Lived experience of individuals who had a disruption in ability to drive

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Lived Experience of Individuals Who Had a Disruption in Ability to Drive

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An Independent Study

Submitted to the Occupational Therapy Department

of the

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In partial fulfillment of the requirements

for the degree of

Master of Occupational Therapy

Grand Forks, North Dakota

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Approval Page

This Scholarly Project Paper, submitted by Shelby Hoskinson, MOTS and Graydon Larsen, 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.

Faculty Advisor

April 5, 2017

Date
PERMISSION

Title: Lived Experience of Individuals Who Had a Disruption in Ability to Drive

Department: Occupational Therapy

Degree: Master of Occupational Therapy

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Purpose: Driving is both a highly valued occupation within the United States and an occupation that is frequently addressed by occupational therapists. According to the CDC (2017) there are more than 40 million older drivers ages 65 years or older within the United States. There is extensive research pertaining to the value of the occupation of driving as well as evaluation and treatment approaches for the occupation of driving following an injury or illness. While driving is sometimes the best option after an injury or illness, there are situations when returning to driving is not realistic or safe for the individual or others on the road. However, there is less research about the role that occupational therapists play for older adults during the transition period following a driving cessation.

Methodology: A phenomenological qualitative research design was used to gather information about individuals’ experiences related to driving disruption or cessation for older adults. Purposive sampling was utilized to locate and select subjects who met the inclusion criteria from a local retirement community/assisted living facility within the western United States. Two graduate level occupational therapy students who were trained in qualitative research used semi-structured interviews with open-ended questions. The graduate students and their graduate advisor using the Moustakas (1994) approach manually analyzed data from interviews. The occupation-based model, MOHO, was utilized to create an occupation-based understanding throughout the research study.

Results: As a result of data analysis, five themes were identified. The themes are as follows 1) driving is an important factor that influences life roles, 2) making sense of driving cessation, 3) strong emotional responses are associated with driving and driving disruption, 4) the importance
of context in meeting needs following driving disruption, and 5) familial influences on driving disruption and transportation needs.

Conclusion: The purpose of this study is to learn about individual’s experiences and perceptions related to driving disruption or driving cessation for adults aged 55 or older. Based on the results of this study and the existing research, it is clear that occupational therapists have the skills to assist individuals following a driving cessation. Occupational therapy practitioners can utilize the firsthand information gained through this study as they prepare individuals and help them adjust to a cessation or disruption in driving.
CHAPTER I

INTRODUCTION

Rationale

Driving is an occupation that receives a great deal of attention within the occupational therapy profession for several reasons. One major reason being the life satisfaction and independence that driving brings to everyday life. Often, occupational therapists’ role within the driving realm include in-office driving evaluations, on the road driving evaluations, and driving rehabilitation following an injury or illness. Due to the complex nature of driving, the various skills required for safe driving, as well as the high level of occupational value that driving provides for an individual, the profession of occupational therapy is well suited to address driving. Occupational therapy practitioners are trained in evaluating and treating the visual, perceptual, motor, and cognitive skills, among others, necessary for safe driving. Additionally, occupational therapists have extensive training and knowledge about psychosocial factors associated with driving as well as the value, independence, and access to other meaningful occupations that the occupation of driving provides. Furthermore, occupational therapy practitioners also have skills to assist individuals adjust and continue performing daily occupations during difficult transition points in life. One such time of transition may be when an individual is no longer able to drive.

While driving is an occupation commonly treated by occupational therapy practitioners, there are instances when continuation of driving is not realistic and unsafe for both the individual as well as others on the road. However, occupational therapy practitioners rarely play a role in the vital transition period following a driving cessation. This transition period can be filled with highly emotional experiences as well as need to fill various occupations and life roles. Every
year older adults lose their licenses and therefore their driving privileges, and the increased risk of fatality from a crash increases for drivers starting at ages 70-74 (Centers for Disease Control and Prevention [CDC], 2017). However, this does not account for those individuals who do not feel safe driving and make the personal choice to cease driving. There continues to be a lot of older drivers on the road today. According to the CDC (2017) there are more than 40 million older drivers ages 65 years or older within the United States. So, while occupational therapy is well suited for both treating individuals during essential transition periods and the occupation of driving, there is limited practitioners, research, reimbursement, and resources, related to the field of occupational therapy following a driving disruption or cessation for older adults.

**Theoretical Framework**

The Model of Human Occupation (MOHO), an occupation-based and client-centered model, helps to explore and explain how value and meaning are brought to life through human occupation (Turpin & Iwama, 2011). Furthermore, MOHO provides a focus for and a therapeutic reasoning process for how occupational adaptation occurs (Kielhofner, 2008). The main components of the person within MOHO include volition, habituation, and performance capacity. These components will help to inform how driving is experienced in terms of motivation, pattern, and performance. In this study, driving is examined as an occupation that provides both meaning in life as well as access to other valued occupations. MOHO helps to explore every component of driving in an integrated and holistic manner. Furthermore, MOHO is also used to explain more fully the lived experience of driving and driving disruption within individuals (Turpin & Iwama, 2011).

**Statement of the Problem**
As stated above, driving is often a focus of occupational therapy practitioners in helping individuals either regain their driving abilities or evaluate their safety and effectiveness.

Therefore, there is varying degrees of literature present on the value of the occupation of driving, the benefits such as access to other occupations, and driving rehabilitation. However, there is much less research in the occupational therapy literature as well as a gap in the real world, about occupational therapy's role in treating individuals during the transition period following a disruption or cessation in driving. Additionally, there is less research on experiences and individual perceptions of a cessation in driving for older individuals. Besides the lack of research in the occupational therapy literature, there is also a lack of understanding among practitioners, clients, families, and reimbursement agencies about the strategies and resources used by practitioners during the transition period following a cessation in driving. Therefore, The Lived Experience of Individuals who had a Disruption in Ability to Drive will fill the gap by providing first-hand information about individual experiences during this vital transition period.

Assumption

The primary assumption of this research is that the information provided by the participants will yield useful information to occupational therapists for providing driving rehabilitation services and/or post-driving recommendations to individuals who have experienced a driving disruption.

Score and Delimitation

The exact delimitation was utilized by the researchers to benefit the study and participants, provide trustworthiness, and for access and convenience purposes. The justification for the need of this study is the fact that there is a gap in everyday practice as well as the occupational therapy literature about occupational therapy services provided following a
cessation in driving. However, the even greater justification for the need of this study is the fact that individuals who experienced a driving disruption are missing out on the skills and expertise of occupational therapy practitioners in either a direct or consultative role. This study took place within a rural area in the western United States between September and December of 2016.

**Importance of the Study**

This study will contribute to the occupational therapy literature by providing real-life experiences of individuals who have had changes to their driving status. These experiences will allow therapists to understand the feelings associated with driving disruption, the needs an individual may have following a disruption, the needs that the family may have, and the recommended supports that should be put in place. Additionally, occupational therapists will also better understand the impact driving has on occupational participation and the far-reaching effects driving cessation presents.

**Definition of Terms**

It is prudent to operationally define common terms that are used within this research study. Within the boundaries of this study, driving disruption refers to a temporary or permanent cessation of driving, or a restricted license due to unsafe driving ability as a result of injury or illness. Driving cessation is defined as an element underneath the umbrella of driving disruption and refers specifically to stopping driving due to any number of reasons including but not limited to illness, injury, or personal reasons. Driving cessation and driving disruption can be used synonymously throughout this study. Phenomenology can be defined as a research method to gain an understanding of human consciousness and awareness (Merriam-Webster, 2017).
CHAPTER II

REVIEW OF LITERATURE

Introduction

Engagement in meaningful and valued occupations support life satisfaction and meaning in life (Eakman & Eklund, 2012). The occupation of driving is classified as an Instrumental Activity of Daily Living (IADL) in the *Occupational Therapy Practice Framework* (OTPF) (American Occupational Therapy Association [AOTA], 2014). This IADL is important to the participation in and completion of other meaningful occupations for older adults. Lee, Steinman, and Tan (2011) found that non-drivers or limited drivers aged 65 years or older were less likely to engage in volunteer activities. Furthermore, volunteering was strongly associated with lower mortality for individuals who were no longer driving or limited in driving (Lee et al., 2011). Pachana, Leung, Gardiner, & McLaughlin (2016) found that driving cessation in older women was associated with lower levels of social interaction and engagement in social activities. This evidence supports the fact that driving is an essential occupation for engagement in other meaningful activities for older adults. In addition to life satisfaction, meaning in life, and access and engagement in other occupations, independence and community integration for older adults is highly correlated with the occupation of driving. Extensive literature is available on the occupation of driving. Specifically, literature related to driving rehabilitation, skills necessary for driving, and the individual meaning surrounding driving. However, there is less research focused on individual experiences of driving cessation, or strategies used by occupational therapists to prepare older adults for driving cessation. Therefore, the aim of this study is to learn about individual perceptions and experiences related to driving disruption or driving cessation for adults aged 55 and older.
Driving

It was estimated that older drivers (65+) made up 18% of all licensed drivers in 2014, a number that continues to rise as the U.S. population ages (National Center for Statistics and Analysis, 2016). Thus, the need for occupational therapists and other health care providers to support and address the occupation of driving in order to support independence, life satisfaction, community integration, socialization, and engagement in additional occupations for a large portion of the U.S. population is apparent.

The implications of age-related changes along with common conditions affecting older individuals are alarming for safety during driving. In 2014, a total of 4,192 people aged 70 years or older died in motor vehicle crashes (Insurance Institute for Highway Safety [IIHS], 2016). While this number is down since 1997 by 29% it has rose in one year’s time from 2013 to 2014 by 2%. While these statistics are somewhat promising due to a decrease in deaths of people aged 70 years and older, this age group is keeping their licenses longer and driving more miles than in the past. Additionally, the IIHS (2016) points out that per mile traveled, fatal crash rates have increased starting at the ages of 70-74 and peaking at age 85. Thus, there is a need for occupational therapists to not only address skills associated with driving and the occupation of driving for older adults but also adults facing implications associated with diseases or conditions that may lead to a cessation in driving.

A Framework to Explore Driving: The Model of Human Occupation

An occupational therapy perspective values the meaning, sense of satisfaction, and purpose that engagement in daily occupations brings to everyday life. The Model of Human Occupation (MOHO), an occupation-based and client-centered model, helps to explore and explain how value and meaning are brought to life through human occupation (Turpin & Iwama,
Furthermore, MOHO provides a focus for and a therapeutic reasoning process for how occupational adaptation occurs (Kielhofner, 2008). The main components of the person within MOHO include volition, habituation, and performance capacity. Each separate component is interrelated, makes up the total person, and are influenced by the environment. Volition, habituation, and performance capacity explain how human occupations are motivated, patterned or organized, and how objective and subjective performance occur, respectively (2008). These components will help to inform how driving is experienced in terms of motivation, pattern, and performance. The environment, another essential aspect in MOHO, provides a complex and multilayered background for which all occupation occurs. Specifics of the environment include the spaces humans utilize, the objects used, the people they interact with, and possibilities and meanings derived from engagement or doing (2008). Other important aspects such as occupational identity, occupational value, and the result, occupational adaptation, along with the therapeutic reasoning process provide therapists with an anchor to build assessment and intervention planning off of to support daily occupations, such as driving (Turpin & Iwana, 2011; Kielhofner, 2008). Models are an integral part of the occupational therapy profession and in supporting therapists in providing the best client-centered care possible. In this study, driving is examined as an occupation that provides both meaning in life as well as access to other valued occupations. MOHO helps to explore every component of driving in an integrated and holistic manner. Furthermore, MOHO is also used to explain more fully the lived experience of driving and driving disruption within individuals (Turpin & Iwama, 2011).

**Personal Aspects of Driving**

**Volition.** As Kielhofner (2008) describes there are three separate aspects that make up the personal component of volition within MOHO; values, interests, and personal causation. As
demonstrated above by Lee et al. (2011) and Pachana et al. (2016), driving supports engagement in other occupations such as volunteer activities as well as social participation. The engagement in other occupations provides validity to the volitional concept within MOHO, because it further supports interests and values. In addition, driving helps to support independence in life. These two factors, supporting engagement in other occupations and independence in life, form the basis for motivation for many individuals, no matter the age. The ability to jump in a vehicle and drive to a vast array of desired locations is fed by people’s individual motivations, and therefore volition.

The component of personal causation is affected by how a person views their self-efficacy in relation to engagement in occupation (Kielhofner, 2008). Driving is a complex task that requires a variety of skills. Not surprisingly, driving is even classified as the most complex IADL (Radomski & Trombly Latham, 2014). This is due to the many skills required; physical, visual, perceptual, psychological and cognitive skills. In addition to the variety of skills, it is also imperative that the driver is able to integrate these skills quickly and dynamically. Therefore, it is concerning that any number of injuries or disease processes can affect these skills. Even in the absence of injuries or disease processes, normal aging affects both skill integration and the skills themselves, thus creating a concern for safety, occupational performance, and the individual's sense of personal causation.

**Habituation.** Driving is an occupation that becomes routinized in nature; meaning that specific aspects of driving become and are habitual. For example, putting on a seatbelt or always taking a familiar route are engrained into the occupation of driving through repetition for individuals. Kielhofner (2008) identified three types of habits, habits of occupational performance, habits of routine, and habits of style that change over the course of the lifespan. For
example, taking a familiar route is a habit of routine because it explains how a person uses time and space to make the occupation routinized, but this habit changes as the person is required to take new routes due to changes in life roles (Kielhofner, 2008). Due to the habitual nature of driving, a disruption in driving can cause even more disruption to daily life roles, routines, and rituals. In addition, driving is seen as a sign of independence for a number of people, and the loss of the privilege to drive is seen as a loss of independence to participate in other meaningful occupations. This leads to occupational deprivation, social isolation, and symptoms of depression.

Eakman & Eklund (2012) explored the life satisfaction of individuals and found a positive correlation between participation in meaningful activities and level of life satisfaction. They further found that occupational value was also a determining factor in satisfaction felt with participation. Additionally, the authors postulated that personality factors such as conscientiousness and emotional stability contributed further to a person’s level of life satisfaction. In this sense, driving fulfills the habit of occupational performance because the authors point out that how people habitually perform the occupation leads to life satisfaction (Kielhofner, 2008). This would suggest that engagement in occupations such as driving supports life satisfaction and provides meaning to the roles that we fulfill on a daily basis. Additionally, those occupations that are habitual in nature and become internalized provide a continual sense of emotional stability and life satisfaction.

Chihuri et al. (2016) summarized that a person’s general, social, and physical health declines at a more rapid rate following cessation of driving when compared to older adults who continue to drive. Furthermore, depressive symptoms increase as occupational and social participation decreases. This information suggests that when an occupation such as driving is
disrupted, it becomes the source of depressive symptoms and declines in health. This can be even more devastating for the client because an occupation that once was taken for granted due to the routine nature, is now the source of the problem. This describes a habit of style, because it explains how the person functions within the world over the course of the lifespan (Kielhofner, 2008). Choi and DiNitto (2015) also found that non-driving adults both showed an increase in depressive symptoms and a decrease in overall health when compared to adults who currently drive. These results were also tied to the amount of walking a person could do around their community to participate in social activities as an alternative to driving.

Betz, Jones, Petroff, & Schwartz (2012) found that most clinicians recognize that driving is an important occupation that fits with other health promoting occupations, but also found through patient reports that their clinicians did not know whether or not they were driving or had the ability to do so safely. However, patients did feel that it was a responsibility of the clinician to ask for this information as a part of the overall occupational profile. Chacko, Wright, Worrall, Adamson, & Cheung (2015) also recognize the importance of driving as an occupation as well as its importance to the independence of an individual in accessing other resources, a point which was also made by Lee et al. (2011). The authors specifically mentioned the importance of driving as an occupation used to support rural-dwelling individuals’ participation in other meaningful occupations. Therefore, the habitual act of driving supports client’s engagement in additional meaningful occupational roles.

Liddle, Fleming, McKenna, Turpin, Whitelaw, & Allen (2012) postulate that driving is of great importance to participation in life roles associated with family and social lives for young people in particular. They further discuss that cessation can affect a person for the rest of their life, which consequently has far more reaching effects on younger persons. For young people,
employment is more of a factor than with older people, whereas Lee et al. (2011) state that volunteerism is of greater importance to older people. Additionally, the issuance of a driver’s license is seen as a rite of passage. Therefore, the occupation of driving seems far more important to the younger generation (Liddle et al., 2012). The implications of driving as an everyday task, the roles that are supported through driving, and other factors enhanced by driving, such as employment, point to a need for health care professionals to consider the habituation of driving as an essential component when analyzing driving abilities or preparing individuals for cessation of driving.

**Performance Capacity.** There are few tasks that involve the number of skills, abilities, and input from a variety of different body systems than that of driving. Consequently, a disruption in some way to any number of these skills or abilities can have a lasting influence on the ability to drive.

Older individuals can expect age-related changes in the sensory, vestibular, nervous, musculoskeletal, cardiovascular, and cognitive systems (Radomski & Trombly Latham, 2014). Specifically, of concern are age-related vision and cognitive changes. Radomski & Trombly Latham (2014) found that 18% of older adults experience visual impairments with deficits in acuity, light/dark accommodation, night vision, color vision, and musculature affecting smooth eye movements. Age-related cognitive changes include intelligence, problem solving, abstract reasoning, memory, memory processing and attention. The authors also point out that the most noticeable cognitive changes occur after the age of 70. Due to the complex nature of driving, age-related cognitive changes could play a role in driving cessation or limitations in driving for older adults.
Common conditions that typically affect older adults – such as stroke – may play an even larger role in the occupation of driving, thus affecting independence, life satisfaction, and engagement in further meaningful occupations. Radomski & Trombly Latham (2014) found that several key factors may play a role in resuming driving following a stroke. These factors include younger age, higher functional status, and higher scores on visual attention tasks (2014, p. 1027).

Chihuri et al. (2016) found several studies indicating that not only does a decline in health status typically lead to a change in driving status, but that a loss of driving privilege itself leads to a decline in health status. It seems to be a two-way street. Driving cessation has been shown to correlate with poorer health status; what is unclear in the literature is whether the decline in health is what leads to driving cessation or if driving cessation leads to a decline in health. It is a complicated and not well understood issue. Liang, Gustafsson, Liddle, & Fleming (2015) further indicated that there is a correlation between health decline and driving cessation. They found that physical, cognitive, and behavioral changes could all lead to unsafe behaviors behind the wheel. A person’s overall functional status in a number of areas is a strong indicator as to whether or not they are able to perform the tasks associated with driving.

Choi, Adams, & Kahana (2012) measured characteristics of participants that led to driving cessation such as comorbidity, functional and cognitive impairments, and visual impairment. Participants who had stopped driving were older, had higher rates of functional and cognitive impairments, and had more comorbid diagnoses than their currently driving counterparts. There were also higher rates of glaucoma, cataracts, and other visual impairments. Visual impairments are a major reason for a person to stop driving or to have never been licensed to drive to begin with, a point which was emphasized in a study by Gallagher, Hart, O’Brien, Stevenson, & Jackson (2011). It is clear from the literature that the complex nature of driving
and the even more complex nature of the human body and the insults and injuries that can happen to it are major factors in the difficulties that come with deciding when a person should or should not be driving.

In addition to the objective components within the different body systems, the client’s subjective experience of these insults or injuries also affects whether a person should or should not be driving. In a narrative reflection on their respective experiences regarding driving and driving cessation, Liddle, Gustafsson, Mitchell, & Pachana (2016) explain that there are many factors that can lead to unsafe behaviors behind the wheel, and that age and medical diagnoses are not always good predictors of a person’s ability to drive. Rather, it is multifaceted and not easy to predict whether or not a person can or should be driving following an injury, illness, new diagnosis, or another medical event or emergency. There is no way to easily know or predict if or when a person should stop driving. There are many mixed feelings about these issues from providers, patients, and their families and how to best approach the subject of driving and discuss openly the needs of each person as pertaining to the safety and well-being of all involved.

Environmental Aspects of Driving

Social. The occupation of driving both supports social engagement, as well as being a social experience in nature. Many first time driving experiences take place with friends and family members in the social context. In addition, driving may impact or add a dimension to social roles that one fills. For example, a mother or father may always fill the role of driving when on family outings, thus affecting social perceptions of oneself and of family members.

Family member’s experiences. Along with the importance of driving in the lives of individuals, the role of a driver has an effect on other members of the family as well. If one
member of the family is seen as the driver, the one who takes others to where they need to go, it can be a difficult transition if the driver role has to be filled by another member of the family.

Liang et al. (2015) explored strategies used by family members to aid in the process of driving cessation, including when and how an individual should stop driving. The same authors, in an additional study on family member experiences, found that family members experienced frustration, strain, and ultimately acceptance of the driving disruption in their family member following a traumatic brain injury (TBI) (Liang et al., 2016). Similar results were found by Liddle et al. (2012), who found adjustment for individuals and family members to the loss of driving to be extremely difficult for both the person with a TBI as well as their family. These results suggest that there is a lack of overall information regarding how to help families deal with and understand the process of aiding a family member who is going through a disruption or complete cessation of their driving abilities.

Chacko et al. (2015) described the issues family members had with the inconsistencies in the process of taking away the driving privileges of a person. Experiences varied widely from a person being told they could no longer drive by a health care provider but keeping their license to a person’s condition being reported to the licensing agency and their license being revoked. The lack of general consensus on the process led to frustration on the family member’s part and questions as to what their role is in the process.

Connell, Janevic, & Kostyniuk (2012) found that adult children were typically the ones who told their family member to cease driving rather than waiting for a health professional to make the recommendation. Liddle, Tan, et al. (2016) found similar results when interviewing people with dementia, their family members, and several health care providers. Family members were equally as frustrated as those with dementia with the challenges faced following driving
cessation or disruption. It is a difficult and confusing time for all parties involved. These results illustrate the difficulties with the unclear procedure following the recommendation that a person should no longer drive and with the enforcement of driving cessation by family members, healthcare providers, and/or authorities.

Physical

Due to the nature of driving, the physical environment can be a complex concept. The outside physical environment is in a constant state of change as a person navigates and maneuvers their vehicle. The inside of the vehicle is often a more constant environment that can either support or hinder effective and safe driving. Furthermore, the rural or urban environment may have a large impact on a person's ability to drive safely and their access to driving alternatives following driving cessation.

Access to community mobility in rural areas following driving cessation. For those who cannot or do not drive, it can sometimes be difficult to find alternative means of transportation. While options such as buses, trains, and taxis exist, they are not always readily available in all areas, especially rural areas. This can make it even more difficult for people to get around when driving is not an option, which can lead to isolation and lack of occupational participation. Currently one-fifth of the U.S. population lives in rural areas where living in a rural setting has several implications (Caldwell et al., 2016). For example, Caldwell et al. (2016) point out that access to health care may be limited due to exposure to unequal social conditions, thus supporting health care disparities. The term rural can be a complex concept to grasp due to the many aspects that separate rural and urban. For example, rural can be defined in terms of population size, industry, or culture. Cromartie and Bucholtz (2008) in an article through the United States Department of Agriculture point out that it is often best to define rural as the
territory not included in the definition of urban. In addition, asking the correct questions determines how rural should be viewed in order to best answer the research questions. For example, should administrative boundaries, land-use, economic influence, or general population be considered when determining between rural and urban (Cromartie & Bucholtz, 2008). In terms of this study, rural will be defined in terms of population size, culture, and access to mass transit.

Johnson (2008) found that those who had a large support system, i.e. family and friends, tended to be more involved in their community, participate more in their valued occupations, and have better access to alternative means of transportation. Those with smaller networks tended to feel isolated and were more limited in their access to and participation in occupations. They were also more likely to resume driving even when unsafe, feeling that they had no other choice. Gallagher et al. (2011) found similar results, explaining that participants had many difficulties meeting their transportation needs. This was particularly evident for individuals residing in rural areas. This group experienced social isolation and feelings of loneliness as a result of not being able to readily access transportation. These findings show that the difficulties experienced when dealing with driving disruption increase when a person resides in a rural area versus an urban area.

**Cultural, Economic, & Political**

The cultural, economic, and political factors surrounding the occupation of driving are highly individualized. Culturally, there is an unfortunate trend when it comes to the media portrayal of older drivers. While age is not a predictive factor of driving ability, it is stereotypically portrayed as such. For example, Liddle, Gustafsson, et al. (2016) report that the media will focus on the driver if an older driver is involved in a crash, but the same is not true if
the driver is younger. This perception creates an unfair view of older drivers and older people in general, creating widespread ageism. This is a huge disservice for older drivers, particularly for those that have been safe drivers their whole driving lives who are asked to stop for reasons unrelated to accidents or other incidents.

Economically, the average cost of driving a sedan in 2016 – which includes insurance, gasoline, registration/licensing, and general maintenance – ranges between 47.6 cents per mile to 75.4 cents per mile depending on distance driven annually (Automobile Association of America [AAA], 2016). While this is lower than in years past due to the decline in fuel prices, the costs can add up, especially if you have higher insurance premiums due to accidents or tickets. Accidents and tickets are also an additional cost not included in these calculations. Costs also go up if you drive a minivan or an SUV (2016).

**Approaches to Driving**

It is widely accepted that in some cases the safest and best answer for clients is to give up their driving license and stop driving altogether. While this can lead to feelings of isolation and fear, losing a driving license does not mean that individuals have to withdraw from meaningful activities or refrain from social activity. Consequently, there is a necessary call for action for occupational therapists to help clients reintegrate back into society and regain participation in meaningful occupations.

**Driving Rehabilitation**

While cessation of driving is often the best option, return to driving is sometimes a viable option for those individuals who suffered a change in health status, but then were able to make sufficient adaptations in order to return to driving. For these individuals, the transition back to driving may be faced with physical as well as psychosocial challenges. Occupational therapists
may play a large role in helping these individuals regain their independence through
development and implementation of driving rehabilitation or community mobility programs.

**Community mobility and driving rehabilitation programs.** The American
Occupational Therapy Association (AOTA) along with The National Highway Traffic Safety
Administration (NHTSA) have acted on the need of driving resources, by producing the Older
Driver Initiative (AOTA, 2016). The NHTSA have recognized the lack of occupational therapy
practitioners or programs to help support older driver’s needs. Therefore, they funded AOTA’s
Older Driver Initiative to identify barriers to the development of driving and community mobility
programs. The aim of the Older Driver Initiative “is to build the capacity of occupational therapy
programs to address the needs of at risk senior drivers, with the goal of ensuring IADL
independence, including driving, for as long as safely possible” (AOTA, 2016).

Stav (2012) conducted a qualitative study to better understand occupational therapists’
experiences with developing driving rehabilitation programs. The results of this study indicate
that practitioners recognize that much more than clinical skills are necessary for the success of
occupational therapy driving rehabilitation programs. Stav (2012) identified the barriers to
development and sustaining driving rehabilitation programs as staffing, interdisciplinary conflict,
funding, and certification. Some themes that therapists identified as necessary for the
development and sustainment of driving rehabilitation programs include institutional support,
clear role expectations such as who is in charge of ancillary duties including promotion and
marketing, and continued professional development (Stav, 2012).

In 2014, Stav conducted a systematic review to determine the effects of policy and
community mobility programs on occupational performance in older adults. Several factors were
examined within this study, including driver licensing policy, driving cessation programs,
community mobility programs, and walkable communities. Stav (2014) found that although several states have policies to identify at-risk drivers, reduce crashes and improve safety for older drivers, there is inconsistencies in both the outcomes of the policies as well as the policies themselves varying state by state. In terms of driving cessation programs, Stav (2014) found that driving cessation is related to declines in overall health and that support group intervention is helpful to assist older drivers transition in terms of self-efficacy and preparedness. In addition, that educational health promotion programs for community mobility and group transit training can be used as useful intervention strategies to support community mobility among older drivers.

Lastly, Stav (2014) determined through the systematic review that walking in terms of community mobility varied greatly depending on the physical environment. For example, those who lived in areas with high levels of density and in rural locations had more limitations for walking as a form of community mobility. The results of this study imply the need for occupational therapists to address community mobility as a concern for older drivers as well as through wellness programing and direct intervention for individuals who are or are not able to return to driving.

As discussed above, several factors impact an individual's ability to drive safely. Stroke, a relatively common incident, has a significant impact on these individuals return to driving. Following a stroke, individuals are often faced with several challenges and the need to adapt daily living situations to continue to achieve occupational competence as described in MOHO. Montgomery et al. (2014) are currently conducting a two-year mixed-methods study to evaluate a community navigation intervention in an outpatient stroke clinic. This proposed study may help to inform occupational therapists providing comprehensive care to stroke patients. In addition, this proposed study will also help to inform the actualization of care to stroke patients within
small urban and rural communities (Montgomery et al., 2014). In addition to stroke, other conditions also have an impact on driving such as Multiple Sclerosis (MS). Archer, Morris, and George (2014) explored how current services, supports, and protocols in driver assessment and rehabilitation impact people with MS and their families in South Australia. The results of this study indicate that symptoms related to MS such as difficulties with vision, physical movement, cognition, and fatigue affect both driving ability and the individual's level of confidence with driving (Archer et al., 2014). The results of this study also highlight the importance that self-management and self-regulation have in managing driving. In addition, alternative transport was expressed as unsatisfactory in terms of accessibility and convenience, and therefore impacted self-management.

**Driving Cessation**

*Alternatives to driving.* Occupational therapists play a large role in advocacy and locating available services for their clients to improve or regain social and occupational functioning. Therefore, it is not unexpected that these roles come with challenges for occupational therapists. In addition, there are several challenges that clients face related to mobility, access to transportation, and community reintegration. Gallagher et al. (2011) completed a study on issues related to mobility and access to transportation for people with visual impairment in urban and rural Ireland. Several issues were raised by participants throughout this study, including specific challenges that participants faced for mobility. For example, participants felt that the bus systems should have an electronic voice system announcing stops and approaching stops so that they could effectively utilize the bus system. In addition, participants felt that people providing mobility or transportation services should receive some training in disability awareness so that they could better meet their individualized needs.
An interesting trend was discovered by Choi et al. (2012) when it comes to alternative transportation methods for older adults. While the authors found that although it was common that former drivers receive support from family members for transportation needs, it was also very common for support to be provided by non-family peers. Additionally, when peer supports were in place and utilized, former drivers were much less likely to return to driving against advice of medical professionals and/or their family. Thus, the more supports a person has in place, the more likely they are to adhere to driving cessation. This highlights the importance of family and caregiver education for the provision of alternative transportation methods and assurance that driving cessation protocols are kept.

Finestone et al. (2010) discusses that although rides from family members and friends may be available alternatives, they may become overburdened with the responsibility. Additional options such as public transportation and taxis may or may not be available or affordable depending on location and cost. Many seniors are reluctant to use taxis, in particular, due to safety and cost concerns. Bus systems may not offer the adequate coverage necessary to get to all locations a person may need to travel on a day-to-day basis. This study highlights that even public transportation is not always a usable or utilized alternative method for transportation. There is also the issue of caregiver burnout or overburdening that needs to be addressed when considering the far-reaching effects of driving disruption on people and their families and friends.

Liddle et al. (2012) found that there are gaps in information provided to patients and family members, particularly in the area of alternatives to driving. This information is particularly mentioned by patients as necessary for meeting their needs and enhancing understanding of what to do now that they cannot drive. For a therapist to provide client centered
care, it becomes paramount that they do their research and provide resources to their patients to meet this need. For example, a therapist can make a list of locations a person needs to go and find ways to get there utilizing alternative methods of transportation. This can be done through communicating with family members about their availability, communicating with taxi services, providing bus and/or train routes, and providing information on any other alternative means available for usage such as Uber, Lyft, or other rideshare services. Information can also cover alternative ways to participate and stay involved in the community without relying on driving (2012).

The individuals who had the most difficulty adjusting to driving disruption were those that initially believed that they would be able to return to driving in the future. They were less likely to access alternatives, believing that they did not need to. It was then more difficult for them to adjust their roles or participation in meaningful activities, if necessary (White et al., 2012). This highlights the need for clarity in the process of driving cessation and delivery of information. There is no straightforward protocol and it leads to confusion and further frustration for the patient and their family.

**Competence and Identity: Individual Perceptions of Driving**

**Cessation of Driving.** There are a wide range of feelings associated with losing the ability to drive. Whether it is by choice or by mandate, emotions range from a sense of safety and contentment to a sense of anger and frustration. It is especially frustrating when a former driver feels a sense of role loss and occupational deprivation due to a lack of transportation. These feelings lead to further isolation and lack of participation as a person gets more frustrated. Conversely, a person who is better prepared to handle the major changes that will come about
can still find meaning and a sense of personal causation as they learn to utilize alternative methods for getting around in their community.

Archer et al. (2014) found that clients do not want to confront the issue of driving following an injury or change in function out of fear. Patients were afraid if they asked whether or not they should be driving, the answer would be an automatic no due to raising the awareness of the healthcare provider about concerns related to driving. The authors also observed strong reactions when the issue of driving was confronted. A particular reaction to being told they could no longer drive witnessed by the authors was crying. While this is an extreme example, it illustrates the sheer emotion associated with a perceived loss of independence that comes with driving cessation, a phenomenon also noted by Liddle, et al (2012). The authors found that sadness and anger were typical responses and made it difficult to steer the patient away from those feelings and achieve positive outcomes with therapy unrelated to driving itself.

Betz et al. (2014) approach driving cessation differently. They believe that a clinician is the one that should begin the discussion and, as such, should be prepared for strong emotional reactions. In their experience, patients have never reacted well to the discussion or the decision to cease driving. However, patients also felt that clinicians were not initiating these discussions with the intent to take away driving privileges every time, but only to ensure the safety of the patient and their possible passengers. There were also patients who felt whether or not to discontinue driving was their own decision to make and felt that clinicians were stepping over boundaries. This highlights the importance of building rapport when it comes to collaboratively making tough decisions, like that of driving cessation.

A primary determinant of whether or not the decision to stop driving would be accepted or not, as found by Chacko et al., seems to be cognitive level. Patients who had a greater
understanding as to their limitations and safety concerns were more accepting of the decision, whereas patients with decreased judgement and lack of insight into their unsafe behaviors were less so. Some even still drove against medical advice (2015). This lays out further the need for rapport building and a strong therapeutic relationship, as well as for family education on how to help their loved one to make the safe choice. Unfortunately, there is no simple solution or single answer to make driving cessation any easier when the patient is not cognitively aware enough to understand why.

An additional concern for therapists to bring up during the discussion about cessation of driving is the possibility of negative outcomes, and how to combat these outcomes. Chihuri et al. (2016) found several areas of concern for health status following driving session. Within the systematic review driving cessation was closely related with a decline in general health, poor physical functioning, slight declines in social health, faster cognitive decline than drivers, and significantly greater depressive symptoms (Chihuri et al., 2016). While addressing these issues may be difficult, it opens the door for discussion about alternatives to driving to support community mobility, and therefore physical and social functioning.

**Conclusion**

The occupation of driving is a highly valued occupation for the majority of the U.S. population. This occupation helps to support additional occupational engagement, life satisfaction, role identity, and community involvement. However, life circumstances, illness or medical insults, and normal aging declines may impact a person's ability to participate in the occupation of driving in a safe and effective manner. Personal elements, such as motivation, and environmental elements, such as rural or urban settings, also impact a person's abilities to drive. For some of these individuals driving or community mobility rehabilitation programs are useful
to remain or regain access to driving, and therefore independence and social participation. In many cases, driving is not a safe or viable option to return to after a disruption. While there is extensive research on the impacts of driving cessation on life satisfaction and overall well-being, there is less research on individual perceptions and strategies to help older adults prepare for driving cessation. Therefore, there is a need for our study; to learn about the individual perceptions of an older adult who has lost the ability to drive and their experiences related to driving cessation or a disruption in driving.
CHAPTER III

RESEARCH METHODOLOGY

Research Design

A phenomenological qualitative research design was used to gather information about individuals’ experiences related to driving disruption or cessation for older adults. This research design allows for an understanding of thoughts and feelings of driving disruption, the effects on occupational engagement and participation, and how individuals feel they will be able to meet their community mobility needs through alternative methods. Additionally, a phenomenological design allows for an in-depth understanding and exploration of the lived experience for those individuals who have experienced a driving disruption or cessation.

Data was collected from older adults aged 55 years or older who had experienced a disruption in their ability to drive. The research participants all resided in the same assisted living facility in the western United States. The primary data gathering technique used in this study was a semi-structured interview with open-ended questions. The researchers conducted interview sessions individually. This study received institutional review board (IRB) approval from the University of North Dakota. All subjects also signed an informed consent form prior to completing an interview (Appendix A).

Participants and Context

Research was conducted at the assisted living facility/retirement community where the subjects were recruited from. Interviews took place within the subjects’ individual apartments with a closed door for privacy. Data collection took place at the facility where the participants lived for convenience purposes, due to their inability to drive, and to help make them feel more
comfortable during the interview process. No additional resources, staffing, funding, or space was necessary to conduct research.

Purposive sampling of typical cases was utilized to locate and select subjects who met the inclusion criteria. Inclusion criteria included any disruption in driving, including cessation or restrictions at any time along the lifespan, and at least 55 years of age or older. Exclusion criteria included participants who were unable to provide informed consent and participants with impaired cognition to ensure the validity of information gathered through the data collection process. Additional exclusion criteria included participants who were unable to read and speak English, due to researchers’ inability to access resources to allow them to accurately transcribe and understand languages other than English.

Fliers were disseminated at local independent and assisted living centers in a medium sized city in the western United States (Appendix B). The content of the flier included a general invitation to participate, the purpose of the study, and the contact information of the researchers. Representatives from each facility, such as an activities director, were asked to read the contents of the flier at common meeting times for residents, or where potential subjects would be present. The potential subjects were asked to provide their contact information to the representative from each facility, in order to forward the information to the researchers.

Once the researchers had the list of potential subjects from the facility representatives, the researchers contacted the study participants via telephone. A total of five participants were identified by facility representatives. One participant was not able to complete the interview due to scheduling conflicts; therefore, a total of four participants were interviewed. Each subject was interviewed by a researcher who was versed in effective interviewing techniques.

Data Collection and Procedure
Face to face meeting times were arranged as convenient for both the researchers and the participants. Two-graduate level occupational therapy students, who have completed foundational coursework in qualitative research and had brief prior experiences in conducting qualitative research prior to the initiation of this study, implemented data collection procedures. Researchers also had access to additional information and received guidance from their graduate advisor, who has extensive experience in qualitative research.

The primary technique used in this study was a semi-structured interview with open-ended questions answered by each subject during individual interview sessions (Appendix C). Interview questions were designed to capture the essence of individuals’ feelings and experiences associated with driving disruption, as well as to gather insight in the psychosocial, contextual, and physical factors associated with driving disruption, in order to meet the purpose of the study. Each interview lasted approximately one hour, with each researcher individually conducting two interviews apiece, for a total of four participant interviews. Informed consent of the participants was obtained prior to participating in the interviews and to allow digital recording of the interviews. All data collection procedures took place in the month of October, 2016. Interviews were digitally recorded and transcribed verbatim. Recordings were then used for data analysis.

Data Analysis

Researchers manually coded information that was gathered during data collection using a method from Moustakas (1994). The researchers began the data analysis process starting with developing an *epoche*, in which the researchers identified their own thoughts, feelings, and biases related to driving disruption. Following the *epoche*, *phenomenological reduction* was used to pull key phrases or statements from the interviews. Within the process of
phenomenological reduction, four steps were completed as follows: (1) bracketing, (2) horizontalizing, (3) clustering into themes and (4) organizing themes into a description of the phenomenon. *Imaginative variation* was then used to gain a deeper understanding and develop different perspectives of the identified themes. *Synthesis*, or the final step used by the researchers, helped to enhance the meaning or essence of the themes to create an overall understanding of a disruption in driving (Moustakas, 1994).

**Trustworthiness**

Triangulation of data was used throughout the data collection and analysis. Specific methods to enhance trustworthiness and achieve triangulation included member checking of the participants’ responses, both researchers and their graduate advisor reading all four interviews, verbatim audio recording of interviews, note taking during interviews to capture body language used by participants and in-depth analysis of all 4 interview transcripts. The researchers then compared their analyses and developed themes together, with the graduate advisor checking the themes and analysis to further add validity to the data analysis process. Themes were further validated by the use of direct quotes from participants. The themes as presented in the results of the study were later mailed to each participant, who filled out a brief feedback form indicating their level of agreement with the findings (Appendix D). Two of the four study participant’s engagement in the member checking process, with responses indicating their agreeableness with the results of the study closely aligning with their thoughts, perceptions, and experiences of driving disruption or cessation.
CHAPTER IV
PRESENTATION, ANALYSIS & INTERPRETATION OF DATA

Following careful data collection and analysis, the researchers arrived at the results when examining the lived experiences and perceptions of the individuals who have experienced a disruption in driving. The Moustakas (1994) approach to phenomenological analysis was utilized to capture the participants’ experiences and reflections on driving. As per the Moustakas (1994) approach, the researchers began the data analysis process starting with developing an *epoche*, in which the researchers identified their own thoughts, feelings, and biases related to driving disruption. Following the epoche, *phenomenological reduction* was used to pull key phrases or statements from the interviews. Within the process of phenomenological reduction, four steps were completed as follows (1) bracketing, (2) horizonalizing, (3) clustering into themes and (4) organizing themes into description of the phenomenon (Moustakas, 1994). *Imaginative variation*, as described by Moustakas (1994), is then used to gain a deeper understanding and develop different perspectives of the identified themes. *Synthesis*, or the final step used by the researchers, helped to enhance the meaning or essence of the themes to create an overall understanding of a disruption in driving. Throughout this process, five themes were identified that were consistent with all four participants. Pseudonyms were used to enhance understanding of all four participants, while remaining anonymous.

**Theme 1: Driving is an important factor that influences life roles**

When describing their past driving experiences, all four participants spoke of driving in relation to their past life roles as well as relationships that driving supported. While driving in and of itself was not a particularly meaningful occupation alone, rather it was important as a secondary occupation that facilitated participation and engagement in other life roles and
occupations. Participants spoke fondly of their past driving situations, where driving was a small aspect in the plot of their overall life experience. In speaking about life experiences, Participant 4 explained, “[Driving] was no problem. It was just...second nature like eating and sleeping. You just drove whenever it was necessary” P4.

Daily life roles, specifically work and social roles, were enhanced by driving for all of the participants. For example, driving a sick husband, getting to work as well as completing work tasks, military experience, and driving in rural areas at a young age were all concepts that were discussed in detail. Participant 3 discusses the social and work roles that she fulfilled through the occupation of driving, stating:

I picked up 4 girls and drove them to work. I used to get migraine headaches and I’d even pick them up in the morning, take them to work, and then go back home. I figured I owed them to get them to work P3.

Two participants spoke about role changes associated with driving disruption, along with other concerns. Participant 2 discusses frustration and lack of occupational engagement following driving disruption, “Principally because I ran out of things to do that was of interest in the area in which I lived. It involved a significant change in lifestyle” P2.

**Theme 2: Making sense of driving cessation**

A variety of perceptions were presented by the participants when talking about their initial and continuing views associated with driving disruption. Three participants mentioned very little hardship when reflecting upon driving disruption, while another had much more difficulty giving it up and still holds onto hope that she can drive again. Participant 1 details her perception of driving as being very valuable, stating “[driving] was part of my life, like you took my glasses away from me” P1. In this statement, Participant 1 uses the sensation of sight as
being just as important as driving, a difference when considering the perspectives of the other participants. Three of the participants use age as a factor when describing their perceptions of driving disruption, similar to a rite of passage for older individuals. Participant 4 explains that he is 92 years old and “a lot of people at that age have hung it up” P4.

Three of the participants mention confidence in their abilities to drive safely, reasoning with themselves to further accept the notion to stop driving. “I came to the conclusion because I couldn’t tell whether my right foot was on the accelerator or on the brake, that I was a menace to myself and to everybody around me. So, I quit driving” P2. Participants tended to be more worried that they would injure someone else as a result of their driving and would never want to be the cause of someone else’s accident or injury.

**Theme 3: Strong emotional responses are associated with driving and driving disruption**

For the majority of the participants, their emotional response to a driving disruption was discussed in detail. Participants often laid the groundwork in describing the emotions that driving had brought prior to their disruption. This was made evident with participants using words such as joy, happiness, calm, focused, and the love for driving. Participant 2 describes his emotional response to driving prior to disruption, stating “Well I would say it probably gives you a sense of independence that you otherwise wouldn’t have and that you can go where you want to go when you want to go. That is really satisfying” P2.

In contrast to the positive emotional responses driving provided, a disruption in driving produced negative and difficult emotional responses. The participants used words such as anger, frustration, depression, anxiety and concepts such as missing driving and decreasing independence to describe their emotional responses surrounding driving disruption. From their comments, it appeared that the majority of participants had a negative emotional experience with
driving cessation. Participant 1 describes her response to driving cessation, “It’s tough mentally, and I’ve never believed in the word depression, but I think there are times that if I looked up the definition of depression, I have been at that for a period of time.” When talking about her response when first asked to stop driving by her son, Participant 3 says “At first I kind of missed it” and explains further “I still kind of miss it” P3. A loss of independence and frustration are described by participant 2 when he was asked his experience with driving cessation. He expresses feeling unhappy because as you know we are an automobile society and I had been driving so long and had such a sense of independence and that I could get in the car or my truck and go where I wanted to when I wanted to. And in this instance after I stopped driving that wasn’t possible. That was frustrating P2.

While frustration and unhappiness were felt by participants, there were others that did not feel as strongly about disruption due to the hope they have of continued driving. Participant 4 had only a temporary period where he was not doing any driving, and says “I can still drive” P4, although he allows his wife to do the driving since she took over while he healed from an injury. Participant 1 feels that “next spring when the snow is gone, if I haven’t had another stroke and my legs keep getting better...I could drive again” P1. This holding out for driving again in the future allowed the participants to move forward and not dwell upon the loss of driving as being ultimate.

**Theme 4: The importance of context in meeting needs following driving disruption**

An important aspect of transitioning from driving whenever and wherever the participants wanted is the maintenance of participation in meaningful activities and occupations. It was important that needs could still be met without having to drive. A majority of participants
spoke particularly of the importance of staying active and finding fulfilling things to do, after driving cessation or disruption. Participant 3 explains, “I like to do anything I can do just to...keep active and it’s very important when you get older that you stay active” and “I still like to do things and keep busy” P3.

The physical environment surrounding the participants, seemed to play a significant role in their needs being met. All four participants spoke about the retirement community in which they live, and how their transportation as well as other occupational needs were being met, after a disruption in their ability to drive. For example, the community has a bus for all residents to utilize for doctor’s appointments as well as for social outings that all participants take advantage of. Participants also mentioned help from family members and even a private, paid driver as further needs arose that could not be met using the bus.

**Theme 5: Familial influences on driving disruption and transportation needs**

Important members of a social circle, such as family members, influence the perceptions and experiences of those individuals who have experienced a disruption in their ability to drive. Influence can come from providing transportation following the disruption, providing support, or even suggesting a cessation in driving due to a concern of safety. All four participants referenced their social influences in their driving disruption experiences to some degree. Participant four mentions his wife as being the main support when he stopped driving. “[It] didn’t bother me that I couldn’t drive because my wife was driving. I still let her do the driving because it’s easier… She likes to drive, so I just let her drive” P4.

Support continues to be a factor for participant 1 as she describes the sensitive nature in which both the doctor and son approached driving cessation, following a stroke. “[The doctor] asked him (the participant’s son) to be there when she told me I couldn’t drive anymore, because
she knew how I would handle that. On our way home, he said, ‘mom, I know this is going to be tough on you’” P1. Both the support of her doctor as well as her son, made the transition from driving to not driving easier. Similarly, Participant 3 was also asked by her son to stop driving. Reflecting back on that situation, her response was: “It was fine. I didn’t say no and I figured what’s the point? This way they’ll be at peace and they won’t sit there and worry where is she now, what is she doing now” P3. Her son offered to drive her places following their discussion and she relies on him to drive her places.

**Summary of Results**

Five primary themes emerged from the data provided by each participant. The five themes are (1) driving and driving disruption are important factors that influence life roles, (2) a dichotomy of perceptions surrounding driving disruption, (3) strong emotional responses are associated with driving and driving disruption, (4) the importance of a retirement community in meeting needs following driving disruption, and (5) familial influences on driving disruption and transportation needs. In synthesizing the five themes into one central meaning, the emergent statement is: the responses to driving disruption are varied, contextual, and often include strong emotions and multiple needs. The influences of retirement communities and family support are strong indicators of the amount of social engagement and sense of independence perceived by individuals following driving disruption.

**Discussion**

The purpose of our study, *Lived Experience of Individuals who had a Disruption in Ability to Drive*, is to examine the feelings and experiences of individuals who have been unable to drive for a period of time. In addition, to examine the psychosocial, contextual, and physical factors that were impacted due to driving disruption. Throughout the data collection process and
as participants explained their driving disruption experiences, it was evident that the driving disruption or cessation is often a process rather than a singular event. In some instances, the process of driving disruption, that eventually lead to driving cessation, was during a time span of 15 years. This concept of driving disruption being a longer process was evident in both themes one and two, as participants discussed previous and current life roles and attempted to make sense of their driving disruption. Next, all five themes speak to the fact that driving is an element within a larger life narrative. It is not the central focus of a story, but a detail of the overall central idea. The research by Liddle et al. (2012) about cessation of driving following a traumatic brain injury and the direct negative impact on fulfillment of life roles, specifically family and social roles, parallels our findings in theme one. While Liddle and colleagues (2012) research highlights the inability for younger individuals to access work roles following injury, the participants in our study discussed the both work and social roles as a fond memory when reflecting on driving before the disruption. To continue, the research by Johnson (2008) about the impact of a large support system in community involvement and occupational engagement aligns with themes four and five. Lastly, as is evident in both the literature review as well as the themes within this study, driving cessation is brought up by a number of different influential people, including family members and health care providers. However, there is no consensus as to whose role it is to approach the subject. In conclusion, our study enhances the occupational therapy literature by adding insight into individual experiences and perceptions after driving disruption or cessation. The themes mentioned previously will help occupational therapy practitioners have a better understanding of the lived experience after driving cessation. The research and information gained through this study will help to inform and prepare occupational therapists as they inform and prepare older individuals for a driving cessation after injury or
illness. Lastly, this research highlights yet another niche or area of practice, that would benefit both the aging population as well as the community as a whole achieve occupational engagement and occupational adaptation.
CHAPTER V

SUMMARY, CONCLUSIONS, & RECOMMENDATIONS

Summary of Findings

The purpose of this study was to understand the lived experience of driving disruption. The findings of this phenomenological study are presented in the form of five themes that are consistent among all four-participant perspectives. In summary, the first theme speaks to how past driving experiences and the ability to drive help to support valued daily life roles for individuals, specifically work and social roles related to relationships. In understanding the value placed on past driving experiences, as described in theme one, it allows for a greater understanding of the current perspective and therefore a true phenomenally-based perspective. The second theme describes how driving disruption is varied and truly takes on an individual perspective as people try to make sense of their driving cessation. This perspective was very clear throughout the stories told by all four participants. For example, a perspective of great loss was presented in contrast to a perspective of a rite of passage for older individuals as they transition into older adulthood. Theme three was readily apparent across all four interviews as participants told life stories related to past driving experiences and their new experiences trying to understand and cope with a loss in driving. It was obvious that strong positive emotions were being associated with past driving experiences and strong negative emotions being associated with the participants’ current disruption or cessation in driving. Theme four shows the influence of the physical context on the perspectives of the participants regarding their current driving disruption. Participants frequently cited staying physically and socially active and the various amenities that support physical and social occupational engagement at their place of residence, a retirement community, as having a positive effect on their current situation. Lastly, theme five
describes the importance that a strong social support plays in helping individuals transition successfully to a cessation in driving. Family members were mentioned as specifically important during this transition period.

**Recommendations**

Based on the five themes that emerged from the data, it is recommended that occupational therapists be involved at every level with persons who are undergoing changes in their driving status. Because driving affects occupational participation and exploration, it is important that these impacts are understood and considered when helping a person maintain their independence to the extent possible. An occupational therapist can be a valuable resource for identification of alternative means of transportation and/or alternative means of access to and participation in the meaningful occupations of everyday life.

In addition to resource identification, an occupational therapist is also uniquely positioned to understand the multiple influences of physical, social, and community contexts on occupational participation, particularly following a driving disruption. There is a myriad of factors that can influence a person’s continued participation in and meaning devolved from participating in valued occupations. Furthermore, additional recommendations can be made not only to the person who is unable to drive, but to their family members, friends, places of residence, places of employment, and other public or private community locations of interest to the person.

**Limitations**

The limitations of this study include the small number of participants who were interviewed for data collection purposes as well as that all four participants lived in the same independent living facility. It is recommended that future studies include more participants and
recruit participants from other residences such as in homes, apartments buildings, or other private dwellings.

Conclusions

As mentioned previously, all five themes are congregated in the form of an assertion statement. The assertion statement reads as follows:

The responses to driving disruption are varied, contextual, and often include strong emotions and multiple needs. The influences of retirement communities and family support are strong indicators of the amount of social engagement and sense of independence perceived by individuals following driving disruption.

Along with the five major themes and the cumulating assertion, it is relevant to mention other factors associated with the findings of this study. Throughout all four interviews, the participants described their driving cessation as a process rather than a singular event. This process included many emotional ups and downs including periods of despair as well as hope. For some individuals, their experiences lasted for several years as illnesses progressed or additional illnesses compounded, leading to unsafe driving. The results of this study developed from the four individual perceptions enhance the occupational therapy literature. The themes that emerged through data-analysis as well as the specific stories told by the participants will help occupational therapy practitioners develop and enhance their understanding of a driving disruption or cessation. The results of this study will further help occupational therapy practitioners as they work to prepare and enhance the lives of those individuals where it is necessary to cease driving due to safety purposes. Lastly, the field of occupational therapy is well suited to assist individuals during transition periods, specifically the transition period following a cessation in driving. However, little research and effort has been placed on this vital
transition period for older individuals as they continue to move through the developmental continuum, thus the relevance for developing a greater understanding.
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Appendix A

THE UNIVERSITY OF NORTH DAKOTA
CONSENT TO PARTICIPATE IN RESEARCH

TITLE: The Lived Experience of Individuals Who Had a Disruption in Ability to Drive

PROJECT DIRECTOR: Shelby Hoskinson

PHONE #: 307-267-6241

DEPARTMENT: Occupational Therapy

STATEMENT OF RESEARCH

A person who is going to participate in research must give his or her informed consent in order to participate. 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 participate. 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 the experiences you have had upon a disruption in driving.

The purpose of this research study is to learn about the thoughts and feelings a person has when going through a disruption in driving. This information will be used to help health care providers understand what a person may be going through when experiencing partial or complete loss of driving privileges. This information will allow health care providers to better meet the needs of this population. You were selected for this study due to your firsthand experience with these changes in your driving status.

HOW MANY PEOPLE WILL PARTICIPATE?

Four people will participate in this study. Research will take place at the location most convenient to the subject in a quiet environment with a closed door.
HOW LONG WILL I BE IN THIS STUDY?

You will be asked to complete up to two interviews with a researcher. Each interview may last up to one hour. All interviews will be completed by December 1, 2016.

WHAT WILL HAPPEN DURING THIS STUDY?

Each visit you will be asked a set of open-ended interview questions. With your consent, interviews will be digitally recorded and transcribed word for word. You do not have to answer any questions that you do not want to.

WHAT ARE THE RISKS OF THE STUDY?

There may be some risk from being in this study. Some questions may be of a sensitive nature, and you may become upset as a result. However, these risks are not viewed as greater than “minimal risk.” If you become upset by a question, you may stop at any time or choose not to answer. If you would like to talk to someone about your feelings about this study, you are encouraged to contact a mental health professional.

WHAT ARE THE BENEFITS OF THIS STUDY?

We hope that in the future other people might benefit from this study because of the knowledge gained from the experiences shared by each subject. You may benefit from knowing that the information you give may be used to provide services to people who are undergoing similar life changes due to a disruption of driving.

ALTERNATIVES TO PARTICIPATING IN THIS STUDY

If you choose not to participate in this study, you are free to do so and will not be contacted again about this research project.

WILL IT COST ME ANYTHING TO BE IN THIS STUDY?

You will not have any costs for being in this research study.

WILL I BE PAID FOR PARTICIPATING?

You will receive a $5 gift card to a local food and drink establishment upon completion of the interview(s)
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 to the extent permitted by law. Your study record may be reviewed by government agencies, the UND Research Development and Compliance Office, and the University of North Dakota Institutional Review Board.

Any information from this study that can be identified with you will remain confidential. Your information will be shared only with your permission or as required by law. You should know that there are some circumstances in which we may have to show your information to other people. For example, the law may require us to tell authorities if we believe you may be dangerous to yourself or others. Fictitious names will be used on all interview transcripts and audio recordings to maintain confidentiality. All audio recordings, interview transcripts, and any other documentation used in the study will be destroyed after data analysis has been completed.

Study results will be written in a summarized manner so that you cannot be identified. If direct quotes are used, fictitious names will be used to maintain confidentiality.

IS THIS STUDY VOLUNTARY?

Your participation is voluntary. You may choose not to participate or you may stop your participation at any time without penalty. Your decision to participate or not will not affect your current or future relations with the University of North Dakota, Casper College, or your referring community center.

If you decide to leave the study early, we ask that you tell the researchers your decision so that other subjects may be recruited, if necessary. There are no consequences for leaving the study.

CONTACTS AND QUESTIONS?

The researchers conducting this study are Graydon Larsen, OTS and Shelby Hoskinson, OTS. Dr. Debra Hanson at the University of North Dakota will oversee the research. You may ask any questions you have now. If you have questions later please contact Dr. Debra Hanson at 701-777-2218. Dr. Debra Hanson can also address any concerns or complaints you may have about the research.

If you have questions about your rights as a research subject, you may contact The University of North Dakota Institutional Review Board at (701) 777-4279 or UND.irb@research.UND.edu

- 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 the research staff, or you want to talk with someone who is not part 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; I understand however that 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 information with the subject or, where appropriate, with the subject’s legally authorized representative.

______________________________________________________________
Signature of Person Who Obtained Consent              Date
Participant Recruitment Flyer

Appendix B

This study includes individuals who have had a disruption in driving. This research study would help to inform healthcare professionals about thoughts, feelings, and concerns surrounding a disruption in driving. If you have questions or would like to participate in our study please contact us at the phone numbers provided below.

What is a disruption in driving?
- Limited to driving shorter distances
- Limited to driving during the day
- Stopping driving altogether

What will you have to do?
- Answer questions related to your driving disruption experience
- Engage in one or two interviews

How long will this last?
- Interviews will take place in October, 2016.
- Each interview will last approximately 1 hour.

Where will the interviews take place?
- At your most convenient location

What do you get out of participating?
- $5 Gift card to a local restaurant

Please Contact
Shelby Hoskinson
Phone: 307-267-6241

Or

Graydon Larsen
Phone: 801-386-3967

Occupational therapy students at the University of North Dakota are seeking individuals to participate in a research study about driving.

This study includes individuals who have had a disruption in driving. This research study would help to inform healthcare professionals about thoughts, feelings, and concerns surrounding a disruption in driving. If you have questions or would like to participate in our study please contact us at the phone numbers provided below.
Appendix C

Interview Schedule

Introduction: I am an occupational therapy graduate student at the University of North Dakota at the satellite campus in Casper. I am currently working on an independent study research project with one of my colleagues and am interested in learning about your thoughts and feelings associated with a disruption in driving and how this impacts daily life functioning. Throughout this research process, you will participate in one to two interviews for approximately one hour. The interviews will take place in the most convenient location for you. Please be as expansive as possible in your answers, so we can obtain a thorough understanding of your experiences living with a disruption in driving.

Purpose: The purpose of this qualitative research study is to gain an understanding of the experiences of people who have had a driving disruption and how this affects all aspects of life. By gaining knowledge about experiences associated with a driving disruption, healthcare professionals may have a better understanding of the impacts on daily life, access to healthcare, physical functioning, social functioning, and psychological functioning. In addition, this qualitative research may inform future research or development of community programs or driving rehabilitation programs.

Interview:

1. I would like to get an idea about your past driving situation.
   a. Tell me about how your driving status has changed over time.
   b. How have your thoughts about driving changed over time?
2. What happened that made you stop driving or disrupt your driving routine?
   a. How did that influence you?
   b. Describe driving rehabilitation or community mobility programs you were or are involved with during this process.
   c. If you did not participate in driving rehabilitation or community mobility programs, how do you feel these programs would have affected you?
3. Tell me about how your social life and engagement in activities has changed since your driving disruption.
   a. How have your family members or friends played a role since your driving disruption?
4. Describe your use and access to other methods of transportation in rural Wyoming since your disruption in driving.
   a. Describe how you access community events or healthcare appointments.
5. Explain how you feel about having to give up driving.
   a. Have your perceptions of yourself changed over time?
   b. Explain how your feelings of independence and life satisfaction have changed over time.
   c. Explain your thoughts about your future without driving.
Appendix D

Participant Member Checking Form

Please take a few moments to review the results of our study, *The Lived Experience of Individuals who had a Disruption in Ability to Drive*. The results of our study are presented in the form of five major themes that emerged from the data that you helped to supply during the interview process. Following a review of the attached document, please answer the following questions. Please return this form to Shelby Hoskinson at P.O. Box 1303 Glenrock, WY 82637 with the envelope provided, by January 5, 2017.

Please circle response that you agree with most accurately.

1. My thoughts and perspectives about driving disruption and life roles were well represented under Theme 1.

   Yes   No   Somewhat

2. My thoughts and perspectives about driving disruption and making sense of driving cessation were well represented under Theme 2.

   Yes   No   Somewhat

3. My thoughts and perspectives about driving disruption and strong emotional responses were well represented under Theme 3.

   Yes   No   Somewhat

4. My thoughts and perspectives about driving disruption and the physical context is well represented under Theme 4.

   Yes   No   Somewhat

5. My thoughts and perspectives about driving disruption and familial influences were well represented under Theme 5.

   Yes   No   Somewhat

Please provide further details about how your thoughts and feelings are represented within the results of our study.

___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________

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