SERVICES FOR COLLEGE STUDENTS WITH TRAUMATIC BRAIN INJURIES

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By

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SERVICES FOR COLLEGE STUDENTS WITH TRAUMATIC BRAIN INJURIES

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ABSTRACT

SERVICES FOR COLLEGE STUDENTS WITH TRAUMATIC BRAIN INJURIES

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There are many students who have sustained a Traumatic Brain Injury (TBI) who are pursuing post-secondary education each year and many of these students will need accommodations to successfully graduate from college. Accommodations for students with TBI in primary and secondary education are well documented; however, accommodations that are provided for students in post-secondary education have not been studied to date. Further, there have not been studies examining what services may be helpful for students with TBI in post-secondary education. The present study examined the college disability services provided for students with TBI in post-secondary education and what accommodations may be beneficial, using a qualitative design. Respondents from twelve colleges were interviewed to gain insight about accommodations in their setting. The results provide a better understanding of what accommodations are provided and those that may be beneficial for students with TBI in
college settings. Suggestions are made for staff at universities to help better serve students with TBI, improving their successful completion of post-secondary degrees.
To my family, who have supported me throughout my journey to where I am today. Especially to my father, Brian, who has always inspired me with the sacrifices he has made and his determination to beat Wegener’s Granulomatosis.
ACKNOWLEDGEMENTS

I cannot thank my committee enough for all of their help with this study. Without Dr. Susan Davies, Dr. Elana Bernstein, and Dr. Molly Schaller, I could not have completed this. I would also like to thank Carol Borchers for laying some of the groundwork for this study. Thank you to Ryan May for helping me find some of the citations in this study. Finally, thank you to my family for supporting me during this project.
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CHAPTER I

INTRODUCTION

It is estimated that 1.7 million people have experienced a traumatic brain injury (TBI) in the past year and similar rates are expected in the coming year (Centers For Disease Control and Prevention, 2012). TBI has recently gained attention in the popular media, largely due to concussions sustained by professional athletes and TBIs sustained by military personnel. In fact, the National Football League is now encouraging and funding research on TBIs to better protect athletes. However, TBIs do not only occur while playing professional sports or in military combat. TBIs can occur at any time to individuals of all ages. In fact, the most common groups to sustain TBIs are children zero to four years and adolescents fifteen to nineteen years old (Centers For Disease Control and Prevention, 2012). Thus, it is important for educational systems to understand how to identify and respond to the needs of children and adolescents with TBIs.

Individuals who sustain a TBI may experience a range of physical, cognitive and social-emotional symptoms (Lewandowski & Rieger, 2009), all of which impair a student’s learning capability. Students who experience TBIs may struggle in school (Lewandowski & Rieger, 2009; Yeates & Taylor, 2006). These students may struggle with remembering information, focusing, with fatigue, and/or with their behavior.
(Lewandowski & Rieger, 2009; Yeates & Taylor, 2006). For this reason, school-based accommodations are mandated for students in primary and secondary education settings who are identified with a TBI under the Individuals with Disabilities Education Improvement Act of 2004 (IDEA). Unfortunately, there are no mandated accommodations for college students, and there are scant studies of what accommodations are provided in postsecondary settings (Kennedy & Krause, 2010; Todis & Glang, 2008). Thus, the purpose of this study was to explore the quality of services college students with TBI receive and what services and accommodations might improve their learning. Additionally, typical services and accommodations were reviewed and assessed for feasibility in the college setting.
CHAPTER II
LITERATURE REVIEW

The following literature review describes the definition and prevalence of TBI, effects of TBI, problems faced by college students with TBI, recommended accommodations for students with TBI, and current post-secondary supports for students with special needs, including TBI.

Definition and Prevalence of TBI

Traumatic brain injury (TBI) is defined as any acquired injury to the brain (National Institute of Neurological Disorders and Stroke, 2012). The injury often develops from some form of trauma. Common sources of trauma resulting in TBIs include: injury causing penetration of the skull, deceleration of the head or blow sustained to the head, or a surgical or medical procedure that causes damage to the brain and disrupt normal functioning for a period of time (National Institute of Neurological Disorders and Stroke, 2012). A mild TBI (mTBI) includes a concussion that may include only a short loss of consciousness, though a loss of consciousness is not required for a diagnosis of a mild TBI (National Institute of Neurological Disorders and Stroke, 2012). A severe TBI is one that results in a prolonged coma (National Institute of Neurological
Disorders and Stroke, 2012). For this thesis, the term TBI will include all injuries to the brain from mild to severe, except those that occurred before or during the birth process.

Of the 1.7 million people who sustain a TBI each year, 52,000 will die from complications caused by their TBI (Centers For Disease Control and Prevention, 2012; National Institute of Neurological Disorders and Stroke, 2012). Another 1,365,000 will be treated in the emergency room, and another 275,000 will be hospitalized for a period of time (National Institute of Neurological Disorders and Stroke, 2012; Centers For Disease Control and Prevention, 2012). The most common causes of TBIs include falls (35%), motor vehicle accidents (17%), and being struck by or against an object (16%) (Centers for Disease Control and Prevention, 2012).

According to the Centers for Disease Control and Prevention (CDC), the most common groups to sustain TBIs are children aged zero to four years and adolescents aged fifteen to nineteen years old, due to falls and automobile accidents, respectively (Centers For Disease Control and Prevention, 2012). Therefore, school-based personnel will likely work with students who have sustained a TBI. It is estimated that five to ten students in a high school of 1000 have sustained a TBI requiring hospitalization annually (Lewandowski & Rieger, 2009). Many of these students may continue to have symptoms throughout college. This group, along with students who sustain a TBI while in college, highlights the need for accommodations at the postsecondary level.

**Effects of TBI**

A student who sustained a TBI may experience physical, cognitive and social-emotional symptoms (Lewandowski & Rieger, 2009). Physical symptoms include
headache, nausea, fatigue, light and/or noise sensitivity, sleep disturbances, and ringing in the ears. Cognitive symptoms include confusion, memory loss, working memory impairment, inability to concentrate, inattention, slowed processing, and trouble finding the right words for things. Social-emotional symptoms include irritability, nervousness, difficulty regulating emotions, social withdrawal, becoming easily overwhelmed and decreased motivation (Lewandowski & Rieger, 2009). These symptoms can adversely impact a student’s performance in school. Students may easily tire after tasks for which they once had more stamina, such as taking tests or doing homework.

In addition to physical, cognitive, and social-emotional symptoms, students who experience TBIs are more likely to exhibit behavioral problems after sustaining a TBI (Yeates & Taylor, 2006). These behavior problems can lead to adverse effects on academics as well as general social functioning in students (Yeates & Taylor, 2006). This can be a factor in determining a need for special education services. The types of problematic behaviors exhibited by students with TBIs include both externalizing and internalizing behaviors (Fowler & McCabe, 2011). Externalizing behaviors may include aggression, noncompliance, inattention, and emotional outbursts (Fowler & McCabe, 2011). These symptoms have been linked to more serious behaviors including aggressive and assaultive behaviors (Fowler & McCabe, 2011).

**College Students with TBI**

The aforementioned symptoms can present unique difficulties for college students. During high school, many students received help from their parents as well as an individualized classroom experience (Gil, 2007). College classes tend to be larger and
less individualized, making it more difficult for students to access their professors for extra help (Todis & Glang, 2008). The help students previously received from their parents may have included advocacy, which students in college are expected to do independently. For many students, college involves less structure and more unsupervised free time (Gil, 2007; Todis & Glang, 2008). The lack of structure can lead to confusion and/or frustration. The unsupervised free time can lead to students participating in activities that could re-injure the brain while it is still healing. Some of these activities may include intermural sports, which would not involve an athletic trainer who might suggest that the student refrain from play after a blow to the head. Finally, the lack of required accommodations for students with TBIs could result in difficulties with academic tasks.

**Suggested Accommodations for Students with TBI**

Some long-term accommodations that tend to help students with TBIs include extended time on tests and assignments, the ability to take breaks as needed, and distraction-reduced environments (Yeates & Taylor, 2006). Extended time is effective for students with TBIs because individuals tend to have slower processing speeds following a TBI, particularly during the healing process. McAvoy (2012) recommends the following accommodations that can be helpful for students experiencing slower processing speed: reduced workloads, use of a tape recorder, use of organizational helpers or technology, and adjusted due dates. Extended time and distraction-reduced environments are effective for students who have difficulty sustaining attention after a TBI. The increased fatigue often seen in students with TBI makes taking breaks very
important; studies have shown that this leads to faster and more complete recovery (Yeates & Taylor, 2006). Further, to help with fatigue, shortened days are recommended immediately after a TBI as needed as a student needs rest during this period of time.

Other accommodations that can help with mental fatigue include cutting back on work, sunglasses for light sensitivity, and headphones to dampen sound for noise sensitivity. To help with difficulty learning new concepts, especially immediately after a concussion, it is recommended that any tests or projects are dismissed or at least postponed.

Other accommodations that are helpful include ensuring the student understands material (rather than just memorizing), and trying to teach only the most concrete and salient elements of a lesson rather than requiring students to memorize a large number of facts. All of these accommodations should be provided to students immediately after a concussion. For moderate and severe TBIs, it is recommended that material is repeated and spaced out in small chunks rather than presented all at once (Hillary et al., 2003). As symptoms improve, accommodations should be scaled back as appropriate as students no longer need them. For students who are experiencing long-term issues because of their TBI, continuing accommodations is recommended (Yeates & Taylor, 2006).

Some students with an acute TBI may need accommodations only during the recovery period. Receiving extended time, small group testing, reduced or excused assignments, frequent breaks, and being allowed as much rest as possible are very helpful (Yeates & Taylor, 2006). Shortened days, and teaching only the concrete parts of lessons with checking for comprehension tend to be very helpful as well (Hillary, et al., 2003).
Many times, for acute concussions or mild TBI, direct instruction for functional academic skills and social skills is not necessary (Yeates & Taylor, 2006).

**Transition Services**

When a student is transitioning back to a primary or secondary school setting after sustaining a TBI, it is the responsibility of the parent to contact the school and request an evaluation of their child if they feel one is needed (Disability Rights Ohio, 2012). The school will then respond, conduct the evaluation if it is deemed necessary, and meet as a team with the student and parents to decide what services are needed (Individuals with Disabilities Education Act, 2004). Sometimes, the student’s teacher, school nurse, or doctor may suspect a disability and recommend an evaluation. This would then trigger Child Find laws, which would start the evaluation timelines and process (Individuals with Disabilities Education Act, 2004). When a child who is identified with a TBI of any severity under IDEA is turning 14, the school-based team will start to plan for transitions after high school (Individuals with Disabilities Education Act, 2004). If the student is planning to attend college, this should be included in the student’s required transition plan. Such planning should include researching what colleges the student is interested in, contacting disability services at the college, and attempting to work with the college to ensure appropriate services will be provided to the student when they begin attending college (Disability Rights Ohio, 2012; Gil, 2007). Most colleges will require, but cannot ask for, proof of a traumatic brain injury as well as what accommodations were provided in high school (Disability Rights Ohio, 2012). The information about accommodations must be from within the past year and needs to include evaluation data such as
intelligence and achievement testing performed by the school (Disability Rights Ohio, 2012; Gormley, Hughes, Block & Lendmann, 2005). It is the student’s responsibility to make sure the college receives this information and to advocate for the student to make sure he is receiving the appropriate services. If a student sustains a TBI during college, all information from a psychological evaluation must be sent to the college in order for the student to receive services (Disability Rights Ohio, 2012). The student will not have a team helping to ensure that this data is forwarded, so this may take more work for the student.

**Post-Secondary Educational Support**

Some barriers exist at the college level for students with TBI who would benefit from special services. In high school, students who sustain a TBI may be evaluated to determine if they qualify for special education under the TBI category if the student’s team suspects a disability and that this is adversely impacting their education. If a student qualifies for special education in high school, he or she is provided with individualized supports, which target any deficits that may impact educational performance.

Most colleges do not have a team that will test and evaluate a student to determine specific needs or write up an individualized education plan (Scott, 2011). Instead, a college office of students with disabilities may receive paperwork from the student’s high school or a doctor and will then decide if the student is likely to need accommodations (Gormley, Hughes, Block, & Lendmann, 2005; Scott, 2011). Students who have had well written effective transition plans as part of their Section 504 plan or IEP are more
likely to have the proper paperwork and are more likely to seek out accommodations in post-secondary education (Gormley, Hughes, Block, & Lendmann, 2005; Joshi & Bouck, 2015; Lindstom & Lindstrom, 2011; Newman, Madaus & Javitz, 2016). Instead of being bound by the Individuals with Disabilities Education Improvement Act (IDEIA), colleges are legally required to follow the Americans with Disabilities Act (ADA) and the legislature included as part of the Rehabilitation Act of 1973 (Scott, 2011). These laws differ greatly from IDEA. The main difference is that IDEA mandates a school to provide individualized education to meet the needs of a student, while ADA and the Rehabilitation Act of 1973 provide protection from discrimination based on a disability. Such protections are provided through accommodations to entrance criteria; testing; mobility around campus; and modified educational materials, such enlarged texts, braille, or e-books. (Scott, 2011). Despite these protections, most participants in a previous study of college students with TBI reported receiving inadequate or no services at all during college (Todis & Glang, 2008).

Another barrier is encountered when college students with TBIs must self-advocate, as it is unlikely they will have someone to seek services for them or monitor whether provided services are meeting their needs (Eddy, 2010). In high school students with TBI typically have a case manager or lead teacher who will monitor how they are doing and ensure they are receiving the services they need to be successful. In college, it is the student’s responsibility to advocate for their own needs. The student is the one responsible for informing the office of disability resources and their professors that they
are a student that requires accommodations and in ensuring that the professors provide them with the accommodations that they need.

Further barriers can be seen in the medical model of providing support for students with TBI or other disabilities. The medical model has highly influenced education as many disability categories and identifications have been taken from the medical model (Triano, 2000). In many cases, both in post-secondary education and in school-age education, students need to have a diagnosis or educational disability label in order to receive the accommodations they need (Triano, 2000). This can lead to some students not wanting to acknowledge their disability or wanting to receive services because this label or diagnosis, in the eyes of some educators, can become their identity (Triano, 2000). Further, the students or diagnostician have to prove that the disabling condition adversely impacts the student’s educational performance (Triano, 2000). The intent of structuring the educational system this way is to ensure that accommodations and services are not abused (Triano, 2000). While no one wants to see this happen, there are undoubtedly cases where students are overlooked or do not receive accommodations because they do not fit the definition of a certain diagnosis or educational label or refuse services to avoid stigma.

The need for appropriate documentation can lead to even more barriers to a student’s education. Post-secondary institutions do not have teams that actively seek to find students with disabilities. Instead, students need to submit documentation of a disability that meets an institution’s criteria to be considered a student with a disability. Unfortunately, institutions frequently deny students accommodations because the
documentation provided does not meet their standards, especially if non-medically based means are used such as Response to Intervention (Harrison, Lovett & Gordon, 2013; Weis, Speridakos & Ludwig, 2014). Educational institutions do not always provide clear expectations for documentation, leading to students submitting substandard documentation (Harrison, Lovett & Gordon, 2013). Further, many diagnosticians are unaware of what needs to be included in a report, or the criteria for a diagnosis and what an institution seeks differ (Harrison, Lovett & Gordon, 2013). Some studies report barriers at institutions to include failing to acknowledge students with disabilities with others remain ignorant of legislative mandates to providing students with accommodations (Katsiyannis, Zhang, Landmark & Reber, 2009; Troiano, 2003). Despite all of these barriers, many students in college do still receive accommodations and supports.

Many supports provided to college students with other types of disabilities (such as learning disabilities or ADHD) may benefit students with TBI. Other categories typically seen include intellectual disabilities, and “a range of conditions includes speech, orthopedic, hearing, and health related disabilities, the largest category of disability, however, is learning disabilities” which represents “41% of college students with disabilities” (Scott, McGuire & Foley, 2003). While there are studies that show mentors or coaches can help students with intellectual disabilities in college, there is a gap in the literature examining the support provided by mentors to students with TBIs in college settings (Kleinert, Jones, Sheppard-Jones, Harp, & Harrison, 2012). Accommodations that may be offered for students with learning difficulties in college include testing in
distraction-reduced environments, providing breaks as needed, extended time on tests, priority seating, recording lectures, and priority registration (Eddy, 2010; Kim & Lee, 2015). Using a framework for instruction like universal design for learning (UDL) has also proven itself to be very helpful (Scott, McGuire & Foley, 2003). UDL describes a system of setting up the learning environment in a way that all students, especially those with disabilities are supported and have equal opportunities to be successful (Scott, McGuire & Foley, 2003). Essentially, with UDL accommodations are built into the course for all students. Such accommodations may be provided to students with learning disabilities or attention-deficit/hyperactivity disorder (ADHD), but may also be useful for students with TBI.

Many students who sustain a TBI experience deficits in skills that require accommodations to be successful academically. For this reason, accommodations are provided, even mandated under IDEIA, during school age years. Accommodations in college are still mandated under the ADA; however, there are many barriers students may face in receiving these accommodations. While there is research on accommodations for students with TBIs through high school, there is minimal information about what accommodations are typically provided for students in college and what accommodations are beneficial.

The Present Study

The present study examined the quality and type of services provided for students with TBI in post-secondary institutions, as well as what accommodations respondents perceive students with TBI will need. This study explored this through a qualitative lens
using semi-structured interviews as the data collection method. While research exists on the accommodations provided in primary and secondary education settings for students with TBI, for the literature is scarce in terms of post-secondary services for this population. This suggests a need for more research about the quality and type of services provided for students with TBI in post-secondary education.
CHAPTER III

METHOD

Research Questions

The current research project explored the services available to students in college who have sustained a TBI. Initially the research questions focused on specific accommodations that were provided; however, the nature of the line of questioning led to the expansion of the research questions to the following:

1. What do college disability services look like for college students who have sustained a TBI?
2. What do college disability services staff perceive as the needs and challenges for college students experiencing prolonged effects of TBI?

Participants

The participants in this study included \( n = 12 \) staff members responsible for determining accommodations for students from offices for student learning services at several different post-secondary institutions. The institutions included twelve schools from across the entire country. The colleges at which each participant was employed were classified as small colleges, medium colleges, large colleges, public colleges,
private colleges, four-year institutions, and two-year institutions. The college sizes were classified using the Carnegie Classification of Institutions of Higher Education (2015).

Table 1

*Demographic Descriptors of Colleges*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Size</th>
<th>Population</th>
<th>Public/Private</th>
<th>Type of Institution</th>
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<td>Small</td>
<td>1,144</td>
<td>Public</td>
<td>4 Year Institution</td>
</tr>
<tr>
<td>College 2</td>
<td>Large</td>
<td>17,360</td>
<td>Public</td>
<td>4 Year Institution</td>
</tr>
<tr>
<td>College 3</td>
<td>Large</td>
<td>30,135</td>
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<td>4 Year Institution</td>
</tr>
<tr>
<td>College 4</td>
<td>Large</td>
<td>12,892</td>
<td>Public</td>
<td>2 Year Institution</td>
</tr>
<tr>
<td>College 5</td>
<td>Large</td>
<td>33,317</td>
<td>Public</td>
<td>2 Year Institution</td>
</tr>
<tr>
<td>College 6</td>
<td>Medium</td>
<td>8,935</td>
<td>Public</td>
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<td>College 12</td>
<td>Small</td>
<td>998</td>
<td>Private</td>
<td>4 Year Institution</td>
</tr>
</tbody>
</table>

A database of colleges with offices for disability services was obtained from the Association on Higher Education and Disability (AHEAD) as well as from targeted searches on the Internet. Originally, schools were only contacted in Ohio, Michigan, and Indiana. With a low response rate, schools from the rest of the country were contacted as
well. At first, colleges were randomly selected from this database to receive an email inviting them to participate in the study. Along with these participants, fifteen colleges were specifically contacted because they mentioned accommodations for students with TBI on their website with one of these colleges mentioned having a program specifically designed for students with TBI on their website that is a one year program that uses specific cognitive retraining that focuses on improving areas of need in verbal skills, critical thinking, memory, attention, and organization. These schools were specifically targeted because they would be able to provide better, and richer data. This email also described the purpose of the study, assurance that their responses cannot be linked back to them, the questions asked in the study to preview for the interview, and an offer to send the results to the participants as an incentive to participate. One person at 166 colleges was contacted until saturation was reached. The sample size was 12. An interview was used because a lot of rich detailed information can be obtained through interviews (Weiss, 1994). The interviews were conducted over the phone at a mutually agreed upon time.

**Research Design**

This study used a grounded theory qualitative research design to obtain information about what services are available for college students with TBIs, what services are accessed, and what services are desired by the respondents (wanted or needed but not available). Information about the best practices for planning services for students transitioning from high school to the university setting was also collected. Grounded theory was selected because generalizations and theory about services and
accommodations provided to students in college is not currently available; however, it was identified through this study through data collection, analysis, and further reflection on the interview data (Corbin & Strauss, 2008). Semi-structured interviews were used to gain information about what accommodations are provided in post-secondary education and information was compared across the different types of post-secondary institutions.

**Procedures**

Institutional Review Board (IRB) approval was obtained before this study commenced. Originally, random sampling was used, as names of colleges were drawn until saturation was reached. This later changed due to low response rate and a need for more rich data leading to targeted purposive sampling. Some colleges were contacted because they listed programs for students with TBI on their websites. Other colleges were chosen by recommendation of others who knew the colleges had a program specifically for students with TBI. The coordinator for the office of disability services, or other staff member at this office at each college was sent an email inviting them to participate in the study. This email explained the meaning of the study and assured the participants that the responses would not be able to be linked back to them. The email included the informed consent form to be signed and returned and informed the participant that they would receive the results of the study as an incentive to participate. Informed consent (see Appendix A) was obtained from all participants as they were recruited either by a signed form or from verbal consent at the beginning of the interview. The participants were informed that they were being recorded and provided consent for
the phone call to be recorded. Participants were informed that their participation was voluntary and that they could withdraw at any point without penalty.

After providing recorded verbal consent, participants were interviewed by phone by the researcher. The interview took an average of twenty minutes and was conducted over the phone. Some of the interviews were shortened for the staff member’s convenience. In these situations, the questions deemed most important were asked. Responses were tape recorded in a way that could not identify the participants to anyone except for the researcher. The researcher used an iPad app with the phone on speakerphone to record the conversation. Each participant was identified by “staff member at College x”; the real name of the participant was only available to the researcher. Actual institution names were not utilized. Instead, colleges are listed by category they belong to. All of the interview responses and data were kept in a locked filing cabinet, which was only available to the researcher. All data was shredded after completion of the study. A semi-structured interview protocol (see Appendix B) was developed by the project chair for the study and piloted with one practice interview. The interviews were then transcribed for coding. The transcriptions were coded in NVIVO, and these codes were analyzed for potential themes.

**Measure**

The semi-structured interview protocol was designed to take about 20 minutes to complete with the participant. This was designed to gather information about each participant’s views on what assistance the participant perceives students needing in college, the participant’s involvement with students, what programming the participant
provides for students with TBI, the participant’s views on how well these programs are working, the challenges experienced for students transitioning from high school, how to improve transition from high school, how to help students take advantage of the services provided, and how many students with TBI attend the participant’s college. The interview protocol was pilot tested in person at one college, and through email with participants at six different schools to determine the clarity of the questions and test for unforeseen problems with the interview.
CHAPTER IV

RESULTS

Data Analysis

This research project examined accommodations for college students who have sustained a TBI. An inductive analysis process was used for interpreting the interview data to identify patterns and themes. This method was used because it condensed and summarized data making it possible to identify links between data and the research questions and because of the lack of previous studies addressing this topic (Elo & Kyngäs, 2008). Two reviewers were used to eliminate potential bias and to ensure a high level of inter-rater agreement. Another researcher independently reviewed and explored the interview transcripts, data analysis and emerging themes. This process helped to provide additional insights into theme development. The data was then coded to look for recurring themes. All data was sorted into appropriate categories for a preliminary analysis. When needed, recoding of existing data was performed. The data was then analyzed again to ensure that all categories were identified. The categories were then compared across the types of institutions and summarized.

Two research questions were explored in this study:
Research Question 1: What do college disability services look like for college students who have sustained a TBI?

When the transcribed interviews were analyzed for responses pertaining to service delivery models for college students with TBI, three main themes emerged. These themes included: 1) inconsistent knowledge of TBI, 2), numbers students with TBI the college served, and 3) accommodations and services provided.

Theme 1: Inconsistent knowledge of TBI. The first theme that emerged in this study was that the respondent’s knowledge of TBI varied tremendously from college to college. This had a wide range from no knowledge to respondents from colleges that continuously search out knowledge of TBI through research or conferences focusing on TBI. Almost half of the respondents reported little to no education on TBI specifically. The rest of the respondents reported some sort of education on TBI through various means such as reading, attending conferences, personal experiences, and staff researching TBI.

The respondent from College 1 reported that they conducted their own research on TBI, stating:

Mostly we have kind of done our own. In research and looking at faculty members here who are doing research on brain injury. We have a woman who was working here, who has since left and she did a “returning to college after brain injury” program with students and so we did a lot of training with her as a whole staff, but then also for the brain injury group. Also locally we have a brain injury alliance,[State] Brain Injury Alliance, that we connected with, and we have support through them and our head up at county medical center has a mild to moderate TBI outpatient program.
The respondent from College 3 reported that the main source of education on TBI that their staff had come from working directly with students with TBI one-on-one.

I have worked through the years both when I was in school and doing my training as a Special Education instructor, but, also I worked specifically with a student who had a traumatic brain injury, but I have worked on a couple different campuses with primarily student veterans who have had traumatic brain injury… Working one-on-one, like I said when I was working on my Masters in Special Ed., we had a student on campus who had just recently had a traumatic brain injury, and had returned to school. He had been in a car accident, and he had some severe cognitive impairments. So I worked one-on-one with this student trying to develop some strategies so that he could be successful in school.

The remaining respondents who discussed education relating to TBI all reported that their education on TBI has come from conferences. The respondent from College 5 reported, “I attend conferences on a regular basis, do reading, keep up to date on research”. The respondent from College 6 reported that she attends yearly conferences on TBI.

Okay, well I’m a Speech and Language Pathologist by training so, I have CEUs to do every year. And a lot of those are through, I do that, those under the, topic of TBI. Most recently, the, Scripts Tech Annual Acquired Brain Injury Conference is one I’ve gone to. I’ve also go to and present at the [State], it’s called [State]APED, I wrote it in the e-mail, [State] Association for Post-Secondary Educators of the Disabled. That’s a smaller group that I will go to every year. There’s a variety of others that may be more focused on say executive functions, or things like that with brain injury, but my favorite is definitely the Scripts in [City] Annual Brain Injury Conference.

The respondent from College 8 also reported attending yearly conferences.

I wanted to make sure that I did enough professional development for myself to be prepared in working with the population so we’re very fortunate. We have, probably within a 5-mile radius, two rehab centers within the area. So when I reached out to the professionals in both of those areas and really kind of started training like with the OT, the speech, the psychologist, the neuropsychologist to really understand. And I quickly became connected with the state brain injury
association and attended, I would say probably in the last 10 years, averaging about 1-2 workshops or conferences a year to really hone my skills and to help me feel prepared working with this population and to be able to assess appropriate and reasonable accommodations as well.

The respondent from College 9 reported that they continuously attend conferences and workshops on TBI.

We do professional development all the time on a variety of different things. We’re members of the HEAD association, we are constantly doing professional development in a lot of areas. You know, specific to TBI, spectrum disorders, emotional service animals, whatever the hot topic is, we’re reaching out and doing webinars, going to national HEAD conferences…so I think TBI is included in a lot of things we do.

**Theme 2: Number of students reported with a TBI the college served.** The second theme that emerged was the number of students each College’s respondent reported who had sustained a TBI. The number of students with TBI varied greatly between the respondents from different Colleges. Of course, this is due in part to the wide range of sizes represented in this study from small colleges with fewer than 10,000 students to large schools with more than 10,000 students. It may also be attributed to the differences in academic rigor from college to college, as students in less rigorous programs may not demonstrate as much of a need for accommodations. Some of the respondents reported that they do not track the number of students with TBI, so they could only guess how many students they had with TBI.
Table 2

*Number of Students Reported with a TBI the College Served*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Size</th>
<th>Population</th>
<th>Students with TBI</th>
<th>Type of Institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>College 1</td>
<td>Small</td>
<td>1,144</td>
<td>50</td>
<td>4 Year Institution</td>
</tr>
<tr>
<td>College 2</td>
<td>Large</td>
<td>17,360</td>
<td>15 or 20</td>
<td>4 Year Institution</td>
</tr>
<tr>
<td>College 3</td>
<td>Large</td>
<td>30,135</td>
<td>1</td>
<td>4 Year Institution</td>
</tr>
<tr>
<td>College 4</td>
<td>Large</td>
<td>12,892</td>
<td>6 or 8</td>
<td>4 Year Institution</td>
</tr>
<tr>
<td>College 5</td>
<td>Large</td>
<td>33,317</td>
<td>200</td>
<td>2 Year Institution</td>
</tr>
<tr>
<td>College 6</td>
<td>Medium</td>
<td>8,935</td>
<td>100 to 120</td>
<td>2 Year Institution</td>
</tr>
<tr>
<td>College 7</td>
<td>Large</td>
<td>44,741</td>
<td>Not Sure</td>
<td>4 Year Institution</td>
</tr>
<tr>
<td>College 8</td>
<td>Large</td>
<td>38,786</td>
<td>65</td>
<td>4 Year Institution</td>
</tr>
<tr>
<td>College 9</td>
<td>Large</td>
<td>18,863</td>
<td>30</td>
<td>4 Year Institution</td>
</tr>
<tr>
<td>College 10</td>
<td>Small</td>
<td>990</td>
<td>2</td>
<td>4 Year Institution</td>
</tr>
<tr>
<td>College 11</td>
<td>Medium</td>
<td>4,573</td>
<td>1</td>
<td>4 Year Institution</td>
</tr>
<tr>
<td>College 12</td>
<td>Small</td>
<td>998</td>
<td>Not Sure</td>
<td>4 Year Institution</td>
</tr>
</tbody>
</table>

Several of the respondents reported having very few students with TBI. The respondent from College 12 reported, “I do not know of any”. The respondent from
College 3 reported having one student with TBI. The respondent from College 11 also reported having one student with TBI specifically saying,

I worked with one particular student that had been involved in an accident that I guess would qualify as having traumatic brain injury of some sort. Primarily, we track specifically learning disabilities and physical disabilities. We don’t really have any records specifically of students that have had a traumatic brain injury.

The respondent from College 10 reported having two students with TBI. The respondent from College 4 reported, “we probably, at any given time, have 6 or 8 on our list”. The respondent from College 2 reported, “It may be 15 or 20”. The respondent from College 7 was not sure how many students with TBI they had saying, “I would have to check and get back with you. More and more, I have several of my own student list that have TBI’s. I’d have to check the number”.

The rest of the respondents had more students with TBI on their campuses. The respondent from College 9 reported that they had 30 students with TBI. The respondent from College 1 reported, “Wow, you know, I don’t know the answer to that. I think approximately 50”. The respondent from College 8 reported, “approximately 65”. The respondent from College 6 reported, “100 to 120 a year”. Finally, in stark contrast, the respondent from College 5 reported, “Our acquired brain injury program, well, annually we serve about 200 students who have acquired brain injuries through our program and our services”.

**Theme 3: Accommodations and services provided.** The third theme that emerged was the services and accommodations that the respondents at different colleges provided for their students. Specific services and accommodations varied significantly
between the respondents at the colleges. Some of the services and accommodations were rarely mentioned while others were mentioned by a majority of the respondents at colleges. The most commonly provided accommodations were having a testing center that offers extended time, small group testing, and tests read aloud.

The other most commonly provided service was colleges that provided some type of special programming. This took several different forms. Respondents at several colleges discussed how they advise students to take a smaller course-load, sometimes with non-credit classes, until they are ready for college level classes. The respondent from College 3 discussed the different skills that are taught to students:

I have worked of course as a disability service provider, as a learning support, learning specialist, I teach time management, organizational skills, so on all of the campuses that I’ve been in, I’m either doing that professionally, under my title, or else I’m going out into the classrooms and working with the students, you know, I may be brought in to special groups whether they would be athletic groups or campus groups, dealing with that transition issue. And then I’ve also served as a first year seminar instructor, not here, but at the other campus where I was. And that essentially is an academic success type model for the first year seminar. To teach, to help students in that transition from high school to higher ed(ucation).

The respondent from College 9 also provided services for academic needs:

So we have academic coaches who can meet with students and do time-management skill training so it’s academic-based. So there’s definitely a difference between the two. I get that question a lot from parents of students who are on the spectrum, you know, so but the academic coaches they work with students to fill out a planner, look at their syllabus to determine deadlines, tests, when papers are due. They will help them meet deadlines and help them with resources on campus, whether it’s tutoring, the writing center, things like that.

The respondent from College 4 provided special programming that went beyond academics and into campus life:

Things like priority registration, housing, dining, all of those things are, provided by the different, offices on campus, but we coordinate those services. So if a
student has a need say for single housing, oh well they would apply for housing like everybody else, and then would come to us, we would view documentation, then we would send our recommendation to housing.

The respondent from College 7 also discussed services that went beyond academics and into self-advocacy:

It’s more like a counselor that helps the student learn about the accommodations or the policies and procedures of initiating accommodations in the classroom. We help them learn how to schedule exams, how to advocate for themselves so it’s more an academic counselor, but also their life on campus, not just academics.

The respondent at College 8 also provided services to address the possible needs a college student can have beyond academic needs including mental health, emotional, and health concerns:

Working with say a newly registered that has a brain injury, I will really encourage them to schedule regularly occurring appointments, maybe on a weekly or bi-weekly basis, to really assess how are they doing academically…are they struggling with time management? And really taking that time to review some strategies…are they struggling with test-taking strategies…you know, to kind of meet them where they’re at, as far as needs. And we’re seeing if they need a referral…If they’re struggling with mental health, mood disorders, referring them to the counseling center, connecting them with a member of a support group and so forth, connecting them with the writing center, learning resource center for tutoring, you know speaking with their academic advisor, speaking with financial aid, housing staff…we provide a tremendous amount of support because we want to make sure that they’re successful. You know, academics, they’re a student first, but what comes with being a university student, you need to have a balance. You need to have a social life, you need to take care of yourself mentally, physically, emotionally, while utilizing the academic supports as well.

The next most commonly provided accommodation was using some sort of alternative media such as Irlen overlays (which are colored transparencies that can be laid over a page), audiobooks, screen readers, digital tests, and digital textbooks. The majority of participating colleges provided alternative media for their students. Only the
respondent from College 1, offered Irlen overlays; this was the only type of alternative media they offered.

The next most common accommodation provided was a peer note taker. The respondent from College 6 best described this as “they get note-takers, which is another student in the class taking notes on carbonized paper and sharing it with them”.

Attendance flexibility was mentioned by a few respondents, which allows students to miss class if symptoms of their TBI are preventing them from attending. Respondents from Colleges 2 and 8 provide students with a memory aid, which is “is the use of a formula sheet on math-related exams.” Respondents from Colleges 6 and 8 provide a scribe where the “student verbally dictates, the scribe will then write down verbatim what the student said or fill in the scantron sheet for that student but it’s all based on the student’s answers.” The respondent from College 6 allows students to bring cold drinks to exams and wear headphones to dampen noise or listen to calming music. The respondent from College 6 also allows preferential seating. The respondent from College 4 allows students to request handouts of lectures. The respondent from College 8 allows a reader for exams. Lastly, the respondent from College 3 reported allowing “special lighting when testing, not the regular fluorescent lighting but a small light or a small light bulb, on the table, on the desk where they are at.”

Respondents from all of the colleges were asked if they differentiated accommodations and services for students with TBI. The respondent from College 4 simply said that they did not differentiate accommodations. The respondent from College 2 said, “There’s nothing set out especially for TBI”. The respondent from
College 6 reported that while they do not differentiate for TBI, they do look at and accommodate some unique needs that students with TBI may have.

For the most part no. We may more commonly see things like some of the more unusual ones. Like a student with TBI who might still be having seizure issues might need an attendance flexibility or even in some cases an attendance contract in which assignments and tests get alternate due dates, in case a person is not, able to come that particular day. They may be more likely to get approval for a memory card than some of the other students. But other than that, from the, chart I showed you, we do a lot with strategies. And then the same accommodations as other students.

The rest of the respondents from different colleges provided answers regarding how they provide different services and accommodations for students with TBI than for other categories of disabilities. The respondent from College 5 has a program for students with TBI in particular. The respondent from College 3 discussed some of the different challenges a student with TBI may have and how they accommodate these challenges.

Some of the difficulties these students have are recalling information, but again, it, often times it really just really depends, it’s on a case by case basis. Because if you have an individual whose been in like a car accident that has a traumatic brain injury, they may not have the psychological components where if they were like that of a student who may have returned from a war zone. And they may not have the same type of physical injuries so it really does depend. But, a lot of times those individuals will need support and that’s the key component. So working with that individual and helping them to develop some strategies for remembering information. We do have one accommodation that we have been able to provide to some students, and that is splitting an exam up in to maybe two sessions, that’s opposed to one, and then that way the individual does not have to retain so much information for and entire test that way they can go back and study and come back and take the other part of the test.
Research Question 2: What do college disability service staff perceive as the needs and challenges for college students experiencing prolonged effects of TBI?

The transcripts were also analyzed to determine what accommodations and services respondents thought would be beneficial for college students with TBI. While reviewing the transcripts the following three themes emerged: 1) accommodations and services needed, 2) transition from high school, and 3) barriers students and colleges have in post-secondary education.

Theme 1: Accommodations and services needed. The first theme that emerged was what accommodations and services participants perceived students with TBI need. This ranged from one respondent not perceiving unique needs for students with TBI, academic accommodations, and/or more holistic views of an individual enrolled in college and in life.

Aside from a need to rest the brain after a TBI, the respondent from College 4 did not perceive any unique needs that a student who has experienced a TBI might have, stating:

Not anything beyond what is available to them based on their documentation. The main thing kids with TBI need. . . is they need to be able to do the brain rest right after the injury.

The respondent from College 1 reported they thought students with TBI needed to focus on memory and vision saying, “Memory, …and vision tend to be the biggest things”.

The remaining of the respondents from different Colleges reported multiple areas that included things like concentration, counseling, and training about how to be a college
student. Organization was an area that was frequently reported as an area of need that a student with TBI would have. The respondent from College 10 reported that memory, organization, counseling, and managing frustration were needs that they have previously seen.

Areas include organizational skills, which is the case for one of these students but soon after he acquired the brain injury and he would meet with me and we would go over his courses and the requirements for his classes and list them out and put in his planner what he was going to do when. Another area would be psychological support, emotional support. This was a very strong student with very high ACT scores and sustained a blow to the head in an athletic game and suddenly cannot remember a thing of what he’s doing and he was totally together, organized, and very independent prior to that so he also experienced some personal frustration and trying to keep his spirits up about what happened to him...so yeah, for some students, you know, meeting with a counselor too would be very beneficial but as far as academic supports the organizational skill are important or may be important.

The respondent from College 11 also reported that counseling and coaching for academic skills were needed. They also reported seeing a need for assistive technology.

You know, some students, I would surmise that students might need to access assistive technology like screen readers and things like that. I think students with TBI might need access to professional counseling. I think a lot of students with TBI benefit from like a coach counselor, if you will, which is a term for someone who works with the students on academic skill sets that they might be struggling with, like note-taking or test-anxiety. So those are things or areas that we would try to address.

The respondent from College 12 also discussed a need for coaching with academic skills and expanded these to discussing personal experiences with a student who was experiencing processing and memory delays.

She came to me about a year later and said that she had during that year she had a car accident and after the accident she noticed that she could not process certain information and couldn’t remember formulas and stuff. I’m thinking that it had some sort of impact on her brain so I had to work with her to coach her how to memorize information without relying on actual numbers. So I’m thinking that
potentially it affects the way a person processes information, that it can take
different forms so there has to be flexibility in coaching students in how to deal
with difficult situations…and working as an intermediary between students and
faculty because faculty often find themselves very nervous about dealing with
students especially if they don’t know how to deal with a certain condition.

The respondent from College 2 discussed changes in cognitive processing and how a
student may need to re-learn who they are after experiencing a TBI. They also
highlighted how a student’s identity may change after a TBI and how important it is for
the student to find out who they are now.

I think preparation, the, the especially for people who acquire the TBI post-
accident. Who am I now? Who am I in the context of my disability? How have I
changed? What does that change mean for me and for my cognition, my cognitive
abilities?, How do I adjust to the new person that I’ve become?

The respondent from College 6 also identified several cognitive processes needed to be a
successful student after experiencing a TBI, as well as sometimes needing to take a break
from academics to learn how to be a student again. Particularly, they addressed learning
how to use accommodations.

There certainly are students who are sometimes in credit classes, and sometimes
we can’t snag them and get them to do some non-credit time with us. Sometimes
we’d really like them to just step out of the academics completely and work for a
couple semesters with us on memory and, memory reasoning, attention, all of
those different areas that we work with as well as having time to look at some of
the assistive technology with them. Some of them really benefit from the screen
readers for their books, so that they are hearing the book as well as reading it at
the same time. One program called the Kyzweil [Kurzweil], K-Y-Z-W -I think it’s
E-I-L, shows up on a computer screen, and highlights the sentence that it’s
reading, so it really helps their attention, and keeps them moving which really
helps their, comprehension and retention. We like to have time to get them
acquainted with that, get them comfortable with it, before we throw them into
academics or have them try to learn that while they’re doing academics. We do
have a couple of classes that we sometimes start them with, that helps them.
That’s a memory strategies class and we have an assistive technology class.
The respondent from College 7 observed student needs regarding focus, memory, and comprehension. She framed this within the accommodations they provide for their students.

They might have difficulty with focus and concentration during lecture so they might need a note-taker or other accommodations such as second set of notes or a peer note-taker, which we can initiate that with the student. They can also use the Smart Pen that we lend out to students. We can provide read-and-write goals software that helps them with comprehension. Extended time for exams because often have difficulty with stamina and concentration so that allows them to have enough time to refocus attention.

The respondent from College 8 discussed how students might have both cognitive and physical deficits after sustaining a TBI. They focused on learning how to use strategies. They also focused on accommodations beyond just those to support academic progress, including housing, financial aid, social events, and counseling.

So let’s say I have a person in my office that has sustained a pretty extensive traumatic brain injury. They’re having a lot of deficits, definitely neural fatigue, slower processing speed, they may have some photosensitivity or photophobia. They may have some attentional difficulties and even some physical disabilities. Working with say a newly registered that has a brain injury, I will really encourage them to schedule regularly occurring appointments, maybe on a weekly or bi-weekly basis, to really assess how are they doing academically…and are they struggling with time management? And really taking that time to review some strategies…and are they struggling with test-taking strategies…you know, to kind of meet them where they’re at, as far as needs. And we’re seeing if they need a referral…If they’re struggling with mental health, mood disorders, referring them to the counseling center, connecting them with a member of a support group and so forth, connecting them with the writing center, learning resource center for tutoring, you know speaking with their academic advisor, speaking with financial aid, housing staff…we provide a tremendous amount of support because we want to make sure that they’re successful. You know, academics, they’re a student first, but what comes with being a university student, you need to have a balance. You need to have a social life, you need to take care of yourself mentally, physically, emotionally, while utilizing the academic supports as well.
Finally, the respondent from College 9 discussed time management and a student’s need to learn more about themselves specifically learning how they learn best.

I think it’s just understanding that time management is a little bit different, and I don’t know if it’s so different for students with TBI than other disabilities, but just understanding the set-up of the day or how the responsibilities inside the classroom are matched three-fold outside of the classroom like work and projects. And if it takes a student with a traumatic brain injury a little bit longer…it’s important to help that student understand that transition, so I think I’m going to go beyond that a little bit, it kind of depends on where, when, how old the TBI is where is the student in understanding how they’re learning. Do they know how to ask for resources? They may not know that yet. So it’s really kind of getting to know the student, what are their strengths, what were their strengths before, how has it impacted them, but also you know continuing to have that dialogue because that may change in a month, when they understand a little bit more. If they’ve had the TBI for a while, they may understand. If they just got the TBI, they may not know that really, it can have long-term effects. It’s...students go through, it’s almost like the stages of grief in terms of how you’re dealing with learning in a different way. That you’re not learning how you used to learn, that you’re not the same person you used to be in terms of your skill set. We also have counselors because of this who work with students.

Theme 2: Transition from high school. The second theme that emerged for research question two was transition from high school, which included ideas of how to make the transition better for all parties. All of the respondents, except for one, had several ideas for how to facilitate this process. The respondent from College 1 reported “all of my students have acquired their brain injuries as a student here”; however, they did contribute ideas from students with other disabilities that may be beneficial for students with TBI.

With other disabilities, transition, I think the biggest difficulties with transition are a) knowing to self identify. In the institution, so just knowing where to go and who to go to is part of it. And also, the piece of being their own self advocate. Expressing their needs, connecting with faculty, scheduling their own exams, basic things like that. So we kind of spend, like I said our initial intake meeting is scheduled for an hour to an hour and a half so that we have time so that we can go through those changes like that with them.
Self-identification, communication, and self-advocacy were the most commonly reported skill areas that respondents reported that students needed to possess to be successful in college. Many expressed a desire for students to already have these skills before entering college. The respondent from College 11 focused mainly on communication and socialization.

One of the challenges there that I experienced in the transition from high school to college is communication for one. I think one of the other challenges is socialization to the campus and other students. They know what a credit hour is and they may have taken dual credit classes but they are not specifically acclimated to you know what a credit hour, what a bursar is. They have to deal with a lot of interaction with faculty in class or online, which can be another challenge for students with a disability … coming to us. I would say getting acclimated and being socialized to our system and learning how things work here administratively and then socially, like getting connected. I think those are some of the transition challenges that a student would have, depending on their, you know, their need and what they’ve been used to. I think that for students who have been in, you know especially, these types of issues that your study is focusing on, I think the socialization part is probably going to be one of the bigger challenges.

The respondent from College 12 also discussed communication, self-reliance, and concerns about stigma as the main challenges their college sees with students with disabilities in college.

One of the challenges is that students with disabilities come from high school, come with a mindset that I guess is prevalent in high school, that you don’t want to have diagnosis because you’ll be labeled so we have some students. not TBI, but primarily with like ADHD, dyslexia, things like that, that they have school counselors who told their parents and then their parents kind of told them not to tell anyone you have a disability because you’ll be labeled. And then they go without proper assistance or accommodations so when they get to college, we have to undo that mentality and tell them there is no labeling here. It’s a way to support you and it’s beneficial for you. So that’s one challenge they bring from high school. We have I guess another thing is that if they’re on some sort of medication or some management plan, that they have to…the opposite I guess, the opposite end of that is that someone that comes in thinking that if they were
diagnosed in high school and were provided with accommodations in high school then they will continue the same exact way in college and that however they were treated in high school will be how they’ll be treated in college. So for example, like an IEP, the college will just provide automatic accommodations so we have to tell them no because we have to have certain documentation and the testing has to be conducted in a certain time frame. Also we don’t give accommodations automatically, you have to...you’re an adult now. So I guess the transition is...before, they were treated as kids and taken care of in a certain way...but in college, they have to learn to take responsibility and ownership and handling their education. I don’t know how other universities do it, but here they have to register every term if they want to continue the accommodations and have their plan sent to their new faculty. So there is a lot of responsibility on the student but again, they didn’t have to think about those things before they were in college.

The respondent from College 8 also reported self-advocacy as an important factor with transition.

I think one of them is self-advocacy… You know, you have individuals who are in high school that may have already received those accommodations or 504 plans and those services have always been implemented and they’ve always had that support. And then you come to college, and they have to self-identify and it puts more ownership and responsibility on the student to really understand okay how do I advocate for myself? How do I utilize these accommodations? And how do I communicate appropriately with my faculty? Knowing that, as a specialist in the office, you know, we are here to help with verification and advocacy and determination so if the faculty have questions, we can definitely intervene and support...And I think too that because there’s so many more supports, I think it’s more rigorous quite honestly in high school. Students come to post-secondary and they really don’t realize the expectation of them academically. They truly still feel like you know, I was able to get through my exams, but I didn’t really have a whole lot of reading to do in high school whereas in college, students are approximately having to read like 2-3 chapters a night in reading and manage like 4-5 classes at a time. So I think it’s really like preparing them and equipping students to use strategies and to use that support or like connecting them with tutoring, working on their time management skills, their executive functioning skills. That’s critical. These are the areas that I feel like students that are matriculating to a university and already have an existing brain injury are struggling with.
Another common point raised when discussing transition was knowing and understanding the differences between academics in high school versus post-secondary education. The respondent from College 2 reported, “Probably just the biggest barrier is understanding the differences between what high school is and that K-12 model and the university model. Which is you know, no one is going to call you if you don’t come to class”. The respondent from College 4 reported that they felt the conversation happens too late or not at all prior to post-secondary education. They added that too few people are aware of what all is available to students in college.

Well the biggest issue with transition that we see here as a program is that it begins to late. I contend that if transition processes haven’t started by the time a kid is in 6th grade, it’s going to be a real uphill battle. So you know, and we see families all of the time that come in during the Senior year, and they say, you know, ‘We’re here, you know, ahead of the curve’ and I mean we can’t obviously say anything, but they are way behind the curve. Because nobody has guided the coursework, nobody has guided the efficacy skills, nobody has guided the development of executive functioning skills, and, those are all things kids need when they come to college. Kids in high schools and staff, teachers, counselors, etcetera, frequently don’t have good information about what is available in college. And the implication is always that if you go to Disability Services, it means, you know, that you can’t move, blindness, deafness, mobility is what everybody presumes. And those are our very low incidence populations. On this campus, and we’re about, oh I don’t know, maybe 15,000 students on this campus, we have 7 who use mobility devices. I mean, that’s real low incidence.

The respondent from College 5 also noted challenges with the differences in the types of programming provided between high school and college.

I think that the hardest thing for a student who is now a community college student and has been a special education student in the K-12 is the difference in our expectations of that particular student as they enter a mainstream class. And so, with those particular students and their families, I still, one of my roles is to educate them about how the rules of the game change. They may be used to having a program that allowed that particular student that guaranteed them, or tried to guarantee them success. And when they come to the community college system they have to realize that we can provide services and accommodations for
them but we aren’t going to reduce the work load, we’re not going to extend deadlines to submit a course, we don’t have that kind of flexibility, the course has a specific beginning and end. Oh sometimes, there’s a little bit, actually in some cases, there’s quite a bit of education in how they, the student should take a lighter load, and then that they have to work longer hours, or work harder, and that we don’t require that they take, to carry, a certain load. So I guess that sometimes becomes a bit of a shift. I think, I do a lot of work with our high schools, and our high school transition counselors to ensure that they understand what I just said. That when a family comes to the college setting, that they it doesn’t even matter how in need a student is, they are a college student. And so mom and dad calling the professors and expecting to get a response is probably not realistic and it’s certainly not going to happen without a release. That the anticipation is, well, they are going to go to college to and that the college is going to have all of the resources that the K through 12 system has for an individual with intellectual disability. We on my campus have a lot of services for individuals with intellectual disabilities, but they may have to travel to get those. And so, sometimes even the transition, the high school transition counselors, may not understand why they can’t just go to the most local community college and get everything that we offer. Our system is just not set up that way. We don’t have to provide programs.

The final respondent that discussed this issue was from College 9. She focused more on time management and the student’s knowledge of their own limits with a TBI as the most important transition topics.

I think it’s just understanding that time management is a little bit different, and I don’t know if it’s so different for students with TBI than other disabilities, but just understanding the set-up of the day or how the responsibilities inside the classroom are matched three-fold outside of the classroom like work and projects. And if it takes a student with a traumatic brain injury a little bit longer…it’s important to help that student understand that transition so I think I’m going to go beyond that a little bit, it kind of depends on where, when, how old the TBI is, where is the student in understanding how they’re learning. Do they know how to ask for resources? They may not know that yet. So it’s really kind of getting to know the student, what are their strengths, what were their strengths before, how has it impacted them, but also you know continuing to have that dialogue because that may change in a month, when they understand a little bit more. If they’ve had the TBI for a while, they may understand. If they just got the TBI, they may not know that really, it can have long-term effects. It’s…students go through, it’s almost like the stages of grief in terms of how you’re dealing with learning in a different way. That you’re not learning how you used to learn, that you’re not the
same person you used to be in terms of your skill set. We also have counselors because of this who work with students

**Theme 3: Barriers students and colleges have in post-secondary education.**

The final theme that emerged for research question two was the barriers that colleges face in providing optimal services for post-secondary students and for the students in receiving them. These barriers came from several different sources, such as legal issues, how students are identified, lack of understanding of TBI, and the previously reported transition concerns.

The respondent from College 1 reported a barrier with a lack of understanding of TBI. She reported, “The barriers we were encountering were that we were not, maybe, fully accessing a student’s barriers or impacts. With having little understanding about maybe the intricacies of brain injury, which is why we formed the brain injury group.”

The respondent from College 2 also reported a lack of understanding of TBI as a barrier saying, “Maybe a barrier would just be the lack of understanding of what a TBI is, across the community. And how, how a person with TBI thinks differently or processes differently, and sort of sensitivity on those issues”. Finally, the respondent from College 3 approached the awareness barrier from the student perspective, discussing how a student’s awareness of TBI and disability services may be a barrier.

one of the barriers is that individuals who acquire a TBI are generally acquiring it later in their life. And sometimes, they may be a student on campus and then in like a car accident or then they get deployed and something happens, and now they have a TBI. Because they did not grow up through the K through 12 environment as a student with a disability, they may not be aware of the services that exist on a college campus. The disability services that would be helpful to them, so they would not even know to look for them, or know of their existence. And oftentimes, disability services, even though we post information on our website, in our orientation guides, and so on and so forth. If you’re not that
student and you don’t really understand that process, that’s really not going to be like a flag to you to say ‘hey, I need this’. So the biggest barrier that I see is how to get that information out, how to identify, because we don’t. We are not in a position of going out and identifying students on campus who have disabilities and bringing them in. So how do you make that connection between a service that is provided on campus that is often one of the best kept secrets on campus.

The respondent from College 10 noted that some students do not want to take advantage of the accommodations and services that are provided, saying: “Many don’t want to utilize services in college like they did in high school; they want to do it on their own in college”. The respondent from College 4 also reported that students did not want to identify themselves or take advantage of accommodations.

The big issue, even with TBI, is the kids don’t think they need the help. It’s embarrassing to say they need the help, and so they try to avoid coming to get help. And so, that why we try to be present in all kinds of ways on campus. It’s not our role to seek out students.

The respondent from College 12 reported barriers to ensuring that staff provided the necessary accommodations.

There are challenges…in terms of getting faculty and staff on board, getting them to actually do things they’re supposed to do. We’ve had cases where faculty debate whether they’re going to apply the accommodations or not and we tell them it’s the law, you don’t have a choice, you have to do it.

The respondent from College 11 reported barriers with communication, identification, legal issues, and the transition process from secondary education.

I think the main thing would be communication, ensuring that the student again has walked through and has a life-skills coach and has connection with our staff … trying to tackle these logistical things, getting their identification card made, establishing a meal plan. We have an entirely-commuter campus so getting their parking pass housing, appropriate housing. So other logistical things would be communication and mainly you know administrative things that would need to get done before we get into working with the faculty. From my viewpoint, it’s really up to the student to inform us of what their needs might be so we can develop the appropriate accommodations … They have to deal with a lot of interaction with
faculty in class or online, which can be another challenge for students with a disability coming to us.... Again, there are a variety of legal things, FERPA, privacy laws that specifically and sometimes hinder, as well as you know the student’s personal privacy. Sometimes, when they go through this, students don’t want to inform us right away of these types of things they don’t want it be used as a crutch.
CHAPTER V
DISCUSSION

Review of Purpose and Major Findings

The purpose of this study was to examine what accommodations are provided to college students with TBI, as well as what services and accommodations might be most beneficial for college students experiencing prolonged effects of TBI. Results of this study demonstrated an inconsistency between how respondents perceived the needs of students with TBI. Many perceived fewer needs than the current research suggests by not perceiving a need for reduced workloads, tape recorders, or adjusted due dates (Eddy, 2010; Kim & Lee, 2015; McAvoy, 2012). The respondents tended to assume students with TBI would have the same needs as any other disability. Conversely, the respondents who reported having more knowledge of TBI tended perceive that students with TBI do have specific and unique needs. With more knowledge of TBI, these respondents understand that students with TBI may experience more fatigue, trouble with social skills, and have more cognitive processing needs than students with other disabilities such as ADHD or a specific learning disability. They reported knowing a student with TBI may need to take a reduced course load, rest more than typical students, and may struggle with
social skills. Most of the participating colleges provided accommodations consistent with what they reported as perceived needs that students would have.

Despite not being required to provide more than “reasonable accommodations,” some respondent from colleges mentioned providing many more services than would be expected (Yeates & Taylor, 2006). Some respondents reported providing what would fall more into the realm of a direct service.

**Acquired brain injury program.** One respondent provided an entire specialized program for students with TBI. This program featured non-credit classes to help students become accustomed to the post-secondary setting while focusing on functional life skills as recommended in some studies (Hillary, et al., 2003; McAvoy 2012). This program lasts a year and provided structured cognitive retraining focusing on improving attention, concentration, memory, language skills, and reasoning skills. Counseling is provided to help form new personal goals that are more realistic, if needed. Also, counseling is provided to help with depression, feelings of isolation and alienation, and dealing with unemployment. The goal is to move beyond unemployment, increase career readiness skills, improve responsibility, improve independence, and improve socialization. Critical thinking skills, organization, and emotional adjustment are all taught to be applied to practical real-life settings. This was also the only respondent that mentioned providing a neuroeducational assessment to assist with this process. This was the most beneficial service mentioned through the results of this study as it addresses the physical, cognitive, and social-emotional symptoms that adversely impair a student’s learning capacity as discussed in previous literature (Lewandowski & Rieger, 2009). This program would be
considered best practice for assisting post-secondary students with TBI, especially students who are still showing a great need for assistance. While this program is unique to one school, it appears to be feasible for other universities to implement programs like this. This would be dependent on a school’s resources and the knowledge their staff have of TBI. Other services will also be beneficial combined with or in place of a TBI program.

**Other differentiated services.** While a TBI specific program was the most beneficial service provided to students, other schools mentioned services that are easily implemented and highly effective for students with TBI. For students with TBI who are still experiencing fatigue and still recovering from a recent TBI or still experiencing long term symptoms of a TBI, attendance flexibility, adjusted due dates, and a reduced workload were all equally noted as the second most important services provided services. This aligns closely with what research has shown to be a necessary for students experiencing symptoms of TBI (Maclennan & Maclennan, 2008; Yeates & Taylor, 2006). Many participants in this study reported providing these services. These services are easily implemented at all universities, and can be crucial in ensuring success for students and in preventing long term effects and helping with students recovering from their TBI (Yeates & Taylor, 2006). Without these services, students may not fully recover and may not be able to function to their fullest potential (Yeates & Taylor, 2006). The attendance flexibility will help with symptoms of fatigue and the need to rest immediately after a TBI or with long-term fatigue from a more severe TBI (Lewandowski & Rieger, 2009). A reduced workload will also help with fatigue and a need to rest (McAvoy, 2012). A
few schools mentioned assisting students with scheduling to help them take a reasonable course load for their specific needs. Adjusted due dates will be beneficial for a student’s fatigue by allowing them to work at their own pace and reducing anxiety from a pressure to perform at a level of work output a student may not be physically or mentally ready to achieve (Lewandowski & Rieger, 2009; Maclennan & Maclennan, 2008; McAvoy, 2012). These services will also help a student adjust to the demands of college as they learn how to schedule themselves and access the college environment.

While also important, and easily implementable, service such as tape recorders for classes, volunteer note takers, memory aids, and extended time were also frequently reported by participants as being important for students with TBI though not as beneficial as a TBI specific program, attendance flexibility, reduced workloads, and/or adjusted due dates. Tape recorders for classes, volunteer note takers, memory aids, and extended time were highlighted in previous research as being beneficial for students with TBI to help cope with the cognitive deficits and memory impairment a student may experience (Eddy, 2010; Kim & Lee, 2015; Maclennan & Maclennan, 2008; McAvoy, 2012).

**Identity.** While rarely mentioned by participants in the study, a great need for some students with TBI, especially if it occurs while the student is in college, is understanding the changes that they are experiencing. As a participant pointed out, a student may not understand who they even are after sustaining a TBI. This can be because they may now be processing information differently, experiencing fatigue, need more time to complete tasks, struggle with social skills, and/or may be struggling with regulating their emotions (Lewandowski & Rieger, 2009). This could be very frustrating
for a student to understand and coping with these issues could greatly impact their academic performance (Lewandowski & Rieger, 2009). For this, some participants reported providing counseling for students. This would be very beneficial in helping a student understand all of these changes they are experiencing and would then increase their success in completing their studies.

Knowledge and responsiveness of participants. Respondents from smaller two-year community colleges tended to provide more accommodations than respondents from larger four-year institutions. TBI-specific programs were only found at small two-year community colleges. To further support this, staff from larger four-year Colleges tended to report having fewer students with TBI than the staff from smaller two-year community colleges or even the smaller four-year colleges. This may likely be due to the colleges being too large to have a good sense of their students with TBI. The respondents from these colleges may also be more easily found on campus and more approachable as they would be able to be more visible on a smaller campus. On a smaller campus, it is easier to get to know more of the students helping staff members to appear more approachable and increasing students’ knowledge of their availability and what services they can provide.

Respondents from the smaller schools also tended to report greater knowledge of TBI. This could lead to them being able to provide better suggestions for services for students. With a smaller caseload, staff may be better able to research best practices for providing services for students with TBI. Also, they would have more time to educate other members of the staff at their college what students with TBI may need to be
successful in class. Finally, at a smaller school, due to a smaller caseload, staff will be better able to check in with their students to determine how helpful the services they are providing are for their students and would help them to better tailor the services to a student's unique needs.

**Barriers**

The current study revealed many barriers that exist for students with a TBI in receiving services and accommodations needed to be successful in post-secondary education that are consistent with previously reported barriers (Eddy, 2010). Participants perceived barriers experienced by both the universities and the students. Universities experienced barriers through the red tape of privacy laws, staff not wanting to provide accommodations, and a lack of knowledge of TBI for staff at disability services offices, professors, and even the students (Eddy, 2010; Harrison, Lovett & Gordon, 2013; Triano, 2000; Troiano, 2003; Weis, Speridakos & Ludwig, 2014). This red tape was noticed in both wanting to have conversations with parents, and in not receiving notifications from medical providers that could help universities proactively try to help students. Respondents perceived that students barriers included: not having help with the transition to post-secondary education, lack of knowledge of the services available, concerns over stigma, and overconfidence in their ability to be successful without services or accommodations. Interestingly, respondents from smaller colleges had greater knowledge of TBI and reported fewer barriers to serving students with TBI. There could be several reasons for this finding. For the schools with programs specifically designed for students with TBI, the very nature of the program would lead to it being designed
without these barriers. For other smaller community colleges, this could be the result of having smaller caseloads and more opportunities to participate in a student’s post-secondary transition plan during high school (Joshi & Bouck, 2015; Newman, Madaus & Javitz, 2016). A smaller caseload would allow staff members to have a stronger connection with students to better individualize accommodations to their needs. Also, this would allow for better professional development for other staff members regarding their legal obligations to provide accommodations as well as professional development on TBI, which can lead to better services that are more specifically tailored for students with TBI. Finally, this could lead to better outreach to help students with TBI find the services they need.

Limitations

There were several limitations with this study. The first limitation is with the design of the study. This study only examined the need for services and accommodations and what was provided from the perspective of the respondent from the universities. It did not examine the perspective of students. While the goal of qualitative research is to reach theoretical saturation, it is unlikely that it has been reached in the current study. This is because many potential participants did not respond to the invitation or declined to participate. Further, the timeframe for the study was limited which would not allow for contacting a potential participant at every college in the United States of America. The goal of saturation is to continue interviewing more participants until every possible answer has been recorded (Guest, Bunce, & Johnson, 2006). Despite receiving consistent
similar results, it is impossible to truly tell if all possible responses and themes have been discovered and is unlikely it can ever be reached (Guest, Bunce, & Johnson, 2006).

Another limitation that could have limited the results of the study was the sampling method. While random sampling would be more ideal for this design, convenience sampling was used due to time constraints. Some participants were specifically contacted because they have programs for students with TBI or mentioned a focus on students with TBI on their website. This may have increased the amount of accommodations listed making it appear that more respondents from different colleges provide a greater amount of accommodations.

The final limitation noted was the nature of the semi-structured interview. With this method, there is always the potential that the answers could be skewed. Despite assurances of confidentiality, further chances of the interviews being skewed could come from the participants’ attempting to tailor their answers to what they expected the researcher to want to hear. Finally, several of the interviews had to be shortened and opportunities to ask for elaboration on answers were cut due to participants’ time schedules. Several participants were willing to participate; however, they only had ten to twenty minutes to be interviewed, leading to shorter answers and questions being cut from the interview. This could have led to more rich and varied data.

Implications for Future Research

This study is a starting point for examining what accommodations are needed for students with a TBI to be successful in post-secondary education settings. Further studies might expand on the sample size of the current study or could use quantitative designs
such as surveys to capture a larger audience. It would also be helpful to conduct similar interviews with students with TBI to ascertain their views on what they need to be successful in post-secondary education compared to what is currently provided. Finally, further studies that examine what services and accommodations were provided that increased completion of post-secondary degrees are warranted. With these studies combined, a guide for students and universities could be developed to help students with TBI successfully complete post-secondary education programs.

Conclusion

The present study examined what accommodations are available to post-secondary students who have sustained TBIs and what services and accommodations they might need. Findings suggested that a university personnel’s knowledge of TBI greatly influenced the needs they would expect students to have as well as what services and accommodations they would provide. The respondent from colleges interviewed in the current study provided services and accommodations to suit all of the needs they would expect a student to have. The services accommodations provided seemed to be limited greatly by the expected needs as well as the knowledge the respondents had on TBI. Educating respondents from offices of disability services from colleges on the needs of students with TBIs might greatly enhance the amount of services and accommodations they would provide.

The findings also revealed that accommodations provided by some colleges extend beyond general accommodations that tend to be provided to most students with disabilities. One even had full programs dedicated to students with TBIs. These staff
members perceived more potential needs for students and found some creative ways to ensure their students success both academically and with life skills. While this would not be something to be expected by respondent from all universities, it may behoove students with TBIs to seek out colleges with faculty members that perceive more needs to ensure the student’s needs are appropriately served. It would also behoove staff members from disability services offices to expand their knowledge of TBI. Outcomes from this study showed that respondent from some community colleges offered more than respondents from many of the larger four-year institutions. This was also true for respondents that had greater knowledge of TBI. A student with TBI may benefit from considering attending a two-year community college for their education, or at least to begin their post-secondary education as well as inquiring about how much knowledge the staff at disability services offices has.

This study is important to the literature because it can start a conversation with post-secondary institutions about the different needs of students with TBI and provides suggestions for how to appropriately serve students with TBI. Results of this study show that respondents from many universities have limited to no information about the unique needs of students with TBI and how to appropriately accommodate these needs. This can lead to limited, and more standard (extended time and small group testing), accommodations that do not fully meet a student’s needs. If we want to truly ensure students with TBI successfully complete post-secondary education, we need to better educate individuals who work with students with disabilities in college settings so they can provide better and more tailored accommodations to students with TBI.
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doi:10.1177/0022219413483175 [doi]


APPENDIX A

INFORMED CONSENT TO PARTICIPATE AS A RESEARCH PARTICIPANT

Project Title: Accommodations for College Students with Traumatic Brain Injuries
Investigator: Dr. Susan Davies and Michael Crenshaw

Purpose of the Research: The present study will describe accommodations that are recommended for students with TBI and will explore accommodations that are available for and accessed by college students with TBI.

Expected Duration of Study: This research will be completed over the course of six months.

Procedure: This study will employ an interview-based design to obtain information regarding the needs of college students with TBI compared to what these students need. The primary researcher will conduct interviews.
Anticipated Risks and/or Discomfort: There are no anticipated risks to the physical and mental health, comfort, and privacy of the participants in this study.

Confidentiality: Identifying information will not be recorded on the interview sheets, and each participant will be given a pseudonym. Responses and data will not be able to be traced back to the participants. The interviews and data generated from them will be secured in a locked filing cabinet.

Contact Person for Questions or Problems: If you have questions about the study, contact Dr. Susan Davies at 937-229-3652. Questions about the rights of the participant should be addressed to Dr. Mary Connolly, IRB chair at 937-229-3493.

Consent to Participate: I have voluntarily decided to participate in this research project. The investigator above has adequately answered all questions that I have about this research, the procedure involved, and my participation. I understand that the researcher named above will be available to answer any questions regarding the data collection process throughout this study. I also understand that I may refuse to participate or voluntarily terminate participation in this study at any time without penalty. The researcher may also terminate my participation in this research at any time if they feel this is in my best interest.

____________________________________________  __________________
Participant’s Signature                          Date
APPENDIX B

SEMI-STRUCTURED INTERVIEW PROTOCOL

For the College Office of Disability Resources

1. Describe your service delivery model.

2. How many students with TBI are assisted by your office? How does this compare to the actual estimated number of college students with TBI?

3. Describe areas in which you feel students with TBI might need assistance in college.

4. What is your involvement with service provision to students with TBI?

5. Describe the logistics of how you might serve as a liaison between college students with TBI and their service providers (e.g., life skills coaches).

6. Describe your expectations for what a life skills coach might do for a student with TBI.
7. Describe benefits and drawbacks of specific service provision programs for students with TBI.

8. Describe any professional development you have had about TBI.

9. Describe any challenges you have had with students with TBI, or any disability, in transitioning from high school to college?

10. What could high schools do to improve the transition process and outcome for students with TBI who are entering post-secondary education?

11. Are there any specific things that would help with this process?

12. What approaches have you taken to encourage students to take advantage of the services provided by your office?