The Experiences of Individuals with Visual Changes After a Traumatic Brain Injury (TBI): An Emphasis on Coping

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THE EXPERIENCES OF INDIVIDUALS WITH VISUAL CHANGES AFTER A
TRAUMATIC BRAIN INJURY (TBI): AN EMPHASIS ON COPING

by

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Masters of Occupational Therapy, University of North Dakota, 2016

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An Independent Study
Submitted to the Occupational Therapy Department
of the
University of North Dakota
In partial fulfillment of the requirements
for the degree of
Master of Occupational Therapy

Grand Forks, North Dakota
May 14, 2016
This Independent Study Paper, submitted by Katie Kruger, MOTS and Suzanne Vetter, MOTS in partial fulfillment of the requirement for the Degree of Master of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

[Signature]

Faculty Advisor

4/18/16
Date
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Title  The Experiences of Individuals with Visual Changes after a Traumatic Brain Injury (TBI): An Emphasis on Coping

Department  Occupational Therapy

Degree  Master of Occupational Therapy

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We would like to thank Dr. Jan Stube for her guidance and support throughout this process. She brought valuable perspective, knowledge, and experience to this research study. We are thankful for Dr. David Biberdorf’s generosity and assistance. His passion for helping this population contributed greatly to the outcome of our study. In addition, we are thankful for all the participants who were willing to take part in this study. They provided us with an unbelievable experience. Lastly, we would like to thank all of our family and friends who have provided us with support and encouragement throughout our educational experience.
Problem: The Center for Disease Control Prevention (CDC, 2010) reports that 2,611,129 individuals visit the Emergency Room each year due to a traumatic brain injury (TBI). In addition, approximately 50% of individuals who have a TBI report visual inefficiencies (Bulson, Jun, and Hayes, 2012; Lew et al., 2009; McKenna, Cooke, Fleming, Jefferson, & Ogden, 2006). Researchers have identified the effects these diagnoses have on ADLs and IADLs. Yet, there is a further need for understanding the experiences of persons post-TBI who have visual inefficiencies, including their coping in everyday life.

Aims: This qualitative research study is aimed at determining the challenges that individuals with a dual diagnosis of a TBI and visual inefficiencies are faced with throughout daily life; and, secondly, to identifying common coping strategies used to approach these challenges.

Methodology: Following a review of literature, semi-structured interview questions were designed using the model of Occupational Adaptation (OA) (Schkade and Schultz, 1992). After IRB approval, a list of potential participants was obtained from an area optometrist. A sample of three individuals consented to two approximately one-hour long interviews. Using a phenomenological research design and analysis process, coding was utilized to support theme development and synthesis.
Findings: The qualitative findings show that participants commonly experience challenges in regards to their occupational performance in the areas of driving, education, sports/exercise and social participation. These occupations were made difficult by a variety of symptoms which complicate participation. TBI and visual inefficiencies impact relationships and support systems. The participants also experienced changes in ability to adapt and cope. Overall, there is a lack of awareness about brain injury with visual inefficiencies among research participants.

Conclusion: These findings suggest that people with brain injury and visual inefficiencies do experience daily challenges and could benefit from healthcare services to promote education, preparedness, and coping strategies to enable a smoother return to participation in life activities. We plan to publish these findings and disseminate the information to improve the quality of tertiary healthcare for this population. Healthcare professionals, such as occupational therapists, have the opportunity to make a positive impact on this population’s recovery.
CHAPTER I

INTRODUCTION

“When I first tell people that I have a head injury, they go “yuck!” and they back off. I think they don’t know enough about the issue of brain injury and the problems associated with it” (Karlovits & McColl, 1999, p. 852). The participant in this research study had had a traumatic brain injury (TBI) and was in the process of integrating into the community, where a variety of obstacles were described by him or her, and other participants within the study. As the participant explains, TBI and associated issues are not well known to the general population. Those who were interviewed for the small qualitative research study by Karlovits and McColl (1999) could hardly reflect all people who are impacted by TBI each year.

The Center for Disease Control Prevention (CDC, 2010) reports that 2,611,129 individuals visit the Emergency Room each year due to a traumatic brain injury (TBI). To add perspective, every person who has experienced a TBI in a year, could hold hands and circle the earth over eight times. TBI is a serious and sudden physical damage to the skull, face, scalp, dura or brain which is caused by a force that can induce catastrophic comorbid psychosocial, cognitive, and physical disabilities (Moore, Terryberry-Spohr, & Hope, 2006). Considering the vast amount of body systems managed by our brain, injury and its effects can vary significantly for each individual. The brain contributes to
personality, learning, and body control, which together play a role in our sense of self as a whole (Bear, Connors & Paradiso, 2007). Therefore, a TBI is classified into three different categories: mild, moderate, or severe, with the results ranging from a mild concussion to death (Sigurdardottir, Andelic, Roe, & Schanke, 2014).

Evidence from research demonstrates that about 50 percent of individuals experience visual changes after a TBI (Bulson, Jun, & Hayes, 2012; Lew et al., 2009; McKenna et al., 2006). Visual inefficiencies consist of a large range of changes, including difficulties with convergence, accommodation, and oculomotor eye movements (Brahm et al., 2009). Functionally this means that challenges can arise during activities of daily living (ADLs) and instrumental activities of daily living (IADLs) including reading, writing, dressing, eating, hygiene maintenance, driving and other daily tasks (Greenwald, Kapoor, & Singh, 2012; Boyd & Dawson, 2000; Warren, 2009).

Combining visual changes with the other effects of a TBI, a person integrating back into daily life can experience stress. This challenges each person to cope with the changes they are experiencing. The plethora of change impacts an individual's ability to flourish independently in activities of daily living, and it also affects their overall mental health.

Each individual affected by the diagnosis of TBI with visual inefficiencies will utilize different coping strategies to effectively manage. This has been a concern in research since Strauss and Savitsky’s first use of the term, “Post Concussional Syndrome” in 1934 (as cited in Livneh & Antonak, 1994). Coping can be understood to mean any thought or behavior a person utilizes to manage stressors occurring internally, externally, or situationally (Maestas et al., 2014).
Ultimately, Williams (1995) found that occupational therapists can assist with the recovery process for individuals post TBI experiencing vision changes. Occupational Therapy (OT) services are provided to train individuals in compensatory strategies, as well as to provide recommendations for environmental adaptations (Williams, 1995). Therefore, occupational therapists play a valuable role in recovery for individuals with visual changes after a TBI regarding return to daily life.

The present qualitative research study aims to add to the body of knowledge by understanding the daily life experiences and coping challenges of persons with visual inefficiencies after TBI. The present study was guided by the Occupational Adaptation (OA) Model (Schkade & Schultz, 1992). The focus of this model is on the interactive process between the person and his or her occupational environment (Cole & Tufano, 2008). It guides occupational therapists as they assess an individual's adaptation process and explains how an individual's adaptive capacity can impact their success or lack of success in occupational performance (Cole & Tufano, 2008). In other words, this model highlights the ability of study participants to adapt to their environment during major transitions. Highlighting strengths, through the use of this model, enable the researchers to understand the participants as the agents of change.

A large emphasis of this model involves the term, relative mastery. Relative mastery is experienced when a person completes an interaction within their environment and the result provides perspective to their level of success. Person-environment interactions do not always successfully occur. A misfit between the person and their environment can happen for multiple reasons. These reasons include the person, the environment, or the techniques needed to complete activities of daily living. Individuals
who have experienced vision changes after TBI often face difficulties achieving *relative mastery* in their everyday life, making adaptation necessary to successfully complete activities of daily living.

The purpose of this independent study, a phenomenological qualitative research project, is to explore the barriers and facilitators to independence and the common coping methods used by individuals who have experienced visual changes following a traumatic brain injury. The researchers hope to inform healthcare workers, family members, and community members about the perceptions and feelings of individuals who have had visual changes post TBI. This is important for gaining an understanding, so all people can approach clients and friends with empathy, and better solutions for coping with these major medical changes. Ultimately, the goal is to facilitate occupational therapists and other healthcare providers in providing the best quality of care for individuals with visual inefficiencies after TBI.

In Chapter two, a comprehensive literature review is provided related to individuals’ ability to cope with major medical changes, including traumatic brain injuries and visual changes. Chapter three describes the methodology used with this independent study, and how the interviews were used to find common themes among individuals’ experiences with visual changes after a traumatic brain injury. Chapter four includes the results obtained from the interviews and phenomenological qualitative research methods. Chapter five summarizes the research, the interview findings, and includes recommendations, limitations, and final conclusions.
CHAPTER II
LITERATURE REVIEW

The Frequency of TBI and Visual Changes

Hundreds of thousands of individuals experienced Traumatic Brain Injuries (TBI) each year within the United States (Brahm et al., 2009). Although not all of these cases involved visual changes in addition to the TBI, approximately 50 percent of persons with TBI had some form of visual impairment (McKenna et al., 2006). This shows it is a dual diagnosis for which clinicians would benefit from further education (Brahm et al., 2009). Brahm et al. (2009) studied the frequency of visual impairments and the most commonly diagnosed dysfunctions which occurred among military personnel with TBI; which included visual acuity, oculomotor function amongst other eye movement diagnoses. Bulson et al. (2012) also researched veterans with a TBI and determined the frequency of the visual and ocular symptoms that occurred. Out of the 100 individuals who participated, 50 percent of the individuals who had TBIs also had visual symptoms (Bulson et al., 2012). A different study by Lew et al. (2009) concurred with this understanding that visual changes occurred after a blast related TBI; evidence showed that 34 percent of the participants had a visual impairment and 20 percent had visual and auditory impairments. The findings of this study provided evidence for the Veteran Affairs (VA) hospital mandate that states all veterans with blast related TBIs must have a visual screening (Lew et al., 2009). A visual screen is not currently required at all hospitals (Cate & Richards, 2000; Lew et al., 2009; McKenna et al., 2006).
Research by McKenna, et al. (2006) provided a deeper understanding as to the frequency of TBI and visual perceptual changes among civilians, showing that nearly half (45.2%) of their TBI sample demonstrated unilateral neglect. It was also found that body scheme, and constructional skills were significant occurrences in the TBI population, with agnosia, acalculia and apraxia also discovered in the pool of participants (McKenna et al., 2006). The study gave strong evidence supporting the use of a visual screen post-TBI in all hospital environments (McKenna et al., 2006). Cate and Richards (2000) also indicated the necessity for clinicians to screen for visual impairments post brain injury. Together, the evidence demonstrated that TBI and visual changes occurred in about 50 percent of cases post-TBI; therefore supports the need for therapist awareness in regards to this dual diagnosis (Cate & Richards, 2000; Lew et al., 2009; McKenna et al., 2006).

**Common Visual Inefficiencies Post TBI**

Individuals with moderate to severe TBIs were found to have a higher frequency of visual acuity loss; however, most patients maintained normal acuities (Brahm et al., 2009). Brahm et al. (2009) and Greenwald et al. (2012) found convergence insufficiency and accommodative insufficiencies to be the most common visual dysfunction among those with a traumatic brain injury. Although visual fields had a tendency to be close to normal, it is still important to note this possible dysfunction, since it can greatly impact an individual's ability to complete tasks involving scanning, which plays a valuable role in daily function (Brahm et al., 2009). In fact, visual changes after TBI manifest as problems while reading, blurred vision, eyestrain and dizziness (Greenwald et al., 2012). Specifically, Bulson et al. (2012) discovered that the most common symptoms included blurred vision, photosensitivity, and accommodative problems. Sigurdardottir, Andelic,
Roe, Jerstad, and Schanke (2009) completed a study with similar results, where participants experienced blurred or double vision amongst other somatic complaints such as headache, dizziness, nausea, noise sensitivity, sleep disturbance, fatigue, light sensitivity and double vision. In agreement with the above, stereopsis, visual attention, smooth pursuit, light sensitivity, visual perceptual impairment, ocular disease, and useful field of view were shown to all adversely be affected in a review of literature conducted by Greenwald et al. (2012).

That vision matters in daily function was evidenced in a study evaluating basic visual functional screening scores and their relation to the scores on a test examining more complicated visual functions in participants who had a CVA (Cate & Richards, 2000). The results demonstrated that there is a correlation between basic visual skills such as reading acuity, visual field, eye movement, scanning and attention; with higher level perceptual skills, such as visual spatial relations, discrimination, crowded visual images, closure and visual memory (Cate & Richards, 2000). The study gave evidence to the idea that simple eye movements could be challenging for individuals after a brain injury, specifically CVA in this study.

**Vision’s Role In Daily Function**

Numerous studies demonstrated that ADLs and IADLs are affected after visual changes due to TBI or brain injury (Greenwald et al., 2012; Boyd & Dawson, 2000; Warren, 2009). Boyd and Dawson (2000) add to this understanding in a research study that showed how perceptual impairments impact self-care, regardless of demographic situation. In fact, the researchers stated, “It is clear that perceptual impairment is related to ADL status and this should continue to be a consideration for clinicians working in this
area” (Boyd & Dawson, 2000, p. 13). The evidence has continued to show decrease functional participation in ADL and IADLs after brain injury (Boyd & Dawson, 2000).

The importance of vision to daily functioning may be underestimated at times. Warren (2009) conducted a research study in order to identify the most challenging activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Warren (2009) primarily researched individuals with visual field deficits post-stroke; however, one participant within the study had a diagnosis of TBI. When considering ADLs, Warren (2009) found that individuals most commonly identified hygiene/grooming and feeding to be the most difficult post injury. Specifically, applying makeup, cutting nails, and cleaning personal devices were the most difficult aspects of grooming. In addition, locating food and knocking over unseen items was most challenging in regards to feeding (Greenwald et al., 2012; Warren, 2009). ADLs could be adapted for a variety of reasons including changes with balance, gait, attention, and reading habits (Greenwald et al., 2012).

Similarly, IADLs were noted to be affected post injury and Warren (2009) identified driving, shopping, financial management, and meal preparation to be most challenging. Greenwald et al. (2012) identified similar IADL challenges as Warren (2009), and found that this was primarily due to difficulties with reading, mobility, or safety concerns. Warren’s (2009) research also identified social and community involvement as anxiety provoking, at least partially due to the challenges individuals faced with mobility. Fisk, Novack, Mennemeier, and Roenker (2002) found driving to be another significant area of daily function affected post-TBI. In fact, only 60 percent of
individuals resume driving after experiencing a TBI, which is primarily due to changes with perception and attention (Fisk et al., 2002).

Individuals who experience a TBI also experience significant changes in their daily function. Challenges such as memory loss, inability to process information, barriers with communication, and changes in personality can all occur (Kosminsky, 2011). According to Kosminsky (2011), this ultimately could affect an individual's ability to function within their work or school environment, as well as having a significant impact on relationships. The inability to control emotions could result in misunderstandings, ultimately leading to broken relationships and loneliness (Kosminsky, 2011). The future can seem uncertain due to negative impacts and changes towards life goals. Ultimately, individuals with TBI have to learn to recognize the significant loss they have endured in order to begin making a recovery within their daily function and independence (Kosminsky, 2011).

Vision and Auditory Systems Impact on Daily Function

Many aspects contribute to an individual's ability to recover and function within daily life. Bohnen, Twijnstra, Wijnen, and Jolles (1992) conducted a study that addressed both the participants’ visual and auditory systems post TBI. Through exposure to intense sound and light, Bohnen et al. (1992) found that 10 days after an individual experienced a TBI they had a significantly lower tolerance to light and sound. After five weeks of recovery, Bohnen et al. (1992) found that 25 percent of the participants were still experiencing the intolerance to light and sound.

In addition, Lew et al. (2009) demonstrated the importance of both vision and auditory systems to daily function by examining the relationship between auditory
impairments, vision impairments and the two combined. Functional difficulties with auditory and visual systems are common after a blast-related TBI; it was shown that 34% of the participants had a visual impairment, compared to 20% with both, 19% with hearing and 9% with neither (Lew et al., 2009). Using the FIM, Lew et al. (2009) showed that all groups demonstrated functional improvements throughout the course of rehabilitation. The FIM assessed functional motor tasks, self-care tasks, mobility, locomotion and sphincter control, as well as a cognitive subscale, assessing communication and social-cognition (Lew et al., 2009; McKenna et al., 2006). The participants with both auditory and visual impairments made lesser overall functional gains than those who had only one sensory impairment (Lew et al., 2009). Lew et al. (2009) provided evidence in this study that TBIs result in vision and auditory dysfunction and that these sensory impairments can occur together, which significantly impacts functional independence. This study also demonstrated opportunity for functional improvements with the appropriate rehabilitation (Lew et al., 2009). Use of the FIM provided objective data that the sensory systems matter in daily function, as most individuals began with FIM scores averaging 95 with 126 as the highest possible score (Lew et al., 2009). At discharge, FIM scores were as high as 120 out of 126 (Lew et al., 2009).

**Emotional Symptoms and Coping with Visual Changes**

The research indicated that daily life is altered after TBI injury (Boyd & Dawson, 2000; Cate & Richards, 2000; Fisk et al., 2002; Greenwald et al., 2012; Kosminsky, 2011; Lew et al., 2009; McKenna et al., 2006; Warren, 2009). One can assume that a person learns to cope with those daily changes. Boerner, Reinhard, and Horowitz (2006)
conducted a two-phase longitudinal study in order to gain an understanding of how an individual might cope with vision loss initially after the visual change occurs, and two years after its occurrence. The participants consisted of individuals 65 years and older who had experienced visual impairments later in life due to a variety of diagnoses; therefore, the visual changes were not linked exclusively to TBIs. Through interviews, Boerner et al. (2006) discovered that participants experienced changes in their coping strategies after two-years. When an individual initially experienced a vision change, it was common for that person to seek information and to explore alternative treatments (Boerner et al., 2006). As individuals found seeking information and exploring alternative treatments less beneficial, they had a tendency to move away from these coping strategies (Boerner et al., 2006).

Ultimately, Boerner et al. (2006) found that vision rehabilitation programing could play a role in an individual's coping pattern over time, such as the two-year time period used in this study. Specifically, those who received counseling were more likely to utilize an affective strategy, which are coping skills based on emotions, in their follow-up interview. Examples of affective (i.e. emotion based) coping included expecting the worst, feeling lost, crying, being irritable, or blaming others (Boerner et al., 2006). Individuals who used more optical aids had a tendency to use coping methods such as escaping or seeking distraction, which included trying to see humor in the situation, not worrying about the problem, forgetting the problems, or using activity to take the mind off the problem at hand. Finally, those who used assistive aids had a tendency to use instrumental coping strategies. Instrumental coping strategies consisted of getting
information, talking to others about the problem, complaining to individuals in charge, depending on people who are trustworthy, or relying on oneself (Boerner et al., 2006).

Correspondingly, Boerner (2004) addressed coping, disability, and mental health in regards to adults who have experienced age related vision loss. Two common coping methods addressed included assimilative and accommodative. Assimilative was classified as coping by attempting to adjust circumstances to an individual's preference (Boerner, 2004). On the other hand, accommodative consisted of an individual adjusting their preferences based on the current circumstance (Boerner, 2004). Both accommodative and assimilative modes of coping were found to be valuable to mental health outcomes of individuals in middle age and elderly populations. However, accommodative coping had a tendency to be more effective for those with lower levels of disability in the younger adult population compared to the older population (Boerner, 2004). Overall, Boerner (2004) suggested that individuals who are middle aged may have a more difficult time coping with disability, resulting in higher rates of mental health challenges. Therefore, the severity of the injury and the age of the person seems to have an effect on mental health and recovery.

Coping Post TBI

The importance of coping strategies and adjusting to change are not to be underestimated. People with TBI have an increased risk of death by suicide that was three to four times greater than the general population (Simpson & Tate, 2007). Emotional adjustments individuals made can be related to psychiatric conditions. Researchers Moore et al. (2006) completed a review linking anxiety conditions post TBI. Anxiety is not the only psychiatric condition that could potentially occur after a brain injury.
according to Mooney and Speed (2001). Depression and dissociative phenomenon also have correlations to occur after a brain injury among those who fail to recover as expected (Mooney & Speed, 2001). In fact, while 29 percent (23 out of 80) of participants had mental health conditions prior to their injury, 76 percent (60 out of 80) participants had psychiatric conditions after injury, demonstrating a 47 percent increase in psychosocial conditions (Mooney & Speed, 2001). This study was composed of 80 participants who were from an outpatient clinic receiving services for mild brain injury, and were not recovering as expected (Mooney & Speed, 2001). It was shown that mental health conditions such as anxiety impact rehabilitation negatively (Mooney & Speed, 2001; Moore et al., 2006). Mooney and Speed (2001) presented the relationship between recovery time and psychiatric conditions. The finding that psychiatric comorbidity was associated with a worse mild TBI outcome was highly significant in this study, statistically shown with n=80, and p=0.0002. According to Field (2012) “n” is representative of the sample size and “p” represents statistical significance, where .05 is statistically significant in most non-pharmaceutical studies, and results that lay closer to zero are of more significance. Therefore, .0002 is a highly statistically significant correlation found in the study by Mooney and Speed (2001). Bearing in mind that the population pool consisted of individuals who were not recovering as expected, the statistics continued to demonstrate a high correlation between psychiatric conditions and compromised recovery time in mild TBIs (Mooney & Speed, 2001). Moore et al., (2006) was in concurrence with these findings, and provided additional information about how those with mild TBI and comorbid anxiety have reported to have lower self-efficacy.
regarding daily function, and to perceive their impairment level as more severe than what was objectively documented (Moore et al., 2006).

Sigurdardottir et al. (2014) also researched coping; however, these researchers had a population consisting of individuals who had experienced a TBI without visual inefficiencies. Similarly to Boerner et al. (2006), interviews were conducted in order to determine emotional distress symptoms experienced (Sigurdardottir et al., 2014). They found that most of the population was resilient after receiving this diagnosis; indicating lesser amounts of emotional distress over time. Veritably, it was determined that 73.5 percent of the population researched were considered resilient, while 6.8 percent had delayed distress, 14.6 percent were considered part of the recovery category, and only 5.1 percent experienced chronic distress (Sigurdardottir et al., 2014). Sigurdardottir et al. (2014) defines delayed distress as low levels of distress for the first year post TBI, and increased levels of distress over time, until there was a marked high in distress symptoms five years after the TBI. The recovery category was the opposite, meaning that an individual’s symptoms of distress improved as time progressed. In other words, Sigurdardottir et al. (2014) found less stress within the individuals over time.

A study by Maestas et al. (2014) evaluated how an individual’s coping style before a mild TBI could impact their mental health recovery after the injury. The clusters of coping styles used in Maestas et al. (2014) research study included problem-focused and avoidant coping strategies which were cluster analyzed into four groups (a) high use of both problem focused and avoidant; (b) high use of problem focused, low use of avoidant; (c) low use of both problem-focused and avoidant; (d) high use of avoidant, low use of problem focused coping. The results of this study showed that preinjury
coping habits that involved avoidant coping could predict a higher likelihood of depression, anxiety and overall mental health quality of life symptoms at three months after a mild TBI (Maestas et al., 2014). This research recognized the importance of bringing an awareness to non-avoidant coping strategies to enable the best quality of life after injury (Maestas et al., 2014).

**Community Integration Stressors Post- TBI**

Adjustments after experiencing a TBI can lead to stress in returning to community environments. Karlovits and McColl (1999), describe adjusting into a community, as well as the different coping strategies participants used post-TBI during stressful events. Participants described stressors as: integrating back into work or school, experiencing a loss of orientation while driving or navigating, returning to an independent living situation, or the stress that can occur with changing living situations (Karlovits & McColl, 1999). A loss of independence was also recognized as an adjustment when integrating into the community (Karlovits & McColl, 1999). Tasks such as making new relationships and maintaining old ones increased in difficulty, leading to loneliness; stress developed upon initiation and maintenance of a routine (Karlovits & McColl, 1999). The researchers highlighted the stressful community integration events, and how the participants coped with the changes (as described on page 12), which can help clinicians identify stressors that may be faced by their patients, and a variety of strategies available to cope with those changes (Karlovits & McColl, 1999).

Community integration can involve many types of visual scanning tasks, which are commonly compromised after a brain injury (Brahm et al., 2009; Greenwald et al., 2012; Sigurdardottir et al., 2009). Reading is necessary in many community tasks such as
shopping, driving, returning to work or school, indicating visual scanning as a necessary function (Cate & Richards, 2000). In fact, returning to school after a brain injury is challenging for students and teachers (Halstead, et al., 2013). Headaches, dizziness, light sensitivity, double or blurry vision, noise sensitivity, cognitive and sleep changes play a role in how a student returns to learning (Halstead, et al., 2013). Visual changes add to this stress, because basic visual functions are vulnerable after brain injury; also, high-level visual skills are required in the community for independence with IADLs such as driving (Cate & Richards, 2000). Returning to learning, community integration, and IADLs were stressful after TBI.

Stressful circumstances can lead to a variety of coping strategies individuals use to process change (Karlovits & McColl, 1999; Maestas et al., 2014). In an interview-based study, individuals post TBI used different coping strategies, including problem focused (changing a situation), perception focused (changing the meaning of a situation), and emotion focused (control the emotional reaction in a situation) strategies (Karlovits & McColl, 1999). The different types of coping strategies a person used preinjury played a role in how the individual coped during recovery (Maestas et al., 2014). Researchers developed the following coping strategies: avoiding, doing things differently, getting involved, reaching out, ignoring, relying on oneself, persevering, and using substances (Karlovits & McColl, 1999; Maestas et al., 2014). Maladaptive coping strategies that participants’ utilized prior to injury contributed to predictive depression, anxiety and mental health quality of life (Maestas et al., 2014). The researchers highlighted that most individuals involved in the study used problem-focused coping strategies, which may be associated with the environmental atmosphere of the rehabilitation settings (Karlovits &
McColl, 1999). The researchers raised awareness of coping strategies to offer possible ways to alleviate stress and assure safety for clients with TBI who are integrating into the community (Karlovits & McColl, 1999). In addition, Maestas et al (2014) provided evidence that people who used high levels of avoidant style coping had poorer outcomes, yet this same cluster also reported high use of problem-focused coping strategies. There are multiple explanations for this phenomenon, including the possibility that those who had poorer rehabilitation outcomes varied between avoidant and problem solving coping strategies too quickly to make the strategy effective (Maestas et al., 2014). The coping strategies used within the stressful changes post TBI are varied and dependent on the person's experience.

Ponsford et al. (2002) conducted a study in order to assess individual's coping abilities; however, this study was based on the education the participants were provided with post mild TBI. A booklet was available for one group of individuals, which outlined symptoms, time courses, and possible coping strategies, while the other group did not receive this information booklet (Ponsford et al., 2002). Overall, Ponsford et al. (2002) found that individuals who were provided with educational resources reported fewer symptoms. Specifically, individuals who did not receive the educational materials reported more stress, anxiety, paranoia, and hostility (Ponsford et al., 2002). Similarly, Hanks, Rapport, Wertheimer, and Koviak (2012) looked at the effects of mentoring on individuals post TBI. Mentors received 20 hours of training, and each individual with a TBI or their significant other was matched with one mentor who had previous experience within that role (Hank et al., 2012). The mentor communicated with the participant, either over the phone or in person, to discuss their emotional well-being, quality of life, and...
community integration (Hank et al., 2012). Overall, individuals who received mentoring reported a favorable experience and had better control within their typical living environment. Additionally, rates of alcohol dependency were lower, there were fewer reports of avoidant coping methods and, in general, participants reported a better quality of life (Hanks et al., 2012). It is apparent that cognitive, emotional and physical changes occur after a TBI, and individuals participate in a variety of strategies to cope with these changes.

**Cognitive and Emotional Challenges**

After experiencing the changes due to a TBI and visual inefficiencies, there are commonly cognitive, emotional and physical challenges. Spitz, Schonberger, and Ponsford (2013) and Maestas et al. (2014) speak to these challenges in research that evaluated the relationship between cognition, coping strategies and emotional adjustment after a TBI. They suggested that the use of therapy could prevent maladaptive coping strategies. Maestas et al. (2014) uncovered that coping strategies become habits. The established habits after a TBI can predict the mental health status of patients three months into recovery. The researchers found that education about coping strategies in therapy could help reduce anxiety and depression symptoms among people after experiencing a TBI (Maestas et al., 2014; Spitz et al., 2013). Additionally, the researchers hypothesized cognitive capacity may influence the coping strategies a person has available (Spitz et al., 2013). The results of the cross analysis were significant, indicating that coping strategies were connected to cognition (i.e. idea generation) and emotional adjustment after a TBI (Spitz et al., 2013). The researchers found that a lower cognitive capacity relates to higher levels of self-reported anxiety, and depression (Spitz, 2013). It was evident, based
on the research by Spitz et al. (2013) that individuals often rely on non-effective coping strategies for adapting to the variety of changes occurring post TBI. Adversely, McKenna et al. (2006) identified that visual perceptual impairments were unrelated to not only cognition, but also the severity of injury. Therefore, it is understood that coping strategies relate to cognitive changes, but visual perceptual changes are not related to cognitive status (Spitz, 2013; McKenna et al., 2006).

**Physical Challenges**

In addition to the cognitive and emotional challenges patients face, physical changes also present opportunities for adjustment. A study by Sigurdardottir et al. (2009) identified visual changes as problematic post TBI. All participants in this study experienced blurred or double vision amongst other somatic complaints such as headache, dizziness, nausea, noise sensitivity, sleep disturbance, fatigue, blurred vision, light sensitivity and double vision (Sigurdardottir et al., 2009). Kraus et al. (2005) also considered the symptoms that individuals experience post TBI, and compared these to participants with an equally serious injury without a brain injury. Individuals with a TBI experienced, on average, four symptoms, in comparison to other participants who usually reported three (Kraus et al., 2005). Symptoms included vision difficulties, fatigue, weakness, memory problems, headaches, dizziness, and several more (Kraus et al., 2005). Ultimately, individuals with a mild TBI reported more neurological symptoms than participants without a mild TBI (Kraus et al., 2005). Kraus et al. (2005) concluded that individuals with mild TBIs experience health problems, which are not life threatening, but still require medical management on a routine basis. Sigurdardottir et al. (2009) intertwined the physical changes with emotional challenges faced post TBI. This
particular research described post-concussion syndrome, and the symptoms related to the diagnosis, which occurs when challenges persist past 3 months after a mild or severe TBI (Sigurdardottir et al., 2009, p. 496). Bohnen, Twijnstra, and Jolles (1992) also researched both the cognitive grievances, such as headache, dizziness, intolerance to light, noise and other external stimuli, decreased work capacity and efficiency, tiredness, difficulty completing tasks, and decreased concentration, as well as considered emotional symptoms. Emotional symptoms included heart palpitations, perspiring hands, digestion difficulties, feelings of tenseness in the chest, and depression (Bohnen et al., 1992). Bohnen et al. (1992) found that individuals who had experienced a TBI, when compared to individuals without a TBI, had significantly higher scores in regards to the cognitive grievances; however, the same did not hold true for the emotional complaints.

**Occupational Therapy's Role in Rehabilitation**

There are many challenges associated with TBI and visual changes; and rehabilitation is helpful for individuals experiencing these changes. Researchers Dawson and Trueman (2010) were curious about how OT might play a role in rehabilitation particularly focusing on the mental health challenges individuals experience. Mental health conditions often co-occur with brain injuries, influencing the course of rehabilitation (Mooney & Speed, 2001). With this understanding, researchers hypothesized improvement in overall therapy outcomes by addressing particular psychosocial factors in therapy, including coping, locus of control, and self-efficacy (Dawson & Trueman, 2010). Dawson and Trueman (2010) discovered that nearly all OT practitioners in Canada (99.4%) agreed that the three psychosocial factors were relevant to OT; nearly all participants (96.7%) reported these factors were a part of the OT role.
Self-efficacy is increasingly important in recovery, having an impact on potential aspirations of a client (Livneh & Antonak, 1994). In fact, upon returning to learning after a concussion, self-efficacy and a sense of control are important for students by providing more time to complete assignments successfully, promoting individualized attention until recovery from concussion, or until a plan is established for the student (Halstead, et al., 2013). In Dawson and Truman’s study (2010) all of the participants incorporated the psychosocial factors of coping, locus of control, and self-efficacy into their practice when working with individuals who had brain injuries. Coping was addressed by teaching clients how to problem solve and providing counseling for emotional distress (Dawson & Trueman, 2010). Self-efficacy was addressed by providing opportunities for the clients to succeed in a task (Dawson & Trueman, 2010). Last, the therapists fostered a sense of control by allowing the clients to make decisions (Dawson & Trueman, 2010). Prior to this study, it was unknown if these mental health topics were addressed in occupational therapy. Dawson and Truman (2010) identified that Canadian OTs use the three psychosocial factor interventions within their practice and find it important for the rehabilitation process. Addressing these factors in rehabilitation is theoretically linked to better overall functional outcomes (Dawson & Trueman, 2010).

**Conclusion**

The literature indicated that TBI with visual changes are impactful on an individual’s life. Each person is unique in his or her experience. Evidence from research demonstrated that about 50 percent of individuals experience visual changes after a TBI (Bulson et al., 2012; Lew et al., 2009; McKenna et al., 2006). A variety visual changes can occur, and these changes, in addition to the brain injury, impact an individual's ability
to cope and function within daily life (Boyd & Dawson, 2000; Cate & Richards, 2000; Fisk et al., 2002; Greenwald et al., 2012; Kosminsky, 2011; Lew et al., 2009; McKenna et al., 2006; Warren, 2009). Different forms of coping styles occur for individuals who came across stress while having visual or TBI diagnoses. These included Boerner’s (2004) discussion about either assimilative or accommodative coping methods, and referenced coping strategies that included instrumental, affective, and escaping (Boerner et al., 2006). Additional coping strategies included avoidant, problem solving, seeking information, exploring alternate treatments (Karlovits & McColl, 1999), problem focused, perception focused or emotionally focused coping styles (Maestas et al., 2014). Adjustment also took place with mental health, as shown by the evidence that individuals with a diagnosis of a TBI have an increased risk of death by suicide that is three to four times greater than the general population (Simpson & Tate, 2007). Additionally, there was a correlation in the increase of mental health diagnoses post TBI (Dawson & Trueman, 2010; Mooney & Speed, 2001; Moore et al., 2006).

These physical and emotional adjustments post-TBI had an impact on many different ADLs and IADLs, which included hygiene, grooming, driving, and community reintegration (Greenwald et al., 2012; Boyd & Dawson, 2000; Warren, 2009). Rehabilitation was typically successful for visual changes after a TBI, dependent on individual experiences within the person (Lew et al., 2009). The literature supported the need for clients to receive more information about visual changes after a TBI, and instruction about effective coping skills utilized (Boerner et al., 2006; Boerner, 2004). The research showed the importance of visual screens after a brain injury, though this was not required at all hospitals (Cate & Richards, 2000; Lew et al., 2009; McKenna et
al., 2006). Throughout this literature review, few studies assessed visual changes and TBI together, and these studies focused on the quantity of people rather than their experience. Previous researchers have recommended future studies in evaluating the experience of persons with TBIs and visual inefficiencies resulting from their condition (McKenna et al., 2006).

This research study aimed to address this gap in literature by using a phenomenological qualitative design to assist in understanding the experience and coping methods utilized by individuals with a dual diagnosis of visual inefficiencies and post TBI. The following chapter addresses the methodology used to conduct this research. A presentation of the themes from qualitative analysis are also available.
CHAPTER III

METHODOLOGY

A review of literature was conducted on topics related to TBI, visual inefficiencies, and learning to cope with either diagnosis. This research along with the model Occupational Adaptation (OA) (Schkade & Schultz, 1992), were used to guide the development of interview questions for individuals with a dual diagnosis of TBI and visual inefficiencies. The focus of this model is the interactive process between the person and his or her occupational environment (Cole & Tufano, 2008, p. 107). The OA model has demonstrated success in identifying adaptive responses for individuals with brain injury in previous studies (Klinger, 2011). The review of literature began with searching and critiquing research articles which focused on visual changes experienced after a TBI, coping with either a TBI or changes in vision and other TBI and visual research that was rooted in occupational therapy. The searches were conducted through databases which included, but were not limited to: CINAHL, SCOPUS, AJOT, OT Seeker, OT Practice, OT Search, PubMed, Google Scholar, Journal of Head Trauma Rehabilitation, and PsychInfo. The primary research investigators were two graduate level occupational therapy students from the University of North Dakota, advised and assisted by one Doctoral Level Occupational Therapist. The purpose of the research study was to answer the question; what are the experiences of people who have visual inefficiencies after a TBI, and how do they cope with these changes?
Qualitative methodology was chosen for this research study in order to encompass the experience of the population. Individuals with TBI and visual inefficiencies were chosen for research, because they were consistently unaddressed throughout healthcare literature, which was evident during completion of the literature review. Furthermore, occupational therapists play a significant role in addressing affected occupations such as ADLs and IADLs, yet there is a dearth of research to support the OT role.

After the literature review, semi-structured interview questions were designed focusing on the whole experience of individuals with visual changes after a TBI, with an integrated emphasis on coping. The questions were categorized within the subsections of OA; including: occupations, relative mastery, adaptive capacity, and the occupational adaptation process (Schkade & Schultz, 1992). Semi-structured interview design benefitted this research study by allowing probing questions within specific topics designed with OA (Berg & Lune, 2012). Approval from the University of North Dakota IRB was received prior to contacting participants. Researchers met with a local optometrist and proposed the project seeking his or her participation. A purposive sampling method was utilized to obtain the research population (Berg & Lune, 2012). The optometrist served as a gatekeeper and utilized a script to provide a list of potential participants who met the inclusion criteria, to the researchers. The local optometrist specifically specializes in quantitative research involving the same population. Inclusion criteria for this study included participants with any form of visual inefficiency after a TBI. All participants were required to be 18 years or older and be cognitively aware, in order to answer interview questions and provide consent. Participants were excluded from this study if they were under the age of 18 years, and/or unable to provide consent.
for themselves due to cognitive impairments. Participants were excluded from this study if they had a history of significant visual impairments prior to the TBI. In addition, all participants were psychosocially stable. Individuals with visual impairments due to a stroke were excluded from this study. Based on the potential participant list provided, both researchers conducted scripted phone calls to search for interested participants, allowing the option of phone or personal interviews. A total of three individuals were recruited; two females and one male. Demographic information was not obtained from the participants, however, all were young adults, lived in Grand Forks, North Dakota and were practicing higher education studies. The three participants chose to be interviewed in person and were provided the HIPPA release form and consent form upon the initial meeting. Participants were provided time to review and sign both, prior to the initiation of the interview. In person interviews were conducted at Valley Vision Clinic in Grand Forks, North Dakota. Researchers increased dependability by conducting trial interviews on each other to ensure consistency in semi structured interview practices. This practice controlled for the performance bias of different therapists. Each participant took part in two, one-hour long interviews. One researcher conducted interviews for two participants, and the other conducted the interviews for one participant. The researchers were blinded to the medical history of participants, to ensure collection of unbiased information. The collection of data via interviews for this research study occurred from November, 2015 through February, 2016.

All interviews were audio recorded and transcribed verbatim by the researchers. Data analysis aligned with qualitative strategies utilized by Patton (2002). Researchers analyzed the interviews in order to identify common themes, beginning with *epoche*
Phenomenological coding methodology was used, to identify experiences related to their phenomenon within the transcribed data, which is consistent with the *bracketing phase* of the phenomenological coding process described in Patton, (2002). Researchers then interpreted the codes to find meanings within the essential recurring features of the phenomenon being studied. Next, data was narrowed to produce themes from each interview to be checked by participants. The researchers then combined the themes, using *horizontalization*, to develop and *synthesize* the phenomenological research themes (Patton, 2002). Finally, the essence of meaning was established. The themes and statement of meaning will be introduced in chapter four.

A review of research produced common themes which included: adjustments following a traumatic brain injury and visual changes; impacts on daily function; emotional symptomology after a TBI and visual changes; cognitive, emotional, and physical challenges; and rehabilitation with functional gains. Overall, the evidence for TBI with its resultant visual changes is very limited. There was a scarcity of literature about the dual diagnosis especially with a focus on coping.

To increase rigor and trustworthiness, the researchers utilized techniques such as member checking and *epoche exercises* (Lettts et al., 2007; Patton, 2002). Data analysis were inductive with a data trial established. A script was designed for the initiation of contact with participants, to keep data gathering between researchers standardized, and for procedural rigor purposes. Transferability was reinforced through interviewing both genders. The researchers synthesized common themes found in the literature review and the interviews in order to develop the final research themes and essence of the phenomenon studied.
Chapter four will consist of the results from the interviews completed with the three participants. The results from the interviews will be compared to literature that supports or deviates from the findings in the review of research. Discussion of these results and limitations to the research study will be described in detail.
CHAPTER IV

PRESENTATION, ANALYSIS & INTERPRETATION OF DATA

Three participants partook in the current research study. The sample included two females and one male, all Caucasian young adults enrolled in secondary educational classes. Two of the participants obtained brain injury from athletics. One participant was injured during an incident of domestic violence. A total of two, one hour long interviews were recorded per individual. Following careful analysis of the transcribed data, the researchers produced results that encompass the experiences of the participants. A process described by Patton (2002) was followed; it began with *epoche*, followed by *bracketing*, interpreting meaning, offering a tentative statement, organizing information into clusters, eliminating excess data, producing themes and last, *horizontalization* of the themes. Within this process a total of five themes were developed and the essence of meaning was established. Throughout this segment the use of pseudonyms were used to encompass the experience of each participant in a manner to make the identity completely anonymous.

**Theme one: Symptoms complicate daily living tasks and self-esteem because of perceived lack of progress. Symptoms include changes in vision, light sensitivity, memory, headaches/migraines, and dizziness.**

All three participants expressed difficulties with symptoms, which ultimately affected their ability to participate in meaningful daily living tasks. Due to symptoms, one participant reported challenges with school attendance for three months post-brain injury; while another participant expressed having to take “a couple weeks” off work due
to symptoms. The inability to participate in these occupations ultimately affected the individuals' self-esteem. Morgan exemplified a reduction in self-image post-brain injury as can be seen through this explanation, “Yeah, it [self-esteem] affected it a lot. Um, and not in a very positive way.” Taylor conceded stating, “Yeah, after I that, not a whole lot of self of esteem.”

Specific daily living tasks that were complicated post brain injury included social participation, driving (particularly at night), and participation in exercise. These different aspects were described as important for the individuals’ coping and self-identity prior to the injury. The occupational disruption made an impact on the daily life of the participants after the injury.

Probably my social life a little bit. ‘Cause you know, I was staying at home for three months. I can’t go out and be with friends, I can’t do anything like that… I can’t do everything that they do. I can’t go over to their house and hang out with them and watch TV because you know… ‘cause there was a time when I couldn't watch TV, or be in like bright light.

Participants all expressed difficulty understanding the progress they were achieving. Symptoms lasted an extended period of time and the slow progress of recovery fluctuated, which resulted in many participants misperceiving their gains and not comprehending their progress. This ultimately played a role in the participants’ self-esteem.

Yeah, that was one of the hardest parts, was not knowing when or if I’d be… like I feel like, at the time, I felt like this is going to go on forever, isn’t it? But eventually I got past it.

In addition to a decrease in self-esteem, one participant also expressed feelings that included lack of control. Jamie expresses, “Yes, yes, because I couldn't do so many things that I did like every day... It just sucked. And like now it makes me appreciate a lot
Theme two: Negative emotions are associated with occupational disruption in school, driving, sports/exercise and social participation.

The participants experienced disruption in a variety of their daily occupations. With these disruptions, many different emotional experiences occurred. Unfortunately, they were primarily negative feelings associated with disruptions. Participants were aware of this change in their emotions, and expressed feelings of frustration, anger, and an overall sense of being overwhelmed. Participants identified the uncertainty of the healing process both in regards to the symptomatology and the time-frame. These contributed to the negative emotions during occupational disruptions. Frustration was a constantly expressed emotion during occupation dysfunction, explained by Taylor as follows:

There is a lot of frustration when you can't do something. You know, it's easy for other people. Like, other people should be able to see just fine, why can't I? It's frustrating when you can't, you have to work so hard to see normal and other people take it for granted.

Fear of engaging in occupations, such as social participation produced anxiety in regards to being perceived differently to peers because of the symptoms of TBI being experienced. Jamie explained that the fear of making symptoms worse caused withholding from participation in certain occupations. When the symptoms were experienced, Jamie described feeling angry, but identified having to “pull back a little.” The symptoms did not only initially hold participants back from engagement, but they also felt very overwhelmed in returning to occupations when they felt they were able to do so. The participant Jamie expressed feelings of being overwhelmed, “I was like, really overwhelmed at first when I started going back to class...It literally felt like everything
was super bright or super loud, like everything was…. [overwhelming].”

**Theme three: TBI and visual inefficiencies impact relationships and support systems.**

There were positive and negative impacts on the participants’ support systems and relationships during the recovery process after TBI with visual inefficiencies. A wide range of social relationships were affected. Family, friends, romantic relationships, coaches, and counselors all played a role in recovery, and the perception of its success. Jamie expressed isolative habits while experiencing brain injury symptoms, “I guess I was maybe more antisocial when I had my concussion and stuff because like the stimulation…” Another participant, Taylor, reported isolative habits during a social outing with friends:

Um, if I was in a large group, in like a big room, and I kind of just talked to who was around me. Like I couldn't see like across the room to see if there was other people I knew...So you kind of end up being a little bit closed off. You kind of stay in your little group ‘cause you can see those people just fine.

More specifically, one of the primary relationships affected were within family roles. While two of the three participants expressed feelings of growing closer to family members, one participant felt that this injury contributed to separation from family; closer bonds maintained and grew stronger, but strained relationships drifted further apart. Taylor explained a strengthening relationship by stating, “So it was tough but my mom was great, she did [help] you know...She has always been really good and really supportive of me.” Morgan agreed, proclaiming, “I think it made my relationship with my parents stronger ‘cause they were kind of going through it with me… So yeah, I think
that it affected that relationship in a positive way.’” Taylor elaborated about a distancing relationship as follows:

Um, it kind of, it kind of started a snowball effect. Like I, after the injury, you know, I was very quiet, closed off cause I didn’t…. I didn't want to discuss anything. So then there was that. And I kind of distanced myself from my family, and I’ve never been close to my two sisters or my brother. We've always had that very, very rocky relationship and then, in the time that I was closed off, my daughter started acting out really bad. So, I was really frustrated with that, and I kind of took that out on my family. Yeah, I kind of ruined the relationship with my sisters. My brother got kind of iffy, but it's all being mended now. I don't know what started, but it ah, really strained the family relationships.

Multiple participants had difficulties with maintaining involvement with friends. Since two of the three participants were athletes, a majority of their friend group also consisted of athletes; therefore, many of the activities that their friends engaged in were difficult to participate in post-injury. In addition to affecting peer relationships, one participant discussed an experience in regards to romantic relationships after the brain injury, “I actually had a girlfriend at the time... it affected that relationship a lot, because I couldn't really be who I was prior to the concussion.”

In addition to personal relationships, two of the three participants reported professional relationship changes:

[Coach] was like, I want to see you as a normal person a few years down the road, not having like, I don't know, assistance or something, so that was kind of the big decision for playing and stuff, to not have [another brain injury].

Yeah, with one, with my counselor. She um, she did a lot…she helped me talk to the teachers. So you know, kind of like what I’m going through, ah, she was definitely a huge role player in this concussion. It was good that I had her on my side otherwise I don't know what I would have done.

Overall, the relationships of these individuals were impacted enormously. There were fluctuations in the strength of the support participants received through the recovery process. One participant expresses the positive changes in social relationships as follows:
I really think having that support system though was like huge, without that I was really sad. Having them to cheer me up and stuff, it just got me through every day. I kind of saw the light at the end of the tunnel. That is super cliché… but you know, they’ll always be there, they’ll help me through it.

Theme four: TBI and visual inefficiencies lead to changes in ability to adapt and cope.

Participants were initially asked about coping styles and methods prior to obtaining a brain injury. Data was reported in narrative and numerical styles. Participants were provided a list of coping methods consisting of: avoiding, doing things differently, getting involved, reaching out to others, procrastinating, relying on oneself, persevering, using substances, and trying to control emotional responses. The coping methods were obtained from several research articles, addressing coping with either a brain injury or visual inefficiencies. Although not every participant reported using every coping style type, the most commonly reported methods used prior to brain injury included persevering, reaching out to others, avoiding, ignoring, trying to control emotional responses, procrastinating, relying on others, and doing things differently. Additionally, participants reported coping habits to include: working out, listening to music, watching TV, playing sports, and driving. One participant elaborated about the enjoyment of driving and its facilitation of coping.

I love to drive. I love road trips and if I’m feeling super stressed and just whatever and I need to get out, I’ll get my vehicle. I’ll put on music that I love and I’ll just drive. And that clears my mind.”

Participants reported a change in their coping styles during the acute phase of the injury. Throughout this time period participants reported using the following coping styles: reliance on others, reaching out to others, reliance on self, persevering, trying to control emotional responses, and avoidant. All participants experienced difficulties with
coping during this time period. One participant described feelings of helplessness, and stated, “I won't even wish it upon my worst enemy, that concussion.”

After the acute phase post-brain injury, the participants reported a variety of coping styles that included: returning to activities from prior to brain injury, getting involved, relying on oneself, persevering, trying to control emotional responses, and trying to do things differently. Although these were the coping styles mentioned by participants, not every participant used every one of these styles. Participants reported feeling improvements in their coping during the post-brain injury phase. They discussed returning to coping activities that they had completed prior to their injury, which included, but is not limited to, listening to music and driving.

Participants rated ability to cope using a Likert Scale, with a rating that comprised of 1 being unable to cope and 10 being excellent at coping. When asked about coping during the acute phase, Jamie verbalized, “oh, not at all,” providing a zero rating. All either maintained a low ability to cope, or experienced a decrease in ability to cope during the acute phase of their injury. In addition, all participants experienced a significant increase in ability to cope currently (i.e. since recovering from the acute phase of the injury). A visual representation of the coping trends are provided in the chart below.
During an interview, one of the participants reported increased personal strength and self-image after recognizing the significant gains she had made after recovery from the brain injury.

Very strong. Like I know that I'm going to go through things in life that are going to be tough but I'm going to be able to get through it. I know that I will find a way to get through. There's always a way. There's always something you can do to make your situation better.

**Theme five: There is a lack of awareness about brain injury with visual inefficiencies and how to seek and apply resources.**

The participants initially struggled to obtain the necessary resources to best reinforce their recovery post brain injury. The lack of awareness about resources left all participants unsure of future assistance. One participant waited seven years to receive any services for visual inefficiencies after experiencing the brain injury. “I was worried that they couldn't fix my problem. That there was going to be no help. Like, what are they going to do…?”
After time participants were able to access varied resources, including a physical therapist, chiropractor, acupuncture specialist, sports psychologist, and vision therapist. Although each participant sought different resources, they varied in accessing each aforementioned health care professional. Unfortunately it was a long process and took time to receive the health care services needed.

I went to a few different places, ah, they might have helped a little bit but they never cured the concussion. I still had it after I went to these places. I probably went to three different places.

Even if the participants utilized the service of professionals, they did not apply the learnings to daily life and if they did, they did not see the progress they were making. Prior to receiving the help they needed, one participant described that the time was “really hard”. After receiving the assistance through a sports psychologist, the participant used journaling to see the progression of her recovery, which improved her overall self-esteem. Another participant described that she did not know vision therapy existed. “I didn’t know of any, until I came here… It was the first time I even knew there was eye therapy, or even got a name for what I had.” Although participants eventually were able to access resources that were able to facilitate recovery, it was time consuming and not cost effective. Morgan voiced, “I tried a lot of things. Spent a lot of money.”

Participants not only experienced difficulty with accessing and applying resources post brain injury with visual inefficiencies, but health care professionals were also not aware of the proper referrals to be made to facilitate the participants’ recovery.

…went to the hospital and talked to one of the…neurologists and ah, that was kind of at the start of everything and that didn’t really help me at all. He kind of… just gave me the facts and said this is it. You can’t really do much about it.
Referrals could be made to other health care professionals including vision therapy or occupational therapy. OT can facilitate participation in daily life during all phases of recovery if necessary. OT also has the opportunity to facilitate healthy coping mechanisms after injury, and are well educated to refer to psychologists if further coping training is needed. None of the participants had received OT services. In addition participants received vision therapy services after waiting from a few months to several years post injury.

**Summary of Results**

A combination of five themes resulted in one final overarching essence of meaning statement. The five themes consisted of: (1) there is a lack of awareness about brain injury with visual inefficiencies and how to seek and apply resources, (2) symptoms complicate daily living tasks and self-esteem because of perceived lack of progress; symptoms include changes in vision, light sensitivity, memory, headaches/migraines and dizziness, (3) TBI and visual inefficiencies impact relationships and support systems, (4) negative emotions are associated with occupational disruption in school, driving, sports/exercise, and social participation, and (5) TBI and visual inefficiencies lead to changes in ability to adapt and cope. Upon combination of the themes, the synthesis statement is: individuals who have TBI and visual changes experience many barriers including lack of resources, extended period of disruptive symptoms, and occupational dysfunction. This ultimately impacts the individual’s self-esteem, ability to cope, and social systems.
CHAPTER V

SUMMARY, CONCLUSION, AND RECOMMENDATIONS

Summary of Findings

A literature review was completed to identify the insufficiencies in research regarding the dual diagnoses of TBI and vision complications. Gaps in research justified the need for further research concerning this dual diagnoses. The principal investigators found that both ADLs and coping mechanisms received an impact after injury. There was previous information concerning TBI and vision changes separately, but there was inadequate combined research available considering the diagnoses. Researchers used the literature to propose the question, what are the experiences of people who have visual inefficiencies after a TBI, and how do they cope with these changes?

To answer the research question, Institutional Review Board approval was obtained through the University of North Dakota. Semi-structured interview questions were formed using the model of OA (Schkade and Schultz, 1992). The researchers sought contact with a local vision clinic and potential participants who met the inclusion criteria were recommended. A total of three individuals agreed to interviews, involving the time commitment of two, one hour long sessions. Phenomenological data was obtained and transcribed.

Data analysis following phenomenological coding processes produced five themes. All three participants agreed to the themes through member checking. The five themes include: (1) there is a lack of awareness about brain injury with visual inefficiencies and
how to seek and apply resources, (2) symptoms complicate daily living tasks and self-esteem because of perceived lack of progress; symptoms include changes in vision, light sensitivity, memory, headaches/migraines and dizziness, (3) TBI and visual inefficiencies impact relationships and support systems, (4) negative emotions are associated with occupational disruption in school, driving, sports/exercise, and social participation, and (5) TBI and visual inefficiencies lead to changes in ability to adapt and cope.

A combination of five themes resulted in one final overarching synthesis of meaning statement. The synthesis statement is: individuals who have TBI and visual changes experience many barriers including lack of resources, extended period of disruptive symptoms, and occupational dysfunction. This ultimately impacts the individual’s self-esteem, ability to cope, and social systems.

**Discussion**

The results of the research study revealed that individuals with TBI and visual inefficiencies experienced many challenges in adapting to daily life during the recovery process. The participants reported occupational disruption primarily in the areas of driving, education, sports/exercise, and social participation. Warren (2009) identified driving, social and community involvement to be the primary IADLs impacted with vision changes; in addition to identifying financial management and meal preparation, which were not identified by participants within the current study. Greenwald et al. (2012) identified similar IADL challenges as Warren (2009), and found that this was primarily due to difficulties with reading, mobility, or safety concerns. In regards to driving, Fisk et al. (2002) found similar discoveries as Warren (2009) for individuals who had a TBI. In fact, only 60 percent of individuals post TBI resumed driving, due to
changes in perception and attention (Fisk et al., 2002). Driving was associated with independence by a participant of the current study, and was identified as a concern for all interviewees.

Although a variety of IADLs were mentioned as being affected, no participants within this current research study identified difficulty with ADLs. Conversely, researchers Boyd and Dawson (2000) noted that perceptual impairments impact self-care. This divergence of information may be stemmed from the age of current participants, length of time post-injury, and the high level of return to function during the time of interview.

The slow recovery process and extended length of occupational disruption lead to a decrease in self-esteem in participants involved in the current study. The participants in a study by Kosminsky (2011) also identified uncertainty in the future due to changes in life goals after a brain injury. The finding that perceptions of progress can be attached to self-esteem is not a new concept in literature. A study by Bookwala and Lawson (2011) identified that the subjective concept of visual changes lead to a predictive increase of depressive symptomatology, due to participants limiting physical and social interactions if they perceived visual changes. The individuals researched in the current study had visual inefficiencies that interfered with meaningful occupations, as substantial as ending a collegiate athlete’s career. These interruptions in occupational participation were described by all interviewees to impact self-esteem; one participant’s feelings of control over his or her life, and another described feelings of helplessness; yet not all hospitals screen for visual changes after neurological disturbances (Cate & Richards, 2000; Lew et al., 2009; McKenna et al., 2006). Limited research is available regarding how coping is
addressed post-TBI in the United States (Dawson & Trueman, 2010), and referrals to OT for occupational participation did not occur for any individuals within the current research study.

In addition to ADLs and IADLs commonly being affected by TBIs and visual inefficiencies, current research also uncovered changes in relationships. Concurrently, Kosminsky (2011) found that TBI can have a significant impact on relationships. A performance skill that Kosminsky (2011) identified as affected included emotional control, which can result in misunderstandings, broken relationships and loneliness. Similarly, the research participants within our current study noted changes in their social supports and relationships. Participants reported both positive and negative socialization changes. While some grew closer to their social supports and relied on them throughout the recovery process, others became more isolated, especially from friends.

Upon disruption in occupations, the participants experienced negative emotions. Information unveiled during interviews consisted of reported frustration, anger and feelings of being overwhelmed. In previous literature, researchers hypothesized improvement in overall therapy outcomes by addressing particular psychosocial factors in therapy. Examples of psychosocial factors include coping, locus of control, and self-efficacy (Dawson & Trueman, 2010). The researchers found that education about coping strategies in therapy could help reduce anxiety and depression symptoms among people after experiencing a TBI (Maestas et al., 2014; Spitz et al., 2013).

The current research study found that individuals’ coping methods changed from before the injury to the time the participants were interviewed. The fluctuation of coping within individuals post-TBI with visual inefficiencies provides opportunity for healthcare
professionals to facilitate the formation of healthy coping habits. Maestas et al. (2014) ascertained that coping strategies become habits. The established habits after a TBI can predict the mental health status of patients three months into recovery (Maestas et al., 2014). Some research has highlighted the importance of recognizing changes in mental health by statically analyzing suicide rates post TBI. According to Simpson and Tate (2007), people with TBI have an increased risk of death by suicide that was three to four times greater than the general population. Although this is a very important item to be conscious of, no suicide ideation or concerns were noted during the participant interviews. Coping is important to address after TBI, but also after visual inefficiencies. In a case study by M. Thurston, McLeod, and A. Thurston (2013), coping with fear, loss, dependency and others’ perceptions were identified as primary themes when transitioning to life with visual changes. Coping with others’ perceptions and identifying social supports was an identifiable theme throughout the current study, as each participant described changes in coping and social structures during recovery.

The current study found that individuals with the dual diagnosis of TBI and visual inefficiencies often have a difficult time identifying and using resources to facilitate recovery. Some participants went several years without receiving assistance for their visual changes; therefore, it is vital to increase awareness of this diagnosis and the role of healthcare professionals involved in the recovery process. Cate and Richards (2000) also indicated the necessity for clinicians to screen for visual impairments post brain injury. The evidence demonstrated that TBI and visual changes occurred in about 50 percent of cases post-TBI; therefore supported the need for therapist awareness in regards to this dual diagnosis (Cate & Richards, 2000; Lew et al., 2009; McKenna et al., 2006).
Conclusions

Overall, individuals with TBI and visual inefficiencies were significantly impacted, both in their daily life and their ability to cope. Symptoms created barriers to not only their occupational participation, but also affected their self-esteem. Participants did not have a strong concept of recovery, and struggled to see the progress they were making daily. Individuals described the hassle to find and apply resources; this information provides an opportunity for health care providers to access this overlooked population. One participant explained her use of healthcare services, “Don’t isolate yourself… talk to someone if you’re not having a good day…see a psychologist, that would really help too…” The results of this study encompass the participants’ experiences and the multitude of challenges they are faced with due to the dual diagnosis.

Limitations and Recommendations

The limited geographical location posed a barrier in the transferability of this research study. All participants were recruited from Grand Forks, North Dakota. In addition, this sample only consisted of Caucasian young adults. Future research studies have opportunity to expand population sample by using probability sampling across a larger geographical area, as well as including a more culturally diverse participant population. The current research study consists of three participants; therefore, future research studies are encouraged to incorporate a larger number of participants. Future studies also have opportunity to better match the population affected with the sample size studied. Typically more males have a diagnosis of TBI; therefore, the researchers suggest using participants that consist of a majority of males. Although it is known in research that males have a higher rate of a diagnosis of TBI, there is little research showing gender
prevalence of visual inefficiencies after TBI. Another idea for future research includes expanding the population age to comprise pediatric and older adults with this dual diagnosis. In addition, there is lack of research addressing the correlation between the cause of injury and relationship changes, as well as ability to cope with new challenges. Further research could be conducted to help create an assessment tool that could be used to identify individuals with this dual diagnosis in the early stages. There is much room for literature to grow to support individuals with TBI and visual changes during their recovery process.

Other limitations noted about this study include memory bias. Participants reported their past experiences, resulting in the researchers relying on memory recall for phenomenological data, which has the potential to be inaccurate. Since there were two different interviewers, there was a risk of performance biases. In order to reduce this risk, the interviewers conducted trial interviews with each other to ensure consistency. Selection biases involved using volunteer participants, which may affect the personality type within the sample, as all were willing to participate. Last, participants were not blinded to the study; this may have affected the responses they provided.

In summary, the researchers plan to publish these findings and disseminate the information to improve the quality of tertiary healthcare for this population. Healthcare professionals, such as occupational therapists, have the opportunity to make a positive impact on this population’s recovery.
APPENDICES
Appendix A
Institutional Review Board Approval

Principal Investigator: Katie Kruger and Suzanne Vetter
Project Title: The Experiences of Individuals with Visual Changes After a Traumatic Brain Injury (TBI): An Emphasis on Coping
IRB Project Number: IRB-201507-015
Project Review Level: Expedited 6, 7
Date of IRB Approval: 07/21/2015
Expiration Date of This Approval: 07/20/2016
Consent Form Approval Date: 07/21/2015

The application form and all included documentation for the above-referenced project have been reviewed and approved via the procedures of the University of North Dakota Institutional Review Board.

Attached is your original consent form that has been stamped with the UND IRB approval and expiration dates. Please maintain this original on file. **You must use this original, stamped consent form to make copies for participant enrollment. No other consent form should be used.** It must be signed by each participant prior to initiation of any research procedures. In addition, each participant must be given a copy of the consent form.

Prior to implementation, submit any changes to or departures from the protocol or consent form to the IRB for approval. No changes to approved research may take place without prior IRB approval.

You have approval for this project through the above-listed expiration date. When this research is completed, please submit a termination form to the IRB. If the research will last longer than one year, an annual review and progress report must be submitted to the IRB prior to the submission deadline to ensure adequate time for IRB review.

The forms to assist you in filing your project termination, annual review and progress report, adverse event/unanticipated problem, protocol change, etc. may be accessed on the IRB website: http://und.edu/research/resources/human-subjects/

Sincerely,

Michelle L. Bowles, M.P.A., CIP
IRB Coordinator
MLB/lje
Enclosures
Cc: Jan Stube, Ph.D., OTR/L
Appendix B

Protocol Change Form

PROTOCOL CHANGE FORM
UNIVERSITY OF NORTH DAKOTA INSTITUTIONAL REVIEW BOARD

Please complete this form and attach revised research documents for any proposed change to your protocol, consent forms, or any supportive materials (such as advertisements, questionnaires, surveys, etc.). All changes must be highlighted. Any proposed change in protocol affecting human participants must be reviewed and approved by the IRB prior to implementation, except where an immediate change is necessary to eliminate a hazard to the participant.

Principal Investigator: Katie Kruger & Suzanne Vetter
Telephone: (320) 292-0883 & (218) 850-2262 E-mail Address: katie.kruger@mayo.edu & suzanne.vetter@mayo.edu

School/College: University of North Dakota Department: Occupational Therapy

Project Title: The experiences of individuals who have visual changes after traumatic brain injury (TBI): An emphasis on coping

Proposal Number: IRB-201507-015 Approval Date: 07/23/2015

THE CURRENT STATUS OF THE PROJECT IS (Check one)

Project currently in progress. Number of subjects enrolled is:

X Project not yet started. No subjects enrolled.

Project closed to subject entry.

1. Briefly describe and explain the reason for the revision or amendment and the justification for the change. Include a copy of affected protocol pages and consent form with specific changes highlighted.

The researchers completed a thorough analysis of literature which better displayed questions that would fill where the literature is lacking. Refer to attached interview question documentation.

Revision also occurred by the researchers adding a script of what to say to the participants upon initial contact over the phone. This was added to increase the participant recruitment percentage, and to provide standardization between the two student researchers. Refer to attached initial contact script.

2. Does the change affect the study or subject participation (procedures, risks, costs, etc.)? Yes X No

Please explain: There is no cost associated with these changes.

3. Does the change affect the consent document? Yes X No

If yes, include the revised consent form(s) with the changes highlighted, and a clean copy of the revised consent form(s).

By signing below, you are verifying that the information provided in the Human Subjects Review Form and attached information is accurate and that the project will be completed as indicated.

Signatures:

Principal Investigator: Katie Kruger, OTS and Suzanne Vetter
Date: 8/25/15

Student Advisor (if applicable)

Date: 8/27/15

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May 2, 2015

University of North Dakota Human Subjects Review Form
School of Medicine & Health Sciences
501 N. Columbia Rd. Stop 9037
Grand Forks, North Dakota 58202-9037

To Whom It May Concern,

This letter is to inform the IRB that Valley Vision Clinic is in full support of the proposed research study by Katie Kruger and Suzanne Vetter of the Department of Occupational Therapy, “The Experiences of Individuals with Visual Changes after a Traumatic Brain Injury (TBI): An Emphasis on Coping”.

Sincerely,

[Signature]
David H. Bibendorf, O.D., FCOVD
Appendix D
Informed Consent

THE UNIVERSITY OF NORTH DAKOTA
CONSENT TO PARTICIPATE IN RESEARCH

TITLE: The experiences of individuals with vision changes after traumatic brain injury (TBI): An emphasis on coping.

PROJECT DIRECTOR: Katie Kruger, MOTS and Suzanne Vetter, MOTS

PHONE #: 701-777-2209

DEPARTMENT: Occupational Therapy

STATEMENT OF RESEARCH
A person who is to participate in the research must give his or her informed consent to such participation. This consent must be based on an understanding of the nature and risks of the research. This document provides information that is important for this understanding. Research projects include only subjects who choose to take part. Please take your time in making your decision as to whether to participate. If you have questions at any time, please ask.

WHAT IS THE PURPOSE OF THIS STUDY?
You are invited to be in a research study about an individual’s ability to cope with visual inefficiencies after a traumatic brain injury because you meet the criteria and accepted the invitation from Dr. Biberdorf.

The purpose of this study is to look at the coping strategies of individuals who have experienced a visual inefficiency after a traumatic brain injury. At this time there is no research about how occupational therapy can assist with the physical and psychological barriers experienced after a traumatic brain injury, so we would like to learn what is beneficial from your perspective.

HOW MANY PEOPLE WILL PARTICIPATE?
Approximately eight to ten people will take part in this study through the University of North Dakota at Valley Vision Clinic. You can be included in this study if you have experienced any form of visual impairment after a traumatic brain injury. You must be of 18 years or older. All participants must be cognitively intact, in order to speak for themselves and give consent for voluntary participation.

Approval Date: JUL 21 2015
Expiration Date: JUL 20 2016
University of North Dakota IRB
HOW LONG WILL I BE IN THIS STUDY?
Your participation in the study will require you to be available for two separate interviews that each will last approximately one hour. These times and dates will be at your personal convenience. You will need to visit Valley Vision Clinic for each interview. If a telephone interview is more convenient for you, please let us know.

WHAT WILL HAPPEN DURING THIS STUDY?
You will be asked a series of questions through an interview conducted by one the researchers. The interview process will be comprised of various open-ended questions regarding your experiences and perspectives in coping with vision inefficiencies after a traumatic brain injury. The researchers will record/audiotape the discussion in order to carefully recall your responses. Your responses will be confidential and will be analyzed by the researchers in order to find commonalities among all participants. You are free to skip any questions that you prefer not to answer. You may also drop out from the experiment at any time with no repercussions.

WHAT ARE THE RISKS OF THE STUDY?
There are no physical or financial risks that will result from this study; however, there is a minimal chance that questions may trigger an emotional response for you. Some questions may be of a sensitive nature and you may become upset as a result. You may stop participating at any time or choose not to answer any question. Referral to counseling services will be provided if necessary.

WHAT ARE THE BENEFITS OF THIS STUDY?
You may not benefit personally from being in this study. It is possible that you will benefit from additional discussion on coping with the researchers. Additionally, we hope that in the future other people might benefit from this study because increased knowledge and understandings can help healthcare professionals provide a higher quality of service to individuals who experience this diagnosis.

WILL IT COST ME ANYTHING TO BE IN THIS STUDY?
You will be responsible for your own transportation cost to come to and from the two interviews. Otherwise you will not have any costs for being in this research study.

WILL I BE PAID FOR PARTICIPATING?
You will not be paid for being in this research study.

Approval Date: July 21, 2015
Expiration Date: July 20, 2016
University of North Dakota IRB

Initial
Date
WHO IS FUNDING THE STUDY?
The University of North Dakota and the research team are receiving no payments from other agencies, organizations, or companies to conduct this research study.

CONFIDENTIALITY
The records of this study will be kept private and confidential. Only researchers and the study faculty advisor will have access to these records. A coding system will be utilized to protect your confidentiality. All interviews will be audio recorded, which you reserve the right to review/edit at any time. After recordings have been transcribed by the researchers and reviewed, all recordings will be deleted. All hard copy forms and transcribed data collected will be stored safely and maintained securely for at least three years after the study has ended; at the end of three years, records will be destroyed by shredding by the faculty advisor. In any written report or publication of this study, we will describe results in a summarized, grouped manner so that you cannot be identified.

IS THIS STUDY VOLUNTARY?
Your participation is voluntary. You may choose not to participate or you may discontinue your participation at any time without penalty or loss of benefits to which you are otherwise entitled. Your decision whether or not to participate will not affect your current or future relations with the University of North Dakota.

If you decide to leave the study early, we ask that you call the study coordinator about your decision. There is no penalty for leaving the study early. Please contact the study coordinator for any further questions.

Circumstances that may arise that will result in your dismissal from the continuation of this study could include the development of a serious health condition.

CONTACTS AND QUESTIONS?
The researchers conducting this study are K. Kruger and S. Vetter. The advisor for this study is Dr. Jan Stube. You may ask any questions you have now. If you later have questions, concerns, or complaints about the research please contact The University of North Dakota’s Occupational Therapy Department at (701) 777-2209 during normal business hours; or if you call after hours leave a voicemail at the department’s number to be contacted the following business day.

Approval Date: JUL 21 2015
Expiration Date: JUL 20 2016
University of North Dakota IRB

Initial ________
Date ________
If you have questions regarding your rights as a research subject, you may contact The University of North Dakota Institutional Review Board at (701) 777-4279.

- You may also call this number about any problems, complaints, or concerns you have about this research study.
- You may also call this number if you cannot reach research staff, or you wish to talk with someone who is independent of the research team.
- General information about being a research subject can be found by clicking "Information for Research Participants" on the web site: http://und.edu/research/resources/human-subjects/research-participants.cfm

I give consent to be audiotaped during this study.

Please initial: _____ Yes _____ No

I give consent for my quotes to be used in the research; however I will not be identified.

Please initial: _____ Yes _____ No

Your signature indicates that this research study has been explained to you, that your questions have been answered, and that you agree to take part in this study. You will receive a copy of this form.

Subjects Name: __________________________

________________________________________
Signature of Subject Date

I have discussed the above points with the subject or, where appropriate, with the subject’s legally authorized representative.

________________________________________
Signature of Person Who Obtained Consent Date

Approval Date: JUL 21 2015
Expiration Date: JUL 20 2016
University of North Dakota IRB
Appendix E
HIPPA Compliance

HIPAA  AUTHORIZATION TO USE AND DISCLOSE
INDIVIDUAL HEALTH INFORMATION FOR RESEARCH PURPOSES

1. Purpose. As a research participant, I authorize Katie Kruger, MOTS and Suzanne Vetter,
MOTS, and Jan Stube, PhD, OTR/L, to use and disclose my individual health information for the
purpose of conducting the research project entitled, The experiences of individuals with visual changes
after a traumatic brain injury (TBI): An emphasis on coping.

2. Individual Health Information to be Used or Disclosed. My individual health information
that may be used or disclosed to conduct this research includes: my age, gender, and date of brain
injury.

3. Parties Who May Disclose My Individual Health Information. The researcher and the
researcher’s staff may obtain my individual health information from:

   Hospitals: ___N/A_____  
   Clinics: ___Valley Vision Clinic_____  
   Other Providers:  
   Health Plan:  

   and from hospitals, clinics, health care providers and health plans that provide my health care
during the study.

4. Parties Who May Receive or Use My Individual Health Information. The individual health
information disclosed by parties listed in item 3 and information disclosed by me during the course
of the research may be received and used by Katie Kruger, MOTS, Suzanne Vetter, MOTS, and Jan
Stube, PhD, OTR/L.

5. Right to Refuse to Sign this Authorization. I do not have to sign this Authorization. If I
decide not to sign the Authorization, I may not be allowed to participate in this study or receive any
research related treatment that is provided through the study. However, my decision not to sign this
authorization will not affect any other treatment, payment, or enrollment in health plans or
eligibility for benefits.

6. Right to Revoke. I can change my mind and withdraw this authorization at any time by sending
a written notice to Katie Kruger, MOTS, Suzanne Vetter, MOTS, or Jan Stube, PhD, OTR/L, to
inform them of my decision. If I withdraw this authorization, the researchers may only use and
disclose the protected health information already collected for this research study. No further health
information about me will be collected by or disclosed to the researcher for this study.

7. Potential for Re-disclosure. My individual health information disclosed under this
authorization may be subject to re-disclosure outside the research study and no longer protected.
For example, researchers in other studies could use my individual health information collected for
this study without contacting me if they get approval from an Institutional Review Board (IRB) and
agree to keep my information confidential.

1 HIPAA is the Health Insurance Portability and Accountability Act of 1996, a federal law related to privacy of health information.
7A. Also, there are other laws that may require my individual health information to be disclosed for public purposes. Examples include potential disclosures if required for mandated reporting of abuse or neglect, judicial proceedings, health oversight activities and public health measures.

This authorization does not have an expiration date, but I can withdraw at any time.

I am the research participant or personal representative authorized to act on behalf of the participant.

I have read this information, and I will receive a copy of this authorization form after it is signed.

<table>
<thead>
<tr>
<th>Signature of research participant or research participant’s personal representative</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Printed name of research participant or research participant’s personal representative</td>
<td>Description of personal representative’s authority to act on behalf of the research participant</td>
</tr>
</tbody>
</table>
Appendix F

Scripts

Script for Participant Recruiter

I am working with two students and one professor at the University of North Dakota. They are working on a research study and you are invited to participate. The study will be looking at individuals, such as yourself, who have experienced a traumatic brain injury and vision problems due to that injury. The students will be looking at how you go about your daily life and cope with any challenges you have faced after this injury. Are you interested?

(If yes read the following...)

This study will consist of two one-hour interviews held with a UND occupational therapy student here at Valley Vision Clinic. As stated before, they will be asking you questions about your everyday experiences and coping methods you have used since your injury. There is no payment for this study, but the UND students would greatly appreciate your participation. Is it okay for the students to contact you?

If you have any questions, please contact either:

Katie Kruger (320) 292-0983

Suzanne Vetter (218) 850-2262

Initial Contact Script

Hi, my name is _______. I am a student at the University of North Dakota. Dr. Biberdorf gave me your name and phone number as a potential participant in a research study, do you have a few minutes to talk?

(If Yes) Another student, (Katie or Suzanne) and I in the UND Occupational Therapy program are doing an interview-based research project for our final year in the program. We are looking for potential participants who have experienced visual changes after a TBI, and would like to interview individuals on 2 separate occasions about your experience and coping with those visual changes. Dr. Biberdorf thought you would potentially be willing to participate in this study. Would you like to hear more about it to decide if you’d be interested in participating?

This study is intended to benefit health care workers by expanding their knowledge to provide the most support and quality care to future patients who are experiencing what
you’ve experienced. We hope that you will also benefit from study participation by reflecting upon your experiences and telling us about them.

For this study, it consists of 2, roughly 1-hour long, audiotaped interviews at the time of your choice. Throughout the 2 interviews you can skip any questions you feel uncomfortable answering, or ask us any questions you may have. It is entirely your voluntary choice to participate and will, in no way, affect the care you receive through Dr. Biberdorf at Valley Vision Services. We will keep your information confidential during and after the research process. This is a UND-approved research project.

If you are willing to participate, we have a couple options for you to choose from. We can talk by phone, or in person. If you feel more comfortable completing the 2 interviews over the phone, it would happen between September-December. If you prefer meeting in person, the interviews will take place January- April of 2016. They will be held at Valley Vision Clinic, where Dr. Biberdorf works.

Do you think you would be willing to participate?

(Yes) Thank you! Which do you prefer, talking over the phone or the in person discussion?

PHONE: Thank you very much. Okay, we will be mailing you a consent form and a HIPPA form to sign and return to us prior to our first interview. Can we please have your address? There will be a copy for you to keep, and one for you to sign and send back. We will also have an addressed and stamped envelope inside that you can use. We cannot continue with the research until we received those forms back. But once we’ve received the signed copies in the mail, is it okay to call you and set up a time for the first interview? If we don’t get the signed copies back within 2 weeks, is it okay to call you and remind you about them?

PERSON: Thank you very much. Alright, is it okay to call you at the end of December, beginning of January to set up the first interview?
Member Checking Script
Hi, this ________, who interviewed you in January; the OT student from UND. How are you?
Do you have about 5 minutes right now? I am just calling to review our results with you, to see if you feel like it fully encompasses your experiences with visual changes and brain injury.
I will not record this at all, but if it is okay with you, I will share what you said with my research partner. Is that okay?

1. There is a lack of awareness about brain injury with visual inefficiencies and how to seek and apply resources.

2. Symptoms complicate daily living tasks and self-esteem because of perceived lack of progress. Symptoms include changes in vision, light sensitivity, memory, headaches/migraines, and dizziness.

3. TBI and visual inefficiencies impact relationships and support systems.

4. Negative emotions are associated with occupational disruption in school, driving, sports/exercise, and social participation.

5. TBI and visual inefficiencies lead to changes in ability to adapt and cope.
Appendix G
Interview Questions

Interview One

Greeting/ Rapport Building:

Thank you very much for participating in this research study about TBI and Vision experiences. As the informed consent stated, some questions may lead to emotional responses, so feel free to pass on any questions, or to leave the study if need be. Today has easier questions to begin to know you and your story.

● Prior to starting we want to double check to ensure that you fit the inclusion criteria for this study:
  ○ How old are you?
  ○ Do you have a guardian who helps you with answering questions in legal documents?
  ○ Did you have visual problems before your TBI?
  ○ Have you had any recent hospitalizations?

● Can you tell me a little about yourself?
  ○ Job/Education
  ○ Family
  ○ Leisure
  ○ Driving

● If you are willing, can you tell me the story of how you obtained your TBI
  ○ What forms of visual inefficiency do you have?
    ■ How does that impact your daily living?

● When you first learned about your vision being impacted, what were some initial thoughts?

● In our literature we found that independent living was a big concern. What are your thoughts about this?

● How would you define the term “coping”?
After your TBI have you ever received education, counseling or any type of assistance in defining or learning about coping?

○ If yes, what types of materials were you provided with?

Prior to your TBI what was your view on the word disability and how has that changed since you experienced your TBI?

**Occupations:**

- What are some changes experienced in your everyday life after the visual changes you experienced after your TBI?
- What activities do you have a hard time with because of this? (Greenwald et al., 2012).
- Was there any therapy services that you were able to utilize that assisted in either your ability to accept your vision inefficiency, or the improvement in your vision?
  ○ How did this have an impact on your ability to cope with your diagnosis?

**Relative Mastery**

- Was there any task you felt successful in during your recovery that assisted in you feeling competent?
- What community resources (if any) were used to help assist with your recovery or ability to cope?
- Was it easy or difficult to see the progress you were making during recovery? Why?
- Did you/do you feel like your vision is making any improvements?

**Adaptive Capacity:**

- What do you think you did well to facilitate a successful recovery?
○ What do you think you could have done better?

● What are some specific things that help you stay independent despite vision problems?

**Closing for interview one**

Is there anything else you would like us to know about your experiences with TBI at this time? Do you have any questions or concerns for us? Thank you so much for your time today. Let’s schedule the next interview at a time that works best for you.
Interview Two

Introduction:
How are you today? Thank you very much for coming back for the section portion of this research study. Some questions today may lead to emotional responses; so if you feel like you wish not to answer, feel free to let me know. Is there anything you thought of since the last interview you would like us to know?

Occupations:

● What were some activities you have returned to or/want to get back to?

Relative Mastery:

● Can you think of at least one task that was a part of your routine that required more energy or time after your TBI?
  ○ How did you handle that (emotionally and physically)?

● How did your injury impact self-esteem? (Dawson & Truman, 2010)
  ○ Feelings of control?

Adaptive Capacity

● What were some difficult transitions during this time?
  ○ How were you able to deal with these difficult transitions?

● Can you tell me a story about a time when you were unable complete a meaningful activity that you used to do every day?
  ○ How was the task changed so that you were able to complete it?

● What feelings arise when you are unable to complete something due to the TBI or visual problems?

● Present cards of types of coping- avoiding, doing things differently, getting involved, reaching out to others, procrastinating, relying on oneself, persevering, using substances, trying to control your emotional responses (Karlovits & McColl, 1999).
○ Which of these did you do before your injury most often?

○ Has that changed? If so, which do you use most often now?

■ Do you feel like it has changed for better or worse?

**Occupational Adaptation Process:**

- How did you cope with all of the changes during the time of injury?

- How did your TBI and visual changes have an impact on the relationships and roles you had in your life?

  ○ Positive and negative factors

- On a scale of 1-10, 1 being unable to cope with stress and 10 being excellent at coping with stress, how were you able to deal with stress:

  ○ before

  ○ the initial after the TBI

  ○ now

- What are ways you cope with stress?

  ○ before the TBI

  ○ initially after the TBI

  ○ now

- How did the TBI and vision inefficiencies affect your peer relationships?

- How did you communicate your experiences and your needs to your peers and family?

  ○ How effective was this form of communication?

  ○ How change or develop over time in order to ensure that your needs were met?
• Consider a scenario where a family member or friend had a TBI…
  ○ Based off your experience, how do you think you could best assist them and meet their needs in order to promote recovery?

Closing for interview Two

Is there anything else that you can think of that you want therapists and healthcare workers to know about your experience with TBI and vision impairments? Do you have any questions for us as researchers? **Thanks so much for your participation in this research study.** We really appreciate your help, and know that this will help healthcare workers better understand vision problems after a TBI in the future.
REFERENCES


Spitz, G., Schonberger, M., & Ponsford, J. (2013). The relations among cognitive impairment, coping style and emotional adjustment following traumatic brain


