THE POSTSECONDARY TRANSITION EXPERIENCE FOR YOUNG ADULTS
WITH TRAUMATIC BRAIN INJURIES

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THE POSTSECONDARY TRANSITION EXPERIENCE FOR YOUNG ADULTS
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ABSTRACT

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Students who have sustained a traumatic brain injury (TBI) may experience a number of cognitive, academic, behavioral, social, emotional, and physical consequences. These consequences often present challenges for students transitioning from high school to a postsecondary setting. The present study involved interviews of three young adults who had sustained a TBI and their parents to gain a deeper understanding of the postsecondary transition experiences of young adults who have persistent problems related to a TBI. This study also examined the participants’ perceptions of challenges, as well as factors that facilitated a successful transition. The young adults, all of whom were enrolled as college students at the time of the study, reported significant challenges with attention and focus, fatigue, short-term memory, and social situations. Parents reported their young adult children having significant challenges with fatigue and social situations; they also reported more prior injuries (repeated injuries) than the young adult participants. Suggestions are made for school-
based practice to promote strategies and services that might support this population of students as they transition to a postsecondary setting.
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Traumatic brain injury (TBI) is the leading cause of death and disability in children and young adults worldwide (World Health Organization, 2006). According to the Centers for Disease Control and Prevention [CDC] (2012), approximately 1.7 million people sustain a TBI each year. Of these, nearly 700,000 are children ages 0 to 19 (Faul, Xu, Wald, & Coronado, 2010), and the vast majority of these children survive their injuries and return to school. Students who have sustained a TBI may experience a number of cognitive, academic, behavioral, social, emotional, and physical consequences. These consequences can adversely affect a student’s transition between classes, grades, schools, and tasks (Jantz, Davies, & Bigler, 2014). For adolescents with TBI, the transition from school to college or independent living can be particularly challenging. For example, such students may have difficulty planning long-term projects, organizing personal and class materials, or living with a roommate and making friends.

The successful transition from high school to postsecondary education (e.g., technical, vocational, community, or four-year college or university) or the workforce is critical for positive life trajectories (Heckhausen, Chang, Greenberger, & Chen, 2013). Such a transition requires several skills that may be difficult for students who have sustained a TBI; thus, accommodations and support services may be beneficial. Under
the Individuals with Disabilities Education Improvement Act (IDEIA, [IDEIA 04], P.L. 108-446, §601 et seq., 118 Stat. 2647 (2005), students who qualify for special education services must have a transition plan in place for after high school. Students who did not qualify for special education services prior to entering a postsecondary institution may or may not receive transition supports. They may also lack the data and documentation that postsecondary institutions often require for students to receive services (McGuire, 2010; Shaw, Madaus, & Banerjee, 2009). Therefore, such students may experience adverse short- and long-term consequences during and after the postsecondary transition process. The purpose of the present study was to understand the experiences that students who have sustained a TBI face during the transition to a postsecondary educational setting or place of employment.
CHAPTER II
LITERATURE REVIEW

The first section of this literature review summarizes the causes, severity, symptoms, prevalence, and identification of TBI. The next section discusses outcomes and problems associated with sustaining a TBI, including cognitive, academic, behavioral, social, emotional, physical consequences, as well as the effect a TBI can have on various transition points in a student’s life. Finally, this literature review describes general transition supports that postsecondary education settings may offer to students with disabilities, including TBI.

Overview

The Brain Injury Association of America (2011) defines TBI as “an alteration in brain function, or other evidence of brain pathology, caused by an external force”. A TBI can also occur from a fall or blow to the body that causes the head and brain to move quickly back and forth (Centers for Disease Control and Prevention [CDC], 2014). According to the World Health Organization (2006), TBI is the leading cause of death and disability in children and young adults worldwide. The World Health Organization further projects that TBI will be the leading cause of morbidity and mortality by 2020, costing an estimated 60 billion dollars (Asemota, George, Bowman, Haider, & Schneider, 2013). TBI can result in short- and long-term cognitive, academic, behavioral, social-
emotional, and physical problems, and school personnel should ensure that the needs of this population of students are being met (Schilling & Getch, 2012).

**Prevalence.** A number of TBIs are mild head injuries that do not receive any medical treatment. Each year in the United States, approximately 90 out of 100,000 people will be hospitalized as a result of a TBI and an additional 465 out of 100,000 will visit a hospital emergency department (Coronado et al., 2012). Nearly 275,000 of these incidents will result in hospitalization and 52,000 will result in death. Over half a million of these injuries will affect infants, children, and adolescents between the ages of 0 and 19, and of the school-age children in the U.S. who survive their injury, it has been estimated that 1 out of 550 will experience a TBI severe enough to result in a long-term disability (Arroyos-Jurado, Paulsen, Ehly, & Max, 2006; Faul et al., 2010). Regardless of age, males are two to three times more likely to sustain a TBI than females (Faul et al., 2010). TBI accounts for one-third of all injury-related deaths in the U.S., and there are particularly high incidence rates among the younger age group. In 2000, there were approximately 50,000 TBI-related hospitalizations in children and adolescents who were 17 years of age or younger, which equates to more than one billion dollars in acute care costs (Asemota et al., 2013).

The likelihood of a TBI resulting in hospitalization or death increases with age. Adolescents ages 15 to 19 are twice as likely to be hospitalized and 1.5 times more likely to die as a result of a TBI (Faul et al., 2010; Shi et al., 2009). This is often linked to participation in high-risk activities among this age group. High-risk activities may include not wearing a seat belt when riding in a car driven by someone else, riding in a
vehicle driven by someone who is intoxicated, being involved in a physical fight, carrying a weapon, engaging in competitive contact sports, and using drugs and alcohol (CDC, 2010, 2011; Johnston, O’Malley, Bachman, & Schulenberg, 2011; Shi et al., 2009). Additionally, according to the CDC (2011), approximately 2.6 million children and adolescents ages 4 to 19 will need emergency care for a sports or recreation-related injury. Nearly 7% of these injuries will be TBIs; 75% will occur among males, and 71% will occur among children and adolescents ages 10 to 19. Because of the relatively high rates of injury in adolescents and the transition many adolescents will soon experience, it is particularly important to plan educational transitions for this group of students when additional supports are needed.

**Etiology.** Causes of TBI may include injuries sustained from motor vehicle accidents (occupant, motorcyclist, pedal cyclist, or pedestrian), falls, assaults, and other external causes (Faul et al., 2010). Because adolescence is characterized by risk-taking behavior, this age group is particularly susceptible to intentional and unintentional injuries (Asemota et al., 2013). Participation in high school sports, exposure to assault, and experience of motor vehicle injuries all increase the likelihood of an adolescent sustaining a TBI (Asemota et al., 2013). Asemota et al. (2013) found that 35% of adolescent TBIs were the result of a motor vehicle occupant injury, 14% were from falls, and 12% were from being struck, cut, or pierced by an object or person. Motor vehicle occupant accidents were the leading cause of injury among older adolescents, accounting for 23% of TBIs in youth ages 14-15, 42% ages 16-17, and 46% ages 18-19. Falls were found to be the leading cause of TBI among the younger adolescents, causing more than
20% of TBIs among adolescents ages 10-13. Other leading causes of TBI in younger adolescents include motor vehicle occupant accidents and bicycle accidents. Additional causes of TBI include injuries sustained as a pedestrian, from another type of transportation, or from the use a firearm (Asemota et al., 2013).

Severity. There are varying levels of TBI severity, and the severity levels are used to make treatment decisions and predict outcomes. According to Posner, Saper, Schiff, and Plum (2007), consciousness is defined as “the state of full awareness of the self and one’s relationship to the environment” (p. 5). TBI is typically classified along a descriptive severity continuum ranging from mild to severe, depending on the level of altered consciousness one experiences as a result of a head injury. The level of altered consciousness can range from confusion, in which some degree of consciousness is retained, to a permanent vegetative state, in which there is total loss of consciousness (TLOC). Injuries that result in a less serious TBI may include lacerations caused by blows to the head; injuries that result in a serious TBI may include motor vehicle traffic/pedestrian injuries, serious assault injuries, injuries obtained in falls from heights (Jantz et al., 2014).

The Glasgow Coma Scale (GCS) is a widely used assessment that measures the level of altered consciousness experienced as a result of a TBI (Teasdale & Jennett, 1974). It measures this by a person’s ability to open their eyes, communicate with others, and move their limbs. A point system is used to classify a TBI; the point designation can also facilitate decision-making and outcome prediction. A scale of 1-4 is used for eye opening, 1-5 for verbal response, and 1-6 for motor response with a total ranging from 3-
15 points. Higher scores indicate a less severe TBI. Scores of 13-15 indicate a mild TBI, including concussions; scores of 9-12 indicate a moderate TBI; and scores of 3-8 indicate a severe TBI (Teasdale & Jennett, 1974). According to Borg et al. (2004), mild TBIs represent approximately 85% of all TBIs in North America. While measures of severity such as the GCS are important indicators of TBI severity, educators must be mindful of the fact that an individual who sustained a TBI and received a relatively high GCS score at the hospital could ultimately have greater long-term impairment than an individual whose TBI was assessed as more severe (lower GCS). This is because a TBI can produce different effects from one person to another; the recovery trajectory is impacted by quality of rehabilitation and intervention, pre-injury characteristics, and age at injury, just to name a few (Arango-Lasprilla & Kreutzer, 2010; Ashley, O’Shanick, & Kreber, 2009; High, Boake, & Lehmkuhl, 1995).

Cognitive and Neurological Consequences of a TBI

Following a TBI, an individual may experience a range of cognitive difficulties, including impaired executive functioning as well as information processing and memory difficulties. In fact, a recent study found that 67% of individuals with severe TBI displayed residual cognitive impairments and 33% of individual did not demonstrate cognitive impairments one year post-injury (Sigurdardottir et al., 2015). These problems can range from subtle to obvious. Further, according to the CDC (1997), repeated mild TBIs occurring over an extended period of time (months, years) can result in cumulative neurological and cognitive deficits; repeated mild TBIs occurring within a short period of time (hours, days, weeks) can be catastrophic or fatal. The nature, location, and severity
of the injury, the age at the time of the injury, and the availability and quality of medical and rehabilitation services all contribute to a person’s cognitive recovery and the difficulties experienced (Jantz & Coulter, 2007). Typically, there will be an accelerated rate of cognitive recovery during the first five months following a TBI (Spitz, Ponsford, Rudski, & Maller, 2012). Post-injury difficulties may also be delayed, not surfacing until a later time (Kiraly & Kiraly, 2007).

Because humans are forward-moving beings, TBIs often result in damage to the frontal lobe, located at the front of the brain. The frontal lobes are involved with executive functioning, which is defined as an individual’s “ability to reason, problem-solve, set goals, prioritize, self-monitor, self-correct, self-regulate, initiate or inhibit response behavior, organize and plan, and effectively execute purposeful behavior” (Jantz & Coulter, 2007, p. 88). As a result, when there is damage to the frontal lobes following a TBI, people often experience executive dysfunction and may struggle with problem-solving, reasoning, organizing and planning, and self-monitoring. The ability to quickly and efficiently process information may also be impaired. The executive functioning difficulties experienced following a TBI depend on an individual’s age, stage of brain maturation, and stage of executive functioning skill development at the time of the injury. Because executive functioning skills are often the last to develop, problems that result from damage to the frontal lobe may not be apparent until much later when the skills are needed (Jantz et al., 2014). Schmitz, Rowley, Kawahara, and Johnson (2006) found that self-awareness impairment after a TBI may be associated with abnormal activity in the right prefrontal cortex, which is the thick outer layer of the prefrontal lobe. Thus, it may
be difficult for people to accurately self-report their experiences and difficulties following a TBI as a result of their impaired awareness (Ham et al., 2014). Further, a study conducted by Richardson, McKay, and Ponsford (2015) found self-awareness of deficits did not change over time.

The frontal and temporal lobes of the brain are also involved in memory, so when a TBI affects these parts of the brain, the individual is at risk for memory difficulties. Individuals with TBI often lack awareness of their cognitive deficits and subsequent impairments. As a result, these individuals are less likely to accurately self-report cognitive difficulties, especially difficulties with memory skills (Long, Rager, & Adams, 2014). Memory difficulties can persist through life and are often slower to recover (Vakil, 2005).

**Physical Consequences of a TBI**

Nearly 75% of individuals in a recent study reported headache symptoms during the first year following their injury and many continued to report symptoms beyond one year (Hoffman et al., 2011). Post-traumatic headache (PTH) is one of the most commonly reported symptoms experienced after sustaining a TBI. A PTH typically occurs within days after the injury or shortly after awakening from a coma, but it can also be delayed (Dikmen, Machamer, Fann, & Temkin, 2010; Formisano, Bivona, Catani, D’Ippolito, & Buzzi, 2009). Individuals have reported persisting PTH as a result of TBI, regardless of the severity level (Jantz et al., 2014).

Individuals who have sustained a TBI may also experience sleep-wake disturbances (SWD), occurring in one-half to three-quarters of those who have sustained
a TBI (Jantz et al., 2014). SWD include insomnia, hypersomnia (increased need for sleep within a 24 hour period), sleep apnea, excessive daytime sleepiness, and fatigue. These individuals may experience loss of vitality, which has been found to significantly affect quality of life and social functioning (Jantz et al., 2014). As a result, coexisting conditions, including depression, anxiety, irritability, fatigue, cognitive deficits, pain, and function impairment, may exist (Jantz et al., 2014).

Sensory-motor difficulties (SMD) following a TBI may go undetected unless they are visibly apparent (Davis & Dean, 2010). SMD can include vision difficulties, motor difficulties, and difficulties with balance, and dizziness. Vision difficulties may include double vision; difficulty controlling the muscles that move the eyes when finding, identifying, and tracking things in the environment or on printed material; difficulty controlling the muscles of the eyes used to focus the field of vision when changing from near vision to far vision and vice versa; difficulty with peripheral vision; and sensitivity to light (Heitger et al., 2009; Niemeier, 2010). Common motor problems include difficulties with fine motor hand control (e.g., motor skills, speed, coordination); motor weakness; difficulties with gross motor speed, balance, strength, coordination, and gait; and partial or full paralysis (Jang, 2009; Kuhtz-Buschbeck et al., 2003). Impaired balance and dizziness are commonly reported and include lightheadedness, vertigo, poor hand-eye coordination, and imbalance with stance and gait (Childs, 2010; Gottshall, 2011; Gottshall, Drake, Gray, McDonald, & Hoffer, 2003).

Immediate and early epileptic seizures can also occur following a TBI; these most commonly occur after a severe TBI (Vespa et al., 2010). An immediate seizure is one
that occurs within 24 hours after the injury, and an early seizure is one that occurs within one week post-injury (Hesdorffer, Benn, Cascino, & Hauser, 2009; Lowenstein, 2009). Depressed skull fractures, intracerebral hematoma, and subdural hematoma are considered risk factors for immediate and early seizures as well as risk factors for later development of epilepsy (Christensen, 2012).

**Behavioral, Social, and Emotional Consequences of a TBI**

Behavioral, social, and emotional difficulties after a TBI are common, particularly with moderate and severe TBIs (Gouick & Gentleman, 2004; Gould, Ponsford, Johnston, & Schonberger, 2011; Max et al., 2012; Williams & Wood, 2010; Rapoport, 2012). The frontal and temporal lobes are especially susceptible to damage following a TBI. The temporal lobe includes the amygdala and hippocampus, both parts of the limbic system. The limbic system also includes the hypothalamus, cingulate gyrus, and other brain structures. Both the frontal and temporal lobes of the brain are involved in the monitoring and regulation of emotion. The executive dysfunction associated with damage to the frontal lobe may result in increased impulsive behavior. Additionally, the cognitive difficulties experienced as a result of damage to the frontal lobe can have a direct effect on emotions. With increased emotional and behavioral difficulties, an individual who has sustained a TBI may, in turn, experience difficulties with peers (Jantz et al., 2014).

Depression is the most common psychiatric complaint following a TBI. As a student’s age increases, so does the risk of experiencing clinically significant levels of depression following a TBI (Max et al., 2012). Risk for the onset of depression has been
found to be related to the severity level of the TBI but does not appear to be related to the injury location. Additionally, Rapoport (2012) found a relationship between the onset of depression post-TBI and family discord, the amount of available social support, the lack of adequate rehabilitation treatment, and socio-economic status. Anxiety may also be experienced following a TBI. Risk for anxiety symptoms post-injury is increased by (1) age at the time of the injury (the younger the child is, the higher the risk for anxiety symptoms), (2) the presence of concurrent affective dysregulation (e.g., separation anxiety, social phobia), and (3) damage to the superior frontal gyrus or frontal white matter (Max et al., 2011). Anger and irritability are also common following all severity levels of TBI. Preexisting or new mental health issues, new levels of dependency on others, and damage to the areas of the brain involved in executive functioning may all contribute to anger and irritability following a TBI (Hart, Vaccaro, Hays, & Maiuro, 2012). Executive functioning difficulties may also impair students’ self-awareness and ability to deescalate anger or irritability, recognize cause and effect relationships, or understand consequences (Jantz et al., 2014). Finally, students who experience apathy following a TBI typically are those with damage to their front lobes or limbic system (Lane-Brown & Tate, 2011).

**Academic Difficulties and TBI**

As a result of cognitive, emotional, behavioral, and social difficulties experienced following a TBI, students often have short- or long-term academic difficulties as well. Short-term academic consequences of mild TBI may temporarily affect educational performance, but long-term consequences after a more acute mild TBI or a moderate or
severe TBI may lead to significant academic difficulties. Gil (2003) also found that the younger the student is at the time of the injury, the more academic difficulties they experience due to the amount of learning that is ahead of them. In other words, if they did not build a significant foundation of knowledge and skills prior to the injury, new knowledge and skills gained using a damaged “processing system” may make it much more difficult to learn new things and to connect information to prior knowledge.

Students who sustained a severe TBI often have difficulties keeping up with the rigorous demands of the academic environment. Although these students may first seem to perform normally, consequences of a TBI that result in academic difficulties and lack of educational progress may not be apparent until later. Students with a TBI may have difficulty with academic skills such as learning and processing new information, processing speed, retrieving previously learned information, integrating new and previously learned information, short- and long-term memory, attention, psychomotor skills, and executive functioning skills (Jantz et al., 2014). With deficits in these skill areas, students with a TBI are at a significant disadvantage compared to their peers, as it can impact all academic areas and processes involved with learning (Jantz et al., 2014).

Parents are often in the best position to evaluate a child’s functioning following a TBI (Gfroerer, Wade, & Wu, 2008). Parents know their children’s strengths and weaknesses and would likely recognize when there is a change in behavior that is adversely affecting the child’s educational performance. For example, the parents may be the first to recognize behavior changes that are impacting the child’s ability to socialize and learn (Gfroerer et al., 2008). It may be months before many of the
cognitive, physical, and psychological consequences of a TBI are identified, but it may be even longer before academic consequences are noticed (Clark, Russman, & Orme, 1999). For this reason, it is important that school personnel and parents understand the unique educational needs of students who have sustained a TBI so that needs can be identified early and appropriate services can be provided (Gfroerer et al., 2008).

**School-Based Identification of TBI**

Students with disabilities are at risk for future difficulties; however, if used effectively, special education can improve outcomes for young people with disabilities (Heward, 2002; Landrum et al., 2003). Because parents are often the first to recognize a child’s difficulties following a TBI, they are critical partners in school-based intervention assistance teams and multi-factored evaluations so that students with TBIs are identified and served appropriately (Gfroerer et al., 2008).

TBI became an official special education disability category under the Individuals with Disabilities Education Act (IDEA) in 1990. The special education definition of TBI reads:

> “Traumatic Brain Injury means an acquired injury to the brain caused by an external physical force or by other medical conditions, including but not limited to stroke, anoxia, infectious disease, aneurysm, brain tumors and neurological insults resulting from medical or surgical treatments. The injury results in total or partial functional disability or psychosocial impairment or both, that adversely affects a child’s educational performance. The term applies to open or closed head injuries, as well as to other medical conditions that result in acquired brain
injuries. The injuries result in impairments in one or more areas such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech. The term does not apply to brain injuries that are congenital or degenerative, or to brain injuries induced by birth trauma” (U.S. Department of Education, Federal Register, 57 [189], September 29, 19, p. 44802).

In Ohio, children can qualify for early intervention services for TBI from birth to less than three years without a special education classification label. Beginning at age three, children with TBI who qualify for special education services can do so under the Traumatic Brain Injury special education classification (Ohio Department of Education, 2013). Parents and guardians of infants and toddlers often do not consider contacting the school after their child sustains a TBI to obtain services. Additionally, symptoms of a TBI are commonly mistaken for symptoms of other disabilities and may go unnoticed until several years after the TBI was sustained (Jantz et al., 2014).

**Misidentification and underrepresentation.** More than 6.5 million students in the U.S. between the ages of 3 and 21 are receiving special education services under a special education classification and of these, approximately 26,000 students are classified under Traumatic Brain Injury (Data Accountability Center, 2012). This number does not include the students with TBI who are receiving special education services under another special education category (i.e., Other Health Impairment). It also does not include students who have educational needs as a result of sustaining a TBI but did not qualify
for special education services. Finally, this number does not include students who have sustained a TBI but did not bring it to the attention of the special education multidisciplinary assessment team (Jantz et al., 2014). However, more than 44,000 school-age children and adolescents (ages 15-19) are hospitalized as a result of a TBI each year, many of whom experience permanent impairment that adversely affects their educational performance (Faul et al., 2010). This suggests that there is an underrepresentation of the number of students classified under the Traumatic Brain Injury disability category.

Many students who have sustained a TBI may not be receiving the services, accommodations, or modifications they need. The underrepresentation of students receiving special education services under the Traumatic Brain Injury classification may be attributed to the student not qualifying for special education services, already receiving services under another special education category, or qualifying under another disability category as a result of misidentified needs (Jantz et al., 2014). For example, a child who exhibits behaviors that are typically associated with executive functioning deficits, such as attentional control, inhibition, organization, planning, and self-monitoring, may be misidentified as having attention-deficit/hyperactivity disorder (ADHD) (Biederman et al., 2004) and classified under the disability category of Other Health Impairment rather than Traumatic Brain Injury. In addition, if a child was very young at the time of the injury, the parents or guardians may not have considered how the TBI would affect the child’s educational needs in the future. Finally, the underidentification may be a result of delayed symptoms. Often with a TBI, a child
appears to be functioning normally and the effects of a TBI do not become evident until much later. If a TBI was sustained as certain regions of the brain were maturing, the effects may not become apparent until those regions of the brain begin to mature and develop. For example, the prefrontal cortex is one of the last regions of the brain to develop and is responsible for executive functioning, planning, organizing, and decision-making. If a child injures the prefrontal cortex at a very young age, before it is fully developed, effects of the TBI may not become apparent until later in life (Jantz et al., 2014).

**Transitions for Adolescents**

Students transitioning from high school to a college or university setting need to adjust to the required academic and social demands (Bayram & Bilgel, 2008). With the transition to a college or university, adolescents will likely experience practical issues and potential stressors. Additionally, postsecondary students must cope with the loss of one’s school friends, the need to form fresh relationships and groups, potentially moving away from home and becoming acquainted with new college roommates, dealing with different methods of learning, and the expectation of increased autonomy in life and studies (Cleary, Walter, & Jackson, 2011). Further, college students, especially for those students living away from home, have lessened parental oversight, generally have complete responsibility for self-management of their own mental and physical health (e.g., seeking care, taking medications, keeping medical appointments), and are often away from their family support network (Cleary et al., 2011). Many students transitioning to a college or university are often ill-prepared for these academic and social
adjustments and have difficulty effectively managing study, work, and extracurricular demands (Cook, 2007). Students who have a difficult adapting to these academic and social demands may experience mental health issues, such as anxiety and depression, as a result (Cleary et al., 2011).

The characteristics associated with psychoanalytic theories of development may explain human behavior with the transition to a high school to postsecondary setting. Erik Erickson recognized that humans develop in psychosocial stages and that the primary motivation for human behavior is social and reflects a desire to affiliate with other people (Erickson, 1950, 1968). According to Erik Erikson’s theory, eight states of development unfold as we go through life. During the young adulthood years (ages 18-40), Erikson’s theory states that individuals face the developmental task of forming intimate relationships. Healthy friendships are an important part of this stage of psychosocial development, and this is how intimacy is achieved; if healthy relationships are not developed, isolation will result, according to Erikson. An inability to development meaningful relationships with others may affect an individual’s personality as well. Isolation may lead to depression and a mistrust of others (Santrock, 2011). Thus, this stage of development is important to consider as young adults transition to a postsecondary setting.

Transitions for Adolescents with Severe TBI

Students who have sustained a TBI may experience difficulties at a number of transition points in their life, including returning to play (i.e., returning to a sport team after a break for recovery), returning to school, transitions between classes, transitions to
new schools, and transition from adolescence to adulthood. To maximize recovery efforts and minimize problems, it is important for school-based professionals to provide appropriate services that support students at each transition point.

The transition from the hospital or rehabilitation center back to school is a critical point. It is imperative that school-based professionals, medical professionals, neurological professionals, rehabilitation specialists, and parents are all involved in the recovery process. To help maximize the efforts of everyone involved, ongoing communication and collaboration is needed to ensure all those involved are updated on the student’s medical and rehabilitation progress and educational needs. Roles for those involved should be clearly outlined, and the professional and legal guidelines (both medical and educational) should be discussed (Jantz et al., 2014).

School-based professionals (e.g., psychologists, counselors, nurses, teachers, speech-language pathologists, occupational therapists, physical therapist) often lack adequate training in assessment and intervention for students with TBI, which can make effective transitions quite challenging. These professionals often do not know how to best meet the needs of students who have sustained a TBI (Glang, Dise-Lewis, Tyler, & Denslow, 2006; Jantz & Coulter, 2007), nor do they know the consequences and difficulties students with TBI experience (Davies, 2013; Funk, Bryde, Doelling & Hough, 1996; Frank, Redmond, Ruediger, & Scott, 1997). Additionally, although districts are legally required to provide special education and related services under IDEIA (2004), they may lack sufficient financial resources to provide quality and extensive services to meet students’ needs (Jantz et al., 2014).
Students who qualified for special education services in high school under the TBI disability category typically sustained a severe TBI resulting in cognitive, physical, and behavioral/social/emotional difficulties that adversely affected their academic progress to such a degree that special education services were required. In high school, these students were protected under IDEA, ADA, and Section 504; IDEA mandated that an appropriate transition plan be in place for them post-high school. A review of the literature shows that a well-crafted transition plan for students with a disability, including those with TBI, is associated with positive educational and career outcomes (Heckhausen et al., 2013). However, students who sustained a TBI and did not qualify for special education services may experience transition issues after graduating from high school. These students may have had needs in high school that were unidentified because with the support of parents and the school, the student was not often required to use independent living skills that are necessary after entering a postsecondary setting. Students who suffered a TBI who are now entering a postsecondary setting may experience challenges with organizing class materials, planning long-term projects, and managing finances because of the cognitive and social impairments resulting from a TBI (Biederman et al., 2004).

Students with TBI may particularly be at risk for academic failure, and adults with TBI may have difficulty maintaining a job as a result of the social, emotional, and behavioral consequences (Hartley, 2010). These consequences are typically not immediately evident, may not be fully understood, or may be overlooked by professors, peers, or coworkers. Students and employees who have sustained a TBI may experience
problems with memory or information encoding, which can be a cognitive or emotional consequence of TBI. Additionally, students and employees may experience lowered self-confidence and difficulty with social relationships (Hartley, 2010).

**Transitions and Supports for Students with Disabilities**

According to Hamblet (2014), many students with disabilities who attend college do not complete their degree at the same rate as their typical peers. This may be explained by the differences in the educational environment and the disability services that are provided at a postsecondary institution (Hamblet, 2014). Students with disabilities often have difficulty keeping up with the pace of the postsecondary academic environment. This setting typically places higher demands on students than the high school setting; college students are often assigned heavy reading loads, must maintain focus through long lectures, and prepare for exams and write papers that are often weigh heavily on a final grade. Further, these rigorous demands are typically provided without the structure or supports that were provided in high school (Hamblet, 2011).

Students with learning disabilities attending a postsecondary institution have reported difficulties with feeling overloaded with work, prioritizing and knowing where to begin with assignments, the amount and standards of their writing, the lack of regular assignments and feedback, study skills, test-taking and preparation, note-taking, listening comprehension, organization, and reading (Hadley, 2007; Skinner, 2004). College students with ADHD have reported that they struggle due to deficits in their organizational skills, academic coping strategies, executive functions, and focusing and sustaining attention (Norvilitis, Sun, & Zhang, 2010). Additionally, Pineau, Marchand,
and Guay (2015) recently found that individuals with mild TBI report significantly higher levels of distractibility and difficulties with focus. Although most students transitioning to a postsecondary setting must make adjustments, the new challenges presented to students with learning disabilities and ADHD may be more difficult for them than their typical peers because their disabilities affect learning, concentration, and planning, all of which are critical to success in this new educational environment (Hamblet, 2014).

As a result of the transition challenges students with disabilities face, formal supports are put in place to help them with the transition from high school to postsecondary settings or the workforce. In high school, students may have also received informal support from parents and school staff. These supports will not exist in the same form in college or work settings; thus, students’ needs may not be met. The transition to college or independent living can especially be difficult for a student with a TBI because the cognitive, physical, and behavioral difficulties they experience may pose challenges for independent living (e.g., difficulty planning long-term projects, difficulty organizing personal and class materials, or difficulty with living with a roommate and making friends). The successful transition from high school to college or the workforce is critical for positive life trajectories (Heckhausen et al., 2013).

**Legal protection.** To support the transition process for students with disabilities, including those identified with a TBI, the following legislative acts were passed: Individuals with Disabilities Act (IDEA, 1990), Americans with Disabilities Act (ADA, 1990), and The Rehabilitation Act of 1973 (Section 504). These legislative acts provide
legal protection to students with disabilities in high school and include transition plans and supports (Naugle & Campbell, 2010).

IDEA (1990), which was reauthorized in 2004 to become the Individuals with Disabilities Education Improvement Act (IDEIA, 2004), is the primary legislation governing transition services for students with disabilities. This law guarantees that students with disabilities receive appropriate transition supports as they prepare for postsecondary education or the workforce (Individuals with Disabilities Education Improvement Act of 2004 [IDEIA 04], P.L. 108-446, §601 et seq., 118 Stat. 2647 (2005)). This involves a written plan as part of the student’s Individualized Education Program (IEP) when the student is 16 years old (and earlier in some states) that helps prepare the student for life after high school. The written plan must include the student’s strengths, preferences, needs, and interests. It must also include appropriate measurable postsecondary goals related to training, education, employment, and independent living skills as well as the transition services needed to assist the student in reaching the goals (Individuals with Disabilities Education Improvement Act of 2004 [IDEIA 04], P.L. 108-446, §601 et seq., 118 Stat. 2647 (2005)). However, while IDEIA protections help prepare students for life after high school, postsecondary students are no longer eligible for the modified instruction offered through IDEA. They are, instead, permitted appropriate instructional accommodations under the American with Disabilities Act, or ADA of 1990 (revised version is the Amendment Act of 2008) and the Rehabilitation Act of 1973 (Naugle & Campbell, 2010).
The ADA prohibits the discrimination of otherwise qualified individuals with disabilities in employment within both public and private sectors (Barnard-Brak, Lechtenberger, & Lan, 2010). It also mandates that institutions must provide “reasonable accommodations in such areas as academic programming, examinations and evaluations, housing, and recreational facilities” (Barnard-Brak et al., 2010, p. 411). In order to be protected by the ADA, one must have a disability as defined by the ADA. The ADA defines a disability as a “physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment” (Americans with Disabilities Act, 42 U.S.C. § 12101 et seq. (1990)). Programs, activities, and services made available by state and local governments must not discriminate on the basis of disability, regardless of whether an entity receives federal financial assistance. The ADA requires accommodations to be reasonable and timely and includes any accommodations, modifications, or work adjustments that make it possible for a qualified person with a disability to participate in and enjoy an opportunity (Americans with Disabilities Act, 42 U.S.C. § 12101 et seq. (1990)). Although many people who have sustained a TBI experience symptoms severe enough to affect their functioning, they often do not meet the ADA’s definition of a disability and, therefore, are not protected by the ADA (Americans with Disabilities Act, 42 U.S.C. § 12101 et seq. (1990)). According to the ADA (1990), a disability means that an individual has (a) a physical or mental impairment that substantially limits one or more major life activities, (b) a record of the impairment, and (c) being regarded as having the impairment.
While the ADA protects the rights of individuals with disabilities in employment (ADA, 1990), Section 504 of the Rehabilitation Act of 1973 (Section 504) was established, in part, to protect the rights of students with disabilities. Section 504 ensures that individuals with disabilities cannot be denied access to federally funded activities or programs based on their disability (Yell, 2006). Therefore, no colleges or universities receiving federal funds can exclude a qualified applicant because of a disability (Rehabilitation Act of 1973, Section 29 U.S.C. § 794(a). A Section 504 plan provides an opportunity for students who did not qualify for special education services (i.e., an IEP) to receive accommodations for their disability. If a student’s academic progress is impacted as a result of a TBI but the student did not qualify for special education, a Section 504 plan can provide the student with accommodations to support academic advancement (Ohio Department of Education, 2013).

**Transition plans.** Legal protections under IDEIA (2004) that applied to students with disabilities who qualified for special education services in high school do not apply to these students in postsecondary settings. Thus, it is important to provide students with disabilities with accommodations and interventions that promote independence. Accommodations might include a shortened day, extra travel time to and from class, elevator keys, extra set of books for home, shortened workload, class or schedule changes, assistive technology, waived physical education requirements, frequent breaks, peer buddies, note takers, and advanced organizers (Chesire, Canto, & Buckley, 2011). The postsecondary transition plan should align with the services a student needs as well as those the student can receive in a postsecondary setting. An individualized transition
plan post-high school is critical for students’ success (Turner, Fleming, Ownsworth, & Cornwell, 2010).

**Transition to postsecondary institutions.** Postsecondary education refers to educational options including short-term vocational training (e.g., childcare, food service), schools that focus on social skills development, and vocational or technical schools that teach a trade (e.g., plumbing, carpentry). Additionally, postsecondary education can refer to technical, vocational, and community colleges that provide preparation for employment, short-term continuing education, and/or academic coursework leading to a certificate, a license, or an associate degree. Finally, a postsecondary option may be to attend a four-year college or university that provides a bachelor’s degree upon completion of the program (Shaw, Madaus, & Dukes, 2010). As of 2000, 56% of workers in the U.S. required some education post-high school for their jobs, as compared to 20% in 1959 (Carnevale & Fry, 2000). This suggests that training after high school is becoming increasingly important, and President Obama’s initiative for Americans to complete at least one year of college after high school will be particularly critical for students with disabilities. It is vital and legally required that students with disabilities have a transition plan in place to provide positive outcomes and ensure access and success in postsecondary education (Shaw, 2009).

One in ten college freshmen have a documented disability, which is three times the percentage in 1978 (National Center for Educational Statistics, 2006). Additionally, approximately 44% of students with a disability enrolled in postsecondary education after high school, as compared to 26% in 1990 (Wagner, Newman, Cameto, Levine, &
Marder, 2007). Despite this increase in enrollment, individuals with disabilities in the U.S. are still significantly less likely to complete their college degree (Marshak, Van Wieren, Ferrell, Swiss, & Dugan, 2010). Further, Hartley (2010) reported that students with disabilities have higher postsecondary dropout rates and greater overall academic challenges compared to their non-disabled peers. According to Shaw (2009), 52% of students classified under the Traumatic Brain Injury special education category enrolled in a postsecondary school after high school. With more students with disabilities planning to obtain a postsecondary education, it is essential that transition supports are in place for them after high school.

There are significant differences in the instructional environment in secondary versus postsecondary settings, particularly in the amount of structure and the expectation for students to function independently (McGuire, 2010). Student responsibilities also differ from high school to postsecondary education. Unlike in high school where the IEP team (including the student’s parents) develop a plan to support the child, the postsecondary student is responsible for selecting courses, making sure appropriate accommodations are implemented and executed, and monitoring the effectiveness of the accommodations. Students with disabilities in postsecondary education settings must self-disclose their disability and present supporting assessment data and documentation outlining the nature of their disability (Shaw et al., 2010). In higher education institutions, the provisions of the IDEA no longer apply to students with disabilities, regardless of the nature or severity of the disability. Further, there is no legal mandate requiring public or private higher education institutions to deliver a free and appropriate
education (FAPE). Students with disabilities are held to the same academic standards as their non-disabled peers, and it is the responsibility of the student with a disability to inquire about eligibility for accommodations through their university’s office of disability resources (Wisbey & Kalivoda, 2011). Students with disabilities in postsecondary education need to self-advocate and self-determine their needs (Shaw et al., 2010).

Colleges are not required to offer individualized special education services to students with disabilities, and special education services end after completion of high school (or up to age 21 if one continues using the service in the workplace). However, colleges are required to offer reasonable accommodations to students with disabilities who qualify for services, as long as documentation is provided (McGuire, 2010; Shaw et al., 2009). These services are provided to the student at no cost as long as the services are necessary to provide equal access under the ADA. Some colleges and universities offer more intensive special education accommodations and services, but these are not required by law and typically require students to pay an additional fee (McGuire, 2010; Shaw et al., 2009).

Certain curricular accommodations and modifications allowable in high school may not be permitted in a postsecondary education setting. For example, colleges will deny accommodations that are not reasonable or that lower institutional standards, such as course waivers in a foreign language or math (Shaw, 2009). Depending on the data and documentation provided on the disability, students may receive accommodations for one course but not another. Course modifications, such as not penalizing spelling in a writing class, are typically not permitted. Additionally, colleges usually do not allow for
untimed tests, but students with disabilities may receive an accommodation of having extended time as long as data and documentation reflect a need for it because of the student’s disability (Shaw, 2009).

There is limited research regarding the specific transition challenges for students who have sustained TBI experience. However, studies examining the challenges that students with other disabilities face may provide useful information for students with TBI. For example, Marshak et al. (2010) investigated barriers that students may encounter in seeking and utilizing accommodations in higher education institutions.

The first barrier to seeking and utilizing services is the students’ desire for self-advocacy and self-sufficiency as a college student (Marshak, 2010). As part of independent living, students must seek out services they may need to succeed in college, and this is often a challenge for students with TBI. Students may also not want to seek out their own services because they do not want to “integrate the presence of a disability into their college identity” (Marshak et al., 2010, p. 154). Students with TBI may not believe the injury will impact their functioning at the higher education level, and as a result, may reject this identity. According to Marshak (2010), a second barrier is the fear of a potential negative social stigma of being classified as a “person with a disability.” Students reported during interviews that they did not want to be seen as different or “singled-out,” and thus were less likely to use accommodations for which they may have been eligible. A third barrier is the students’ lack of knowledge about their disability, which affected their ability to accurately and sufficiently explain their unique needs to professors and student affairs professionals. A fourth barrier was the inferior quality of
services delivered when accommodations were requested. That is, students found the accommodations were of little help, which lessened the likelihood of requesting accommodations in the future. Finally, the most highly reported barrier is past negative experiences with professors and other university personnel. Several students reported being confronted by professors regarding the legitimacy of their disability and whether or not accommodations were actually warranted. Questioning the legitimacy of a disability is often the case for individuals with TBI, who may appear to be “fine” to those outside of their close circle of friends and family (Marshak et al., 2010).

To ensure a successful transition from high school to postsecondary education settings, it is important to have an age-appropriate transition plan in place for students with disabilities that aligns with the services they will be able to access in a postsecondary setting (IDEA, 2004, §300.320 b).

**Transition to the workforce.** Vocational status is a strong predictor of overall satisfaction with life (Corrigan, Bogner, Mysiw, Clinchot, & Fugate, 2001). TBI commonly affects young adults in their economically productive years (Zaloshnja, Miller, Langlois, & Selassie, 2008). The cognitive, behavioral, and physical consequences associated with a TBI can impact social functioning and roles as well, including employment (Morton & Wehman, 1995). Obtaining and maintaining a job can be difficult for individuals with TBI. In one study, only 27% of people with TBI were competitively employed at one year post injury (Malec, 2005). In another study, only 41% were competitively employed one or two years post injury (van Velzen, van Bennekom, Edelaar, Sluiter, & Frings-Dresen, 2009). The unemployment rate for people
with TBI three to five years post injury is five times greater than the general population for men and three times greater for women (Doctor et al., 2005). The loss of productivity and costs of continued dependency as a result of unemployment of those with TBI is tremendous (Finkelstein, Corso, & Miller, 2006), but many people with TBI do not receive help finding work (Hart et al., 2010). Students who have sustained a TBI and are transitioning to the workforce should have supports in place to help them find and maintain a job.

Current supports in the workplace include comprehensive programs that focus on work readiness training and sheltered work trials. Additionally, early intervention and on-the-job training and coaching should be implemented to support the individual on the job. Accommodations should be “individualized” and work to meet the individual’s unique needs (Hart et al., 2010). Employers can also provide workplace accommodations to promote employee success and satisfaction. Kirsh et al. (2009) defined workplace accommodations as “changes that are made in a particular workplace environment or in the way things are usually done that make it possible for a person with a disability to do the job” (Kirsh et al., 2009, p. 396). Workplace accommodations may include physical changes to the worksite or changes to job tasks and routines (Kirsh et al., 2009), such as providing additional time to learn new responsibilities.

There are many accommodations that can be made for individuals in the workforce who have sustained a TBI. Because this population often experiences difficulty maintaining stamina during the day, accommodations may include the following: permitting flexible scheduling and allowing longer or more frequent work
breaks, providing additional time to learn new responsibilities, providing a self-paced workload, providing backup coverage for when the employee needs to take breaks, allowing time off for counseling, allowing for use of supportive employment and job coaches, allowing the employee to work from home during part of the day, providing job sharing opportunities, and allowing part-time work schedules (Hirsh, Duckworth, Hendricks, & Dowler, 1996). For memory deficits, accommodations may include the following: providing typed written minutes of each meeting; allowing the employee to record meetings; using notebooks calendars, or sticky notes to record information for easy retrieval; providing written and verbal instructions; allowing additional training time; providing written checklists and using color-coding to help identify items; and posting instructions close to frequently used equipment (Hirsh et al., 1996). For visual problems, accommodations may include the following: providing written information in large print, changing florescent lights to high intensity and white lights, increasing natural lighting, providing a glare guard for computer monitors, and consulting a vision specialist (Hirsh et al., 1996).

Students with TBI may experience roadblocks that could impede their success in postsecondary settings. Specifically, they may have difficulty using skills required of for independent living, and these challenges may be unidentified until they transition to the postsecondary setting. It is important that students’ needs be addressed prior to attending a postsecondary institution or entering the workforce to help equip them with the tools and accommodations needed for a successful transition.
Purpose of the Present Study

Little research exists on the postsecondary services and supports received by students with TBIs. There is also limited research on the transition planning and supports available for these students and what is most and least helpful in the transition process. The purpose of the present study was to understand the experiences of college students who have sustained a TBI as they transition to postsecondary settings.
CHAPTER III

METHOD

Research Questions

The following research questions were examined in the present study:

Research question 1. What are the postsecondary transition experiences and perceptions of young adults who have sustained a TBI?

Research question 2. What are the postsecondary transition experiences and perceptions of parents of young adults who have sustained a TBI?

Research Design

This research study employed a qualitative design. This design was selected because the goal of this study is to gather detailed descriptions from participants about their experiences/perceptions. The thick and rich descriptions of multiple participants’ experiences will allow for generalization of findings (“transferability”) so that interpretation and meaning of data collected can be applied across similar situations involving TBI (Mertens, 2010). The goal in qualitative interview research is reach a point of theoretical saturation, which Guest, Bunce, and Johnson (2000) define as a point in data collection and analysis when new information produced little or no change in coding. Therefore, response saturation occurs when the addition of new participants no
longer produces novel responses. Moreover, saturation occurs when every response possible is provided by the participant pool and is therefore represented in the data set.

Qualitative data were collected through in-depth one-on-one interviews with participants who met the study’s criteria. The methodology used to collect the data was a case study approach by which characteristics and experiences of each participant are examined in close detail. Triangulation of data was met by interviewing both the young adult and parent participant in order to enhance the study’s validity and credibility. The nature of qualitative data collection and analysis involves a degree of inference and interpretation by the researcher. It is possible that verbal responses were misunderstood during data collection or that unconscious bias existed during data analysis.

This research study was developed by the researcher with an interest in determining how young adults experienced TBI consequences after transitioning to a postsecondary setting and how they varied from those experienced prior to the transition. As the researcher, interview questioning and prompts were directed by the information I was seeking based on what was known from the literature on TBI; therefore, these biases that exist in myself as the researcher may have influenced the experiences and perceptions the participants in this study discussed.

Participants and Setting

Young adults. Participants in the current study included three young adults ages 18-22 attending a postsecondary institution in a mid-size Midwestern city in Ohio. The young adults included those who have sustained at least one TBI at some point in their lives and experienced persistent difficulties post-injury. Young adults with TBI who
have transitioned to the workforce after high school were difficult to recruit; as a result, only young adults who have transitioned to a postsecondary institution participated in this study. Young adult participants who have sustained multiple TBIs were not excluded from participating, and there was no specification of age at the time of the injury. Student participants were recruited and identified though snowball and criterion sampling. Snowball sampling was used because the study will begin with a short list of informants who will ask about other possible informants. Criterion sampling was used as students who are identified and meet the criteria of having sustained a TBI and experienced persistent symptoms. Each of the participants is described in detail to follow. All names are pseudonyms to protect the participants’ confidentiality.

“Kyle” is a 20-year-old junior student currently in the pre-medicine/pre-dentistry program at a private, Catholic university in Ohio. Kyle also attended a private, Catholic high school. He reported that he was very involved in high school and was a good student, which continued throughout his postsecondary education as well. Kyle’s first TBI occurred his freshman year of high school. He got hit in the head during a soccer game, lost consciousness, and was immediately taken to the hospital. He recalled having a bad headache and difficulties with memory and recall following the injury, and he did not return to school for two weeks after the injury. At that time, he considered himself to have made a full recovery but was still having to work harder, especially with reading material. He sustained a second TBI when he was a junior in high school, again during a soccer game. He was 17 years old at the time of the injury. He got hit in the head but continued playing the game. It was not until after the game that he began to acknowledge
his symptoms and his parents took him to their doctor, who diagnosed him with another TBI. Again, he was out of school for two weeks and was also advised to refrain from physical activity for four months following this injury. He recalled that he was often tired after his second TBI but did not remember experiencing any other persistent symptoms. Kyle noted that he did not stay overnight in the hospital for his first or his second TBI. Kyle’s third TBI resulted in the most significant symptoms, and it occurred during another soccer game in his senior year of high school. He was hit in the head and sustained another TBI. Kyle also ruptured his eardrum as a result of the accident. He lost consciousness and was immediately taken to the hospital. Following this injury, Kyle returned to school later that same week and realized his memory was significantly impaired when he attempted to take a calculus test and could not remember anything. After his third TBI, he experienced several TBI-related symptoms. Kyle reported that he did not receive any direct school-based services following his TBIs but that he did receive rehabilitative services that included speech, physical, and occupational therapies. Kyle’s fourth TBI occurred from a car accident in which he was rear-ended. The accident happened his sophomore year of college (post-transition), and Kyle reported that following this accident, his TBI symptoms flared up again. Kyle was eligible to receive accommodations for his disability at his postsecondary setting, including taking tests in an alternate setting because he had difficulties focusing in the classroom, but he chose not to continue taking advantage of those services.

“Jace” is a 20-year-old sophomore student attending a private, Catholic university in Ohio, currently majoring in biology. He attended a public, suburban high school. He
reported that he was very involved in high school and was a good student, and he was also very social and made friends easily, which continued throughout his postsecondary education as well. The first head injury Jace recalled sustaining occurred when he was a very young boy and hit his head on the corner of a kitchen table. The next and most significant reported head injury resulted from an accident that took place during marching band practice in which he stood up into a steel beam while loading the band truck. Jace explained that the impact of the blow to his head also jammed his spine down and he knew it was something serious. This occurred during the summer before his senior year of high school. Jace recalled telling an adult that he needed to go to the emergency room to be checked for a concussion but no action was taken. Jace sat unsupervised in the truck for approximately two hours until the end of band practice. After band practice, he called his mother to pick him up and she brought him to the emergency room that night. During the emergency room visit, Jace was put in a neck brace, which he continued to use for the next two months. He described that his most significant TBI-related symptoms after his injury included needing sleep, having headaches, experiencing dizziness, and having difficulty focusing. Jace reported that a Section 504 plan was implemented following this TBI and included accommodations such as extended time on tests, home tutoring, shortened school day (checking in and out of school), frequent breaks, permission to leave class early to avoid crowded and noisy hallway, and the ability to wear earplugs in the hallway. At the postsecondary institution he currently attends, services he receives include extended time on tests, permission to take tests in an alternate setting, permission to take breaks during class, and excusal from class if it is due
to symptoms of his brain injury. He received several other types of services as well but received the most consistent and intensive services from a therapist who helped him with tactical training. He also reported that he found massage therapy helped relieve the tension and pain in his muscles and chiropractic care helped readjust his neck after it stabilized. Jace did not take any prescribed medication to manage his TBI symptoms (e.g., headaches, depression), but he did take an herb and vitamin supplement, St. John’s wort, to help with symptoms of depression.

“Aaron” is a 23-year-old senior student attending a private, Catholic university in Ohio currently majoring in marketing with a concentration in sales management. He reported that he was very involved in high school and was a good student, which continued throughout his postsecondary education as well. Aaron sustained his first and most significant TBI during a basketball game in his junior year of high school when he was hit in the back of his head. He was 17 at the time of the injury. He reported that he was unconscious for approximately two to three second and had difficulty walking in a straight line back to the bench. He also reported that for about 20 seconds following the injury, the lights in the gym continued to dim. The medical staff at the game provided care and diagnosed Aaron with a concussion, but no other treatment was rendered necessary at that time. Aaron sustained another TBI two weeks after his first concussion. This TBI was a result of a collision during a baseball game in his junior year of high school when he fell and, again, hit the back of his head. Following this concussion, Aaron’s parents took him to the hospital. He experienced TBI-related symptoms for the next eight weeks, including headaches and dizziness with physical exertion. He received
physical therapy following this TBI for four months that included eye exercises and balancing exercises. He sustained his most recent TBI from a falling accident that took place during college (post-transition). He hit the top, left side of his head and was taken immediately to the hospital. According to Aaron, he was diagnosed with a moderate to severe concussion. Following this TBI, Aaron’s doctors recommended him dropping some classes and avoiding his computer screen, TV, and loud music. Aaron reported that after this TBI, he experienced headaches and ringing of the ears for a while, but he also began to notice that his focus, attention, and memory were impaired significantly more than they have been previously. He reported that he received accommodations such as extended time and having a note-taker at his postsecondary institution. Aaron also reported that he was diagnosed with attention deficit hyperactivity disorder (ADHD) in the seventh grade. He was taking a prescribed medication for his ADHD in seventh grade but discontinued taking it. He reported that although he believed medication may have helped his attention difficulties experienced as a result of his TBIs, he chose not to take it because of the side effects.

**Parents/Guardians.** Participants in the current study included two parents/guardians of the young adults recruited and interviewed according to the inclusion criteria described above. If a student had two parents interested in participating, they were interviewed separately so that the researcher could obtain their perspectives individually.

“Mrs. J” is Kyle’s mother. She is married and has two children, including Kyle, and lives in a suburban city in Ohio. Mr. J is a dentist and Mrs. J is a director of a child
care program. Both of their children attended a private, Catholic high school. Mrs. J reports that her job was flexible enough that she could drive Kyle to his appointments. She recalled additional head injury incidents that Kyle did not report. She recalled Kyle sustaining a TBI when he was much younger while playing indoor soccer and another one during his freshman year of college when he hit his head on the side of a pool while swimming. Mrs. J reported that Kyle was prescribed medication for his depression during his freshman year of college but that he quit taking it mid-year due to the side effects.

“Mrs. C” is Jace’s mother. She is married and has two children, including Jace, and lives in a suburban city in Ohio. Mr. and Mrs. C own a small family business. Mrs. C also reported that she experienced communication barriers with the school following her son’s most recent TBI. Mrs. C recalled additional head injury incidents that Jace did not report. She recalled Jace sustaining a TBI when he was a child as a result of a roller skating accident and another time when he fell into a flower pot. Mrs. C explained that she was against medication and that her family experienced some financial difficulties. As an alternative to taking medication, she encouraged Jace to take a multivitamin to maintain an elevated level of vitamin D, St. John’s wort to help manage symptoms of depression, magnesium to help manage symptoms of anxiety, and melatonin to help regulate his sleep cycle. According to Mrs. C, these vitamins and supplements seemed to help Jace’s functioning that was impaired by his TBI symptoms.
Materials

Young adult and parent/guardian participants were interviewed separately by the researcher (see Appendix C and D for the young adult and parent interview questioning routes). Interviewing guidelines for young adult and parent/guardian interviews included:

- Description of child pre-TBI
- TBI incident and experience
- Support services following TBI
- Challenges after high school
- Support services after high school

The researcher conducted the interviews and guided each participant with open-ended prompts as needed. Interviews were audio recorded with a digital voice recording device, and the researcher used a computer for note-taking during the interview. The data from each interview were transcribed in entirety using a word processor.

A computer software program, NVivo, was used to assist with coding the data. NVivo is software that supports qualitative research by allowing the researcher to collect, organize, and analyze content from interviews. It also allows the researcher to deeply analyze data using powerful search, query and visualization tools (QSR International Pty Ltd., 2012). Using software such as NVivo to code data provides a more methodological way of analyzing data and adds trustworthiness, rigor, and quality to qualitative research (Richards & Richards, 1991). NVivo’s search options facilitate interrogation of data to help with consistent and accurate data analysis.
Procedures

Approval for this research design was obtained by the Institutional Review Board (IRB) at the University of Dayton (UD) prior to data collection (see Appendix A and B for young adult and parent consent forms). Participants were recruited, in accordance with the IRB, by contacting hospitals, rehabilitation facilities, and other institutions or individuals who may have serviced TBI patients (see Appendix E for participant recruitment materials). An informed consent form was given to participants (including both the young adults and parents/guardians) to sign and date upon review, understanding, and agreement prior to the start of the interview. Data were collected through in-depth interviews with participants to obtain a better understanding of each participant’s experience before, during, and after the TBI. The interviews were conducted individually and face-to-face in a semi-structured format. A pilot interview was conducted with a participant within the target age range with neurological impairments who experienced the transition process, similar to the participants in the research study. This pilot interview was also used for peer debriefing to enhance the study’s credibility. The interviewer engaged in pre- and post-interview rapport building and debriefing with each participant (young adults and parents/guardians). Young adult and parent participants were each given a $10 Panera Bread gift card for participating in the study. Participant names were replaced with a pseudonym to protect confidentiality. The transcription and the data collected did not include any identifying information to ensure that the data was kept confidential.
CHAPTER IV
RESULTS

This research project examined the postsecondary transition experience of young adults who had sustained a traumatic brain injury (TBI). The research questions were analyzed using transcription, coding, and thematic analysis. The recorded interviews were transcribed verbatim to create written transcripts of the participants’ narratives (Turner, Fleming, Ownsworth, & Cornwell, 2010). The researcher reduced the data collected by exploring and “memoing” the data to select parts for coding (Mertens, 2010). Thematic analysis of the narratives was used to identify themes, codes, groupings, or categories of reports (Turner et al., 2010).

Research Question 1: Postsecondary Transition Experiences of Young Adults with TBI

Upon reviewing and coding the transcribed interview protocols, four major themes regarding the postsecondary transition experiences and perceptions of young adults who had sustained a TBI emerged from the data, including: (1) Attention and focus difficulties, (2) fatigue and the need for unusual amounts of sleep, (3) short-term memory difficulties, and (4) social issues.

Attention and focus difficulties. The most common theme that emerged from young adult participants was difficulties with attention and focus after having a TBI and
transitioning to a postsecondary setting. Participants reported that their attention and focus difficulties affected both their academics and social interaction.

Aaron explained that his attention difficulties were apparent during a normal conversation with others. He also described that after transitioning to a postsecondary setting, he experienced difficulties focusing due to environmental changes.

...I would just notice that if having conversations with people, I would just remember being frustrated because I didn’t have the same level of attention that I normally would have within a normal conversation.

For me, the biggest adjustment to college was my ability to focus because when you get to college, there are so many forms of distraction.

Jace described that his difficulties with focus also affected his ability to have a conversation.

Focusing was number one, the most difficult. I called it like jello because every time I had a thought or conversation, I would have to grab onto this conversation and pull it in.

Kyle explained that he had difficulties paying attention and focusing in the classroom, especially when taking tests.

I used the Learning Teaching Center (LTC) to take tests and stuff just because I couldn’t focus in the classroom to take tests.

**Fatigue and the need for unusual amounts of sleep.** Young adult participants and their parents who participated in this research study reported that after the last and most severe TBI, the young adults who sustained the injury were consistently fatigued and required a great deal of sleep. Kyle explained how fatigue was the most prominent symptoms following his second major soccer-related TBI.

I just was out of school for two weeks, just wasn’t feeling right, but I didn’t really notice any lasting stuff from that except just being tired a lot at the time. I just
felt more fatigued and then I wasn’t really allowed to do any physical activity for four months after that.

He reported that he continued to experience fatigue and exhaustion after his third major soccer-related TBI.

And trying to work on getting my stamina back up because I was constantly tired, my body was constantly tired, during this period too.

Taking a test is probably one of the most tiring things I do in my daily life now.

Aaron’s reported experiences with fatigue were related to the effort it took for him to focus. He stated:

It was very frustrating that if I really exerted myself cognitively after a half hour, 45 minutes, I was very exhausted.

And throwing myself back into an environment with a lot of distractions and still when I would exert myself cognitively, I would just be really exhausted.

Aaron also discussed how he developed a time management strategy that included incorporating breaks into his schedule that would his brain to rest in an attempt to avoid feeling so fatigued. He reported:

It was just really focused on my time management and setting the expectation that you’re going to need to take breaks every, like, half hour when you’re doing something in order to give you something to look forward to so you’re not dwelling on the fact that you’re about to get exhausted…And what I really learned was the time management of being able to structure my day through a calendar, sticking to it, and just giving myself the proper breaks in order for my brain to kind of reboot itself.

I put in a lot of hours in high school, but I guess that’s the thing. When I look at the hours I put in in high school and how it seemed like I was able to get through that more without that like, ‘Oh my gosh, it feels like I just ran a marathon with my brain,’ like how it is now, would be the biggest difference.

**Short-term memory difficulties.** Young adults with TBI who participated in this study also reported experiencing difficulties with memory after transitioning to a
postsecondary setting. In the interview, Kyle stated that his short-term memory
difficulties were one of the most prominent experiences he has had since transitioning to
a postsecondary transition. He explained that he has to write down more than he used to
in order to remember information but that in the past, he would be able to “hear or read
something once and it would just be there”. He stated:

From that point on, I just started having issues with memory; where, prior to that,
I could pretty much read something and remember almost every detail of it. But
after that, I had a much harder time with that recall.

Aaron continues to experience difficulties with his short-term memory. He
described that he finds it challenging to retain information. Like Kyle, Aaron reported
that his short-term memory difficulties were one of his most prominent experiences after
transitioning to a postsecondary setting. He stated:

I’d say it was pretty sound and concrete that the biggest things I took away from
this concussion were struggles to retain my memory and my focus seemed to be a
little worse.

Aaron explained that work would take him a significantly longer period of time to
complete than it used to because of his issues retaining information. He stated that
routine was an important aspect of him completing school work and that what he “really
learned was the time management of being able to structure his day through a calendar,
sticking to it, and just giving myself the proper breaks in order for my brain to kind of
reboot itself”. He also mentioned that not getting enough sleep may have heightened his
short-term memory challenges. He stated:

He [Aaron’s doctor] actually really said almost every student has a calendar, but
what I use is an hour-by-hour slot because that forces me to look at how I’m using
my time. Whereas, okay, you spent four hours in the library, but what did you get
done in that four hours? So it’s like you’re looking at a mirror, like what did you
actually get done? They said how important your sleep is for your memory. And so I feel like where I would always stay up late freshman, sophomore year, I really try to focus on getting seven to eight hours, which I’m pretty good at now. And they just said routine is just the biggest thing. I go to the same spot in the library now; I’m so comfortable there. Whereas, in the past, I’d much rather study in my room because that was a comfortable thing. But once I was able to develop that, now I enjoy going to the library because I see the work I’m getting done and everything like that.

**Social issues.** Kyle reported significant challenges with social relationships and situations following his TBIs. He described social stimuli as being overwhelming and as a result, he had a difficult time being around people. This has impacted his ability to make new friends and socialize with others as he transitioned from high school to a postsecondary institution. Kyle discussed his experiences with social anxiety as he drove to the postsecondary institution he was attending:

> And there was almost this crippling social anxiety—and I drove to school, I wasn’t living at school—where every time I drove to school, I’d almost feel like I was going to throw up because I was just so nervous. I was like shaking, it was just bad. And this went on pretty much the whole first year.

Kyle also described what it was like for him as he tried to meet new people and make new friends upon transitioning to a postsecondary institution. He explained how difficult it has been for him because he had not experienced social challenges in the past and stated:

> I just can’t make friends…I just can’t talk to new people, it’s really difficult…It’s not even that I don’t want to. I just feel like I can’t…All my roommates are people I went to high school with that I knew before all this stuff happened. I probably made about five friends that I didn’t know previously…All through college now. It’s just so frustrating. Because I wish I could. I tell myself before we go out and hang out on the weekend, ‘You’re going to talk to new people tonight, you’re going to get to know them’ and then I get there and just sit in the corner and act like a wallflower, I guess is the term. It’s just weird.
I feel like it was very demeaning to me I guess. Just go from being just a normal person to almost not being able to function regularly. And the thing is, I have a cousin who has some pretty bad learning disabilities, and I felt like him. Where you just can’t go to school because you can’t remember any of the information and then you’re just really awkward socially…You lose something. You just lose part of you. And it’s just gone. And you just have to try to find a way to get it back.

Kyle also explained that prior to experiencing social difficulties associated with his TBIs, he would easily meet people his age when his family went on cruises.

However, more recently, Kyle avoids socializing and described how his personality has changed from being outgoing to being much more introverted:

Before, we used to always go on cruises. And the cruises had the things for people all your age. And before this, I just loved hanging out with people there. It was fun. Had a couple week-long girlfriends…But since then, and of course, you go on the excursions with your family and stuff but all the social stuff… But after that, I’d just pretty much lock myself inside the cabin and just read. Like don’t hang out with people even though there’s more stuff to do now…Just don’t do it. It’s been like the trend for three years now I think…Where before it was always just like more outgoing.

**Research Question 2: Parent Reports of Postsecondary Transition Experiences of Young Adults with TBI**

Upon reviewing and coding the transcribed interview protocols, three major themes regarding the postsecondary transition experiences/perceptions of parents of young adults who have sustained a TBI emerged from the data: (1) Fatigue and the need for unusual amounts of sleep, (2) repeated injuries, and (3) social issues.

**Fatigue and the need for unusual amounts of sleep.** The most common theme that emerged from parent participants is recognizing fatigue and the need for unusual amounts of sleep in their young adult child with TBI. Following Kyle’s most severe TBI, Mrs. J, Kyle’s mother, reported:
That is another thing. He still struggles with fatigue. Every day, ‘I’m tired, I’m tired, I’m tired, I’m tired.’ And I only see him not fatigued when he’s home in the summer. Because now even, he’s not a social butterfly. He doesn’t go out much. He’s kind of a homebody. He’s comfortable there. And he’s not as tired at home. But during the school year, he’s exhausted. And if you see him on the weekend, he’s exhausted. So it does really take a lot out of him.

Mrs. J disclosed in her interview that Kyle was working at a local market following his most recent TBI and continues to work there today. Mrs. J stated the following in response to a prompt about how Kyle feels following a typical shift at his current job:

Exhausted. Exhausted. Four hour shift too. Some of them, ‘I’m so tired”…But now he’s working, they usually have him 4-12, and he’s exhausted from that too when he does get home or goes back to school.

When discussing changes in Kyle’s self-regulation and irritability, Mrs. J also stated that Kyle’s attempt at controlling his impulsivity also resulted in him becoming very fatigued, stating:

And he doesn’t have that as much anymore. He’s got it a little. I mean he can drive and not get upset if somebody cuts him off or whatever. But yeah he doesn’t have that totally in check all the time. And then when he has to, i.e., if he’s in the class or he’s at work, then he’s really tired.

Mrs. C reported that Jace was sleeping for 20-22 hours per day. She recalled that Jace was sleeping for the majority of the day for approximately two weeks following his most recent TBI. Mrs. C recognized that Jace’s recovery post-TBI required a considerable amount of sleep. She stated:

And then he would come home, sleep again, get up and do a little homework, go to sleep again, and do it. The main thing through the concussion is just that it required lots and lots of sleep, time for the brain to shut down and heal.
Mrs. C also highlighted the importance of Jace taking naps throughout the day, even today, and stated:

So through this whole time thing, it just takes sleep. We have just gently, gently been weaning him off of it. And he still takes naps. One of the scholarships he was awarded at UD was a counselor for freshmen that would call and help to make sure he was still on track. Had nothing to do with his head injury. It was just a scholarship he was awarded to help freshmen stay attuned, which was a blessing that we received it. Stay attuned and on track in classes. And one of the things she helped him realize is that when you plan your college days, you need to make sure, with your injury, you have to plan out nap time. And so by him working that into it, he was able to go back and take naps and then he continues. Yeah and this year we’re barely up to any kind of naps. He might still take one a day or so.

Repeted injuries. All of the parent participants in this study reported that the young adult had sustained more than one TBI. Kyle sustained several brain injuries; the most significant were soccer-related injuries. Mrs. J, Kyle’s mother, recalled three additional brain injuries Kyle had in the past that Kyle had not reported during his interview. Mrs. C, Jace’s mother, reported that Jace sustained several TBIs. She recalled six to seven incidents in which Jace hit his head severely and probably could have been diagnosed with a TBI. However, Jace only reported three incidences. Aaron also sustained injuries, both prior to transitioning to a postsecondary institution and after he began attending college.

Mrs J stated about Kyle’s TBIs:

He had another one that was just a collision that was with club…He got hit in the head with a tube tubing up at our cabin in Wisconsin. So that was another one. And then the last one was senior year. It was during soccer…but the coach was sitting right here and he’s like, ‘He’s out for the season.’ Because he knew. He got clocked. So took him to the ER. He had a ruptured ear drum and another concussion.

Mrs. C also recalled Jace sustaining multiple head injuries:
Jace was a child who was very clumsy…So as we look back after all this had happened, we did realize, “Oh he did do this” and “Oh he did do this.” So there was a roller skating accident. He fell into a flower pot. And there are probably about three or four other times he hit head severely.

**Social issues.** Parents of the young adult participants also reported that their young adult child with a TBI experienced difficulties with social situations and relationships post-injury and upon transitioning to a postsecondary setting. Kyle’s mother, Mrs. J, recalled changes and challenges with Kyle’s social functioning in high school after his third soccer head injury:

His friends, and they didn’t mean it to be malicious, they didn’t see him. They came over for about a month or so just to visit, but he was not social whatsoever. He’d look away, he couldn’t look at them.

He went to homecoming with kind of a girlfriend. And we kind of laid down the rules. She came over and got him and her parents came and my husband talked to her parents and said, ‘Kyle’s not great. She needs to bring him home after the dance.’ And she was like kind of snitty and all of that…And then he didn’t go to prom. She called him up and dumped him on the phone. She couldn’t handle this.

Mrs. J also described her perception of Kyle’s social experiences upon transitioning to a postsecondary institution:

And in a new situation, or if he’s meeting a bunch of new people, he kind of hangs back. He’s very uncomfortable about that. He’s still got his core group of friends, and he’s fine with that. My husband keeps saying, ‘You need to meet more kids in the pre-med.’ ‘No, I want to study by myself. I’ll be fine.’ So that’s a difference too.

Mrs. J also discussed the social difficulties Kyle had as he transitioned to independent living at the university he attended:

But since he’s transitioned to college and living here [on the university’s campus]—and this came out last summer, so after sophomore year—walking to classes, he still gets really anxious. And he said sometimes so much so that it’s panic attacks.
Jace’s mother reported in her interview that Jace experienced social difficulties following his most recent TBI as well and describes how his relationships with peers were impacted post-injury:

Friends didn’t come around. He doesn’t know this, but I would call his friends and be like, ‘Please, just stop by and visit him. Very few ever did. I would say maybe we had five visits the whole six months.’ There was one friend that came a couple of times, but Jace’s friends just kind of forgot him, and that was hard. And I don’t think he knows that part of it. But yeah it was hard on him…The school is so big that you don’t know that your friend’s hurt. You forget. You just don’t normally see your friends. So to forget that your friend is gone and had a head injury, you don’t realize it because you don’t see them every day. In the small school where I came from, you would know that your buddy was sick. But not here.

Other Findings

Results of the current study revealed that other common themes among young adults with TBI and their parents included: (1) Headaches, (2) personality change, and (3) recognition of the injury’s impact and the need for a reduced course load. Although these themes were consistent among both groups, they were not as prominent.

Aaron reported that his doctors suggested for him to avoid a computer screen, TV, and loud music, which he found to be challenging as postsecondary student attending college. Aaron believes that because he found he could not avoid his computer for everything, this may have contributed to the headaches he experienced as a result of his TBIs. He stated:

And they [the doctors] recommended don’t be in front of a computer screen, no TV, avoiding loud music, and everything that’s really hard to do when you’re in college…So it definitely hampered the way I conducted myself as a student…And I couldn’t avoid my computer screen for everything. And I think that’s probably what really kept the headaches going for me, or really triggered it.
Mrs. C explained what she thought may have triggered Jace’s headaches, which he continued to experience upon transitioning to a postsecondary setting:

As far as what he was doing in college, I think all freshmen going into college have trouble adjusting to learning your independence and what you can handle and what you can’t handle. So you have the normal situation, then you have a child with a concussion who needs extra sleep. So I really don’t know. And Jace’s over-the-top active and going to dive into something. He wants to do that. So I can’t tell you what he did for sure. Did he party? I don’t know. I can’t tell you. I think he did, but I don’t know. Did some of those trigger the headaches? I don’t know. Did the extra homework, the stress? I don’t know.

Jace underwent changes in personality post-injury. He stated:

I’m much more in tone with my body. And people see that. I’m more reflective. I’m more, a lot of people say spiritual, which is fun. Faith-based. But they see me still as an extrovert, and I can help get the party started. It’s just kind of who I am when I’m in a group. Prior to the injury, it was very much more, I was super outgoing. It was 100% and 110% just because. I didn’t look at myself much. And the head injury was a blessing in the sake that I learned how to stop myself and slow down. Prior, I think a lot of people could see me as superficial too.

Mrs. J described Kyle’s personality change as a result of his TBIs in much greater detail than Kyle. Kyle’s mother stated:

And then his personality HAS changed HUGELY. He’s no longer tolerant of people. He has a short fuse. He just gets SO frustrated with people in general. And if people do something wrong, ‘Ugh, gosh, I can’t believe that.’ Before he wouldn’t have done that. He would have just said, ‘Ah, well, you know, it is what it is.’

Two participants in this study reported that after transitioning to a postsecondary institution as a student, they recognized the impact of their injury and the need for a reduced course load. Participants explained that they enrolled as a full-time student but needed to reduce the number of credit hours they were taking in order to meet the often rigorous demands of the course. Kyle explained that when he started at his postsecondary institution, he had to work much harder than he had to in the past:
I was taking 7 credit hours just to start off with, which isn’t that much, and I was having to work a lot harder.

After Aaron’s moderate to severe TBI that happened in college, Aaron’s doctors recommended that he reduce his course load:

And through that, I would say the doctor’s recommended that I drop some classes because when I filled them in that this was my third or fourth concussion, they said, ‘Don’t take this lightly.’ And so what I ended up doing was, I was taking 17 credit hours, and so I dropped, or put on hold, two of my classes to finish off whenever I healed.

Aaron also explained that he studied abroad during the summer of his sophomore year in college and found that he was very challenged by the one class he was taking. He described:

So I go to Rome in late May and it was a struggle. I had an adjustment as far as being halfway across the world, but I started to really get freaked out because I’m only taking one class, and I was really struggling. I found myself reading the chapters in the book and just having to reread them and reread them to understand the material. And for me, that material wasn’t hard at all.

Accommodations that the young adult participants in this study reported that they found valuable included: (1) Reducing exposure to computer screens, TV, and loud music in order to help minimize headaches, (2) flash cards and notecards that help with repetition (memory) and focusing on one concept at a time (control strain), (3) journaling as a way to focus and collect thoughts, (4) use of a calendar or hour-by-hour planner with breaks incorporated to help with remembering scheduled events and managing time, (5) peer notes or recording device to keep up with fast-paced lectures, (6) extended time on tests or taking the test in a place with less distractions, and (7) frequent breaks.
CHAPTER V  
DISCUSSION

Review of Purpose and Major Findings

The purpose of this study was to explore the transition experience of young adults who have sustained a traumatic brain injury (TBI). The results of this study can be used to direct future research, as well as provide strategies for school-based professionals and parents to best support students with TBI as they transition from high school to a postsecondary setting.

Sleep-wake disturbances, including fatigue, have been found to occur in one-half to three-quarters of those who have sustained a TBI (Jantz et al., 2014). Findings from the current study revealed that young adults with TBI experience fatigue for a variety of reasons related to their TBI and require unusual amounts of sleep as a result. Parent reports confirm that sleep was an important aspect of the brain’s recovery from a TBI and that it was critical for the young adult with a TBI to incorporate time into their schedule to rest and take naps throughout the day to allow the brain time to heal. This finding could especially benefit students attending a postsecondary college or university because of the lack of structure a typical day may include compared to the high school setting. Students will need to plan their day and designate specific time for rest and sleep.

Findings also indicate that with the transition to a postsecondary setting, young
adults with TBI experienced difficulties with attention and focus, both academically and socially. Additionally, according to the results of this research study, postsecondary students with TBI have more difficulty paying attention and staying focused in the classroom as well as when completing their work. According to Pineau et al. (2015), individuals with mild TBI also report significantly higher levels of distractibility and difficulties with focus. As a result, it may take them longer to complete their work than it has in the past or pre-injury. In high school, the school day is typically very structured with bell schedules and little time in between classes. In addition, parents often have a set of guidelines or rules for high school students to follow. It is also common for parents to have their own schedule for their children when they get home from school, and students often follow fairly rigid extracurricular schedules. However, the postsecondary environment has multiple forms of distraction with less structured schedules. Attention and focus are important for postsecondary students in order to achieve academically. Socially, students with TBI have also reported that challenges with attention and focus have impacted their ability to maintain a conversation, according to this research study’s findings.

Another key finding is that young adults with TBI who participated in this research study experienced social issues as they transition from high school to a postsecondary setting. Friends and peer relationships were challenging post-injury as the young adult with TBI was absent from school for an extended period of time. Other social issues resulted from difficulty with social adjustment related to newly acquired
language deficits in pragmatic communication as well as the social anxiety experienced as a result of sustaining a TBI.

Results of this study revealed that young adult participants experiencing persistent difficulties have sustained more than one brain injury in the past. All three participants in this study reported that the TBIs they have had in the past seemed to accumulate over the years and that the last brain injury they sustained resulted in the most severe and prolonged symptoms. Therefore, this study highlights the importance of preventing repeated brain injuries in an effort to avoid experiencing challenges that may occur as a result. Males are two to three times more likely to sustain a TBI than females (Faul et al., 2010). Additionally, adolescents are characterized by risk-taking behavior, which makes this age group particularly susceptible to intentional and unintentional injuries. Further, participation in high school sports increases the likelihood of an adolescent sustaining a TBI (Asemota et al., 2013). The male young adult participants in this study engaged in behaviors that made them more prone to these repeated injuries (e.g., playing sports). Taking precaution and using safety equipment when engaging in physical activity may also help to prevent repeated brain injuries.

**Other Findings**

Participants in this study recognized the impact of their injury and the need for a reduced course load in the postsecondary academic setting. Students with TBI often have difficulties keeping up with the rigorous demands of the academic environment (Jantz et al., 2014). Following the transition to a postsecondary institution, the participants realized that the challenges and changes experienced due to their TBIs required them to
take fewer classes in order to succeed. Youth reported that it took more time and effort to accomplish tasks and complete work than it did previously. Issues with short-term memory also required them to work harder to remember and learn course material.

This study found that young adult participants used accommodations to promote their success in high school and at their postsecondary institution. Findings suggest that students with TBI may require appropriate accommodations in order to access the same curriculum as their peers. These accommodations may provide students with TBI strategies for overcoming challenges they may experience at the postsecondary level, and they may be especially beneficial to these students as they transition to independent living at a postsecondary institution.

**Differences in Experiences and Perceptions**

Young adult and parent experiences and perceptions aligned in that both groups reported that fatigue and the need for unusual amounts of sleep as well as attention and focus issues were among the most prominent themes experienced as a young adult with TBI transitioned to a postsecondary setting. However, parents recalled a greater number of injuries that the young adult participant sustained in the past; whereas, young adult participants reported experiencing a more significant level of attention and focus difficulties than parents reported. According to Gfroerer et al. (2008), parents are often in the best position to evaluate a child’s functioning following a TBI, and they are also able recall more details from previous TBI experiences. As research suggests, parents in this study were able to recall a greater number of previous brain injuries.
Parent participants may not have recognized as many attention and focus and short-term memory difficulties experienced by the young adult participants because these difficulties are more covert and subtle. However, sleep is a more overt and apparent symptom experienced as a result of a TBI, and parents may have recognized their young adult child sleeping before they would have recognized the attention and focus difficulties the child was experiencing.

**Limitations**

There are several limitations to this research study, beginning with the limited scope of the design. This study utilized a small sample from a similar geographic. One young adult participant’s parent did not participate in this study, which could have impacted the results. The young adult participants consisted of male students attending the same four-year, private, Catholic university; the parent participants were both female. The male and female experience may vary, and this study is limited to the male’s perspective and experiences. Additionally, the culture and background attracting a student to a four-year, private, Catholic university may differ from a student attracted to attending a different type of university, such as a two-year or public university. This limits the breadth of postsecondary experiences that the participants had to share. The sample cannot be considered representative of all postsecondary experiences for young adults with TBI; therefore, the generalizability of this research is limited. This is a limitation of in-depth interviews with a small number of participants—their perceptions may be unique and not indicative of a common experience.
The limited sample size prevented this research study from capturing all the
different postsecondary experiences of young adults with TBI. While the subject pool of
the current research project did produce many of the same themes, due to the
geographical and logistical limitations, theoretical saturation could not be reached.
Further, the descriptive nature of some data gathered may lead to some degree of gender
or cultural bias, again due to limited size.

The sample consisted primarily of middle to upper-middle class young adults and
parents from suburban areas with the financial means to be able to access or provide
services that may aid in the recovery and/or rehabilitation process post-injury. The
participants in this study also reported that they had availability of transportation to
recovery and/or rehabilitation facilities and that the young adult participants also had the
support of family members during recovery and the transition to a postsecondary
institution. These are factors that can influence an individual’s recovery and/or
rehabilitation following a TBI and also include access to health insurance; differences in
health insurance benefits; access to, and availability of, inpatient and outpatient
rehabilitation services; duration and quality of rehabilitation services; availability of
transportation to facilities; and language barriers (Arango-Lasprilla & Kreutzer, 2010;
Ashley, O’Shanick, & Kreber, 2009).

Another limitation of this study is the student participants’ ability to recall and
clearly explain accurate and detailed information about their experiences. This could be a
result of the TBI or that the TBI occurred a while ago, making the experiences more
difficult to recall. Parent participants may also have difficulty recalling information
about the experiences if the TBI incident occurred a while ago or if they were not very involved with the experience.

Participants’ experiences may have also been impacted by comorbid diagnoses. This may have also caused participants to misidentify symptoms they experienced as a result of their TBI, and the symptoms may actually be a result of, or augmented by, a comorbid disorder, such as ADHD. Finally, changes that young adults experienced may have been a natural course of life (developmentally, environmentally), so it is difficult to determine that all of their reported experiences are a result of a TBI.

**Implications for School-Based Practice and Future Research**

While there is still no clear data to describe every postsecondary transition experience for young adults with TBI, the current study’s findings indicate that support and accommodations may foster and promote the success of students with TBI as they transition from high school to a postsecondary institution. According to Cleary, Walter, & Jackson (2011), postsecondary students must cope with the loss of one’s school friends, the need to form fresh relationships and groups, potentially moving away from home and becoming acquainted with new college roommates, dealing with different methods of learning, and the expectation of increased autonomy in life and studies. Students who have sustained a TBI may experience difficulties at a number of transition points in their life, including returning to play (i.e., returning to a sport team after a break for recovery), returning to school, transitions between classes, transitions to new schools, and transition from adolescence to adulthood. School psychologists in particular are in a unique position to provide services and implement transition plans for students with TBI.
School psychologists may recognize the need for transition planning and are often in a position that would allow them to assess the student’s anticipated postsecondary environment and determine needs. This may allow the school psychologist to identify potential problems and include these areas of need in the student’s transition plan so that the postsecondary institution can provide appropriate and effective services and accommodations. Students with disabilities transitioning to a postsecondary setting are often required to advocate for their needs (Shaw et al., 2010). This includes advocating for appropriate and necessary accommodations. As part of the transition planning process, school psychologists may teach students how to self-advocate for their needs in the postsecondary setting.

Prior research has found that a barrier to seeking out services is the fear of being classified as a “person with a disability” (Marshak, 2010). Thus, school psychologists in a high school setting may consider counseling students with TBI on seeking services. Young adult participants in this study reported that post-injury and after making the transition to a postsecondary institution, they had to work much harder than they have had to in the past. However, if the young adult students sought services to accommodate them, the students may have found that they would not have had to put forth so much effort to understand concepts or obtain a desired grade in a course. Disability services can provide support to students with TBI to promote a more positive academic and postsecondary transition experience.

**Recognition of injury’s impact and the need for a reduced course load.**

Findings from this research study suggest that attention and focus difficulties as well as
fatigue and need for unusual amounts of sleep were prominent experiences among young adults with TBI transitioning to a postsecondary institution. The study also found that young adult students recognized the impact of their injury and the need for a reduced course load after transitioning to a postsecondary setting. Hamblet (2011) found that students with disabilities often have difficulty keeping up with postsecondary academic demands, including heavy reading loads, maintaining focus through long lectures, and preparing for exams and writing papers that are often weigh heavily on a final grade. Students with a TBI may have difficulty with academic skills such as learning and processing new information, processing speed, retrieving previously learned information, integrating new and previously learned information, short- and long-term memory, attention, psychomotor skills, and executive functioning skills (Jantz et al., 2014).

Findings from this study suggest that young adults with TBI may need to reduce their course load after transitioning due to attention and focus difficulties as well as the fatigue experienced. Therefore, school psychologists may consider recommending that students with TBI consider a reduced course load at a postsecondary institution. This may be another component to include in the student’s transition plan prior to transitioning.

Findings from this research study suggest that attention and focus difficulties as well as fatigue and need for unusual amounts of sleep were prominent experiences among young adults with TBI transitioning to a postsecondary institution.

**Social issues.** Given the results of this study, school psychologists may also consider counseling students with TBI on social skills and the use of pragmatic communication. Behavioral, social, and emotional difficulties after a TBI are common,
particularly with moderate and severe TBIs (Gouick & Gentleman, 2004; Gould, Ponsford, Johnston, & Schonberger, 2011; Max et al., 2012; Williams & Wood, 2010; Rapoport, 2012). Further, students transitioning from high school to a college or university setting need to adjust to the required academic and social demands (Bayram & Bilgel, 2008). A key finding from this study indicates that young adults with TBI have experienced difficulties with social adjustment and peer relationships. School psychologists may counsel students with TBI who are having difficulties with social conversation and teach them specific skills on initiating and maintaining a conversation, turn-taking, and active listening. They may collaborate with the student on strategies that may be effective in using these skills in the student’s secondary and postsecondary environment. This may help prepare the student for the various social situations s/he will likely experience in the postsecondary environment.

**Repeated injuries.** Another finding from this research project is that repeated injuries were a recurring theme among participants. Repeated mild TBIs occurring over an extended period of time can result in cumulative neurological and cognitive deficits, and those occurring within a short period of time can be catastrophic or fatal (CDC, 1997). School psychologists should educate coaches and administrators on TBIs, especially on preventing repeated injuries to the head. Additionally, school psychologists should educate school-based personnel and parents on identifying students with TBI so they can be served early and appropriately and training should include how to support students with TBI and what is required to receive services at postsecondary institutions. This can be achieved through the development and implementation of a Section 504 plan.
School psychologist’s training should include when and how to design a 504 plan to best accommodate for a student with a disability’s needs. School psychologists should be able to identify accommodations that are necessary in order for a student to have equal access to the curriculum. For example, one of the young adult participants in this study indicated the importance of structure on his ability to conduct himself as a student. Structuring the classroom and school environment, such as providing preferential seating to control noise and activity levels and reducing unnecessary distractions and sensory stimulation, may be an appropriate accommodation to include on a 504 plan for a student with a TBI.

Because findings from this study reveal that parents recalled more TBI incidences than their young adult child, reported their young adult children’s experiences with TBI in greater detail, and recognized more changes in their child’s functioning than young adult participants, school psychologists should involve parents in transition planning and services.

Future research is necessary to determine other postsecondary transition experiences of young adults with TBI, including challenges faced and skills that may have been lacking that were not recognized prior to the transition.

**Conclusion**

The present study examined the experiences of young adults with TBI as they transition from high school to a postsecondary setting. Results of the current research study suggest that persistent difficulties following a TBI that continued with the transition to a postsecondary institution include issues with attention and focus, the recognition of
the need for a reduced course load due to postsecondary academic demands, and being fatigued and requiring a great deal of sleep. Strategies to manage difficulties experienced as a result of a TBI and accommodations to provide support are found to have been beneficial to the young adult participants in this study. These experiences should be considered as school-based professionals and parents develop transition plans for high school students with TBI in order to best meet the needs and provide support as they transition to a postsecondary setting. Additionally, college student personnel should consider all aspects of development and focus on accommodations for social challenges experienced by young adults with disabilities attending a postsecondary institution in addition to academic challenges.
REFERENCES


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APPENDIX A

CONSENT FORM: YOUNG ADULTS

UNIVERSITY OF DAYTON - CONSENT TO PARTICIPATE IN RESEARCH

YOUNG ADULTS

TITLE OF STUDY: The Postsecondary Transition Experience for Young Adults with Traumatic Brain Injuries

You are asked to participate in a research study conducted by Dr. Susan Davies and Michaela Kramer from the Department of Counselor Education & Human Services at the University of Dayton. Your participation in this study is voluntary. Read the information below, and ask questions about anything you do not understand, before deciding whether or not to participate.

PURPOSE OF THE STUDY

The purpose of the study is to understand the experiences of students who have sustained a traumatic brain injury (TBI) as they transition to postsecondary educational or work settings.

PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:

- Coordinate with the primary investigator on a data and time to meet for the interview(s)
- Meet with the primary investigator in a quiet, secluded place for the amount of time the primary investigator needs to gain a comprehensive understanding of your background and experiences
- Review the consent form, complete the necessary information, sign, and date
- Respond to the interviewer’s questions/prompts and discuss your experiences
- Meet for additional interviews as necessary
Inclusion Criteria: Young adult participants will include those who have sustained at least one TBI at some point in their lives and experienced persistent difficulties post-injury. Young adult participants who have sustained multiple TBIs will not be excluded from participating, and there is no specification of age at the time of the injury. University of Dayton students may be included in the participant population if they meet the study inclusion criteria.

Exclusion Criteria: Individuals who do not meet the age range or inclusion criteria.

POTENTIAL RISKS AND DISCOMFORTS

This project involves no more than minimal risk. Your participation in this study is completely voluntary, you may refuse to answer any question, and you may end the interview at any time. You may experience some sensitivity or frustration when discussing certain aspects of your life; in the event of discomfort, you may choose to stop the interview at any point or skip certain questions. If you were to become distressed, the interview would be immediately terminated.

Steps taken to minimize risk: I will keep all data collected secure and confidential. I will periodically ask you how you are feeling and be cognizant of your body language and nonverbals to determine if you are feeling any discomfort. If you are uncomfortable, I will provide you with the option to take a break.

ANTICIPATED BENEFITS TO PARTICIPANTS

This research may provide you with the opportunity to share and reflect on your experiences before, during, and after sustaining a TBI. You may recognize and assess challenges and difficulties you faced as a result of your TBI.

PAYMENT FOR PARTICIPATION

You will be given a $10 Panera Bread gift card at the end of each initial interview for participating in the study.

IN CASE OF RESEARCH RELATED ADVERSE EFFECTS

If you are experiencing any kind of discomfort as a result of your participation in this study, you agree to promptly notify the Principal Investigator. You may contact the University of Dayton Counseling Center at (937) 229-3141. The Counseling Center is available free of charge to undergraduate students. If you find yourself experiencing distress after the Counseling Center is closed for the day, you may call the number and you will be connected to an answering service, and a counselor will return your call.

If you are experiencing any kind of discomfort as a result of your participation in this study, you may contact Michaela Kramer at 419-733-9897 or Dr. Susan Davies at 937-229-3652.
CONFIDENTIALITY

When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity.

Audio recordings of you will be used; however, your identity will be protected or disguised by using a pseudonym (fictitious name) which will be used in any reports, presentations, or publications. The audio recordings will be in the possession of the primary investigator. Your interview will be transcribed within three days of the event. All recordings and notes will be kept secure on a password protected laptop that will remain in the possession of the primary investigator. All records of this research will be kept secure for at least three years after the end of the project. After the interview has been transcribed and a pseudonym is assigned, the audio recordings will be destroyed after three years.

PARTICIPATION AND WITHDRAWAL

Your participation in this research is voluntary. If you choose not to participate, that will not affect your relationship with the University of Dayton or other services to which you are otherwise entitled. If you decide to participate, you are free to withdraw your consent and discontinue participation at any time without prejudice or penalty. The investigator may withdraw you from participating in this research if circumstances arise which warrant doing so.

IDENTIFICATION OF INVESTIGATORS

If you have any questions about this research, please contact one of the investigators listed below. (Identify the research point of contact. Include title, affiliation, a daytime telephone number with area code, and e-mail address. If you are a student investigator, you must include contact information for a responsible faculty member as well as your own information.)

Michaela Kramer, Principal Investigator, University of Dayton, Department of Counselor Education & Human Services, 419-733-9897, kramerm1@udayton.edu.

Susan Davies, Ed.D., NCSP, Faculty Advisor, University of Dayton, Department of Counselor Education & Human Services, 937-229-3652, sdavies1@udayton.edu.

RIGHTS OF RESEARCH PARTICIPANTS

If you have questions regarding your rights as a research participant, you may contact the Chair of the Institutional Review Board (IRB) at the University of Dayton: Dr. Mary Connolly, 937-229-3493, IRB@udayton.edu.
SIGNATURE OF RESEARCH PARTICIPANT (or legal guardian)

I have read the information provided above. I have been given an opportunity to ask questions and all of my questions have been answered to my satisfaction. I have been given a copy of this form. **I certify that I am at least 18 years of age.**

Name of Participant (please print) ______________________________

Address _________________________________________________________

*Signature of Participant* ____________________________ Date________

SIGNATURE OF WITNESS

My signature as witness certifies that the Participant signed this consent form in my presence.

Name of Witness (please print) _______________________________________

*Signature of Witness* ____________________________ Date________

*(Must be same as participant signature date)*

CONSENT TO USE IMAGES OR RECORDINGS FROM RESEARCH

*(Participant or legal guardian)*

I consent and give permission for the researcher to use any photographs, video-recordings, or audio-recordings made during the course of this research. My identity [select one: will / will not] be protected or disguised by the researcher prior to publication or use in presentations of their results. By signing below, I acknowledge that I understand that these images or recordings may compromise the confidentiality of my participation in this research.

Name of Participant (please print) ______________________________

Address _________________________________________________________

*Signature of Participant* ____________________________ Date________
UNIVERSITY OF DAYTON - CONSENT TO PARTICIPATE IN RESEARCH

PARENTS/GUARDIANS

TITLE OF STUDY: The Postsecondary Transition Experience for Young Adults with Traumatic Brain Injuries

You are asked to participate in a research study conducted by Dr. Susan Davies and Michaela Kramer from the Department of Counselor Education & Human Services at the University of Dayton. Your participation in this study is voluntary. Read the information below, and ask questions about anything you do not understand, before deciding whether or not to participate.

PURPOSE OF THE STUDY

The purpose of the study is to understand the experiences of students who have sustained a traumatic brain injury (TBI) as they transition to postsecondary educational or work settings.

PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:

- Coordinate with the primary investigator on a data and time to meet for the interview(s)
- Meet with the primary investigator in a quiet, secluded place for the amount of time the primary investigator needs to gain a comprehensive understanding of your background and experiences
- Review the consent form, complete the necessary information, sign, and date
- Respond to the interviewer’s questions/prompts and discuss your experiences
- Meet for additional interviews as necessary
**Inclusion Criteria:** Parent/guardian participants will include those who have had a young adult child sustained at least one TBI at some point in their lives and experienced persistent difficulties post-injury. Parents/guardians of young adult participants who have sustained multiple TBIs will not be excluded from participating, and there is no specification of age at the time of the injury. Parents/guardians of University of Dayton students may be included in the participant population if they meet the study inclusion criteria.

**Exclusion Criteria:** Parents/guardians of individuals who do not meet the age range or inclusion criteria.

**POTENTIAL RISKS AND DISCOMFORTS**

This project involves no more than minimal risk. Your participation in this study is completely voluntary, you may refuse to answer any question, and you may end the interview at any time. You may experience some sensitivity or frustration when discussing certain aspects of your child’s life; in the event of discomfort, you may choose to stop the interview at any point or skip certain questions. If you were to become distressed, the interview would be immediately terminated.

**Steps taken to minimize risk:** I will keep all data collected secure and confidential. I will periodically ask you how you are feeling and be cognizant of your body language and nonverbals to determine if you are feeling any discomfort. If you are uncomfortable, I will provide you with the option to take a break.

**ANTICIPATED BENEFITS TO PARTICIPANTS**

This research may provide you with the opportunity to share and reflect on your child’s experiences before, during, and after sustaining a TBI. You may recognize and assess challenges and difficulties your child faced as a result of your TBI.

**PAYMENT FOR PARTICIPATION**

You will be given a $10 Panera Bread gift card at the end of each initial interview for participating in the study.

**IN CASE OF RESEARCH RELATED ADVERSE EFFECTS**

If you are experiencing any kind of discomfort as a result of your participation in this study, you may contact Michaela Kramer at 419-733-9897 or Dr. Susan Davies at 937-229-3652.

**CONFIDENTIALITY**

When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity.

Audio recordings of you will be used; however, your identity will be protected or disguised
by using a pseudonym (fictitious name) which will be used in any reports, presentations, or publications. The audio recordings will be in the possession of the primary investigator. Your interview will be transcribed within three days of the event. All recordings and notes will be kept secure on a password protected laptop that will remain in the possession of the primary investigator. All records of this research will be kept secure for at least three years after the end of the project. After the interview has been transcribed and a pseudonym is assigned, the audio recordings will be destroyed after three years.

PARTICIPATION AND WITHDRAWAL

Your participation in this research is voluntary. If you choose not to participate, that will not affect your relationship with the University of Dayton or other services to which you are otherwise entitled. If you decide to participate, you are free to withdraw your consent and discontinue participation at any time without prejudice or penalty. The investigator may withdraw you from participating in this research if circumstances arise which warrant doing so.

IDENTIFICATION OF INVESTIGATORS

If you have any questions about this research, please contact one of the investigators listed below. (Identify the research point of contact. Include title, affiliation, a daytime telephone number with area code, and e-mail address. If you are a student investigator, you must include contact information for a responsible faculty member as well as your own information.)

Michaela Kramer, Principal Investigator, University of Dayton, Department of Counselor Education & Human Services, 419-733-9897, kramerm1@udayton.edu.

Susan Davies, Ed.D., NCSP, Faculty Advisor, University of Dayton, Department of Counselor Education & Human Services, 937-229-3652, sdavies1@udayton.edu.

RIGHTS OF RESEARCH PARTICIPANTS

If you have questions regarding your rights as a research participant, you may contact the Chair of the Institutional Review Board (IRB) at the University of Dayton: Dr. Mary Connolly, 937-229-3493, IRB@udayton.edu.
SIGNATURE OF RESEARCH PARTICIPANT (or legal guardian)

I have read the information provided above. I have been given an opportunity to ask questions and all of my questions have been answered to my satisfaction. I have been given a copy of this form. **I certify that I am at least 18 years of age.**

Name of Participant (please print) ____________________________________________

Address _______________________________________________________________

Signature of Participant ___________________________ Date ___________

SIGNATURE OF WITNESS

My signature as witness certifies that the Participant signed this consent form in my presence.

Name of Witness (please print) ____________________________________________

Signature of Witness ___________________________ Date ___________

(Must be same as participant signature date)

CONSENT TO USE IMAGES OR RECORDINGS FROM RESEARCH

(Participant or legal guardian)

I consent and give permission for the researcher to use any photographs, video-recordings, or audio-recordings made during the course of this research. My identity [select one: will / will not] be protected or disguised by the researcher prior to publication or use in presentations of their results. By signing below, I acknowledge that I understand that these images or recordings may compromise the confidentiality of my participation in this research.

Name of Participant (please print) ____________________________________________

Address _______________________________________________________________

Signature of Participant ___________________________ Date ___________
APPENDIX C

INTERVIEW QUESTIONING ROUTE: YOUNG ADULTS

| Introductory Comments | “Thank you for meeting with me today. My name is Michaela Kramer, and I am a graduate student in the School Psychology Program at the University of Dayton. The purpose of this interview is to get an understanding of what the transition from high school to a postsecondary setting was like for you (e.g., challenges you faced, skills you recognized you were lacking that you had not noticed before, etc.). I’m going to be audio recording our discussion and may take some notes during the session. You may choose to stop the interview at any point or skip certain questions I ask. If you need me to clarify something or if you have any questions, please do not hesitate to ask before responding or continuing with the interview. You will be given a $10 Panera Bread gift card at the end of your initial interview for participating in the study. Do you have any questions so far?” |
| Opening Introductory | “I want to eventually hear about your concussion/traumatic brain injury (TBI), but first I want to learn more about you. Tell me about yourself.” |
| Key | Prompt to get information on cognitive, academic, physical, social, emotional, and behavioral functioning.  
- Talk to me about high school.  
- Tell me about what that was like for you.  
- Tell me about your friends/family.  
- Tell me about how others might describe you.  
- What are some things you enjoy doing?  
- What are some things you’re really good at?  
- Tell me what you’re doing now.  
  - What year in school are you?  
  - What’s your major?  
  - What do you want to do when you graduate?  
  - When will you graduate?  
- Tell me about your concussion/TBI.  
  - How were you injured?  
  - How severe was it?  
  - What do you remember about the recovery period?  
- Tell me a story of what you were like before your concussion/TBI.  
- Tell me a story of what you were like after your concussion/TBI.  
Prompt to gain information on home, school, and community supports.  
- Tell me about the support you had after your TBI. |
| Conclusion | • Briefly summarize main discussion points and ask if the summary is accurate (e.g., “It sound like your relationships were really different.”).  
• Ask if participants have additional questions or comments.  
  “Thank you for participating in this interview and sharing your experiences.” |
APPENDIX D

INTERVIEW QUESTIONING ROUTE: PARENTS/GUARDIANS

| Introductory Comments | “Thank you for meeting with me today. My name is Michaela Kramer, and I am a graduate student in the School Psychology Program at the University of Dayton. The purpose of this interview is to get an understanding of what your child’s transition from high school to a postsecondary setting was like (e.g., challenges your child faced, skills you recognized you were lacking that you had not noticed before, etc.). I’m going to be audio recording our discussion and may take some notes during the session. You may choose to stop the interview at any point or skip certain questions I ask. If you need me to clarify something or if you have any questions, please do not hesitate to ask before responding or continuing with the interview. You will be given a $10 Panera Bread gift card at the end of your initial interview for participating in the study. Do you have any questions so far?” |
| Opening Introductory | “I want to eventually hear about your child’s concussion/traumatic brain injury (TBI), but first I want to learn more about your child. Tell me about your child.” |
| Key | Prompt to get information on cognitive, academic, physical, social, emotional, and behavioral functioning.  
  - Talk to me about your child’s high school experiences.  
  - Tell me about what it was like for your child.  
  - Tell me about your child’s friends/family relationships.  
  - Tell me about how others might describe your child.  
  - What are some things your child enjoys doing?  
  - What are some things you child’s really good at?  
  - Tell me what your child’s doing now.  
  - Tell me about your child’s concussion/TBI.  
    o How was your child injured?  
    o How severe was it?  
    o What do you remember about the recovery period?  
  - Tell me a story of what your child was like before the concussion/TBI.  
  - Tell me a story of what your child was like after the concussion/TBI.  
Prompt to gain information on home, school, and community supports.  
  - Tell me about the support your child had after the concussion/TBI. |
| Conclusion | • Briefly summarize main discussion points and ask if the summary is accurate (e.g., “It sound like your child’s relationships were really different.”).  
  • Ask if participants have additional questions or comments.  
  “Thank you for participating in this interview and sharing your experiences.” |
APPENDIX E

PARTICIPANT RECRUITMENT MATERIALS

RESEARCH PARTICIPANTS NEEDED

Have you or your young adult child had a concussion or brain injury and experienced persistent difficulties as a result?

Dr. Susan Davies and graduate student Michaela Kramer from the University of Dayton are conducting a study about the transition experiences of young adults ages 18-22 who sustained a traumatic brain injury in childhood or adolescence.

Participation in this study will involve a face-to-face interview with the researcher to discuss your experiences.

In appreciation of your time, you will receive a $10 Panera gift card.

If interested, please contact Michaela Kramer at 419-733-9897 or kramerm1@udayton.edu.
Subject: Research participant referrals - Your help

Dear [Source of Participants],

I am a second-year graduate student in the School Psychology Program at the University of Dayton (UD). I am collaborating with Dr. Susan Davies, Associate Professor and Program Coordinator for UD’s School Psychology Program, on a project examining the experiences of young adults who previously sustained a traumatic brain injury (TBI). I am studying this to explore how we can better serve this population during and after the transition from high school.

I am contacting you to ask for your help connecting us with participants. Would you be willing to meet with me to discuss our project and ways we could reach participants?

Thank you, and I look forward to hearing from you.

Michaela Kramer, M.S.
University of Dayton
Master of Science in Education
419.733.9897
michaela.m.kramer@gmail.com