

EXPLORING THE EXPERIENCES OF YOUNG ADULTS LIVING IN A RELATIONSHIP  
WITH A VISUALLY IMPAIRED PARTNER

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By

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## ABSTRACT

This research explores the lived experiences of young adults living in an intimate relationship with a visually impaired partner. The aim of this research was to explore how young adults viewed their role in the relationship in terms of how they accommodate their partners with a visual impairment to understand feelings of and experiences with community supports; and to explore what partners felt they required for personal supports. This study employed a transcendental phenomenological approach, using semi-structured interviews with five adults age 23 to 39. The findings revealed the overall essence of participants' experiences to be *second nature*. The *essence* emerged through various themes and sub-themes created from the voices of participants. The themes included adapting to the situation, environmental awareness, patience, and the need for support groups. Throughout this thesis the themes and *essence* of the participants' experiences will be discussed, along with the implications for social work and future research in the area.

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## Glossary of Terms

**Legally Blind** - A visual acuity of 20/200 or less is required to be considered legally blind (American Foundation for the Blind, 2015).

**Low Vision** - A visual acuity of 20/70 causing an individual to have uncorrectable vision that interferes with daily activities (American Foundation for the Blind, 2015).

**Phenomenology** – An approach in research to describe and understand phenomena as experienced by individuals (Wojnar & Swanson, 2008).

**Salutogenesis** – An approach that considers any phenomenon that causes stress and impacts one's well-being. This approach attempts to explain what contributes to a positive continuum of health and well-being, rather than explaining an individual's problems (Antonovsky, 1987).

**Sense of Coherence** – A sense of coherence essentially means to whatever extent an individual is able to see an adversity as comprehensible, manageable, and meaningful, they will be able to mobilize their resources to adapt and cope (Antonovsky, 1987).

**Transcendental Phenomenology** – This is a search for a central underlying meaning of experiences with a particular phenomenon (Moustakas, 1994).

**Visual Impairment** – A disability that falls under one of two categories; vision loss or complete blindness (American Foundation for the Blind, 2008).

## **Chapter One: Introduction**

### **1.1. Thesis Structure**

This thesis will consist of five chapters. Chapter 1 includes the introduction to the research. Chapter 2 will provide an in-depth overview of the literature on vision impairment, and the impact of disability on partners in relationships. Chapter 3 will then provide a history of phenomenology, and the use of phenomenological approaches in qualitative research. This chapter will also include the procedures of this study; a description of the participant recruitment process, ethical considerations, data collection, and the data analysis process.

Chapter 4 will provide the findings of the study. This chapter will discuss the three themes and ten sub-themes that emerged from the data analysis process, using the voices of participants to portray their lived experiences with the phenomenon. A collective description of participants' experiences, along with the overall "essence" of their meanings will conclude this chapter. Finally, Chapter 5 will further discuss the findings based on theoretical analysis, as well as provide discussion on research limitations and how this study may allow for future research in the area.

### **1.2. Background to the Study**

It is estimated that approximately 500,000 Canadians have some form of vision impairment that impacts quality of life, and approximately 50,000 Canadians will lose their sight each year (Buhrmann, 2007; Statistics Canada, 2013). In Saskatchewan, it is estimated that 14,256 people are living with vision loss (Buhrmann, 2007; Statistics Canada, 2013). The Canadian National Institute for the Blind (CNIB) recently estimated that over one million Canadians are living with some form of vision impairment, and this number is expected to dramatically increase in the near future (Canadian National Institute for the Blind [CNIB], 2014).

It is likely that individuals with vision impairments will enter into intimate relationships and live their lives with loving partners. These partners may or may not be experiencing vision loss. However, they are still impacted in many ways as they live their lives alongside with their visually impaired partners. Partners of persons with disabilities tend to be forgotten even though they may also require support. Westaway and Wittich (2011) state that spouses of those with disabilities should be a part of the rehabilitation process; yet their needs are rarely met. Service providers focus their attention on their clients (those with the disability) due to budgetary and strategic planning priorities. In a similar argument, Strawbridge, Wallhagen and Shema (2007) state that spouses of those with visual impairments do not live in isolation. In other words, they also require support from professionals in the community. Treatment and rehabilitation programs need to include both spouses and other family members such as parents or children of the visually affected client. It is important to consider the young adult population who live with visually impaired partners because the majority of the research has placed its focus on disabilities other than vision loss, and on aging populations such as seniors age 65 and older (Feigin, Sherer & Ohry, 1996; Strawbridge, Wallhagen & Shema, 2007; Westaway & Wittich, 2011).

### **1.3. Personal Reflection**

At the age of seven, I was diagnosed with Stargardts disease, a form of macular degeneration that causes central vision loss. During my childhood and adolescence, I recall doctors and counsellors in numerous meetings focusing on my well-being and assisting me with the implementation of accommodations. Despite my parents and other family members attending these important meetings, the impact of my disability on their lives was rarely a concern. I have always considered myself to be extremely independent, but due to the nature of my disability I still must rely on others for on-going support. The need for on-going support was

not only the case during my childhood when I was with my parents but also exists currently in my relationship with my partner today.

I have a subjective understanding of how my disability impacts my partner's life. She chooses to alter her daily life in order to accommodate my visual impairment. For example, this can include planning her schedule in order to make time to drive me to an appointment, reading an article for a university course out loud because a magnifier is not available, and reading subtitles that appear on screen while watching a movie. My understanding of how my disability impacts my partner on physical, emotional, and social dimensions will differ from her understanding of her experiences because we experience the world through our unique lenses. Our individual values and lived experiences shape the meanings we place on my disability and our relationship as a whole. Furthermore, I believe that every couple living within the context of this phenomenon will have both similar and unique experiences to mine.

Understanding these unique experiences is not only important for my personal life, but also for my social work practice. I have worked with children and adults with vision loss in many areas including life skills counselling and job development. Parents and spouses of these individuals are usually involved throughout the process. While speaking with parents and partners it is clear that that they are all impacted by their loved one's disability in unique ways. In my experience as a support worker for youth and adults with vision loss, and generally in my observations of others living with vision loss, it is difficult to assist the family and partners when the main duty of support workers is to assist the individual with his/her disability. My experience has been that families and partners often have concerns and requests that tend to include counselling for working through their feelings surrounding a loved one's disability, education on vision loss and how to provide support, and assisting with finances in order to purchase

accommodative equipment. I believe that support workers have a lack of understanding regarding the needs of partners and families, as well as a shortage of funding that is required to respond to these needs.

#### **1.4. Research Question and Rationale**

Because there is little research focusing on young adult populations living with vision impairment specifically, the purpose of this research was to explore the lived experiences of young adults, ages 21 to 30 years, who are living in an intimate relationship with a visually impaired partner. The central research question for this study is: “*What are the experiences of young adults living in an intimate relationship with a visually impaired partner?*” This study had three main objectives: (a) to explore how participants view their role in the relationship, in terms of how they accommodate their partner; (b) to explore participants’ perceptions of and experiences with community supports; and (c) to explore what participants feel they need for personal supports. This qualitative phenomenological study utilized a social constructivist framework, along with a salutogenic approach. Furthermore, it incorporates Moustakas’s (1994) transcendental phenomenological methodology.

To answer the research question and address the aims of this study, a qualitative approach to inquiry was selected as the best fit, specifically transcendental phenomenological methodology (Moustakas, 1994). This study also uses a social constructivist framework, critical disability theory, and a salutogenic perspective.

The methodology and theoretical framework was chosen for this research to gain an understanding of the experiences of young adults living in relationships with visually impaired partners. Research focusing on older adults’ experiences living with partners with disabilities has been conducted using similar approaches; however this leaves a gap in the research for

understanding the experiences of younger populations. Young adults may experience this phenomenon both similarly and differently from older populations. These individual experiences may be shaped due to the ways in which accommodations are made, interactions with the physical environment, interactions with others in the community, and the unique personalities portrayed by those experiencing the phenomenon. Further explanation of these topics will appear in the sections on theoretical framework and methodology.

### **1.5. Chapter Summary**

This study will focus on the experiences of young adults living in an intimate relationship with a visually impaired partner. When an individual is diagnosed with a visual impairment, or any disability for that matter, the first instinct of doctors and family members is to immediately determine how to best support that individual (Westaway & Wittich, 2011). It is common for the partner of the person with the disability to be forgotten, when in reality she or he may also require supports to cope with the situation (Westaway & Wittich, 2011). According to Rubin and Rubin (2005), people see situations in unique and individual ways, and through their own conclusions attribute meaning to what they experience. These authors state that because there are multiple interpretations of a situation, all of these interpretations must be seen as true. This study will draw upon these meanings and interpretations, and form an overall essence of the participants' experiences.

## **Chapter Two: Literature Review**

### **2.1. Chapter Overview**

Even though there is a need for further research in the area of the experience of young adults involved in an intimate relationship with a visually impaired partner, the current literature provides useful information that must be acknowledged. Given the scarcity of literature that specifically addresses the impact of living with a partner with a visual impairment the following literature review will discuss the impact of vision loss as well as other impairments on both partners within a relationship. Furthermore, it will look at specific factors such as the age of participants, relationship satisfaction, and psychological stressors. This chapter will start by discussing the theoretical framework utilized in my study.

### **2.2. Theoretical Framework**

This study utilized a social constructivist framework, along with a salutogenic approach and critical disability theory. I believe this theoretical framework has provided me with an understanding of how people may experience a particular phenomenon. As a researcher, this understanding was important because it provided a foundation in the development of interview questions for data collection. While people may experience similar phenomenon when living with a partner with a disability such as a visual impairment, the meaning of this experience may differ from person to person. The current literature lacks a rich understanding of these subjective experiences of young adults living in relationships with visually impaired partners. Denzin and Lincoln (1994) suggest that an interpretive perspective is important in qualitative research, because it focuses on understanding each participant's internal reality and meaning of a given phenomenon (as cited in Willis, 2007, p. 162). An interpretive framework moves away from objectivity and cause/effect relationships. Instead, it emphasizes socially constructed realities,

intersubjectivity, and ordinary talk (Willis, 2007, p. 161). In this thesis research, using interview questions formulated from the theoretical framework, and allowing participants to openly speak about their experiences led to the emergence of meanings and an overall essence. Understanding individual meanings can provide an overall essence of the phenomenon being studied (Willis, 2007, p. 161). Forming an essence involves going beyond conventional patterns of thought and action in order to expose the meaning structures. In other words, essence is the universal meaning of participants' experiences (Lin, 2013; Moustakas, 1994). Social constructivism, critical disability theory, and salutogenesis informed the structure of the interview questions used in data collection. This framework allowed for the construction of interview questions, which encouraged participants to share their experiences living with a visually impaired partner. Transcendental phenomenological methodology then provided a means to data analysis that shaped these experiences into an overall essence.

Constructivism is an interpretive paradigm that states that people develop subjective views of a situation based on what they experience; they construct their realities based on everyday experiences (Coffey, Holbrook & Atkinson, 2007). The environment plays a major role in shaping people's subjective experiences. Critical disability theory views disability as being a socially and culturally constructed phenomenon. Furthermore, a salutogenic perspective will be used within this framework because individuals have various strengths and beliefs which help to positively cope with certain situations (Antonovsky, 1993). Data was collected through in-depth individual interviews. The utilization of Moustakas's (1994) suggested approach of data collection and analysis provided a greater understanding of "what" people experience and "how" they experience it in terms of a particular phenomenon. Moustakas's analysis will then lead to capturing the experience or essence shared by all of the participants.

**2.2.1. Social constructivism.** A social constructivist worldview suggests that individuals seek an understanding of the world in which they live. Furthermore, subjective meanings are developed based on their experiences (Creswell, 2013, p. 24). Creswell (2013) suggests that qualitative research with an interpretive and/or a social constructivist lens must focus as much as possible on participants' views of a situation. The general assumptions within the interpretive paradigm- the qualitative approach- include an ontological worldview that is subjective. Phenomenological research often uses an interpretivist lens with broad and general questions that allow for the opportunity of participants to construct meanings of a situation (Creswell, 2013, p. 25).

The body of knowledge and understanding of a particular phenomenon is continually shaped by subjective experiences of multiple individuals who experience the phenomenon. The interpretations of a situation may differ from person to person; therefore there is not one objective truth about a phenomenon. The meaning of a situation is co-constructed by individuals based on their subjective experiences (Cohen & Manion, 1994; Mills, Bonner & Francis, 2006). As discussed in chapter one, I have a subjective understanding regarding the phenomenon of living with a visually impaired partner. My experiences are unique based on my interactions with my partner. Furthermore, I believe my experience and understanding are shaped by interactions with the environment and the way in which I handle certain situations. These personal beliefs, along with the theoretical framework outlined in this chapter, contributed to the development of research questions in this study.

**2.2.2. Critical theory and critical disability studies.** The goal of critical theory is to change processes that marginalize certain groups in society. Durkheim, (as stated in Feys, 2015) stated that people conform to societal norms in the attempt to gain some form of personal

improvement. Furthermore, critical theorists believe that larger societal change is beyond their control (Agger, 1991; Feys, 2015). Critical theorists attempt to create alternatives to undemocratic practices (Feys, 2015). In other words, critical theory looks at societal structures and those who are impacted by “norms” in society. Critical theorists see these individuals as being experts of their own experience and they must have a voice, in order to change society on a macro level (Bohman, 2005; Feys, 2015). Critical disability studies are one of many sub-categories emerging from critical theory.

Understanding disability as a socially and culturally constructed phenomenon, rather than an objective reality, will move away from a medical model that views disability as a functional limitation and a personal problem (Hiranandani, 2005). Unlike the medical model, critical disability theory incorporates the perspective that disability is a social construct, not the inevitable consequence of impairment. Critical disability theorists describe the construct of disability as a complex interrelationship between impairment, individual responses to impairment, and the social environment. Furthermore, the social disadvantage experienced by disabled people is caused by the physical, institutional and attitudinal (together, the ‘social’) environment which fails to meet the needs of people who do not match the social expectation of normalcy (Hosking, 2008; World Health Organization, 2002). When explored through a social constructivist lens, significant insight can emerge into the views of disability. Most individualistic accounts of disability fail to recognize that even the most objective of disorders, such as visual impairment, do not exist independent of culture and society (Hiranandani, 2005).

Critical disability theory builds on the views brought forth by critical legal studies. Critical legal studies contest the fundamental principles of liberal conceptions of law. Liberalism views law as the codification of objectively normative rules to govern society. Critical legal

studies argue against this view, stating that law reflects subjective value choices which may be contested by those who have interests that are not being served. Laws are deconstructed using critical disability studies to show how they reflect class interests and relations of power (Hosking, 2008).

Critical race theory, feminist theory, and critical disability theory came forward to point out limitations in critical legal studies. These theories evolved due to the inability of legal studies to account for the role of disability and race in society; along with the failure of the legal system to respond to the interests of these groups (Hosking, 2008). It is important to note that disability may not exist independent of race, gender, or other identifying characteristics. Kimberle Crenshaw (1989) created the term “intersectionality”. Laws focusing on discrimination tended to look at one characteristic, which neglected to consider intersections of other characteristics. Crenshaw (1989) states that single characteristics such as race, gender, and disability may not exist independent of one another. They can intersect, and people may experience multiple forms of discrimination.

Critical disability theory views disability as concerning not only the individual, but also the environment. In other words, the social environment must be the target for change. Focusing on the environment as the target for change stems from the social model of disability. The social model of disability looks at society’s failure to provide adequate services to persons with disabilities. This model focuses on all factors that cause barriers for persons with disabilities, including social attitudes and a lack of change to the physical environment (Hiranandani, 2005; Oliver, 1996). Although focusing on societal structures are necessary, it is important not to disregard individual experiences (Oliver, 2013). The ideas brought forth in critical theory and critical disability studies assisted in the development of research questions for this study.

Focusing on participant experiences with the physical environment and interactions with others in the community also shaped the way in which data was interpreted during the analysis process.

**2.2.3. Salutogenesis.** A salutogenic approach considers any phenomenon that causes stress and impacts one's well-being. This approach attempts to explain what contributes to a positive continuum of health and well-being, rather than explaining an individual's problems (Antonovsky, 1987). The basis of a salutogenic perspective is a sense of coherence (SOC), which is involved in the mediation process between stressful life events, well-being, and health. SOC involves three concepts including comprehensibility, manageability, and meaningfulness. Comprehensibility refers to the extent to which one understands the phenomenon. Manageability involves whether or not one believes she or he has the necessary resources to cope with the phenomenon. Meaningfulness refers to the extent to which one believes that problems and demands are worth commitment and engagement (Antonovsky, 1993; Antonovsky, 1994). In other words, SOC is a way of seeing the world in ways that facilitate successful coping with the complex stressors that confront us throughout the course of life (Antonovsky, 1993; Forsberg-Warleby, Moller & Blomstrand, 2002).

Social constructivism, critical disability theory, and salutogenesis connect together when looking at the experiences of young adults living in a relationship with a visually impaired partner. Each participant will have a unique and subjective understanding of his or her lived experience with the phenomenon. These unique understandings will differ depending on participants' surrounding environment and persons whom they interact with on a day to day basis. The surrounding environment including, day to day interactions, and the participants understanding of disability may impact participants' SOC in regards to the phenomenon or vice versa.

Social constructivism, critical theory, and salutogenesis guided the development of research questions for this study. Interview questions focusing on individual experiences living with a visually impaired partner, experiences with the physical environment and interactions with others, and the impact of personality traits on individual experiences were all used for data collection. These theories were used to guide the data analysis and interpretation. Analyzing participant transcripts for specific words or phrases related to personality, environment, and interactions assisted with the development of findings in this study.

### **2.3. Gaps in the Literature**

Upon reviewing the literature related to experiences of persons living with a partner with a disability, I have discovered that there are multiple gaps in the research. First, most of the research focuses on older adults ages 49 years and older (Ghosh, Greenberg & Seltzer, 2012; Scarinci, Worrall & Hickson, 2009; Strawbridge, Wallhagen & Shema, 2007; Westaway & Wittich, 2011). Second, a large amount of the research focuses on disabilities other than visual impairment. Literature focusing on the experiences of persons living with a hearing-impaired partner was most common when compared with other disabilities (Scarinci et al., 2009; Westaway & Wittich, 2011). Other disabilities such as mental health disorders were also present in the literature (Feigin et al., 1996; Ghosh et al., 2012). Finally, the vast majority of research is quantitative in design using questionnaires and closed-ended questions for data collection. These studies are an important contribution to the literature; however, a gap exists for understanding the lived experiences of participants (Feigin et al., 1996; Ghosh et al., 2012; Scarinci et al., 2009; Strawbridge et al., 2007; Westaway & Wittich, 2011). One exception to this gap was a mixed methods study that focused on older citizens and hearing impairment (Scarinci et al., 2009). Because of these gaps in the literature, a study is needed that contextualizes the voices of young

adults in intimate relationships with visually impaired partners. Thus, a qualitative design will allow for a deeper understanding of experiences, which will contribute greater insight to the current knowledge base.

## **2.4. Describing Vision Loss**

Vision loss or impairment is a physical disability that can fall under two categories, including low vision or complete blindness. The American Foundation for the Blind (AFB) defines low vision or legal blindness as having some form of useful vision, whereas complete blindness is referred to as having no useful vision (AFB, 2008). To determine whether an individual has low vision, optometrists will test for a measure known as visual acuity. Visual acuity is a number that indicates the sharpness or clarity of vision. Being diagnosed with low vision requires a visual acuity of 20/70 or lower. In other words, a person with 20/70 vision means someone who is 20 feet from an eye chart will see what a person with unimpaired 20/20 vision can see from 70 feet away (AFB, 2015).

It is important to recognize the difference between vision loss and legal blindness. Vision loss starts at a visual acuity of 20/70 and refers to an individual having uncorrectable vision that interferes with daily activities. Legal blindness is a term created by the American government that determines whether an individual is eligible for funding to receive such services as vocational training, rehabilitation, or accommodative equipment. Persons must have a visual acuity of 20/200 or less in order to be considered legally blind (AFB, 2015). The loss of vision may also lead to various psychological impacts for both the visually impaired individual and his or her partner.

**2.4.1 Psychological impacts of vision loss.** Psychological impacts are a concern for those who have vision impairment, and who are at greater risk of losing their vision later in life.

The most common psychological concern linked with vision loss is depression. Research conducted in 2007 on preventing depression in persons with age related macular degeneration suggests that 30 percent of those with macular degeneration will experience depression due to their loss of vision (Fox, 2012). Along with depression, anxiety is another common diagnosis among those with vision loss (Canadian Association for Mental Health [CAMH], 2012; Fox, 2012;). Anxiety arises due to fear of one's partner leaving them due to the disability, as well as the fear of being left alone in public places (Fox, 2012). Persons with vision impairments are not the only group who may experience psychological struggles. Partners of those with vision loss are also at risk of being impacted on a psychological level (CAMH, 2012).

Research has shown that persons living in relationships with a disabled partner have negative psychological effects (CAMH, 2012). This includes developing mental health conditions such as depression and anxiety. Symptoms of depression can include trouble sleeping, sudden changes in eating habits, feelings of constant sadness, and a loss of interest in relationships (CAMH, 2012). Those who experience anxiety may feel as though they are not in control of their life, be in a state of constant fear, or have high levels of stress that impact performance on various tasks (CAMH, 2012).

In a study of 19 elderly spouses living with sensory impaired partners, Westaway and Wittich (2011) focused on the impact of an individual's visual, hearing, or dual-sensory impairment on the level of burden and/or level of depression on the spouse. This quantitative study used tools such as the caregiver burden scale and geriatric depression scale. Participants were between 65 and 93 years of age. Results of the study suggest that the majority of spouse participants had high levels of burden and depression related to all three forms of partner impairment (Westaway & Wittich, 2011).

In a similar study of elderly couples, Strawbridge et al., (2007) focused on the impact of a visually impaired spouse on her or his partner's health and well-being. This was a longitudinal study consisting of 418 couples age 51 to 90. The researchers looked at multiple variables, including physical well-being, mental health, social involvement, and marital satisfaction. The results suggest that having a visually impaired spouse negatively impacts a partner's relationship satisfaction with his or her spouse. It also impacts mental health in such areas as the development of depression. Another interesting finding from this study revealed that women are more negatively impacted by their husband's visual impairment compared to men with visually impaired wives (Strawbridge et al., 2007).

Spouses are also negatively impacted by a partner's disability when they have children. In a longitudinal study consisting of 1,690 elderly participants, Ghosh et al., (2012) looked at the impact of a partner's disability on the spouse. The researchers divided the participants (age 52 and older) into three groups: couples with an adult child without a disability, couples with an adult child with a developmental disability, and couples with an adult child with a severe mental illness. Among all of the participant pairs, one of the partners had a disability. Results suggest that spouses with a disabled partner and a child with a severe mental illness had the highest level of negative well-being (psychological, physical, social, and financial). Those with a disabled partner and no disabled child were the least affected on a negative level, but still showed signs of psychological and physical strain (Ghosh et al., 2012). The authors conclude that support workers must develop interventions to help address the needs of these parents, such as planning for the provision of long-term care for their children as they grow older.

The research suggests that both persons with vision loss and their partners are negatively impacted on a psychological level. Depression, anxiety, and fear are all concerns that must be

addressed while working with both groups. These psychological concerns may also impact individuals differently, depending on age, gender, and whether there are children or other family members involved. Struggling with these psychological impacts may also lead to issues with relationship satisfaction. Although participants discussed in the literature are in an older age group than that of those in this current study, psychological impacts and relationship satisfaction may still be similar in younger populations.

**2.4.2 Relationship satisfaction and vision loss.** The literature suggests that levels of relationship satisfaction among persons living with a disabled partner are negatively impacted. This includes their relationship with their partner and with others in the social sphere. Many participants in past studies state that because of their partner's hearing impairment or spinal cord injury, they are unsatisfied with the physical and emotional relationship between them and their partners (Feigin et al., 1996; Scarinci et al., 2009). Participants also show high levels of dissatisfaction in their social lives (Feigin et al., 1996; Scarinci et al., 2009).

Scarinci et al., (2009) conducted a mixed methods study on the effects of hearing impairment in older adults age 49-87 on the spouse. They first conducted a qualitative study consisting of interview questions in order to develop themes that were discussed by people whose partners had a hearing impairment. Participant interview data revealed themes such as frustration, embarrassment, sympathy, lack of communication, dissatisfaction with the relationship, and the need to adapt to daily activities. The researchers then used the results from their qualitative study to develop a questionnaire based on the *Significant Other Scale for Hearing Disability*. One hundred couples age 49-87 were given the questionnaire and the findings were similar to that of the qualitative study. Results suggested that spouses were frustrated because they had to adapt to their partners' hearing disability, they were afraid for their

partners' safety while in public, and they were required to change daily activities in order to accommodate their partners (Scarinci et al., 2009). The extent to which partners are satisfied in their relationships and how they are impacted on a psychological level, may differ depending on their age.

## **2.5. Age of the Population**

The age of participants is the most common feature in the literature. The majority of the research participants were adults ages 49 years and older in studies that examined the impact of partner disability on spouses (Ghosh et al., 2012; Scarinci et al., 2009; Strawbridge et al., 2007; Westaway & Wittich, 2011). Although it is important to understand how older adults are impacted by a partner's disability, this leaves a gap in knowledge when it comes to a younger adult demographic. The experiences of younger adults who are living in a relationship with a partner with a disability may differ on many levels. For example, younger populations may tend to be more knowledgeable in the use of technology. Having access to various forms of technology can drastically change an individual's ability to gain information on the availability of accommodative supports. Having access to how disability affects partners is important information and has the potential to change the way in which someone experiences a specific situation (Williams, 2015).

Other differences among age groups may involve social life and sharing of activities. For example, younger individuals tend to be more socially active in certain areas. Plus, they may be raising a young family and there may be other effects. Work-life balance and financial decision making may also differ among the younger and older populations (Xiao & Chen, 2015; Marcum, 2012). Qualitative research focusing on younger adult populations will provide a stronger comparison of differences and similarities with older populations. In addition, personal resources

such as having a strong sense of coherence and how this may impact one's capacity to adjust to life's challenges may differ among younger and older populations. Possessing certain personality traits and having varying levels of understanding and knowledge of the situation will impact experiences living with a partner with a disability.

## **2.6. Sense of Coherence & Studies on Disability**

Having confidence, knowledge, and positive thought processes allows for one to better cope with certain situations. Sense of coherence (SOC) is a:

global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable; that resources are available to one to meet the demands posed by these stimuli; and, that these demands are challenges worthy of investment and engagement. (Antonovsky, 1993, p. 725)

In other words, having a high SOC means the person has an understanding of the environment and a feeling of being in control of a given situation (Antonovsky, 1993, Collingwood, 2013). Past studies have measured participant's levels of SOC in order to determine the extent to which these individuals positively handled certain situations. For example, persons living with a partner with a disability may have minimal negative symptoms such as depression and anxiety, when they have a high SOC (Boeckxstaens, 2016; Feigin et al., 1996).

In a recent study looking at how sense of coherence impacts health outcomes, Boeckxstaens and colleagues (2016) determined SOC levels of 567 seniors who were 80 years and older. This was a quantitative study that examined the relationship between SOC and

characteristics such as depression, cognition, and disability. The researchers found that those participants with a higher SOC showed less functional decline than those with a low SOC.

In another quantitative study on the impact of disability on disabled individuals and their spouses, Feigin et al., (1996) focused on the relationship between an individual's SOC and their adjustment to the disability. In this study, disability referred to a spinal cord injury or cerebrovascular disease. They looked at how one's personality traits helped with positive adjustment rather than how disability severity affected adjustment. The sense of coherence was defined as the "internal resources that enable individuals to cope with stressful situations and to maintain psychological and physical health" (Feigin et al., 1996, p. 163). According to these authors the term *adjustment* referred to acceptance, health, marital satisfaction, social activities, and work/study hours (Feigin et al., 1996, pp. 163-64).

These authors used a variety of questionnaires that were given to 71 couples ages 28 to 65, which asked questions related to SOC (personality traits) and adjustment to the disability (Feigin et al., 1996). The results revealed that the spouses who had a higher SOC were more able to positively adjust to their partners' disability. More specifically, spouses who felt they understood the disability, who believed they had the necessary resources, and who were willing to do whatever they needed to support their partner had the most positive adjustment. Spouses who had a lower SOC showed more signs of anxiety and were less satisfied with their marital and social relationships (Feigin et al., 1996). As discussed in the literature, there are a number of factors that contribute to the experiences of adults living with a disabled partner. These include psychological well-being, relationship satisfaction, age, and the extent to which persons understand their partner's disability. These factors may also be impacted by one's experiences with the physical environment and interactions with others in the community.

## 2.7. Critical Disability Studies

Critical disability studies are an interdisciplinary approach to research. Based on critical theory, studies in disabilities argue against the view that disability is a personal tragedy or individual pathology. Instead, a critical disability studies perspective views disability as a cultural, social, and political phenomenon (Ferguson & Nusbaum, 2012; McGrath, Laliberte-Rudman, Spafford, Trentham & Polgar, 2017). Furthermore, disability should be seen as a social or political category, rather than something that is diagnosed or labelled onto an individual (Ferguson & Nusbaum, 2012).

In a qualitative study of ten seniors age 75 and older, McGrath and colleagues (2017) looked at how the social environment marginalizes and causes barriers to seniors with age related vision loss. The researchers conducted semi-structured interviews, as well as observing the ten participants performing various activities in public. Findings from this study revealed that the social environment negatively impacted visually impaired seniors in three areas. These areas were eating in public restaurants, mobility issues out in public locations, and shopping at grocery stores (McGrath et al., 2017).

According to McGrath et al., (2017), participants stated having difficulty reading the menus due to the small print size when eating in restaurants. This difficulty was escalated when restaurant menus were shiny due to lamination. Participants experienced difficulty shopping due to the size of the print on grocery items, along with the placement of items in stores. Mobility in the community was also a concern, due to not being able to see crosswalk lights and signals, and insufficient lighting in certain locations. McGrath et al. (2017) also mention another important finding that emerged from their study. Rather than participants having a desire to see change within the social environment; they simply conformed to the environment and made individual

changes, in order to continue with their daily lives despite having some struggles doing so. The researchers brought intersectionality theory into their study. Participants not only faced barriers due to their vision impairments, but also due to their age. For example, while navigating a busy street, participants had difficulty seeing when a crosswalk light indicated it was safe to cross. Crosswalks only give a certain number of seconds to cross, before traffic begins to move. Due to mobility issues related to age, some participants struggled to navigate across the street in the amount of safe time provided (McGrath et al., 2017).

In a similar study of 364 older adults age 65 with age related macular degeneration, Cimarolli and colleagues (2011) looked at the functional, social, and psychological impacts of having a vision impairment in older adulthood. This was a qualitative longitudinal study, where the researchers interviewed participants at three stages over a two year period. In terms of functioning in the social environment, findings revealed that participants struggled in areas such as shopping and eating in restaurants. More specifically, being unable to see product labels or price tags, and struggling to read the small print on restaurant menus. Other findings revealed that participants spent less time involved in social gatherings because they could no longer drive to the events, and because of feelings of frustration and anger due to their sudden decrease in vision (Cimarolli, Boerner, Brennan-Ing, Reinhardt & Horowitz, 2011).

## **2.8. Chapter Summary**

Despite the negative impact on partners of those with a disability suggested in the literature, research also reveals that abled partners have a strong desire to stay in the relationship and support their significant others. These individuals stay in the relationships despite the hardships that arise. They support their partners in daily activities, show concern for their partners' safety, and strive to become educated in the area of disability in order to positively

strengthen their relationships (Feigin et al., 1996; Scarinci et al., 2009).

As shown in this literature review, there are many reasons that support the need to pursue a qualitative study focusing on the experiences of young adults living in intimate relationships with a visually impaired partner. First, the majority of existing research in this area involves adults and seniors age 49 and older. Second, in terms of the disability, some research has looked at vision loss; however, the majority of studies focus on other physical disabilities such as hearing loss, and disabilities impacting mobility, or mental health disorders. Third, with the exception of Scarinci et al.'s (2009) mixed methods study, research in the area of the impact of disability on spouses tends to be quantitative in nature. The results of quantitative studies provide valuable evidence showing that adults living with a partner with a disability often exhibit particular strengths that can offset the potential negative impact of their experiences. It is important to be aware of the potential strengths of the non-disabled partner as well as the potential negative impact of living with a partner who has a visual impairment. The following study gathered participants' data about their lived experiences. A qualitative design allowed for a rich and detailed description of these experiences.

## **Chapter Three: Research Design**

### **3.1. Chapter Overview**

This chapter will present a background of phenomenology which will be used as a research approach. A discussion of the research design will then be presented, followed by sections outlining ethics and trustworthiness. I chose to pursue a qualitative study with a young adult participant sample because qualitative research provides the opportunity for the voices of those experiencing a phenomenon to be heard. Young adults living with visually impaired partners often do not experience the phenomenon in isolation. Therefore, by interviewing multiple participants and utilizing transcendental phenomenology the participants voices and experiences can be merged together to form an essence (Moustakas, 1994). The older population represented in the literature may have different experiences than that of younger adults experiencing the same phenomenon of living with a partner with a disability. These experiences may be different due to the social environment, personal supports, and how one views her or his relationship. Furthermore, the ways in which one experiences the phenomenon is not permanent and may change over time. As Bryman (2001) describes social phenomena and its meanings are continually being changed and altered through social interaction, therefore truth only occurs in the moment (Bryman, 2001; Vanson, 2014).

I have chosen to use a phenomenological approach in this qualitative study that will incorporate broad questions in order to develop a rich and detailed understanding of participants' experiences living in intimate relationships with their visually impaired partners. At its most basic form, phenomenology attempts to synthesize individual experiences of a phenomenon into a description of the universal essence (Creswell, 2013, p. 76). The essence of an experience

consists of “what” participants experienced and “how” they experienced it (Creswell, 2013, p. 76).

### **3.2. Qualitative Paradigm**

Qualitative and quantitative approaches are rooted in interpretivist and positivist philosophical traditions (Edirisingha, 2012). These approaches have differing ontological and epistemological assumptions. Furthermore, paradigms are frameworks that are derived from belief systems about the nature of knowledge (Robert Wood Johnson Foundation, 2008).

Qualitative approaches to research focus on social inquiry and follow many assumptions. Qualitative researchers are primarily concerned with process rather than outcomes or products. Qualitative researchers are also concerned with understanding meaning, in other words, how people make sense of their experiences and the world around them (Creswell, 1994).

The second assumption in qualitative research relates to how the researcher is the primary instrument for data collection and analysis. Data is most commonly gathered through the use of interviews or other interactions with participants, rather than using inventories or statistical software. This research also involves field work, where researchers may spend lengthy amounts of time interacting with participants in their natural environments. Finally, the third assumption is that qualitative research is inductive, meaning that researchers develop concepts and theories from the details that are gathered during data collection and analysis (Creswell, 1994; Merriam, 1988).

Multiple realities exist in qualitative research, including that of the researcher and those who are participating in the study. Understanding the multiple realities and experiences of participants involves gathering data and presenting findings that include the voices of those involved in the research. Engagement with participants is important in order to accurately

represent these voices in the research. Qualitative researchers interact with participants and the goal of researchers is to minimize the distance between them and participants (Marion, 2007).

Much of qualitative research also involves field work, where the researcher enters the physical environment to gather data. This form of data collection usually involves the researcher observing participants in their natural environment, and making field notes based on what has been observed. Finally, researchers may spend extensive amounts of time in the field gathering data. This may involve conducting multiple interviews with each participant over time, as well as continually engaging with participants during data analysis (Creswell, 1994; Marion, 2007). Subjective experiences of individuals and their interpretations of the world tend to be the focus in qualitative research (Marion, 2007). The goal is to understand the lived experiences of participants. Because of this goal, phenomenology as a methodology fits well with qualitative research.

### **3.3. Phenomenology**

Phenomenology has its roots in the discipline of philosophy. Edmund Husserl, a German philosopher and mathematician, is considered to be the founder of phenomenology (Wojnar & Swanson, 2008, pp. 172-174). Husserl was concerned with the consciousness of the individual. He argued that people can be certain about how things appear and how they present themselves in terms of their consciousness. In order to arrive at certainty, anything outside of the immediate experience must be ignored (Groenewald, 2004). These philosophical ideas about human consciousness and immediate experiences allow phenomenology to have a unique place in qualitative research.

At its core, phenomenological research attempts to describe and understand phenomena as experienced by individuals (Wojnar & Swanson, 2008, pp. 172-173). Husserl's ideas form a

*descriptive phenomenology*. In descriptive phenomenology, the purpose of research is to understand the meanings that people give to lived experiences and to describe the universal essences of a particular phenomenon. It is also important in descriptive phenomenology for the researcher to abandon her or his lived reality in order to fully understand the phenomenon. Separating the researchers' reality and values is also known as "bracketing," where the researcher neutralizes personal biases and experiences (Wojnar & Swanson, pp. 173-174). Wojnar and Swanson (2008) state that some researchers believe you cannot and should not bracket your personal experiences regarding the phenomenon. These researchers believe that all experiences are important and these experiences, including that of the researcher's, should be blended together to form meanings of the phenomenon. Despite this belief, I have chosen to attempt to bracket my experiences while conducting this study. This will allow me to gain a full understanding of participants' experiences without my views impacting the overall meanings and essence. However, a tenet within the social constructivist perspective is the belief that knowledge is co-created by both participant and researcher. Even though there is acknowledged tension with the constructivist perspective and bracketing, I feel it is important to attempt to bracket my experiences in order to focus entirely on participants' experiences with the phenomenon.

As a person in the relationship with a visual impairment, I have my own understanding of how my partner experiences our relationship. Through conversations with my partner before and during this study, I have come to understand how my partner experiences our relationship. Reflecting on these conversations and personal experiences while collecting and analyzing the data in this study has helped with putting personal information aside and not allowing it to find its way into the data, thus ensuring that participants' voices are heard.

Even though attempts were made to bracket my personal experiences with the phenomenon, it is impossible to completely accomplish this task of phenomenological reduction. Given my experience as a visually impaired person and as a counsellor who has worked with other visually impaired individuals and their families, it was impossible to ignore my beliefs about the phenomenon being researched. However, by reflecting on these beliefs and attempting to place them aside, a new or fresh understanding of the phenomenon can be discovered by speaking with others. As Boyd (1989) suggests, bracketing is a temporary suspension of prior beliefs, in order to allow for new perspectives and questions to emerge.

According to LeVasseur (2003), we bracket our beliefs and understandings when we become curious about a phenomenon. When we begin to inquire and seek further knowledge about a phenomenon, we recognize that we do not have a full understanding of the phenomenon. Therefore, we put our pre-existing beliefs aside in order to gain further understanding. My curiosity of the experiences of young adults living with a visually impaired partner stems from my having a visual impairment, living with my partner, and previous experience working with others who have vision loss.

**3.3.1. Transcendental phenomenology.** I utilized Clarke Moustakas's transcendental phenomenology (1994) in this study. Moustakas's transcendental phenomenology borrows ideas from Husserl's descriptive phenomenology, while adding a more systematic, step-by-step approach to data analysis (Creswell, 2013; Moerer-Urdahl & Creswell, 2004). Moustakas (1994) places a focus on the wholeness of human experience and an understanding of the essences of experiences. Researchers must set aside their personal experiences with the phenomenon in order to develop a fresh perspective of meanings and lived experiences.

Moustakas (1994) describes transcendental phenomenology as searching for a central underlying meaning of experiences with a particular phenomenon. In other words, it is the search for the essence of these experiences. Because transcendental phenomenology involves searching for an overall essence, all individual experiences with a particular phenomenon hold an equal level of importance. These experiences must be thoroughly analyzed to form significant statements and themes, which then can be formulated into an overall essence of the experience.

### **3.4. Research Design**

Prior to beginning the research, a study proposal was developed and approved by my thesis supervisor and committee members. An application for ethics approval was then completed and submitted to the University of Regina Research Ethics Board. Once approval was granted, I began the process of participant recruitment.

**3.4.1. Participant recruitment.** Phenomenological research typically involves a small sample size, usually between three and ten participants, due to the amount of time required for data collection and analysis (Creswell, 2013). All participants must have experience with the phenomenon under examination (Creswell, 2013; Groenewald, 2004 & Hycner, 1994). Purposive sampling was used to recruit participants. Purposive sampling is used based on knowledge of the population and purpose of the research. Participants are selected based on specific characteristics (Babbie, 2001). Snowball sampling was also used for recruitment. This involves asking current participants to spread the word to others who meet the necessary criteria that are needed to participate in the study (Creswell, 2013, p. 158).

For the purpose of this study, the participants were defined as young adults who were living in an intimate relationship with a visually impaired partner. Because current research has primarily focused on adults age 49 and older, the main criterion was that participants must be

between the ages of 21 and 30 years, this criterion was later increased to 40 years. The age of participants was increased to 40 years due to difficulty recruiting at least five participants between the ages of 21 and 30. Two additional participants were successfully recruited once this age range was increased. It was also important to have both female and male participants. The findings of Strawbridge et al.'s (2007) study suggest that women between the ages 51 to 90 years, are more negatively impacted than men because they place a greater importance on communication. Male partners with a disability were found to have poor communication with their female spouses, which caused extreme frustration among the spouses (Strawbridge et al., 2007).

Two methods of recruitment were identified as being possible strategies for finding participants. These methods included posting study information on a local Facebook group titled "The Regina and Area Visually Impaired", and contacting various organizations who work with persons with vision loss. Information about this study was posted on the Facebook group site for "Regina and Area Visually Impaired". Members of the group were asked to respond to the post if interested, as well as to forward the study information to others who may have fit the criteria.

Various organizations were also contacted and provided with a recruitment poster and letter, which outlined the research as well as contact information (see Appendix C & Appendix G). The organizations included the Canadian National Institute for the Blind (CNIB), University of Regina and University of Saskatchewan Disability Services Centre's, the Regina Public Library Accommodation Centre, and various optometry clinics. Follow-up postings and phone calls were made if there were no responses after the first month.

A copy of the consent form was emailed to each interested participant once initial contact was made. Initial contact was made by telephone. One participant was contacted by the

researcher. The other four participants initiated contact by telephone once hearing about the research. A copy of the consent form is in Appendix F. The consent form explained the purpose of the research, how the data would be collected and analyzed, as well as information regarding the risks and benefits of participating in this study. Pseudonyms were chosen by each participant in order to ensure confidentiality. Participants were also asked permission to have their interviews audio recorded. Once the consent forms were signed, a private location and date were agreed upon to conduct the interviews.

Two months into the recruitment process an amendment request was submitted to the University of Regina Research Ethics Board. The request was for the approval to expand recruitment into other locations outside of Saskatchewan due to difficulty finding an adequate number of participants or a low response rate. Approval was granted from the University of Regina, Research Ethics Board to expand recruitment to include British Columbia, Alberta, and Manitoba. The second amendment also allowed the participant age group to be increased from ages 21-30 years to 21-40 years of age. These two amendments allowed for the successful recruitment of five participants and are included in Appendix A and Appendix B.

**3.4.2. Data collection.** Phenomenological research is widely understood as having more than one means of investigation (Englander, 2012; Streubert & Carpenter, 1999). One-on-one semi structured interviews were used for data collection in order to learn the meaning of the phenomenon as lived by each participant (Englander, 2012). The interviews consisted of broad, open-ended questions based on a semi structured interview guide, which is included in Appendix E. This was chosen as the only means of data collection, in order to speak directly with participants and gain an understanding of their experiences through their voices. Prior to the start of the interview, there was casual conversation between myself and each participant to

develop rapport. The consent form was discussed and participants were asked if they had any questions. Consent forms were then signed and a password protected audio device was set up in front of the participant.

All interviews consisted of the same open-ended questions. These included questions related to experiences with personal and community accommodations, views about personality traits and knowledge, and experiences with personal supports. Follow-up questions were asked if I needed participants to expand on a specific answer. The interviews concluded when participants acknowledged that they had sufficiently answered the questions. Participants were then thanked for their time. All interview tapes were transcribed and each participant was given the opportunity to review their interview transcription with the option to complete a second interview if requested. This allowed participants to ensure their voice was heard and their experiences with the phenomenon were accurately expressed. There were no requests for second interviews from any of the participants or from the researcher. All of the participants confirmed that the transcripts accurately portrayed their experiences with the phenomenon, and did not request any further changes.

My original intention was to conduct multiple interviews with each participant, however as stated above, upon reviewing their transcripts all of the participants felt their experiences were fully described in the first interview. Many researchers have argued that single interviews can be sufficient in qualitative research. Passerini and Sandino are cited in Baker and Edwards (2012) as stating that single qualitative interviews can provide rich accounts of subjectivity. Similarly, Baker and Edwards (2012) describe Jensen's argument that it is important to focus on the quality of the interview analysis rather than the quantity of interviews. Finally, Wolcott states that the

researcher should keep asking, until receiving similar descriptions or answers (as cited in Baker & Edwards, 2012).

**3.4.3. Data analysis.** Transcendental phenomenology has a systematic process for data analysis that is both rigorous yet accessible (Moustakas, 1994). Moustaka's data analysis was used to gain an understanding of the meaning, structure, and essence of a phenomenon as experienced by a group of individuals (Patton, 2002). Transcendental phenomenology involves a step-by-step reductionist approach where interviews are analyzed for significant statements, which are then categorized into themes, and then formed into a universal description or an overall essence of a phenomenon (Moustakas, 1994).

Moerer-Urdahl and Creswell (2004) provide a detailed description of the step-by-step analysis process used in this study. There are multiple stages in the data analysis process. The first stage is known as epoche which means to refrain from judgment in order to gain a fresh understanding of a phenomenon as experienced by others (Moustakas, 1994). I attempted to set aside my preconceived ideas and experiences of the phenomenon in order to gain a full understanding of participants' experiences. This involved constant reflection of my experiences with the phenomenon under investigation and talking to others about these experiences prior to conducting the interviews and while analyzing the transcripts. Due to the lack of compatibility between data analysis software and computer programs that accommodate my vision impairment, manual analysis of the transcripts was necessary. Transcripts were opened in Microsoft Word and voice reading software and magnifiers were utilized.

The second step in the data analysis process is known as horizontalization. Each transcript was read multiple times and significant statements were extracted from the textual

data. These statements were compiled into a list and phrases that did not have importance to the research question were removed.

Step three involved clustering the significant statements into meaning units or themes. The list of significant statements was read over multiple times and a list of themes was developed. Step four involves using the meaning units or themes to develop textual description (what was experienced by each participant) and a structural description (how it was experienced). The final themes were developed from these descriptions and a universal description or essence of the experience was formed (Moerer-Urdahl & Creswell, 2004; Moustakas, 1994).

### **3.5. Ethical Considerations**

It is important to be sensitive to ethical considerations during all phases of a research study (Creswell, 2013, p. 55). The processes and procedures of the study will be discussed in detail. These processes and procedures were discussed in the consent form which was then provided to participants. Ethics included respecting the rights and well-being of all persons involved in the study, as well as being aware that sensitive topics may arise for participants while reflecting on their experiences. Furthermore, being mindful during interviews and actively engaging participants allowed me to obtain a full understanding of their experiences (Eide & Kahn, 2008; Walker, 2007). As previously stated, this study received ethics approval from the University of Regina Research Ethics Board prior to beginning participant recruitment. Informed consent, confidentiality, and risk to participants were considered prior to beginning data collection.

**3.5.1. Informed consent.** All participants were provided with a consent form that clearly outlined the purpose of the research, their role in the study, how confidentiality and anonymity

would be handled and the processes of data collection. Prior to signing the consent form, participants were asked if they had any questions, concerns, and if they understood their participation in the research. Participants had the right to withdraw from the study at any time. If a participant withdrew from the study prior to data analysis and findings being written, all information related to that participant would be destroyed.

**3.5.2. Confidentiality.** The confidentiality of participants was ensured throughout this study. Interviews were conducted in private away from any public location. Three of the interviews were conducted face to face in the participant's home. The final two interviews were completed by telephone while participants were at home without other individuals or distractions. Privacy was ensured by asking each participant to schedule a time to complete the interview, such as when partners were at work and children were at school. Each participant chose a pseudonym to use prior to the start of the interviews. One of the five participants did not want to use a pseudonym and requested to use her or his real name in the research. The audio recorded interviews were stored on a password protected device. All participant information including consent forms, transcripts, and data analysis documents were stored on a password protected computer. Only the researcher and supervisor had access to the information as outlined above. All study documents were stored in the supervisor's office for a set period of time of five years once the research was complete, as per University of Regina Research Ethics Board procedures.

**3.5.3. Risk to participants.** This study was deemed to be minimal risk to participants. Within the consent form, it was acknowledged that participants may experience some psychological stress due to talking about certain experiences during the interview process. If this was to occur, I would provide referral information to the participant to speak with a counsellor.

Participants had the right to refuse to answer a question if they were not comfortable and the right to withdraw from the study at any time was also an option.

### **3.6. Trustworthiness of the Research**

Lincoln and Guba (1985) state that trustworthiness is important in a research study in order to evaluate its worth. Trustworthiness involves four criteria including credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985; Shenton, 2004). In other words, trustworthiness involves being confident in the truth of the findings by showing that the findings have applicability in other contexts, showing that the findings are consistent and could be repeated; and confidence that the findings are shaped by participants' responses and not by the researcher's bias (Lincoln & Guba, 1985; Shenton, 2004). The strategies for meeting these criteria include member checking and ensuring rich, descriptive findings (Creswell, 2013).

Multiple steps were taken in order to ensure trustworthiness in this study. As discussed earlier, I followed the epoche process in order to set aside, as much as possible, my personal experiences and ideas regarding living in a relationship with a visually impaired partner. I reflected on my personal experiences and spoke with others about these experiences prior to engaging with participants. Speaking with my wife for example, gave me the opportunity to understand our thoughts and experiences living with my vision impairment. Having these discussions and reflecting on them before and during data analysis allowed me to avoid bringing my personal experiences into the data and interfering with participants' voices. This allowed for a fresh and clear understanding of the phenomenon as experienced by each participant. Reflecting on, and understanding my personal experiences with the phenomenon helped separate my experiences from the data collected on participant experiences. Furthermore, the bracketing process allows for new ideas and experiences to enter into consciousness (Moustakas, 1994).

Reading over the participants' transcripts multiple times allowed for full emersion and preservation of participants' voices throughout the findings.

Member checking is also important to establish trustworthiness and credibility (Creswell, 2007; Moustakas, 1994). Participants were given the opportunity to read through their transcribed interviews in order to determine accuracy. Participants were satisfied with their transcripts and felt that they accurately described what they wanted to express in regards to their experiences with the phenomenon. Once significant statements and emerging themes were developed through analysis by the researcher, participants were contacted and asked to review this data to ensure that what they said during the interviews matched the statements and themes. Two of the five participants felt the emerging themes fit well with their experiences. The other three participants decided not to review this data and felt that their review of the transcripts was sufficient.

The strength of qualitative research is in its rich and detailed descriptions of participants' experiences (Creswell, 2007). While presenting the findings of this study, detailed descriptions of participants' experiences are provided. Participant quotes were used to describe participants' experiences. By using quotes it gives voice to each participant, allowing for a full understanding of what was experienced and how it was experienced. The voices of participants in the form of quotes provide support for the themes that emerged during data analysis.

### **3.7. Chapter Summary**

This chapter discussed the research methodology including the history of phenomenology and the use of transcendental phenomenology in qualitative research. A thorough explanation of the research design was then presented, including a discussion on the participant recruitment process, method of data collection, and the step-by-step process used in data analysis. The

importance of ethics was then considered, along with a discussion on the trustworthiness of the research.

## **Chapter Four: Findings**

### **4.1. Chapter Overview**

The purpose of this study was to explore the lived experiences of young adults living in an intimate relationship with a visually impaired partner. Five participants were interviewed using open-ended questions. The interview questions were as follows; (1) What are your experiences in terms of accommodating your partner on a day to day basis?, (2) What are your thoughts on community accommodations, and what changes need to be made in the community to better accommodate your partner?, (3) What personality traits and knowledge do you feel you possess that helps you accommodate your partner?, and (4) What personal supports do you feel you need?

This chapter will provide a brief description of each participant, followed by a presentation of the various themes that emerged from each question during the participant interviews. Three main themes emerged. These themes will be presented with ten sub-themes along with quotes to represent the voices of participants. Participant transcripts were read over multiple times, pulling out a variety of significant statements related to participant experiences. Similar statements from participants were then clustered together to develop the main themes, sub-themes, and an overall essence of the experience.

### **4.2. Participant Profiles**

Two female and three male participants between the ages of 23 and 39 years of age were interviewed. All participants were Caucasian. All participants were living with their visually impaired partners at the time of the interviews. The following is a brief description of each participant.

**4.2.1. Pierre.** Pierre is a 29-year-old male who is married to his partner. They have been together for 12 years. Pierre is employed and working two jobs. He has a university degree in music and is currently studying a trade. He and his partner have no children and they live in an urban center.

**4.2.2. Amanda.** Amanda is a 26-year-old female who has been dating her partner for two and a half years. She is a university student studying biology and is also employed. She and her partner have no children and they live in an urban center.

**4.2.3. Bill.** Bill is a 23-year-old male. He and his partner are married and have been together for five years. He has a university bachelor's degree in Arts and is employed. Bill and his partner live in an urban center.

**4.2.4. James.** James is a 39-year-old male who is self-employed with a college degree. He and his partner have been married for eight years. They have two children and they live in an urban center.

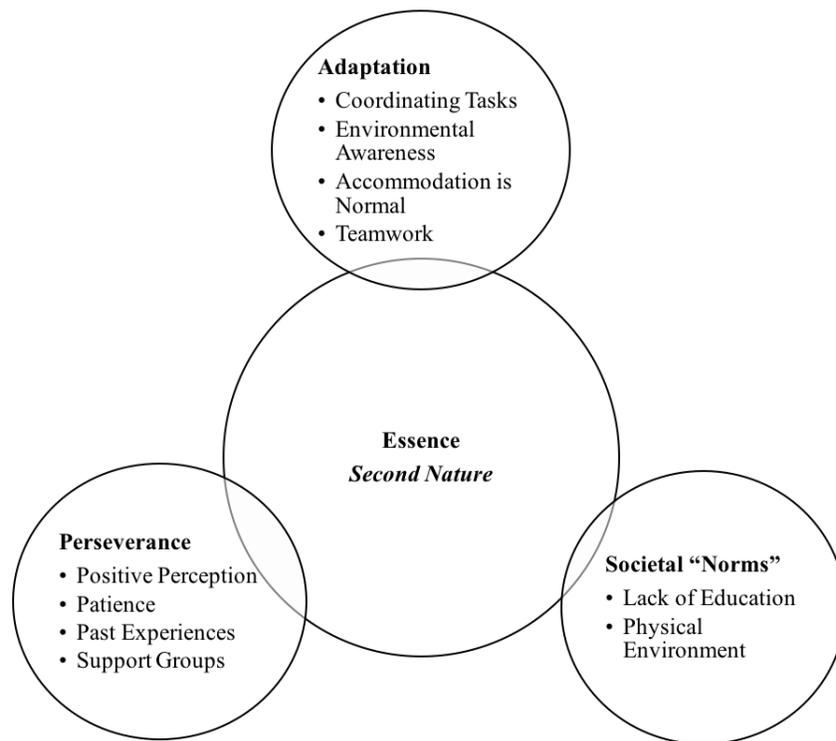
**4.2.5. Rhonda.** Rhonda is a 34-year-old female. She and her partner are married and have been together for 14 years. They have two children and they live in a small rural community.

### **4.3. Overview of Themes**

Three themes emerged from the participant interviews, along with ten sub-themes and an overall essence of participant experiences. Figure 1 provides a visual diagram of these themes, sub-themes, and essence of the experience. The three main themes included adapting to the situation, social “norms,” and perseverance. Ten sub-themes emerged within the three main themes including driving, environmental awareness, past experience, and lack of education. An overall essence of *second nature* was present through the analysis of participant interviews and

constant reflection of the themes and sub-themes. The following sections will provide detailed descriptions of the findings. Quotes will be used to represent participants' voices in order to fully present their experiences living with a visually impaired partner. A visual diagram outlining the themes, sub-themes, and essence of participant experiences is presented.

**Figure 1. Diagram of Themes that Emerged from the Data.**



#### **4.4. Theme 1: Adapting to the Situation**

The five participants in this study explained how they adapted to various situations in order to accommodate their partners. Adaptation is not always easy; however they work alongside their partners to shape their experiences as positive and worth the effort. The adaptations included areas such as driving, scheduling, and being aware of the environment. Furthermore, adaptations became easier over time and participants viewed their experiences as normal everyday routines.

**4.4.1. Coordinating daily tasks.** The first question asked was general and open-ended. Participants were asked, “What are your experiences accommodating your partner on a day to day basis”? Each participant spoke about driving as being the number one supportive activity they provide on a regular basis. Pierre and Bill both stressed that driving was the number one adaptation, especially in the evenings when it is too dark outside for their partners to see. James discussed how his wife’s vision was still strong enough for her to drive occasionally, however her vision will gradually worsen to the point that eventually she will no longer be able to drive in the future. He stated, “It is getting to the point where I’m going to be the only one driving. Umm, but you know we’ve been dealing with that for a number of years already. So, we’re getting pretty used to it”. James further states, “All the kids’ activities, anything like that, like grocery shopping, I’m the main driver”.

Amanda and Rhonda spoke about planning ahead of time and making schedules, in order to ensure they were available to drive their partners around town. Amanda said, “I have to drive him places. Umm, I mean that’s like, it’s kind of just a matter of making sure that our schedules match up properly so that I can do that”. Similarly, Rhonda said, “I have to make an effort, or make it work into my schedule to take him to different places”. Later in her interview she discussed driving again when she stated:

But yeah even with something like a haircut. I have to leave work to go get him, and take him to the haircut. Then sit and wait for the haircut to be done, and then take him back again. You know, instead of me going back to work for 15 or 20 minutes.

**4.4.2. Environmental awareness, safety and independence.** The second theme that emerged from the first question was environmental awareness. All five participants spoke about being aware of the household environment in order to ensure their partners’ safety. Their

awareness was also present in order to allow for partners to be more independent around the house while performing certain tasks. Pierre and Amanda talked about making sure areas at home are clear. Pierre said, “I have to make sure in the house I’m not leaving something laying around or umm... Because she trips over it. You know, she can’t necessarily see that it was in front of her”. Amanda similarly talked about ensuring items are stored away at home because it’s not something she would normally think of doing on a regular basis. James goes one step further with this issue because he must be aware of the items his children leave around the house, as well as his own. James states, “We do have two kids, and they do tend to leave things on the stairs and that sort of thing. In places that are high traffic areas. So yeah, I have to keep a look out for that”.

Rhonda also spoke about being aware of items around the house, and making sure they were stored away so her husband does not bump into them. She said:

When it comes to placing things in the house. For example, if I were to leave a laundry basket or something in the hallway that usually isn’t there or somewhat in the way he will bump into it. So things have to be placed as usual so the pathways are clear and normal.

Bill discussed how he is aware of certain locations in the home that must be altered in order to ensure that his partner can be as independent as possible. He said:

She does a lot of the cooking. The only thing is I put the dots on everything. And an appropriate amount of light in the house is helpful to help her see certain things and that kind of stuff, but as long as she has enough light and nothing gets moved, then we are good.

**4.4.3. Accommodating is just normal.** Amanda, Bill, Pierre, and James all referred to their experiences with accommodating their partners as being second nature. They have been supporting their partners for so long, that it has become normal for them, and they do not think about providing this support. Pierre stated, “It’s just something that’s always been second nature to me”. He later said, “I mean really it becomes second nature and it’s not really, I don’t see it as a big deal”. Amanda views her experience as not really accommodating, and just a normal routine. She said, “I’ve never really thought of it as accommodating him. I guess it’s just what we do. But yeah, it’s just normal”.

Bill’s thoughts on his experience are similar to that of Amanda and Pierre. When talking about his experiences supporting his partner, Bill said, “the accommodations aren’t really they, don’t really affect me anymore. It’s just second nature just because I have been doing it for so long”. James discussed how certain accommodative activities such as driving have become normal. He stated, “It is getting to the point where I’m going to be the only one driving. But you know we’ve been dealing with that for a number of years already. So we’re getting pretty used to it”.

**4.4.4. Teamwork and communication.** The next theme that emerged from question one of the participant interviews was teamwork. Bill spoke about the importance of communicating to one another about their needs, and knowing when to back away if he is being overly accommodative. He stated, “She has my back when I need support. Like when she explains what she needs from me”. He also said, “I know when to back off when she wants to do it on her own... I know my boundaries and I know her boundaries”. Pierre talked about working together when he and his partner are out in the community. He said, “I can warn her on what’s coming up without even saying anything now. We’ve just got it down to a science”.

James spoke about the importance of him and his partner working together to educate their children on his wife's vision impairment and how to positively work her disability. He said:

Unfortunately there's a chance that RP can be passed onto them as well. So that's one of the things that we are together working at, is trying to make them aware of it, kind of in a way that if they have it, they can deal with it themselves.

Similar to Pierre, Amanda spoke about working with her partner while walking outside in the community, and communicating with one another on where to go. She said, "Places walking outside. There will be holes or something, and it's like we have to be very specific about where we go".

#### **4.5. Theme 2: Societal "Norms"**

The participants discussed their thoughts, feelings, and experiences regarding members of the community and the physical environment. They perceived people in the community as having a lack of education on disability or vision impairment specifically, therefore treating persons with vision loss as though they were inferior, and refusing to provide the necessary accommodations for their visually impaired partners because it would change what is considered to be "normal." The participants also viewed the physical environment as having a lack of accommodative supports; however they felt they could adapt alongside their partners and overcome these barriers.

**4.5.1. Lack of community understanding.** The second question of the interviews focused on participants' opinions of community accommodations, and what participants wanted to see changed in their communities to better support their partners. Discussions about other persons within the community were voiced by participants. People in the community were

perceived as not accommodating due to a lack of education; not wanting to change what they believe is normal behaviour; or simply being rude. Pierre talked about his experience with his partner while they were interacting with security personnel at the airport. He said:

We've had some particularly ornery people working behind the airport counter... Like going through security and stuff like that. I remember this one time, this guy behind the airport thing when they were checking our boarding passes. He got a little pissy cause I was the one that handed him her passport and umm... He couldn't figure out why.

Bill told a discouraging story about his partner's friend and how she chose to move to a new community due to the way she was treated by others. Bill said:

A friend of hers is visually impaired as well. She felt like, out in (a small town near an urban center) she felt like she was outcasted, and any time she was out walking, even in grocery stores and that kind of stuff, people would purposely run into her. And it's like, how do you not accommodate someone like that, and that forced her to move out of Martinsville and back into the city. Because you can't take that on a daily basis.

During the interview with James, he talked about his experiences at restaurants when he has tried to request more lighting so his partner could see at their table. James stated:

There has also been times when we have asked for even a candle or something at our table, and most people are accommodating, but there's been a couple people where they flat out said no. Because it will change the ambiance of the restaurant.

**4.5.2. Issues in the community and the physical environment.** All the participants talked about aspects of the community that they felt were lacking accommodations for persons with vision loss. These issues included problems with crosswalks, Braille indicators in the

community, problems with public transportation, and certain locations that lacked the appropriate amount of lighting. Pierre referred to crossing certain streets with his partner when he said, “It would be nice if there was something in place that would make it easier for someone to cross the road”. In terms of public transportation, Bill discussed how frustrating it is to see his partner and others who cannot drive, waiting to access the city bus on its strict schedule. Bill said, “The thing that could change is that if transit was a better service here. Instead of running on the hour, it ran every 20 minutes or something”.

Rhonda felt that certain locations in the city are lacking the appropriate amount of lighting to accommodate her partner, and other individuals with low vision. She said, “It’s not as bad in a small town like here, but especially in the city lots of places are very dark”. She went on to say, “in certain restaurants, making sure things are spread out better”. James also talked about the issue of lighting when he said:

Lighting in restaurants is an issue. For sure it is. And not I mean, not just in restaurants but that would probably be the biggest one. I often have to read the menu for her and have to tell her what’s going on.

Amanda spoke about her thoughts on placing Braille around certain locations to help those who are blind. She believed adding Braille would be a great accommodation, however she was unsure how much an accommodation such as this would help people if they cannot see the Braille display to begin with. Amanda said:

In front of things they will have Braille. But it seems like I don’t know if somebody would even think to go look for it you know? Like they’ll have like, like it will say fire exit use stairs, but somebody probably wouldn’t think to actually go feeling for it.

#### **4.6. Theme 3: Perseverance**

Despite the need to adapt to the situation and feeling as though accommodations for their partners were lacking, participants found ways to persevere and shape their relationships into positive experiences. The findings revealed that perseverance and determination comes from participants' personality traits and how they relate their past experiences with the current situation. Furthermore, when participants had the understanding that there are others who have similar experiences helps them persevere. Having the desire to see places emerge where partners of visually impaired people can come together and share their experiences provides hope. Hope that there are other possibilities that can create more positive outcomes.

**4.6.1. Positive perception of the situation.** Participants saw their experiences as very positive, because of the way they perceived their situation. All participants stated they felt as though there were access to supports such as services at CNIB. Participants also stated having an accommodative work schedule and acceptance of a partner's disability from day one helped them cope with their situation. Pierre discussed his thoughts regarding the ease of availability of information if he ever requires support. He said:

Whatever we have to deal with on a day to day basis is probably something that has already come up for someone else in the past. So you know, it's pretty easy to go and find, you know if you do a quick a quick Google search it's pretty easy to find someone who is doing the exact same thing as you right now".

Amanda spoke about not seeing her partner and their relationship as being any different from other couple's that are not impacted by a disability. She said, "We are no different than any other couple. It's just one little thing that is different and we deal with it". She goes on to say,

“I’m not seeing him as the visually impaired guy, more like a guy who just has a problem with his vision”.

Bill and James discussed how it is easy for them to accommodate their partners because of their flexible work schedules. Bill stated, “The only thing we really have is the transportation issue. Like at night but it’s just really easy for me because nights are always free, because I work 8:00 to 4:30, so yeah”. Similarly, James said:

I’m lucky because I run my own business, so I can set my own hours, so we’re extremely lucky because I go to work, and I’m done by 4:00. So I have really short hours and I can get the kids to where they need to be in the morning, and I can pick them up afterwards.

Lastly, Rhonda talked about accepting her partner’s vision impairment from day one, before moving forward in the relationship. She said, “I know it was a big thing at the beginning when we first started dating, that I had to say to myself, well I have to accept it because it’s going to be with me forever kind of thing”.

**4.6.2. Patience and positivity.** The third question in the interviews asked participants to reflect on their personality traits and knowledge surrounding vision impairments. More specifically, the personality traits and knowledge that participants felt assisted with positive coping with their partners’ disability. Two themes emerged from these questions which were having the personality trait of patience and the ability to stay positive and cope with their experiences. These themes were mentioned by all the participants. Pierre spoke about the importance of being patient, especially if he was not sure how much his partner could see in particular situations. However, he stated that positive communication can help with this. Pierre said, “Have patience, that’s a big one (laughs) Umm... The best thing you can do is to talk with your partner and get a sense of how much can my partner see?”.

Rhonda mentioned how she needed to stay patient in terms of driving and accommodating her partner to get him around town. Amanda and James both talked about how being patient is sometimes hard, however they do their best to stay positive. James also discussed how patience can be difficult, especially when he finds out that his wife actually requires assistance with a task. He said:

Yeah umm, patience, that's not an easy one to master. But because my wife still has decent vision, I also forget daily that she even needs extra help, because my wife is the type of person where she just doesn't tell anybody. And in some cases she doesn't even tell me if she needs help. So I sometimes overlook it, and then something might happen and we both feel bad about it, but yeah, that's the biggest one for me is patience.

Bill did not specifically use the term patience; however he regarded himself as a caring and considerate person who was always ready to help his partner. He stated that he has no problem waiting for his partner to ask him for help. He feels she is extremely independent and it is important to avoid forcing his assistance if she does not require it.

**4.6.3. Past experiences, observations, and preparation.** The second theme developing from question three was past experiences. Participants spoke about people they knew from their past who had a vision impairment or some form of disability. The participants felt knowledgeable and prepared to support their partners if they had past experiences supporting family, and observing others with disabilities. Amanda spoke about observing a member of her church when she was a child. She said, "I sort of had an acquaintance who had no sight at all... The whole church would have to think about him all the time and think to pick him up".

Pierre discussed his experiences growing up with a brother who had autism, and how he learned to accommodate his brother's disabilities at a very young age. He said:

My entire life I grew up around a brother with autism so, someone in the family with a disability has always been a reality in my life. So it's, so when umm... I started dating my wife and you know, that was the first thing she told me is I have vision impairment. I was like, okay whatever... it didn't even phase me. So I grew up, it was just second nature for me to have to make special accommodations and to make sure the one in the household who needed the most help got it.

James also reflected on his experience as a child when he learned to support his mother who was living with a visual impairment. He said:

My mom did have Thieves disease, which actually I have too. She had cornea transplants to, so her eye sight was really bad. So yeah when I was younger, I had to deal with that for a little bit, as best we could.

Rhonda talked about her experience as a child when she would observe one of her mother's acquaintances. She stated:

There was one person that I've only really known who had a vision impairment. Not that I knew him well, but once and a while I would see him, maybe three times a year. It was my mom's piano tuner actually.

Rhonda also mentioned having a brother and sister in-law who have the same eye condition as her partner, however their vision loss was much worse than that of her partner's. She said, "It's easier to prepare for it if you know what could maybe happen in the future".

Before meeting his partner, Bill did not have experiences with others who had vision loss; however he felt his experiences learning from his partner once they started dating greatly benefited his ability to accommodate her in their present relationship. Bill said:

Well actually before her I never met anybody with vision loss, so it was kind of a learning curve. Especially when we started first dating, it was definitely a big learning curve because I had to learn how to guide and then I had to learn how to accommodate her and all the other things. Umm, but even when we were coming to get to know each other quite well, it just becomes, like even now sometimes she is so independent sometimes I forget. Like in the evening, I'm starting to walk away and she's like excuse me, you're forgetting someone. You tend to forget that they have the visual impairment. So yeah that's exactly it, you completely forget that they have a visual impairment, and it just becomes, it just sits in the back of your head and you don't really ever think about it.

**4.6.4. The need for support groups.** The final question asked during the interviews focused on what participants felt they needed in terms of personal supports. All participants spoke about how it would be helpful if there were support groups for partners or families of persons with vision loss. Having a supportive group would provide a space where people could discuss their experiences and provide advice to one another on how to stay positive and understand vision impairment on a whole new level. Pierre said, "Maybe that's something CNIB can look at is a place where parents or spouses or siblings even, could get together and talk about their experiences around someone with a disability". Bill also stated that there needed to be support groups for family members.

In terms of communication among partners of persons with vision loss, Amanda said, "If there was a way for partners to talk to each other" it would be beneficial. Rhonda similarly stated, "A support group or counselling, like people to talk to about it". Lastly, James commented, "Something for people that have RP and for the spouses and or the families, where they can go and talk together about what other people's experiences are".

#### 4.7. Other Findings to Consider

Although additional information gained from the interviews was not compiled into specific themes, I believe it is important to briefly discuss. Additional information showed that supportive community accommodations do exist and that education and advocacy are important to further increase positive supports, and accommodations differ in rural communities from that of urban areas. Some of the participants mentioned the fact that there are positive resources in the community that provide accommodations to persons with vision loss. Amanda mentioned the use of the Paratransit bus service system in the city where she and her partner reside. Despite the service requiring some upgrades, she thought it was a positive support for her and her partner. She said, “I think the Access Transit is very good. Like it’s very helpful for us. The only thing is it’s kind of umm, like we have to plan the week in advance”. Furthermore, Bill and James both spoke about the importance of CNIB’s services for persons with vision impairments which were seen as extremely helpful.

Bill spoke about his feelings on the lack of funding in communities to give persons with vision loss the opportunity to participate in sports and other leisure activities. This topic was important to Bill because his wife has always been an active person and interested in many sports. He believed working towards funding increases in this area is extremely important. Bill said:

Umm, there needs to be more support and more funding. For more research like this obviously, but there also needs to be support for finances. Places like the blind sports association. They have a hard time finding funding for all this kind of stuff... Like I said Sask Sports needs more funding because obviously there isn’t enough funding for sports that they actually have. Because my wife is such an athlete, she’s always, you know,

their funding was always lacking always, so yeah I feel as though there isn't enough financial support and there isn't enough coaching in the province that they can't really make teams. And when they do make a team, they are from all over the province. You got people coming up from Saskatoon to Regina just for a practice.

Rhonda was different from the other four participants in that she and her partner lived in a small rural community. Her experiences differed from that of the other participants in terms of transportation and access to community support services. In Rhonda's rural community, there are no organizations that provided support services for persons with vision loss, such as CNIB, which is available for people living urban centers. There are also no additional forms of transportation, such as a transit service for people who cannot drive. This lack of supportive transportation forces Rhonda to drive her partner around town, or her partner must walk to his destination. Rhonda said:

I mean like a community this size, some sort of transportation I guess. Like if he were to walk across town to a friend's house even, it would be a 30-minute walk. And when we first moved here, he lived with that friend, so he walked to work every day in the winter, and it was a good half hour to work, and a good half hour back from work in the middle of winter.

The additional information discussed by participants was important to consider because it showed how current community supports can be enhanced, and because it provided ideas for future research. In summary, the public transit system is seen as providing positive service; however its scheduling system can be improved by providing more flexibility in booking times. Furthermore, advocacy and education around funding for persons with disabilities is needed, in

order for additional programming in areas such as sports. Further research is also needed on the comparison of accommodations in rural and urban communities in order to improve services for persons with vision loss in rural communities.

The next section will provide a collective description of what participants experienced and how they experienced living with their visually impaired partners and the essence of the experiences.

#### **4.8. Exhaustive Description of the Experience**

The collective voice of participants was used to provide an overall description of “what” participants experienced, and “how” participants experienced the phenomenon. These descriptions were then formed into an overall “*essence*” of the experience of living in an intimate relationship with a visually impaired partner. All of these themes were analyzed and woven together, a process also known as intuitive integration, in order to develop the essence of the experience (Moustakas, 1994).

**4.8.1. Textural description.** What did participants experience? Pierre, Bill, Amanda, Rhonda, and James all had to adapt their daily routines and activities to accommodate their partners. They set aside time in their day to drive their partners to work and other activities, especially in the evenings when it is dark outside. They are also constantly aware of their environmental surroundings, both in the home and out in the community. In the home environment having this awareness was important because their partners may bump into something or injure themselves if certain items were not put away from general walking locations. Environmental awareness was strengthened because participants had the belief that certain accommodations were lacking in the community. Therefore, they must ensure that they were accommodating their partners while walking outside or navigating through dimly lit

locations. All the participants worked with their partners as a team. Whether it was through communicating with one another about their needs or working together on household tasks, the participants found ways to accommodate their partners that allow them to be independent at the same time.

**4.8.2. Structural description.** How did participants experience the phenomenon?

Participants experienced living in an intimate relationship with a visually impaired partner in a positive light. Their partners were visually impaired when the relationships began, so living with a visually impaired partner was normal from the start. Believing that there is access to informational supports and knowing their partners' work schedules was accommodative in terms of leaving work to drive their partners and helpful for staying positive. Patience is sometimes a struggle, however participants were always working on their ability to stay patient, to continue to be supportive and accommodative towards their partners. Having past experiences with other visually impaired individuals also contributed to participants' ability to experience living with their partners in a positive light.

**4.8.3. Essence of the experience.** The overall "essence" of the participants' experiences living in intimate relationships with visually impaired partners was *second nature*. Second nature involves adapting or attuning to a task or experience. When a task for example, becomes second nature, one's ability to accomplish the task is effortless with very little thought (Cambridge Dictionary, 2017). Participants viewed their relationships as being "normal," or just like any other relationship. Since the beginning to date their partners, the participants accepted the fact that their partners may require additional support in order to accomplish tasks and be more independent. In many situations, it was even easy to forget that their partners require assistance. Driving, guiding in the dark, changing the home environment, and working as a team

were simply normal every day activities that must be done in order to ensure a positive relationship. Furthermore, with a little patience, accomplishing these daily tasks became easier. Despite the belief that community accommodations must be improved and support groups would be helpful, participants feel they are not struggling within their relationship because it was all they have ever known.

#### **4.9. Chapter Summary**

Three themes and ten sub-themes emerged from the data collected through five participant interviews. These included:

1. Adaptation: Coordinating daily tasks, environmental awareness, accommodating is normal, and teamwork.
2. Societal “Norms”: Lack of education, and physical environment.
3. Perseverance: Positive perception, patience, past experiences, and support groups.

The voices of participants were presented using quotes, to describe each theme in greater detail. Despite having some concerns about the lack of community accommodations and support groups for partners and families, the participants’ experiences were positive. This positive outlook on their experiences living with a visually impaired partner was possible due to participants’ having a patient personality, past experiences with other persons with disabilities, and working with their partners as a team. Participants viewed their relationships as being normal, or similar to any other relationship, even though some extra accommodations were required to make everything work. Viewing accommodations as normal and being second nature contributed to the overall essence of the experience. The following chapter will provide a discussion on the limitations of the research, and the implications on social work and future research in the area.

## Chapter Five: Discussion

### 5.1. Chapter Overview

The final chapter of this thesis will provide a review of the research findings. A discussion of the limitations of the research will follow, as well as the implications for social work practice and suggestions for future research in the area. Conclusions of this research will then be provided.

### 5.2. Review of the Findings

This qualitative phenomenological study has given voice to participants, showing their experiences living in an intimate relationship with a visually impaired partner. Five participants were asked open-ended questions, either face-to-face or over the telephone. Once these interviews were transcribed, the participants were given the opportunity to read through their transcript to ensure accuracy prior to further data analysis.

The voices of participants were represented through the use of quotes from the interviews, to support the discussion of the various themes. Through the use of transcendental phenomenology, descriptions of participants' experiences and the overall "essence" of the experience were formed from the themes. The interview questions were structured around critical disability theory and sense of coherence.

**5.2.1. The findings in relation to the literature.** The three main themes emerging in the findings included adapting to the situation, social norms, and perseverance. For theme one, adapting to the situation, participants viewed their experiences as partners with someone with a visual impairment as being (for the most part) positive. They looked at their relationships with their partners as being similar to other relationships, with some additional accommodations to make everything work. Coordinating daily tasks such as driving and working with their partners

as a team contributed to their continued view of the relationship as being positive.

Accommodating their partners was seen as being “second nature” because of the acceptance of the disability and the need to accommodate on a day-to-day basis. All participants in this study began their relationships with partners who already had a vision impairment. This fact contributes to the reason why experiences were mainly positive. The participants in the majority of past research focused on couples where one partner developed a disability after the relationship began (Feigin et al., 1996; Scarinci et al., 2009; Strawbridge et al., 2007; Westaway & Wittich, 2011).

The research literature suggests that partners of those who have a disability are at high risk of developing mental health concerns such as anxiety and depression (Ghosh et al., 2012; Strawbridge et al., 2007; Westaway & Wittich, 2011). Furthermore, these mental health concerns were found to be even more significant among those individuals who were also raising children while living with a partner with a disability (Ghosh et al., 2012). These suggestions in the literature did not emerge in the findings of this current study on young adults living with visually impaired partners. All five participants viewed their relationships as positive and did not reveal any mental health concerns. This may be the case because participants in the current study entered into the relationship knowing their partners already had vision impairment. These visually impaired partners may also be more independent, without the need to heavily rely on their partners for support. Furthermore, the two participants in the current study with children felt that working as a team with their visually impaired partners to raise their children contributed to the relationship being positive.

Given their knowledge based on past experiences, personalities, and their view of the situation the participants’ experiences within the relationship were perceived as positive.

Thoughts surrounding the community however, were somewhat different. In theme two, social norms, participants discussed their thoughts and experiences surrounding communities and the environment. Participants discussed their views on community as needing change to better accommodate their partners. This was the case particularly with transportation, lighting, and treatment by other community members. Although transportation was seen as more accommodative in cities compared to rural areas, it was suggested that improvements can be made around schedules and consistency.

Lighting was seen to be a problem, particularly in restaurants. Furthermore, people throughout the community were seen as being rude or not accommodative mainly because of a lack of education or not wanting to change “normal” behavior. These findings related to accommodative issues in the community are similar to those found in the literature. For adults over the age 65 with vision loss, struggles with eating in public and navigating the physical environment are common. This is due to poor lighting and a lack of accommodations outdoors around crosswalks and street lights (Cimarolli et al., 2011; McGrath et al., 2017). These same concerns are present for young adults, as discussed by participants in the current study. McGrath and colleagues (2017) also found that persons with vision loss would rather change aspects of their lives in order to adapt to the environment, rather than work towards changing the environment to better accommodate their disability. This is similar to the current study, where participants acknowledged that changes should be made to the physical environment, however these participants feel they have the ability and desire to adapt their own lives to better support their partners when the environment fails to do so. For example, coordinating schedules to drive their partners if there are no other transportation methods available, or reading restaurant menus out loud because of a lack of lighting or small print.

Theme three, perseverance, related to participants' personality traits and their positive perception of the situation. In terms of personality traits, all participants viewed themselves as being extremely patient. This patience was seen as being an important contributor in staying positive and working with their partners to provide the best possible accommodations. This positive outlook also arose from participants' belief that they understood their partner's disability and had access to information through the use of technology and contact with agencies such as CNIB.

The literature presents similar findings on relationship satisfaction and one's sense of coherence (Feigin et al., 1996; Scarinci et al., 2009). Persons in these studies who were in relationships with partners with hearing loss or a spinal cord injury were satisfied in their relationships if they possessed a high sense of coherence. In other words, if they felt they understood their partner's disability and had the necessary resources to help cope with the situation (Feigin et al., 1996; Scarinci et al., 2009). The five participants in the current study also discussed their desire to see the development of support groups for partners or families of those with vision loss. Support groups were conceived as a place where people can come together and talk about their experiences or share ideas on how to cope and better accommodate their partners. Having these support groups would further strengthen one's belief that supportive resources are readily available.

**5.2.2. The findings in relation to the theoretical framework.** Many people may be living within the same phenomenon; however their views of the phenomenon will differ based on their subjective experiences. By gathering information on these subjective experiences, meanings of the phenomenon can then be formulated (Coffee et al., 2007; Creswell, 2013; Willis, 2007). Participants in this study all experienced the phenomenon of living in an intimate

relationship with a visually impaired partner. Despite living in this similar situation, each participant came with subjective thoughts and meanings based on how they experienced living with their partners. Unlike the other four participants, Rhonda lived in a rural community. Her experiences with transportation accommodations differed from those who lived in a larger city. James and Rhonda were both raising children with their partners. This extra responsibility shaped their experiences differently from that of the other three participants, in how they interacted with their partners and coordinated their day-to-day tasks. How participants experienced the phenomenon was also impacted by their thoughts and interactions with the community and physical environment.

When looking at the findings of this study through a critical disability lens, critical disability theory would suggest that the social environment is failing to meet the expectations of persons with vision impairments who do not fit in with what is considered to be “normal” (Hiranandani, 2005; Hosking, 2008). Persons with vision loss need to be able to adequately function in the community. Furthermore, partners of these individuals, despite being willing and able to change aspects of their lives to accommodate their partners should not be required to be the sole accommodative support. Findings in this study revealed that participants coordinate their daily schedules in order to drive their partners, due to a lack of appropriate transportation. Participants also assist their partners with navigation and reading of signs and menus, due to inappropriate lighting and objects that may cause dangers to those with vision loss. Finally, participants view others in their communities as being rude or non-supportive due to a lack of education or conforming to what they believe is “normal” in society. Efforts must be made to improve community accommodations such as transit systems and lighting. Public education on

the impact of vision loss would also go a long way in reducing the negative treatment of persons with vision loss by others in the community.

In regard to the theory of salutogenesis, the sense of coherence (SOC) among participants was not measured, however questions related to personality traits and knowledge were asked during the interviews (Antonovsky, 1994; Antonovsky, 1993). Participants felt as though they understood their partners' vision impairment and knew how and when to provide accommodations, through the use of communication and teamwork (comprehensibility). They also felt as though they had the necessary resources to handle the phenomenon and stay positive within the relationship (manageability). This manageability arises from the feelings that they have immediate access to information, as well as having the opportunity to speak with family members going through similar experiences. Manageability however, would be increased if participants had access to support groups for partners of those with vision loss. Finally, participants believed that living within the context of this phenomenon is worth the effort because they love their partners, and work together as a team to accommodate one another (meaningfulness).

### **5.3. Implications for Social Work**

This study presents findings that have various implications for social work practice. The findings suggest that there is a lack of accommodative supports in both cities and small communities. Furthermore, persons living in relationships with visually impaired partners have a desire to see the development of these supports for both themselves and their partners. Being denied supports that accommodate daily living is a violation of human rights, which warrants social workers to step in and aid in this development. Such rights for persons with disabilities are discussed and outlined in the *Convention on the Rights of Persons with Disabilities* (CRPD,

2006) and the Saskatchewan Disability Strategy (United Nations, 2008; Government of Saskatchewan, 2014). The CRPD (2006) for example, states that all persons with all forms of disabilities must enjoy all human rights and fundamental freedoms. Furthermore, it identifies where adaptations must be made to allow these persons access to these rights (United Nations, 2008).

Critical disability studies aligned with the goals of the *Convention on the Rights of Persons with Disabilities*. As discussed previously, one of the aims of critical disability studies is to challenge societal norms and make changes throughout communities rather than forcing individuals to adapt themselves (Bohman, 2005; Feys, 2015). The profession of social work also shares a close relationship with human rights development, due to the values followed and outlined in its Code of Ethics. The Canadian Association of Social Workers (CASW) *Code of Ethics* describes social work principles and values such as respect for the inherent dignity of all persons, and the pursuit of social justice (Canadian Association of Social Workers [CASW], 2005). McGhee (2017) suggests that in order to adequately follow the principle of respect, social workers must treat others' knowledge and experiences as valued contributions. Listening to what others have to say and incorporating their perspectives into the planning process will allow for stronger programming and accommodations for both persons with vision loss and their partners.

Many social workers at organizations such as CNIB and the Saskatchewan Abilities Council have the task of researching areas of the community that are lacking appropriate accommodations, and advocating for change. The findings in this study show that possible changes must be considered in areas such as public transportation, crosswalks on busy streets, lighting in certain buildings, and Braille throughout the community. Support workers at these

organizations can also advocate for support groups for partners of those with vision loss. The findings of this study show this as being the most needed personal support.

The findings also show that by looking at the relationship through a positive lens and seeing it as “normal” or “second nature” goes a long way in accepting a partner’s vision impairment. Based on a sense of coherence, seeing the situation as meaningful, comprehensible and manageable enhanced the satisfaction of relationships (Antonovsky, 1994; Collingwood, 2013). Social workers practicing counseling can use this knowledge to support their clients. People living in a relationship with a visually impaired partner may have negative thoughts and feelings because they do not understand their partner’s disability or feel as though there are no supports available. According to Feigin et al. (1996), this will affect their *sense of coherence* (SOC). These individuals may attempt to receive support from a social work counselor. It is important to provide this support because the sighted partner in a relationship is equally important in the treatment process (Strawbridge, Wallhagen & Shema, 2007). Social workers can help these clients assess their situation in order to ensure they have adequate knowledge and resources.

#### **5.4. Future Research**

This study suggests that future research is necessary to further enhance the knowledge and understanding of vision loss and its impact on partners and families. Only one participant in this study lived in a rural community. Her experiences differed from that of the other participants, especially in terms of driving her partner due to the lack of public transportation in small towns. Pursuing future research with a larger sample of participants from various rural communities would allow for an understanding about the differences in rural community experiences, as well as further differences from that of people living in larger urban areas.

All participants in this study resided in Saskatchewan, despite attempting to recruit from other provinces. It is important to expand the participant sample to other geographic locations to gain a deeper understanding of experiences. Persons in different locations in Canada may have very different experiences. This may be the case for transportation, as well as having the opportunities to interact with others going through similar experiences.

Open-ended interviews being the only form of data collection, and the shorter than expected length of participant transcripts is a limitation to this research. Future research in the area will provide an opportunity to expand on data collection using interviews, as well as other forms of data collection to strengthen the findings. Questionnaires about personal experiences could be provided to participants alongside the interviews, allowing for additional data to analyze in a mixed-methods study. Participants could also be asked to take photos of their lived experiences, allowing for a different perspective and giving participants the opportunity to share their voice and experience in multiple ways. Photovoice as a means of data collection empowers individuals and allows these participants to become co-researchers in a study. This form of data collection provides participants with a unique method of sharing their experiences, and may be beneficial to those who are uncomfortable telling their story in an interview setting (Palibroda, Krieg, Murdock & Havelock, 2009).

Personality traits are one contributor to the way people experience a situation. Participants in this study discussed the importance of being patient in order to stay positive and successfully accommodate their partners. Future research can place a stronger focus on personality traits of individuals to determine how different traits impact experiences living with visually impaired partners. For example, someone who views him or herself as a caregiver and has a calm personality may see their experiences as positive, compared to others who become

stressed easily and complete tasks for themselves rather than thinking about others first. Assessment tools such as the Myers-Briggs questionnaire or the Sense of Coherence questionnaire can be used alongside interviews to gain a stronger understanding of participants' personality traits (Antonovski, 1993; MBTI, 2015).

### **5.5. Limitations of the Study**

The use of phenomenology as a research approach has its limitations that must be considered. First, the participants in this study are not representative of the entire population of young adults who are in intimate relationships with visually impaired partners. The goal of this study was to gain a rich and deep understanding of a small number of individuals who have lived experience with this phenomenon. Due to limited time in the field to complete this research, five participants was decided upon as the minimum requirement.

Three males and two females participated in this study. Although five participants are considered adequate in phenomenological research, having two or three additional participants may have enhanced the findings with more diverse experiences. Having an equal number of female and male participants may have also benefited the findings. In their study of elderly individuals living in relationships with visually impaired partners, Strawbridge and colleagues (2007) found that women with visually impaired husbands were more negatively affected than that of male participants. Heteronormativity is another limitation of this research. All participants involved in this study were in heterosexual relationships. Including participants in homosexual and heterosexual relationships in future research would enhance understanding of experiences.

The second limitation relates to the epoche, or bracketing process. Due to my personal experience of having vision loss and with the phenomenon, I attempted to engage in the

bracketing process throughout this study. Bracketing involved constant reflection and speaking to others about my experiences in order to enter the interviews with a fresh mind. According to Hamill and Sinclair (2010) however, when researchers have experiences with a phenomenon, it is impossible to have complete objectivity. As the researcher, I am unique in that I experience and perceive the phenomenon from two different angles. I am the visually impaired partner in a relationship, as well as I perceive how my partner experiences our relationship.

There are also some limitations, or challenges, when using transcendental phenomenology as an approach for qualitative research. According to Moerer-Urdahl and Creswell, (2004) the essences of any experience are not exhaustive. The description of the essence of an experience can only reflect the place, time, and experiences of those who are interviewed for the study. Interviewing a larger sample of participants may have resulted in a different description of the essence. Furthermore, it can be difficult for a researcher to completely bracket her/his biases and personal experiences with a phenomenon in order to bring a fresh perspective, and focus entirely on participants' experiences (Moerer-Urdahl & Creswell, 2004, p. 24). It was not challenging to bracket my experiences while conducting this research. This is because I have visual impairment and did not interview the visually impaired partners in the relationships. I have my ideas of how my partner experiences our relationship; however I do not have firsthand experience with this phenomenon.

Another limitation of this research was the length of the transcripts from the participant interviews. Many of the participants struggled to expand on their answers to the various interview questions, which resulted in shorter transcripts than initially expected. Analysis of these transcripts revealed important findings; however additional data such as a second interview would have provided a deeper understanding of participant experiences. Conducting the

interviews face to face rather than over the telephone may have resulted in participants revealing a wider range of experiences.

Finally, it is impossible to know for certain if participants were completely open and honest about their lived experiences with the phenomenon. From the point of initial contact up until the time of the interviews, I had ongoing conversations with participants in order to develop a rapport and a sense of trust. These conversations consisted of phone calls with each participant, where I would explain the research, provide information about my educational background and reasons for pursuing the research, and answer any additional questions asked by participants. Participants were welcome to contact me by phone or email with any further questions, and contact was also made to discuss possible interview times and locations. This is important for participants to feel comfortable speaking about their experiences during the interviews. Participants in this study may have volunteered to participate because they viewed their relationships as being positive with minimal negativity.

## **5.6. Conclusion**

This phenomenological study focused on five young adults living in intimate relationships with a visually impaired partner. When compared to past research in the area, the findings of this study suggest that entering into a relationship with a person who already has vision impairment will develop into a satisfying, positive experience (Feigin et al., 1996; Scarinci et al., 2009; Strawbridge et al., 2007; Westaway & Wittich, 2011). If one's partner develops a vision impairment, or other disability, later into the relationship, experiences are seen to have more negative outcomes (Westaway & Wittich, 2011; Scarinci et al., 2009; Strawbridge et al., 2007; Feigin et al., 1996). Despite having positive experiences with their relationship specifically, participants in this study expressed the need for support groups for partners and

families. They also discussed the need for change within the community. More specifically, changes in the physical environment to accommodate people with vision loss, and education for others in the community to better understand vision impairment.

The findings of this study suggest implications for social work practice. Based on the findings presented in this research I believe that social workers and organizations must advocate for additional funding and programming that supports partners and families of persons with vision impairments. This can be in the form of support groups where partners and families can discuss the experiences and provide advice on how to accommodate. Advocacy for additional community accommodations is suggested to be the other main implication for social work practice.

Each participant in this study had a subjective understanding of how she or he experienced the phenomenon of living with a visually impaired partner. Rhonda lives with her partner in rural Saskatchewan, and the other four participants live in urban centers. James and Rhonda are raising children, where the other three participants do not have children to look after. Some of the participants had more past experiences with disabilities than that of others. All of these unique situations contribute to an individual's overall experience with the phenomenon. Despite these unique situations, all participants in this study viewed their experience as positive, with very little need for additional support. Entering into the relationship knowing one's partner already had vision impairment, having certain personality traits, and developing a normal routine of accommodations allowed people to see their experience as second nature.

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## APPENDIX A: CERTIFICATE OF AMENDMENT

***Research Ethics Board***  
***Certificate of Amendment Approval***

PRINCIPAL INVESTIGATOR	DEPARTMENT	REB#
Brennan Lane	Graduate Studies and Research	2016-064

**CO-APPLICANTS:**

Dr. Darlene Chalmers and Dr. Donalda Halabuza

**SUPERVISOR**

Dr. Randy Johner

**TITLE**

Experiences of Yong Adults Living in an Intimate Relationship with a Visually Impaired Partner

AMENDMENT APPROVAL OF	ORIGINAL DATE of APPROVAL	NEXT RENEWAL DATE	Date of Amendment Approval
Expanding recruitment to Manitoba, Alberta and British Columbia	May 9, 2016	May 9, 2017	July 7, 2016

Full Board Meeting

Delegated Review

**AMENDMENT CERTIFICATION**

The University of Regina Research Ethics Board has reviewed the changes to the above-named research project as outlined in your e-mail dated June 29, 2016, and they are approved.

**ONGOING REVIEW REQUIREMENTS**

In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: <http://www.uregina.ca/research/for-faculty-staff/ethics-compliance/human/forms1/ethics-forms.html>




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University of Regina  
 Research Ethics Board

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Telephone: (306) 585-4775 Fax: (306) 585-4893 [research.ethics@uregina.ca](mailto:research.ethics@uregina.ca)

## APPENDIX B: CERTIFICATE OF SECOND AMENDMENT

***Research Ethics Board***  
***Certificate of Amendment Approval***

PRINCIPAL INVESTIGATOR	DEPARTMENT	REB#
Brennan Lane	Graduate Studies and Research	2016-06 4

CO-APPLICANTS:  
 Dr. Darlene Chalmers and Dr. Donalda  
 Halabuza

SUPERVISOR  
 Dr. Randy Johner

TITLE  
 Experiences of Yong Adults Living in an Intimate Relationship with a Visually Impaired Partner

AMENDMENT APPROVAL OF	ORIGINAL DATE of APPROVAL	NEXT RENEWAL DATE	DATE OF AMENDMENT APPROVAL
Expanding recruitment to ages ranging from 21 - 40.	May 9, 2016	May 9, 2017	October 20, 2016

Full Board Meeting  Delegated Review

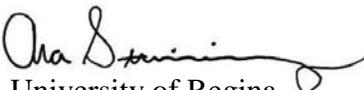
**AMENDMENT CERTIFICATION**

The University of Regina Research Ethics Board has reviewed the changes to the above-named research project as outlined in your e-mail dated October 19, 2016, and they are approved.

**ONGOING REVIEW REQUIREMENTS**

In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions:

<http://www.uregina.ca/research/for-faculty-staff/ethics-compliance/human/forms1/ethics-forms.html>

  
 University of Regina  
 Research Ethics Board

## APPENDIX C: CONTACT LETTER

Brennan Lane  
Graduate Student  
Faculty of Social Work  
(306) 713-8951  
lane203b@uregina.ca

November 7, 2016

To Whom It May Concern:

My name is Brennan Lane and I am a graduate student in the Faculty of Social Work at the University of Regina. To complete my thesis, I am conducting a study on the experiences of young adults living in an intimate relationship with a visually impaired partner.

This letter is to request your assistance in the participant recruitment process. In order to participate in this study, individuals must meet the following criteria: must be between the age of 21 and 40; and, must be living in an intimate relationship with a partner who has a vision impairment. If you become aware of any clients who fit these criteria, please forward my contact information to these individuals. I can then provide them with additional study information once they make contact.

If you have any questions please do not hesitate to contact me via telephone or email. Thank you for your time and assistance.

Sincerely,

Brennan Lane

## APPENDIX D: ETHICS BOARD APPROVAL LETTER

*Certificate of Approval*

2016-064

Investigator: Brennan Lane, Randy Johner

Department: Social Work

Experiences of Young Adults Living in an Intimate Relationship with a Visually

Title: Impaired Partner

APPROVED

RENEWAL DATE: May 9,

ON: May 9, 2016

2017

APPROVAL Application for Behavioural Research Ethics Review

OF: Form,

invitation to participate, participant consent form,

interview guide, transcript release form, recruitment

poster

FULL BOARD MEETING

X DELEGATED REVIEW

The University of Regina Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol, consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

## ONGOING REVIEW REQUIREMENTS

In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions:

<http://www.uregina.ca/research/for-faculty-staff/ethics-compliance/human/forms1/ethics-forms.html>.



Dr. Larena Hoeber, Chair  
Research Ethics Board  
Please send all correspondence to:

## APPENDIX E: INTERVIEW GUIDE

*Interview Guide*

**Date:**

**Location of Interview:**

**Interviewer:**

**Interviewee:**

*Briefly provide an overview of the study and the interview process; Ask if interviewee has any questions.*

**Questions:**

- 1. What are your experiences in terms of accommodating your partner on a day-to-day basis?**
- 2. What are your thoughts on community accommodations? What changes to the community, if any, need to occur in order to better accommodate your partner's disability?**
- 3. What personality traits and/or knowledge, if any, do you feel you possess that helps you accommodate your partner?**
- 4. Are there any personal supports that you feel you need? Please explain.**

## APPENDIX F: PARTICIPANT CONSENT FORM

### *Participant Consent Form*

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**Project Title: Experiences of Young Adults Living in an Intimate Relationship with a Visually Impaired Partner**

**Researcher:** Brennan Lane, Graduate student, Faculty of Graduate Studies and Research, College of Social Work, 306-713-8951, [lane203b@uregina.ca](mailto:lane203b@uregina.ca)

**Supervisor:** Randy Johner, Faculty of Social Work, 306-585-4549, [randy.johner@uregina.ca](mailto:randy.johner@uregina.ca)

**Purpose(s) and Objective(s) of the Research:**

- To explore the lived experiences of young adults ages 21 to 40, who are living in an intimate relationship with a visually impaired partner. To give participants a voice and allow each participant to fully express, in their own words, their experiences living with their partner.
- The data collected will be used for a Master's of Social Work Thesis. It may also be used in presentations.

**Procedures:**

- Data will be gathered through an interview consisting of open-ended questions. The interview will last approximately 60 minutes. With participant permission, the interview will be audio recorded. A follow-up interview may take place at the request of the participant. The anticipated number of participants will be between 5 and 8.
- Please feel free to ask any questions regarding the procedures and goals of the study or your role.

**Potential Risks:**

- Psychological impacts including anxiety or stress may occur while talking about experiences during or after the interview.
- **This risk will be addressed by referring participant(s) to a counseling agency.**
- **Contact information for a counselor at the Canadian National Institute for the Blind (CNIB), and/or a private clinical counselor, will be provided upon request. These professionals have been contacted and are aware of this research project**

**Potential Benefits:**

- Participants are given the opportunity to have a voice and discuss their experiences.
- Will provide support workers with a greater understanding on the impact of an individuals visual impairment on the partner and family
- Provide direction for the development of future policies and programs surrounding accommodations for persons with disabilities and their families
- **Benefits are not guaranteed**

**Confidentiality:**

- The data from this research project will be used for a thesis, published and presented; however, your identity will be kept confidential. Although we will report direct quotations from the interview, you will be given a pseudonym, and all identifying information will be removed from the final report.
- Consent forms and master list will be stored separate from collected data. All data will be stored for a minimum of five years, securely at the University of Regina in the supervisor's office. Data will then be destroyed (deleted from password protected computer if electronic; shredded if hard copy).
- After your interview, and prior to the data being included in the final report, you will be given the opportunity to review the transcript of your interview, and to add, alter, or delete information from the transcripts as you see fit.
- Interviews may be audio recorded with a password protected device. You may request to turn the audio device off at any time during the interview.
- Participation in this study is voluntary and you have the right to withdraw at any time.

Please put a check mark on the corresponding line(s) that grants me your permission to:

I grant permission to be audio recorded: Yes\_\_\_ No\_\_\_

The pseudonym I choose for myself is: \_\_\_\_\_

You may quote me in the final report: Yes\_\_\_ No\_\_\_

**Right to Withdraw:**

- Your participation is voluntary and you can answer only those questions that you are comfortable with. You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort.
- Should you wish to withdraw, all identifying information and data will be destroyed.
- Your right to withdraw data from the study will apply until data begins to be taken from the transcribed interview and included in the final report

**Follow up:**

- You may request a copy of the final report to be sent to you via email.

**Questions or Concerns:**

- Contact the researcher using the information at the top of this consent form.
- This project has been approved on ethical grounds by the University of Regina Research Ethics Board on \_\_\_\_\_. Any questions regarding your rights as a participant may be addressed to the U of R Research Ethics Board at 306-585-4775 or [research.ethics@uregina.ca](mailto:research.ethics@uregina.ca). Out of town participants may call collect.

**Consent:****Continued or On-going Consent:**

- You will have the option to read your transcript following your interview.
- Upon your request, you will have the opportunity to participate in a second interview

**Please sign and**

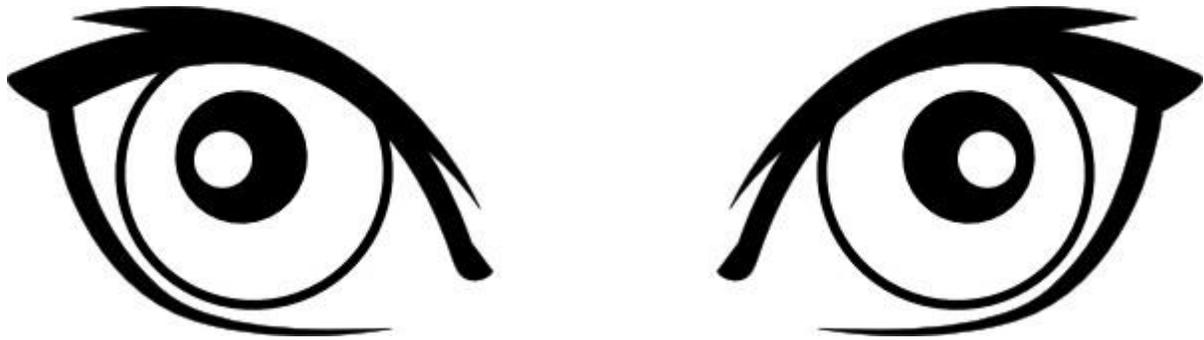
Your signature below indicates that you have read and understand the description provided; I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

_____	_____	_____
<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>
_____	_____	
<i>Researcher's Signature</i>	<i>Date</i>	

***A copy of this consent will be left with you, and a copy will be taken by the researcher.***

**APPENDIX G: RECRUITMENT POSTER**

**Department of Social Work, Faculty of Graduate Studies and Research  
University of Regina**



We are looking for volunteers to take part in a study of  
*The Experiences of Young Adults Living in an Intimate Relationship with a Visually Impaired Partner*

As a participant in this study, you would be asked to: *Participate in an interview consisting of multiple open-ended questions. You must be between the age of 21 and 40*

Your participation would involve *one or two interviews lasting approximately 60 minutes*

For more information about this study, or to volunteer for this study,  
please contact:

*Brennan Lane*

*Graduate Student, Faculty of Social Work*

at

306-713-8951 or  
lane203b@uregina.ca

**This study has been reviewed and received approval  
through the Research Ethics Board, University of Regina**