, UID is the notion that instruction should be designed to be inclusive to all students (McGuire, Scott, and Shaw 2006; McGuire, J., Scott, S. and Shaw, S. 2006. Universal design and its applications in educational environments. *Remedial and Special Education*, 27(3): 166–175. [Crossref], [Web of Science ®], [Google Scholar]). UID should be considered a reflective tool (McGuire, Scott, and Shaw 2006; McGuire, J., Scott, S. and Shaw, S. 2006. Universal design and its applications in educational environments. *Remedial and Special Education*, 27(3): 166–175. [Crossref], [Web of Science ®], [Google Scholar]) that encourages instructors to provide various methods of presenting, interacting, and assessing information rather than a prescription of providing specific accommodations to all students. In practice, providing some of accommodations as used by the participants to all students may not be practical. Alternatively, making active steps to provide various methods of presenting and assessing information when planning courses has been suggested to negate the need for many accommodations (McGuire, Scott, and Shaw 2006; McGuire, J., Scott, S. and Shaw, S. 2006. Universal design and its applications in educational environments. *Remedial and Special Education*, 27(3): 166–175. [Crossref], [Web of Science ®], [Google Scholar]). For example, providing an outline of the lecture notes that includes the key points of the lecture and provides space for additional notes negates the need for note-takers and has been found to be beneficial to all students (Kiewra et al. 1995; Kiewra, K.A., Benton, S.L., Kim, S.L., Risch, N. and Christensen, M. 1995. Effects of note-taking format and study technique on recall and relational performance. *Contemporary Educational Psychology*, 20: 172–187. [Crossref], [Web of Science ®], [Google Scholar]). Implementing UID requires additional preparation in designing courses, but it has been perceived positively by both students and instructors (Higbee 2009; Higbee, J. 2009. Implementing universal instructional design in postsecondary courses and curricula. *Journal of College Teaching and Learning*, 6(8): 65–77. [Google Scholar]). UID has been found to be successfully implemented when courses are assisted with computer technology, where material can be presented in a variety of forms, where course-work can be self-paced, and when instructors can incorporate a variety of methods to develop and demonstrate mastery of information (Brothen, Wambach, and Hansen 2002; Brothen, T., Wambach, C. and Hansen, G. 2002. Accommodating students with disabilities: PSI as an example of universal instructional design. *Teaching of Psychology*, 29(3): 239–240. [Web of Science ®], [Google Scholar]; Mino 2004; Mino, J. 2004. Planning for inclusion: Using universal instructional design to create a learner-centered community college classroom. *Equity & Excellence in Education*, 37(2): 154–160. [Taylor & Francis Online], [Google Scholar]).

Caution should be noted regarding the interpretation of these findings. The participants' reports reflect individual perception of their experience at university. It is possible that other factors about the participants' lives have influenced their perception. Furthermore, only 10 female students were interviewed and their experience may not be reflective of a universal experience. Also, although participants' perceived their experience as unique and suggested that they are required to put forth additional effort, comparisons cannot be confirmed given the research design. Future research should be conducted to determine the extent to which these experiences relate to those of students without disabilities and other students with invisible disabilities. Finally, in considering the transferability of the research, it is important to consider the specific context of the research. Several participants reported that the university was especially accommodating and has a strong commitment to and awareness of disabilities. Despite this aforementioned commitment, the presence of social and organizational barriers was reported, which they felt marginalized and further disabled students with invisible disabilities. It is suggested that professors and administrators should consider the extent to which they engage in these practices, with the hope that these barriers can be eliminated in the future.

This study makes a valuable contribution to the literature by providing insight into how individuals with invisible disabilities believe they are perceived within the university context. Canadian institutions have done well to attend to the physical access for students with disabilities; fewer changes have been made regarding eliminating the social barriers to address the needs of students with dyslexia and mental health issues (Wiener and Siegel 1992; Wiener, J. and Siegel, L. 1992. A Canadian perspective on learning disabilities. *Journal of Learning Disabilities*, 25(6): 340–350. [Crossref], [PubMed], [Web of Science ®], [Google Scholar]; Hill 1992; Hill, J. 1992. Accessibility: Students with disabilities in universities in Canada. *The Canadian Journal of Higher Education*, 22(1): 48–83. [Google Scholar]). It is hoped that this study enhanced understanding of the lived experience of having an invisible disability, and provided both individuals with and without disabilities strategies to facilitate an open and accessible university environment.

