

Female Students' with Acquired Brain Injury: Experiences in University

by

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Submitted in partial fulfilment of the requirements
for the degree of Master of Social Work

at

Dalhousie University
Halifax, Nova Scotia
July 2013

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ABSTRACT

Brain injury has become a more topical issue over the past decade, however limited research has been done on experiences of university students and few are specific to female students. The research question became: “How has having an acquired brain injury impacted the experience of female students within postsecondary education?” Narrative and auto-ethnographic methodologies were employed; semi-structured interviews with five participants were conducted, and text boxes were utilized to weave the researcher’s voice as a student with a brain injury into the narrative. Findings indicate brain injury has diverse implications depending on severity. Some participants spoke of accessing (dis)Ability resource centres, while others did not utilize formal accommodations. Findings revealed that participants navigate the academy in isolation yet wanted to connect with fellow students who have acquired brain injuries. Social workers can facilitate this process and provide counselling, challenge negative social implications and work toward building an inclusive educational environment.

LIST OF ABBREVIATIONS USED

ABI Acquired Brain Injury

TBI Traumatic Brain Injury

ACKNOWLEDGEMENTS

I would like to thank my family first and foremost for supporting me throughout my years of education, I would not have pushed myself to keep attaining higher education without your belief that I could reach the goals I had set out for myself. My brother Brian, in his determination to keep working and improving his rehabilitation, has been a source of inspiration for me. To my partner Andrew, thank you for understanding my dedication to this work and for accepting the demands this has placed on my schedule.

Thanks to the participants who shared their stories for this research. The stories told were touching and you willingly exposed your experiences to me. I felt a sense of community with each and every one of you and this reinforced my feeling that this research was valuable and these stories had to be told.

To my supervisor Dr. Judy E. MacDonald, thank you for being there for me throughout my time at Dalhousie University. The day we first met, before I was ever accepted into the program, confirmed that this school and the social work program was the right fit for me. Thanks for being there for me throughout all the changes I have experienced in my life. Over the years, I have come to understand your experiences and I strive to achieve the same dedication that you have achieved, despite obstacles that life may throw at me.

Chapter One: Introduction

The idea for this research project originally began when I thought I might like to become a social worker. My mother and I met with the undergraduate coordinator of the School of Social Work to explore the possibility of my fit within the program. You see, I was not an average student. I might have been of average age, educational background, and even ethnicity, but I had one thing that certainly was not average. I had an acquired brain injury. In May 2004, when I was nearing the end of my grade 11 education in high school, I was involved in a motor vehicle accident that led to me acquiring several serious physical injuries, including a brain injury. I utilized my own experiences of living with a brain injury, specifically drawing upon my experiences of pursuing academic qualifications through postsecondary education. I began the Bachelor of Social Work program and during my studies I took a (dis)Ability elective. There I learned the political positioning of (dis)Ability, the history of (dis)Ability rights and critiques of (dis)Ability policies. I also learned a new way of spelling “disability” that addressed concerns I had with the term that could be considered oppressive. By placing “dis” in brackets, the focus is taken off of the things that a person cannot do and capitalizing the first letter of “ability” highlights the importance of the things that one is able to do (MacDonald & Friars, 2010). When I went on to take my Masters program I knew that I wanted to do a thesis on students with acquired brain injuries and in preparation to developing my proposal my supervisor suggested I do an autoethnographical reflection on my experiences of living with an acquired brain injury, particularly as it related to engagement in postsecondary education. In doing this autoethnographical reflection I recounted my days in rehabilitation following my accident, I re-read the journal I had written during those initial days, and I recounted how I was able to begin my studies

again in spite of all the barriers. This preparation work was important to do before beginning to write about my personal experiences with brain injury and also interviewing five others. I believed my story was worthwhile telling, as did my supervisor, so we discussed how I could incorporate my voice into the research process. We came up with the ‘Researcher’s Reflections’. My struggles and successes since acquiring my brain injury and throughout my seven years of postsecondary education are cumulated in the “Researcher’s Reflections” portion of this study. The negative occurrences and struggles have been suppressed by my desire to persevere regardless of obstacles. I realized the experiences of others with brain injury have also been silenced and I believed these were valuable and important to unearth. Therefore, the research question was developed: How has having an acquired brain injury impacted the experience of female students within postsecondary education? I have learned much from considering the experiences of others and will bear this knowledge in mind in my social work practice. I hope that in telling their stories to me, participants felt a sense of liberation and support in revealing their struggles. The ultimate goal of completing this research was to expose the barriers imposed on university students who have brain injury and to identify strategies for addressing their educational needs.

In Chapter two, literature focused upon the experiences of students with acquired brain injuries (ABI) is highlighted. A consideration of how (dis)Ability has been viewed throughout history provides the basis for understanding how students with (dis)Abilities have been perceived. (dis)Ability and education generally are discussed before delving deeper to consider experiences with postsecondary education and brain injury. The importance of first voice accounts contributing to policies and services concerning persons with brain injury is highlighted. Reflecting upon existing

literature allowed a more in-depth consideration of participants' experiences as they relayed them to me.

The next chapter discusses the methodology utilized in conducting this study. Qualitative research, in the form of narrative methodology, was employed eliciting the experiences of female students with an acquired brain injury within postsecondary education. An autoethnography frame was also utilized to convey my personal experiences, which are presented in text boxes throughout this study. A detailed report on recruitment and sampling criteria is presented along with demographic details about each participant. The data collection process included a pre-participation interview, followed by the main interview and a debriefing procedure, which are discussed in more depth in this chapter. How the data was transcribed and analyzed is discussed and ethical considerations are acknowledged, along with measures taken to account for these issues. The limitations of this study are also raised.

Prior to presenting the findings, a chapter dedicated to storying aspects of each participants' life is provided. Stories provide context and it is through context that meanings are derived and subsequently understood (Atkinson, 1998). The unique lives of participants shape how they experience brain injury and the struggles and successes they encounter. Further, I wanted the readers to meet these amazing young women, to get a sense of who they are before readers were introduced to the struggles and barriers they faced. While the focus of this research is on female students with acquired brain injuries experiences within postsecondary education, the participants are not solely defined by their (dis)Abilities. Learning a bit about each participant helps off-set a singular lens to their (dis)Ability.

In Chapter five, an analysis of participants' narratives is presented and this involves

five key themes. Different ways of incorporating the experience of acquiring a brain injury into one's life was first explored. Participants provided their perspectives on services offered by (dis)Ability resource centres, the impact of stereotypes, disclosing their injury to others and feelings of mutual experiences with other students with brain injury. The next key theme participants identified was the overall experience of being a student with brain injury at university. Both positive and negative aspects of being a student with an acquired brain injury at university were identified. Participants highlighted policies, expectations of professors and expectations of employers as being major concerns. One participant also emphasized her desire to not be seen as complaining about her situation and this is explored in detail. The third key theme that emerged in participant's narratives was experiences with particular professors. Positive experiences with accommodations provided by professors and more negative experiences with accommodations or lack thereof, provided by professors are described. Specific strategies for dealing with the implications of brain injury at university served as the fourth theme associated with participants' narratives. Participants spoke of the usefulness of both formal and informal supports. Accommodations that participants were seen as "deserving" or being "undeserving" of and associated policies and processes for determining eligibility was an important topic. Memory problems were another significant implication of brain injury that was raised and participants' provided varied perspectives on the impact of this on their life. The final theme identified in this study is the issue of bringing awareness (coined awareness-raising) to brain injury, on both a small and large scale. The sociopolitical beliefs of others in the lives of participants and the impact on emotions for one participant were a significant issue. Awareness-raising in

relation to the potential for brain injury in sport activities was discussed by several participants and the importance of fitness was also highlighted.

In Chapter six, participants' narratives are considered and several implications for social work practice with students with brain injury are presented. Suggestions for the role that social workers can play in the lives of students with an acquired brain injury are presented. The findings of this study are also useful for others, such as family members and friends, who play an important role in the lives of students with brain injury. Dissemination of the research findings is discussed in the concluding chapter, along with future prospects for research with this population.

Participants' voices were heard, knowledge to better service female students with acquired brain injury within postsecondary education was formed, and a link between social work and this client population was established. Furthermore, this study highlights gaps in existing policies and areas where more research is needed to provide optimal services to people with acquired brain injury. Changes in practice and policy can be made to account for areas of concern, as highlighted by participants in this study. If people with brain injury have access to services that address issues of concern for them, increased access to postsecondary education would result and truly accessible education could be attained.

Chapter Two: Literature Review

Introduction

The experience of students with acquired brain injuries within postsecondary education is a topic that has not been fully explored by social work researchers within the literature. While people with acquired brain injuries are beginning to be invited into postsecondary institutions, little support exists for those who choose to accept this invitation. Authors are currently examining services and supports for people with (dis)Abilities within postsecondary education (Carter, Hanes & MacDonald, 2012; Dunn, Hanes, Hardie & MacDonald, 2006; Dunn, Hanes, Hardie, Leslie & MacDonald, 2008). However, services that do exist for students with (dis)Abilities may or may not be appropriate for students with acquired brain injuries. Specific investigation need to take place whereby the barriers faced by students with acquired brain injuries are exposed, and an understanding of required services, supports and resources become clear.

Theoretical Literature

Acquired brain injury is generally understood as a (dis)Ability, although some people with this injury may chose not to identify with this label and all of the notions it encompasses. Academics strive to portray an understanding of (dis)Ability that accurately describes how (dis)Abled people experience the world and how this relates to the experiences of people who do not identify as (dis)Abled (Corker 1999). Much debate exists between the two dominant models within (dis)Ability theory: the medical model and social model (Oliver, 1990). The medical model of (dis)Ability is rooted in notions of normalcy and treatment to return the (dis)Abled person back to previous ways of being,

as close to ‘normal’ as possible (Oliver, 1990). The social model conversely views (dis)Ability as a social phenomenon rather than deficits within the individual. What is understood as (dis)Ablement is identified and defined by society and the costs of this fall upon (dis)Abled people as a group, alienating them from full participation in society (Oliver, 1990).

It is vital to consider the implications that these theoretical models have upon service provision, particularly for students with (dis)Abilities in postsecondary educational institutions. Universities tend to say they operate from social model conceptions of (dis)Ability, but the medical model is upheld and adhered to daily, resulting in tensions at the core of the institution’s provisions (Borland & James, 1999). Requesting diagnosis before students with learning (dis)Abilities can receive services is an example of how universities still operate based on the medical model.

Standpoint feminism is another perspective from which (dis)Ability can be understood and from this view, every person’s experience is a starting place of inquiry. The inconsistencies that emerge between socially constructed knowledge and the experience of people within a socially constructed society are at the centre of standpoint feminism (Fawcett & Hearn, 2004). Standpoint feminism is a useful theoretical perspective from which to view experiences of (dis)Ability, such as those resulting from brain injury, that contradict traditional notions. This is the perspective from which I view (dis)Ability.

Literature Review

Definitional. The terms acquired brain injury (ABI) and traumatic brain injury (TBI) are used throughout existing literature in discussing brain injuries; they are also utilized interchangeably throughout this document. ABI is a broad term that includes

varied conditions that can affect the brain such as stroke, infections, erroneous surgery procedures and TBI (Mantell, 2010). TBI describes physical trauma to the brain, such as trauma that can occur through involvement in motor vehicle accidents. A distinguishing feature is that TBI is not progressive in its implications, whereas ABI might be (Mantell, 2010). I was involved in a motor vehicle accident and acquired a TBI; I discuss the implications of this further on in another chapter and at various points throughout the study. Students with ABI have been interviewed and these include people who have TBI, like myself.

The introduction of legal rights for people with (dis)Abilities sparked the discussion of inclusive education and posed challenges in how education was delivered (Bolt, 2004). The fact that people with (dis)Abilities challenged education to be more inclusive shows that societal values and legal responsibilities affect the provision of education. When legal rights were introduced, presumably alongside a shift in public opinion, this meant that educators had a professional responsibility to consider the needs of students and provide accommodations. The Charter of Rights and Freedoms, enacted in 1982, protects the interests of people with (dis)Abilities within Canada, while the Americans with (dis)Abilities Act was enacted in 1990 to protect the interests of American citizens with (dis)Abilities (Prince, 2010). The 2006 United Nations Convention on the Rights of Disabled Persons is “...the first UN treaty in the twenty-first century with legally binding obligations for the nations that ratify it (Shik Kim, 2010, p. 104; Rioux, 2011). Canada just ratified this treaty in 2010, whereas other nations have had an earlier start with this endorsement (Shik Kim, 2010).

In the Twentieth century, life expectancy rose and the emphasis of medical professionals shifted from curing illnesses to managing chronic conditions (Lornez,

2010). Acquired brain injury was included in this new emphasis and managing life with brain injury is a fairly new phenomenon because people traditionally did not survive this injury. This is why only limited discussions around the repercussions of acquiring a brain injury exist. In addition to this, there are some generalizations that can be posited about the effects of brain injury and general rehabilitation timelines; however it is acknowledged that each person experiences brain injury in a very specific and unique manner and, therefore, require different supports (Degeneffe, 2001). According to Degeneffe (2001)

Although TBI severity predicts long-term functional capacities and rehabilitation potential, the expression of this injury's effects are unique for each affected person. This is dependent on the specific area of the brain damaged as well as the presentation of various secondary mechanisms to the injury such as cellular disturbances and infections. (p.258)

The wide range of the possible effects of brain injury has been a key understanding throughout my study. According to Foster, Tilse and Fleming (2004), medical practitioners consider both clinical and non-clinical factors to make judgments about the “rate and extent of progress, recovery potential, safety and burden of care and potential for independence in the context of making referral decisions.” (p. 1875) This speaks to the complexity of considering how traumatic brain injury is incorporated into one's life. Despite the unique nature of the individual experience of brain injury, themes for practice can be discussed, as is argued in this study.

Gender. Studies report traumatic brain injury occurs more often in males, but high levels of resultant (dis)Ability and high levels of incidence occur for females (Chase, Ratcliff, Vernich, Al-Sukhni, Yasseen & Colantonio, 2012). Additionally, “research shows that caregiving was and continues to be primarily women's work” (Pollett, 2008). Therefore, it is vital to explore the topic of brain injury in relation to the role of gender.

Little research has been conducted on the unique experiences of females with brain injury so this is an important topic to investigate. Chase et al. (2012) also found that it is critical to make mental health supports available to women who are survivors of traumatic brain injury.

Less access to education and employment are known to be characteristic of women with (dis)Abilities (Nosek, Hughes, Taylor & Taylor, 2006). Social resources and roles also impact the experience of (dis)Ability for women, particularly in the work force. McDonough (1997) examined a Statistics Canada health survey and found that women who were younger, married and had higher levels of homemaking responsibilities were less likely to report work-related (dis)Ability than women without these social roles and resources.

Doctoral research conducted by Iaquina (2007) on the topic of career-decision making for women with brain injuries is an example of useful research related to the experience of brain injury. Iaquina (2007) explores the experience of career-decision making by women with brain injuries and this seems especially relevant to the topic of postsecondary experience. University education is intimately linked with career-decision making as strengths are discovered and training is obtained that ends up influencing future employment decisions (Iaquina, 2007). Iaquina's work finds that career-decision making by women with acquired brain injury is a highly emotional experience that differs in meaning for each participant in the study due to social and environmental factors. The implications of brain injury were described by participants as affecting their life in significant ways, such as being labeled "non-compliant" in relation to efforts made to assert autonomy in career decision-making. Another significant factor to note in Iaquina's (2007) study is that all participants were engaged in work considered to be

“part-time” employment and their successful work engagement countered expectations of rehabilitation assessments.

Inclusivity. MacLennan & MacLennan (2008) conducted a study assessing readiness for postsecondary education for a small number of participants after traumatic brain injury by utilizing a college simulation procedure. The college simulation program was predictive of both successful and unsuccessful performance in postsecondary educational domains. The simulation offers several advantages for people with brain injury who wish to attend postsecondary education, such as allowing people to identify strengths and weaknesses in academic skills; it also provides information about study skills and allows people to practice these skills and if the person chooses to pursue their education, the information can be used to formulate an individualized plan to maximize success (MacLennan & MacLennan, 2008). MacLennan and MacLennan’s (2008) study has been valuable in policy development and implementation and can enrich the knowledge of those who regularly interact with people with acquired brain injuries. Knowledge about the struggles endured by people with acquired brain injuries is identified as being useful in the eyes of the student on an emotional and personal level.

Inclusive education is a topic of much controversy as debates around the meaning of inclusivity are prevalent. Much like the notion of equity/equality, where people often said, “I treat everybody the same!” inclusivity can be conceived of in the same way. Whether inclusive education means providing specialized, individualized instruction to a certain population or incorporating students who have (dis)Abilities into standard classrooms to be taught in the same manner as their non-(dis)Able peers, is often debated. Which method of “inclusive education” better serves the needs of students with (dis)Abilities must be considered. Corker (2000) argues for the inclusion of perspectives

of people with (dis)Abilities in developing policies and said that the power of language should not be ignored in scripting policies. Kenworthy and Whittaker (2000) note the danger of the compulsory segregation of students with special needs, and say that this separation functions to, “define the limit of adult society’s tolerance for children.” One’s interpretation of inclusivity must therefore be carefully considered in relation to the education.

The impact of policies that are designed to meet the needs of one specific population, and how these come to be seen as “inclusive” even though they do not address the needs of all students with (dis)Abilities, can result in harmful experiences. As noted above in relation to policy-making, pushing people into categories that do not necessarily speak to their abilities can be damaging. The refusal of schools to adapt to the specific needs of pupils by developing special education programs that only speak to one population creates barriers rather than the intended inclusive outcomes (Nes & Stromstad, 2006). This, again, has implications for the continued education of students, particularly those who have dealt with oppressive experiences in relation to education and may have internalized the negative emotions associated with oppressive services.

Barriers experienced by people with brain injuries. Historically, people who acquired traumatic brain injuries often died from their injuries; advances in emergency health care technologies have meant that people can survive these experiences (Degeneffe, 2001). Survival after a brain injury however, means that new issues are emerging in relation to how people with acquired brain injuries (ABIs) experience their world. While services for people with various other (dis)Abilities exist, they are often inappropriate for people with acquired brain injuries because they do not meet their needs. With more and more research being completed on traumatic brain injury, deeper

understandings will emerge that speak to the experiences of people who have acquired this injury. This exploration needs to continue to improve the experiences of people with (dis)Abilities.

Research has emerged over the past twenty years with academics such as Clark (1996) and Farmer et al. (1996) exploring challenges for students with traumatic brain injury in the reintegration into school process. Clark (1996) discovered that some students have a positive experience with reintegration into a school environment immediately after acquiring a brain injury, however the researcher noted that this is not always the case. According to Clark (1996), educators are not well informed about the needs of students with acquired brain injuries reintegrating into the classroom. According to a study conducted by Arceneaux, (2006), many people with (dis)Abilities that impact their learning, such as brain injury, think that they are considered to be lazy or are trying to “get something they don’t deserve,” like accommodations. This indicates a lack of education about the implications of ABI (Asch & Rousso, 1985). Frequent reassessment and modification of goals and plans, facilitated by informed teachers, will result in the best chance at helping students with brain injury meet the academic challenges they face (Asch & Rousso, 1985).

A key understanding to bear in mind when considering people who have brain injuries and the impact on their lives, is the role of policies related to access to accommodation services and equipment. The perspectives of those affected by policies should be given value, yet existing policies and procedures tend to push people into categories that may not reflect their abilities or special needs (Gottschall, 2009). The principle of affected interest can be considered in relation to policy-making as this asserts that, “everyone who is affected by a decision of the government should have a right to

participate in that government” (Dahl, 1970, p. 64 as cited in McKenzie & Wharf, 2010, p. 128). More specifically, Dahl notes that acknowledging the personal choice of a person regarding whether or not to participate in policy-making decisions and the competence to participate in policy making in relation to knowledge and specialized skills, is vital (McKenzie & Wharf, 2010). With this in mind, the perspectives of people with (dis)Abilities and those affected by the services afforded to them, such as family members, should be taken into consideration when policies are established (Gottschall, 2009). While in previous research completed in relation to elementary education for students with (dis)Abilities, I have found that individual perspectives are not taken into consideration, it has been fascinating to see whether personal perspectives play a role in relation to postsecondary education.

Supports for people with brain injury. Farmer et al. (1996) note that communication about assessment information related to the person with brain injury is essential in supporting successful transition into schools and communities. The medical and health domain, intellectual and cognitive domain, speech and language domain, sensorimotor domain and behavioural domain are noted as major areas of functioning substantial to school reintegration following brain injury (Farmer et al., 1996).

Reiss (2006) has researched the experiences of youth who have a (dis)Ability in preparation for the transition to adulthood, a process that can include higher education such as university. Participants in Reiss’ (2006) study compared the way they are treated during the transition to adulthood process, with the experiences of their non-(dis)Able peers. Findings indicate that positive support systems and treatment from others influence self-determination in areas like overcoming negative treatment.

Education and (dis)Ability. Statistics Canada provides some information regarding children and youth with (dis)Abilities and the education system. According to Statistics Canada, 4% of children aged 5-14 experience “limitations in the kinds or amount of activities they can do” (Statistics Canada, 2009). This seems to note a common enough occurrence that services that speak to the needs of youth with (dis)Abilities should be available. In terms of the type of educational services provided to youth with (dis)Abilities, there has been debate around whether special education classes or standard classrooms are most useful for students with (dis)Abilities. Within Canada, the types of classrooms vary from province to province, with specialized classrooms being provided in some areas, while integration into standard academic classes occur in other areas (Statistics Canada, 2009). Higher education for people with (dis)Abilities was virtually impossible in the past due to few available resources; however the recent emergence of support services for people with special education requirements allows for an enrichment of the considerations of these needs (Barnes, 2007). It has been my experience that brain injury and the implications of this is not a well-known area as inappropriate services are offered that do not speak to the educational needs of students with acquired brain injuries. In previous research conducted regarding the topic of education for students with (dis)Abilities, I have found that educational policies tend to reflect the concerns of those with power (Gottschall, 2009).

While specialized educational institutions at the elementary and secondary level are popular, these facilities are not available in every geographic location so mainstream school teachers who possess the skills to address the needs of students with (dis)Abilities is a practical alternative (Jenkinson, 1998). According to an American study, “parental dissatisfaction with special education services is a national problem” (Mueller, Singer &

Draper, 2008, p. 191) and this seems to speak to the concerns of those who are closest to children in their early years of education. While this quotation reflects the concerns of a study conducted outside Canada, this understanding may be relevant for parents of Canadian children who may enter university education at a later period in their life.

Postsecondary education and brain injury. (dis)Ability services in higher educational institutions have evolved over the past twenty-five years from a fledgling component of higher education to an established professional service offered to students (Madaus, 2011). There are now universities in Nova Scotia that are known as being more accommodating for students with (dis)Abilities and this is a progressive occurrence. I think that this speaks to the power of the social location of (dis)Ability presently and the perseverance and determination of students with (dis)Ability to complete higher education by being provided with the services necessary to do so. The existence of (dis)Ability resource services provides the basis for understanding the experiences of students with particular (dis)Abilities at different educational institutions.

Bearing in mind the implications of acquired and traumatic brain injury, it is intriguing to consider experiences with postsecondary education. Data indicate that 4-5% of university students have some sort of (dis)Ability; however it is believed that this number could be much higher due to the under-reporting of (dis)Abilities such as mild traumatic brain injury (Borland & James, 1990; Laforce & Martin-MacLeod, 2001; Marschark et al., 2000 as cited in Lin Haag, 2009). Brain injury in relation to postsecondary education is a significant matter to consider. One such issue is the belief that accommodation for students with (dis)Abilities compromises academic standards and integrity (Boxall, Carson & Docherty, 2004; Collins & Mowbray, 2005 as cited in Lin Haag, 2009). This conviction is rooted in westernized mainstream ways of learning that

speak to the abilities and strengths of only one group of people. If more diverse ways of learning are to be considered, I think that more enriched graduates would result and this could contribute to more effective, flexible and diverse workers in the workforce.

Educational institutions need to have a more inclusive definition of what accessible education includes. While equity-based admission procedures are a beginning step, and are common in Schools of Social Work in particular, accessible standards need to be maintained throughout the university experience (Carter et al., 2012) for all programs of study. In terms of students with brain injuries, this includes professors meeting with the student to discern the impact of their injury on their studies and accommodation needs. Nes and Stomstead (2006), note that it is often not made a priority by schools to adapt their education to specific students' needs as a convenient solution is assigning students to special education as this is seen as an all-encompassing solution. When students pursue university education, however, their needs cannot be ignored as they are expected to learn the same material as all other students in classes.

Accessible education is often thought of as including programs that meet a set of goals that are pre-determined to be reflective of the needs of students with a particular (dis)Ability. In interviewing parents of students in public school systems, I have found that students' experiences with (dis)Ability differ, therefore their educational requirements vary as well and this should be taken into account when developing and implementing educational programs (Gottschall, 2009). While this previous research focused on elementary education in the public school system, I think that even more issues arise when this is considered in relation to postsecondary education as support in this sphere is not as accessible to obtain. If mainstream university programs do not address the concerns of students with (dis)Abilities, then resources to assist in making

accommodations and discerning special needs, need to be more easily accessible.

Personal responsibility and work to achieve one's goals are reflective of postsecondary educational goals. King (2010) discusses the privilege associated with doctoral experiences in particular and notes that expectations for becoming leaders in a chosen field are often dashed by experiences that counter inclusion and support for achieving advanced knowledge. Achieving doctoral education for students with (dis)Abilities is made difficult as little support is offered by educational institutions.

Postsecondary education as it relates to Schools of Social Work will be considered. The profession is concerned with "individual and collective well-being" (Canadian Association of Social Workers, 2011) and this can be considered in terms of social work students who are learning the theoretical and practical implications of the profession. Students' social welfare needs to be taken into consideration. Positively, declaring (dis)Ability as part of an equity statement during the admission process, is provided by most schools (Carter et al., 2012). Despite this, not all schools that offer social work programs have courses specifically related to persons with (dis)Abilities and field placements that specifically deal with (dis)Ability-related issues (Carter et al., 2012). The few studies that have been completed that investigate (dis)Ability inclusion within schools of social work suggest that change to incorporate (dis)Ability concerns into social work education has been slow (Dunn et al., 2006). Social work champions the cause of recognizing abilities that exist among (dis)Abilities and if social work education does not reflect this concern, this diminishes the aims of the profession.

Universities in contemporary society seem to have (dis)Ability resource centres as a standard, but underlying concerns can be raised. As noted above, it is a common misconception that (dis)Abilities that are given the same label or name to result in "the

same” or similar outcomes for students who in turn have similar educational requirements. In speaking with students who all have different experiences with brain injury, and different needs because of this, this notion is refuted. Dunn et al. (2008) describes the problematic assumption that all people with (dis)Abilities have the same requirements saying, “...to treat persons with (dis)Abilities equally results in their continued discrimination and oppression as it ignores their differences and their need for accommodation” (p.2). The narratives of participants in this study are particularly interesting considering that stereotyped views of their (dis)Ability may have been experienced. Related to this, accessibility and accommodations are primarily seen as a responsibility of university administration or (dis)Ability service centres (Dunn et al., 2008). The common belief that university administration are in charge of arranging accommodations takes pressure off individual instructors but can alienate students with (dis)Abilities who may feel as if any accommodations can not occur at the classroom level and grand adjustments single them out making them feel incapable. Another concern is that when more advanced postsecondary degrees are considered, supports diminish. Dunn et al. (2006) compared the percentage of people with (dis)Abilities in Bachelor of Social Work, Master of Social Work and doctoral programs and there was a steady decline in the rates. The percentage of faculty versus staff rates also declined with respect to people with (dis)Abilities and this suggests that few supports exist for teachers of the social work profession, in addition to the disparities experienced by learners.

The belief that people with certain (dis)Abilities are unable to continue their education to the degree that others are able to, is common. According to Iaquina (2007), however, there is emerging consensus in vocational rehabilitation that (dis)Ability alone does not determine vocational and educational development; rather, (dis)Ability is a risk

factor that may or may not influence a person's career development and a homogenous theory about the impact of (dis)Ability upon vocational success is not appropriate. Nonetheless, participants in Reiss' 2006 study spoke about how teachers set limitations on decision-making and reaching one's goals. One participant noted that when they spoke about their career aspirations, other people, including the teacher, cited reasons why they could not attain this vocational goal and made the student feel "useless" (Reiss, 2006, p. 46). Participants also noted how the treatment they got in high school could possibly influence their abilities as adults (Reiss, 2006). Brain injury is one of the (dis)Abilities that I think is seen as impacting a person in severe ways over a long-term period and this contributes to preconceptions that they are unable to partake in higher education in any way, much less excel at it. The idea of simply obtaining a degree and how this is "good enough" is reflective of this idea and I believe little consideration is paid to how education impacts the individual and drives their future opportunities. It has been my experience that as my educational journey progressed, I became more comfortable with learning and required less support. My comfort, however, is particular to my individual experiences and circumstances, my particular (dis)Ability and my educational requirements and this does not reflect all experiences. For some people, the differences between undergraduate education and, for instance, doctoral work, could highlight an increased need for supports. It has been instructive to consider particular programs participants in this study are enrolled in and how this relates to their experiences of being a student with a (dis)Ability in postsecondary education overall.

As noted above, research related to the experience of brain injury is a relatively recent emergence and these studies inform my current exploration and the work that needs to be done in the future. I encountered several studies, such as those by Lin Haag

(2009) and Lorenz (2010) that are directly related to my study and influence the theoretical and methodological underpinnings of my work. One significant notion that I have considered is the value of knowing that acquiring a brain injury “increases stress and reduces stress management [capabilities]” (Long et al., 1984, p. 40 as cited in Lin Haag, 2009, p. 8-9). It is commonly understood that involvement in postsecondary educational programs is associated with stress, so this correlation is vital to bear in mind as it indicates the barriers to educational success that are presented by acquiring a brain injury. In MacLennan and MacLennan’s study (2008), which explored readiness for postsecondary education following a traumatic brain injury using simulated college experience, an individual study subject was advised by rehabilitation staff to not return to school right away, yet he remained dedicated to his studies until he completed the college simulation test administered by the researchers and then he decided to discontinue with postsecondary education (MacLennan & MacLennan, 2008). I find this thought provoking and I discuss my personal experiences in relation to being told that returning to school was not an option, in further detail in the analysis section of my study.

First voice accounts are crucial to explore and there is a gap in existing literature of these first voice accounts of the experience of living with a brain injury and attaining postsecondary education. Considering the historical and theoretical underpinnings of brain injury and education has been useful in increasing my knowledge about the various factors that contribute to the experiences of students today. A historical and theoretical review has enriched my understanding of my own experiences and my interpretation of the experiences of others. The review of literature enhanced my analysis of the data collected and has contributed to a rich consideration of the experience of having a brain injury in postsecondary education.

The gap. More significance should be given to the expertise of people in their lived experiences, rather than viewing professional information as holding more expertise (Lin Haag, 2009). It is vital to ensure that research is not used as a means to exclude the voices of people but to use research as a vehicle for their voices so that personal stories can be shared and the improvement of services will result. The first voice accounts that have emerged in research such as that of Lorenz (2010) and Lin Haag (2009) need to continue and this gap in literature is what motivated me to complete this research. Lorenz (2010) focuses on the issue of identity and how this is impacted by brain injury. Like Farmer et al. (2006), Lorenz (2010) acknowledges the value of information sharing. The researcher asserts that this process contributes to shared power and information, which benefits healthcare systems and society more broadly. Lin Haag (2009) provides a glimpse into the experiences of university students in Ontario and the lived experience of participants. Several areas for future exploration are posited in this study, including whether the individual has begun their program and how this influences the impact of brain injury, age upon acquisition of brain injury and the role of inner strength and determination (Lin Haag, 2009). These are factors that I have considered while conducting my study and it has been thought provoking to compare and contrast findings.

Chapter Three: Methodology

Introduction

Related to the theoretical perspective of standpoint feminism, Brown's (2007) conceptualization of knowledge and adopting a "partial-knowing" stance, a qualitative approach was utilized in completing this study. The gap in literature on first-voice perspectives of the lived experiences of postsecondary education for students with brain injury, motivated me to complete this research. Qualitative research also allows for the researcher's voice to be incorporated into the data in transparent ways and, given that this research topic is one of personal relevance to me, this is a useful way to acknowledge my perspective alongside the data accumulated. The following question guided my study and informed participant selection and methodology:

How has having an acquired brain injury impacted the experience of female students within postsecondary education?

I explored participants' experiences in postsecondary educational institutions utilizing a narrative framework (Bryman, Teevan & Bell, 2009; Flick, 2006). I also considered my own experiences with brain injury in relation to postsecondary education utilizing the method of autoethnography (Ellis, Adams and Bochner, 2011; Ellis and Bochner, 2000; Ellis and Bochner, 1999) . My experiences are presented in text boxes titled "Researcher's Journey," throughout the analysis of this study. I feel this allows for sharing of my experiences in a way that values participants' contributions.

Researcher's Reflections

My injuries have had a dramatic impact on my life and the scholarly research I have completed in several programs. In an independent study as part of my Master of Social Work degree, I completed an illness story. The illness story, along with other related scholarship, was the driving force behind crafting this study. The work I have done in relation to my experience of brain injury has provided insights about the challenges and rewards of telling my own story. Both have informed my methods for this study, autoethnography (in utilizing my story) and narrative (in seeking out the storied experiences of participants).

Narrative

In the interviews conducted for this study, I employed a narrative method as I think that this best suits my research aims and framework. Narrative analysis of research involves approaches that search for and analyze the stories that people tell to understand the lives of others and their world (Bryman, Teevan & Bell, 2009). In employing semi-structured interviews, I felt that I provided the framework for academic research that focuses this study, but also allowed for the voices of participants to be heard and contribute to a deeper understanding of their story. While the approach itself appears fairly broad, importance is given to the connections within events throughout a person's life, the stories they tell about them, the context they are told within, and people's sense of their role within them (Bryman et al., 2009).

In the interviews conducted, I employed this narrative method by asking participants about their overall experience with acquiring a brain injury. I then asked

participants to expand on their stories by asking follow up questions relevant to the narratives they provided. In narrative research, “narratives are stimulated and collected...in order to reconstruct biographical processes...in order to analyze the narrative construction of reality” (Bruner, 1987, 1991 as cited in Flick, 2006, p.330). In employing several general questions, the stories participants told were pieced together to provide a comprehensive illustration of their experience of acquired brain injury and how this impacts their postsecondary educational journey. How stories are constructed and how they have come to impact the lives of the participants, rather than how they can be re-constructed to alter their impact on the lives of participants, was interesting to consider (Flick, 2006). The construction of stories is discussed in the analysis and conclusion chapter.

In terms of the utilization of narrative analysis in this study, I believe that two models in particular were helpful. Structural analysis places importance on the way a story is related and the use of narrative mechanisms for escalating the persuasiveness of the story (Bryman et al., 2009). In considering the narratives that are relayed in this study, noting where emphasis seems to be placed by participants was valuable in discussing their stories. Interactional analysis views the dialogue between the storyteller and the listener, particularly the co-construction of meaning, as being particularly important (Bryman et al., 2009). The co-construction of meaning was significant due to the shared experience between the researcher and the participants in this study. Dialogue emerged that was understood by exploring the shared experiences of the participant and I. According to Bryman et al. (2009), “with narrative analysis, attention shifts from ‘What actually happened?’ to ‘How do people make sense of what happened?’” (p. 271) The focus of narrative analysis holds true in relation to the interviews I conducted in this

study, as the emphasis was not on injuries, diagnosis or resulting (dis)Ability, but on the implications for people's lives and how they speak about these implications.

Autoethnography

The power that is attached to stories is significant for autoethnographic research in the personal value it carries and the ability to talk about what is most significant for the self (Atkinson, 1998). According to Atkinson (1998), the spiritual value associated with telling your own story is present in interviewing others' about their story, and this is relevant for the autoethnographic portion of this study. While there are risks associated with this form of research in terms of emotional issues that may arise, mutual benefits also exist and these should be recognized.

Autoethnography is understood as a relatively novel approach to doing research. Further, there are many misconceptions about the use of autoethnography, and skepticism about its validity as a research methodology. According to Carolyn Ellis, "Autoethnography is an approach to research and writing that seeks to describe and systematically analyze (graphy) personal experience (auto) to understand cultural experience (ethno)" (Ellis, Adams & Bochner, 2011, p. 1). While the components that comprise autoethnography are easily understood in relation to their research value, the roots of ethnographic research are useful to consider in relation to autoethnography as a specific tool utilized in academia. Ethnography is a research methodology that is centred on cultural behaviour and the organization of society (Faulkner & Faulkner, 2009). With this in mind, autoethnography was a useful tool in exploring my personal lived experience with an acquired brain injury. The research method of autoethnography utilizes a theoretical position of describing social realities and develops theories based on detailed

descriptions of case studies (Flick, 2006). In the case of the method utilized in this study, autoethnography was useful in considering my own experiences and developing postulations about the experience of acquired brain injury in society.

Autoethnography involves “research, writing, and method that connects the autobiographical and personal to the cultural and social. Autoethnography... feature[d] concrete action, emotion, embodiment, self-consciousness, and introspection” (Ellis, 2004, p. xix as cited in Averett, 2009, p. 361). By employing text boxes surrounding stories that describe personal experiences, I brought my understandings into the work, but in a protected and specific manner. The text boxes exist separately from the rest of the document, which provides clear distinction from the experiences of participants. My understandings are still presented, however, as this is significant to my role as the researcher. While participants’ personal experiences were the focus of interviews, I nonetheless divulged pieces of my own story in connecting and emphasizing with participants. While conducting interviews for this study, my own experience as a person living with an acquired brain injury could not be divorced from my position as a researcher and social work student and the methodology used allowed these identities to co-exist.

Researcher’s Reflections

The subject of this study is most significant to me as a student with an acquired brain injury. All aspects of my life within postsecondary education can be mirrored to the issues raised by the participants. It is one of great emotional significance, and I have also incorporated my experience with acquiring a brain injury into my work in various other ways. Through discussing my acquired brain injury in courses, professional endeavors,

and speaking with peers who are dealing with brain injury, it has become my passion. I have written about the impact of acquiring a brain injury related to various different aspects of my life, such as relationships with peers, relationships with family members and academic struggles.

The meaning of the personal stories that are told can be understood in connection with social structures (Averett, 2009). While personal stories might have tremendous significance for the individual who has lived them, how these stories interact with social constructions in society can significantly impact future endeavors, such as attaining postsecondary education. The variable interactions with social constructs speaks to the lack of generalizability associated with the narrative method and indicates that stories told by the self, which might be seen as even more subjective, should be considered more critically in terms of how they have emerged and what factors have impacted them.

Autoethnographic research is a method that presents the writer as the main topic of the study (Burnard, 2007). The value of autoethnographic accounts is that they are subjective and speak to the particular truths of particular instances. The value in considering the self from the perspective of others however is useful in bringing about new self-considerations that may not have been contemplated previously. Considering the self from the perspective of others is also useful for those outside the narrative in that the effect of their considerations can be explored.

Researcher's Reflections

The telling of my own life story through autoethnography was personally rewarding. The journaling I completed related to my experience of acquiring a brain

injury, as well as the illness story I completed prior to conducting this study, was a valuable aspect of this study. Doing this work allowed me to more deeply consider my own feelings and reactions and this was critical to explore before I began interviews, asking participants to describe their experiences. I learned a lot about myself by doing this preliminary work and this helped to shape this study. This allowed me to gain context and recognize meaning (Atkinson, 1998, p. 7) and was therapeutic for me in that I was able to divulge all my experiences in one place, something that I have never experienced before. According to Atkinson (1998), “The life story narrative may be the most effective means for gaining an understanding of how the self evolves over time or at least in seeing the subjective perspective on that” (p. 11). During the process of telling my story, I encountered emotional processes and revelations, something that also occurred for me in the journaling process. Recalling my experiences and writing about my true feelings without worrying about academic penmanship has been extremely beneficial for me. In addition to journaling as a beginning step in completing this study, I have spent time reading the journal I began keeping shortly after sustaining my injuries. The journal ranges from two months post-injury to 5 months post-injury. In considering this journal, it is fascinating to see my penmanship getting progressively neater as time passed. Prior to acquiring my head injury, I recall having extremely neat writing and this was lost in the wake of my injuries. The first few sentences of the journal are also revealing. I wrote, “Dear Journal, I’m still at Rehab, it’s been two weeks and three days. I’m counting.” This reflects my unhappy feelings about being “stuck” at the rehabilitation centre following my injuries and my desire to return to life as it was before the accident. Reflecting on my feelings at the time of my injury has been useful in increasing my recollection of my perceptions at the time. The evolution of my considerations is important to consider as

well and this is useful in exploring my post-injury rehabilitation and educational journey. Having designated sections to divulge my own experiences is useful in that when I discuss one issue that comes to mind, I can continue to explore this issue without fear that I am straying off point. This has resulted in considerations that I do not think would come to mind via any other method. For a student like myself, who has been a full time student for most of my life, writing without the regard of judgment by any outside person has been a novel experience. Autoethnography appears to hold value in a personal way for myself as the researcher and in the data it generates for the research process.

As part of the process of telling my own story for this research, I began journaling to explore my experiences. Liz Stanley notes the value of interviews as narratives as both biography and autobiography are fundamental aspects of qualitative research (Stanley, 1993). The process of journaling began with considering a diary that I kept while I was a patient at the Rehabilitation Centre shortly after sustaining my injuries. The journalling was part of the data I used for analysis of my own experiences that are conveyed in text boxes throughout this research. The muddled handwriting and simplistic thoughts conveyed in this diary served as a reminder of my thoughts and feelings. The diary continues for several months after I was discharged from the Centre and reflects the social difficulties I experienced. These thoughts contributed to my recollection of my emotions immediately following the accident and triggered memories about how my understandings of the world were shaped by the brain injury, and other injuries, I had acquired. “Orthodox social science seeks historical, representational truth, thus emphasizing accuracy – telling the way events ‘truly’ happened” (Ellis & Bochner, 1999, p. 233). While my scribbles cannot be understood as accurate representations of events

that occurred in the spring of 2004, they do reflect my thoughts and emotions. My writing is of relevance in this study, as I draw upon my experiences of acquiring a brain injury and how this has impacted my educational journey. Many personal challenges in relation to this kind of research have been discussed, including physical and psychological effects of trauma, the risk of making assumptions about participants' experiences and being overly critical (Shah, 2006 as cited in Lin Haag, 2009; Lin Haag, 2009). I have considered these challenges when completing this study and I think that the benefits have trumped the risks in terms of affect on participants.

In considering how my own experiences are presented in this study, I investigated the method of "bracketing." Bracketing involves the researcher suspending personal assumptions and understandings to allow the phenomena to speak on its own (Rolls & Relf, 2006). I reflected upon this and considered it to be a valuable way of disclosing my own experiences and the impact they have on the present research. Bracketing, however, seems to be related to the idea of pure knowledge and this reduction of knowledge has been problematized. The idea of bracketing, however, is valuable in considering how I have incorporated discussions related to my own experiences with acquiring a brain injury into this study. As previously noted, I discuss my experience via text boxes entitled "Researcher's Journey" and this encompasses the advantages of bracketing and bridling by providing a distinction between my personal experiences and that of research participants, but also by being an ongoing project throughout the study, continually shaped by the stories participants tell.

Recruitment & Sampling

I choose to focus on women in particular in my study due to statistics that indicate that women with (dis)Abilities have had a largely negative experience in various

domains.

Researcher's Reflections

I would also like to discuss my personal experiences in relation to those of participants, and I think that gender has played a role in this. In my rehab journal, I spoke about how I disliked having short hair after my head was given a buzz cut so that it could be operated on due to injuries sustained in the accident. My partner at the time who was a male with a longer hairstyle cut his hair into a shorter style following my accident. In relation to this, I wrote in my journal, "It was weird... but cool I guess! His hair is shorter than mine now!"

I also talked about buying multiple pink clothing items and I think that this was to account for the lack of femininity that I felt while having short hair. Many of my experiences have been around societal expectations of the role I play and issues of independence and I often think about issues of gender in relation to those around me who have had (dis)Ability impact their life. The role that my mother played after both my younger brother and myself acquired brain injuries can be considered in terms of gender. Caring for people with (dis)Abilities typically falls to female relatives (Rowbotham, Cuskelly & Carroll, 2011). I think my mother felt a push to take on a caregiver role, and this could be related to her profession, as she is a licensed nurse. My mother has talked about her reasons for entering the nursing profession and these are clearly related to her gender, as she said, "that was really my only option at the time and that's what all the girl's did." This is just one example of the intertwining impact of gender and (dis)Ability, which will be explored in the analysis chapter in relation to participants' narratives.

After obtaining ethical approval from Dalhousie Research Ethics Board, I contacted

(dis)Ability resource centres at Dalhousie University, St. Mary's University and Mount Saint Vincent University to talk to them about displaying my poster at their centre and sending it out to people who were registered with the centre via an e-mail listserv. One participant was recruited via this method. I am also involved with the Brain Injury Association of Nova Scotia, as I sit on the board of directors for this association. There is a listserv associated with this provincial organization for all people registered with the association. I also sent notice of my study via this listserv with the thought that if there was someone who was interested in participating who meets the criteria I was searching for but may reside outside the Halifax region, accommodations may be arranged so that they would be able to participate in the study. No participants were recruited via using this method, so in addition to this recruitment technique, I employed a snowball sampling technique by recruiting participants through my existing social connections.

In completing work for this study, I employed semi-structured interviews with five participants who have brain injuries. I utilized criterion sampling to recruit participants. "Criterion sampling is a kind of purposeful sampling of cases on preconceived criteria" (Sandelowski, 2000, p. 248). With criterion sampling, cases can be chosen because they are thought to be representative of a population or may represent extreme cases. For inclusion in this study, participants had to meet three criteria; they had to identify as female, be a student enrolled in postsecondary education and have acquired their brain injury over a year ago. These criteria speak to the focus of this study on female university students and also seek to ensure that the participant is not harmed by partaking in the study due to not having adequate time to cope with the implications of their injury. A brief overview of some demographic details is useful when considering the narratives of participants in this study.

Name	Approximate Time Elapsed Since Acquiring Brain Injury	Postsecondary Study
Jolene	1 year	Graduate- attempted, on leave due to injuries now
Francine	8 years	Undergraduate-completed and enrolled in another program
Lisa	6 years	Undergraduate
Adele	3 years	Graduate
Louise	7 years	Undergraduate- completed and enrolled in another program
Researcher	8 years	Graduate

Although Jolene did not meet the criteria for inclusion in my study in terms of the number of years that had passed since acquiring her injury, she came to learn about the study and was eager to participate. After critically considering the benefits and risk to including her in the study, I determined that her input was valuable and not including her in the study would result in more harm than that could possibly be attained by participating. If Jolene were not included in this study, she would miss out on the opportunity to connect with the researcher who has shared her experience with brain injury and Jolene's voice would not have been heard. The mean age of participants was 24 with ages ranging from 20 to 26

years old.

Data Collection

Interviewing. I included the voices of five participants, as well as my own autoethnographic account, in this study. Prior to beginning our interview, I provided participants with a storyboard (see Appendix A) to give a general idea of what information I was looking to glean. I asked semi-structured interview questions to participants (see Appendix B). I believe that the number of students enrolled in postsecondary education who have acquired brain injuries and identify with this label, particularly in the Halifax region of Nova Scotia, is relatively low.

Pre-participation interview. At the first contact with potential participants, I presented them with information about the research, for their review (see Appendix C). Time was allotted for the potential participant to consider the risks and benefits of participation in this study before they were contacted again. Two days for consideration occurred in one case, due to the participant being scheduled to leave the area shortly after she found out about the study. In each of the other cases, one week was given for consideration of participation in this study. The interview process in the aforementioned case was hurried as she noted that she really wished to participate prior to leaving the area. In the second point of contact, which occurred via telephone call, space was provided for participants to consider whether they wanted to participate. I asked each participant whether they had any questions about the study or about my experience and this tended to evoke some brief discussion about my personal history. I asked each participant how long they had been dealing with the implications of brain injury, checking out my establish criterion of six months post injury, and this lead to some brief discussion about the use of accommodations and struggles with being a student. Following this, I

inquired if the potential participant would like to participate in this study and then arranged a time for the first interview.

Main interview. All interviews were conducted in the spring of 2012. The interviews were completed at a location at the campus where the research participant studies or an alternate location of the participants' choice. Two participants elected to conduct the interview on their university campus, while the other three participants met with me at more preferable locations for them. Participants were presented with a consent form (see Appendix D) with information about the study. The consent form was read and explained to each potential participant. They were then asked to sign as verification of consent for their participation in this study, which included being interviewed, contacted for a follow-up interview, audio-taping of the interview, and quotations from the interview being used in the final research and dissemination. The interviews sought thick description of individual experiences so 2.5 hours were allotted for the process to occur, although no interview lasted that long.

Participant	Length of Interview
Lisa	1 hour, 4 minutes, 11 seconds
Francine	37 minutes, 1 second
Louise	35 minutes, 5 seconds
Jolene	1 hour, 34 minutes, 21 seconds
Adele	1 hour, 16 seconds
Total Interview Time	4 hours, 46 minutes, 54 seconds
Mean Interview Time	57 minutes, 24 seconds

A digital audio recording device was used to record the interviews and hand written notes also accompanied the audio recording. I was cognizant of the potentially emotional nature of the stories I was asking participants to tell. Jolene, for example, became visibly upset and was crying while telling her story during our interview, so I had tissue readily available for her and offered support. Through the telling of my own story I know how difficult it can be to recall events, emotions and thoughts so I was cognizant that participants might also encounter this challenge. Each participant displayed different needs and I was attentive to these during interactions with each individual student. The length of time varied between participants, with some people going into more detail than others. I provided ample time for participants to tell their stories, leaving space open for them to expand, but also respecting that some participants could tell me their entire story in a shorter length of time than others. Throughout the interview process, I was cognizant of adhering to the predetermined structure of the interviews, while also permitting a critical lens and preliminary considerations to inform probing questions.

Debriefing

After the primary interview was completed, participants were presented with a debriefing sheet with resources they may wish to contact, including contact information for the Brain Injury Association of Nova Scotia, Postsecondary Disability Services and the counselling centre at their respective university. I contacted each of these agencies prior to beginning interviews to assure that they would accept participants' requests for assistance, if needed, subsequent to our interviews. I transcribed the interviews myself as soon as possible following the interviews, so that any written notes about verbal cues, along with my memory of the interview, were included in the data. Narrative methodology encompasses a postmodern view that holds that realities are socially

constructed, constituted through language, organized and maintained through narratives and that no essential truths exist (Freedman & Combs, 1996). A narrative and social constructionist perspective consists of a constantly evolving set of questions concerned with the analysis of data, including concern over whether meaning or “facts” are being focused on and staying away from “expert” hypotheses or theories (Freedman & Combs, 1996). I think that this description adequately describes my concerns and attention during the interviews conducted for this study.

Transcription

From a narrative perspective, transcripts in this study were closely and repeatedly read to get intimately familiar with the content. Electing to transcribe data personally relates to upholding the proponents of narrative methodology. Transcribing was a process of becoming intimately familiar with the data and the same connection with participants’ stories would be compromised by having an outside person, who was not personally involved with the entire study, transcribe the interviews. Riessman (2002) said that the transcription process should include “close and repeated listenings, coupled with methodical transcribing” (p. 253) to capture tone and pitch changes in vocal presentation. The rigorous consideration of each interview, coupled with transcript verification where participants reviewed written accounts of the interviews, adhered to Riessman’s (2002) notations about the attention that should be paid to recorded interviews. Notes in the margins also served to remind me of initial thoughts when the data was considered and then revisited after reading other transcripts. Aspects of the story that might be missed with one reading of the transcript, might be picked up with subsequent reads (Riessman, 2002).

Transcript verification is another process included in my study and this involved

setting up follow up meetings with the research participants so that they could ensure that I captured the information they provided in an accurate manner. Depending upon personal preferences and realities, such as time constraints and school work commitments, meetings to discuss transcript verification took place two days following the interview or up to three weeks later. These meetings occurred in person and lasted an average of 30 minutes. According to Atkinson (1998), “both the interview and the person telling their own story are involved in meaning-making work, which turns the interview into an active process that is unavoidably collaborative” (p. 40). The danger associated with this is that the researcher could come to believe that they understand what the research participant is alluding to, without them actually speaking the words. I believe that because shared experiences exist and no deception about this fact occurred, research participants may have made assumptions that their point was clear and that I understood what they were saying, without them actually vocalizing their point. I tried to avoid making assumptions by asking clarifying questions. Transcript verification processes allowed for miscommunications or other concerns that participants had about the data they provided to be identified and corrected.

Narrative Analysis

Data analysis was a thought-provoking process for me and I feel I gained new perspectives on the struggles and rewards of dealing with brain injury in university. It was nevertheless emotionally tolling to hear about ongoing struggles that I could offer my perspective and opinion on, but was powerless to make changes in. The shared experiences between myself as a researcher and participants was a salient characteristic of the interviews for me, and this meant that ample attention had to be paid to the interview process and aims of this study (Clandinin & Connelly, 2000). The semi-structured nature

of the interview guide meant that each interview followed a different discourse and this predetermined the intimate attention that was paid to each transcript during the analysis phase. Utilizing a narrative methodology and a semi-structured interview guide also speaks to the challenges students with brain injuries may face. From considering my personal experiences as well as existing literature, the challenges brain injury often presents involve impediments to writing and expression. Providing flexibility in terms of story-telling and considering oral presentations speaks to the population being explored in this study.

The process of analysis involved much revisiting of transcripts and the process of formulating comprehensive categories of thought in relation to the data was ongoing throughout the writing process. Color-coding was utilized to categorize themes for discussion in the analysis chapter. When common themes or stark disparities in experiences were noted, transcripts were re-considered to formulate analysis of this content. When the women interviewed for this study did not choose to elaborate on experiences or where thoughts were not completed, the analytical process used in this study lead to questioning why this was so. The transcript verification process also formalized participant analysis of their own words and was vital in combating misunderstandings that could have arisen from my interpretation of participant stories (Beverley, 2000; Tierney, 2000). Transcript verification was especially salient given the shared nature of the overall experience of brain injury in conjunction with the vastly diverse effects that this injury could have.

Ethical Issues

The shared experience between participants and I was a key feature of this study for both myself as a researcher and participants. While no participant identified an ethical

dilemma related to participating in this study, I was cognizant of how knowing that I had experienced a brain injury might impact the participant and I was prepared for this to present ethical challenges related to differing perspectives on (dis)Ability and how this impacts the educational process. As the researcher, I played a significant role in the interviewing process, by using my own experiences of both acquiring a brain injury and navigating postsecondary education with this injury, using self-disclosure to empathize and join with participants, and weaving researcher's reflections throughout the my writing to stay grounded and connected to the study (Ellis & Bochner, 1999).

“Researchers do not exist in isolation... when we conduct and write research, we implicate others in our work” (Ellis et al., 2011, p. 8). In sharing my personal experiences, I put much thought into how this would impact those who read my study and also how my lived experiences impact the research process itself and my interviews with participants. The impact that brain injury has on one's life can often be traumatic and emotional, so the benefit in provoking these thoughts needs to be considered. The contribution to knowledge or improved services is a motivating factor for some people to participate in research, however the risks versus the benefits of participating in research for each individual must be acknowledged (Padgett, 2004). Participants should have a clear understanding of what they are being asked to discuss. What will be done with the information provided was discussed prior to beginning the interview process. The aims of the research and debriefing matters were also acknowledged.

In considering the shared experiences of acquired brain injury between the study participants and myself as the researcher, the concept of dual relationships was significant. The study subjects were engaged in postsecondary education, as I was, and all participants were around the same age range as me. We bonded over shared experiences

and being at similar points in our lives. I also had pre-existing relationships with all participants except Lisa and this had to be considered in terms of the effect of these relationships upon the research process and data that emerged from this. In building rapport with participants and engaging in self-disclosure, blurred relationships can result and cause misunderstandings, particularly for when the research has been completed and expectations of continued support might result (Padgett, 2004). It was therefore vital that I worked to ensure that I gained the trust of study participants so that they felt comfortable in sharing their experiences with me and they did not feel as if participating would harm them. Gaining participants' trust was accomplished by offering resources for support for them related to issues discussed. Further, I utilized the counselling skills that I have acquired throughout my social work education to provide verbal and non-verbal cues of support. While I wanted to ensure that participants felt comfortable sharing their experiences with me, my role as a researcher and not a therapist had to be asserted. One goal of the research process was establishing working relationships where the boundaries and limitations of my relationship with participants were clear. In an introductory letter, I discussed debriefing procedures so that participants were aware of the expected outcomes of the study.

Limitations

One limitation of this study is its lack of diversity in terms of participant pool. The study did not explore the intersection of (dis)Ability with other social constructs such as race, age, sexual orientation, or class (Stienstra, 2012). Although this is recognized as a much needed area of scholarship, my participant pool did not allow for reference of this. The focus of (dis)Ability research has been on providing improved culturally competent services rather than looking at the root causes of inequalities in the first place (Stienstra,

2012). The intersection of other social constructs might lead to different results as well and is a drawback of this research.

Another limitation of this research is the stories that were not told by participants in the interviews, such as encounters that they did not expand upon or topics that were not discussed. Some of these have emerged through the analysis of the interviews.

Participants sometimes touched on stories but even when I tried to extrapolate more information, I could not get enough information to bring the stories into the analysis or findings of this research. A tension existed in this research process of asking semi-structured questions but not wanting to push “too much” or invade participants’ privacy. By pushing participants to expand on their stories beyond their comfort level would have created an ethical dilemma and may have resulted in harm to participants.

A constraint of this form of recruiting participants is that those people who are not registered with the (dis)Ability resource centre at their university, or who perhaps do not consider their injury to have resulted in (dis)Ability or do not associate with the label of brain injury, are excluded from the study. With this in mind, I was aware that I might not reach as many participants as I desired. Another limitation to my study is that I did not have the ability to travel outside bus limitations within the Halifax Regional Municipality, so the area where interviews were conducted was constrained by this reality.

A common critique of the narrative process is its lack of generalizability. Findings presented in a narrative format are said to be case studies and while they cannot be generalized, they can provide knowledge that may be useful to other people dealing with similar issues or aspects of issues in the personal narrative (Faulkner & Faulkner, 2009). Certain aspects of one’s personal story, therefore, may be similar to that of another person who hears the story. The sharing of information can lead to enlightenment and more

useful way of approaching barriers that result from acquiring brain injury. When stories are considered in terms of the elements that compose them, similarities and relatable situations emerge that can indeed be helpful for a wide range of people dealing with the implications of acquired brain injury.

One critique of the narrative method that is offered is related to the telling of stories that come to be understood as absolute truth. The social conditions that prompt narratives and the form the narratives take are themselves often revealing (Bryman et al., 2009). As Brown (2007, p. 178) notes, “suppressed... or subjugated stories are not inherently more true than those that reflect dominant knowledge.” With this in mind, it was vital to remain reflexive while engaged with participants’ stories during the interview process as this led to some prompting and follow up questions that were revealing. Brown notes that the authority provided to first voice accounts is often seen as forbidding the challenging of these stories (2007). It seems, then, that a fine balance must be struck between upholding the value of the perspectives of people whose lived experience is vital to the study at hand and the constant questioning stance that is characteristic of the social work profession.

The critique of the narrative method, as outlined above, seems to relate well to postmodern views of reality. Postmodernity holds that “there are limits on the ability of human beings to measure and describe the universe” (Freedman & Combs, 1996, p. 21). A postmodern view of reality also holds that power, knowledge and “truth” are negotiated in societal institutions (Freedman & Combs, 1996, p. 22). The postmodern view of reality relates to the reflexive understanding of participants’ views and what is true for them and the necessity of the researcher constantly questioning what they come to understand as truth.

Chapter Four: Storied Lives

In keeping with narrative methodology, the storied lives of participants are meaningful beginnings to understanding their experiences within postsecondary education as students with an acquired brain injury. Variability in the lives of students with brain injury in postsecondary education shape how they experience their brain injury and, in turn, this has an impact on their postsecondary educational journey. The following short stories provide a foundation for understanding these experiences and should be kept in mind as the findings of this study are considered.

Francine

Francine has experienced brain injuries at various times throughout the past eight years, having acquired concussions when she was in grade nine, grade eleven, in her third year of university and most recently, in her fourth year of university. Francine has been an avid basketball player for this period and the roughness of the sport has lead to her multiple brain injuries. She focused on her last concussion in our interview, saying that this occurred at an unfortunate time because it was in the middle of the basketball season and it sidelined her for a month. Acquiring this injury had negative implications in terms of her athletic career. Francine said, “I was not able to practice or even be in the gym because the sound of the basketballs [bouncing on the gym floor] would give me a headache” Francine said she worries about the cumulative effect of concussions. She said she is supposed to play basketball at her new school when she begins there, but she is unsure of whether she will do this or not. Francine’s acquired brain injury affects her emotionally. For example, she is hesitant to play basketball due to acquiring a number of concussions through play.

It was nearing the end of the academic term and final papers and examinations were soon due, when Francine acquired her most recent concussion. Francine felt she could “not really put [her] full 100% effort” into assignments due to the effects of her injury. Extensions for papers and extra time for exam writing were accommodations that she truly needed. Francine was able to attain these accommodations through the (dis)Ability resource centre at her university. She found these accommodations to be extremely helpful as they helped compensate for the impact of her injury and thus made a difference in terms of her marks. At the time of our interview, Francine had just completed all requirements for her first undergraduate degree and was preparing to begin a second undergraduate degree.

Adele

Adele acquired a concussion while playing recreational rugby approximately three years ago, when she was completing her second undergraduate degree. The implications of what she called “the big concussion” have affected her significantly. Adele also suspects that she has had smaller concussions throughout the years that did not affect her in the same way as this most recent concussion. “The big concussion”, as she called it, occurred in May, which gave Adele several months to deal with the side effects prior to returning to her academic study at university in September. Acquiring a brain injury impacted Adele’s emotional health insofar as her friendships and social life were intimately connected to participation in rugby and she felt unable to partake in this following her injury.

At the time of her injury, Adele had several years in postsecondary education already completed. While she was aware of supports for students with (dis)Abilities, she did not utilize these services. Adele said, “I felt like I needed to figure out what I could do

and then make strategies because if this was something that I was going to have, I needed to figure out ways around it.” Adele also felt she had the support of her classmates and professors so if she was struggling she could go and talk to them. Adele adopted a positive attitude following her brain injury “...I knew it was such... a small thing, like I knew I may not get the grades I want to but I knew I’d still get through.” At the time of our interview, Adele had previously completed two undergraduate degrees and had just finished all the requirements for her masters degree.

Louise

Louise attained her brain injury seven years ago when she was horseback riding. She fell off the horse that then got spooked and kicked her. Louise felt there was not a lot of awareness about brain injury in the general public when she acquired her injury. Louise now believed that awareness about brain injury has increased and said, “now... everyone is getting concussions and there’s concussion awareness all over the place so everyone is a little more aware of it.” Aside from being in hospital for a month, Louise also went to a rehabilitation centre for a month, although she initially believed she did not require rehabilitative therapy. It was not until she researched her injury on her own and spoke with family members that she truly understood the seriousness of her injury and how this would impact her recovery.

Louise had completed a year of an undergraduate degree prior to acquiring her brain injury. After taking a year off from university following her injury, she began a different undergraduate degree at a university closer to where her family lives. Some credits from her previous coursework were transferred to meet her new degree requirements. Despite the transferred credits, Louise repeated some courses and she said that she was glad to have done this because she felt she would not have remembered the

material otherwise. Some of the material she learned before her brain injury was foundational and Louise believed she would have struggled with future courses had she not repeated the foundational material. Louise began by taking three courses, which went well. However, when she increased her courses to five she ran into difficulty. Louise reached out to the (dis)Ability resource centre and by eliciting their help she was able to successfully complete her courses. At the time of our interview, Louise had recently finished her undergraduate degree and was enrolled in a diploma program that teaches practical application of the theory she had learned in her undergraduate degree.

Jolene

Jolene acquired her brain injury only a year prior to our interview and she was still in the midst of negotiating the challenges her injury presented to learning. Jolene's brain injury occurred because of a chance mishap where an object struck her on the head and this incident was unavoidable. Jolene's unexpected concussion occurred only days before she was set to begin her masters degree. Prior to this education, Jolene had obtained two undergraduate degrees.

Jolene's acquired brain injury has impacted her educational experience dramatically. While she was on-track to commence full-time studies in her masters degree, after understanding how her injury would impact her learning, she reduced her course load to part-time. Reducing her course load was not sufficient. Jolene was ultimately forced through her embodied experience of her injury to declare medical leave from school. She became overwhelmed by the challenges she was encountering, and thought that she had little choice. At the time of our interview, Jolene had coursework outstanding but was unable to complete this work due to the consequences of her brain injury. Further, she did not know when these symptoms would subside. Jolene had

encountered many barriers established by the existing policies of educational funders.

Although the impact of her brain injury upon her ability to learn and work was noticeable, she did not seem to “fit” into a category and was extremely frustrated that no student loan assistance could be provided to her.

Lisa

Lisa acquired her brain injury approximately six years prior to our interview, and in total she has suffered between seven or nine concussions. These stemmed from blows to the head while playing soccer when she was a high school student. The symptoms of Lisa’s concussions were slow to present following the onset of the brain injuries. The most significant symptoms emanated from sustaining four concussions in a six-week period. Playing soccer was a meaningful part of her identity and ultimately, Lisa had to stop playing and subsequently has excelled in other sports requiring less contact. Lisa’s brain injury significantly impacted her learning in high school and she needed to take an extra year to complete grade twelve. After beginning university and completing her first year, Lisa took a year off before returning for the current academic year, which was coming to an end at the time of our interview. Lisa plans to continue her education at the master level after completing her undergraduate degree.

Lisa recently achieved grades that were the highest they have been since her injury. She credited this success to the help she received from the (dis)Ability resource centre at her university. Additionally, she said, “...I’m kind of learning what’s working for me I guess but at the same time there’s still so much to work on.” Lisa utilizes a combination of formal supports provided by the (dis)Ability resource centre and informal methods that she had devised herself to meet her unique learning needs.

The common denominator for these female students is that they have all acquired a brain injury. Their stories are different, yet they share common elements within their experiences. Each participant provided a unique perspective that is significant in coming to understand their lived experience through (dis)Ability and how we might improve access to postsecondary education for students with acquired brain injuries. We can learn from their successes and struggles and utilize this foundational understanding to improve upon services when working with future students. Assisting others in the telling of their life stories, or a segment of their life story in this case, “guides them to a deeper understanding of their own lives” (Atkinson, 1998, p. 22).

Chapter Five: Analysis of Participant's Narratives

Introduction

Within this study, I interviewed female students in postsecondary education who had acquired brain injuries to investigate their experience. Engaging in semi-structured interviews was a useful process that met the purpose of this study. The following findings were derived from conducting these semi-structured interviews and considering the resulting transcripts. A narrative analysis of semi-structured interviews occurred and the method of extracting common themes in interviews lead to the findings below. Themes emerged in what each participant discussed and these, along with stark contrasts and unique perspectives, allowed me to critically consider the experience of female students in postsecondary education who are living with a brain injury.

In divulging my own experience in this study, and seeking to explore the experiences of others, I believe both personal empowerment and the empowerment of research participants resulted. When participants provided their perspectives and shared their voices to be heard, I believe this was empowering for them. While engaging with participants and the narratives they told, I kept in mind the notion that knowledge is never only innocent and power is never just constraining (Brown, 2007). Brown's (2007) understanding allowed me to consider participants' stories from a critical perspective and pushed me to ask additional questions that evoked rich detail in their narratives, such as when Lisa talked about not being able to excel and "pull off" honours-level grades and I asked whether this was related to a feeling of not knowing or not having control over her academic success. While this conceptualization of knowledge is discussed by Brown (2007) in relation to therapist-service user relationships, I feel the similar dynamics played out in the interviewing process and instead of adopting an "all-knowing"

stance, a “partial knowing” standpoint was effective in gaining knowledge from participants’ stories, challenging oppressive social discourses and deconstructing negative identity conclusions (Brown, 2007). A partial-knowing stance is taken with the realization that my experience and viewpoint impacted the interviews conducted, but in a clear and known manner. In the consent form for participating in this study, I state that I have personal experience with acquiring a brain injury and negotiating a university education, indicating to participants that I have personal experience related to the research.

Theoretical understandings, such as those identified above, also influence the interviews I have conducted and it is my hope that this occurred in a way that was empowering for participants and did not have a negative influence on their involvement with the interview process. In conversation with participants, I conveyed interest and curiosity related to their individual experiences and the questions I asked aside from the semi-structured interview guide, varied depending on the narratives participants told about their experiences. Utilizing a narrative approach allows participants to deconstruct and reconstruct their own life stories, and thereby to empower themselves (Kelley, 1995). While my experiences and ideological positioning are bound to have an influence on the study, all findings are anchored in (dis)Ability theory. Further, safeguards to my personal lenses to the study are applied in a particular manner that is discussed in greater detail in the methodology chapter of this document.

Participants interviewed for this study displayed a variety of outlooks to the experience of acquiring a brain injury. The literature on acquired brain injuries highlights both negative implications of living with this (dis)Ability (Mukherjee, Reis & Heller, 2003; Simpson, Simons & McFadyen, 2002), and positive life changes resulting from coping with their injury (Jaquinta, 2007; Lorenz, 2010). Participants in this study shared

what life has been like for them in living with an acquired brain injury. The following sub-sections are key themes that emanated from the storied experiences of the study participants. Educational models participants encountered are first discussed and the helpful and unhelpful aspects of these are highlighted. The supports female students with brain injury experience are discussed next. Individual strategies and coping mechanisms are discussed, along with support provided by family and friends for individuals dealing with acquired brain injuries. Support related to academic experiences, including assistance provided by professors, (dis)Ability resource centres and encounters with existing policies and procedures related to (dis)Ability resources are discussed. Barriers encountered by students with acquired brain injuries, including experiences related to individual circumstances and expectations of self, are discussed. Barriers related to the role of family and friends in the lives of individuals with acquired brain injuries are discussed next. Barriers encountered in the academic sphere, including involvement with individual professors, medical professionals, (dis)Ability resource centres, issues related to memory, (dis)Ability-related policies and procedures and problems with memory are discussed. The obstacles presented by stigma and ignorance about acquired brain injuries and the impact of this upon one's life is discussed, along with discourses around asking for help, being seen as "complaining" and socio-political beliefs related to this. Throughout the findings, new knowledge provided by considering participants' narratives are highlighted and these contribute to the make-up of the following chapter, which presents recommendations for social work practice with students who have acquired a brain injury.

Gender

Participants in this study spoke about the impact of gender upon their experience of acquiring a brain injury. Being female has affected participant's understanding of their brain injury, and the role of family members who act as caretakers. While literature has communicated the gendered version of caregiving that often exists, with the bulk of caregiving responsibility falling upon the shoulders of women, this study suggests a deeper entrenchment of the role of gender in the lives of people with acquired brain injuries. Lisa spoke about the support her mother provided her from the time she began to experience the consequences of brain injury and throughout her educational journey. She talks about her father and how he was not supportive and she mentions that she no longer speaks with him. Adele notes that her mother was there for her consistently in the days after acquiring her brain injury, often checking in with her every few hours, even throughout the night, to make sure she was "ok". Adele's experience speaks to the role of females in providing emotional support in addition to traditional caregiving roles. The emotional support offered by females also could indicate a lack of communication or feeling unable to communicate personal experiences with male caretakers.

Learning Strategies and Methods

Helpful Learning Strategies and Methods

Participants spoke about educational models that have been useful in dealing with the implications of brain injury in postsecondary education. For Louise, repetition aided her rehabilitation and healing with brain injury as well. Re-taking courses that she had already completed prior to her injury was beneficial, as discussed previously. The negative consequence of this was that it left her with a feeling of being "behind" other

people who did not have to re-take courses. Despite this, Louise was grateful that she made the decision to repeat courses, and feels this is beneficial in her long-term academic success. Not all accommodations come from the University (dis)Ability Resource Centre, students with (dis)Abilities can forge their own accommodations by speaking directly with professors, by eliciting support from other professionals such as doctors, or find their own way of working, as in Louise retaking courses to condition her brain in remembering significant concepts for the courses ahead of her. “Faculty, staff and students need to embrace a critical disability lens to accommodation whereby the inability or un-willingness to accommodate is recognized as an oppressive act.” (Dunn et al., 2006). Creative strategies that go beyond traditional accommodations to meet the needs of students with brain injury are needed in postsecondary institutions.

Researcher’s Reflections

Despite the memory prompts discussed previously, testing has been an ongoing challenge for me, although one that I regularly practice in the hope of improving. I recall taking formal memory tests when I was a patient at a Rehabilitation Centre following my acquisition of a brain injury. This was part of my Occupational Therapy, as my occupation at the time, as a 16-year-old youth, was to go to school. Following my stay at the Rehabilitation Centre and continuing to this day, testing my memory, as been an ongoing part of my therapy and everyday routine. In my first formal evaluation upon my return to high school, following my brain injury, I felt the need to prove my competency and dedication, and studied profusely for several days before the test. I can recall the feeling of knowing that I had studied all necessary material for the short definition-based quiz that consisted of approximately ten definitions. During the examination, however, I

was unable to recall one definition. I knew I had learned the definition and I could even recall where it was situated on the page I was studying, but I was unable to locate the words that was hidden somewhere in my memory. This left me feeling frustrated yet determined to regain the memory I had prior to the accident.

Louise also developed methods to account for the difficulties she experienced in following step-by-step instructions, as this impediment had a profound impact on her learning. Once Louise was aware of the problems she experienced in following step-by-step instructions, she decided to address this issue. Louise said, "...because I was aware of it... I could kind of come up with my own little solutions just like you know, like every time I came to directions I was [like]... 'ok I gotta read these good'". Louise said that she brought this difficulty to the attention of Occupational Therapists she was working with, but when they were unable to come up with solutions that were beneficial for her, she decided to come up with her own solutions. Similarly, Jolene had an experience with Occupational Therapists that was not helpful, as she was hopeful that they could provide her with strategies to improve her learning ability, but felt that the options they presented were "band-aid" solutions, which did not meet Jolene's unique requirements. When she conveyed this to them they put it back on her to research some ideas. Jolene describes the strategies presented by Occupational Therapists saying, "you work for the people you work for, but for the people you don't work for, you're useless."

Having the opportunity to speak to a professional with authority, such as a doctor, seems to be a positive strategy for Adele in the aftermath of her brain injury. Adele, who has not utilized services of the (dis)Ability Resource Centre on her campus, says that her brain injury has affected her speech insofar as she tends to stutter, have aphasia in terms

of forgetting words or spoonisms, where she combines two words that mean the same thing. Adele was concerned at first, but now realizes her difficulties with speech only minimally affect her life. Adele has learned to see the humor when her brain injury affects her speech.

Unhelpful Learning Strategies and Methods

Lisa spoke about her frustration with different formats of evaluations utilized in learning environments. For Lisa, comparing definitions and fill-in-the-blank without word options were difficult for her because she is unable to “pull the word out of thin air.” Multiple choice questions, short answer and fill-in-the-blank questions with several word options are evaluation formats that Lisa works well with. Learning what worked for her was a trial and error experience: an experience marked by successes and failures until she came to understand how her brain injury affects her performance. Chouinard (2008), a (dis)abled feminist scholar, notes that the struggle for accommodations in the academic sphere can seem overwhelming and unending, and this can be daunting and dispiriting for some. The effort expended in determining educational accommodations, and navigating the systems, that may deny these accommodations due to lack of proof or uneducated service providers, can be disheartening.

Francine experienced difficulties with writing papers, expanding upon her thoughts and reading and writing longer pieces of material, because of her brain injury. She said, “for my 20 page paper, I had over 25 sources and one of them, I read a whole book, like for the... paper... it’s really hard cause articles these days are like, what, 30 pages? Maybe longer. And you can’t really skim” Lisa expressed difficulty with expanding on her thoughts as well. She talked about filing in forms and how she often

does not know how much detail to include, saying, “I’ll just give one word answers really well and I know you’re not supposed to do that on forms and I’ll be like... I don’t know how to word this.” She went on to say that sentence structure and getting thoughts out in an organized manner are things that she struggles with in other situations as well, particularly when it comes to writing examinations. Organization of thoughts in written format and comprehension of longer written material is something that participants expressed having difficulty with, however no formal accommodations were discussed in relation to this difficulty.

Researcher’s Reflections

I have also experienced difficulties with expanding my thoughts and focusing on reading and writing longer papers. In the journal I began to write in shortly after acquiring my brain injury, the sentences are often short and concise, with topics being raised sporadically and then re-visited in future sentences. I feel as if my difficulties in this area were emphasized by my awareness that this was now a challenging task for me. As I have mentioned previously, I found history class particularly challenging and I now ponder whether this is because I found the material difficult to relate to my own life. This may have presented challenges in expanding upon the concepts I have learned. While the strategy of remembering key concepts by memorizing the first letter of key words, as discussed previously, was a useful method in completing my history course, this did not come naturally to me even after much practice and I continued to struggle. Currently, with writing, I find myself being perhaps over-aware of the need to expand and this has often resulted in non-comprehensible sentences. This is something that I have realized on occasions before, but it has been especially highlighted through writing this thesis. The

importance of editing has been highlighted through reviewing my written academic material.

Louise said her struggle with academia post-brain injury has been related to theoretical requirements. Having completed her Bachelor of Science degree, she is enrolled in a more “hands-on” program to complement this credit. Louise noted that she believes this will be more suited to her individual strengths. I postulate whether Louise will experience difficulties coping with a changed academic environment and different program expectations. Transitional supports have been found to be vital in the success of students with (dis)Abilities that affect their learning, such as brain injury (Nicholson, 2008). Jolene talked about difficulty adapting to changed online learning systems within her program. While she acknowledged that the changes may have been subtle from the perspective of others, she found these differences profound and this is something that those working and studying with her did not understand until she brought this to their attention.

Supports

Individual Supports

Adele noted that going to see a “sports doctor” who, when he came to understand Adele’s specific circumstances, advocated on her behalf was a beneficial experience. Adele said this doctor believed she should take a leave from work and the gym. The doctor advocated that her gym membership fees be waived and also liaised with supervisors at her place of employment. These accommodations were particular to Adele’s life and, although a medical professional supported them, they were not

legislated. The ability to explain brain injury to others was an area that many described in their interview. Speaking about the experience of acquiring a brain injury with others connects with the importance of disclosure of my own injury to study participants. I was able to establish rapport with the participants by appropriately using self-disclosure of my own experiences of living with an acquired brain injury. Participants did not have to explain or justify their feelings or thoughts, as they knew I have first hand experience with living with a brain injury. Self-disclosure with attention paid to why one is disclosing, has been a meaningful lesson in my social work education (Lin Haag, 2009). In these interviews, self- disclosure was an appropriate and vital process. When I offered my opinion that each brain injury is different, Jolene noted, “Yeah. Everyone experiences it differently but you know... we’ve just realized... a lot of things that I’ve said to you, you’re like, ‘oh ok yeah I kind of understand how that would go and how you could feel that way.’” Jolene vocalized the experience that I had throughout conducting interviews, which was the sense of community with participants. In considering my interview with Lisa, at many points throughout the process, she asked, “I don’t know if this is something you experienced?” and I believe that realizing someone else shares some of her experiences provided Lisa with validation that she does not struggle in solitude. The difference between Lisa, being at an earlier stage in her postsecondary career, and Adele, who has many years of university education completed, was suggestive of confidence in ability. Lisa has been dealing with struggles due to brain injury at a much earlier time in her university career than other participants. Being involved in this study, the fact that a graduate student, such as myself, is wanting to know about students with acquired brain injuries experiences within postsecondary education, has assured her that this is a topic of concern. In providing support for individuals with acquired brain injuries, recognition of

the unique nature of this injury, along with recognition of the value of community support from others who have experienced brain injury, is important.

Researcher's Reflections

Lisa's sense of solidarity in her experiences is one that I felt for many years, but I no longer feel this way. Having acquired my brain injury, and completed university in the same small community, I felt that no other people shared my experiences. This was certainly true at the time of my injury, but I have since met others, both within and outside this small community, that I can relate to on this level. I have also been involved in learning about different (dis)Abilities through education, work and volunteer activities and this has been beneficial to my healing process. I have learned that there are similarities between people who have different (dis)Abilities and also between those who have (dis)Abilities and those who do not. The ability of some people, who have not acquired a brain injury, to understand my experiences is surprising to me but offers hope that people in positions of power, who do not have an ABI, may be able to understand the experience. As Jolene noted, however, this is not often the case and the consequences of people in positions of power making critical decisions for people with brain injuries, can negatively impact recovery and coping mechanisms.

Experiencing a brain injury can enhance one's ability to perform specific jobs. Ellis and Bochner (2000) advocate for utilizing negative experiences to contribute to meaningful activities. Adele, for instance, said that she has utilized her experience with ABI to educate young players on the rugby team she coaches and warn them of the potential repercussions of brain injury. In Adele's case, experiencing a brain injury has

enhanced her knowledge of sports-related injuries and has increased her expertise in coaching.

Researcher's Reflections

Where I did not utilize available accommodations in the academic sphere, I similarly have not asked for them in employment settings. I think that not asking for accommodations in the work place occurred for similar reasons that no accommodations were asked for in the academic sphere. Memory has been my biggest obstacle following my brain injury and rather than asking for accommodations related to this, I have approached work environments as a test to my memory. While I think that this constant testing has contributed to improving my memory, it has failed me on several occasions and this could have resulted in negative implications for clients. Not disclosing about my brain injury may have contributed to an unawareness of the part of many employers, that I even had an ABI. While I did disclose my ABI to some employers, the response that I received was positive. My employment experience after acquiring a brain injury has been mostly social service related, and this may have contributed to employers having some background information about my injury and could have lead to the positivity I experienced. In my non-social service work, I worked under the direction of a family member who had an intimate knowledge of my limitations. I have had one negative work experience where I was employed at a retail outlet and my manager was unaware that I had a brain injury. This largely lead to a negative work environment and increased stress upon me. I became unable to handle working while also being a full-time student and eventually had to resign.

A positive aspect of being a student with an ABI that Lisa noted was her ability to remain optimistic and think critically. Positive self-esteem and conceptions of self-worth are associated with individual's belief that there is value attached to their life and they are capable and successful (Smith, 2007). Smith (2007) talks about the influence of completing creative projects and how this is associated with positive feelings for people who have had head injuries and are in the rehabilitative stage. These positive feelings associated with completing creative projects may include completing university credits and having an optimistic outlook on life, as one study participant conveyed. Lisa said, "...one of my good...friends, he's like, 'I complain about stuff but you actually have stuff to deal with.' Yeah... I have food to eat; I have a roof over my head... I don't really have anything to complain about in my life either." Lisa also noted that a 'pet peeve' of hers was when her friends complain about tests in which they have received respectable grades. Her friends' notion of high marks in relation to the effort expended differs from Lisa's own marks in relation to effort put forth. The realization that learning styles change from acquiring a brain injury and more effort is required to achieve the grades was something that Louise identified as well. Louise said that she initially took three university courses following her ABI and she found this manageable, but when she added two more courses to her workload, she found completing the work to be difficult. Louise discovered repeating classes she had already taken was beneficial. Being exposed to curriculum a second time around, as in repeating or auditing a course, seems to work for students with ABI. According to Iaquina (2007), a positive correlation exists between time passed and quality of life; the more time that has past since injury the more positive one's quality of life. Jolene has had the least amount of time that has passed since

acquiring her brain injury, while Lisa has been dealing with the implications of her brain injury for many years.

Researcher's Reflections

I have not been required to repeat courses or deal with any of the financial implications, due to the timing of my injury. I acquired a brain injury while I was still in high school, so while it was a struggle to complete high school, I did so with much support from family and others in my life. Due to taking advanced courses prior to my ABI, I was able to finish high school taking easier courses. For those courses that I did struggle with after my injury, I had tutoring support from a neighbor. However, I have found repetition to be a valuable study method, as this leads to the material being retained in my memory. Once I discovered the method of repetition as a learning tool that worked for me, I incorporated this into each of my courses, as well as in other areas of my life. I strive to over-achieve in many areas of my life because “you never know what could happen.” The experience of not remembering anything about my life prior to the accident is fresh in my mind in this way. Repetition allows me to have a sense of control over current circumstances in my life, while also preparing for negative situations that might arise in the future.

Lisa said that she works harder now that she has a brain injury than she ever used to prior to her injury, and that some days she just doesn't want to do this anymore. Lisa also noted that her mom urges her to seek support when she needs it, but that she has often felt accommodations she may obtain are unfair. Feeling that accommodations are unfairly acquired seems to reflect the ongoing stigmatization of learning (dis)Abilities

(Arceneaux, 2006) and denotes that, despite enduring consequences that other students may not have to face such as short-term memory recall problems and taking a particularly lengthy amount of time to complete examinations, Lisa feels she should not ask for all accommodations that may be available to her. Lisa seemed to be uncomfortable utilizing accommodations for school-related activities that she may be able to adequately perform without adaptations. By accepting as few accommodations as possible, Lisa has been able to minimize the impact of brain injury upon her core sense of identity (Arceneaux, 2006).

Support of Family and Friends

Playing rugby is a big part of Adele's identity. When she was unable to play the sport following her injury, this negatively impacted her friendships that were linked to playing rugby, and subsequently, her self-confidence waned. Research indicates that individuals who have traumatic brain injury have more unmet social needs in relation to those who do not have a (dis)Ability (Reiss, 2006). For Adele, not being able to participate in sport was a consequence of her brain injury and this indeed led to unmet social needs. Francine, who also acquired her brain injury via participating in sports, had a different experience. Francine felt her brain injury was a temporary (dis)Ability, while other aspects of her identity, like the anxiety she deals with, are long term (dis)Abilities. Jolene also deals with multiple (dis)Abilities and was informed by medical professionals that the implications of her ABI would most likely subside within a few weeks. It became clear that this will not be the case, as Jolene's injury still impacts her and she now talks about incorporating the experience of having a brain injury into multiple aspects of her life including relationships with friends. Given her past experience with concussions, Francine said, "I don't feel like it [brain injury] stays for a long time" and does not think that the two (dis)Abilities she deals with intersect in any way. While the implications of

concussions for Lisa were cumulative and she has incorporated brain injury into her life as a significant factor, Francine believed the impact of brain injury upon her life has been limited and talked about a definite point in time when the implications of her concussion will be concluded. Through her experience with acquiring a brain injury, Francine has learned a great deal about (dis)Abilities, for example she has learned that not all people living with (dis)Abilities identify as having a (dis)Ability. She has also learned to identify her own experiences with anxiety as being a form of (dis)Ability and this has contributed to her feeling of camaraderie with others who use the (dis)Ability resource centre at her university. Francine was, however, aware of the negative connotation that can often be associated with identifying as having a (dis)Ability. According to Ellis (2012),

People with disability negotiate a complex identity that involves both physical difference and social stigma. Yet disability is often individualized and treated as something that a person must overcome—social restrictions are not addressed (p. 3).

After acquiring her brain injury, Adele talked about the support her mother provided by spending the weekend with her and waking her up every two hours to ensure that she was not suffering from any negative effects from the blow to her head. Adele laughed when she remembered thinking, "... I'm not dead, let me sleep." Lisa also noted that her mother has been supportive in her life following her ABI. Lisa said that her father did not support all that her mother did to arrange supports and believed that she was "faking" her injury. She said she no longer talks to her father because of this. Lisa's experience with her father relates to Pollett's (2008) finding that caregiving continues to be predominately women's role. In Lisa and Adele's case, their mothers seemed to be adhering to this maternal caregiving role by expressing concern and protectiveness.

Researcher's Reflections

This maternal caregiving role is something that I experienced as well, especially given the traditional nursing background that my mother had. At the same time, I found a form of protectiveness expressed by my father that other participants did not discuss in our interviews. It may be that I was unaware of this protectiveness prior to acquiring my injury, however I think that it is more likely that my experiences highlighted my vulnerability and both of my parents adopted the belief that they must provide security in my life. While this has lessened with years, I think that this protectiveness is an exclusive characteristic of my parent's relationship with me, and this is not represented in their connection with any of their other children.

Supports in the Academic Sphere

Whether they acquired a brain injury more recently, or have been dealing with the implications of brain injury for several years, all participants discussed strategies used to deal with their brain injury while being a university student. Both formal and informal accommodations were utilized to address a range of needs related to brain injury. Informal accommodations arose by trial and error and individual exploration of learning needs. Formal supports required more documentation and assistance of university support staff. For (dis)Ability resource centre staff at universities, the increased workload created by providing individual accommodations impedes the provision of (dis)Ability accommodations (Williams-Whitt, 2007). Navigating systems to attain accommodations requires support of others in places of influence. Additionally, the support of significant others is essential in the academic success of university students with brain injury. Lisa

acknowledged that her mother has been a source of support in various ways throughout her educational journey, such as assisting her with filling out necessary forms, providing proofreading services, and offering insight into how Lisa's (dis)Ability may be viewed by outsiders in different capacities, such as professors or employers.

Researcher's Reflections

The support of my parents has been vital throughout my educational journey. Self-doubt and uncertainty are things that I struggle with after acquiring a brain injury. Self-chastising is discussed previously in relation to memory loss and mistakes being made. I constantly worry about making the "right" decision and what the outcomes of choices will be for me. The love and encouragement of my parents has helped me through these negative feelings. They have constantly countered these negative self-perceptions and I could not have gotten through my years of university education without them by my side. Related to consequences of my brain injury, I have experienced difficulties in interpersonal relationship, such as with friends and intimate partners. It has been difficult to accept the people in my life who were not there to support me following my brain injury, and this is reflected in insecurities I have experienced in relationships since acquiring my injury. I have felt a lack of trust in the intentions of others and this is something that I am constantly aware of and working toward overcoming. Having family to debrief with and reassure me that decisions I make are "right" has been beneficial to my well being in the personal and academic spheres.

Jolene described the experience of learning new information after acquiring her brain injury saying,

... a train of thought for me is like a ball... this is the train of thought or concept that I want to talk about and then I read another post and suddenly there's three other balls in my hands here and I have to remember which one of them was the first one that I wanted to talk about... there's like another three or four or five balls there and then suddenly I have an entire room of balls and I'm trying to find that one and I can't.

For Jolene, the expectation that she will be able to find that one ball in a ball pit of similar balls was frustrating. When she has described her experience to professors in this way, however, they expressed understanding. Having to explain the impact of brain injury speaks to the belief that accommodations should be supported with rigid evidence and having to prove their (dis)Ability is a barrier that participants said they have encountered in postsecondary institutions.

Supports related to experiences with professors. Francine, a social sciences student, noted that her professors were exceedingly accommodating to her needs after she acquired a brain injury. Accommodations Francine found helpful included extensions for completing assignments, professor's understanding when she had to miss class due to headaches and doing alternate assignments. Francine emphasized the limited period in which she believed her academic career was influenced by her brain injury. She questioned if her accommodations would have continued if her injuries persisted over a lengthy period. Francine said that she thinks she also had the support of the registrar, who e-mailed her professors to tell them she had a brain injury. Francine did not speak about the registrar referring her to the (dis)Ability resource centre and this may be because she told the registrar that she only needed short-term accommodations. Francine did not utilize services at the (dis)Ability Resource Centre at her university because she

felt she had overcome the effects of her brain injury by the time exam season started. The registrar at Francine's university may have been influenced by Francine's confidence that the injury would only have short-term consequences and may have felt registering with the (dis)Ability resource centre was unnecessary since Francine would not require these services after a short time. In considering the influence of brain injury upon the learning process, Arceneaux (2006) found that people with learning (dis)Abilities were concerned about their intelligence and view grades received in school as "confirmation of their ineptitude" (p. 91). Francine did not talk about feeling negatively about her intelligence or grades and in fact presents an overall positive experience with navigating educational systems after she acquired a brain injury. Francine credited her positive experience to the support of staff and faculty at her school.

Francine had a positive experience with her university and professors who helped her build self-confidence and aptitude. In Arceneaux's (2006) study on students with learning (dis)Abilities, most participants thought their learning (dis)Ability was a "non-issue" and viewed mistakes made as small blunders rather than a testament to their general aptitude. Francine had a very similar view of her brain injury and how it impacted upon her studies.

Researcher's Reflections

My own thoughts as a student with an acquired brain injury would not align with Arceneaux's (2006) findings. Even making small mistakes, such as forgetting a small detail, has left me with feelings of shame and inadequacy. I often dwell on memory slips for hours, and consider ways to improve my memory or not make similar slips in the future. For me, short-term memory problems were one of the most significant losses that my injury inflicted, which continues to impact my everyday life. Prior to acquiring my

brain injury, I had an exceptionally good memory, which made it even more difficult to cope with the loss. My problems with short-term memory bother me more now than it did immediately following my injury. In my journal, four months after acquiring my brain injury, I wrote, “I’m doing well in school but it is and will continue to be a lot of really hard work. Ah well!” I think that immediately following my injury I simply appreciated being able to pass courses with marks I considered to be moderately satisfactory. As time has passed, it has become apparent that short-term memory problems will affect me long-term and this has been difficult to accept and incorporate into all aspects of my life.

Some professors throughout my university education have been accommodating with my short-term memory problem, for example a history professor provided me with assistance for exams by providing me with one essay question in advance of the exam. This professor also took my word about my injury and how it impacts upon my short-term memory. I did not have to provide medical proof. While I was not registered with the (dis)Ability centre at this time, I suspect that this professor had heard of my accident simply by being a member of my community. Predominantly dealing with the implications of short-term memory loss has been a solitary battle for me until recently. This relates to my progression in postsecondary education and eventual acceptance and embracement of my (dis)Ability.

When accommodations are provided by the (dis)Ability Resource Centre, professors need to sign documents to allow the centre to provide assistance. Lisa has not had any difficulties with this process. She said, “... no professors are like, ‘you don’t need this’ or anything like that... they’re all like ‘ok I’ll sign the form’... they don’t even know like what your (dis)Ability is I guess.” A study by Brandes and Crowson (2009)

exams the impact of conservative ideology upon disposition toward people with (dis)Abilities. In this study, “cultural conservatism” was defined as, “a dimension of conservative ideology that is represented by traditionalism and conformity at one pole and openness, autonomy, and personal freedom at the other” (Brandes & Crowson, 2009, p. 272- 273). The authors found that “culturally conservative” professor prejudice, those who prefer the learning style of non- (dis)Able students, is often only directed against people who present a perceived threat to the existing social order- those whose difference is visible. For culturally conservative professors who can not visibly discern that a student has a (dis)Ability, as is often the case with brain injury, prejudice may not impact the learning environment. Lisa was near the beginning of her university experience and was taking a broadly defined undergraduate degree with professors from various departments and disciplines. For Lisa, one of the perks of being registered with the (dis)Ability Resource Centre was having a face-to-face meeting with your professors so they come to know you. The relationship building that comes from personal meetings with professors had positively impacted her learning experience. Lisa may have had both liberal and conservative professors, however they signed accessibility documentation willingly. Perhaps this was in part due to the invisibility of her (dis)Ability. If Lisa’s (dis)Ability was more physically apparent, professors might be more likely to critically consider Lisa’s capabilities and accommodation needs before signing off on (dis)Ability resource centre accommodations.

Researcher’s Reflections

I have had positive experiences in speaking with professors privately outside the classroom. In any case where I think that having a brain injury may impact my

performance in class, I have shared my concerns with the professor. I disclose that I have a brain injury and discuss the impact of the injury on my studies, including the barriers I encounter. I have found this relationship building with professors to be helpful in increasing my comfort in the classroom. When professors are aware of my brain injury, I believe they understand me on a deeper level and I feel less anxious exploring and discussing my experiences related to course material. Similar to Lisa's values, this speaks to the importance I place upon relationship building with people who are significant in my life, such as professors Relationship building is a key element of social work practice, if I cannot build relationships on my own behalf how am I going to be able to assist clients in this regard?

Jolene reported both positive and negative experiences with professors, both as a student in the classroom and in terms of working for professors. It took Jolene a while to fully comprehend the impact of her brain injury, however once she understood the effects she disclosed this information to her professors. She had positive responses from all of them. Jolene said, "I think in general all of them said the same thing, 'oh take as much time as you need.'" But I don't think anyone realized how much time that was going to be."

Louise was still in contact with one of her professors, a professor whose partner had a stroke. Louise believed this professor's compassion and understanding toward her accommodation needs stem from his own experience with (dis)Ability. Louise said that when the affect of her brain injury was apparent through receiving a poor mark in this professor's class, she met with him privately in his office. Meeting with her professor outside of class was an effective strategy for Louise in that she came to know the

professor on a more personal level. Louise said that after she disclosed her injury, the professor acknowledged his experience with his partner contributed to him being “really sensitive to stuff like this.” Amendments were then made to how Louise’s marks in class were weighted and he provided extra assistance in terms of providing explanation about how questions were worded, as Louise acknowledged that she had difficulties with this in this particular class. The kindness and understanding of this professor has stayed with throughout the years. Other participants did not disclose their injury to professors, but instead used other disclosure strategies to positively influence their coursework. For example, Adele never specifically spoke about her brain injury with professors, but would address it with classmates when assigned group-work.

Supports related to experiences with (dis)Ability centres. According to Louise, Francine and Lisa, the (dis)Ability resource centres at the universities they attended were helpful in providing accommodations to meet their educational needs. Louise said that staff at the (dis)Ability resource centre on her campus were helpful insofar as they often provided emotional support when she felt overwhelmed by the demands of postsecondary education. When asked about the (dis)Ability resource centre at her university, Francine noted, “I got nothing bad to say.” She went on to inform me that out of the two different universities she completed her undergraduate degree at, she had only utilized the services at one of the universities. She said she found the centre extremely accommodating and that she has friends who have utilized the services at the second university she has attended, and that she has heard from them that this centre is very helpful as well. Lisa said she felt “totally comfortable” talking to staff at the (dis)Ability resource centre at her university. Lisa wrote all of her exams in separate rooms through the (dis)Ability resource centre and appeared to employ a combination of formal and informal supports, such as

getting her mother to proof-read paper, to succeed in university courses. Louise, Francine and Lisa appear to have an overall positive perspective on the services provided by (dis)Ability resource centres at their universities. Participants in Lin Haag's study (2009) expressed similar sentiments, noting that (dis)Ability support offices "bend over backwards" to provide assistance and ensure that students succeed, so any complaints should be curbed

Francine, in recalling her past use of the resource centre, identified benefits and restrictions to writing examinations in separate rooms from classmates. A limitation that Francine identified is being unable to ask the professor questions about requirements on the examination. Francine may have been unaware of the possibility of staff at the (dis)Ability resource centre where she writes exams phoning the professor if she had a question, or this may have been considered excessive effort to put into asking questions, that may not be crucial, so not asking seemed like a better option. Despite this limitation, Francine believed writing in a separate room can be useful, for example you do not have to put up with shoe-tapping or other distractions. Francine found the atmosphere of the Centre to be extremely positive and comfortable. She says, "no one, like, looks down upon you... They just want to help you, which I think is great... I'm really glad I got to meet people in the (dis)Ability room and talk to them because a lot of kids don't know those services are there."

Adele has not had experience with utilizing services for students with (dis)Abilities provided at her university. Adele said that her doctor did not advise her to contact the (dis)Ability resource centre on her campus following her acquired brain injury, "because he fully expected me to resolve everything and I eventually did... like I can't pinpoint exactly when I got to the point where I felt comfortable in my studies

again”. Adele’s narrative speaks to the variable factors that medical practitioners take into consideration when making judgments about the impact of brain injury upon patients, as described by Foster, Tilse and Fleming (2004). Adele said that while she did not utilize formal accommodation services, she would often disclose her injury to classmates if they were working on a group project together, and that accommodations would be devised informally among the group members.

Researcher’s Reflections

In critically reflecting upon my own experiences, I think that I put more effort into schoolwork now that I have acquired a brain injury (ABI), than previously. I think that this effort yields the same results that a smaller amount of effort prior to my injury would have amounted to. Rather than feeling that accommodations I receive are unfair, I believe it is unfair that I acquired the injury in the first place. In the journal I kept shortly after acquiring a brain injury, I do not express frustration related to needing to work harder at school; alternately, the anger I express is over the negative social implications my injury resulted in. Due to being uneducated about the supports and accommodations that universities offer to students with (dis)Abilities until years after beginning my postsecondary educational journey, I have not utilized any accommodations offered by the (dis)Ability Resource Centre. While I think I may have benefited from utilizing services at one point, by the time I had become aware of the services I had already adapted to university. I had developed and utilized informal supports and had my own personalized accommodations that I put in place when needed. Identifying with having a brain injury and being a person who qualifies for supports was also an identity that I did

not immediately associate with. This is something that took years to develop, subsequent to acquiring my injury.

Louise and Lisa both utilized the option to write exams at the (dis)Ability Resource Centre, in a private room free from distractions. After acquiring a brain injury, Louise found it took longer to do things, such as write exams. In writing her exams through the (dis)Ability resource centre, she was given more time to complete the examination. For Louise, this was extremely helpful. Lisa also had a positive experience with the (dis)Ability Resource Centre on her campus. Aside from writing examinations in a private room at the Centre, Lisa had a note taker available to her in each class. She said that, despite this, she also takes her own notes. She has found taking her own notes easier if the information is also displayed on PowerPoint slides but she has a “delayed reaction time” so viewing other student’s notes is helpful when she misses key points.

Supports related to experience with existing policy and procedures. Lin Haag (2009) focuses on individual experiences and only provides brief description of policy implications for students with ABI, however, my study focuses more on the implications of policy in relation to postsecondary study. While various other avenues of research could have been explored, including structured surveys or interview questions, I think that uncovering participants’ stories through engaging with their narratives reflects the best possible research.

Participants discussed academic funding as being significant to their postsecondary educational journey. Lisa noted positive aspects of being a student with an ABI, such as benefits gained through student loan grants and scholarships specifically created for students with (dis)Abilities. For Lisa, who was completing her first

undergraduate degree, no issues have arisen with student loan providers and she was content with the amount being loaned to her.

Adele said that one strategy she used for accommodation in the classroom was sitting with people who took good notes so she could look at them if she required assistance during class. Adele also said that she found it useful to bring her book to class and follow along and highlight critical material identified by the professor. Adele has experienced severe migraines since her acquisition of a brain injury and this results in pain. The pain Adele experienced had a negative impact on all areas of her life, including academic endeavors. Taking over-the-counter medications to alleviate symptoms has been useful for pain, however she was aware that this overuse of medication might negatively impact her health in other ways. Jolene experienced migraines as well and said that doctors and physiotherapists advised her to stop reading for class and simply physically attend the class. Jolene said this advice was given as a strategy to allow her brain to heal, but not doing readings, and consequently not being able to complete assignments based on these readings, was not realistic for her. Attempting to follow medical advice and consequently not making progress in the program, eventually led to Jolene taking a medical leave from her degree program, as outlined previously.

Throughout the interview, Francine emphasized the usefulness of being provided extensions for outstanding assignments, as she notes that having time to deal with the implications of her brain injury before challenging it with schoolwork was crucial. Francine's emphasis on the usefulness of time extensions for assignments relates to MacLennan and MacLennan's (2008) claim, as stated above, that time constraints of classes can be difficult to deal with for students with acquired brain injury. Francine felt that having extensions has made a difference in terms of her marks, saying, "at the time

when I had my [brain injury] there was no way I would be able to do an assignment and really put my full 100% effort into it because my head was hurting and like I couldn't focus" Francine said that she was given the opportunity to do different assignments to meet the requirements of the course, such as presenting privately instead of in front of a classroom full of students. Francine acknowledged that she has struggled with class presentations due to a pre-existing (dis)Ability, but this has been steadily improving and she found this accommodation useful. Lisa also said that speaking in front of groups of people is something that she now struggles with, although she excelled at this prior to acquiring her injury. "Finding things to say, organizing the material, finding the right way to put things and dealing with stigma are common experiences with individuals with learning disabilities" (Arceneaux, 2006, p. 2). Difficulties with presentations make sense, considering the influence brain injury has upon ability to learn. As the nature of brain injury is so diverse, not all participants expressed difficulties with in-class presentations. Jolene said that her academic strengths following her injury have shifted as well; in her graduate program she had difficulty with completing papers and this is what halted her university career. Presenting, however, came easier to Jolene and she says that by doing this, she remembered and processed new information. The course requirements for Jolene's program were intensely focused on paper writing and this is why, even though she discovered effective accommodations, Jolene took a medical leave from school.

For Francine, having already been enrolled in courses and considering her brain injury to be a short-term impediment, no long-term accommodations were arranged. Louise considered dealing with the implications of her brain injury on a long-term basis and intentionally spaced out her courses, extending the time it will take for her to complete her degree but also reducing the stress associated with workload. Lisa's

experience has been that she is allowed time and a half to write her exam at the centre. So if the examination were to be two hours in the classroom, she would be given three hours to complete her exam at the resource centre. “Time and a half” for exams is noted by Lisa to be helpful, as she says that she has needed this extra time often when writing exams. For students with ABI, memory and comprehension impairments may have resulted from their injury and this can make completing assignments on time and dealing with the time demands of classes, difficult to manage (MacLennan & MacLennan, 2008).

Barriers

Individual Barriers

Jolene talked about academic excellence and how other perceptions of her have not changed, even though her abilities have changed. Jolene’s experience relates to Asch and Rousso’s (1985) assertion that expectations are influenced by cultural values and when these expectations do not shift to account to changes such as acquired injuries, difficulties can emerge. Jolene’s academic success and analytic ability are sources of pride for her and significant others in her life share these values. While these significant others still value academia, she believed they do not understand her newborn struggles in this area. When she spoke about being chosen to represent the department on the university website, Jolene laughs saying, “Yeah. Jolene’s great! Have you met our great alumni who’s now a master’s student who... can’t read a kid’s book?”

Adele said that prior to acquiring her brain injury, she had some understanding of the possible implications of this and when she was injured, she knew that she needed medical attention and that the implications of the injury could be long lasting. Louise, conversely, talked about being unaware of how her injury had impacted her until others brought it to her attention. In terms of identity and brain injury, Louise said that having

the injury and requiring accommodations made her feel “weak.” Cultural ideals and the inability to accept less than perfection, can lead to preconceptions about what is acceptable and reasonable to expect of a student who has an ABI (Asch & Rousso, 1985; Lin Haag, 2009). While all participants noted areas of their lives that were impacted by their brain injury, Louise was the only participant that uses the word “weakness” to describe her experiences. Louise’s use of the term “weakness” seems related to other’s feelings about her, where as ideas such as “not living up to other’s expectations” convey a more personalized feeling of inadequacy.

Researcher’s Reflections

The experience of a feeling of “weakness” is one that I can identify with. Louise noted that the thought of conveying to her professors the difficulties that she experienced with school and explaining how this relates to her brain injury, was one that left her with feelings of weakness. For me, speaking about my experience does not leave me with a feeling of weakness, but pushing myself to complete tasks that came more easily to me prior to my injury is often frustrating and can leave me with negative feelings. In situations where I feel frail and inadequate, I am constantly combating this sense and striving to feel successful in academia. With each accomplishment I experience in my life, I reflect on the difficulties I have encountered due to acquiring a brain injury and how, despite these barriers, I have persevered. This leaves me with a feeling of strength. Conversely, when I perceive failures in my life, the feeling of weakness is experienced. This does not occur when I speak with professors about acquiring accommodations, but is something I feel if I do not succeed academically despite having informal

accommodations in place. When I forget things that I have told others I would remember, for example, I feel a sense of weakness and chastise myself internally.

Several participants who were interviewed acquired their injury because of participating in sport. Lisa said her dreams and goals associated with competition may be dashed, but she realizes that even if acquiring a brain injury has halted those dreams, making new goals and having new desires is possible. Lisa said that more awareness about the issue of brain injury has occurred recently with well-known athletes experiencing brain injuries. While she is pleased with the increased awareness about brain injury, Lisa said that serious bodily damage resulting from sport competitions in both major and minor leagues is alarming. Adele's experience relate to this concern. Adele said that her hand-eye coordination and reaction time were negatively impacted by her brain injury. Adele also experienced panic attacks when she considered playing and approaching fields and this has been physically draining for her. The panic attacks led to her inability to return to the sport and this has negatively impacted her self-esteem and sense of identity. The negative experience, however, may be counter-acted by Adele's work in awareness raising for young athletes about the consequences of brain injury. Louise has also been influential in increasing awareness of the potential for brain damage related to sport and works with medical professionals to deliver presentations in her hometown. Jolene said she was involved in organized sport and said that people often assume that her brain injury resulted from participation in this rough sport, which it was not. Jolene said that she often considers athletes who have dealt with brain injury and the advantages of their profession in terms of small role that memory plays and the fact that

these well-paid athletes have the ability to take time to heal. In Jolene's life, memory and financial difficulties have been prominent problems.

Francine focused on how her brain injury has affected her ability to play basketball saying, "it just completely took me out of the sport," referring to the period immediately following acquisition of brain injury. Francine said that her decision to continue playing sports even when she was dealing with the implications of her brain injury have contributed to some negative effects, such as headaches and feeling sick and she describes the experience as being "really rough." Francine said that she is now "really scared" that she is going to injure herself when she plays sports, but does not have any fears related to her brain injury in other areas of her life. Francine felt that her professors have been accommodating in dealing with both her brain injury and her sports career-allowing her time off to both heal from her injury and participate in sporting events. Adele said that athletes in the media that continue to play sports through serious brain injuries send out the wrong message to fans, particularly youth. She said that these athletes are role models and when they do not do proper management for brain injuries it can demonstrate to youth that time for healing from brain injury is not crucial. She said that "playing through the pain" can have fatal consequences for youth under 18 whose brain has not yet reached maturity and is still at risk of damage.

Louise said that her physical fitness prior to her injury is what contributed to speeding up her recovery, according to her neurosurgeon. When she began playing a sport known for being physically aggressive years after her injury, Louise said this surprised people. Safety and avoiding unnecessary roughness, however, are things that Louise incorporates into her involvement in the sport. Louise appeared to not allow her brain

injury to prevent her from engaging in activities she enjoys, although it has increased her awareness of the need to protect her brain.

Researcher's Reflections

While I have not been involved with organized sports on an ongoing basis, physical fitness became meaningful for me prior to acquiring my brain injury. Family members have often posited that this recently acquired physical strength may have contributed to the speed of my recovery. Physical fitness, regardless, was not an important matter of concern for me prior to my injury. Subsequent to attaining my injury, and associated to the feelings of non-control that I have related to my memory, pushing the physical limits of my body became extremely important to me. I believe, while I may be unable to control my memory abilities, my body is something that I do have control over. I know my limitations and, much like I test my memory, I test my body's limits in safe environments like the gym. Health has also become profoundly significant to me now and I believe physical fitness and the materials that I choose to not subject my body to, such as junk food or cigarettes, is a matter within my control.

Adele spoke about other's perceptions of her brain injury and how, because she had no visible injuries, people had no way of knowing what she was experiencing. Although, as noted previously, Adele had some pre-understanding of the possible implications of brain injury, Adele dealt with her emotions by "shutting herself down" and not opening up to friends about her experiences. According to Adele, the emotions she experienced were "irrational" or an over reaction but she could not control them. Although Adele felt that her emotions were irrational, given her story, a highly emotional

response seems fitting. Adele said she did not want to let her emotions impact her actions toward friends, but this is indeed what occurred.

Researcher's Reflections

The feeling of being unable to control one's emotions is something that I have experienced as well, and this has affected many relationships throughout the years of dealing with the implications of brain injury. Emotional regulation is something I still struggle with, although this is not on a consistent basis. I experienced intense feelings of anger following my injury, which have become controlled with time. Several journal entries from the summer and fall of 2004 illustrate these feelings of anger, which were uninhibited at the time. On August 4th, 2004, approximately two month after my injury, I wrote angrily about not receiving a correct order for breakfast during my stay at the Rehabilitation Centre. I had written about receipts that came with my food and how they varied from what the actual order was previously. In this entry I wrote, "They messed up my breakfast this morning AGAIN so I'm just about at the end of my rope with them. I'll make my own RIGHT food thank you very much." These angry and self-righteous feelings were associated with practitioners' opinions that I would not be capable of excelling at schoolwork. Health professionals at the Rehabilitation Centre told my parents that they advised that I wait six months before returning to school. This would have put me one semester behind in my high school studies, and while I can now see the reasoning behind this, that they thought returning to high school would have been too difficult while I was in the midst of dealing with my injuries, this did not account for the determination I had to excel and finish high school with my peers. On September 13th, after I had returned to high school, I wrote, "I got my first test back... 95%... in your face rehab shits!" These

feelings were also associated with the protectiveness of my parents in my life. In my last entry in the journal on October 30th, 2004, I wrote about being “unbelievably mad” that my parents would not allow me to go out. “I CAN DO STUFF!!!!” I wrote, before going on to lament about how I felt that my friendships were deteriorating due to my lack of time spent with peers. I even wrote, “I wanna die, that’s how bad things are.” Although therapy was suggested following my discharge from the rehabilitation centre, I did not seek this help. Looking back now, I feel I was angry at my brain, my body and myself. I knew my parents were simply being protective given the injuries I had sustained, but in my mind I thought I was fine. This also speaks to my values at the time; after being involved in this life changing accident, I just wanted to appear as close to “normal” as possible. While my family life had been drastically impacted, at least if I could do the things my friends were doing, I could appear as if things had not changed. While I believe my parents thought it would be overwhelming for me at the time, along with returning to classes, I now believe I may have benefited from this. Increased awareness of the general public about the emotional distress that can result from brain injury would be useful for those in the lives of people who have recently acquired a brain injury. The consistent support of my family, as discussed previously, was vital to my coping with injuries.

While they could be expected to experience a range of emotions in relation to viewing my emotional distress, they also took time to reflect on my emotions and to connect this with my experience with brain injury. If there was a greater general awareness about brain injuries, perhaps my peers and family would have understood what I was going through and through that understanding the intensity of my emotions would have been reduced. Having an increased awareness of brain injury can only help people communicate more

effectively with those experiencing the brain injury. The saying “a joy shared is doubled, a burden shared is half” could be applied within this context.

Adele, who acquired her brain injury from participating in sports, now coaches this same sport as mentioned previously. She is conscious of providing information related to brain injury to players on her team and is quick to challenge players who dismiss the seriousness of acquiring a brain injury. Adele says she has told players about her experience and all that she has endured and often connects this to precautions that she insists players take. As outlined previously, Adele’s experiences have positively contributed to her coaching knowledge. Louise was also involved in raising awareness about the issue of acquired brain injury in connection with sport that she was involved with that lead to her acquisition of a brain injury. Adele and Louise noted a wish for their consciousness-raising activities to increase awareness of individuals and they hope that this leads to the spreading of awareness about brain injury.

Barriers Presented by Family and Friends

Participants expressed a variety of reactions related to their acquiring academic accommodations at university. Stereotypes related to the experience of acquiring a brain injury affected relationships with friends and family, as participants noted. Lisa vocalized the concern that others, such as peers, viewed her as receiving unfair advantages. Lisa’s concern supports Arceneaux’s (2006) assertion that many students with (dis)Abilities that impact their learning think others view them as undeserving of accommodations. I posit that this might be one reason for the repeated explanation that despite the struggles she was telling me about, Lisa was not complaining. Lisa said the friends she has now understand the impact of brain injury upon her and how she has incorporated this

experience into her life, although this has not always been her experience. When she acquired the brain injury, while she was in high school, Lisa said she “lost all [her] friends because they thought [she] was faking it,” referring to the consequences of her ABI. Louise spoke in less detail about how her brain injury impacted friends, but noted that she felt “behind” in her university degree, as she acquired her brain injury mid-degree and had to take some time off, presumably while other people, such as friends, continued onward with their academic careers.

Researcher’s Reflections

Like Lisa, I acquired my brain injury when I was a high school student. My friendships at this time in my life focused upon “partying” and living a carefree lifestyle. I enjoyed freedom from rules, particularly those devised by my parents. I associated the freedom to drive and go wherever I wanted with making choices, like choosing to drive fast and do “tricks” while driving the vehicle. After I acquired my brain injury, staying on par with friends remained important to me. I wanted to graduate at the same time as my friends that I had grown up with, however I now needed to put more effort into schoolwork. Worrying that I would not pass the courses I was enrolled in and that I would have to complete an extra year of high school after my friends had already graduated, was motivation for me to put forth extraordinary effort to ensure that I completed all of the courses I was enrolled in. While I still valued the carefree lifestyle I enjoyed prior to my injury, this was difficult to achieve given my memory problems and other implications of injuries acquired during the car accident. I had to pay intentional thought to remembering facts for tests or homework assignments to be completed. I now had limited movement in my left arm and all limbs had been weakened due to my extended time spent in coma and hospital bed. Simply walking up the stairs became a chore insofar as I had to pay

attention to not tripping, as my balance had been affected by the brain injury, and movement of my legs still took more effort than it previously had.

In the journal I kept shortly after acquiring my brain injury, I wrote about going on a trip to an art museum that the recreational therapist at the rehabilitation centre had organized. I wrote, “OW my feet. I had to walk for like two hours with two breaks. It sucked. When I got back here [rehabilitation centre room] I rested til Mom came then I went to the MicMac Mall. I kept on resting because I was soo tired out.” I became “high strung” and I had to pushed myself to excel, which prior to the accident had come naturally to be. While my friends never outwardly suggested that I was exaggerating the implications of my injury, they indicated a feeling that I was undeserving of the accommodations I had attained. This supports the assertions of Asch and Rousso (1995) and Arceneaux (2006), that many people who have an acquired (dis)Ability such as a brain injury endure oppressive experiences due to other’s perceptions that they are undeserving of accommodations or could do without the use of these. The accommodations I had in place included having a free period each day so that I could catch up on course work that I was unable to complete during the regular class schedule. Renovations to our house also occurred and these were required because of the physical limitations both my brother and I had due to injuries sustained during the accident. My friends knew that these renovations had taken place but apparently did not associate them with physical limitations. I recall one friend telling me that she felt I had become “stuck-up” because I was getting special treatment at school and home renovations. My friends were unaware of my brother’s profound physical limitations that resulted from the accident and, I think that they did not fully understand my physical limitations because they were mostly invisible. When compensated for, my physical injuries did not present a

readily visible obstacle to participation in daily living activities. I remember having a “countdown” to when high school would finally be over, as I believed that things would get better when I started university. I was not disappointed. I focused on developing my friendships with different people at my high school and eventually began to meet new friends once I began university as well.

The way in which one incorporates the experience of brain injury into their life also impact social variables, such as friendships and groups of people one identifies with. Many people lose friends following a brain injury, in part this is due to identity reconstruction that is often part of the rehabilitation process with ABIs (Lorenz, 2010). Adele said that her belief that the injury was self-inflicted and therefore she had to deal with the consequences alone impacted her ability to share her feelings with friends. Although she felt unable to share her emotions with friends, Adele said that she was personally more aware of her emotions than she was prior to acquiring her brain injury and she felt she was able to consider these emotions in a critically reflective manner. She described this process when she talked about getting upset with a friend whom she worked with after acquiring her brain injury, saying:

I knew I was being irrational in my own mind. I knew that these emotions weren't right cause I would go, one minute I would just want to sit down and cry, to being in a huge rage. Like from being absolutely happy and laughing to, you know what I mean? Like I had no control over it. And so I would just shut myself down so I wouldn't show any of these mood swings because I knew that it wasn't me, it was something that was going on in my head and I didn't want to take out any of those emotions on her that weren't her fault cause I knew that.

Adele discloses the impact of acquiring a brain injury on her emotions and said that this, in turn, impacted her friendships. Adele said that related to her emotional fluctuations following her acquired brain injury, she will “never” again be close with some friends she was once close to.

Barriers in the Academic Sphere

Participants in this study identified times when their academic needs were being met, yet all participants were also able to identify times when their needs weren't being met. This indicates that changes to accommodation policies could be made to better serve students with acquired brain injuries, who require these accommodations in order to succeed in the classroom. In the case of this study, students with acquired brain injury experiences with university education specifically related to the supports they are able to access while at school contrast to what they believe they need to succeed. Contradictions related to accommodation emerges from my own experiences with university education and was supported by both past and present research on education and brain injury.

Barriers related to experiences with professors. Included in the participants' stories were experiences they had with individual professors. Sundock (2010) notes that the labels given to students with (dis)Abilities reflects an archetype of thought about how this person should be integrated into mainstream society. Brain injury is not a well known (dis)Ability as is evident from participants' encounters with professionals who knew little about their injury and how to support them, which means people with acquired brain injury are more vulnerable to assumptions being made about the effects and implications of this (dis)Ability. Assumptions could be based upon media representations, past experiences with people with brain injury or other factors. The assumptions are

particularly significant in relation to students with brain injuries in university classrooms. The preconceptions professors have about brain injury can influence how they treat the student and this impacts the student's overall experience with university education. Having a supportive instructor can make a significant difference in the academic success and overall experience of students with acquired brain injuries (Nicholson, 2008).

The impact of brain injuries vary and it is not a widely understood (dis)Ability. Jolene's professors may have held assumptions about the recovery time she would need and how significantly the brain injury impacted her completion of coursework. Tension was created when Jolene encountered her professors in the hallway at school and they would verbally remind her about the outstanding work she had due. Jolene said this left her feeling negatively about her academic life, as she realized she had outstanding work but was simply unable to complete it. If Jolene had realized what she was going to need in the form of accommodations earlier, it would have been helpful. If this was the case, professors could have provided a consistent response to those needs and Jolene would know that all professors were aware of her progress on completing outstanding work, rather than feeling as if particular professors were hounding her. Had Jolene been able to articulate her accommodation needs, this would have eliminated tension-filled encounters in the school hallways. "Because of a lack of knowledge and training, teachers and support staff are often inadequately equipped to cope with the extent and variety of behaviours that are exhibited by returning students with [brain injury]" (Richey, 2008, p. 15). While teacher's formal education may not include information on working with students with brain injury, it seems that university professors, who often do not have teachers formal education, require this training as well.

Louise spoke about the harmful effects of a professor, including the implications

had on her educational experience. The particular professor Louise discussed taught her a course and supervised her research assistant work. Louise said, “He kind of made me feel a little bit like a ‘retard’.” When I inquired about how this person had this influence on her, Louise said that she did terrible on an examination in his class and when she approached the professor to discuss how she could do better in his class, he told her that she should talk to people at the (dis)Ability Resource Centre, as “they are better at dealing with special people like yourself.” These words and the tone of voice used to convey this message left Louise feeling any struggles she had were personal reflections of inadequacy. Louise also believed she was not “on par” with the rest of the students in the classroom. Research has supported the effectiveness of assisting instructors in understanding their attitudes toward inclusion of students with (dis)Abilities when they are completing education and training to become school teachers (Brandes & Crowson, 2008). The impact of teacher’s beliefs on supporting students with (dis)Abilities in meeting academic goals is something that should be explored when they are completing formal education and training for this profession (Brandes & Crowson, 2008). University professors have advanced knowledge about particular subjects they teach but may not necessarily possess effective teaching methods or a desire to improve upon the delivery of material in the classroom. Louise said that following this encounter with the professor she experienced “a bout of depression,” for which she blamed this particular professor. Louise has not experienced negative feelings to this extent since this incident, nor did she believe she would experience the intensity of these feelings again. One has to wonder if professors realize the potential impact they can have upon their students’ lives, particularly students in vulnerable positions who are requesting assistance.

The director of Jolene's department had heard amazing stories about Jolene's abilities as an undergraduate student, prior to her acquiring a brain injury. These preconceived notions of Jolene's ability had a negative impact upon Jolene as she felt pressure to perform at the same level as she had prior to her injury. Jolene could no longer live up to her reputation; her brain injury had taken that away from her. Often times the difficulties Jolene experiences with specific processes are overlooked as being minimal until she vocalizes the enormous impact they have on her and her ability to learn in the classroom or work as a student researcher. Jolene's experience with trying to obtain computer software to assist her with marking papers is an example of this. Jolene was unable to remember to incorporate new things into her routine and she believed that employees at the (dis)Ability resource centre at her university did not truly understand this. She was asked by workers at the centre to research a computer program, however she was unable to remember to complete this task due to implications of her brain injury and no one ever checked in with her about whether this task was completed. The negative experience with the (dis)Ability resource centre occurred shortly after Jolene acquired her brain injury and she was unaware of the impact her brain injury had on her ability to recall tasks, at this time. Jolene said, ideally, employees at the (dis)Ability centre would be supportive by checking-in with her about her progress on task completion after an agreed upon period. Checking-in would serve as a reminder of the task, if she forgot to complete it. Jolene had also experienced difference between her professors, who have a professional designation, and administrative staff at the school. Jolene said she was mystified by the "red tape" and conflict she has encountered at her school, a school that embraces a critical reflective perspective. Jolene noted a contradiction between what her

school espouses in the way of values and principles, and the rules and regulations of the institution that are not supportive of students with (dis)Abilities.

Researcher's Reflections

In reflection on Jolene's experiences I was reminded of a situation I encountered during my undergraduate degree. I had an encounter with an administrative staff person who outwardly blamed my behaviour on my (dis)Ability, when I clearly interpreted the same behaviour as self-advocacy. She went as far as to suggest I get help for this behaviour. From my perspective, I was acting on a situation when the School failed to do so, I was looking out for my own learning needs. If I did not have an acquired brain injury, I have to ask, how would the behaviour have been understood? Several harsh assumptions about the effects of my (dis)Ability were conveyed to me and suggestions around how to deal with future situations that might arise related to my (dis)Ability were presented. While this left me with negative feelings, I was able to self-reflect and consider whether this person, who had limited knowledge of me, was correct in her evaluation. After consulting with several people in my personal and academic networks, I decided to challenge her perspectives. I was so up-set from the situation that I wrote this person a letter explaining my actions and clearly letting her know that I thought she had crossed the line in stereotyping and type casting (dis)Abled persons. Specifically, within the letter I wrote, "It is unfortunate that this is not recognized as being a positive thing but is instead looked upon as a negative implication of a (dis)Ability that I willingly noted I had, and that is unrelated to my ambitious personality and dedication to excelling in the academic environment." This experience was significant and personally empowering and

after conveying my opinions through writing a letter, I received no further communication from this administrative staff.

Lisa talked about one professor whom she did not have a positive experience with, saying, "...I don't even know what [she's] asking because... she would put double negatives in and we're all like 'I have no idea. Just ask it right'". In this instance, Lisa's words seem to reflect that more people other than herself, had difficulties with understanding this professor's questions. In relation to this professor, then, I question whether she had a teaching method that did not appeal to the majority or whether her teaching method was ineffective for Lisa solely because of the implications of her brain injury. Regardless, this experience speaks to the aforementioned need that teacher's have specific knowledge and training in working with students with brain injury (Richey, 2008).

Lisa described her experiences with another professor who tested students in his class by providing "pop quizzes," which consisted of PowerPoint slides, which were presented on a screen that was controlled by the professor. The professor would switch the slide after giving what he considered to be adequate time to read the question and respond to it. Lisa described the panic she experienced when she realized she had not had adequate time to consider and respond to the question, as one of the implications of her brain injury is that it takes her additional time to process questions before responding to them. Lisa said she did not address this issue with the professor because she believed that the chances of having another in-class quiz were slim and the grade she received for the quiz met her standards of being a satisfactory grade. Lisa also may not have trusted what the professor would do with the information that she has an acquired brain injury. Lisa,

like Adele, did not address the impact of brain injury with particular professors and one possibility is that they did not think the implications of their injuries were severe enough to merit “special treatment.” It is also possible that Lisa and Adele had difficulty accepting their identity as a (dis)Able person. Lisa and Adele’s considerations are interesting to consider in relation to the thoughts of the participants with learning (dis)Abilities in Arceneaux’s study (2006), who see errors that they may make because of their (dis)Ability as not being significant or reflective of their overall ability. Adele and Lisa attempted to complete coursework without accommodations they are entitled to and this may adhere to beliefs about inner strength. Completing work without the use of accommodations may also adhere to Adele and Lisa’s beliefs about the impact of brain injury upon their life. By not utilizing available accommodations, (dis)Ability was rendered less significant in relation to Adele and Lisa’s overall life. Not utilizing accommodations available to them may also speak to their desire to “return to normal” or appear as close as possible to this and societal assumptions and stereotypes regarding normalcy would influence this.

While developing a sense of community with other university students who have ABI can lead to positive individual outcomes, feeling that their concerns are not understood was a negative experience for participants. Jolene felt others, particularly professors and doctors, couldn’t comprehend her experiences and this has impacted her ability to receive rehabilitative equipment and advice on furthering her university career. Professional opinions are upheld as being of vital importance in contemporary society so disbelief or dismissal of the perspectives of people with ABI could have negative implications for them. Participants noted several occasions where professional perspectives have not been beneficial. Lisa, for example, said that her mother was left to

advocate for her and write letters in support of services she needed related to her brain injury. Lisa felt her mother was the strongest advocate in her case.

Barriers related to experiences with medical professionals. For Francine, impractical methods for coping with her brain injury were also presented to her by medical professionals. Francine suffered from headaches, which were provoked by computer work. Francine was advised by medical professionals to sit in a dark room to alleviate these symptoms. When Francine did this, however, she found that it led to feelings of tedium and monotony. Francine, who also suffers from anxiety, felt that the apprehension she experienced sitting in a room and not getting her schoolwork completed was nearly as bad as the headaches she experienced when she did complete work on the computer. Francine and Jolene's experiences highlight the (dis)Abling nature of policy and structures in contemporary society. Dossa (2009) speaks about the demolition of social barriers like policies, which is said to amount to productivity and autonomy, saying, "an exclusive focus on (dis)Abling society renders invisible the lived reality of an impaired (different) body" (p. 270). Liberal democratic policies are both positive and negative, and the "in-between space" that exists in the contradictory nature of liberal democracy where "possibilities of progressive change can be explored" (Dossa, 2009, p. 271). For service providers working with students with (dis)Abilities, the voices of those who have lived experience with brain injury should be taken into consideration alongside the existing policies and space for creative solutions to problems should be allowed.

Barriers related to experiences with (dis)Ability centres. Jolene, unlike Lisa, Francine and Louise, said that she has not found the (dis)Ability resource centre at her university to be helpful in struggles related to school work and her acquired brain injury. Jolene said that she has found resources within her specific academic program to be more

accommodating than those offered by the (dis)Ability Resource Centre on campus.

Specifically, Jolene noted that she found that the (dis)Ability resource centre provided services that did not seem to be tailored to dealing with her particular (dis)Ability.

Adele said that she has not utilized formal accommodations and has never utilized the services of the (dis)Ability Resource Centre on campus. She said that she feels “alright” with her academic performance after acquiring a brain injury and she does not regret her decision to not contact the service, although she wonders whether accommodations would have made schoolwork easier. The timing of her injury contributed to her not seeking formal services, as she acquired her brain injury at the beginning of summer recess and had several months to cope with the results of her injury. According to Adele, “...I had already learned to cope with most of it, I mean good or bad coping mechanisms, I had figured out ways to cope... you know, it’s a little, it’s harder, but I don’t feel like I can’t do it.” According to Johnson, Crane and Tatekawa (2004), when dealing with medical crisis, external support is often only sought after personal resources have been exhausted. The 2004 study highlights seeking family support as being significant before pursuing formal resources. In Adele’s case, this seems to hold true in that her mother provided encouragement and support throughout her ordeal with acquiring a brain injury.

The timing of injury in relation to one’s academic career seems to be significant. For Francine, the timing of her injury negatively impacted her ability to cope, as she was hurt midway through the school year. Francine felt pressure to complete her schoolwork, so she spoke with her professors and was provided extensions on her assignments. Francine did not utilize the (dis)Ability resource centre services because, like Adele, she had already coped with the implications of her brain injury and her professors had already

agreed to informal accommodations in the form of extensions. Further, she did not need the accommodations that the centre provides, such as examination or note-taker services. She was however offered these services. Francine utilized the services at the (dis)Ability Resource Centre with a previous (dis)Ability, contributing to her understanding of the services available, should she require them. Adele and Francine similarly appeared to be aware of services, but tried to manage without using these supports. It was vital to deal with their situations on their own because they felt that a lack of support existed for students with brain injury. Adele noted that she did not believe her brain injury qualified for services. Francine attempted to secure accommodations from the (dis)Ability resource centre at her university, but when barriers were presented, she found it easiest to develop personal accommodations.

Lisa stated that while she finds the services available through the (dis)Ability Resource Centre on her campus helpful, a list of available supports for students would improve her experience. For Lisa, sometimes it's hard to think of what you need and if a list of accommodations was available, students could look at it and begin to try different strategies that might improve their educational experiences. According to Lisa, when students are left to determine services that might accommodate their learning needs, questions about what is offered and the reception of even asking for certain things can result. When a student believes that their request for accommodation may be met with questioning and skepticism, they may not bother to even ask for accommodations. The belief that their sincerity will be questioned can lead to oppressive experiences where service providers who are uneducated about brain injury and how this affects learning restrict access to accommodations.

Jolene, who has a pre-existing (dis)Ability like Francine, has considered utilizing

services available through the (dis)Ability Resource Centre on her campus, as she is familiar with how they provide assistance to students with (dis)Abilities. As discussed previously, however, Jolene said that she has found accommodations provided by her academic department to be more useful than what is offered through the (dis)Ability Resource Centre. Jolene describes the experience of telling the people she met with at the Centre about what accommodations would be useful for her. The example of being told to research computer software, as outlined above, reflects this feeling. In considering services provided through (dis)Ability resource centres, best practices include “taking an active interest in promoting and advocating understanding of the accommodation process throughout the university” (Dunn et al., 2008, p. 5). In Jolene’s case, services seem to have been provided haphazardly and without critical thought paid to the realities of her life. Jolene’s experience speaks to the social model of (dis)Ability and the (dis)Abling environment that can so easily be created by negative attitudes of people who provide services (Oliver, 1990; Dunn et al., 2008).

Jolene said that she has learned ways of accommodating this difficulty on her own, such as creating to-do lists on her cell phone. Jolene’s injury occurred near the beginning of the school year and she had not yet discovered this strategy due to the extraordinary amount of stress she was experiencing at this time. Jolene said that if workers at the Centre had followed up with her after assigning the task of finding more information about computer software programs, then this would have led to better outcomes for her. Through considering Jolene’s experiences, it seems that following up with students to make sure their needs are being met so that they do not “fall through the cracks” is vital for (dis)Ability resource centres to do. Having appropriate services for the needs of each student they serve, to prevent situations like Jolene’s trouble with searching

out information on computer software, is another recommendation for appropriate service provision for students with ABI.

Barriers related to experiences with existing policy and procedure. Jolene, with years of education and a substantive student loan debt, has had negative experiences with student loan providers. Jolene was on medical leave from school because she was unable to complete papers and meet all the requirements in her master level courses due to acquiring a brain injury. According to Jolene, she was unable to secure a student loan while on medical level. Jolene said that she was able to acquire interest relief on her loan, meaning that she would not have to begin payments. While this is positive, Jolene said she was no longer able to secure student loan funds and this had been difficult, meaning that she had to work full time to pay for her living costs, while also completing her outstanding work. Jolene believed her academic progress would best be served by being granted permission to audit the classes in which she has outstanding assignments. There is a prorated fee for auditing classes and without being able to secure a student loan she was unable to make this financial commitment. Jolene felt she was ‘caught between a rock and a hard place.’ From an academic accommodation perspective Jolene needed to be given permission to audit the classes she had not been able to complete, yet being on medical leave makes you ineligible for a student loan, and without a student loan she could not afford to pay the auditing fees. Further, because Jolene was not enrolled in classes she was expected to start paying on her student loan, which would commence at a rate of \$600 per month. To complicate the situation further, given the effects of Jolene’s acquired brain injury, it was impossible for her to work full time and go to school. Jolene said that she gets concussion-related migraines that make it difficult to complete course readings. She also had difficulty with short-term memory and said that while she can

remember broad concepts, she has trouble remembering specific details, which makes it hard to write papers. Without student loan and the University working together to accommodate Jolene's health and learning needs, she will not be able to return to her masters studies. A couple of changes in policy could make substantive differences for this student.

Lisa described the process of disclosing that she has a (dis)Ability and how this can lead to benefits or barriers for her. While she finds filling out forms particularly difficult, she was also conscious about how disclosing that she has a (dis)Ability will be regarded by others. She told me about one occasion where she "accidentally" disclosed that she had a (dis)Ability to a potential employer and how she felt that this contributed to her not receiving the job. Lisa said that the employer "really wanted [her] for the job but he never called me back" and she felt that this was because she disclosed that she has a (dis)Ability. According to Bricout and Bentley (2000), non-(dis)Able job applicants are rated as more employable than (dis)Able applicants indicating that discrimination may play a role in the failure to hire (dis)Able people. The mis-education of employers about the physical and cognitive implications of having a brain injury may also play a role in this (Bricout & Bentley, 2000). In Lisa's case, she was not given the opportunity to contribute to the work environment and this could be because of negative stereotypes about the implication of Lisa's brain injury upon her ability to be a productive worker.

Jolene said that note taking and organization is an ongoing struggle for her. Unless a syllabus provides extremely specific instructions regarding expectations of papers to be written, Jolene's expectations and thoughts are outside what a professor expects. With note taking, what Jolene regards as significant in a lecture, may not in fact be what a

professor is attempting to emphasize. Organizationally, Jolene described the difference in terms of how she processes information by using a filing cabinet analogy. She says,

...before I could just listen... and in my head be like, 'ok we're talking about the paper now,' open the little... word file that says paper and then just remember this stuff. Ok put that back there, fill it, save, ok. Now when I go to do my paper that information's there.

Jolene said this process does not automatically occur for her anymore. She said, "if I don't write it down, it's gone forever".

Organization was a recurring theme that participants brought forward in the interviews, both in ways that they have learned to deal with being organized and the frustrations that mounted pertaining to organization from living with an acquired brain injury. According to Simpson et al., (2002) common implications of brain injury include memory problems, decreased concentration, trouble with problem solving and difficulties with processing new information. I conveyed my own experiences with increased organization that has been brought to my life from acquiring a brain injury. Adele was the only other participant who spoke about having a similar experience. Adele noted that being a student with an ABI has made her more organized and contributed to her personally developing strategies for learning. Lisa has experienced a great deal of frustration with medical professionals suggesting organizational/coping strategies that she believed are for people "less advanced" in dealing with the implications of their injury. Jolene used technology to help with organizational tasks, but found her lack of short-term memory affected her ability to be successful in this endeavor. For example, Jolene used the calendar option on her cell phone to help keep her organized, however she could not check her calendar when she was talking on the phone and by the time she has completed

the call she forgets to enter the meeting she has just scheduled into the calendar. Not being able to enter meetings immediately often leads to missed or double-booked meetings.

Researcher's Reflections

My ABI has contributed to my ability to be more organized and I think that this has been positively reflected in my school work. Like Jolene, I have recently begun to utilize the calendar option on my cell phone and I find this useful. Negatively, I sometimes feel I am overly organized and when unplanned circumstances arise, I am less able to cope with them. While I am less likely to forget daily activities when something new is introduced, I have a more difficult time incorporating this into my schedule. I also spend an inordinate amount of time on organization and this takes time away from other activities I could be enjoying. Like Lisa, I think that (dis)Ability supports available at university may have been helpful in my immediate recovery following my injury. I was unaware that my brain injury was considered a (dis)Ability when I began university education and now I have adapted my learning style to the classroom without the support of adaptations. When I became aware that I could utilize these supports, I felt that incorporating these into my learning style that had evolved over the several years since my injury, would cause more grief than being useful. Extra time allotted for course work is one adaptation that would be useful for me. Related to my current experience of working full-time and completed coursework part-time, extra time allotted for courses to be completed without extending tuition payments would be useful for me.

Barriers related to experiences with memory. Existing studies note memory loss as one of the predominate results of an acquired brain injury (Simpson et al., 2002; MacLennan and MacLennan, 2008). As might be expected, memory was a topic raised by several participants. To account for short-term memory loss Lisa devised flash cards to aid in studying for every course. While this is often time consuming, she said that the repetition is something she indisputably requires. Adele also said that her brain injury has affected her short-term memory. She said that she now forgets “everything” and relies on writing things down, putting information in her phone, saying things out loud to remember them or texting someone to remind her about things she wants to remember. In the instance of texting others, Adele relies on other people’s memory, with the assumption that it functions better than her own. Adele said she spoke with her doctor about the trouble she experienced with remembering things and he recommended taking more notes in class and developing her own shorthand. Adele has also incorporated research strategies learned in a qualitative research methods class into her note-taking and reading regime. Adele noted,

...I would have different color highlighters and I would write like specific quotes and stuff; I would pull them out and write them on another piece of paper and I would also use coding in the margins, so if I wanted to find something I would use like keywords in the margins next to the stuff so that I was able to pull stuff so... that’s really helped me.

For Adele, academic endeavors have virtually complemented her need to develop unique learning strategies and have lead to educational success. Memory tests were also part of Adele’s rehabilitation with progressively longer lists of words being presented to her for

later recall. Adele said that she used the concept of intentional memory in her school work, where she would tell herself about the importance of remembering certain concepts, and practice recalling it at a later time.

Researcher's Reflections

Like Adele, I struggle with short-term memory loss and I often assume that other people's memory is superior to my own. This has resulted in much frustration with certain people in my life who, although they do not identify as having a brain injury, have difficulty with remembering in certain circumstances. Although prior to my injury I was prone to forgetting things on occasion, I now associate anything I forget with being a negative implication of my brain injury, which has led to much frustration. Reviewing my journal entries during my hospitalized rehabilitation because of my brain injury and the entries that continued after I was discharged, I did not explicitly discuss my feelings around short-term memory problems but expressed anger toward people that assumed I had limitations. I now embrace these limitations and do not feel that they "hold me back." I no longer have intense anger toward those who might assume that I do experience restrictions. While these feelings of anger will be discussed in more detail later, I believe my education on (dis)Ability inclusion within sociology and social work courses has been therapeutic, and contributed to my peace with acquiring a brain injury. When I consider the experience of people who do not have a brain injury, I believe they have the advantage of not having to deal with the implications of forgetting vital material. Memory and subsequently not being able to retrieve my memory, is a constant reminder of how things are different now that I have an acquired brain injury. To compensate for my memory, I utilize a method suggested by Adele's doctor, which involves using my own

shorthand in note taking. I also find that memorizing the first letter of each primary word in a sequence of concepts is a useful strategy. Using these strategies has facilitated my academic success, but despite this I constantly wonder how my learning would differ had I not acquired my brain injury.

Barriers related to stigma and ignorance about acquired brain injury.

Acquiring a brain injury can influence one's sense of self-worth. As noted above, people with (dis)Ability negotiate a multi-faceted identity involving difference and stigma. For postsecondary students who acquire a brain injury, the problems they encounter in the academic sphere can lead to feelings of being "stupid" or "inferior" (Arceneaux, 2006, p. 90) According to Arceneaux (2006), many people manage stigma in individualistic ways, attributing the cause of their difficulties in the school environment to internal factors. Other stigma management strategies involve turning the focus toward others, disclosing the (dis)Ability to others and embracing one's identity (Arceneaux, 2006). Participants in this study conveyed stigma management in a range of ways. Lisa, for example, showed individualistic stigma management when she talked about not being able to attain good grades like she did prior to her injury. Lisa also showed focusing on others as the source of stigma when she discussed accommodations being suggested for her that do not meet her needs, as she talked about this as being frustrating as she wished professionals who are trying to help could take into account her perspective on her injury.

The diverse implications of brain injury upon identity are interesting to consider. Adele felt she "lost" her identity as an athlete because she could not participate in sports following her injury. Francine said her brain injury had not affected her ability to participate in sport, which was a major part of her identity. For Jolene, her sense of

identity was tied to academia and while she has not lost the ability to participate in this, changes in how she goes about this have resulted due to frequent migraines and an inability to retain new information such as specific details about events. For Jolene, feelings of pride and self worth are associated with academic ability and success. While other's perception of her intellect have not changed, and her ability to convey critically reflexive notions with material she attained prior to her injury remains untouched, her ongoing scholarship has changed. Jolene expressed that it has been frustrating when others do not understand the changes she has experienced, whereas for Louise the understanding of the implications of her brain injury left her with negative feelings that she described as others' perception of her as 'weak.' Jolene and Louise's consideration of the experience of acquiring a brain injury seem to differ in that Jolene has sought to convey her experiences in a way that people in her life could comprehend the barriers she encounters, where as Louise has sought for others to recognize her strength and vigor despite her disabling experiences.

While Jolene upholds the importance of academic rigor and scholarship, she also seemed to value the practical application of what she has learned in university. She described an encounter with the director of her academic department and a professor that she had after she suffered her ABI. The professor told the director that Jolene was a wonderful student, even though she had outstanding assignments due for the class the professor taught. In Jolene's words,

Here's what you [the professor] know about me: My reputation that precedes this injury and your experience with me in the [masters program] so my reputation of being a good student, an involved student... what they actually experienced was, I

was a horrible student [laughs]. I still haven't done papers that were due in September

Jolene also reasoned that if this professor was able to convey the excellence of her academic ability to the director, then the tangible consequences should be present as well; she wondered why she had not successfully completed this professor's course, if such positive remarks were to be made about her. Jolene became visibly emotional, crying when she said, "...I have a reputation that follows me that I cannot live up to in the same way and that's really difficult because people still expect me to." Jolene also spoke about the value attached to academia and scholarship but how, in her experience, this has not translated into her everyday life. Jolene said that people value academia but that she felt as if she would not be able to "make a living" doing this, although she noted that she has had many Teaching Assistantship jobs and reasons that this was one of the few jobs that she was able to do given the flexibility of professors in terms of the work expected.

Students with (dis)Abilities often encounter problems with gaining significant employment and working part-time research jobs was not a unique experience for Jolene (Dunn et. al, 2008). For Jolene, the cumulative effect of her (dis)Abilities, which includes physical limitations posed by an unrelated (dis)Ability, means that she has been unable to fulfill the requirements of many professions, both related and unrelated to her training.

Researcher's Reflections

Jolene's concern with academia and the practical application of what she has learned is an experience that I can emphasize with. I have some relatively minor physical limitations from my injuries that prevent me from doing certain jobs. At the time that our interview was conducted, Jolene and I had a discussion about how we had both tried to

uphold academic rigor despite our injuries and the shared feeling of frustration that this had not yet lead to paid employment. I felt as if all the effort I was putting into schoolwork was going to go unrewarded and not benefit me in the long run. Since this time, I have begun employment in my field of practice, and I am extremely thankful for this. The position I hold accommodates my (dis)Ability and allows me freedom to explore alternate routes for completing tasks, should my (dis)Ability pose a problem. While I am grateful that I have been able to attain such employment, it is nevertheless troublesome to me that this is unavailable to many people who have similar limitations to mine.

Participants in this study highlighted the importance of raising awareness about acquired brain injuries to both those servicing and teaching students within postsecondary institutions and the general public, with the aim to improve situations of those living with the effects of brain injuries. “A general lack of education and awareness around disability in general and more specifically, brain injury, combined with an under-funded and over-worked support system” leads to a variety of barriers for students with acquired brain injury (Lin Haag, 2009,p. 3) Awareness-raising can occur on micro and macro levels and the circumstances of each level impacts outcomes for students with brain injury.

Francine said that the (dis)Ability Resource Centre on her campus has been exceedingly supportive and she felt that a lot of students may be unaware that they exist and can help. She believed that making the Centre and services provided here more visible, would be beneficial. Adele also said that she felt that she does not know much about the (dis)Ability Resource Centre on her campus and whether she qualified for assistance. Jolene said that her experience of not having a worker at the (dis)Ability Resource Centre who had experience working with brain injury and accommodations she

might need, was a barrier in accessing appropriate services. Jolene thinks of having a brain injury as being part of a particular culture; while everyone experiences it differently, they all speak the same language and at her (dis)Ability Resource Centre, Jolene felt that no one spoke her language. According to Adele, “I think a lot of people, they see (dis)Ability services as like learning (dis)Abilities or cognitive (dis)Abilities or physical (dis)Abilities.” She went on to say that the Centre’s advertising says nothing about providing services for people with acquired brain injuries. Adele said, “...from an academic standpoint, I just didn’t know what was out there, like I knew if I had a broken leg, I knew I could get...accessible parking, but I had a broken brain. I didn’t know what to do with that.”

Researcher’s Reflections

When conducting research for this study, I investigated several (dis)Ability Resource Centres online. Out of the four that I explored, only one mentioned providing services for students with acquired brain injuries. Categorization of (dis)Ability seems to be significant in contemporary society. The classification of brain injuries has resulted in some ambiguity. While it is not a progressive or genetic-based (dis)Ability, brain injuries have elements of other (dis)Abilities such as learning (dis)Abilities or cognitive (dis)Abilities. Categorizing them in this way seems to be met with some hesitancy by the person who is experiencing the injury. I have thought about this in relation to (dis)Ability services before. I was not born with a (dis)Ability and this is not an experience that I have been dealing with for my entire life, unlike some people with (dis)Abilities. At the same time, I have doctor-provided documentation pertaining to my injuries and the limitations created by the (dis)Ability. This documentation supports my need for services and it have

been recognized by the (dis)Ability resource centres as legitimate proof of my (dis)Ability. However, the centres do not explicitly claim to serve students with acquired brain injuries, which creates in me feelings of ambiguity. It took me several years to acknowledge that my acquired brain injury resulted in me having a (dis)Ability. This label was something that I avoided using to describe my experiences. According to Schneider (2011, p.22), many people struggle to “come to terms with a disability.” When I finally did come to associate with this term, I did not immediately feel a sense of community with other students who utilized the centre’s services as few people shared my experience of living with an acquired brain injury. If acquired brain injuries are accepted as (dis)Abilities that (dis)Ability resource centres can provide services for, this needs to be more explicitly identified in promotional material for the centres. Perhaps if we were able to have our identities mirrored in the delivery of services we would embrace our identity sooner. Perhaps it would not be such an isolating experience, and a sense of community could be found.

According to Jolene, major overhauls of agencies that serve people with (dis)Abilities, such as brain injury, are needed. Jolene believes agencies require broader perspectives in viewing (dis)Abilities and their resulting implications, including acquired (dis)Abilities such as brain injury. Jolene’s struggle with fitting into the fixed criterion of the student loan policies highlighted for her how unpredictable the effects of brain injuries can truly be. Student loan companies, and others like it, have policies that do not seem to take into account the unpredictable and life-altering nature of brain injuries. Further to this, according to Jolene her brain injury has impacted her ability to do a wide range of jobs to earn wages to make student loan payments. Jolene said she felt trapped in

a hamster wheel, where she keeps running and running but never gets anywhere. The combination of these factors has resulted in much stress for her. Simpson et al., (2002, p. 32) note that:

Social workers can work towards changes in government policy and disability service program funding priorities to better meet the needs of people with TBI. Strategies include establishing brain injury service inter agencies, writing submissions to policy review processes and working along side consumer advocacy organizations.

Louise said that when she acquired her brain injury, she felt that not a lot was known about this in the general public. She said that this colored her understanding of brain injury at the time, as she considered her injury to be a minor nuisance, she did not consider the long-term implications of her injury. Louise said this changed when she took the liberty of conducting her own research through online searches. She was startled and surprised by the information she found. As previously noted, Lisa felt her mother has been a source of support in terms of conducting research related to her experience with brain injury, so that she could receive services that she needed. The example that Lisa gives is when her mother advocated that Lisa's doctor write a letter so that she could go to a Rehabilitation Centre. From the participants' experiences it has become clear that the person living with the brain injury and/or their family needs to be able to seek out information about the effects of the injury, treatment options, and rehabilitation and other services to aid in both the healing and living with the brain injury.

Lisa said that another youth from her community acquired a brain injury several years ago. She had given her phone number to guidance counselors at her high school and said that her and her parents would be willing to talk with anyone who had similar

experiences with brain injury and wanted support. When the parent of the youth with acquired brain injury spoke with Lisa, however, she said that this was a mostly negative experience. She said the parent was focused on “fixing” the negative implications of his daughter’s brain injury and when Lisa challenged this, saying that her experiences have made her a “better” person, the parent responded with hostility and disbelief. The parent seemed fixated on the events that lead to the brain injury and Lisa advocated that the parent not punish the daughter for mistakes that may have contributed to her attaining her injury. Lisa realized that the process of dealing with the outcomes of brain injury and incorporating this into your life is one that takes time and she felt this parent was not ready to speak with her yet. Lisa’s story highlights the different stages of coping with an acquired brain injury. Lisa’s story also suggests that someone who has had several years to come to accept their identity as a person with brain injury, may feel ready to share their story. Sharing their story may not be useful to someone who has acquired a brain injury more recently and is only beginning to deal with the implications of this. Support for people at various stages of dealing with the implications of brain injury is crucial.

Barriers related to socio-political beliefs and discourses around asking for help. Jolene’s sense of identity, which was closely related to her academic ability, was negatively impacted by her inability to do research or other academic activities following her brain injury. Francine also talked about the negative effect of brain injury on her ability to complete research papers to meet course requirements. While she sought accommodations in the form of extended time to complete her papers, she found it difficult to read articles, retain the information, and be able to integrate the information into her own writings. Jolene has appreciated and benefited from the support offered by her professors, such as allowing her to do private presentations due to her anxiety. The

support of her professors has helped Jolene with her confidence and in maintaining a sense of academic integrity. Confidence has been key to Jolene having a largely positive experience in postsecondary education with ABI, despite the barriers she has encountered.

Contra-intuitive to Jolene's confidence, her sense of identity has been negatively impacted by her experience with ABI. Brain injury survivors often struggle with re-asserting their own identity and being seen as survivors rather than "tragic victims" (Sherry, 2006 p. 209 as cited in Lorenz, 2010). When I ask Jolene to describe any negative experiences related to being a student with a brain injury in her postsecondary educational experience, she said, "one of the big things was... just seeing how... entrenched we are in the academia of it all... I can't really write papers... I can do other stuff but I can't really write papers so all of my classes are grades outstanding." This means that Jolene's professors have submitted a grade of ILL until which time her course work can be completed. As Jolene articulated, she can demonstrate learning of the material in an alternate manner but her graduate program was unyielding in that certain requirements must be met and Jolene has not met them in the manner required, so she cannot advance in her study. While this was a negative experience directly related to her injury, it has adversely impacted her thought about her field of study in particular and university education more broadly.

How people with brain injury are considered by mainstream society was vital to consider in this study. Refraining from "complaining" or speaking negatively about their experiences was an issue raised by several participants. My identity as a student with a brain injury was vital to ensuring that participants felt comfortable "opening up" to me but this also may have colored the way in which participants' relayed information to me.

As discussed previously, feeling life is unfair can arise following a brain injury, but Lisa stressed that she was happy with her achievements and was not “complaining.” Because she emphasized that she was not “complaining” throughout our interview, I posit that perhaps Lisa felt reluctant to speak negatively about her experiences because she wished to emphasize the strength and determination that have also characterized her experiences in postsecondary education. I think that if I had opened up more about shared experiences of difficulties as a university student with brain injury, this would have lessened Lisa’s concern with “complaining.”

I believe the shared experiences that were divulged contributed to quick rapport building with all participants and comfort with discussing certain topics such as those related to work ethic. Given that I employ self-disclosure of my brain injury in consent form material, as well as in interviews for this study, I felt some of the information conveyed to me would not be provided to an abled-bodied researcher. According to Lisa, “one of the worst parts is working so hard and not getting the grades... Like you would if you didn’t have a brain injury.” Lisa went on to talk about not being able to excel or meet the requirements for further education, such as pursuing master programs but stressed that despite the points she was raising, she was “not complaining”. Francine, conversely, indicated that she believed her brain injury was minor and the negative implications sustained by pushing herself to do school work immediately after acquiring the brain injury are implications that she was prepared to deal with. Francine said, “...that was my own choice so I kinda got what I deserved I guess.” In Francine’s case, “not complaining” but persevering and working hard despite her injury, are focused on. Previous research has indicated that, while some people will have uncomplicated school transition periods, most often complex (dis)Abilities resulting from brain injury require intense planning to

support the student adequately (Simpson et al., 2008). As is apparent in Lisa's case and is indicated in Francine's case, raising the need for academic accommodations is seen as being burdensome.. Adele also talked about changes in her learning strategies, where she was no longer able to retain most information by simply listening to a lecturer but had to begin taking more notes, and says it never occurred to her to utilize the services of the (dis)Ability Resource Centre at her campus because she felt that a concussion did not qualify for that assistance.

Researcher's Reflections

As noted previously, much like Adele, when I began postsecondary studies, I did not utilize (dis)Ability services as I felt that I did not qualify for them. When I consider this now, I wonder if maybe I was aware that they existed, but I did not consider myself to be a person who required such services. When I began university, then, I completed the requirements without assistance. I chose to take an art class in my first year, that did not require much research or academic strives outside the classroom. I spoke with one professor individually and described my experiences that may have contributed to difficulties I was having in his class, which were reflected in my grade for this particular course. In this way, I took personal actions related to difficulties that arose in my education that may have been related to my ABI, but I did not utilize formal services. My academic life would have been easier if I had accessed these services. While my perceptions of these services have now changed, I still do not utilize them due to developing a routinized way of adapting that contributes to rendering these services unnecessary for my academic success.

Feeling alone and isolated in dealing with the implications of brain injury was a theme throughout many of the interviews and this may relate to the reluctance to raise negative experiences that are seen as “complaining”. In terms of recovery and rehabilitation following a brain injury, “For women with TBI [traumatic brain injury] therapeutic goals have to acknowledge societal and cultural expectations of women, individual differences in negotiating role changes and (dis)Ability status and longstanding patterns of interacting in families and society” (Mukherjee et al., 2003, p. 7). Francine talked about her two (dis)Abilities and said when she felt the implications of her anxiety, it was in social situations such as delivering a presentation in front of a class. The implications of her ABI, conversely, were felt in solitude, such as when she was studying for tests. When the two (dis)Abilities intersected was when she felt anxious about receiving accommodations for her ABI, however Francine indicates that this was not a significant negative implication of brain injury for her. Francine, in fact, emphasized that her experience with two (dis)Abilities, anxiety and acquired brain injury, have been two distinct experiences and she did not believe that the two (dis)Abilities impact each other at all. Francine’s consideration may relate to a lack of sense of community in dealing with the implications of brain injury whereas Francine may have felt a more collective concern for issues related to anxiety. Raising issues that are not shared by a larger community, or at least not vocalized by others, may be seen as “complaining” whereas when issues are shared by others, such as other students who experience anxiety, they may be more likely to be raised and viewed as legitimately raised concerns. Many of the consequences of brain injury described by participants seem aligned with symptoms of other (dis)Abilities, such as assistance needing with reading article and writing papers, however ambiguity still seems to surround accommodations provided for brain injury in particular. Recently,

this has been addressed with increased discussion about concussions and much media attention being paid to the experience with ABI of celebrities like athletes. The proper balance must be struck in respecting the connections between people who have experienced brain injury and learning from unique situations and adapting service provision to meet the needs of these students, thereby reducing the risk of feelings of isolation.

Asking for help is something that many of us struggle with. Social workers are sometimes the worst culprits when it comes to this issue. Social workers operate in settings that may be challenging because of scarce resources and the needs of marginalized people and this can create vulnerability to distress (Pooler, 2011). For others, personal or social reasons, such as self-definitions related to independence and social taboos that urge self-sufficiency to avoid labels, may present difficulties with asking for help (de Zeeuw Wright, 2010). Adele talked about when she acquired her brain injury during an athletic event and how sports professionals were prepared to argue with her, insisting that she go to the hospital when she showed symptoms of a brain injury. She laughed as she talked about a first responder who spoke with her. “He’s like, ‘you have to go [to the hospital]’, he said this over and over again and I was just like, ‘I’m not arguing with you!’” I think this speaks to the common assumption that people, perhaps athletes in particular, want to persevere through whatever symptoms they experience and would rather not ask for help with situations involving their personal functioning. Adele’s experience relates to accommodations at university insofar as the effects of brain injury are often not immediately apparent and the person who sustained the injury, or others around them, may not feel that accommodations are needed. In Adele’s case, she was urged to seek assistance, however the converse may be true in academic settings. The

women in this study found that their (dis)Abilities were not physically visible and as a result they felt they were asked to provide proof of their condition. When university as an institution is considered, the exclusion of people with (dis)Abilities from organizational and educational planning committees can negatively affect their experience (Williams-Whitt, 2007). People with (dis)Abilities, including those with a brain injury, need to be represented on university committees, and they need to hold managerial and faculty positions within the institution. Having people with (dis)Abilities in these positions would be beneficial in at least two ways; one is that perspectives similar with those of students with (dis)Abilities would be represented, at least in understanding the needs and rights to accommodations, and two, students with (dis)Abilities would envision themselves as part of the university, knowing that they were welcomed through this mirrored image.

Jolene said that despite claiming anti-oppressive and critically reflective perspectives, her experience with her academic department has highlighted adherence to academic rigors. Adherence to academia means that the high standards of university were focused on when she sought accommodations. In considering the (dis)Ability Resource Centre on her campus, Jolene said that accommodations are mandated but that this simply means that they're "mandated to do something and they're doing something, which is great for some people and apparently that's enough." Jolene's critique of the services provided through the Centre recognized that the service meets the needs of some students but it fails to meet the needs of all (dis)Able students., specifically students whose accommodation needs may be unique. "Attitudinal barriers must be challenged for the full accommodation of students with (dis)Abilities" and this includes dispelling myths that students with less visible (dis)Abilities exaggerate their needs (Dunn et al., 2006, p. 14). According to Jolene, (dis)Ability resource centres provide services for students with

(dis)Abilities, but these may not be ideal in meeting students' needs. Jolene believed the best service providers are those who operate within existing policies, yet are creative and willing to advocate for accommodations that best meet students' needs, even if these are unprecedented and beyond the scope of the written policy.

Conclusion

Within this research, new learnings are highlighted about how the experience of acquiring a brain injury impacts one's life. The individual supports and barriers encountered underscore the uniqueness of each person's understanding of brain injury and the importance of open communication about the changes this presents in one's life. As participants' narratives in this research have demonstrated, each person that acquires a brain injury may experience different implications; therefore different accommodations may be required. Through listening to the stories of participant's recommendations, different suggestions for social work practice with students who have acquired brain injuries can be uncovered. The implications of this study for practitioners are discussed in more detail in the following chapter.

In considering participants' narratives presented in this chapter, several findings are significant to bear in mind. While Mukherjee et al. (2003) have found that students with brain injury can experience social isolation, the variable encounters of participants in this study speak to the need for increased support for some people in breaking down these obstacles. Added encouragement is especially needed in building relationships with peers. The differences in personal experiences and how acquiring a brain injury has impacted one's identity play a role in determining utilization of social supports. Mukherjee et al. (2003) note that some people may feel isolated from their existing social groups as well

as groups for people with (dis)Abilities, given the often invisible nature of acquired brain injury. The findings of this study indicate that how a person sees their (dis)Ability significantly impacts whether they accept social supports and whether they feel socially isolated. Findings indicate that connecting with others who have experienced brain injury may be useful only after coming to understand the impact of injury upon one's identity and whether they now see themselves as a person with a (dis)Ability or in some other manner.

The use of (dis)Ability resource centres depends upon personal interpretation of the injury and how the experience of (dis)Ability has impacted one's life. Just because (dis)Ability resource centres exist on university campuses, does not mean that all who could benefit from using their services, are accessing services. The time of onset of injury seems to influence the utilization of (dis)Ability resource centre services. When one has been dealing with the implications of brain injury for some time before beginning university, it seems more likely that they will use supportive services, as is evident in considering Lisa's experiences. This may speak to the usefulness of routines that have been in place for some time in the student's life, such as having accommodations in place in high school education or other post-secondary education. For those who acquire a brain injury later in their educational journey, such as in Adele's case, it seems more likely that they will approach barriers in solitude and find individual ways of coping with the implications of brain injury without the use of supportive services. This could indicate a lack of comfort with being provided accommodations, if one has not been accustomed to this previously in their educational career.

Literature has discussed the impact of policies upon people's lives and the importance of having (dis)Ability resource centres where people with (dis)Abilities can

“feel at home” and receive services to aid their academic journey, related to the (dis)Abilities they experience (Dunn et al., 2008; Megivern, 2002). According to participants in this study, however, the negative implications of policy still exist despite the existence of (dis)Ability resource centres. Some participants talked about not feeling that anything useful for their specific needs was provided by the (dis)Ability resource centre and that the centre did not feel like a welcoming place that spoke to their specific requirements. For (dis)Ability resource centres to provide the accommodation of special educational needs that they claim to provide, more comprehensive services are needed. Working to foster an inclusive environment, is necessary and this could be achieved by more attention being paid to the individual voices of students with (dis)Abilities.

Chapter Six: Implication of Findings for Social Work Practice

The focus of this study was on female students with acquired brain injury experiences within postsecondary education. Five women, from three universities within the province of Nova Scotia, were interviewed and subsequently provided narratives about their experiences in negotiating academic environments. The participants raise a number of issues pertaining to (dis)Ability accommodations and access to education. Both successful accommodations and difficulties in achieving accommodations were shared. Recommendations to postsecondary institutions to facilitate more effective and respectful accommodations emerged. Along with these recommendations, strategies that social workers can use to implement changes are noted.

People with acquired brain injury will encounter social workers, be it initially after the injury in rehabilitation centres, through negotiating structural barriers within society, or in job placement, employment counselling. Social workers must be aware of the institutional and structural barriers people with acquired brain injury face. Likewise, it is imperative that social workers are knowledgeable of the experiences of oppression encountered by (dis)Able persons. Therefore, this research serves to inform university services to students with acquired brain injury, and in general, to social work practitioners, through enhancing their understanding of what people with acquired brain injury go through and the structural barriers that need to be dismantled. Specific practice recommendations that arise from this research are presented below.

Offer Personal Emotion-Focused Counselling

The emotional impact of injury may be important to address with individuals following the acquisition of a brain injury. Participants in this study conveyed varied

perspectives on whether the accommodations available to them were “deserved.” Social workers in agencies that specifically provide individual counselling in relation to coping with emotional difficulties may be helpful in addressing emotional implications of acquiring a brain injury. Counselling related to a changed sense of identity in light of ABI is also relevant to social work practice with students with acquired brain injuries.

Brain injury can prevent participation in activities; activities that helped form the basis of identity for the person prior to their injury, such as driving or playing a sport. In considering the interviews with participants for this study, this is especially true if these were activities that lead to acquiring their brain injury. According to Lorenz (2010), “concerns with identity and self are endemic to surviving a brain injury” (p. 862). Adele and Lisa talked about how their sense of identity was closely connected to participation in sport. Following their acquired brain injuries, both were hesitant to return to playing sports and changes in self perceptions had to be made. Sensitivity to the inner struggles that students with brain injury endure is vital for practitioners to impart. Failure to deliver services in an empathic manner can be destructive to rehabilitative goals and slow the return to daily activities such as work, which can have negative economic consequences (Lorenz, 2010). For social work practitioners working with students with acquired brain injury, recognizing the emotional implications of brain injury is an essential beginning step. The person with the acquired brain injury and/or their significant others require accessible information about the injury and possible side effects, along with information about treatment options to assist with coping. Mukherjee et al., (2003), note that women living with traumatic brain injury may experience social difficulties in addition to emotional troubles. Participants noted negative social implications tied to their acquisition of a brain injury; an example is Lisa’s friends believing that she was “faking” her injury.

These negative emotions could be effectively managed with individual counselling to work through concerns related to acquiring this injury.

Strategy: In order to implement this practice recommendation, the strategy of recognizing where the student is at in coping with their injury is useful. If social workers begin working from this place, rather than jumping ahead to planning that the individual may not be prepared for, this will result in the best possible outcomes for service users.

Connect Students with Others with Similar Experiences

Slowed cognitive processing, memory difficulties and communication deficits can result from acquiring a brain injury, which can have an impact on relationships established prior to injury (Mukherjee et al., 2003). The invisible nature of brain injury can lead to women with brain injuries being excluded from networks for people with (dis)Abilities as well (Mukherjee et al., 2003). The social isolation makes it even more vital for people with acquired brain injuries to connect and share experiences and advice. Associating with other students who have acquired brain injuries can increase awareness of (dis)Ability support services that one may qualify for. Despite the individuality of the experience of brain injury, the importance of connecting with others who have had similar experiences should not be dismissed. My identity as a student with brain injury was disclosed to participants and they noted even small similarities in our collective experiences to be significant. Beginning with individual counselling and then working to connect students with others who have experienced brain injury to alleviate feelings of social isolation, can be an effective strategy for social work practice.

Access to others with brain injury is not always readily available. The Brain Injury Association of Nova Scotia is a province-wide network for people who have experienced brain injury. One of the primary goals of the organization is reduce feelings of isolation.

It is vital that those who have acquired brain injuries, particularly in rural areas, are vocal about their experiences and reach out to support others who have similar experiences. Discovering existing supports or working to establish these networks, are effective practices for social workers serving students with brain injury. Better knowledge and education of (dis)Ability supports, such as the services available through the accommodation centres, is needed in order to reach the most vulnerable students who may not be aware of assistance they can access.

Strategy: A strategy for implementing this practice recommendation is for social workers to facilitate the establishment of relationships with other students who have had brain injuries to increase service user's awareness of support services.

Address the Social Implications of Brain Injury

The social isolation that can occur after acquiring a brain injury can be alleviated by connecting with others with similar experiences, but the need for understanding by others in one's life who have not had similar experiences, persists. Trepidation over the perceptions of others in relation to their injury was a concern expressed by participants in this study. Concerns over the perception of others is something that social workers can address on a large scale, by providing services that promote awareness about the potential implications of brain injury.

Strategy: A collaborative care approach whereby the (dis)Able student is at the centre of care and family, friends and significant others are part of the care strategy. Specific attention is paid to reducing the isolation following the brain injury.

Advocate for Amendments in Policy

Brain injury is becoming a better-known phenomenon, however policies related to accommodation services and equipment that lag behind the realities of current society

can have negative impacts on students with acquired brain injury. One participant spoke about the damaging impact of student loan providers that have policies in place for students with long term (dis)Abilities but for students who have acquired a (dis)Ability mid-study, little support exists. Case specific consideration in special circumstances around the realities in the lives of a person who has recently acquired a brain injury would be useful in alleviating this concern. Social work practitioners can advocate for this cause utilizing skills such as research, navigating existing systems and connecting with those in positions of power to influence policies. For students with acquired brain injuries, having an advocate in a position of power is crucial. While social work professionals can work within systems on behalf of clients, having the support of other helping professionals, such as doctors, physiotherapists and occupational therapists, to reinforce this advocacy is useful. When supportive professionals are open to understanding the lived experiences of people with acquired brain injury, what were once silenced experiences can be vocalized, leading to more complete understandings of living with an acquired brain injury. The heightened understanding of brain injury can transform into identifying the gaps in policy and practice, resulting in better service delivery and ultimately a more accessible environment.

Strategy: Strategies to implement the practice recommendation of advocating for amendments in policy include conducting research on existing systems and connecting with those in positions of power to influence the implementation of change.

Assist Clients in Disclosing Brain Injury and Resulting Implications

Acquired brain injuries can affect one's perceived employability and ability to perform job-specific duties. Social workers can come to understand concerns that might be felt by students and how the issue can be raised in conversation with employers.

Support in all aspects of students' lives that have been impacted by brain injury is vital in ensuring success in the classroom. While the above issues can be addressed by social workers in the community, support within postsecondary institutions is important as well.

Strategy: An effective strategy for implementing this practice recommendation is for social workers to be involved in discussions around the benefits versus risk of disclosure of brain injury.

Advocate for Appropriate Postsecondary Accommodations

Participants note that instructors within postsecondary institutions should pay attention to difference in learning styles that have resulted from brain injury. Social work practitioners can promote such understandings and advocate that students with brain injuries should not have their knowledge tested in ways that do not speak to their particular learning styles that are impacted by their injury. Students with acquired brain injuries may need accommodations outside those that are generally provided by (dis)Ability resource centres and social workers can advocate for services that speak to the individual needs of students with brain injury. Some participants talked about what they seen as standard accommodations for students with (dis)Abilities, including writing exams in separate rooms, being given extra time to complete writing, receiving copies of classmate's notes and using specialized computer software for paper-writing. These accommodations were referred to by the participants as being useful, although not all students needed every service and many believed what they needed the centre did not provide. Organization, for example, was noted as being a major concern for a number of participants; therefore supports related to this would be useful. (dis)Ability resource centre professionals should be creative and innovative in establishing services for all students. From participants experiences this was not the case, as there seemed to be a

checklist of services available, if your needs could not be met from this checklist you were out of luck. Social workers can advocate for innovative accommodations that speak to the learning difficulties of students with acquired brain injuries, at the same time adhering to established academic standards. A strategy to implement the practice recommendation of advocating for appropriate post-secondary accommodations is for social workers to be hired by (dis)Ability resource centres at universities. Knowledge of services available through (dis)Ability resource centres and who is eligible to access these services, are issues identified by study participants. Social workers are known for their skills in navigating and negotiating resources. Applying those skills to working with this specific population of (dis)Able persons would empower the consumer and make for a more accessible postsecondary educational experience.

Many participants talked about developing their own individual strategies for coping with the implications of brain injury as they felt that this is something they needed to do. While trial and error may be necessary to determine what services are appropriate for each student, talking with others who have experienced brain injury may be helpful in discovering useful learning strategies. It is important that the individual voices of students are heard and the role of social workers in recognizing the wide-ranging implications of brain injury and working with students toward self-empowerment and an optimized learning environment is vital in academic, personal and social success in postsecondary education. Social workers should have a place in the academic environment as they could provide advocacy services for students and work with them toward self-empowerment and obtaining appropriate accommodations. The results of this study have the ability to impact services provided by (dis)Ability resource centres at universities. The centres at the universities attended by participants will be provided with an executive summary of

this study. Social workers who serve students with (dis)Abilities can benefit from considering needs identified by students and whether the services they offer meet these needs.

In relation to accommodations in postsecondary educational institutions, it is important that individual voices of students with acquired brain injury are heard. For these students, who may be dealing with emotional and identity challenges related to their injury, self-advocacy may not come easily. Social workers could be part of university counselling services and could liaison with (dis)Ability resource centres to promote ideas in support of students with acquired brain injuries. Vital in contributing to the academic, personal and social success of students with brain injury is the social work role in recognizing the wide-ranging implications of brain injury and working with students to enhance self-empowerment and secure an optimized learning environment.

Chapter Seven: Conclusion

Engaging in this research provided participants, and myself as the researcher, a meaningful avenue for expressing our frustrations and concerns about access within postsecondary education. Discovering shared experiences validates one's struggles and decreases the sense of isolation felt within postsecondary education. Useful strategies in negotiating postsecondary education were /shared and recorded in the findings. Participants will be getting an executive summary of the research findings, which will highlight these strategies. Ideally, it would have been amazing to get participants together in a focus group but time, resources and practicalities did not facilitate this happening. A second tier of research would be to hold focus group of students who identify as being (dis)Abled within postsecondary education. These groups could be formed according to (dis)Ability identities, such as acquired brain injury, mental health (dis)Abilities, etcetera or groups could be formed according to degree level (bachelor, masters, doctoral).

While commonalities existed between participants, there were also unique distinctions within their experiences. The insights and knowledge gained through conducting this research will carry with me into my social work practice and in working with students with brain injuries in the future. During interviews, I had the opportunity to listen to participants' voices and understand how they make sense of their experiences. Comprehending participants' experiences is valuable in understanding how the occurrence of trauma impacts peoples' lives and is significant to my social work practice with various populations.

The results of this study have the ability to impact services provided by (dis)Ability resource centres at universities. The centres at the universities attended by

participants will be provided with an executive summary of the study. Workers at (dis)Ability resource centres can benefit from considering the needs identified by students. Further, this might ignite an internal analysis of their services, whereby they critically examine their own services and what changes need to be made. A copy of the executive summary of this study will also be posted at the Dalhousie School of Social Work for future social work practitioners to view. The Canadian Association for Social Work Education, Disability Caucus has surveyed Schools of Social Work in Canada, the United States, the United Kingdom and beyond, examining services and curriculum pertaining to (dis)Abilities. They might be interested in receiving an executive summary of this research. The Nova Scotia Association of Social Workers will be provided with a brief overview of the findings of this study for publication in their newsletter that goes out to all registered social workers in the province. Participants will also be provided with a summary of findings and these may be useful in going forward in their educational journey. Participants may discover accommodations that they were unaware of previously or they may discover new techniques for learning that speak to their educational needs. Finally, the ultimate goal is to produce a manuscript for peer-reviewed publication on this research, thus disseminating the findings broadly within academic circles, thus reaching as many students, faculty and (dis)Ability centre personnel as possible.

The findings of this study can inform future research. It would be interesting to consider experiences of (dis)Ability related to brain injury and other social constructs such as race, age, and class . The experience of acquired brain injury in rural areas is an area of much interest for me, but could not be undertaken in this research due to practical limitations. For people who acquire a brain injury and are living in rural areas, access to knowledge and services to support their rehabilitation may be limited. Research on the

experience of brain injury for people living in rural areas is another topic for potential future exploration. While this study has focused particularly on females, it would be thought provoking to consider differences and similarities in experiences for male university students with acquired brain injuries.

I have acquired an intimate knowledge about the experiences of participants in this study, however, much more information regarding the topic of brain injury and postsecondary education exists. The experience of acquiring a brain injury is one that has become more prevalent in recent years and, over time, I anticipate that understandings of this injury will be enhanced and this will positively influence service provision. Aids that are appropriate and beneficial to students attaining postsecondary education while dealing with the implications of brain injury are a tenant of accessible education and should be widely available if universities claim to provide comprehensive services.

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Appendix A

Thesis: *Female Students' with Acquired Brain Injury: Experiences of University Education*

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STORYBOARD

Within this research, you will be asked to recall your experiences as a student with an acquired brain injury within postsecondary education. During your studies at university have you requested learning accommodations, such as access to assistive technology, the services of a note-taker, quiet space to write exams and so forth? In requesting these services were your needs met? If you did not request service, how come? If you have had negative experiences at university, what would improve these? Did you find material on (dis)Ability policies, how to make accommodation requests and other (dis)Ability services readily available?

Identify the barriers and facilitators you have experienced in accessing postsecondary education as a student with a (dis)Ability. What could universities do to improve the experiences of students with (dis)Abilities, and particularly student with acquired brain injuries?

Appendix B

Research Questions

Thesis: *Female Students' with Acquired Brain Injury: Experiences of University Education*

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1. Can you describe any experiences, positive or negative, related to being a student with a brain injury in your postsecondary educational experiences?
2. Do you feel able to raise your concerns related to brain injury with staff at the Disability Resource Centre, professors or others at your postsecondary educational institution?
3. Can you describe a time where a concern was raised related to your brain injury and was dealt with in a way that was beneficial to you?
4. Can you describe a time where a concern was raised related to your brain injury and was dealt with in a way that had a negative impact on you?
5. Do you feel as if instructors take into consideration your specific disability and how it impacts your educational needs? How so?
6. What changes would you recommend to improve services provided for students with acquired brain injuries at the university level?

Appendix C

Information on Study

Thesis: *Female Students' with Acquired Brain Injury: Experiences of University Education*

<p>✚ Are you a university student?</p> <p>✚ Are you female?</p> <p>✚ Do you have an acquired brain injury?</p> <p>✚ Have you had the brain injury for at least one year?</p>
--

If you answered yes to the above questions then you qualify for this study. I am exploring female students, who live with an acquired brain injury, experiences of university education. Having acquired a brain injury myself, I had encountered struggles within university and I have experienced accommodations that were helpful in meeting my academic goals. In working in a variety of health areas I have seen the diverse struggles and challenges that can affect people living with brain injuries. I believe that universities can provide an accessible learning environment for students with (dis)Abilities. Hearing from you about your experiences will help shape accommodation recommendations that will be shared with the universities within the Halifax Regional Municipality.

Specifically, I will be asking you to speak to the following:

Within this research, you will be asked to recall your experiences as a student with an acquired brain injury within postsecondary education. During your studies at university have you requested learning accommodations, such as access to assistive technology, the services of a note-taker, quiet space to write exams and so forth? In requesting these services were your needs met? If you did not request service, what prevented you from doing so? What would improve your experience at the university? Did you find material on (dis)Ability policies, how to make accommodation requests and other (dis)Ability services readily available? Identify the barriers and facilitators you have experienced in accessing postsecondary education as a student with a (dis)Ability. What could universities do to improve the experiences of students with (dis)Abilities, and particularly student with acquired brain injuries?

If you agree to participate in this study there will be pre-interview contact where I will explore with you any questions or concerns you might have about your involvement in this research. I will also discuss with you what supports you have in dealing with the affects of brain injury. This interview will not be part of the data collection. This interview will take about 30 minutes.

If you agree to go forward, we will set-up a time for the interview. The interview will take approximately 2 to 3 hours.

I will contact you after the interview and ask you to read the transcript and tell me if I have accurately captured the interview. This should take approximately one hour to read the transcript and one hour to meet following your review.

This research study has been approved by the Social Sciences and Humanities Research Ethics Board of Dalhousie University. Please contact Catherine Connors, Director, Research Ethics, Dalhousie University at (902) 494-1462, or e-mail ethics@dal.ca if you have any questions or concerns.

If you are interested in participating in this study, please contact:

Kendra Gottschall, BA (Hons), BSW, MSW (candidate)

Call: (902) 429-1331

Or

E-mail: Kendra.gottschall@dal.ca

My supervisor for this thesis is Dr. Judy MacDonald and she can be reached at (902) 494-1347 or judy.macdonald@dal.ca

Appendix D

Consent to Participate in Research

Thesis: Female Students' with Acquired Brain Injury: Experiences of University Education

Student Researcher:

Kendra Gottschall
(902) 429-1331
Kendra.Gottschall@dal.ca
1333 South Park St. Apt. 713
Halifax, N.S.
B3J 2K9

Supervisor:

Dr. Judy E. MacDonald
(902) 494-1347
judy.macdonald@dal.ca
1459 LeMarchant St. Suite 3201
Halifax, N.S.
B3H 3P8

Please read this consent form carefully, and after reading through this form if you wish to participate in this research sign and date the form. If you require assistance in comprehending the information presented, such as an auditory presentation, please inform me of this and I will verbally go over the document. If you are physically unable to sign this document, an electronic signature can be provided.

Introduction

In fulfillment of the requirements for my Master of Social Work degree at Dalhousie University, I am conducting research on the experience of students with acquired brain injury within postsecondary education. If you meet the following criteria, you are invited to participate in this research:

- female
- student enrolled in postsecondary education
- acquired a brain injury over a year ago

Please note: Participants whose injury has occurred within the past year will not be included in this study due to evidence that suggests time is needed to incorporate brain injury into one's life and to deal with all the implications that might arise.

Your participation in this study is completely voluntary, and you can choose to withdraw from the study at any point, further you do not have to answer any question that you are not comfortable answering. I will be conducting interviews with five participants who meet the above criteria.

Study Design

I come to this topic with my own personal experience of acquiring a brain injury and subsequently negotiating a university education. My awareness of the diverse implications of brain injury will inform my research approach. The research will consist of one (two to three hour) interview where I will ask you six prepared questions and I may ask additional questions as issues arise. Please feel free to elaborate and include additional information that I have not specifically asked about, as everything that you are willing to share is of value in this study. This is your story and you are encouraged to tell it in your own manner.

What you will be asked to do

The interview will take place at your university campus in a mutually agreed upon location. After I have transcribed the interview, I will forward a copy to you for review and arrange a follow up meeting to discuss any changes you may want to make. If you do not wish to review the data on your own, I will offer to review it with you during a follow up meeting. If you do not consent to either of these options, I will not use your data in my final research. I will provide a resource sheet that includes the contact information for the Brain Injury Association of Nova Scotia, counselling services at the particular university

you attend and contact information for the provincial organization of Postsecondary Disability Services.

Possible Risks and Discomforts

Despite efforts to ensure otherwise, risks involved with participating in this study do exist. I have thought of some, but others may exist that I am not aware of.

- Emotional vulnerability can result from telling your story and difficult emotional and physical times may be recalled. "...Stories are usually constructed around a core of facts or life events, yet allow a wide periphery for the freedom of individuality and creativity in selection, addition to, emphasis on, and interpretation of these "remembered facts" (Lieblich, Tuval-Mashiach and Zilber, 1998, p. 8). A sheet with helpful resources, such as counselling and information related to (dis)Ability and postsecondary education, will be given to the participant following the interview.

- Although confidentiality measures have been taken into consideration and your name will not be attached to any of the information provided, (a pseudonym will be used), the chance exists that someone could identify you through aspects of your story. I will take measures to ensure that identifiable information does not appear in the published data and forwarding you a copy of the transcript upon completion will aid this. A follow up meeting will be arranged where any concerns about the data produced can be discussed and I will make changes where necessary.

- My professional code of ethics obligates me to breach confidentiality if you reveal that you have or plan to harm yourself or others. If this occurs, I will remind you of my professional responsibility.

Possible Benefits

Through participating in this research, it is expected that you will receive the following benefits:

- The opportunity to tell your story can lead to positive emotional impacts, such as feelings of accomplishment in overcoming presented obstacles. This is a direct benefit you may receive from participating in this research.
- The analysis of the research for this study will include implications for practice and the opportunity to contribute to procedures that could be used to make a difference in another person's life can be rewarding for you and can lead to personal and professional involvement in policy-related practices. This is an indirect benefit of participating in this research.
- Following the interview, I will transcribe the data and will forward a copy to you. I will also arrange a follow up interview where any changes you want to make to the data can be discussed. This will ensure that your experiences are captured in a way that is meaningful for you and rings true to how you feel about the experiences. This is a direct benefit you may receive from participating in this research.

Confidentiality and Anonymity

All work for this thesis is conducted in association with Dalhousie University, School of Social Work. There will be no names attached to my research and any identifying information will be concealed in the final product of research. All documents and recorded interviews will be kept in a secured locked cabinet at my place of residence where I am the only person with the combination. I will destroy the data five years

following the defense of my thesis by destroying the tape on which the information is recorded. The information you provide will only be used by me and viewed by my supervisor. No one else will have access to the transcript of your interview. If you have any questions or concerns, please do not hesitate to contact me at (902) 266-5002 or Kendra.Gottschall@dal.ca . My supervisor is Dr. Judy MacDonald and she can be reached at 902 494-1347 or Judy.MacDonald@dal.ca.

Please note all quotations may be used in my research unless you specifically request for this not to occur. If any information is provided that notes abuse or neglect of a child or an adult in need of protection, please keep in mind that it is my professional duty to report this information.

I would like to sincerely thank you for your participation and assure you that the information you provide will enrich my knowledge, as well as others within the social work profession, the university community and disability services specifically. I hope that this enriched knowledge will contribute to more informed and responsive social work practice in the future.

Problems or Concerns

If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, you may contact Catherine Connors , Director, Research Ethics, Dalhousie University at (902) 494-1462, ethics@dal.ca.

Signature Page

I, the undersigned, consent to participate in this research as an interviewee:

Name (Please Print)

Signature

Date

I, the undersigned, agree that quotations from my interview may be used in the final research report:

Name (Please Print)

Signature

Date

I, the undersigned, consent to the researcher contacting me after the initial interview to conduct follow up conversations

Name (Please Print)

Signature

Date

I agree that my interview may be audio-taped

I agree that the researcher, in a final report, may use quotes from my interview

Kendra Gottschall
B.A. (Hons), B.S.W., M.S.W. (Candidate)
Dalhousie University

References

Lieblich, A., Tuval-Mashiach, R. and Zilber, T. (1998). *Narrative Research: Reading, Analysis and Interpretation*. Thousand Oaks, California: SAGE Publications, Inc.

Appendix E-1

Debriefing Protocol

Thesis: *Female Students' with Acquired Brain Injury: Experiences of University Education*

Student Researcher:

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Supervisor:

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Halifax, N.S.
B3H 3P8

The centres listed below are aware of this study and have agreed to serve as a resource to participants. Should you have any concerns or need anyone to talk to about matters that may have arisen from participating in this study, please contact one of the agencies below.

Brain Injury Association of Nova Scotia

bians1@ns.sympatico.ca

13th Floor, Victoria Building VG Site
QEII Health Sciences Centre Halifax, N.S

Phone (902) 473-7301

Fax (902) 473-7302

Mount Saint Vincent University Counselling Centre

Contact Julie Fillmore at (902) 457-6567 to book an appointment.

Evaristus Hall, Room 218 Mount Saint Vincent University
Halifax, Nova Scotia B3M 2J6

Postsecondary Disability Services

Phone: 424-6737 (Halifax) or toll-free within Nova Scotia 1-800-285-1197

Civic Address:

Brunswick Place 2021 Brunswick St, 4th floor

Appendix E-2

Debriefing Protocol

Thesis: *Female Students' with Acquired Brain Injury: Experiences of University Education*

Student Researcher:

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bians1@ns.sympatico.ca

13th Floor, Victoria Building VG Site
QEII Health Sciences Centre, Halifax, N.S

Phone (902) 473-7301
Fax (902) 473-7302

Dalhousie Counselling Services Centre

4th Floor, Student Union Building
6136 University Avenue Halifax, NS B3H 4R2
Victor.Day@dal.ca
Phone: (902) 494-2081
Fax: (902) 494-3337

Postsecondary Disability Services

Phone: 424-6737 (Halifax) or toll-free within Nova Scotia 1-800-285-1197
Please direct your General Enquiries to our secure online form.

Civic Address:
Brunswick Place 2021 Brunswick St, 4th floor

Mailing Address:
Nova Scotia Department of Labour and Advanced Education Postsecondary Disability
Services
P.O. Box 578 Halifax, NS
B3J 2S9

Appendix E-3

Debriefing Protocol

Thesis: *Female Students' with Acquired Brain Injury: Experiences of University Education*

Student Researcher:

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bians1@ns.sympatico.ca

13th Floor, Victoria Building VG Site
QEII Health Sciences Centre Halifax, N.S

Phone (902) 473-7301
Fax (902) 473-7302

St.FX University Counselling Services

Bloomfield Centre 421
Phone: (902) 867-5349
Fax: (902) 867-3979
Email: tramble@stfx.ca

Postsecondary Disability Services

Phone: 424-6737 (Halifax) or toll-free within Nova Scotia 1-800-285-1197
Please direct your General Enquiries to our secure online form.

Civic Address:
Brunswick Place 2021 Brunswick St, 4th floor

Mailing Address:
Nova Scotia Department of Labour and Advanced Education Postsecondary Disability
Services
P.O. Box 578 Halifax, NS
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