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How Not Being Able to Drive Can Affect Routines and Occupations Related to

Transportation

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How Not Being Able to Drive Can Affect Routines and Occupations Related to Transportation

By Stedmon Deon Hopkins Bachelor of Science Eastern Kentucky University Richmond, Kentucky 2014

Submitted to the Faculty of the Graduate School of Eastern Kentucky University in partial fulfillment of the requirements for the degree of MASTER OF SCIENCE August, 2014 Copyright © Stedmon Deon Hopkins, 2013 All rights reserved

DEDICATION

This thesis is dedicated to my parents Renwick and Tracy Hopkins for all of their love and support throughout this process.

ACKNOWLEDGMENTS

I would like to thank my advisor, Dr. Dana Howell, for all of her assistance and support throughout this entire process. I would also like to thank the other committee members, Dr. Melba Custer and Dr. Camille Skubik-Peplaski, for their support over the past year. I would like to thank both of my parents Renwick and Tracy Hopkins for their love and support throughout my entire school career and for always being there for me. I would also like to express my thanks to my fiancée Caitlin Hill for her love and support. Lastly, I would like to thank all of my family and friends for believing in me and cheering me on.

Abstract

The purpose of this study was to examine how individuals who have experienced a TBI described the effects not being able to drive has on their routines and occupations related to transportation. Two participants were interviewed, using a semi-structured interview protocol, about their participation in daily routines and occupations related to driving cessation after experiencing a TBI. Interviews were audio recorded and transcribed. Data was analyzed by coding significant phrases, grouping the codes into categories, and generating descriptions of the participants' perceptions. Member checks were performed for trustworthiness. After analyzing the data, four themes emerged. The themes were; hoping to be a better driver, being able to take myself anywhere and everywhere I want to go at any time, feeling cut off from people, and self-realizations. These themes suggest that there are limited participation and social interactions present with individuals after experiencing a TBI and driving cessation. There were several ways the individual's lives were affected by their inability to drive. These included: limited participation with peers and family, limited community integration, and loss of independence and autonomy.

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Chapter 1

Introduction

Background

A traumatic brain injury (TBI) is caused by a bump, blow or jolt to the head or an object penetrating the skull that disrupts brain function and may be mild, moderate, or severe. According to the Mayfield Clinic, a mild brain injury can be characterized by the individual being awake and eyes open, with symptoms of confusion, disorientation, memory loss, headache, and brief loss of consciousness. With a moderate TBI the individual is lethargic with eyes open with stimulation and loss of consciousness lasting 20 minutes to 6 hours. A person with a moderate TBI may also have some brain swelling or bleeding that can cause sleepiness, but can still be aroused. An individual with a severe TBI is unconscious with their eyes staying closed even with stimulation. These individuals experience loss of consciousness lasting more than 6 hours (Mayfield Clinic & Spine Institute, 2013). The severity of the TBI may be rated by scores from the Glasgow Coma Scale (GCS) and the Ranchos Los Amigos Scale. Of the 1.7 million people that experience a TBI, 1.365 million of them are treated in hospitals and released (Faul *et al.*, 2010, p. 8, 13). This means that nearly 80% of people treated for TBI will be able to return home and back into their communities.

Once a person with a TBI returns home, there will be many changes and adaptations they have to make in their lives. Experiencing a TBI can have adverse effects on an individual's participation in their routines and occupations due to the types of deficits they may present with. An individual may present with physical, emotional, and cognitive symptoms. Physical symptoms may include headaches, dizziness, pain, fatigue

trouble sleeping, spasticity, and sensory deficits that affect their vision, vestibular system, strength, and coordination. Cognitive symptoms can include memory problems, staying focused, poor judgment, and difficulties putting thoughts into words. Emotional symptoms can be depression, anger outbursts, anxiety, and personality changes (National Center for PTSD, 2010). Having a TBI can affect how a person views and participates in social aspects of life, work, community mobility, education, and even leisure activities. Following a TBI, the individual may need assistance with these areas of occupation or may feel as if they cannot complete as much as they could prior to their TBI. One aspect that is often affected as a direct result of a TBI is the individual's ability to drive.

According to Dazio, driving is a skill that requires a variety of cognitive functions including: attention, memory, perception, sequencing, multi-tasking, and decision making. Driving also requires a variety of physical and sensory functions, including physical strength, physical and mental stamina, muscle flexibility, range of motion, and coordination (2008). "After an individual experiences a TBI, they may seem physically intact, but could be experiencing cognitive, psychological, social, emotional, and behavioral problems. Psychosocial difficulties can include impaired judgment, shorter temper, aggression, and intolerance of others. A person that experiences these symptoms along with cognitive problems may have difficulties returning to driving" (Hawley, 2001, p.761). If an individual experiences any of these deficits, their ability to return to driving can be compromised.

Experiencing driving cessation can have a major influence on a person's life. According to Buchanon and Wall (2010), "Driving allows people to participate in various life activities, including basic activities of daily living (ADL's), instrumental activities of daily living (IADL's), work, education, and other preferred activities within the community. Driving is a role that many take pride in and allows for freedom to explore and experience their environment. It enables occupation within the community and provides the opportunity for mobility and participation in desired and expected activities" (p. 2). There are many aspects of occupational performance, including social participation and community mobility that rely on whether an individual can or cannot drive. It is important to understand what daily routines and occupations of an individual are affected when a person cannot drive in order to understand why driving is important to them.

According to Horowitz, Boerner, and Reinhardt, "driving is more than simply a way to accomplish daily tasks, driving is imbued with a host of psychological meanings, including one's sense of autonomy, independence, and self-worth. Giving up driving, for many older adults, is often experienced psychologically as the first step towards a downward spiral of dependency. Available evidence indicates that driving cessation is, in fact, associated with a significant decrease in out-of-home activities, and with increased feelings of depression, regret and isolation" (2002, p. 262). Although this study was directed toward the geriatric population with low vision, it can be assumed that individuals with TBI would have some of the same views on driving cessation. According to Liddle, "driving cessation can be unplanned and therefore associated with serious consequences such as depression, reduced out-of-home activities, isolation and in turn, poorer quality of life. Driving cessation and subsequent limited community mobility can lead to loss of other life roles and impact on feelings of self-efficacy, self-

esteem and life satisfaction" (2003, p. 1). Losing the ability to drive can have a negative effect on a person's routines and on their ability to participate fully in life.

Driving cessation can have an effect on individuals who have experienced a TBI, but research is limited. Liddle et al. (2012) states that, "the experience of driving cessation for people with TBI has not been explored" (p. 80). The authors mention that although the experience of driving cessation has been examined in elderly and stroke populations, it will likely be different for young individuals who have experienced a TBI. This article was written to "examine the experience of loss of the driving role for individuals with TBI and to explore the outcomes associated with driving cessation for both individuals and families, with the aim of informing an intervention designed to assist individuals who are unable to return to driving following a TBI" (Liddle et al., 2012, p. 80). Hoogerdijk (2011) discussed the adaptation process of an individual who has experienced a TBI. Although this article did not specifically identify driving cessation, it did describe how a person who has experienced a TBI may have difficulties adapting and gaining a new identity for themselves. The author drew from various studies that documented stroke survivors and related their recovery to individuals who had a TBI. "This study aimed to understand how individuals valued the performance of everyday life activities within their adaptation process and how those occupational experiences influenced the adaptation process" (Hoogerdijk et al., 2011, p. 123). This article's goal was to understand how people who have experienced a TBI viewed life activities that may have been changed.

Although it can be a difficult task, it is possible for individuals to regain their ability to drive after a TBI. The level of difficulty depends on the severity of their injury.

While some people do regain their ability to drive, for others it can be much more challenging and even result in unsatisfying outcomes. Nearly 50% of people that experience a TBI will not be able to resume their role as a driver, which can have a direct result on their ability to participate fully in life (Liddle *et al.*, 2012, p. 79). Occupational therapists (OTs) often work with individuals who have experienced a TBI and have a goal to resume driving.

Some researchers describe resources that are available for individuals who have a disability and want to return to driving. Stav (2008) discusses the elderly population and how they experience community mobility and driver licensure policies. The author states that "the transportation afforded by driving allows people to travel to and from work, manage household duties, transport children, and explore expanded arenas of recreation and travel. As people age, the need and desire to be independently mobile in the community does not diminish" (Stav, 2008, p. 150). Being familiar with laws and policies along with the ramifications surrounding driving can affect a person's ability to drive and shape a practitioners practice on a community and clinical level. Horowitz et al. discusses how low vision can affect the elderly's ability to drive, noting that "decisions about driving are especially salient for the growing numbers of older adults who experience age-related vision problems" (2002, p. 262). The authors state that the research on the influence of families, friends, and transportation alternatives going from the role of a driver to an ex-driver is limited. The study aims to explore the different factors, influences, and resources available for a person undergoing this transition of driving cessation. Both studies discuss how driving allows for individuals to be independent. Although it can be difficult for a person to learn that he/she will not be able

to drive, it is important to know there are other things a person can do to be independent. When a person has a TBI and learns they may not be able to drive anymore, they may feel a loss of independence and may have to accept the changes that occur in their life.

Problem Statement

Much is known about the symptoms of TBI, and the impact it has on daily tasks. Likewise, much is known about the skills needed for driving and the role of driving in occupational participation. While some research has examined driving cessation with elderly individuals and stroke survivors, little has been done specific to individuals with a TBI. There is little available research looking at how a person who has experienced a TBI describes how driving affects their ability to participate in their routines and occupations related to driving. This research would be beneficial because it would give insight into how a person who has experienced a TBI is or was affected by their limited driving ability and how much it can differ between individuals.

Purpose Statement

The purpose of this phenomenological study was to examine how individuals who have experienced a TBI describe the effects not being able to drive has on their routines and occupations related to transportation.

Grand-Question

How do individuals who have experienced a TBI describe the effects not being able to drive has on their routines and occupations related to transportation?

Sub-Questions

1. What routines and occupations are affected by the inability to drive after a person experiences a TBI?

2. How has not being able to drive affected participation in routines and occupations after experiencing a TBI?

3. How would a person who experiences a TBI describe the meaning and importance driving has to them?

4. How would the individual who experienced a TBI like to see their daily life change after regaining their driving ability?

Significance of Study

The study is significant because it will give rehabilitation professionals, such as occupational therapists who work with clients with TBI and their families, a different perspective on what individuals who have experienced driving cessation or are undergoing driving training are experiencing. The study will also give the opportunity to explore what types of occupations these individuals feel they are missing due to the lack of ability to drive, giving them an opportunity to develop alternative ways to still participate. Having this information will give healthcare professionals information about why individuals want to regain their ability to drive and give them an idea of what is important to the individual. This knowledge can have an impact on the types of interventions done with the individuals. Even if the individual does not regain their ability to drive, the occupational therapist may be able to assist them with other aspects of their lives that the individual can't participate in. This study may also apply to individuals of different populations such as the elderly, individuals with low vision,

history of seizures, and strokes. These populations can all experience driving cessation and would have different views on their routines and how they would be affected.

Definitions

 Cessation: For this study cessation related to driving will be defined as an individual who once had the ability to drive but has had to discontinue due to a disability, or other factor.

(Personal Definition)

 Cognitive: of or pertaining to the mental processes of perception, memory, judgment, and reasoning, as contrasted with emotional and volitional processes. *Dictionary.com.* (2011). Retrieved from

http://dictionary.reference.com/browse/cognitive

- Drive: For this study driving will be defined as a person having the ability to independently operate a motor vehicle as their primary method of transportation. (Personal Definition)
- 4. Glasgow Coma Scale: A standardized system used to assess the degree of brain impairment and to identify the seriousness of injury in relation to outcome. *Rehabilitation for brain and spinal cord injury*. (n.d.). Retrieved from http://www.rainbowrehab.com/Education_&_Publications/ranchos-losamigos.php
- 5. Occupations: Activities of everyday life, named, organized, and given value and meaning by individuals and a culture. Occupation is everything people do to occupy themselves, including looking after themselves, enjoying life, and contributing to the social and economic fabric of their communities.

- American Occupational Therapy Association. (2008). Occupational therapy practice framework: Domain and process (2nd ed.). *American Journal of Occupational Therapy*, 62, 625-683.
- 6. Ranchos Los Amigos Scale: Rates cognitive functioning and expected behaviors through and assessment of levels one through ten.

Rehabilitation for brain and spinal cord injury. (n.d.). Retrieved from

http://www.rainbowrehab.com/Education_&_Publications/ranchos-losamigos.php

(Personal definition)

7. Routines: Routines are patterns of behavior that are observable, regular, repetitive, and that provide structure for daily life.

American Occupational Therapy Association. (2008). Occupational therapy practice framework: Domain and process (2nd ed.). American Journal of Occupational Therapy, 62, 625-683.

 Traumatic brain injury: Occurs when an external mechanical force causes brain dysfunction. Usually results from a violent blow or jolt to the head or body. Mayo Clinic Staff. (2010, Sep 16). *Mayo clinic*. Retrieved from

http://www.mayoclinic.com/health/traumatic -brain-injury/DS00552

Assumptions/Biases

When conducting this research, I must be aware of my assumptions about the topic. Driving is something that I value and find to be significant to all aspects of my life and affects my social participation. I also view being able to drive as my only means of transportation to school, home, and work. I am expecting to hear that this will also be the

case with most of the individuals I speak to. I imagine that not being able to drive will have effects on their lives in some of the same ways and that it was something they relied on. I also view driving as a form of freedom. Being able to drive gave me the ability to leave home whenever I wanted without boundaries. I would imagine that for the individuals that no longer have the ability to drive they may feel that some of their freedom has been taken away. Looking at driving in my life and how important it is, I believe that their occupations and routines will be changed significantly based on their ability to drive.

A bias that I must be aware of when doing this research is the tendency to compare what they are capable of doing and what they want to do with other individuals who have experienced a TBI. Going into the occupational therapist profession and being a current student, I have seen and spent time with individuals who have experienced a TBI and have had an opportunity to observe their abilities. Due to the OT background, I will have a tendency to assess what they can or can't do and try to figure out what types of interventions or techniques could be used to help assist them. It will be important to remember that that is not my role and I am conducting the interviews to gain an understanding of their views of how their routines and occupations have been changed.

In order to mitigate these biases it will be important to ensure that the data collected is accurate and reflects the responses of the individuals. This will require me to reflect on all biases I may have and ensure they do not affect the study. Different techniques that can be used to do this include member checking done with follow-up interviews and reflexivity.

Limitations

As with any study there will be limitations. One limitation may be that the same person doing the interviews will be the person interpreting the data to find codes and themes. This could be a limitation because another team member will not be able to help eliminate some of the researcher biases. While this limitation could have a positive impact since one researcher may be able to better interpret the data and may have a better understanding of attitudes, emotions, and meaning of information conducted during the interviews, this concern will be mitigated by having an advisor review the data collection and analysis. An additional limitation may be that the individuals who participate in the study will all be interviewed in Kentucky which is probably where they have lived for a large portion of their life. Having participants with different demographics would most likely change how they view driving and how not being able to affects their lives.

Summary

With the number of individuals who have experienced a TBI being so prevalent in America, there are many who experience driving cessation. Driving cessation has been recognized by many as a limiting factor in people's lives affecting their ability to participate in activities socially, participate in their regular routines, and affect their daily occupations. It is important to realize that there will be many different views of how driving cessation affects someone's life. Having an individualized view of how their routines and occupations have been affected will give healthcare professionals and families a better understanding of why driving is important to them. Having this information will give everyone a better understanding of why it is important to collaborate with individuals and realize what their goals are and the reasons behind them.

The next chapter will be focused on the research that has been found relating to this topic. General information on the population of the participants will be discussed such as diagnosis, setting, treatment, etc. This section will also discuss the role of the OT in this process with treatment, evaluations, assessments, and anything else related to this study and the participants.

Chapter 2

Literature Review

Introduction

This chapter will review current research on this topic. To understand how individuals who have experienced a TBI describe how not being able to drive has affected their routines and occupations, it is important to understand the different aspects of research. The first topic that will be addressed is general information about traumatic brain injuries. Next information about driving and driving cessation and supporting articles will be addressed. Information on routines and occupations will be discussed, followed by the role of OT in individuals with TBI. Research that has been done on this topic will conclude this chapter.

Traumatic Brain Injury

In order to understand how driving can affect a person's routines and occupations after experiencing a TBI, it is important to understand what a TBI is, how routines and occupations have an impact on a person's life, and how driving can impact an individual's life. A TBI is a type of acquired brain injury that occurs when a sudden trauma causes damage to the brain. There are two main causes of a TBI: the head suddenly and violently hits an object, or an object pierces the skull and enters brain tissue. The symptoms following a TBI range from mild, moderate, or severe. The symptoms generally include headache, confusion, dizziness, lightheadedness, vision problems, ringing in the ears, fatigue, mood changes, and difficulties with memory, concentration, attention, or thinking. Depending on the extent of the damage the symptoms may get worse over time or not go away. If the damage is extensive they may also present with more symptoms including, nausea, seizures, abnormal sleep patterns, and weakness in limbs (National Institute of Neurological Disorders and Stroke, 2013). In America, TBIs are very prevalent and affect millions of people yearly. According to Faul (2010), it is estimated that around 1.7 million people sustain a TBI every year. Of these numbers 52,000 pass away, 275,000 are hospitalized, and 1.365 million are hospitalized and released. Of all injury related deaths in the United States, TBIs constitute 30.5%. The leading cause of TBI is falling, which is highest among children aged 0-4 and adults 75 years and older. Motor vehicle accidents are the leading cause of TBI deaths, being highest in adults ranging from 20-24 years old. Traumatic brain injuries are most common in males ranging in age between 0-4 years old (Faul et al., 2010, p. 7).

After a person experiences a TBI, they should seek medical attention as soon as possible. Although there are some ways to lessen the effects, the individual will still require specific medical needs to prevent further injury. This can include ensuring proper oxygen to the brain and body, maintaining adequate blood flow, and controlling blood pressure. X-rays will also be done to check for bone fractures and spinal instability. For more severe cases the individual may require a CT scan. Individuals that experience a TBI may also require physical therapy, occupational therapy, speech therapy, psychiatry, and social support depending on their status (National Institute of Neurological Disorders and Stroke, 2013).

There are a variety of treatments available for a person that has experienced a TBI depending on their level of injury. There are acute and sub-acute treatments available. Acute treatment occurs immediately after the person experiences a TBI. During this

phase physicians will concentrate on removing blood clots that may be life threatening, clear airways, use medication to calm the patients and prevent seizures, relieve intracranial pressure, and develop support systems for the patients if necessary. Individuals with mild or moderate TBI's spend little time in the sub-acute treatment. During this phase, medical staff will evaluate the patient's impairments along with the probability of recovery. Doctors will also outline appropriate courses of action and treatment plans and assist in the patients and their families building the right team to help the individual during rehabilitation. The last phase is chronic and long term rehabilitation. During this phase, focus is on ongoing treatment and needs of the patient including; assistive technology, counseling, medications, physical therapy, speech therapy, and occupational therapy (Brain and Spinal Cord, 2011).

Driving and Driving Cessation

Driving can be described as an integral part of an individual's life. According to Buchanan and Wall (2010), driving is a task that requires various skills to be successful. These skills include physical, sensory, and mental abilities. According to Dazio (2008), physical abilities required for driving include physical strength, physical and mental stamina, muscle flexibility, range of motion, and coordination. Physical strength is needed in order to hold the body upright and control the steering wheel, maintain a sitting balance, control of the head, neck, arms, legs, feet, and hands, and to get in and out of the car. Physical and mental stamina, along with muscle flexibility, are required to be able to sit and drive for periods of time, focus on the task of driving, twist and turn to see other vehicles and pedestrians, and to move the head and neck side to side, back and forth, and up and down. Upper extremity range of motion and coordination are needed to hold and control the wheel, reach and manipulate controls, use turn signals and wipers, adjust mirrors, and quickly move the foot from the accelerator to the brake. Sensory skills include good distance and close vision and hearing. Distance vision is important to check for intersections, highway changes, and signs. It is also important to be able to determine distances needed for merging, turns, and changing lanes, notice highway and weather conditions, see approaching cars, observe and scan for safety hazards, and watch for pedestrians. Close vision is needed to see the closeness of other cars and people, distinguish between curbs and ramps, read road signs, maps, and other car features, and to see moving objects. Hearing is also an important skill to be able to hear approaching cars, inside car sounds for gas and other features, abnormal car sounds, children or other pedestrians, sounds like horns, trains, and sirens for emergency vehicles, and threatening weather conditions. Mental skills required to drive include the ability to quickly and correctly choose the best options in changing situations, react to prevent or reduce accidents or injuries, make the best decisions in certain circumstances, and recall and apply driving rules and regulations. Due to all the necessary skills and abilities, driving can be a very difficult task to participate in. With the limitations that a person who has experienced a TBI may face, it takes lots of training for them to learn to drive (2008).

Being able to drive has been described in multiple ways as having an effect on an individual's life. One of the more common themes found through research is that driving can be looked at as freedom for an individual. "More than simply a way to accomplish daily tasks, driving is imbued with a host of psychological meanings, including one's sense of autonomy, independence, and self-worth" (Horrowitz et al., 2002, p. 262). "Community mobility, whether achieved by driving or using other transport methods,

enables people to participate fully in life. Because modern life is constructed around the car, driving is an important life role for young people affording independence in accessing the community, access to social activities, and employment opportunities. Gaining a driver's license is one of the major rites of passage to adulthood experienced in our society, and as such has been described as integral to an individual's sense of self identity after TBI" (Liddle et al., 2012). In the two previous passages, driving is described as being not only important to a person being able to complete tasks, but also as a way to participate in life, be independent, and give meanings of self-worth. On the other hand, when an individual has to stop driving or experiences cessation of driving, it will impact their lives in different ways. "Many people see the ability to drive again as a crucial index of recovery. Stopping driving is associated with loss of social activities and depression, even when other forms of transport are easily accessible" (Hawley, 2001, p. 761). "Lack of transportation adversely affects one's ability to participate in desired occupations and can lead to social isolation. Cessation of driving has adverse effects on one's quality of life even when alternative transportation is available" (Buchanon et al., 2010, p. 2-3). When a person is forced to stop driving it can sometimes be sudden, leaving the individual feeling as if they don't have any alternatives. It can also cause depression, leaving the individual with a feeling of diminished quality of life, and feeling as if they have lost their independence.

Routines and Occupations

In order to understand this study, it is important to define routines and occupations, along with how they can impact an individual's life. Routines are "established sequences of occupations or activities that provide a structure for daily life" (American Occupational Therapy Association, 2008). Everyone participates in and has a set of routines that they may follow. They can range from a morning or nightly routine to a daily routine that is followed consistently. It is important for individuals to be able to fulfill their individual routines. When a person loses their ability to drive, their routines may be affected in a negative way. When a person's routines are interrupted, they may feel like their life is disorganized.

Occupation can be defined as "activities of everyday life, named, organized, and given value and meaning by individuals and a culture" (American Occupational Therapy Association, 2008). Occupations are a necessary part of every individual's life. They make up almost everything a person does throughout their day. Occupations can be described as leisure activities, working, playing, education activities, ADL's, and so on. The occupations that are important to someone are individualized. When a person loses their ability to drive due to brain injury, they may also be forced to change or stop occupations they found important.

Role of OT in Driving

According to Davis (2003), all occupational therapists possess the basic skill set necessary to help clients achieve and maintain community mobility. Davis states that driving requires readiness, skill, ability and competence. In the area of mental health, practitioners must consider safety and competence in community mobility. Rehabilitative occupational therapists can use a client's goal for driving in the fabric of the intervention. Occupational therapists' roles in driving will depend on the level of training and specialization they obtain. There are three main levels: generalist, advanced training, and specialized training. At the generalist level, occupational therapists working

with clients who want to drive will evaluate the client's sub skills and consider the implications of the evaluation. Generalists do not evaluate driving competence but will be able to provide resources and identify driving programs as needed. With advanced training, according to Davis, an occupational therapist will "evaluate the integration of and train clients in specific sub skills related to driving. Therapy interventions can be tailored to restore or modify performance skills, patterns, or activity demands that could affect driving" (2003). Last is the role of occupational therapist who has received specialized training. "With this training, an occupational therapist will have expertise in targeted clinical assessment, on-road assessment, driver training for novice drivers, and driver retraining. Along with this training they may prescribe and train clients to use adaptive driving techniques. They may also be able to establish protocols to determine driving competence and appropriate training as well as provide information and counseling" (Davis, 2003).

Role of OT and Traumatic Brain Injury

When working with individuals who have experienced a TBI, occupational therapists can play an important role. During the acute phase of care, the occupational therapist will work on neuromuscular re-education, trunk stabilization, and balance activities. Doing these types of activities will help them prepare for the postural stability necessary to complete self-care and home activities. When in the rehabilitation phase, occupational therapists will focus on activities of daily living, like dressing, eating, meal preparation, and anything else the individual may identify as important. The occupational therapist will also focus on addressing the cognitive and perceptual deficits like memory loss, difficulty concentrating, impaired judgment, and impulsive behaviors.

Once the individuals are able to go home, the occupational therapist may still work with them. They may consider home modifications, adaptive equipment, community mobility, and other factors that may be a barrier to them participating in daily life (American Occupational Therapy Association, 2011).

Current Research

There is currently little research that is related to the topic of routines and occupations as related to driving with a traumatic brain injury. Studies have been done about the quality of life after a traumatic brain injury (Johnston, 2005), ways to adapt (Hoogerdijk, 2011), and the likelihood of returning to driving after experiencing a TBI (Hawley, 2001). There have also been studies relating to how the elderly (Horowitz, 2002) and individuals with low vision adapt to driving cessation (Stav, 2008).

Johnston investigated "the relations between community activities and satisfaction with these activities, desires to change them, and global life satisfaction" (2005, p. 735). The study consisted of interviews that were conducted after the patients left rehabilitation. The study was conducted on individuals that had been hospitalized due to moderate to severe TBI. They used the Community Integration Questionnaire-2 and the Satisfaction with Life Scale. The study concluded that the individuals were satisfied with most of their community activities, but there were exceptions of things they would like to be able to participate in. Dissatisfaction with an activity correlated strongly with desire to change the activity, but general life satisfaction did not correlate with desire to change activities. It is important to realize how important it is to take into consideration the ways a person's life can be changed after a TBI and the types of activities they aren't able to take part in.

Hoogerdijk et al. (2011) studied how individuals with a TBI adapted after the injury. The participants of the study were interviewed twice and narratives were derived from each of the interviews. The results of the study showed that healthcare professionals should allow individuals with TBI to practice their skills and abilities in their own home and provide them with the required space to practice their skills in a way that is efficient and satisfying. This study is important because it looks at the adaptation process after experiencing a TBI. It is possible that while speaking with individuals who have had a TBI and can no longer drive, they may discuss how they have had to adapt. This adaptation process may take place in their routines and the types of occupations they participate in or how they get to the places they need to go.

The objective of a study by Hawley (2011) was "to determine whether patients who return to driving after head injury can be considered safe to do so and to compare the patient characteristics of those who return to driving with those who do not" (2001, p. 761). This research related to my study because it has a similar population of people who can and cannot drive. Adults that have experienced a TBI and their families were interviewed. They used the Functional Independence Measure and the Functional Assessment Measure to measure functional independence. The researchers concluded that although there may be problems that may impact driving, it should not prevent patients from returning to driving after a TBI. According to the study, patients should be assessed for both mental and physical status before returning to driving after a TBI (Hawley, 2011). There should also be clear and consistent advice given to patients about driving. This article discusses how difficult it may be for individuals to return to their driving role after a TBI. The level of difficulty may have an effect on how the

individuals being interviewed view driving along with how close they may be to resuming their driving role.

Liddle et al. (2012) "examined the loss of the driving role and explored the outcomes associated with driving cessation from the perspectives of key people involved within the process: people with TBI, their family members and involved health professionals" (2011, p. 79). The study used semi-structured interviews with 15 people who experienced a TBI and had driving cessation. The family members and the health professionals were also interviewed. The results of the study showed that driving cessation after a TBI is associated with emotional, identity, transport and participation related needs. The researchers also concluded that having an ongoing, individualized approach with information, support and practical experiences can improve outcomes of individuals after a TBI and their ability to cope with driving cessation. This study looks at the loss of the driving role and how the outcomes that the client wants to attain are achieved. Although this article does not directly address how the individuals described their loss and how it affects them, it does discuss how the individual and people working with the patient are affected.

Although an article by Horowitz, Boerner, and Reinhardt (2002) did not discuss individuals with brain injuries, it did describe the transitions that the elderly may go through when they experience driving cessation due to low vision. This study was done because there is not much research done addressing the psychosocial influences on the decision to stop driving. There were two exploratory studies done. The first study concluded that being older, female, more severely visually impaired and functionally impaired, and living in an urban area, was independently related to driving cessation.

The second study showed that the meaning ascribed to driving may influence the decision making process. These studies also showed that family members may have a role and influence on the decision making process. This study shows how when an individual has to stop driving it is not always the individuals decision, but can involve the family as well. Not being able to drive can have a major impact on an individual's life depending on how they view driving and the meaning it has for them.

Stav (2008) reviewed the evidence related to the elderly community mobility and driver licensure policies. The author concluded that "occupational therapists and occupational therapy assistants must recognize the influence of the cultural context, which includes the laws and policies of society because this context affects how older adults retain their driver's licenses and thus influences occupational therapy practice" (2008, p. 156). Overall, for occupational therapists to provide an effective intervention, it is important for the therapists to realize how the context and laws in that community affect an elderly individual's community mobility.

Summary

In order to gain a better understanding of the current research study general information about the major topics of the study have been covered. As previously stated, the current research that has been conducted has covered a variety of aspects that are related to driving and how traumatic brain injuries. Looking at the research that has been done, it is evident that there is no research discussing how an individual that has experienced a TBI would describe their roles and occupations related to not being able to drive. Following this chapter you will see the methods that will be used to conduct the study. This information will include an overview of the research design, how participants

will be chosen including exclusion and inclusion criteria, data collection methods, data analysis methods, and the verification methods.

Chapter 3

Methods

Research Design

This qualitative study used a phenomenological design. According to Creswell (2013), in qualitative research, "assumptions and interpretive frameworks are used to inform the study research problems that address the meaning of individuals or groups ascribed to a social or human problem. Phenomenological studies describe the common meaning for multiple individuals of their lived experiences of a concept or phenomenon" (p. 44, 76). In this study, the phenomenon is driving cessation and how it relates to TBI. In this approach, the main form of data collection is interviews.

Participants

Participants in this study were individuals who had a TBI. The inclusion criteria included the individual being over the age of 18 and their own legal guardian. The individual had to be working with an occupational therapist to regain their ability to drive. The occupational therapist to categorized the participant's brain injury as mild or moderate through personal judgment, expertise, and based on their cognitive evaluation. Participants were excluded if they did not have driving as one of their OT goals, if their cognitive status precluded their ability to participate, and if their cognitive status limited their ability to communicate during the interview. Gender, race, and religious background did not determine whether or not a person could participate in the study.

Recruitment

The prospective participants were identified by an occupational therapist that was currently working with them on driver rehabilitation. The occupational therapist gave the potential participant a flyer (See Appendix-A) that described the study and listed the contact information of the researcher. The participants were asked to contact the researcher if they wanted to participate in the study. Consent was gained from the participants at the time of the interview (See Appendix-B).

Data Collection

Once the participants had been selected and consented they underwent an interview process. The interviews took approximately half an hour and were held in private at Eastern Kentucky University, Cardinal Hill Rehabilitation Hospital, or a private location of their choosing. The interview questions pertained to how they viewed their participation in their daily routines and occupations related to driving after experiencing a TBI (See Appendix-C). During the one-on-one interview, notes were taken and with permission the interviews were audio recorded. A primary interview and a follow up interview was done with Joe in order to gain insight on some of the topics discussed and for him to have a chance to elaborate. Only one interview was done with Mary.

Data Analysis and Verification

After the interviews were conducted, they were transcribed verbatim by the researcher. The transcriptions were initially analyzed line by line using in vivo codes. "The process of coding involves aggregating the text or visual data into small categories of information, seeking evidence for the code from different databases being used in the

study" (Creswell, 2013). This resulted in 119 codes, which were each written on a notecard to allow sorting. Using an inductive analytic process, the codes were grouped into 14 different categories. Ultimately four themes emerged from the data.

The coded transcriptions were compared with each other to gain common themes between participants. Follow-up interviews were requested as a form of member checking. During the member checks for both participants, the data was reviewed with them including the themes and the codes. This gave them both a chance to confirm my findings and see if it was a true representation of what they said. For the first participant interview, a follow-up interview was done to confirm the data and to give the participant the chance to expand on their earlier interview. Another part of the verification process involved an external auditor. The research advisor reviewed the data with the primary investigator throughout the coding and the creation of the themes, along with their interpretations.

Summary

This chapter discussed the type of study that was done, which was a phenomenological design. The phenomenon that was studied was TBI's and how they affect an individual's routines and occupations related to driving. There were two participants in the study, that both met the inclusion and exclusion criteria. Both individuals were currently working with their occupational therapist to regain the skills necessary to drive. Data collection was done through audio recorded interviews. The interviews were transcribed and coded using in vivo codes. From those codes four themes emerged. In the next chapter, you will see the results of the data that was collected.

Chapter 4

Results

Description of Participants

Two participants were recruited for this study. Both participants met the inclusion criteria of being over the age of 18, being their own legal guardian, and currently working with an occupational therapist to regain driving skills. They were both referred to the study by an occupational therapist, and the severity of their TBI did not limit their participation in the research.

The first participant's name was Joe (pseudonym). He was a 27 year old Caucasian male. He acquired his TBI as a result of a motor vehicle accident. He was not able to drive immediately following his injury, but had since begun going to a neuropsychologist who was evaluating his ability to drive. At the time of the interview, he was also working with an occupational therapist on skills such as using peripheral vision, reaction time, and anticipation to regain his ability to drive.

The second participant's name was Mary (pseudonym), a Caucasian female in her forties. She also acquired her TBI in a motor vehicle accident. She continued to drive after her accident, however after getting into two additional accidents, her daughter took her keys away from her. It was at this point she realized she had some residual issues from her TBI that needed to be addressed, so she decided to get a driving evaluation. At the time of the interview, she was working with an occupational therapist on skills such as visual scanning, impulsivity, and reaction time.

Description of Themes

Four themes emerged from the data. Each is described below, using verbatim quotations from the participants as support.

Hoping to be a Better Driver

The first theme was "Hoping to be a better driver." This theme described how the participants felt about their driving skills and what they felt they needed to do in order to be better drivers. This included their feelings about getting evaluations, skills needed for driving, and factors that need to be considered to be better drivers.

Both participants wanted to ensure that they were ready to drive again before actually getting behind the wheel and driving, which is why they were participating in a driving evaluation with OT. Mary noted that getting a driving evaluation was a priority for her, when she said, "I had the opportunity to get another car but I want to do the driver evaluation." Mary also identified what her goal was in order to be a driver by saying "my goal is to have driver evaluation by 2014 and car by 2015 to be financially stable to get a car with no payments." Joe also felt like it was necessary for him to have a driver evaluation along with re-learning some of the skills needed to be able to drive and mentioned it during the interview by saying that he "wants to go to driver school to drive."

Both participants pointed out the various skills that it were important to work on in order for them to regain their driving. Mary stated "if you're not tracking correctly or your reaction time is off or whatever, I've learned to myself that classifies you as an impaired driver." She stated this after explaining that since her TBI she had been involved in two wrecks and has since identified these as two skills that need to be worked

on. Joe also identified skills that he needed to work on to improve his driving skills. He stated that he "needs to work on peripheral vision and speed determination" in order to be a better driver.

The participants anticipated they would be better drivers by making changes in their attitudes and views. For example, Joe identified two ways that he would become a better driver by saying that "when I was driving I was doing stupid stuff like I wasn't following the laws. Now I will and I know that for sure" and "I would severely take all of rehab into perspective and drive carefully." Mary also stated that, "I want the evaluation to make sure I have all my wits and stuff." Both participants know the importance of their rehabilitation and driving evaluations in the success of regaining their role as a driver.

Self-Realizations

The second theme was titled "Self-Realizations." This theme involved all of the things that the participants realized after their accident and after they lost their ability to drive. Mary stated that "when I got upset I said I would tell my clinical team I am so glad I am not driving because I feel like I would grab my keys and off I would drive" and "since coming to the clinic I've realized, yeah, I had issues." This symbolized some things that were eye openers to her once she could not drive. Joe said, "Feels bad knowing life is messed up because of what he did", and that he "learned his lesson the hard way." Joe had self-realizations about things that he should not have been doing when he was driving. Joe stated "I always felt I had to get somewhere by a certain time and when I didn't have people in the car I felt like I could get there a lot faster so I'd leave later"; "it was totally my fault and I realize that because the thing I was doing"; and

that he "used to change lanes without paying attention or signaling and driving really fast." He recognized that he should not have been partaking in these behaviors and says he wouldn't do it again.

Mary had a self-realization about how the expenses related to driving impact her. Mary stated that she "felt discouraged because I felt like if you don't save money you won't drive." She felt like there were a lot of things that she needed to be able to do before she would be able to drive, including handling the costs related to a driving evaluation, gas, upkeep of a vehicle, and buying a car. Since she did not have this money, she felt discouraged and like she may not ever be able to drive.

The participants also realized that their routines had not really been interrupted. Even though they could not drive, they felt that they were able to participate in their general routines and participate in the things they enjoyed doing. Even though they may not be able to drive, they both still got experiences and got to participate in some of the things they would normally do.

Although the participants felt their routines had not been interrupted, they still noted that regaining driving was important to them. Joe stated that, "it just kills me that I can't drive anymore." Driving was meaningful to him and important enough to him that he planned on being able to do again.

Being able to take myself anywhere and everywhere I want to go at anytime

The third theme was "Being able to take myself anywhere and everywhere I want to go at any time." The participants described disliking having to rely on others for their transportation needs and how it could be an inconvenience. Joe said, "my parents are my number one source of transportation", and "I pretty much enjoy driving all the time and prefer it over having a chauffeur." Mary stated that not being able to drive "hit home hard because I felt like I wasn't independent anymore" and "believed that with a car I could be independent and made that association." Both participants felt like they had lost some of their independence and like they could not always do the things they wanted to when they wanted because of it.

The participants described the things they currently did not have the ability to do due to their inability to drive. Joe said that "driving would help get a girlfriend" and how he currently isn't able to see his friends. Mary stated that she has "always volunteered, raised money, socializing but now everything is planned out and precise." Both participants described a variety of activities they would like to do but were missing out on because of their inability to drive themselves. Joe stated that "I used to be a worker. I still am but I just can't do work for a company no more." He mentioned that he was used to being a worker and taking himself to and from his job but how he can't do that anymore and how it makes him feel bad. He would like to pursue a job but wants to be able to drive and have his own transportation to and from.

The participants felt like their days had to be planned out if they wanted to do anything or go anywhere. Joe stated that he "felt isolated due to making plans ahead of time", and "everything has to be planned three days to a week ahead." Mary noted that she can no longer be the "free spirit" she described herself as being, because she has to make plans ahead of time anytime she wants to leave her apartment.

Feeling Cut Off from People

The fourth and final theme was titled "Feeling cut off from people" and described how the participants felt as if they did not have the opportunities to see the people they

would like to be able to see. This was characterized when Joe said that he "can't get out to socialize with people." Mary stated that she "had problems going back to socializing because she would standoff." Both participants in this instance felt like they did not have as many opportunities to see the people they would like to whether it is friends or family although they both felt as if their routines hadn't been affected. Joe said that he "can't spend time with son he thinks he deserves." He felt like he should be able to spend more time with his son and mentioned it multiple times throughout the interview, but due to his inability to get back home on a regular basis, he did not get to spend the time he would like to with his son.

Summary

Two participants were recruited for this research study. Four themes emerged from the interview data: Hoping to be a better driver, Self-realizations, Being able to take myself anywhere and everywhere I want to go at any time, and Feeling cut off from people. In the following chapter, I will address the research questions, the findings and how they relate to the current literature, clinical implications, limitations found throughout the study, and future research.

Chapter 5

Discussion

Review of Research Questions

This study sought to answer the question "How do individuals who have experienced a TBI describe the effects not being able to drive has on their routines and occupations related to transportation?" The participants of this study confirmed that not being able to drive does have an impact on their routines and occupations in several ways although during one part of the interview they felt their routines weren't affected.

A variety of routines and occupations were identified by the participants as affecting their ability to drive. Many of the affected occupations involved not being able to participate in activities with peers and family. These included not being able to go to local social events, and not being able to see some of their family due to the distance and inability to drive themselves. According to Buchanon et al. (2010), "Lack of transportation adversely affects one's ability to participate in desired occupations and can lead to social isolation" (p. 2). As mentioned in the interviews, the participants felt as if they were cut off from other individuals and in some cases felt isolated from others due to their limited ability to participate in the activities they would like. Inability to drive after TBI may lead to increased social isolation.

As seen in the interviews, community integration is an important part of both participants' views of being able to participate fully in life. According to a study done by Burleigh et al. (1997) that focused on the relationship of the degree of community integration to the life satisfaction of individuals with TBI, it was found that, "there is a significant relationship between life satisfaction and social integration" (p. 50). Both

individuals realized the importance of community and social integration for their own lives and their own satisfaction. Although they both expressed that their limited engagement was due to their inability to drive, being able to participate in these types of activities could possibly increase their satisfaction and quality of life.

The participants both noted that when they lost their ability to drive, they also felt like they lost a piece of their independence. A common theme between both interviews was that their routines and occupations were affected by their limited ability to participate in them. They mentioned a variety of things they enjoyed doing or used to do along with how their current inability to drive had caused them to have little to no participation. According to Liddle et al. (2012), "at least half of the population who sustain a severe TBI are unable to resume the role of driver. This can have a profound effect on the rest of their lives, potentially affecting participation in productive, family and social roles and activities" (p. 79). As demonstrated in the interviews, there are obvious limitations in participation when someone loses their ability to be a driver. These can include not being able to see your family, not being able to work, not being able to participate in local events, and having limited social participation.

Both participants described how driving was a major part of their independence, allowing them to do things on their own, not rely on other people, along with allowing them to participate in what they enjoy doing. Without their ability to drive, they felt like there was a loss of independence and autonomy in their daily lives that they both would like to regain. According to Horrowitz (2002), "driving includes a host of psychological meanings including sense of autonomy, independence, and self-worth" (p. 262). These

concepts of independence, self-worth, and autonomy were also identified by the participants as important and were negatively impacted by their inability to drive.

There are various reasons both participants felt as if they had lost their independence. For both individuals, driving was identified as something that allowed them to participate in what they enjoyed and gave them the opportunity to do what they wanted. According to Buchanon (2010), "driving allows people to participate in various life activities, including ADL's, IADL's, work, education, and other preferred activities within the community. Driving is a role that many take pride in and allows for freedom to explore and experience their environment. It enables occupation within the community and provides the opportunity for mobility and participation in desired and expected activities" (p. 2). Driving allows for an individual to be able to take part in many of the roles and activities they want to be able to do. If someone has to stop doing these tasks, they may feel like they have lost their independence due to all the types of activities they may have had to cease or have limited participation in.

Both participants gave examples of how they would like to see their daily lives changed after they regain their ability to drive. The common answer between both participants related to their involvement and participation in social interactions. Overall both participants would like to gain their independence back, which in turn would affect how often they would be able to participate in whatever occupations they choose. According to Liddle et al. (2012), "community mobility, whether achieved by driving or using other transport methods, enables people to participate fully in life. Because modern life is constructed around the car, driving is an important life role for young people affording independence in accessing the community, access to social activities, and

employment opportunities" (p. 79). It can be considered vital for the individuals to regain their driving role in order to be able to participate fully in life.

Clinical Implications

This study can help support occupational therapists who are working with individuals who are working on driving after TBI. Knowing what types of activities an individual views as important can help the therapist support their social engagement and participation. If the individuals cannot currently drive or will not be able to drive, the therapist can assist them with learning to use alternative transportation, along with assisting them in seeking opportunities to participate in activities they enjoy. According to Liddle et al. (2012), "occupational therapists are well placed to monitor and support role participation and facilitate exploration and learning to use alternative transportation travel for people with TBI. Community mobility should be a focus for assessment and intervention regardless of whether returning to driving may be a future option" (p. 87). It is important for occupational therapists to be able to help individuals participate fully in life and be able to engage with others within their communities whether they will be able to drive or not.

Through the results of this study, it was apparent that not being able to drive could be accompanied by psychosocial issues that may need to be addressed. Joe said that one aspect that he wanted to be able to do was drive himself to and from work. Work is not only a place where many social interactions occur, but also a place that may result in a sense of fulfillment and participation. When this role is taken away, there is a chance that depression may result. As mentioned in the interview with Mary, she began to feel isolated due to the inability to participate in social interactions on a regular basis. With

depression already being a symptom that can occur with individuals who have experienced a TBI, it is possible that limited social interactions can also trigger it. Gomez-Hernandez (2007) stated, "during the acute period after TBI, fear of job loss appears to be an important social factor in the development of depression. On the other hand, during the chronic post-TBI phase, a lack of close personal relationships and fear of job loss appear to be important factors associated with depression" (p. 1325). Considering how this may impact OT treatment sessions, it is important to realize that if there is an individual who has lost their driving role, due to the limited opportunities they may have for community involvement, depression is something that may need to be addressed or monitored as a possibility later on in their life. It is important for the therapist to incorporate as many meaningful tasks and opportunities for involvement

during treatment sessions.

Limitations

This study was limited by having only two participants. It is doubtful that data saturation occurred. Although the themes were representative of the two participants involved, with more data, the themes could have been strengthened or further developed. Also, due to the few participants, there was not a wide range of demographics represented in the data. Both participants were Caucasian and had acquired their TBI from a motor vehicle accident. The participants were also from the same geographical location. Because of this, many populations and types of individuals were not represented in this study, meaning the themes do not necessarily pertain to everyone who has had a TBI. Another limiting factor during the study was the exclusion and inclusion criteria. Participants were required to be currently working with an occupational therapist, but the

study could have been strengthened if individuals who had already regained their driving experiences and had the chance to reflect on their time not driving were also included. This would have also given more opportunities for more individuals to participate in the study. Additionally, being their own legal guardian was another criterion that was set in order to obtain consent from the individuals, but it precluded participation by some individuals. Removing these criteria though would've given the opportunity for more individuals to participate in the study.

Future Research

In the interviews with Joe, he mentioned how not being able to see his son was something he could not do as often as he would like because of his inability to drive. When he was able to go visit, he had to rely on his parents to transport him there and he still had a limited amount of time he could see him. For continued research, it would be interesting to learn how different individuals who have experienced a TBI describe their relationships with their families and if they have changed or not, while also gaining insight as to why they think they may have changed.

Additional research that could pertain to how individuals who currently are not working on driving with a therapist and know they will not be driving again would explain how they are coping with not being able to drive and what they are doing to still participate in what is important to them. This study could be used to give advice to other individuals experiencing the same thing on how to deal with the fact that they may not be able to drive again.

Conclusion

In conclusion, it is important to look at how the routines and occupations of an individual change, and how they view their experiences, after driving cessation due to TBI. These experiences may include feeling as if they have lost their independence, autonomy, spontaneity, and loss of participation in activities that they enjoy. There is current research that supports the results of the study and recognizes the importance of driving on an individual's ability to participate fully in life. Clinical implications for this study show that it is important for occupational therapist to be able to assist with the needs of individuals based on their limited ability to participate in community activities. Whether an individual will be able to drive or not, the therapist needs to be able to give them alternatives for participation along with community engagement. Knowing this information, a therapist will have to opportunity to help the individual not only find alternatives but also look for signs that may result from limited participation such as depression.

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amigos.php

Stav, W. B. (2008). Review of the evidence related to older adult community mobility and driver licensure policies. *American Journal of Occupational Therapy*. 62, 149-158. APPENDIX A:

Flyer for Recruitment

Looking for people to help with a study!

I am looking for volunteers to participate in a study. The study is focused on how someone who has a brain injury feels about driving

You will be asked to talk about your experiences of re-learning to drive. All interviews will be kept confidential.

To participate in the study you must:

- > Be over the age of 18
- > Working with an occupational therapist to regain the ability to drive
- > Have a had a brain injury that allows you to participate in an interview
- > Must be your own legal guardian

To participate in the study contact Stedmon Hopkins at:

Stedmon Hopkins14@eku.edu

Cell Phone: (502) 802-7410

APPENDIX B:

Consent Form

Consent to Participate in a Research Study

How do individuals who have experienced a TBI describe the effects not being able to drive has on their routines and occupations related to transportation?

Why am I being asked to participate in this research?

You are being asked to help with this study about how people who have had a brain injury describe the effects not being able to drive has on their routines and occupations related to driving. You are being asked to participate in this research study because you have had a brain injury and have a goal to drive again. If you take part in this study, you will be one of about 5 people to do so.

Who is doing the study?

The person doing the study is Stedmon Deon Hopkins at Eastern Kentucky University. He will be assisted by Dana Howell. There may be other people on the research team assisting at different times during the study.

What is the purpose of the study?

By doing this study, I hope to learn how people who have had a brain injury describe the effects not being able to drive has on their routines and occupations related to transportation.

Where is the study going to take place and how long will it last?

The research procedures will be done at the private location of your choosing. Cardinal Hill Rehabilitation Hospital or Eastern Kentucky University can be used. You will need to come to this location one time during the study. The meeting will take about 1 hour. If a follow-up interview is needed you will be contacted. This meeting will last about 30 minutes and is not mandatory.

What will I be asked to do?

The occupational therapist will give the possible participant a flyer describing the study and the contact information of the researcher. The participant will be asked to contact the researcher.

Once selected, you will be interviewed. The questions will be about how you view your participation in daily routines and occupations that relate to driving. During the interview, notes will be taken and with approval the interviews will be audio recorded. The recorded interviews will be transcribed. After the data is transcribed it will be coded and compared with other transcriptions to find themes. If a follow-up interview is requested you will be contacted. This meeting will last about 30 minutes. Like the original interview, this follow-up interview is not mandatory.

Are there reasons I should not take part in this study?

You may not qualify if you are under the age of 18 and not your own legal guardian. Also you will not qualify if you don't have driving as an occupational therapy goal, if your mental status affects your ability to participate, or if you are unable to communicate during an interview.

What are the possible risks?

To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life.

You may, however, experience a previously unknown risk or side effect.

Will I benefit from taking part in this study?

You will not get any personal benefit from taking part in this study.

Do I have to take part in this study?

If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any benefits or rights you would normally have if you choose not to participate. You can stop at any time during the study and still keep the benefits and rights you had before volunteering.

If I don't take part in this study, are there other choices?

If you do not want to be in the study, there are no other choices except to not take part in the study.

What will it cost me to participate?

There are no costs related to taking part in this study.

Will I receive any payment or rewards for taking part in the study?

You will not receive any payment for taking part in this study.

Who will see the information?

The data you give will be combined with other people taking part in the study. When we write up the study to share it with other researchers, we will write about this joint information. You will not be identified in the materials.

This study is private. That means that no one outside of the research committee will know that the information you give came from you.

However, there are some times in which we may have to show your information to other people. For example, the law may require us to show your information to a court. Also, we may be required to show information that identifies you to people who need to

be sure we have done the research correctly; these would be people from organizations like Eastern Kentucky University.

Can my taking part in the study end early?

If you decide to take part in the study, you still have the right to decide at any time that you no longer want to be a part of it. You will not be treated differently if you decide to stop taking part in the study.

The individuals conducting the study may need to end your participation in the study. They may do this if you are not able to follow the directions they give you, if they find that your being in the study is more risk than benefit to you, or if the agency funding the study decides to stop the study early.

What happens if I get hurt or sick during the study?

If you believe you are hurt or if you get sick because of something that is done during the study, you should call Stedmon Deon Hopkins at (502) 802-7410 as soon as possible. It is important you understand that Eastern Kentucky University will not pay for the cost of any care or treatment necessary because you get hurt or sick while taking part in this study. That cost will be your responsibility. Also, Eastern Kentucky University will not pay for any wages you may lose if you are harmed by this study.

Usually, medical costs that result from research-related harm cannot be included as regular medical costs. Therefore, the costs related to your child's care and treatment because of something that is done during the study will be your responsibility. You should ask your insurer if you have any questions about your insurer's willingness to pay under these circumstances.

What if I have questions?

Before you decide to accept this invitation to take part in the study, please ask any questions that might come to mind now. If you have questions about the study, you can contact the investigator, Stedmon Deon Hopkins at (502) 802-7410. If you have any questions about your rights as a volunteer, contact the staff in the Division of Sponsored Programs at Eastern Kentucky University at 859-622-3636. We will give you a copy of this consent form to take with you.

What else do I need to know?

You will be told if any new information is learned which may affect your condition or influence your willingness to continue taking part in this study.

I have thoroughly read this document, understand its contents, have been given an opportunity to have my questions answered, and agree to participate in this research project.

Signature of person agreeing to take part in the studyDate

Printed name of person taking part in the study

Name of person providing information to subject

APPENDIX C:

Interview Questions

How Individuals who have experienced a TBI describe the effects not being able to Drive has on their Routines and Occupations related to Transportation.

Interview Questions

- 1. Tell me about your experiences driving.
- 2. What does driving mean to you?
- 3. Is regaining your driving ability important to you? If so why?
- 4. Do you feel that your life has changed since you've lost the ability to drive? Why or why not?
- 5. What type of things did you enjoy doing that involved driving?
- 6. Did you have any daily routines interrupted when you stopped driving? If so what?
- 7. Are there any activities you have had to stop or change when you stopped driving? If so what?
- 8. Are there any aspects of your life you have had to stop because of the inability to drive? If so what?
- 9. How would you describe your participation in your routines once you lost your ability to drive?
- 10. Are there any things you are looking forward to doing if you are able to drive again? If so what are they and why?
- 11. If you regain your ability to drive, what do you look forward to being able to do?