

Stephen F. Austin State University

**SFA ScholarWorks**

---

Electronic Theses and Dissertations

---

4-2020

## A PHENOMENOLOGICAL INQUIRY INTO VISION LOSS: INVESTIGATING THE LIVED EXPERIENCES OF ADVENTITIOUSLY BLINDED ADULTS

Jennifer Perry

Stephen F Austin State University, [petite\\_jaune@hotmail.com](mailto:petite_jaune@hotmail.com)

Follow this and additional works at: <https://scholarworks.sfasu.edu/etds>



Part of the [Interprofessional Education Commons](#)

[Tell us](#) how this article helped you.

---

### Repository Citation

Perry, Jennifer, "A PHENOMENOLOGICAL INQUIRY INTO VISION LOSS: INVESTIGATING THE LIVED EXPERIENCES OF ADVENTITIOUSLY BLINDED ADULTS" (2020). *Electronic Theses and Dissertations*. 294.  
<https://scholarworks.sfasu.edu/etds/294>

This Dissertation is brought to you for free and open access by SFA ScholarWorks. It has been accepted for inclusion in Electronic Theses and Dissertations by an authorized administrator of SFA ScholarWorks. For more information, please contact [cdsscholarworks@sfasu.edu](mailto:cdsscholarworks@sfasu.edu).

---

# A PHENOMENOLOGICAL INQUIRY INTO VISION LOSS: INVESTIGATING THE LIVED EXPERIENCES OF ADVENTITIOUSLY BLINDED ADULTS

## Creative Commons License



This work is licensed under a [Creative Commons Attribution-Noncommercial-No Derivative Works 4.0 License](https://creativecommons.org/licenses/by-nc-nd/4.0/).

Flyleaf (the blank page for protection in binding)

A PHENOMENOLOGICAL INQUIRY INTO VISION LOSS: INVESTIGATING THE  
LIVED EXPERIENCES OF ADVENTITIOUSLY BLINDED ADULTS

by

Jennifer Nicole Perry, B.A., M.A., M.A.

Presented to the Faculty of the Graduate School

Stephen F. Austin State University

In Partial Fulfillment

of the Requirements

For the Degree of

Doctor of Education

STEPHEN F. AUSTIN STATE UNIVERSITY  
(May 2020)

A PHENOMENOLOGICAL INQUIRY INTO VISION LOSS: INVESTIGATING THE  
LIVED EXPERIENCES OF ADVENTITIOUSLY BLINDED ADULTS

by

Jennifer Nicole Perry, B.A., M.A., M.A.

APPROVED:

---

Pauline M. Sampson, Ph.D., Dissertation Chair

---

Mary Catherine Breen, Ed.D., Committee Member

---

Shannon Darst, Ph.D., Committee Member

---

Ali Hachem, Ph. D., Committee Member

---

Robbie Steward, Ph.D., Chair, Department of  
Human Services and Educational Leadership

---

Marc Guidry, Ph.D.,  
Associate Provost

---

Pauline M. Sampson, Ph.D.,  
Dean of Research and Graduate Studies

## **ABSTRACT**

The purpose of this study was to share the lived experiences of four adventitiously blinded individuals. The researcher interviewed participants regarding the events surrounding their vision loss. The researcher used a descriptive phenomenological method to analyze the results.

Through analysis, seven themes emerged as essential experiences for experiencing adventitious vision loss: Medical Dysfunction, Others' Reactions, Ancillary Losses, Rehabilitation, Sensory Enhancements, Benefits of Vision Loss, and Participants' Advice.

The study indicated that participants' experiences are influenced by how others in society understand blindness. Suggestions included providing a greater awareness to the public for blindness, its effects, and its available rehabilitation options.

## **ACKNOWLEDGEMENTS**

I would like to thank all of the many people who have helped me to become the person I am today. To my friends, family, colleagues, former clients, past students, and future students, I am grateful for the role you have played in my life.

I'd like to extend special acknowledgements and thanks to Rynita McGuire and Heather Munro. Without you both, I know I wouldn't be here.

## **DEDICATION**

I dedicate this work to people who have lost their vision, and to all the people who dedicate their lives to helping people who have visual impairments.



## TABLE OF CONTENTS

	Page
ABSTRACT.....	iii
ACKNOWLEDGEMENTS.....	iv
DEDICATION.....	v
I. INTRODUCTION TO THE STUDY.....	1
Background of the Problem .....	3
Statement of the Problem.....	6
Purpose Statement.....	9
Research Question .....	9
Significance of the Research.....	10
Assumptions.....	18
Limitations .....	19
Delimitations.....	21
Definition of Terms.....	21
Summary .....	26
II. LITERATURE REVIEW .....	28
Vision Loss and Blindness.....	28
Posttraumatic Stress due to Vision Loss.....	31

Adjustment to Vision Loss.....	32
Shock.....	33
Denial.....	34
Depression.....	36
Coping and Change.....	38
Societal Perceptions .....	39
Too Horrible to Contemplate .....	41
Barriers to Acceptance .....	43
Transtheoretical Model of Change.....	49
Precontemplation .....	50
Contemplation.....	54
Preparation .....	56
Overcoming fears.....	57
Action.....	59
Maintenance .....	61
Summary .....	62
III. METHODOLOGY .....	64
Overview.....	64
Reflection.....	65
Research Design.....	66
Purpose Statement.....	69
Research Question .....	69

Role of the Phenomenological Researcher .....	69
Research Procedures .....	71
Selecting Participants.....	71
Data Collection .....	73
Confidentiality .....	76
Bracketing (Making Reductions).....	78
Data Analysis .....	79
Validity of analyses.....	80
Process of analyses .....	83
Whole–parts–whole process–multiple readings and note taking.....	83
Focus on intentionality and not subjective experience .....	84
Units of meaning, or themes .....	86
Clustering.....	87
Essence.....	89
Communication of the Findings.....	90
Summary .....	91
IV. EPOCHÉ .....	93
Practitioner Experiences .....	93
Personal Experiences .....	95
Advantages of Practitioner and Personal Experiences.....	97
Impact of Researcher’s Experiences .....	100

V.	FINDINGS .....	104
	Participant Demographics .....	104
	Medical Dysfunction .....	105
	Others' Reactions .....	109
	Ancillary Losses .....	114
	Rehabilitation .....	122
	Sensory Enhancements .....	133
	Benefits of Vision Loss .....	134
	Participants' Advice .....	141
VI.	CONCLUSION .....	145
	Introduction .....	145
	Methodology .....	145
	Participants .....	146
	Findings .....	146
	Medical dysfunction .....	146
	Others' reactions .....	147
	Ancillary losses .....	147
	Rehabilitation .....	147
	Sensory enhancements .....	148
	Benefits of vision loss .....	148
	Participants' advice .....	148

Conclusions.....	148
Implications for Practitioners .....	154
Implications for Adventitiously Blinded Adults.....	156
Recommendations for Future Research .....	158
Epilogue .....	160
References.....	162
Appendix A.....	176
Appendix B.....	179
VITA.....	181

## **CHAPTER I**

### **Introduction to the Study**

The event of vision loss can change the course of one's entire life, but in the moments leading up to and in the moments immediately following blindness, one seldom if ever denotes any positivity. "The trauma or disruptive moment may be compounded by a person's preblindness attitudes toward blindness that are stereotypically negative and devaluing" (Tuttle & Tuttle, 2004, p. 153).

After adjustment and retraining, the self can return refreshed and anew, but for a time, the vision loss propels the individual into a state of shock, and individuals must reevaluate their existence. Schulz (as cited in Tuttle and Tuttle (2004) "identified three factors that help to influence the intensity and severity of the shock: 1) the significance of the loss to the individual, 2) the suddenness or unexpectedness of the event, and 3) the degree of visual loss."

The effects of the vision loss, the losses that are suffered that are in addition to the vision itself, are numerous and heartbreaking, and the individual will be forever changed. Indeed, Father Thomas Carroll documented 20 psychological losses to blindness that many adults experience as they adjust to vision loss including losses of self-esteem,

social adequacy, a career or job opportunity, financial security, ease in communication, and an overall loss of independence (Carroll, 1961; Sassani, 1995, pp. 148-149).

How change unfolds in an individual depends upon variable factors including family, medical, and financial support, as well as the internal adjustment and reorganization that must take place. “[M]embers of the support network may need to confront them gently but persistently with the reality of the trauma” (Tuttle & Tuttle, 2004, p. 164), but the process is difficult as Dr. Louis Cholden explained:

The adult who loses his sight faces a task that can be succinctly stated as one of internal reorganization to the fact that he now is a different person. His capacities, his interests, his social position, his body image, his aspirations are all affected, if not completely changed. And it is important to know that until he accepts the fact that he is a different person—a blind person—rehabilitation, or the relearning necessary for adjustment to blindness cannot proceed. This fact, which seems so inevitably simple, remains one of the gravest stumbling blocks in the rehabilitation to the loss of vision. (1954, p. 107)

How well individuals understand their condition and prognosis, as well how they relate their existing beliefs and attitudes about disability will factor into this adjustment (Kleinschmidt, 1999). The question of who the person will become is contingent on the acceptance he or she associates with vision loss (Welsh, 2010, p. 184). In this inquiry, the experiences of vision loss will be investigated, as it relates to adjustment, acceptance, and finding the self.

## **Background of the Problem**

Rev. Thomas J. Carroll (1961, p. 5) reported results from the United States National Health Survey that an estimated 960,000 persons in the United States were blind or visually impaired. By 1993, Nelson and Dimitrova reported 4.7 million people to be severely visually impaired or blind as a result of the same survey (p. 81). Globally, the reported estimated prevalence of blindness can range from between approximately 324 million (Stevens et al., 2013, p. 2377) to upwards of 1.3 billion individuals, according to the World Health Organization (2018).

In the United States as of 2018, approximately 2.4% of the population, or 8 million people, are living with a visual impairment, including blindness (National Federation of the Blind, 2018). This number is expected to double to approximately 16 million by the year 2050 (Varma et al., 2016, p. 805). According to data from the National Health Interview Survey conducted by the Centers for Disease Control and Prevention (CDC) in 2016 and reported by the American Foundation for the Blind in 2019, 25.5 million Americans are already living with vision loss.

The discrepancies in numerical value between the National Federation of the Blind (8 million people) and the American Foundation for the Blind (25.5 million) are created due to reporting inconsistencies and varying definitions of what visual losses may be counted in the report. According to the CDC report displayed on the American Foundation for the Blind (2019) website, their estimated 25.5 million number of Americans living with vision loss represented any individuals "who reported that they



have trouble seeing, even when wearing glasses or contact lenses, as well as individuals who reported that they are blind or unable to see at all."

What this implies is that the CDC report represented anyone who reported having impaired vision of any kind, regardless if it interfered with the way that their daily life was lived. Naturally, this variation represents significantly more people than if the sample were more limited.

The National Federation of the Blind (NFB) (2018) limited the scope of "visually impaired or blind" and defined the terms much more narrowly. To qualify with the National Federation of the Blind as visually impaired or blind, the person with the visual impairment must not only have trouble seeing, but their vision loss must be to the extent that the person with a visual impairment must not be able to continue living life the way they always had been. Assistive technology, Braille, the use of the white cane, or the requirement of modifications to the home, including having training by blind rehabilitation professionals, are prerequisites to satisfying the requirements to be visually impaired or blind by NFB standards. The NFB remains inclusive of individuals only who identified as those who "must use alternative methods to engage in any activity that people with normal vision would do using their eyes."

Discrepancies in estimated calculations for the global population living with vision loss exist as well. Not all countries monitor their national occurrences of blindness, and, for the ones who do monitor blindness, each country may have a differing definition of what is legal blindness (Keys & Resnikoff, 2012, p. 389). Furthermore, not all countries keep a national register for all ages (Stevens et al., 2013, p. 2383) or all

genders (Stevens et al., 2013, p. 2378). Finally, as is true in the United States, different international registers may include visual dysfunction that is not of a magnitude to require rehabilitation or intervention.

Regardless that the estimated number of cases of visual impairment nationally or worldwide varies, there is no question that both the incidence and the estimates of blindness are rapidly increasing (Pashmdarfard, Amini, & Amini, 2016, p. 78). Tuttle and Tuttle (2004) reported that "[t]here are approximately 75,000 newly visually impaired and blind individuals in the United States each year" (p. 17). The CDC (2016) estimated the number of new cases in the United States at 87,500 per year. The World Health Organization (2018) also recognized that "population growth and ageing will increase the risk that more people will acquire vision impairment" and that "the majority of people with vision impairment are over the age of 50 years."

According to the United States Census Bureau (2017), "New detailed estimates show the nation's median age—the age where half of the population is younger and the other half older—rose from 35.3 years on April 1, 2000, to 37.9 years on July 1, 2016." Additionally, the census bureau reported that "Between 2000 and 2016, 95.2 percent of all counties experienced increases in median age," and this number is expected to continue to rise due to the large numbers of baby boomers who are living longer.

In 2016, the census bureau reported 15.2 percent of the United States population as over the age of 65, a statistically relevant age that, according to the 2013 American Foundation for the Blind Special Report on Aging and Vision Loss, will dramatically increase the likelihood of the onset of a visual disability:

A rapidly increasing proportion of the aging population experiences eye problems that make simple daily tasks difficult or impossible, even when wearing glasses or contact lenses. Severe eye problems are not just a matter of "getting older." The risk of severe eye problems has been found to increase significantly with age, particularly in those over age 65.

### **Statement of the Problem**

"Vision is central to the functioning of an individual, and it is clear from numerous studies over the past two decades that impaired vision exerts dramatic effects on function and quality of life" (Kyuk et al., 2008, p. 498). When a person loses vision, the "visual impairment affects the person's quality of life, decreases his/her independency, and also limits their social participation" (Pashmdarfard, Amini, & Amini, 2016, p. 78). Keys and Resnikoff (2012, p. 387) suggest "Blindness and vision impairment affects not only the quality of life of an individual, but also has implications for their educational and employment opportunities." Even mild visual impairments, "despite being classified as mild, [have] a substantial effect on quality of life. For example, in many countries, an individual with this level of vision would be barred from driving" (Bourne et al., 2017, p. 889), in part because "Observers often miss visual changes in the environment when they co-occur with other visual disruptions" (Bergmann, Schubert, Hagemann, & Schankin, 2016, p. 660).

Being unable to observe the environment has an impact beyond not being able to drive, it also impacts one's ability to walk without falling. Kyuk et al. explain:

The visual system provides most of the information we use for day-to-day travel.

When vision is impaired a person's ability to obtain information about the environment is reduced, along with the capacity to perform certain functions.

One of these is safe and efficient movement through the environment, or mobility.

Reductions of mobility are most obvious for those who are totally blind.

However, visually impaired persons generally have a greater difficulty performing mobility tasks than persons with normal vision. (2004, p. 337)

When a person cannot see or see well, they must "rely on other senses such as hearing and touch" (Pashmdarfard, Amini, & Amini, 2016, p. 78). If the person is not trained to rely on these non-visual skills, not having the training to develop the skill sets can "affect economic and educational opportunities, reduce quality of life, and increase the risk of death" (Bourne et al., 2017, pp. 888-889).

As not all blindness is preventable, and as there are millions who are already living with the experience of blindness or low vision, "it has become a necessity to design good and appropriate interventions for them" (Pashmdarfard, Amini, & Amini, 2016, p. 81). The implementation of public health actions [could] improve and monitor the health status in the community" (Jose & Sachdeva, 2010, p. 138). As Yong et al. indicated, "Blindness is an important functional and social limitation and its prevention should be a vital aspect of any healthcare system" (2006, p. 35).

Stroupe et al. (2008, p. 85) opine that "rehabilitation programmes have the

potential to restore independence and improve quality of life for persons with vision loss," but Aliyu, Abdulraheem, and Abdulkabir found that "The challenges to accessing rehabilitation support in the past was mainly due to unavailable services (2014, p. 150).

In areas where rehabilitation services do exist, for example in the United States, Sassani (1995, p. 150) found "that less than half of individuals with low vision are receiving low vision services." In Iran, "Seventy-two subjects (46.6%) were not accessing rehabilitation services during the study period and 59 (81.9%) were due to lack of linkage to the existing RS [Rehabilitation System]" (Aliyu, Abdulraheem, & Abdulkabir, 2014, p. 150). These numbers are discouraging when evidence has shown the benefits that rehabilitation such as "low vision services, vocational rehabilitation, orientation and mobility training, special library services, the availability of low vision aids, professional counseling services, peer support groups, and special services for the elderly and for children" can provide (Sassani, 1995, p. 150).

Part of the reason that rehabilitation may not be readily accessed is due to "that [optometrists and ophthalmologists] had incomplete knowledge of the spectrum of services available in their community" and so did not make appropriate referrals (Sassani, 1995, p. 150). Additionally, people who are blind may not be advised of the benefits they may receive with governmental registration and documentation as a person who is blind (Margrain, 1999).

Moreover, individuals who lose vision may intentionally choose to not identify as blind due to their own psychological inability to do so. This inability arises from a number of internal and external factors. For example, in Iran, Pashmdarfard, Amini, and

Amini (2016, p. 78) found that "people do not employ the services of rehabilitation and occupational therapists due to social and cultural taboos." In the United States, low vision assessments aids are also underused due to "the use of low vision aids are not widely recognised in the community" (Margrain, 1999). "Other reasons why people with impaired vision do not benefit from a low vision assessment include the fact that some may fail to recognise their degree of visual impairment or fear treatment, the stigma of blindness, and differences in ophthalmological referral criteria" (Margrain, 1999).

Without rehabilitation and the use of aids, individuals who are visually impaired may not be able to return to work. Currently 56% of working-age people who are blind or visually impaired are unemployed (American Foundation for the Blind, 2020). "The high percentage of people not participating in the labor force may represent people who feel they cannot work because of their disability, who choose not to work for fear of losing benefits, or who are discouraged workers who have given up on finding a job" (American Foundation for the Blind, 2020). In this inquiry, the researcher will learn of participants' experiences of vision loss.

### **Purpose Statement**

The purpose of this inquiry was to investigate the lived experiences of adventitiously blinded adults.

### **Research Question**

The research question that guided this study was: What were the lived experiences of individuals who were adventitiously blinded?

## **Significance of the Research**

As more people are projected to lose vision due to increases in median age of the world's population, a fact that makes vision loss a greater and more statistically likely event (Margrain, 1999), few have studied the internal psychological events that surround vision loss and make inquiry into the lived experiences of what it means to become blind and to live as a person who was sighted, who now is blind. The reasons behind the limited availability of research may be surprising.

Prior to the 1950s, most work with persons who were blind in the United States was considered to be charity, or voluntary, work. According to Disability Legislation History as identified by the Student Disability Center at Colorado State University (2018), the Randolph-Sheppard Act of 1936 identified that individuals who were blind could have vocational potential under Vocational Rehabilitation. However, money was not specifically designated to rehabilitate individuals with visual impairments.

The Barden-LaFollette Act of 1943 amended Vocational Rehabilitation to provide a direct allocation of funds specifically for the blind. The money went to state agencies that were designated to provide rehabilitation for people who were visually impaired. As such, “The long-established voluntary agencies [for the blind] which had for so many years set the pace were rapidly being overtaken by the state bodies through which were funneled ever larger quantities of federal money for services to blind men, women, and children” (Koestler, 1976, p. 327).

The directors of the state agencies and rehabilitation service centers that were receiving the newly allocated federal money adopted the mindset to have “rapid

placement results” (Koestler, 1976, p. 327). Therefore, to meet the provisions of mental health evaluations and to have rapid turnarounds in the training centers, through the late 1940s and into the mid-1960s, individuals who were accepted for blind rehabilitation training were required to undergo a psychological evaluation.

According to Scott (1969, p. 77), individuals who were referred to an agency would “willingly submit themselves to a prolonged, intensive, and comprehensive program of psychological and restorative services.” However, not all persons who were desirous of services were accepted to the agency; “This is particularly true of the elderly, the multiply handicapped, and the uneducable or unemployable” (Scott, 1969, p. 78).

By 1972, due to a relative boom in availability of devices for the visually impaired, shifts occurred in the prioritization “to both technological and psycho-social research” (Koestler, 1976, p. 331). Items such as Talking Books and magnification devices could be made available commercially, and the new focus of state agencies and rehabilitation centers became centered upon:

- (1) alerting blind people to the availability of goods and services for their use;
  - (2) keeping organizations for the blind aware of professional developments and techniques that could help them upgrade their programs;
  - (3) shaping more constructive public attitudes toward blindness and blind people.
- (Koestler, 1976, p. 331).

Because the state-mandated investigation of psychological adjustment to visual impairment only occurred for a short period in American history, and because of modern day HIPPA laws, very little information about adjustment to vision loss for individuals



who are first experiencing vision loss currently exists. To understand psychological adjustment to vision loss as determined clinical psychiatrists, therefore, we must rely on the works of psychiatrists who not only performed investigations during that small window in history, but who also published their work. Dr. Louis Cholden is among them.

In 1953, Dr. Cholden was working as a psychiatric consultant for the State of Kansas Rehabilitation Center for the Blind, in Topeka. Cholden's position required that all newly referred persons who were blind would undergo psychiatric evaluation and group therapy to determine if they were mentally able to process a rehabilitation agenda. As Dr. Cholden had noted in his published papers, "Three years as consultant to the Kansas Rehabilitation Center for the Blind have acquainted me with the deep need for each blind person to recognize his disability and accept it as part of his life" (1958, p. 54).

Dr. Cholden had previously noted that to study the phenomenon of vision loss is relevant and critical to rehabilitation. If a person was unable to accept his disability, he said, rehabilitation would be nearly impossible to incorporate into the patient's life. "The differences certainly lie in the psychological sphere, in the psychological attitudes of these different people toward their handicaps" (1958, p. 64).

Dr. Cholden identified that until the psychological experience of vision loss could be understood, rehabilitation could be stalled due to the level of individual reorganization that must take place:

The adult who loses his sight faces a task that can be succinctly stated as one of internal reorganization to the fact that he now is a different person. His

capacities, his interests, his social position, his body image, his aspirations are all affected, if not completely changed. (1954, p. 107)

Rev. Thomas J. Carroll (1961) also suggested that people who lose vision are dramatically changed, as they must undergo an incredible transformation to become a person who is blind. Rev. Carroll suggested gravely that the person who was sighted must metaphorically pass away:

When, in the full current of his sighted life, blindness comes on a man, it is the end, the death, of that sighted life. This death may be the rapid one that results from accident or from some culminating disease, or it may be the slow, lingering death to a sighted life that often comes with glaucoma, with uveitis, or, as so often in our day, with diabetes. The death may come without warning; its onset may be hidden by false hopes or false promises; it may come with a terrifying slowness, inevitably.

However it comes, it is death to a way of life that had become part of the man. It is the end of the acquired method of doing things, the loss of built-up relationships with people, of ingrained relationships with an environment.

(1961, p. 11)

The gravity of vision loss as expressed through a metaphorical death cannot be more profound; however, adjustment to vision loss is often expressed through need for rehabilitation:

And it is important to know that until he accepts the fact that he is a different person—a blind person—rehabilitation, or the relearning necessary for adjustment

to blindness cannot proceed. This fact, which seems so inevitably simple, remains one of the gravest stumbling blocks in the rehabilitation to the loss of vision. (Cholden, 1954, p. 107)

Even Rev. Carroll, who so soberly equated blindness with death, recommended solace to overcome blindness by way of rehabilitation interventions:

However, all those closely associated with the blinded person have an important role to play in helping him resume his normal place and function at home and in his society. This role—both before and after the rehabilitation training period—will be indicated in connection with some of the restorations. (1961, p. 97)

What Carroll and Cholden have suggested through the implementation of rehabilitation as a means of adjustment to blindness is commonly equated to physical restoration. Only Cholden however acknowledged the emotional component more comprehensively:

The dictionary defines rehabilitation as the restoration to a former state.

However, with many of our clients we are not attempting to restore them to a former state in terms of complete physical integrity of the body. Rather, what we are attempting to attain is a restoration of the psychological integrity of the individual. (1958, p. 61)

The topic of adjustment to vision loss is one that is uncertain because “It is very difficult to formulate with exactness the nature of this emotion. We have encountered no out-and-out descriptions of it (Chevigny and Braverman, 1950, p. 31). Furthermore,

“observers of the quality of [theory and methods] in this field confess they have seen little to compare with it” (p. 265).

As the emotional adjustment of the blind had been largely ignored in the foundations of rehabilitation, emotional adjustment is rarely discussed in present day rehabilitation. Understanding the premise of and need to understand emotional adjustment however makes my study all the more significant. Chevigny and Braverman explain the emotional component that accompanies perceptions of blindness:

Examination of the history of the blind shows clearly that the ideas and feelings man has entertained about those without sight have varied little. One might term it ‘prejudice’ were it not for the fact that there is evidence showing it all to be less of a prejudice and more of an emotional condition with deep roots in the human psyche. (1950, p. 39)

The “deep roots of the human psyche” (Chevigny and Braverman, 1950, p. 39) have historically affiliated blindness with incredible irrational associations including sin, punishment, and even loss of a sexual organ (Barasch, 2001). Doctors therefore must recognize and deal with any of their own personal misconceptions about blindness such as sin or punishment before relaying those misperceptions and irrational thoughts onto patients (Cholden, 1958, p. 21).

Unfortunately, doctors may suffer anxieties about blindness that go beyond that of the general public. An eye doctor often would take blindness personally, as if it was his fault for not being able to save someone’s sight. Doctors may feel guilty or inadequate for not being able to provide cures (Cholden, 1958, p. 24). Doctors sometimes believe

that telling a person he is blind is like telling him he is dead (Cholden, 1958, p. 18)!

As such, doctors are no better than the general public, and, in some ways, doctors may be worse than the general public for helping people to face the realities of their blindness. Doctors often do the one thing that they should not, which is to try to instill the hope in their patients that their vision will one day return. Cholden (1958) suggested that doctors and members of society try to assure the restoration of sight because that is what Cholden believed they would like to have said to them.

According to the CDC Vision Health Initiative of 2015, most people in the United States who lose vision will have one or more of the four most common eye diseases—cataract, glaucoma, diabetic retinopathy, or macular degeneration—as the cause. Additionally, people in the United States who have insurance will generally go to an eye doctor for their care. The more contact people who are losing vision have with doctors creates more opportunity for a doctor to mislead the patient from the prognosis of blindness. However, feeling betrayed by the doctor may result in traumatic shock as well, if the patient were to find out that his or her doctor had lied or withheld information (Chevigny & Braverman, 1950, p. 225).

“One has long ago come to realize that what matters in therapy is not techniques but rather the human relations between doctor and patient” (Frankl, 1969, p. 6). A feeling of betrayal or distrust therefore could damage the doctor-patient relationship and can cause a decrease in the success of therapy. Additionally, “doctors who follow this practice (of lying or withholding information) risk the future good reorganization of their patients” (Chevigny & Braverman, 1950, p. 235).

In several cases, false hopes and news of cures were nothing but deterrents to adjustment (Cholden, 1958, p. 23). “Why should anyone embark on the hard business of learning to be blind if he still has reason to believe it may not be necessary” (Chevigny & Braverman, 1950, p. 235)? According to Cholden, however, it is not only doctors who may try to encourage a person who is blind that sight will return:

Well-meaning and sympathetic friends and relatives will do everything possible to cheer the patient with news of miraculous cures, or wonderful doctors, or new drugs, to help the patient believe his sightlessness is not final. Ministers will offer the proof of efficacy of faith and prayer in returning vision to the blind. Everyone offers hope for the return of sight. Rarely is any hope offered that the patient may yet have a full life as a blind man, that it is only a different kind of life he must learn to live. (1958, p. 77)

It would seem evident that doctors as well as society need to be better educated about the blind. Putting existing misperceptions to rest would seemingly aid the efforts of adjustment and rehabilitation to be more expedient and successful (Jernigan, n.d.). This inquiry that seeks to examine lived experiences of individuals who have lost vision therefore might provide the benefit of helping to replace existing irrational assumptions about blindness.

Gaining a greater understanding of lived experiences of individuals who have lost vision assumes “not only the possibility of educating the blind but of educating the sighted about the blind” (Chevigny and Braverman, 1950, p. 144). Beneficiaries of the

study therefore could include not only persons or are visually impaired or blind, but also people who are able to see.

### **Assumptions**

Prior to and throughout my inquiry, it was necessary to make certain assumptions related to phenomenological inquiry as well as assumptions related to participants. From the participants, I assumed that all participants were individuals who once had vision and then who lost their vision. It was assumed that the vision would neither return, nor be lost, again. To this end, persons who were sighted and who lost their vision have begun to adjust to life as a person who is blind and to form a new identity as a person who is blind or visually impaired.

From my participants who have lost vision, I assumed that all participants were committed to the inquiry, and I assumed that they were engaging in the study for the generation of understanding into the phenomenon of adventitious vision loss. As the researcher, participants could assume that I, too, was committed to the inquiry.

At one time, theorists concluded that that “only the blind could understand the blind” (Chevigny and Braverman, 1950, p. 123), and that the “problem of emotion under blindness is not accessible to the experimentalist,” (p. 32). Additionally, “He [the blind man] will seldom discuss his blindness; when the subject cannot be avoided he merely says it is too difficult to tell anybody about it” (p. 207).

Despite the limitations of inquiry that were reliant upon self-disclosure, I assumed that participants of this study have answered questions honestly and to the best of their ability. I assumed that, despite the heterogeneous nature of the population of individuals

who are blind, "certain common threads of response may be discerned" (Chevigny and Braverman, 1950, p. 25). Finally, I assumed that I was able to discern the emotion of the individuals who have lost vision and effectively relay the results.

As a phenomenological inquiry, it must be assumed that the information gleaned from this study cannot and will not account for all experiences and circumstances of vision loss, and that this inquiry sought only to understand these particular situations more clearly. Information came first hand from individuals who have had the experience of vision loss, and, after reviewing the transcribed data, I attempted to represent the participants' collective experiences of losing vision.

### **Limitations**

One limitation to phenomenological inquiry of vision loss is that individuals have, at times, an inability to express their emotions clearly. Cholden (1958, pp. 35-36) suggested that people who are blind "seem to have exceptional difficulty in expressing their emotions." Part of this limitation to communicate is found in the participant inability to receive nonverbal feedback from the researcher, such as facial expressions, crossed arms, slouching, or checking the clock.

Additionally, "some of our clients feel that their emotions are mental abnormalities" (Cholden, 1958, p. 37). Several other possibilities exist as to why a person may not be able to express him or herself, including how he or she thinks the information will be received, or if the person has not yet accepted information about the self, then some facets may not be revealed.



A key limitation as to why individuals may also not reveal some information stems from the general misunderstandings of blindness that exist in society. Chevigny and Braverman (1950, p. 1) stated that "No variety of human experience seems less accessible to ordinary understanding." Because there is no experience like it, and nothing with which to compare, similes and metaphors are not able to be used to describe vision loss in a way that the general population might understand.

A second important limitation to this study relates to the ten or more years' experience I have in working with individuals who have experienced vision loss. This is a limitation because, as a rehabilitation provider, for over 10 years, I sought to assist people who were blind to improve their lives through the building of skills and abilities. I used a rehabilitative approach to help them adjust to their vision loss.

During the rehabilitative sessions, I found that people often opened up to me about their personal thoughts and emotions. They shared things with me that they said they had never told anyone before. Having heard these personal stories greatly impacted my personal comprehension of the range of experiences that individuals who have lost vision may face. As such, when I heard stories from the participants in this study, I was not hearing stories of vision loss for the first time. There will be things that I may understand without explanation. I may make connections that even the participant had not yet made.

This inquiry, however, required that I bracketed any existing perceptions of adventitious vision loss and adjustment. As I myself am not adventitiously blind, eliminating my bias and known assumptions about the experience of adventitious

blindness was not challenging. Regardless, as explained in my Epoché, Chapter IV, I assume that I was able to eliminate any preconceptions.

### **Delimitations**

For this study, I limited the participants to individuals who are of adult age and who are adventitiously blind. Participants were required to be able to meet in person or over the phone, and participants were required to consent to allow for audio recording of the interviews.

### **Definition of Terms**

The purpose of defining the following terms was to set the foundation for the reader to understand the conceptual framework in this study.

**Acceptance of self.** Self-acceptance does not necessarily mean that a person likes or appreciates all of her attributes. A blind person does not necessarily need even to like the blindness. To be accepting, the person should not be holding onto a belief that the blindness might be cured or that it could, at some point, end. What's important is that, for acceptance, the person must internalize blindness as one of many personal characteristics (Welsh, 2010, p. 185).

**Adjustment to blindness.** "It is well known that the social workers and the blind themselves tend to hold very different views of what constitutes good [or bad] adjustment to blindness." One may, according to Chevigny and Braverman (1950, pp. 11-12), adjust on different levels to the physical, emotional, financial, or social demands of blindness.

The demands of reality often determine the level of adjustment that an individual will make based on availability of resources, internal and external motivations, age,

cognitive capacities, and necessity. For example, individuals may be adjusted to their financial situations, but they may not be adjusted or comfortable to be seen in public or be seen by others. Other persons may be physically dependent upon others for their personal care, but perhaps they are emotionally content with this arrangement.

Ultimately, adjustment is acceptance of the new reality, but there are many considerations to accept and of which to be accepting, including the self (Werdel & Wicks, 2012, p. 27; Welsh, 2010, p. 185).

**Adventitious vision loss.** Adventitious vision loss refers to the acquisition of a visual disability; for example, an individual who had vision and then lost it due to accident or disease. A person who has adventitious vision loss has “the advantage of visual memories to support learning. However, they experience emotional loss not felt by those born with [congenital blindness]” (Bruce, 2004, p. 1126). See also, Congenital blindness.

**Congenital blindness.** Congenital blindness refers to a visual disability that "occurred at birth or prior to the time when [the individual] would have had useful visual memories" (Welsh, 2010, p. 176). See also, Adventitious vision loss.

**Disability.** A person who has adventitious vision loss acquires not only blindness but also a disability. The person who acquires vision loss not only becomes blind, but also disabled.

"Disability is any restriction or lack (resulting from impairment) of [the body's] ability to perform an activity in the manner or within the range considered normal for a human being" (Jose & Sachdeva, 2010, p. 138). Disability as a result of visual

dysfunction therefore results when the eye or the visual processes of the eye, including the optic nerve, retina, or brain has its functions "disrupted or deranged" (Jose & Sachdeva, 2010, p. 138).

**Legal blindness.** The United States Social Security Administration (2019) states:

An individual shall be considered to be blind for purposes of this title [legally blind] if he has central visual acuity of 20/200 or less in the better eye with the use of a correcting lens. An eye which is accompanied by a limitation in the fields of vision such that the widest diameter of the visual field subtends an angle no greater than 20 degrees shall be considered for purposes of the first sentence of this subsection as having a central visual acuity of 20/200 or less.

What this says about legal blindness is that even when wearing glasses, persons are still so visually impaired that they are unable to read a standard eye chart. The person may not be totally blind, and perhaps could visually recognize where on the wall the chart is, where the door is, or that there are other people in the room. The person however may not be able to identify faces or read letters unless the letters were enlarged, or if the person was very close to the visual target.

This definition is important because it considers that some individuals who are considered legally blind do retain vision that is useable. Legal blindness is not total blindness. In some cases, it may also be called Low Vision (American Foundation for the Blind, 2020).

**Rehabilitation.** In present day rehabilitation, trained specialists instruct on the "broad array of skills needed by individuals who are blind and visually impaired to live

independently at home, to obtain employment, and to participate in community life”

(VisionAware, 2020). According to Du Pré (2018):

Rehabilitation is a service provided to people who are living with vision loss. For older adults, it offers training in new techniques and new ways to do daily tasks of living. Depending on an individual’s preferences and needs, these activities may include:

- managing personal needs,
- preparing foods and eating a healthy diet,
- taking medications,
- paying bills,
- using magnifiers and other low vision devices to read, watch tv, handle mail and medications, etc.
- using technology including computers, talking books, iPhones, etc.,
- staying in touch with friends,
- being involved in the person’s own family, faith or community as much as desired.

For younger individuals, Vision Rehabilitation services also include:

- skills essential to success in school,
- Braille,
- computers,
- job skills and job placement. (Du Pré, 2018)

In more historical terms, the purpose of rehabilitation had a different focus.

According to Cholden (1958, pp. 61-62), "what we are attempting to attain [through rehabilitation] is a restoration of the psychological integrity of the individual...We hope to give this individual a life that has fullness, vocational direction, internal satisfaction, and the optimal use of his potentialities." In other words, rehabilitation used to include a psychological component to help individuals come to acceptance. In present day, rehabilitation focuses primarily on the acquisition of new skills and the understanding of how to perform tasks non-visually.

**Reorganization.** Reorganization "is not merely a matter of learning to depend, in new and complete fashion, on part of the sensorium to which, previously, little heed had been paid, but some change in the musculature also takes place" (Chevigny & Braverman, 1950, p. 236). In other words, people who are blind must now learn to attend to non-visual senses such as hearing and touch, and they must modify their movements such as gait patterns and reaching patterns to accommodate the lost visual sense. These changes result in the reorganization of coordination, and the creation of muscle memory for how to accomplish tasks, including the use of the cane.

It is important to note that reorganization is voluntary, and some individuals do refuse to participate (Chevigny & Braverman, 1950, p. 233). "The acceptance of one's blindness is a necessary prerequisite [to rehabilitation]" (Welsh, 2010, p. 184).

**Vision specialist.** A vision specialist is "any medical, clinical, or educational person with knowledge and/or training in working with persons with visual impairments in order to improve functioning and efficiency" (Barraga & Erin, 1992, p. 24). This term is analogous with the Vision Rehabilitation Specialist, who "helps people adapt to vision

loss and maintain their current lifestyle” (National Academies of Sciences, Engineering, Medicine, 2016, p. 381). As Cholden (1958, p. 111) pointed out, vision rehabilitation specialists do not change people, people themselves must be motivated to change.

### **Summary**

While much of the existing research surrounding rehabilitation and adjustment to vision loss focused on the effects of living without vision, this inquiry examined the experience of adventitious vision loss. This inquiry added an element of documenting the experiences of adventitious blindness for the benefit of vision rehabilitation specialists and for persons who are adventitiously blind.

The experience of becoming adventitiously blind is an experience that has been incomprehensible to most, including to those who have experienced adventitious vision loss first hand. Investigating experiences of adventitious vision loss, therefore, was a study well suited to a phenomenological inquiry.

Chapter II describes the adjustment theories as they currently exist, and the importance placed upon one’s ability to accept a newly acquired visual impairment. Relatedly, Chapter II investigates current adjustment theories related to the external influence that caregivers, from specific individuals such as a doctor or a spouse, to society at large, may have over an individual's outlook and subsequent adjustment.

Pervasive fear of disability and blindness—coupled with the perceptions in which blindness is a punishment, or that vision loss is a disability that cannot be overcome—are beliefs that might be projected—deliberately or inadvertently—onto the person who is now

blind. The person who is now blind, therefore, cannot help but to be influenced at times—positively or negatively—by the opinions of others.

Regardless, that an individual may be influenced externally by others, the individual who is blind must rely on his or her own internal motivations for adjustment. These internal motivational factors are explored in depth in Chapter II.

Chapter III explains the data collection and evaluative methodology, proponents of phenomenological inquiry that aided in the selection of the qualitative of phenomenology, and the role of the researcher. The role of researcher is further examined in Chapter IV, Epoché, as biases, experiences, and preconceptions from the researchers' 10 + years of field work are deconstructed through a disability interpretive lens. A disability interpretive lens focuses on “disability as a dimension of human difference, and not as a defect” (Creswell, 2013, p. 34). Chapter V closely examines each of the four interviews, provides the analysis of the data, and presents the findings. Chapter VI concludes the study, and offers implications and suggestions for future research.



## **CHAPTER II**

### **Review of Literature**

#### **Vision Loss and Blindness**

In my study, persons who were blinded adventitiously were asked to share their experiences with vision loss. A distinction between the condition of blindness and the experience of losing vision was made. To help distinguish vision loss from blindness, the state of blindness must first be understood.

Cutsforth (1951, p. 123) identified the state of blindness as when one is not able to process visual images. He further defined blindness as the "cessation of visual activity, or a sensory absence." Blindness, or legal blindness, may also refer to a loss of vision that results in lowered vision that cannot be corrected with glasses or contact lenses (Medline, 2020).

With adventitious vision loss, the individual who once could visually perceive, or see, now cannot. In other words, persons with adventitious vision loss are those who lived part of their lives as sighted, and then they lost the ability to see.

As the result of the loss of the sense of vision, the person who lost vision must now live as a person who is blind. While the causes of blindness are varied, the result is

the same: the primary sense by which information about the world is received, does not, either in full or in part, register the perception (Medline, 2020).

The distinction between blindness caused adventitiously versus blindness caused congenitally is that persons who were born blind are called congenitally blind, and they have lived all of their lives without vision. They have not ever seen (Welsh & Tuttle, 1997, p. 60). Moreover, by having been born unable to see, and although they are blind, they have not experienced the occurrence of vision loss.

This distinction is significant in that congenitally blind persons not only do not experience the transition from living as a person who could see to a person who cannot see, more importantly, they do not experience the trauma associated with vision loss. Tuttle and Tuttle (2004, p. 153) denote that adventitious blindness is, indeed, a traumatic experience.

Janoff-Bulman (as cited in Werdel and Wicks, 2012) stated that “Trauma can threaten or shatter an individual’s assumptive world.” Matthews and Marwit (as cited in Werdel and Wicks, 2012) stated that the assumptive world is “the very standard against which the self and life is interpreted.” Moreover, Werdel and Wicks assert that, “In each instance [of trauma], there was a ‘before’ and now there is an ‘after’ (2012, p. 25). The juxtaposition of the time periods before and after vision loss therefore represents all that one has known in the world, contrasted with a necessary revision of life's meaning and purpose.

This revision of one’s life meaning and purpose is often written with a negative connotation that can be violent, destructive, and dark (Werdel & Wicks, 2012, p. 25).

However, “Loss of vision, either total or partial, happens to many different individuals. Each person responds in a way that reflects his own personality, skills, goals, personal supports, and life situation” (Welsh, 2010, p. 181).

Cholden (1958) identified that with adventitious blindness, as with other traumatic events, there is a time “before vision loss” and a time “after vision loss,” but “his eyes are the least part of the person that is affected. Mainly, the inner person [the self] is altered.” Cholden had found that “[t]he person who acquires a handicap in essence becomes a *different person* from his former self” (pp 51-52).

Tuttle and Tuttle (2004) further found that for those individuals who experience vision loss, exploring the issues of the inner self become paramount. “One of the next issues to be resolved [after blindness] is the question of one’s identity” (p. 182). Finding and accepting one’s new blind self, a self who no longer is able to function the way he did before, is to accept an entirely different self. The old self and the new self are functionally and inherently different (Powell, 2017).

To enunciate the critical distinction between vision loss and blindness at last, persons who are blinded adventitiously must undergo a trauma that requires them to find themselves again after the trauma occurs, a culminating phenomenon that congenitally blinded persons will not have to endure. According to Cutsforth, (1980), “[t]hose differences which occur result from the conditions that blindness imposes, not from the absence of sight itself” (pp. 121-22).

### **Posttraumatic Stress due to Vision Loss**

Similar to incidents of other types of trauma, individuals who experience the quite literally life-changing event of vision loss are now living post-trauma, and they must attempt to find meaning after their lives have been sufficiently disrupted. “Occasionally, individuals will be told long before the actual onset of blindness that they may be losing their vision. In these cases, the initial trauma is not the actual loss, but the knowledge of the impending loss” (Tuttle & Tuttle, 2004, p. 154).

“Trauma is the response to a deeply distressing or disturbing event that overwhelms an individual’s ability to cope, causes feelings of helplessness, diminishes their sense of self and their ability to feel the full range of emotions and experiences” (Onderko, 2019). While living with the knowledge of an imminent adventitious vision loss is stressful and traumatic, the trauma of vision loss still creates its own effects (Carroll, 1961; Cholden, 1958).

Cholden (1958, p. 18) proposed that among the greatest of these effects that occur upon the loss of vision, “He must die as a sighted man and be reborn as a blind man.” In *becoming* a man who is blind, “He adds, however, the new concept unto himself of being a different kind of person from all other people and the kind of person he was before” (Cholden, 1958, p. 83).

Tuttle and Tuttle (2004) determined that when individuals experience adventitious vision loss, exploring the issues of the inner self become paramount. “One of the next issues to be resolved [after blindness] is the question of one’s identity” (p. 182). Finding and accepting one’s new blind self, a self who no longer is able to function the way he

did before, is to accept an entirely different self. The disrupted self, predicated by vision loss, may therefore be more damaging to the individual than blindness itself.

Werdel and Wicks (2012, p. 21) explained that, following such traumatic events, an “*assumptive* transformation within the self” must follow. This transformation is also known as growth. Because the old sighted self and the new blind self are functionally and inherently different, a transformation must occur.

Calhoun and Tedeschi (as cited in Werdel & Wicks, 2012) noted that, “For the phenomena of posttraumatic growth to occur, a person must experience a significant level of disruption to their assumptive world and personal narrative in a way that alters a person’s experience of everyday life. Posttraumatic growth is a term that recognizes “that value can emerge when cognitive structures undergo the reorganization that results from experiencing stress and trauma” (Werdel & Wicks, 2012, p. 7).

### **Adjustment to Vision Loss**

Often with vision loss, the individual is experiencing "traumatic psychological transitions" to which individuals must adjust internally before interventions can successfully occur (Graetz & Smith, 2010, p. 144). The adjustment process is one that will be examined here because "good and appropriate interventions" are necessary in the lives of the visually impaired (Pashmdarfard, Amini, & Amini, 2016, p. 81). Such interventions are said to be critical for "enhancing the chances of the affected individuals, particularly children, who have their whole life ahead of them, to acquire a means of livelihood, improved social interaction and enhanced self-dignity" (Aliyu, Abdulraheem,

& Abdulkabir, 2014, p. 150). Understanding adjustment to the phenomenon of vision loss and the subsequent adjustment to blindness therefore are crucial.

**Shock.** “The physical or social trauma is the event or circumstance that precipitates the necessity for initiating the adjusting process” (Tuttle & Tuttle, 2004, p. 55). In this case, a person who loses vision will need to adjust. “If an adult suffers loss of sight with any degree of suddenness, he will usually react with a psychological state of immobility that can best be described as a state of shock” (Cholden, 1958, p. 73).

Tuttle and Tuttle (2004, p. 159) agreed that “Shock and denial or disbelief are usually the first reactions to a major trauma or crisis” such as vision loss. Chevigny & Braverman (1950, p. 231) found “With this shock there is a concomitant regression to an infantile level.” Tuttle and Tuttle (2004, p. 55) also identified that “Feelings of unreality, detachment, and disbelief are common expressions during this phase.”

In later studies, Cholden (1958, p. 73) identified that “During this period [of shock], which may last from a few days to a few weeks, he finds himself unable to think or feel (One patient aptly described this time in terms of feeling ‘frozen.’ He felt nothing).” Cholden observed that, as a possible rationale for shock, “the patient seems to need this time to marshal his forces and reorganize his inner strengths to meet the new challenges before him” (1958, p. 75). “It would seem that his new task is so formidable that he must approach it by retrenching his energies for a time” (Cholden, 1958, p. 73).

While doctors may be able to help the adventitiously blinded to handle their emotions and control their feelings, some doctors attempt to circumvent shock by deliberately misadvising the patient that sight will return (Cholden, 1958, p. 78).

Chevigny and Braverman (1950, p. 235) warned against this practice. They said, “Doctors who follow this practice risk the future good reorganization of their patients.”

For the person who is led to believe that his vision might return, it is asked, “Why should anyone embark on the hard business of learning to be blind if he still has reason to believe it may not be necessary?” Furthermore, traumatic shock may subsequently present itself first from learning the truth about permanent blindness and a second time by feeling betrayed by the doctor when the patient finds out the doctor had lied.

**Denial.** In some instances, individuals may elude some of the immobility of shock simply by remaining in denial over their vision loss. Werdel and Wicks offered advice this for understanding:

When working with clients who may be experiencing denial, we must remember that denial must be worked through in order to experience integration and potential growth. However, identification of denial can be honored as a promising step in the clinical process that may allow the therapist insight into a client’s ability to integrate stress and trauma. (2012, p. 43)

Neimeyer, Keesee, and Fortner, researchers of the relationship between grief and meaning, also suggested:

Denial is understood as an individual’s inability to assimilate a death event at a given time. One does not have recourse to the structure necessary to fully perceive the loss or its implications for one’s continued living. Denial therefore represents an attempt to “suspend” the unassimilable event for a time, until its meaning can be grasped in all of its painful clarity. (2000, p. 208)

Werdel and Wicks referenced Tedeschi & Calhoun (2004) who described the difficulty of understanding and giving meaning to traumas such as vision loss:

There is a sense of dissonance between what one's assumption of the world was and the experience of trauma that has proven to be painfully real. Discrepancies between global assumptions and traumatic events may leave a person without a guide or map to follow, which can be quite debilitating. For psychological and emotional health, people need organizational guides. The reconstruction of basic assumptions is a necessity posttrauma. (2012, p. 77)

Of course, reconstructing all of one's basic assumptions is no easy feat. During the periods in which the individual is experiencing shock or denial, meaning and assumption-making are occurring, perhaps unconsciously, as a way of coping with the loss. Park (as cited in Werdel & Wicks, 2012) stated, "coping involves a great deal of intrapsychic cognitive processes or 'meaning-making,' since only through cognitive adaptation can individuals transform the meaning of the stressful experience."

"When a person experiences traumatic life events, coping is necessarily different in nature, demanding the acquisition of new meaning in the unsolvable or irreparable situations of trauma" (Werdel & Wicks, 2012, p. 13). Making meaning and accurate assumptions about a new reality, including the reality that he is now a person who is blind, therefore may depend on the individual's ego strength among other personal characteristics.

"For instance, it has been speculated that the individual characteristics of a person who experiences an event may be of greater concern than the type of event (Werdel &



Wicks, 2012, p. 21).” Moreover, according to Cholden (1958, p. 74), “The degree of damage to the ego and the capacity to recover from the initial shock reaction will depend on the degree of ego-strength and maturity attained at the time of disability.”

Whatever the individual narrative becomes, however, Werdel and Wicks identified that the internalized story is generally tragic in nature (2012, p. 25). The story may also be angry or resentful (Cholden, 1958, p. 20). During these times, no external readjustment effort can be effective (Cholden, 1958, p. 75). All change efforts must first occur internally, as “Disengagement from an old worldview is essential to growth” (Werdel & Wicks, 2012, p. 79).

In the complete absence of internal or external progress toward growth and adaptation, a person can be at risk for death (Bourne et al., 2017, p. 888; Chevigny & Braverman, 1950, p. 229). An observer of someone who is struggling to adjust therefore may wish to rush the processes of adjustment. This practice, however, is ill-advised.

While it may be painful to watch as one struggles internally with the adjustment to blindness, and while a person’s ultimate rehabilitation and acceptance of blindness can be impacted the longer he or she experiences shock or denial (Cholden, 1958, p. 74), Tuttle and Tuttle (2004, p. 174) found the words of Blank (1957) to be relevant in describing the need for these phases of shock, denial, and even depression. Each “is a normal, therapeutic phase of the adjusting process. The inner work of mourning must be accomplished before addressing the problems of the external world.”

**Depression.** As mentioned, during shock and denial, the person is typically unable to think or feel (Cholden, 1958, p. 73); however, when one at last is able to begin

to feel emotions again, that first emotion commonly is depression. Experiencing depression is necessary to recover and to move forward (Cholden, 1958, p. 81).

Cholden (1958, p. 75) purports that any “Attempts to prevent the patient from entering the next stage, that of depression, often leaves him with a prolonged shock stage.” Moreover, according to Cholden, the depression stage is “a necessary precursor to the relearning that is so necessary for the newly blinded adult” (p. 81).

During depression, “We see the usual self-recriminations, feelings of hopelessness, self-pity, lack of confidence in meeting problems, suicidal thoughts and psychomotor retardation” (Cholden, 1958, p. 75). In this time of depression, “The patient then is reacting emotionally to his loss. He recognizes the loss of his vision and begins a period of mourning for his dead eyes” (Cholden, 1958, p. 75).

Along with depression, people are said to feel frustration and anger as a result of pre-reorganization (Chevigny & Braverman, 1950, p. 32). Much of this frustration stems from the inability to be the seeing self he was before. Persons who are newly blind are unable to achieve their goals, even simple ones, like locating their shoes, or reading the mail. Each activity that can no longer be done is counted as an ancillary loss.

Carroll (as cited in Tuttle & Tuttle, 2004) identified that “The perceived negative implications of blindness are highly individualistic. The ‘losses’ people identify are dependent upon their activities, aspirations, standards, values, and relationships.” Tuttle and Tuttle (2004, pp. 171-172) concluded that the losses experienced by individuals will have significant variability and that they “may not be realistic.” The losses felt by individuals are their own “personalized perceptions” Tuttle and Tuttle (2004, p. 172).

Dobson (as cited in Tuttle and Tuttle, 2004) “described depression and emotional apathy as the condition of ‘the D’s’: despair, discouragement, disinterest, distress, despondency and disenchantment with circumstances as they are.” Depression, however, may also result in the person to begin to adjust to the trauma (Tuttle & Tuttle, 2004, p. 173).

Tuttle and Tuttle (2004, p. 170) report that the initial feelings and perceptions surrounding blindness are generally quite negative. “The individual seems to focus only on the negative implications of the trauma, often exaggerating their effects unreasonably. This is the ‘I can’t’ phase when the individual concentrates on abilities and capacities thought to be altered or lost.”

**Coping and Change.** “When the initial period of ‘shock’ and the normal period of depression, which to some extent is an expression of grief over the lost sense, are over, the patient will find his place in society as a blind person” (Cholden, 1958, p. 20). Cholden’s assumption of finding one’s place in society so quickly, however, may be somewhat of an oversimplification, as merely no longer being depressed does not translate into acceptance of self and remediation of all losses.

Unfortunately, recovery from shock and depression is mired in obstacles, both personal and external. Even Cholden acknowledged, “Many obstacles stand in the path of the patient’s acceptance of his handicap and of progress through the above-mentioned stages of shock and depression” (1958, p. 76).

Tuttle and Tuttle (2004) had identified that part of recovery included the ability to organize one’s thoughts in a way that internalizes one’s identity as that of a person who is

blind or disabled. Until such identity as a person who is disabled could be reckoned with, if the internal identity remains as that of a non-disabled person, a person might never seek rehabilitative services. In other words, if individuals cannot accept that they are blind, they will not so willingly enter into—nor benefit from—a rehabilitative program designed for people who are blind. Despite the many benefits of blind rehabilitation, many individuals have difficulty accepting themselves as a person with a disability because of the existing societal perceptions of disability and blindness.

### **Societal Perceptions**

In 1957, Dr. H. Robert Blank, M.D. of New York analyzed the psychosocial adjustment of children and adults who were either congenitally or adventitiously blind. His findings attributed positive adjustment to characteristics beyond rehabilitation itself. Many of his patients were not responding to rehabilitative efforts and had sought psychoanalytic counseling.

Dr. Blank (1957) shared that adjustment processes were often hindered by societal perceptions of blindness and disability and the subsequent transference of negativity from caregivers onto the person who was blind. In one example, "The difficulties between mother and child resulted essentially from her ambivalent identification with him...she unconsciously transferred her self-hatred and contempt to the child" (Blank, 1957, p. 3).

In this particular case, until the mother had received treatment for her fear of blindness, "The child's problems and potentialities could not be evaluated." It was not until "the relationship between parent and child had been bettered [that] child and mother were ready to accept help with the specific problem of blindness" (p. 4).

In examples such as the one above, Dr. Blank (1957) indicated that when the relations of child and parent are disturbed, it can cause the child to have a distorted differentiation of the ego (p. 5). Dr. Blank went on to say that when that happens, the parent's disturbance should not be a measure of the child's disturbance. The questions that Dr. Blank suggested would need to be asked are "Why is the parent disturbed, what help is he really asking for, and what help does he need" (1957, p. 5)?

Interestingly, just as children are impacted by perceptions that parents have toward blindness, adults who are blind also are subject to the perceptions of blindness that others in society may project onto them. Persons who are blind therefore may experience similar discomforts and maladaptation to disability, regardless of rehabilitative intervention.

If a person who is blind feels, or is made to feel, like a burden, as a person who is defective, or as a person who has been punished by God, rehabilitative strategies will not necessarily equate with internal adjustment and positive identity. As another of Dr. Blank's patients had indicated, "I learned a lot of things [in the rehabilitation center] that were good and come in handy now, but I didn't learn how to live with myself in this sighted world" (Blank, 1957, p. 12).

What has been shown, then, is that researchers, including medical doctors, may not be reviewing the internal facets of adjustment as closely as they are scrutinizing the external or rehabilitative facets of adjustment. Relatedly, medical doctors may choose to not pronounce blindness as a final diagnosis upon their patients, and instead will continue to encourage hope that the vision will return (Cholden, 1954, p. 109). Some doctors may

even discourage rehabilitation and a belief in the possibility to live a full and complete life as a person who is blind (Cholden, 1954, p. 109)!

Is it possible that people in society, including doctors, do not believe that living as a person who is blind could be a rich and satisfying experience? Is it possible that society, including doctors, have a fear of blindness for themselves that they project onto their patients? How would this mindset contribute to a society in which individuals are not able to accept themselves or others as people who are blind? Dr. Cholden astutely advanced the answers to these questions:

Another important factor that should be explored in more detail is the concerted effort of society to prevent the patient from accepting his blindness as a fact.

Well-meaning and sympathetic friends and relatives will do anything possible to cheer the patient with news of miraculous cures, or wonderful doctors, or new drugs, to help the patient believe his sightlessness is not final. Ministers will offer proof of the efficacy of faith and prayer in returning vision to the blind. Everyone offers hope for the return of sight. Rarely is any hope offered that the patient may live a full life as a blind man, that it is only a different kind of life he must learn to live. It would seem that in our society the prospect of life as a blind person is too horrible to contemplate. (1954, p. 109)

**Too Horrible to Contemplate.** What do Cholden's words mean that blindness is "too horrible to contemplate" (1954, p. 109)? Could this—being too horrible to contemplate—be among the reasons why adjustment to blindness itself has not been intensely and closely studied? Imagine an ophthalmologist who has dedicated his or her

life to the preservation of vision. Should the doctor feel guilty if a patient who, while in his or her care, becomes blind? Might the doctor feel that the blindness is somehow his or her fault? Might the doctor not advise the patient to attend rehabilitation due to the indoctrination of the medical model of surgery? Might the doctor or the patient truly believe that vision could return? Might the doctor not want to be the bearer of the bad news?

Dr. Cholden looked at these very predicaments and found that "it would appear that sometimes the ophthalmologist has to offer this hope for return of vision in order to lift his own spirits" (1954, p. 110). Dr. Blank supported this statement in his analysis that "Blindness is an unusually powerful instigator of transference and countertransference" (1957, p. 2). It could be, therefore, that these projections by doctors and others of fear of blindness ultimately create discrimination against the blind, even among those men and women who were blind and who had been rehabilitated and educated. In the following paragraphs, we will delve into the story of Newell Perry, a man who was blinded, rehabilitated, and educated, but yet who faced nearly insurmountable discrimination.

Newel Perry was just a young boy when he lost his sight. At 10 years old, Perry lost his sight due to exposure to poison oak, and he was sent to the California State School for the Deaf and Blind (Ferguson, 2007, p. 47). The superintendent of the school felt that Perry would be better suited in public school, but the school was not welcoming. The superintendent then "interceded on Perry's behalf to overcome strong resistance aimed at keeping him [Perry] from attending Berkeley High School and later the University of California (1892–1896)" (Ferguson, 2007, p. 47).

Despite having earned a graduate degree from University of California at Berkeley and a doctoral degree from the University of Munich, Germany, Perry "struggled to secure a faculty appointment" in the United States. "Blindness, not his intelligence, was the barrier in the minds of faculty" (Ferguson, 2007, p. 48). The resolve that Perry had over the situation never lent itself over to depression, and Perry strengthened his resolve to succeed. Unfortunately, he never was able to achieve his goal.

Eventually Perry returned to teach math at the California State School for the Deaf and Blind. Throughout his endeavors, "Perry's understanding of blindness and the needs of blind persons were learned firsthand in the crucible of suffering inflicted as the result of the perpetuation of ancient myths about blindness" (Ferguson, 2007, p. 47). Perry is known for saying that "sighted people have...an utterly false conception of the consequences of blindness. It is their misconception about its nature which creates the social and economic handicap of blindness" (Ferguson, 2007, p. 49).

### **Barriers to Acceptance**

The discussion thus far included the initial ramifications of vision loss: falling into shock, denial, and depression after all that was known was lost. As noted by Schulz (1980) and cited in Tuttle and Tuttle (2004, p. 202), the effects experienced by the newly adventitiously blinded individual are magnified in that the person is both psychologically and physically immobilized. In shock, his mind is paralyzed, and physically, he is unable to see to accomplish tasks in any familiar way.



The person who attempts to adjust to his blindness must adapt not only to his psychological and physical struggles, but he must also negate external pressures and historically negative perceptions and fears of blindness such as becoming a beggar who is unable to work or leave his home, or someone who is not much more than a pitiable charity case (Barasch, 2001, p. 92; Cholden, 1958, p. 21). He must dispel these and other myths— not only in his own mind, but also in the minds of others—before being able to acknowledge and accept the daunting task of having to relearn all of one’s capabilities.

Many capabilities, such as reading, are able to be relearned in alternative ways. Other former capabilities, such as driving, must be permanently foregone. The newly blinded individual likely will not know what is and what is not possible, but at times, even when the possibilities of rehabilitation are known, an individual may still resist due to his unwillingness to identify as a person who is blind (Omvig, 2009).

As evidenced, “Both internal and external forces are operating to prevent the newly blinded individual from the full recognition of his new status” (Cholden, 1958, p. 76). It has further been remarked that “Personality, prior coping experience, prior attitudes toward blindness, intelligence, age, and philosophy of life that members of the support network bring to the trauma also impact on the quality of the adjusting process” (Tuttle & Tuttle, 2004, p. 234).

What Tuttle and Tuttle have suggested, therefore, is that some individuals will show greater aptitudes in adjusting to vision loss than will others based on their previous life experiences (2004, p. 234). Moreover, because “Coping...may involve the acquisition of new skills and the mobilization of internal and external resources” (Tuttle

& Tuttle, 2004, p.188), if the person's previous life experience already endowed them with relevant coping skills, then the process of adjusting also could be expedited. In other words, "the personality and ego strength the individual brings to the situation will determine, in large measure, the nature of the outcome" (Tuttle & Tuttle, 2004, p. 214).

Factors of adjustment beyond the person's initial ego strength at time of onset include his "age of onset [how old he or she was when the vision was lost], degree of vision [how much vision was lost], support of significant other people, availability of professional services, etc." (Tuttle & Tuttle, 2004, p. 56).

"For the adventitiously blind, the trauma or disruptive moment frequently begins in the ophthalmologist's office or hospital when the doctor informs the patient regarding possible loss of vision" (Tuttle & Tuttle, 2004, p. 157). That is to say that individuals may begin experiencing the trauma of vision loss prior to the actual onset of vision loss. Worse, however, is when a doctor is dishonest with the patient about the impending blindness, or if the topic is avoided altogether. "The avoidance of a topic [by a doctor or others]...will make the subsequent adjustment process much more difficult" (Tuttle & Tuttle, 2004, p. 158).

"Rogers's Organismic Valuing Process Theory (1964) articulated that it is a normal, natural tendency for an individual to move toward meaning-making and growth *if* one's social environment supports a person in doing so" (Werdel & Wicks, 2012, p. 10). Unfortunately, very often, the social environment, which includes the self, maintains a negative attitude toward blindness (Chevigny & Braverman, 1950, p. 43). Depending

on how readily the internal facets of shock and depression are worked through, therefore, can help determine when persons could be ready for rehabilitative services.

According to Tuttle and Tuttle, Cholden (1958) identified five internal forces that cause individuals to resist accepting blindness:

- (1) the inertia or resistance to change exhibited by the human personality;
- (2) the negative and derogatory stereotypes concerning blindness held before the trauma;
- (3) the irrational feelings and beliefs concerning blindness with its several meanings and historical connotations;
- (4) the minority group status of blindness with its imputed inferiority; and
- (5) the authentic dependencies in some areas which accompany blindness.

(2004, pp. 202-203)

Five internal forces that cause individuals to resist accepting his handicap according to Cholden himself are:

- (a) the inertia, or resistance to the change of the human personality;
- (b) the stereotypes the patient has held relating to the blind as a class;
- (c) the irrational feelings concerning blindness with its sexual meanings and historical connotation as a punishment for sins;
- (d) the minority group aspect of blindness with its meanings in terms of inferior status and personal devaluation;
- (e) the necessary dependencies which accompany this handicap. (1958, pp. 76-77)

The comparison between the Cholden (1958) and the rewording of Cholden by

Tuttle and Tuttle (2004) is warranted because certain subtleties were erased by Tuttle and Tuttle (2004) when they paraphrased Dr. Cholden's (1958) research. For example, Tuttle and Tuttle portend that inertia and resistance to change are *exhibited by* the human personality. Cholden surmised that inertia and resistance to change *is* the human personality.

In the second assumption, Tuttle and Tuttle (2004) indicated that resistance to change and acceptance may stem from how the individual has, up until this point, thought about blindness in general. Cholden noted in his findings that the resistance to change and acceptance came more from how the individual perceived "the blind" as a collective, and how it will be to put himself in that category.

In understanding the literature of Dr. Cholden's time related to the third assumption, researchers were previously infatuated with the sexual lives of the blind. Those curiosities, as well as the long standing belief that being stricken blind was a punishment from God, were believed by Cholden to be irrational. Both of those ideologies were mentioned in the original document, but Tuttle and Tuttle masked the Dr. Cholden's intent in two important ways.

First, Tuttle and Tuttle paraphrased "sexual meanings" and used "several meanings" instead. Next, Tuttle and Tuttle did not clarify to which historical connotations Cholden had been referring. By exchanging the words "sexual" for "several" and by leaving out the clarification of the historical perspective of blindness as a punishment for sin, Tuttle and Tuttle hid the true intention of Cholden's work and effectively changed the intended meaning of the third assumption.

To this day, while very few might yet believe that losing vision is a punishment from God, many would acknowledge that losing vision could be God's will (Werdel & Wicks, 2012, p. 43). Accepting blindness becomes challenging, not when a person identifies his blindness as the will of God, but when God's will is associated with resentment, or the blaming of God or any person for his loss (Cholden, 1958, p. 20).

In comparing Dr. Cholden and Tuttle and Tuttle on the fourth assumption of internal resistance to change, Dr. Cholden's original work does a better job of indicating the deeply personal nature that is involved with the internalization of blindness, being blind, and being associated with "the blind." Tuttle and Tuttle seemed only to indicate that, by having a disability, inferiority is imputed or inferred, but Cholden more clearly articulated the additional nuances of the inferiority that is assumed by society, as well as the subsequent devaluation of self that occurs.

Finally, Dr. Cholden and Tuttle and Tuttle are most alike in the final assumption, in that blindness has necessary (Cholden) or authentic (Tuttle & Tuttle) dependencies. The dependencies arise from the inability to see, and prior to rehabilitation, individuals who become blind are generally limited in their abilities. Here Tuttle and Tuttle make the point that the dependency that accompanies blindness is authentic, or real. Cholden's word choice suggested that the dependency that accompanies blindness is necessary, or required. Both of these statements are seemingly true, but Tuttle and Tuttle do a better job to denote that dependencies are in some, but not all, areas.

### **Transtheoretical Model of Change**

As has been indicated, the impact of vision loss on individuals is substantial (Bourne et al., 2017, p. 889; Lam, Robertson, Robertson, & Bernstein, 2015, p. 1359). When a person loses vision, unless he is to stay heavily dependent on others, he or she is in need of rehabilitative services to help him or her to adjust to living life as a person who cannot see, or who cannot see well (Rapaport, 2015; Strawbridge, Wallhagen, & Shema, 2007, p. S315). “Rehabilitation, then, is synonymous with an effort toward maximal adjustment, or better stated, readjustment of the person who has a handicap. It also implies helping him find again a place in society” (Cholden, 1958, p. 62).

Occasionally, even when the person wanted to become independent, family members or others “actually resisted and sabotaged efforts directed toward helping the client to become independent” (Cholden, 1958, p. 68; Tuttle & Tuttle, 2004, p. 58). This supports the notion that the person who is blind must surmount incredible odds both internally and externally. Until he or she has battled the internal forces to accept himself as blind, and until the person who is blind is able to overcome or mitigate negative societal perceptions and external barriers, a person may not be able to successfully independently enter into rehabilitative services (Tuttle & Tuttle, 2004, p. 208-209).

In the next part of this discussion, one procedural theory of change is examined: The Transtheoretical Model of Change. This component of pre-rehabilitation is useful to understand because in addition to having to accept oneself internally and externally, one also has to be motivated to make the necessary internal changes that go along with rehabilitation. In other words, reorganizing is voluntary. “Before he can reorganize, he

may need to adjust first to the need to reorganize” (Chevigny & Braverman, 1950, p. 233).

In the Transtheoretical Model, voluntary reorganization means that while individuals may accept themselves as persons who are blind, they still may not wish to receive rehabilitative training. What these individuals may have therefore accepted is that they will be a person who is blind and wholly dependent on others for their care, rather than independent. “They become precisely the defectives that society conceives the blind to be” (Cutsforth, 1980, p. 125).

Investigating a philosophy of change that can lead someone from dependence to independence may be useful, as this is an area that is not well understood. As Cholden (1958) identified, “But how little we know about making a frightened, handicapped person courageous, or a dependent client desirous of independence” (p. 63). The Transtheoretical Model therefore helps to put this process into an operational paradigm, complete with steps and stages (Graetz & Smith, 2010, p. 139).

Like any adjusting process, however, “The phases are more or less sequential, not hierarchical, with a great deal of overlap between one phase and the next” (Tuttle & Tuttle, 2004, p. 54). Using the Transtheoretical Model, definitions and explanations regarding the stages and assumptions that an individual who must change will experience are provided.

**Precontemplation.** Prior to recognizing the need for rehabilitative help, the individual is said to be at the *precontemplation* stage of change. "Precontemplation exists

when an individual is unaware or fails to acknowledge the problems without engaging in any change process activities" (Kritsonis, 2004-2005, p. 3).

When a person loses vision, "Families, friends, neighbors, or employers...are often well aware that the precontemplators have problems" (Prochaska, Norcross, & DiClemente, 2013, p. 10). However, "People in this stage are often unaware that their behavior is problematic or [that it] produces negative consequences" (LaMorte, 2018). Moreover, when individuals who are blind are being catered to and doted upon, an alternative sense of power may develop that they do not want to sacrifice by seeking independence (Chevigny & Braverman, 1950, p. 189).

Cherry (2018) identified two key characteristics of the precontemplation stage, denial and ignorance. Precontemplation is, however, an important first stage of change. At this first stage, others may be able to strategically help the person who is in denial over the need to reorganize to become aware of that need to change (Cherry, 2018).

Even with a growing awareness, however, individuals will remain in the precontemplation stage if they "do not intend to take action in the foreseeable future (defined as within the next six months)" (LaMorte, 2018). In other words, the individual needs more than awareness of the need to reorganize to move past precontemplation. Persons must intend to, at least, consider taking action. Until the time at which the person is ready to consider taking action, the person simply is, broadly speaking, not ready (Prochange, 2018).

The next step after precontemplation is called contemplation, but moving a person from the precontemplation stage to the contemplation stage takes an undetermined



amount of time. A person “may remain in a precontemplation or early contemplation stage for years, rarely or possibly never thinking about change” (Center for Substance Abuse Treatment, 1999, p. 57). Reaching contemplation, however, is an important milestone to achieve because staying home and not contributing to the work force or to personal development has been shown to lead to and to sustain depression, cognitive impairment, dementia, other chronic health conditions, or even hospitalizations (Whitson & Lin, 2014, p. 1740).

Indeed, some may never move past the precontemplation stage no matter how many suggestions or prompts may be given to a person. The fact is, especially as it relates to change and admitting that help is needed, people try to stay "independent" and not ask for help even after so many aspects of their lives have been affected. In some cases, the reasons for this include feeling watched (Chevigny & Braverman, 1950, p. 18) or being otherwise self-conscious, so “they tend to avoid doing anything that will draw further attention to themselves, preferring the ‘safety’ of isolation or withdrawal” (Tuttle & Tuttle, 2004, p.193).

In part due to so few resources to advertise blind rehabilitation options (Lumbres, 2018) and because only 8 million out of 350 million Americans are blind (National Federation of the Blind, 2018), individuals who lose vision are not likely to know other individuals who have lost vision who have been successfully rehabilitated. These factors further comprise part of the reason why the precontemplation phase of visual impairment is not always surpassed.

Cholden (1958, p. 110) described rehabilitation as “a total reconstitution of the being to someone different from the previous being, in preparation for a different life.” Despite perhaps knowing that rehabilitative interventions exist to help persons who are adventitiously blinded to prepare for independence, some individuals who are blind remain resistant to the training options that provide alternative ways to accomplish tasks.

Interestingly, while being helped by family may be seen as socially acceptable, asking for help through rehabilitation may reinforce a personal connotation of societal inferiority (Chevigny & Braverman, 1950, p. 202). Cholden (1958, p. 110) also indicated that this “metamorphosis...is made very difficult by the fact that each person resists such a major change in himself; he has an inertia to the rehabilitation processes.” The reason for this is said to be simple: if the individual is not ready to change, the individual will not change (Prochange, 2018). Some may describe individuals who are not ready to change as resistant or unmotivated, but truly those individuals who are resistant to change are simply not ready (2018).

Cholden suggested a deeper meaning behind not being ready, and that is the person may not be emotionally able to make the change. Cholden described a breakthrough that occurred with some of his patients when the rehabilitation workers did not attempt to motivate them in the usual ways:

The shift in thinking which seemed useful was the eventual recognition that the drive to learn, the inner need to become independent, and a desire to attain maximal fulfillment are *invariably* present in our clients. When we could not discover these drives, it was because we had not looked hard enough. This change

in direction in relation to the source of motivation made considerable difference in our rehabilitation efforts. We could then direct our attention, not to stimulating the client, imposing our goals on him, or offering him motivation, but rather to releasing his own desire to grow. We were then free to focus our efforts on the blocking forces that were impeding the emergence of this maturational drive.

I once heard a staff member ask a question rather different from the one he would previously have used in speaking to a client. When the client said that he could not do something, the worker asked, 'Why do you feel that you can't do it?' Previously he might have said, 'You can do it, I know you can,' or, 'If John can do it, you can too!' The counselor was now wondering what the forces were that were holding the man back from doing this task. When he understood those forces he could then attempt to deal with them. (Cholden, 1958, p. 66)

Until the forces of resistance are understood, individuals may stay in precontemplative, or resistant, stages of change. Resistance to change, is the hallmark of precontemplation (Prochaska, Norcross, & DiClemente, 2013, p. 10). Over time, the more suggestions that can be given to a person, and the longer that he or she struggles with living as a person who is blind, the more awareness the person has regarding what is holding him back emotionally will surface. Eventually, the awareness or consciousness of the issues as they become more prevalent could naturally progress the person into the contemplation stage (Kritsonis, 2004-2005, p. 3).

**Contemplation.** "In this [contemplation] stage, people are aware a problem exists and [they] are seriously thinking about overcoming it, but [they] have not yet made

a commitment to take action" (Prochaska, Norcross, & DiClemente, 2013, p. 10). LaMorte (2018) and Prochange (2018) suggested that individuals who are contemplating change begin to do so by weighing pros and cons. Cherry (2018) and Prochaska, Norcross, and DiClemente (2013, p. 10) suggested that ambivalence or the inability to make a determination is the marker of the contemplation stage.

Cherry (2018) indicated that a person's indecision over whether to move forward can last months or years. Prochaska, Norcross, and DiClemente (2013, p. 10) attributed the individual's inability to take action to the individual's assessment that the work and effort to overcome the obstacles will be too great a burden to bear. LaMorte (2018) further attributed a person's hesitancy to ascribe to blind rehabilitation services, or to any other type of intervention, based on individuals' beliefs either that the rehabilitation might not work, or that they would not be able to learn it.

In some cases, those who have been blind for a long time without any interventions do not know what independence is or what it could be (Chevigny & Braverman, 1950, p. 10). A person who remains stuck may soon therefore be labeled a "chronic contemplator" or a "behavioral procrastinator" (Prochange, 2018).

The issues impacting persons who are blind related to arriving at decisions are compounded by the high propensity for people who are blind to have an inability to readily communicate their feelings and emotions. Cholden provided an explanation:

In order for the individual to express feeling with any degree of comfort, he must be quite aware of the manner in which his communication is received. As the sighted person offers some indication of his emotions, he receives permission to

proceed from the smiles, sympathetic faces, nods, etc. of his listener...Of course the visual cues which are used by the sighted are not available as return stimuli to the blind person. (1958, p. 36)

Important to remember is that although the individual in contemplation may not be taking action quickly, a person is wrestling with a decision to change by acknowledging that change, although hard, is needed. Persons in contemplation are considering the change, and are weighing the pros and cons, but they are still not quite ready to take the leap (Kritsonis, 2004-2005, p. 3).

Moreover, as per Cholden's work, the weighing of pros and cons and the discussion of wants and needs is happening predominately internally. These discussions often are not being shared with others, which potentially may make the processes of change even more lengthy and complicated. Then, as sometimes can happen, a reversion to the ideology that the blindness and dependence are "not *that* bad" could occur, keeping them [the dependent] from advancing ahead (Schulz, 1980, p. 120, italics in original). "There are those who, for inner reason, have found in their helpless condition something that brings them more joy in living than did independence" (Chevigny & Braverman, 1950, p. 9).

**Preparation.** Preparation shows intent of change, and this intent is usually shown not just in attitude, but in the individuals' changing of behaviors (Prochaska, Norcross, & DiClemente, 2013, p. 11). Once the decision is made to prepare for change, the motivation is often high enough that change will occur within a month (LaMorte,

2018; Kritsonis, 2004-2005, p. 4; Prochange, 2018; Prochaska, Norcross, & DiClemente, 2013, p. 11).

Assembling the necessary resources is the precursor to major change (Graetz & Smith, 2010, p. 142). For persons who are blind, preparation to change would include actively seeking resources and attempting to sign up for a rehabilitation program or information session. Individuals in this stage will generally be more receptive to suggestions such as to research companies like *Maxi Aids* that distribute resources for the blind. Any action, however small, can demonstrate that steps are being taken to prepare for a larger change (Cherry, 2018).

In preparing for blind rehabilitation services, one behavioral change that can be identified is the development of a plan (Prochange, 2018). An appointment may be set to see a specialist. A request for consultation may be submitted. Information may be sought about what to do to prepare for the appointments. Family members may organize so that they can be present at the meeting. Further questions might be prepared to ask the specialist when it comes time.

In preparation, individuals may need some counseling or other social supports (Kritsonis, 2004-2005, p. 4). They may need reassurance that their decision is correct, or affirmation in the belief that their decision will lead to a healthier and better life (LaMorte, 2018). Seeking help groups and identifying other individuals who have lost vision can help those who are nervous to overcome some of their fears.

***Overcoming fears.*** “For each individual who takes his first steps as a blind person, the most immediate hindrance is fear” (Chevigny & Braverman, 1950, p. 230).

“The conquest of fear lies in the discovery of what is truly to be feared and what is not” (Chevigny & Braverman, 1950, p. 233). “It requires a very superior intelligence to reorganize a life into some form of healthy activity when the chances are ten to one that there is no choice available” (Cutsforth, 1980, p. 136).

Being blind, “He adds...the new concept unto himself of being a different kind of person from all other people and the kind of person he was before” (Cholden, 1958, p. 83). Those who recognize that they are now blind also believe that they have a characteristic or attribute that makes them different from others in a less than desirable way.

People who are blind or who become blind often sense that the stigma of blindness has reduced them from persons who are whole, to persons who are broken, or defective (Goffman, 1963, p. 3). Adventitiously blinded individuals must therefore defeat the thoughts that tell them that they are irreparable so that they are motivated to be rehabilitated. They must further defeat the originating source of these judgements.

“The blind almost universally complain of the attitude with which the seeing regard them” (Cutsforth, 1980, p. 127). Without any negative social factors, “such as the immediate presence of anxious and solicitous, long-faced relatives,” it has been observed that fear of judgement might be waived (Cutsforth, 1980, p. 124). Therefore, it could be said that “the source of the stigma is not to be found in themselves or their blindness but instead is to be found in the others’ fault and erroneous attitudes toward blindness” (Tuttle & Tuttle, 2004, p. 176).

In a society where independence is highly valued and expected of all (Krogh & Johnson, 2006, p. 169), “It is remarkable how frequently, out of a sense of guilt, society will cater to the dependency needs of a client” (Cholden, 1958, p. 67). Perhaps ironically, then, the infamous “blind beggar” is seen as a social disgrace. The beggar has “the *disgrace* of disability: the idea that one who is disabled is inferior and a burden” (Scott, 1969, p. 24). The disgrace comes despite that the beggar falls exactly into society’s expectations of one who cannot work and one who needs help (Chevigny & Braverman, 1950, p. 238). How then does one manage to be blind, but not like *that*?

The stigma of being a blind, inferior, disgraceful burden is perhaps the largest fear of adventitiously blinded individuals to overcome; therefore, the willingness to publically self-identify as a person with a disability becomes problematic (Hibbs & Pothier, 2006, p. 206). “With society’s prevailing attitudes regarding the helpless and dependent state of blind persons” (Tuttle & Tuttle, 2004, p. 58), what is left but for persons who are blinded to feel shame in their condition?

Shame often makes people want to hide than to become publically visible (Siebers, 2011, p. 163). Seeking training that is designed to put persons who are adventitiously blinded more into the public eye therefore can be a challenge. “The necessity of adjusting to this form of social requirement induces at times an intense emotional strain” (Cutsforth, 1980, p. 133).

With vision loss, the journey to complete triumph over fears may each be



recognized as a "traumatic psychological transition." The emotional changes will be challenging and uncomfortable as each is worked through internally one by one (Graetz & Smith, 2010, p. 144).

**Action.** For initial interventions to be successful and to move individuals into action, "the individual's attitude toward the desired behavior must be positive for change to occur" (Kritsonis, 2004-2005, p. 5). Next, the individual must have "perceived control over the opportunities, resources, and skills necessary to perform the desired behavior" (Kritsonis, 2004-2005, p. 5). Finally, "behavioral achievement depends on both motivation (intention) and ability (behavioral control)" (LaMorte, 2018).

Kritsonis (2004-2005, p. 4) also correlated action as a coping strategy. In taking action, the individual has accepted blindness and the need for rehabilitation. The actions of rehabilitation are proven to help individuals further cope with blindness by achieving greater levels of independence.

LaMorte (2018) suggested that "change leads to more change." As individuals regain independence through rehabilitation, the fears of inability begin to wash away. Instead of believing in "I can't," "I can" becomes the new mantra. The attitudinal shift from "I don't want to" to "I want to" also appears. Once the positive effects of rehabilitation become apparent, individuals typically want more of it (Welsh, 2010, pp. 183-184).

Prochaska, Norcross, and DiClemente (2003, p. 11) documented that change in the action stage often has "successfully altered the dysfunctional behavior." Once the

effects of change become apparent, rarely do individuals wish to go back to how things were before. As new skills are learned, they become readily adopted into daily routines.

Prochange (2018) noted that change is overt and visible because it is impossible to not notice the transformation from dependency to independency. Rehabilitated individuals may be using adaptive devices to set alarm clocks or timers, or they may be using organizational strategies to pick out their own clothes and labeling strategies to sort the clothes appropriately into the laundry. Rehabilitated persons may now be cooking meals in the oven or on the stove, following recipes from audio cards, paying bills and sending emails using adapted computers, and travelling independently to the grocery store. The change, as Prochange (2018) suggested, is evident.

Cherry (2018) cautioned that, in the Transtheoretical Model, some "resolutions fail because the previous steps have not been given enough thought or time." Cherry (2018) suggested that if the steps of contemplation and preparation were rushed or incomplete, resolutions could fail. Other facets to consider may not have been appropriately recognized, such as other health issues, cognitive delays, or conceptual development discrepancies. Finally, it is also true that, "not all respond equally to the training even when equal capacity to receive it is present" (Chevigny & Braverman, 1950, p. 9).

**Maintenance.** Maintenance of the changes is the final stage of the Transtheoretical Model. At any time prior to maintenance, individuals may revert to earlier stages, such as from action to contemplation, or preparation to contemplation. Individuals may remain stuck in stages such as precontemplation or contemplation for

extended periods of time, but if individuals are stuck in the action phase for an extended period of time of more than six months, they are said to be the maintenance phase (LaMorte, 2018).

After one year, 43% of individuals may revert from action to a previous stage; however, after five years of continued implementation of change, the likelihood for relapse dropped to just 7% (Prochange, 2018). If relapse did occur, many individuals learned from their return to contemplation to achieve maintenance in the future (Kritsonis, 2004-2005, p. 4). Prochaska, Norcross, & DiClemente (2013, p. 11) found that among those who do relapse, 85% of them return to action stages and beyond.

According to Cherry (2018), self-analysis of the relapse influenced future success. Individuals may ask themselves, what triggered the relapse? What could I do to avoid a relapse in the future? Cherry (2018) also suggested that looking closely and objectively at a relapse may help to prevent any setbacks to one's self confidence. Feeling like a failure may be natural, but devising a plan for improvement and a strategy to overcome triggers of relapse in the future is important to achieving a lifetime of maintenance (LaMorte, 2018).

### **Summary**

For years, theories about adjustment to trauma and adjustment to change have been studied and applied to grieving a loss. Generalized results have been extrapolated and used to help define and explain adjustment to vision loss; however, many concepts are not fully known or understood. The literature further suggested that concentrated inquiries have been made into the effects of vision loss, but into not the experience of it.

Therefore, my inquiry asking individuals to identify what are their experiences with vision loss is relevant and needed.

The Transtheoretical Model of Change also was adapted to include vision loss, but it was not written specifically for vision loss. Few theories were designed exclusively around populations of individuals who are visually impaired. Part of the reason for this is that there are typically few persons in a given region who are able to be identified, and another part of the reason results from researchers' inability to study blindness. For researchers and doctors, it has been suggested that blindness is too horrible to contemplate, and it has been suggested that people who are blind are not willing to open up fully to someone who does not understand.

In Chapter III, I outline my phenomenological approach to investigating experiences with vision loss, and how I provide participants an opportunity to tell their stories to a person who does understand. Chapter IV goes into more detail about my personal experiences to warrant the trust I have earned through years of professional experience. I will also highlight my desire to critically investigate societal aims and advocate for disabled populations.

## CHAPTER III

### Methodology

#### Overview

“Lived experience is the starting point and end point of phenomenological research” (van Manen, 2016, p. 36). In phenomenology, the researcher makes inquiry into the lived experiences of individuals who have experienced a phenomenon. Husserl, a mathematician and the de facto founder of phenomenology, believed and recognized that "Natural knowledge starts with experience and remains *in* experience" (Husserl, 2014, p. 9, italics in original). Discovering the meanings of a phenomenon, therefore, lies in the inquiry of only those individuals who have experienced the phenomenon (Creswell, 2013, p. 150).

Although the persons with the knowledge of the experience can only exist within those who have had the experience, the understandings held by those with the experience may be subjective and based on their own individual interpretations (Smith, Flowers, & Larkin, 2009, p. 16). Heidegger (2010) also believed that these individual experiences and interpretations were “historical” (p. 37), or otherwise in the past.

The phenomenological researcher therefore must attempt to guide the participant to reflect on those past experiences so that the researcher might elucidate the lived

experiences (van Manen, 2016, p. 27). The goal of such reflection is to move the interpretation of the experience from that which is subjective, toward that which is objective (Creswell, 2013, p. 78).

### **Reflection**

One way to make sense of these aims of transcendental phenomenology was to imagine participants reflecting on the experiences of vision loss as they occurred, instead of after they occurred. Van Manen described this process as the attempt to access "the world as we experience it prereflectively" (2014, p. 28). As the experience was occurring, one had not yet reflected upon the experience, making these experiences known as prereflective experiences (van Manen, 2014, p. 28).

The reflective period is what follows the experience, and the reflective period begins when we start to think about the experience and give subjective meaning to those experiences. To move our consciousness beyond what is known subjectively, we must therefore reflect upon it, and begin to imagine the experience in new ways to create new meanings.

Because this inquiry sought to uncover experiences of vision loss, only those individuals who experienced the phenomenon of vision loss were queried. With guided help from the researcher, individuals had the opportunity to reflect on their experiences with vision loss. Subsequently, the researcher described the individuals' subjective experiences and made new, objective connections from the experiences that the participants had in common. This process that was followed in this inquiry is one which

can “provide the basis for a reflective structural analysis that portrays the essences of the experience” (Moustakas, 1994, p. 13).

### **Research Design**

"The first challenge of the researcher, in preparing to conduct a phenomenological investigation, is to arrive at a topic and question that have both social meaning and personal significance" (Moustakas, 1994, p. 104). Additionally, according to Moustakas (as cited in Creswell):

The type of problem best suited for this type of research is one in which it is important to understand several individuals' common or shared experiences of a phenomenon. It would be important to understand these common experiences in order to develop practices or policies, or to develop a deeper understanding about the features of the phenomenon. (2013)

Phenomenology is a method of inquiry which is particularly relevant to an investigation into lived experiences of vision loss because experiences of vision loss are not well known or understood. Although individuals have been blind and visually impaired throughout history, and although the increase in the prevalence of vision loss will likely double by 2050 (Varma et al., 2016, p. 805), the current misperceptions and fear surrounding blindness and vision loss is unescapable in society. Citing the National Institutes of Health's National Eye Institute, The Chicago Lighthouse for the Blind reported:

According to a recent survey, most Americans fear blindness. In fact, they fear it more than losing their hearing, speech, a limb or their memory...These findings

are not new or surprising—living in darkness is a natural fear humans have had for centuries. This survey only underscores the importance of doing further research on eye diseases, as well as providing more services and resources for people living with vision loss. Unfortunately, many individuals will have to confront this fear in the near future, because the number of people with vision loss in the United States is expected to double by 2050. (Chicago Lighthouse for the Blind, 2020)

Michelle Hackman, a woman who is blind, reported on another relevant topic for the American Foundation for the Blind in 2014. She asked, why do people fear the blind? To answer her own question, Hackman wrote, “The basic problem with blindness, I’ve come to believe, is simply one of relatability. It is so difficult to describe.” She wrote as well that the fear that accompanies the unknown and indescribable “strips blind people of a level of basic humanity.” Hackman also unfortunately admitted that she does not “know a particularly effective strategy of dealing with such prejudice.”

Because the attitudes surrounding people who are visually impaired and blind has been mostly unchanged over the past century, this topic does have social significance. People who are blind are subject to the attitudes of people around them, and the attitudes of people toward blindness are historically not positive (Moshe, 2001). Moreover, due to fear and avoidance, learning about blindness from the people who have experienced it is exceptionally limited. Even reading stories or history about visual impairment is rare, or as Chevigny and Braverman had put it, “obscure in the extreme” (1950, p. 72).



Hackman (2014), a woman who is blind, indicated that people were often surprised to learn that she is able to speak to her students or that she could hear without elevated voices. Despite that she knows where she lives, and she knows how to cross the street, she said people frequently assume that she doesn't know where she is or where she is going.

Like Hackman, any person who loses vision is subject only to the attitudes and beliefs of those people who around them. Like Hackman as well, most often, the majority of the people in any given area are sighted, or able to see. This fact, that the majority of the world is sighted and the minority of the world is visually impaired, limits one's ability to gain understanding about vision loss through communication with others who are also blind or visually impaired. Therefore, without support from the sighted community, and facing their prejudice, discrimination, and fear, the adventitiously blinded individual is often left to work through the experience of blindness independently.

As a result of limited knowledge of experiences with vision loss, this phenomenological inquiry therefore sought to uncover the experiences of vision loss as told by those who have lost vision. Often times, those experiences of losing vision were not revealed to even those to whom the individual may be closest. At times, the understandings of the experiences remained unrevealed even within the individual (Chevigny and Braverman, 1950, p. 207). Creating an avenue by which individuals might share their experiences and reflect upon those experiences uncovered important

considerations that could be shared among those who are struggling to comprehend their adventitious blindness.

### **Purpose Statement**

The purpose of this inquiry was to explore the lived experiences of people who were adventitiously blinded. These individuals were once able to see and accomplish tasks in traditional ways, but, due to vision loss, they must now live as people who are blind.

### **Research Question**

The research question that guided this study was: What were the lived experiences of individuals who were adventitiously blinded?

### **Role of the Phenomenological Researcher**

"Unlike traditional methods of research, phenomenology involves the researcher in an enriched awareness of her own consciousness" (Bentz & Rehorick, 2008, p. 3). To key in on the word choice of "researcher" highlights a point made by Dahlberg, Dahlberg, and Nyström (2008, p. 173) that the researcher identity itself is of utmost importance.

"The researcher should always be a researcher, despite other identities e.g. social worker, nurse, teacher or therapist. Most of all the researcher identity is important because it supports the open and 'bridled', i.e. scientific, approach" (Dahlberg, Dahlberg, & Nyström, 2008, p. 173). The researcher must act as researcher throughout the entire process, from the formulation of the topic and question and throughout the analysis.

Giorgi (as cited in Vagle, 2018), “stresses that the phenomenological reduction demands that the researcher bracket ‘past knowledge about the phenomenon encountered.’” Vagle continued:

In keeping with his concern for rigor, Giorgi asserts that when properly executed, the phenomenological reduction preserves what is presented in the natural attitude except that it moves beyond stating something “is.” Giorgi even stresses that, “No work can be consider [sic] to be phenomenological if some sense of the reduction is not articulated and utilized.” (2018, p. 73)

Here the distinction between the Husserlian concept of bracketing and the Dahlberg, Dahlberg, and Nyström (2008) concept of bridling became important. Again, Vagle succinctly delineates two key differences:

First, bridling involves the essence of bracketing in that pre-understandings are restrained so they do not limit the openness. Second, bridling is an active project in which one continually tends to the understanding of the phenomenon as a whole throughout the study. Dahlberg, Dahlberg, and Nystrom [sic] (2008) add that bridling is forward-looking and that bracketing looks backwards, focusing on pre-understandings and trying to limit their influence on the present. (2018, p. 74)

This particular phenomenological inquiry required the researcher to bracket, not bridle, any preconceptions of vision loss due to the occupation(s) of the researcher. The researcher as a both a blind rehabilitation specialist and as an instructor of blind rehabilitation at the university level has had more exposure and contact than most into the life-worlds of individuals who have been blinded, as well as into the existing operational

theories of adjustment to vision loss. This is not to suggest that the researcher has now or has ever been privy to the actual consciousness of another, nor is it even considered to be possible (Husserl 2014, p. 10). The researcher, however, may simply have more to bracket while analyzing the data.

The attitudes and de-construction of the ideologies and experiences of the researcher are further and more closely examined in Chapter IV; however, Moustakas' (1994, p. 103) requirement of selecting a topic that is relevant socially and personally is met through the researcher's professional associations and extensive experiences in the field of visual impairment, as well as for the impending increase in the prevalence of vision loss in the coming years.

### **Research Procedures**

Prior to beginning any research and prior to inviting any participants to the study, the researcher prepared an Application for Research that was reviewed and approved by the Institutional Review Board (IRB) at Stephen F. Austin State University. Participants were invited to the study by direct invitation after the application was approved.

**Selecting participants.** Moustakas suggested that when selecting participants:

There are no in-advance criteria for locating and selecting the research participants. General considerations include: age, race, religion, ethnic and cultural factors, gender, and political and economic factors. Essential criteria include: the research participant has experienced the phenomenon, is intensely interested in understanding its nature and meanings, is willing to participate in a lengthy interview and (perhaps a follow-up interview), grants the investigator the

right to tape-record, possibly videotape the interview, and publish the data in a dissertation and other publications. (1994, p. 107)

Giorgi (2009, p. 123) further indicated that while having rapport with participants is important, it is not necessarily a deciding factor in selecting participants. This suggests that the researcher need not necessarily know the participants in advance.

For the purposes of this inquiry, the announcement of this research was shared among friends and colleagues who were likely to know individuals who had lost vision. Therefore, direct invitation to adventitiously blinded individuals to participate in the research was extended either by the researcher or by colleagues. Invitation methods included a personal invitation verbally, by email, or through private social media accounts.

For those individuals who expressed interest to participate in the interview for this study, the consent letter was emailed or read aloud to explain the research intent (see Appendix A). Some of the invitees were known to the researcher prior to the study, and some of the invitees were not known to the researcher prior to the study.

Four candidates became participants of this study. Four participants is considered an acceptable number of participants in a phenomenological research inquiry (Creswell, 2013, p. 78). Two participants were known by the researcher in advance of the interview, and two participants were not known by the researcher in advance of the interview. All participants were aware that the researcher had extensive professional experience as a direct service provider and as a university instructor prior to agreeing to participate.

**Data collection.** Individual, open ended questions (see Appendix B) as part of in-depth interviews were selected as the preferred method of collecting data among the individuals who experienced the phenomenon of vision loss (Creswell, 2013, p. 81; Moustakas, 1994, p. 114). The purpose of these questions was to learn about their “experiences and reflections on their experiences in order to better be able to come to an understanding of the deeper meaning or significance” of vision loss (van Manen, 2015, p. 62).

Additionally, Moustakas (1994, p. 47) offered the following regarding the importance of allowing the participants the opportunity to reflect on their experiences in the interview. "The method of reflection that occurs throughout the phenomenological approach provides a logical, systematic, and coherent resource for carrying out the analysis and synthesis needed to arrive at essential descriptions of experience." “Essential” was the operative word in Moustakas' statement because essence is at the heart of transcendental phenomenology. The concept that Husserl proposed through reflection was the ability to find the essence of phenomena and to define something new, rather than to describe already established meanings and interpretations of phenomena (Vagle, 2014, p. 29). The movement toward a greater depth of knowledge in this study occurred via guided reflection by the researcher over the course of four 1:1 interviews.

All participants are legally blind or totally blind, and therefore considerations were taken while conducting the interviews. During a face to face interview, the researcher was careful to not use nonverbal gestures such as hand motions when speaking, in part because the movement may be heard and not seen. During all

interviews, as advised by Cholden (1958, pp. 37, 41), the researcher was to be conscious of all possible sounds, including adjusting herself in her seat, scratching, or coughing, as these sounds could have been interpreted negatively. Also during all interviews, the researcher deliberately made encouraging sounds, such as um-hmm, or other verbal indicators to drive the conversation forward, including by intentionally using the participants' names.

The questions that were asked in the interview (see Appendix B) were designed to allow participants to describe their thoughts, feelings, and experiences of vision loss. The questions that were asked in the interview were also meant to guide the participant in answering the questions fully (Moustakas, 1994, p. 114). The researcher helped the participant to answer in ways that "give a direct description of [the] experience as it is, without offering causal explanations or interpretive generalizations" (van Manen, 1990, p. 54).

Throughout the interview, despite that specific questions needed to be answered, the interview also maintained a conversationality about it as a way to elicit anecdotes, stories, and examples of experiences. Using this approach helped make the interview and its resultant data more concrete (van Manen, 2015, p. 67).

The design of some of the questions were meant to talk about aspects of vision loss that could be disturbing, so that those aspects may be better understood (Cholden, 1958, p. 39). Alternatively, other questions intentionally used a positive psychological approach to find out what has gone right. "The positive psychological approach considers what is working by seeking to understand what cannot be understood and by

accessing what cannot be accessed in the human story when *only* a symptomological (what is going wrong) approach is used” (Werdel & Wicks, 2012, p. 10).

The researcher, in guiding the participant through the interview, was careful to not *lead* the participant "to say certain specific things that the researcher is seeking in the data" (Giorgi, 2009, p. 123). The interview and general structure was however loose enough to allow "an opportunity [for the participants] to tell their stories, to speak freely and reflectively, and to develop their ideas and express their concerns at some length" (Smith, Flowers, & Larkin, 2009, p. 56).

As the expressions were released, the researcher endeavored to find the origins of the emotions, the causes, and the effects (Cholden, 1958, p. 44). In so doing, the researcher offered herself “as a relatively fixed, nonthreatening, warm figure” (p. 55).

Cholden also suggested that, during the interview process, the researcher should be prepared to be assumed ignorant (1958, p. 44). In this series of interviews, however, the participants were well aware that the researcher is not ignorant; she is very well versed in the issues and struggles that accompany rehabilitating the visually impaired.

The researcher’s extensive knowledge and experience of working with people who are visually impaired may have created an advantage in the interview process because, as found by Chevigny and Braverman (1950, pp. 142-143), “within the individual, a structure of contempt for that element in the sighted world which fails to understand: not he, the blind man, but the sighted world is stupid.”

Instead, this series of interviews proved useful for individuals to share experiences with a person who does understand. Had the researcher been a person who



truly is ignorant of the topic, the success of the interviews would be questionable, and it is possible that the interviews might not have occurred at all.

***Confidentiality.*** The researcher's methodology for maintaining confidentiality during the dissertation process was as follows: The researcher ascertained consent from all participants for recording interviews, and all interviews were recorded by using a digital recorder designed for the purpose of recording interviews. After the data was recorded, the digital files were transferred to the researcher's password protected computer. The password protected computer also has password protected access to email. Moreover, access to the researcher's email account is further protected by a two factor authorization process through the company Duo.

After the audio files were transferred to the researcher's password protected computer, the files were erased from the digital recorder. The researcher then began the process of transcribing the interviews.

To fulfill the task of transcription, the researcher engaged the assistance of the commercially available transcription software service, NVivo. The audio files from the computer were individually uploaded to NVivo's transcription service where, for a fee, the system automatically transcribed the audio files into text files.

To confirm the accuracy of the text files, the researcher listened to the audio of each file and edited as needed in the text file. Edits included adding punctuation and capitalization, identifying the speaker, and correcting words or phrases that were inaccurately reflected in the electronically transcribed document.

Once the transcriptions were edited for accuracy and the researcher ensured that the final transcripts did not contain any personal health information, the transcribed text file was emailed back to the participants for their review.

After three weeks, participants did not indicate any discrepancies between the researcher's transcripts and the participants' recollection of events. The researcher then began the process of coding the data for themes. To best assist the researcher in coding data, the researcher printed two copies of each interview. All printed interview files were stored in a locked fire-proof safe in the researcher's home and will be kept for five years.

The researcher was committed to maintaining confidentiality for all candidates and participants to the study, including for participants who wished to withdraw. Participants who withdrew from or who were otherwise not selected to the study were assured that no personal information that was learned or gleaned, including their expressed interest, recruitment, consent, interview, follow-up, or withdrawal, was used by the researcher in the dissertation process or in any other way.

Printed copies of transcripts for candidates who wished to withdraw were shredded immediately; however, all consent letters, all printed emails related to candidate withdrawal, as applicable, and all printed transcripts of participants will be maintained in a locked fire-proof safe in the researcher's home for five years. At the end of five years, all print files will be shredded.

For all candidates and participants, the digital data destruction processes were as follows. All emails that shared data of the interview and its transcription were deleted from the inbox and sent folders, then the email trash was emptied. All audio and text

computer files of the transcribed interviews were transferred to a USB flash drive, and those text or audio files were subsequently deleted from the computer. Once deleted, the “recycle bin” was emptied, the computer cache was cleared, and the “disk cleanup” feature was run. Hard drive reformatting did not occur. The flash drive will be stored in a locked fire-proof safe in the researcher’s home for five years.

At the end of five years, all contents of the flash drive will be deleted. To ensure permanent deletion of the flash drive files, a reformatting of the flash drive is required. Per King (2020), the process is as follows: with the flash drive connected to a healthy computer, right click on the USB drive and select “format.” Set the file system as “NTFS” or FAT32.” Click “OK,” then “Start.”

### **Bracketing (Making Reductions)**

Husserl believed that when making a phenomenological inquiry, the researcher should put aside his or her existing notions and aim toward achieving a phenomenological attitude (Giorgi, 2009, p. 87; Husserl, 2014, p. 53). The phenomenological attitude, where the researcher must “*attempt to doubt everything*” that is previously thought to be known (Husserl, 2014, p. 53, italics in original) was gained through a process called bracketing, or making reductions. "Each reduction offers a different lens or prism, a different way of thinking and reasoning about the phenomena at hand" (Smith, Flowers, & Larkin, 2009, p. 14).

The reduction of subjectivities was designed to increase the researchers' awareness and consciousness of the phenomenon itself, and it "helps to clarify the meaning of the experience...[to] help its exploration" (Giorgi, 2009, p. 91). In so doing,

bracketed ideas were not lost; instead, the preconceptions were simply "not allowed to influence the present intentional conclusion" (Dahlberg, Dahlberg, & Nyström, 2008, p. 126). In other words, when ideas were bracketed, they still existed, but they were not "*engaged* while we are determining the mode and context of the present experience" (Giorgi, 2009, p. 92, italics in original).

Through reflection and reconsideration of known perceptions, the researcher made way for additional, or new, meanings. In this process, first, the researcher made explicit the "understandings, beliefs, biases, assumptions, presuppositions, and theories" that would be reduced or bracketed (van Manen, 1990, p. 47). In other words, whatever information related to experiences with vision loss that the researcher thought she knew had to be set aside to allow for the emergence of new meanings from the data. The culmination of these bracketed ideas is known as epoché.

Epoché "is a difficult task and requires that we allow a phenomenon or experience to just be what it is and to come to know it as it presents itself" (Moustakis, 1994, p. 86). Husserl had hoped that through bracketing, the researcher could attain the complete realization of, and therefore the complete exclusion of past knowledge, inferences, or assumptions so that "critical attention could be brought to bear on the present experience" (Giorgi, 2009, p. 91). In so doing, the phenomenological attitude is achieved for data analysis.

### **Data Analysis**

Once the interviews were conducted, the data were transcribed, and the researcher was in the phenomenological attitude, the data were ready to be analyzed (Giorgi, 2009,

pp. 87, 125; Husserl, 2014, p. 53). The analysis of data may have been conducted either interpretively or descriptively; however, the analytic approach taken by this researcher over the phenomenon of vision loss more closely modeled the descriptive approach advocated by Husserl as pure transcendental phenomenology.

Giorgi (2009, p. 127) explained that descriptive analysis “does not try to go beyond the given.” Instead, it “attempts to understand the meaning of the description based solely on what is presented in the data.” Describing the results of the data rather than making inferences from or interpretations of the data was necessary to ensure that the researcher’s existing knowledge and pre-conceptions that she might have expected to appear in the data, could remain bracketed.

Maintaining alignment with the procedures of bracketing the researcher’s current and past professional experiences was important so as to not taint the meanings of others with her own subjectivity. In this way, procedural validity could be maintained. According to Husserl, as explained by Giorgi, following the “methodical procedures” is “required in order to transform knowledge into truths” (2009, p. 12).

**Validity of analyses.** Freeman, deMarrais, Preissle, Roulston, & St. Pierre (as cited in Vagle, 2018) used the words “trustworthiness,” “credibility,” “relevance,” or “confirmability” as interchangeable with validity. The hope is that the researcher’s methodological approach and the researcher’s findings within the research would be valid, trustworthy, relevant, and confirmable. To these ends, the researcher followed advice from Goetz and LeCompte (as cited in Eisenhart and Howe, 1992). They suggested to provide “careful and extensive descriptions of the settings and people being

studied, of the social conditions of the study, and of the constructs being used give other researchers the information necessary to assess the typicality of a situation.” Eisenhart and Howe continued:

Furthermore, they [Goetz and LeCompte] add to their list of attributes of a good study: completeness (does the report of the study contain all elements considered necessary for a research report of this kind?), appropriateness (are the approach and design used effective and suitable for the research questions posed?), clarity (is it easy and straightforward to figure out what the study is about and why it is approached and designed the way it is?), comprehensiveness (is the scope of the study large enough to address convincingly the questions posed?), credibility (are the conduct and results of the study believable?), and significance (does the study make an important contribution?) (1992, p. 648)

Erikson’s take on validity (as cited in Eisenhart and Howe, 1992, italics in original) “concerns about clarity, appropriateness, and so forth take on the added burden of being clear, appropriate, and *useful* to potential audiences.” What makes something useful to an intended audience?

According to Lincoln and Guba (as cited in Eisenhart and Howe, 1992), the findings may be useful if the researcher is able to “persuade his or her audiences...that the findings of an inquiry are worth paying attention to.” The avenue by which this worthiness or trustworthiness may be accomplished “is the demonstration that the researcher’s interpretations of data (the findings) are credible to those who provided the data” (Eisenhart and Howe, 1992, p. 651).

Interestingly, despite the expectation of the phenomenological researcher to bracket all professional knowledge prior to the analysis of data, Roman and Apple (as cited in Eisenhart & Howe, 1992) encouraged researchers to keep account for “power relations of the wider society” when investigating marginalized groups such as the visually impaired as a way to increase validity. This perspective identified how the practice of research may be analogous to creating a study that:

- (1) resonates with the lived experiences of the group being researched,
- (2) enables members of the group to comprehend and transform their experiences of subordination,
- (3) reduces the divide between the researcher’s intellectual work and group members’ ordinary ways of describing and understanding their experiences, and
- (4) allows the researcher’s prior theoretical and political commitments to be informed and transformed by understandings derived from the group’s experiences. (1992, p. 652)

The researcher believes that the research has met all of the above requirements of being complete, appropriate, clear, comprehensive, credible, significant, and useful. As data were provided back to the participants for review and verification, the impact and relevance of the findings was able to resonate with the individuals who had experienced the phenomenon. Moreover, professionals or future researchers who will seek to understand the phenomenon of vision loss also will benefit. Finally, discussing results through a critical disability theoretical lens accounts for inherent power struggles between those in power and those who are oppressed.

**Process of analyses.** Vagle (2018, p. 72) noted that “As a phenomenological craftsman, I have found entry into discussions of validity to be marked primarily by a consideration of the researcher’s sustained engagement with the phenomenon and the participants who have experienced the phenomenon.” For Vagle, the amount of time spent reading and rereading and familiarizing oneself with the subject matter is another aspect of documenting a valid study. To satisfy these needs, Vagle identified characteristics that he thought should be present in the process of phenomenological analyses and in the processes of communicating the details of the findings:

1. A whole–parts–whole process
2. A focus on intentionality and not subjective experience
3. A balance among verbatim excerpts, paraphrasing, and your descriptions/interpretations
4. An understanding that you are crafting a text—not merely coding, categorizing, making assertions and reporting. (2014, p. 98)

In the next section, Vagle’s four suggestions are explored in more depth and operationalized to the current study.

***Whole–parts–whole process–Multiple readings and note taking.*** Whole–parts–whole means that to begin a textual analysis, the researcher must first read the entire text, whole. From there, multiple line-by-line readings are suggested. As Vagle (2014, p. 98) pointed out, reading and rereading the text creates deep immersion into the text helps the researcher to understand the text as a whole before beginning the process of bracketing and identifying emergent themes.



In the initial reading, the researcher did not take notes, but simply became familiarized with the work. In the subsequent readings, the researcher wrote notes and questions in the margins, and marked excerpts in the text that appeared to contain meanings (Vagle, 2014).

Vagle (2014) also suggested to search for any interpretations that should be bracketed, and to write possible follow up questions. "The questions should be designed to clarify intentional meanings that one predicts, at the early stages of analysis, might be important to describe/interpret/represent the phenomenon" (pp. 98-99). Further, Giorgi (2009, p. 130) suggested, "As one begins to reread the description, one makes an appropriate mark in the data every time one experiences a significant shift in meaning." Throughout the multiple readings, "Your aim is to produce a comprehensive and detailed set of notes and comments on the data" Smith, Flowers, & Larkin, 2009, p. 79).

The researcher's process of creating a deep immersion into the text began with the audio immersion while transcribing or editing word by word. Following the creation of the complete transcriptions, the researcher then listened to the data and read each transcription on the computer screen twice to assure accuracy. Finally, each transcript was printed, and each document was read twice again wholly and line by line. Notes were written and connections were made as themes began to emerge.

***Focus on intentionality and not subjective experience.*** In this phenomenological research, experiences with adventitious vision loss were retrospectively examined. According to van Manen (2015, p. 182), intentionality is only available in this way—through retrospection.

According to Husserl (as cited in Giorgi, 2009), “Under intentionality we understand the own peculiarity of mental processes to be consciousness of something.” Giorgi went to explicate this idea in his own words. “Intentionality refers to the fact that a large group of acts of human subjectivity are directed toward objects or situations in the world. This being directed to other than itself on the part of subjectivity is what intentionality means” (2009, p. 184).

Instead of perceiving and knowing phenomenological experiences for what they are, subjectivity grounds experiences and objects through perception. When we eliminate those existing perceptions and “all prejudices alien to them,” we aim to eliminate the subjectivity and return “to the *things themselves* [Sachen selbst]” (Husserl, 2014, p. 36, italics and brackets in original).

The process of intentionality is important so that, as a researcher, the end result is to understand “the *thing itself*—not a generalization, an approximation, a representation, or a deduced outcome” (Vagle, 2018, p. 7, italics in original). As Moustakis would describe it, “Intentionality offers a freedom to perceive and view things just as they appear, permits them to be, and makes possible the recognition, elucidation, and synthesis of what appears” (1997, p. 81).

The *things* therefore “were the intentional meanings that presented themselves (manifested, appeared) in human consciousness through lived experience” (Vagle, 2018, p. 31). The *things* are not what might have been generalized in one’s mind prior to analysis. Intentionality in this way relates closely with *essence* (Vagle, 2018, p. 31).

*Units of meaning, or themes.* Reading, rereading, and making notes is the continuation of the whole–parts–whole process. The purpose was that the text as a whole would be broken down into its parts (Dahlberg, Dahlberg, & Nyström, 2008, p. 233). Each part may be called "units of meaning" (Giorgi, 2009, p. 130), or themes. Units of meaning, or themes, are "the experiential structures that make up the experience" (van Manen, 1990, p. 79).

According to Giorgi, the meaning units are established in the following way:

One goes back to the beginning of the description and one begins to reread it. Again, the attitude that has to be assumed is that one is in the phenomenological scientific reduction, within an overall psychologically sensitive perspective, and, finally, one is mindful of the specific phenomenon being investigated. (2009, pp. 129-130)

In analysis, the units of meaning, or themes, simply help keep the focus on the parts of the whole so that detailed analysis can take place. Dahlberg, Dahlberg, and Nyström (2008, p. 236) further pointed out that "it is imperative that each part is understood in terms of the whole, but also that the whole is understood in terms of the parts."

To clearly identify an identified theme as essential to the phenomenon, van Manen (2015, p. 107, italics in original) advised that "*our concern is to discover aspects or qualities that make a phenomenon what it is and without which the phenomenon could not be what it is.*" Moreover, van Manen continued:

In the process of apprehending essential themes or essential relationships one asks the question: Is this phenomenon still the same if we imaginatively change or delete this theme from the phenomenon? Does the phenomenon without this theme lose its fundamental meaning? (2015, p. 107)

*Clustering.* Smith, Flowers, and Larkin (2009, p. 96) contended that once the themes are established, "[The] next step involves the development of a charting, or mapping, of how the analyst thinks the themes fit together." Dahlberg, Dahlberg, and Nyström (2008) refer to this grouping process as "clustering."

Although "The clusters are not part of the findings," they do help "the researcher to see the essential meanings and structures that describe and explicate the phenomenon" (Dahlberg, Dahlberg, & Nyström, 2008, p. 244). Giorgi expanded the suggestion:

If [the meaning units] are too small, the researcher usually finds that meaningful transformations cannot be written, so he or she begins combining two or three meaning units so that a meaningful transformation can be made. If the meaning units are too large, then the researcher finds that he or she might have to separate certain parts of the large meaning unit and make smaller ones because it is too rich or complex. (2009, p. 180)

Dahlberg, Dahlberg, and Nyström also allowed for revisions:

Sometimes a preliminary result must be completely changed, a pattern completely destroyed and sometimes it is sufficient to make some minor adjustments. The main idea is to keep one's mind open through the whole process and to be sensitive to nuances and changes in meaning. (2008, p. 244)

Smith, Flowers, and Larkin reminded that "Not all emergent themes must be incorporated into this stage of analysis; some may be discarded" (2009, p. 96). To be sure of accuracy, however, van Manen recommended:

Once transcript themes have been identified by the researcher then these themes may become objects of reflection in follow-up hermeneutic conversations in which both the researcher and the interviewee collaborate. In other words, both the interviewer and the interviewee attempt to interpret the significance of the preliminary themes in the light of the original phenomenological question. Both the researcher and the interviewee weigh the appropriateness of each theme by asking: "Is this what the experience is really like?" And thus the interview turns indeed into an interpretive conversation wherein both partners self-reflectively orient themselves to the interpersonal or collective ground that brings the significance of the phenomenological question into view. (1990, p. 99)

In this study, once the themes were preliminarily established, the themes were then clustered together in ways that created larger, overarching themes. These larger themes were then shared with participants so as to affirm their accuracy and relevance to participants as reflective of essential experiences of vision loss.

With the major themes of vision loss established and verified, the transcripts were read again. This completed the whole–parts–whole recommendation by Vagle (2014, p. 98). Dahlberg, Dahlberg, and Nyström finalized their position on clustering as well:

When the researcher believes that the original data text has been "emptied" of all meanings and that these are neatly noted and clustered by the researcher, it is time

to move on. The text is again treated in its entirety, as a whole, but now with a broader understanding than initially. All clustered meanings [themes] should now be related to each other and form a pattern that describes the phenomenon in focus. The goal in phenomenological analysis is to understand the phenomenon better than before the research, to see the phenomenon, i.e. what makes the phenomenon that very phenomenon. (2008, p. 245)

**Essence.** All of the steps described above lead to the discovery of essence.

Van Manen defined essence as "that what makes a thing what it is (and without which it would not be what it is); that what makes a thing what it is rather than its being or becoming something else (1990, p. 177). Giorgi expected that the researcher would be able to find essence through thematic analysis, and, after having done so, then the researcher must "describe it as accurately as possible" (2009, p. 89).

Dahlberg, Dahlberg, and Nyström knew that, "Even if the goal in phenomenological research is to describe an essence it is possible that this goal cannot be reached" (2008, p. 254). Dahlberg, Dahlberg, and Nyström went on to provide reasons for this possible inability to accurately or adequately describe essence:

There are several reasons to why a whole structure of meanings cannot be obtained. A main reason is that data are too poor. If the interviews have not been deep enough and there is a lack of nuances and no descriptive richness, it might not be possible to obtain an essence. Other reasons could be that the researcher is too afraid of "interpreting" and stays too close to the data to see any structure,

lack language skills, is too inexperienced and/or lack good advice to articulate meanings in a way that make up for a full structure. (2008, pp. 254-255)

This researcher hoped that her experience and language skills proved successful in describing the essence of vision loss. The essential information was hopefully presented in such a way that she was able to describe what makes vision loss what it is (and without which it would not be what it is).

The description, in the researcher's estimation, was as accurate as possible given the parameters of the analysis of human interviews. It may be in fact that essence does exist, but the researcher has failed to extract it and define it properly or clearly (Dahlberg, Dahlberg, & Nyström, 2008, pp. 254-255). This researcher strove to achieve the goal of phenomenology nonetheless: "to grasp and elucidate the meaning, structure, and essence of the lived experience of a phenomenon [vision loss] for a person or group of people" (Patton, 2015, p. 573). The researcher then described the essential meanings of vision loss and the structure of the meanings in the communication of the findings.

### **Communication of the Findings**

At the end of the phenomenological investigation, the essence and meaning of human experience should be detailed into "comprehensive descriptions" and "accurate renderings" of the experience (Moustakas, 1994, p. 105). This aligns with "the aim of phenomenology," which, according to van Manen (1990, p. 36), "is to transform lived experience into a textual expression of its essence." When language, thinking, and being partner with phenomenological research as a method of discovery, phenomenological

research has the ability "to find out what a certain phenomenon means and how it is experienced" (van Manen, 1990, p. 28).

Per Vagle's (2014, p. 98) suggestions, when communicating the findings, the researcher provided a balance among verbatim excerpts, paraphrasing, and the descriptions of essence. The researcher carefully developed the story to explicate the participants' true experiences with vision loss. Although the participants had not all experienced vision loss at the same time or under the same situations, at the end of the process, the phenomenological researcher's purpose was to "describe what all participants have in common as they experience a phenomenon (e.g., grief, anger)" (Creswell, Hanson, Clark, & Morales, 2007, p. 252).

### **Summary**

Chapter III was a compilation of procedures and rationale for the use of phenomenological inquiry into uncovering participants' experiences with vision loss. Provisions for the suitability of the topic and question were outlined, as well as the definition of the role of the researcher and her research procedures.

Chapter III detailed how participants came to be selected for interview and why interview is appropriate in this study. Additionally, processes for recording the interviews and maintaining confidentiality were emphasized.

The researcher disclosed the need for the use of bracketing and the reduction of subjectivities prior to data analysis, and the protocol for establishing themes and the subsequent thematic analysis used to extract essence were specified. The researcher further highlighted strategies to affirm data that is valid or trustworthy. In Chapter IV,



the researcher provided her epoché. Chapter V presents the findings that resulted from thematic analysis of the interviews, and Chapter VI concludes the study and offers implications and suggestions for future research.

## **CHAPTER IV**

### **Epoché**

Prior to 2005, when I began the training process to work as an orientation and mobility specialist for people who are blind or who have other visual impairments, I had not personally known any person who was blind or visually impaired. Through the undertaking of two master's degrees in visual impairment and a subsequent decade of working with people who are blind or visually impaired, I learned about and implemented individualized rehabilitation intervention processes for people without vision across the United States.

### **Practitioner Experiences**

The rehabilitation programs I implemented focused extensively on assisting people with visual impairments to adapt to life with limited or no vision. The goal of such rehabilitation was for people to live as independently as possible despite not having perfect vision. Intervention strategies for people who are blind or visually impaired included training procedures for people to use a white cane, read Braille, and use assistive technology.

Often, while individuals were participating in the training programs, individuals would share experiences and thoughts with me that they admitted that they had not shared with anyone else before. This signified that there is a great need for people who have

vision loss to be able to tell their stories. It also signified that those stories needed to be told.

Due to my extensive experience with implementing rehabilitation interventions for people who have visual impairments, I became familiar with the stories that were shared during rehabilitative sessions. During the dissertation process, therefore, I focused the interview toward individuals' personal experiences of vision loss. I did not include questions that were typical of rehabilitation session interviews.

This scope of questioning contrasted sharply with interview questions that were asked as part of a rehabilitation provider interview. As a provider, I asked questions that were not as directed to the experience itself. Instead, as a practitioner, I focused more on the subsequent effects of vision loss, such as functional losses, so that the processes of rehabilitation interventions could begin in a way that would best meet their needs.

An example of the type of questioning included was, "What did you used to do that you can no longer do because of vision loss?" Then I provided strategies for the person to learn non-visually how to do such an activity again. The interview questions used in the dissertation process, however, asked participants to describe their experiences of the moments leading up to losing vision and the experiences of the loss of vision itself. The resultant stories were in-depth and focused on their personal experiences of vision loss.

Throughout my years of experience of helping to rehabilitate persons who are visually impaired, the dissertation interview represented the first time that I engaged in this type of inquiry. Additionally, the participants also had not been previously asked by

anyone else to share their stories. As a result, the questions in this inquiry directed individuals to reflect on thoughts and experiences that are not commonly shared, and, in some cases, to reflect on experiences and thoughts that have never been shared.

When I was still working as a practitioner, and when my clients would share their stories with me, I never shared the stories with anyone. As a researcher, however, I was able to interview people who lost vision under the condition that any stories told would be shared. This premise of telling and sharing stories was the impetus behind my study. Participants of the study agreed that these stories were important to share, not only for the ability to share stories themselves, but also to have published works of collected stories available for others to read.

### **Personal Experiences**

My experiences as a practitioner who helped individuals who lost vision to become more independent is unequivocal in any way to the experience of actually having lost vision. I myself have never permanently lost vision, and so I am writing from a standpoint of never having experienced adventitious blindness. There was, however, one time in 1993 that I may have come close to losing vision.

I was in Switzerland on a sponsored trip to the sister city of my home town. I had been standing in direct sunlight for several hours while playing a musical instrument as part of a celebration ceremony for the Swiss Parliament. At one point, I passed out, but in the moments before passing out, half of my visual field went dark, and I could only see out of the upper half of both eyes.

I recall saying to the person standing next to me that something was wrong; I could only see from the tops of my eyes. The person standing near said, “What?” Then I woke up from under a tree, fully able to see. I forgot about my lapse in vision until 2006, when hemianopsia was learned about in an eye class in my Master’s program.

I learned in class that loss of vision in half of a visual field is called hemianopsia. When vision is lost in the lower visual field, it is called an inferior hemianopsia. When hemianopsia is temporary, it can also be called transitory. My vision loss only lasted for a few seconds; therefore, I experienced a transitory inferior hemianopsia.

The experience I had never had any bearing on my decision to work with people who are visually impaired, nor did the experience influence any thoughts about what vision loss may be like. At times, when assigned to provide services for a person who had hemianopsia, I felt that I may have better insight into how the person could see with exactly half of a visual field, but as my hemianopsia was temporary and my clients’ hemianopsias were permanent, no correlation into true vision loss could be gleaned.

Had hemianopsia remained with me, I, too, would likely have been the recipient of blind rehabilitation intervention services. Interestingly, I did not immediately suspect that I may be legally blind. The fact that the word blindness tends to assume a meaning of complete blindness helps me to understand why individuals who have partial vision may not consider themselves to be blind.

I would describe my personal experience with vision loss as one that was confusing. The greater question in my mind at the time was, why is this happening? I can still recall only being able to see the tops of trees against the sky.

Had I not passed out, and had I remained visually impaired for longer than a few seconds, I can only hypothesize that anxiety and panic may have set in. As it was, even in those few moments, I did experience a functional loss, as I was unable to read the sheet music I was assigned to play.

Questions related to functioning that may be derived at this time included, how would I have completed the rest of the musical tour? Would I have been sent home? What would my life have been like if I lived with inferior hemianopsia from the age of 18 until now? Would I have done any of the things in my life that I have done? Would I be a university level instructor of orientation and mobility and doctoral student? How would my life trajectory have changed due to having different experiences?

### **Advantages of Practitioner and Personal Experiences**

I believe that my experiences helping people who have lost vision for more than 10 years have helped me to understand some facets of what people with visual impairments may go through when losing vision. Of course, not all facets can be understood, specifically the emotional stress of vision loss that is incurred to the self and to the family. Some of my clients, for example, remained in a depressive state or a state of anger for significantly longer than others, and there was no clear indicator of why or how that was true for some and not for others.

Although I may have learned how to alleviate some of the distress related to losses of functional ability due to vision loss, and although I maintained close personal relationships with people who have visual impairments, these experiences could not predicate an understanding of what it is like to permanently lose vision. Despite that I

myself experienced a temporary, partial loss of vision, I never have had to live with vision loss, and therefore do not make any presumption that I know what it is like.

What I have learned from the experiences of others who had vision loss is that their life trajectories were changed. Many times, individuals have described losing vision as a turn for the worse, but, in some cases, the changes were regarded as for the better. Something else I learned when working with people who lost their vision is that most individuals who lost vision did not become aware of the existence of blind rehabilitation intervention services until several months or years after they experienced vision loss.

From the standpoint of a blind rehabilitation expert and specialist, I am now acutely aware that services for the visually impaired are not well known. The services for the blind, despite being supported by state departments, are not advertised. Non-profit agencies who provide services are limited by law in their ability to market and advertise the availability of their services.

In some cases, a person who has visual impairment may be referred to the services. A referral is dependent upon another person being aware of the services in order to make the referral. Once the services are known about, a person must also agree to participate in the services.

Modern day rehabilitation programs gear their services toward regaining functional ability; they are not typically designed to address the emotional experiences that accompany vision loss. Moreover, people who have vision loss are not always comfortable to share their experiences because they correctly assume that others do not

understand. As a result, people who have lost vision tend to withhold their inner experiences from others.

Through the dissertation process, I asked people who lost vision to describe their experiences with vision loss. Although each person lost vision in ways that were different from one another, I found it unique to hear how the varying experiences surrounding vision loss did have elements of similarity among them. The question remains, was I able to detect strains of similarity based on my personal and previous experiences of working with people who have visual impairments?

To attempt to limit any of my personal bias and to attempt to diffuse the integration of my extensive history in the findings, I did bracket my previous experiences, and I maintained openness about any possible conclusions or findings. To bracket my previous experiences, I asked questions that were unrelated to my previous experiences.

Additionally, I made no assumptions about the experiences that might be shared with me during the interview. I simply allowed participants to tell their story, and I used directed questioning to focus the participants' answers to describe their experiences in a way that best reflected their beliefs in and about those experiences.

One way, however, that I used my experiences to the advantage of the interview was in asking questions that align with general assumptions of vision loss, i.e. "Did any of your other senses become stronger?" In this way, I encouraged participants to reflect on their experiences with that aspect of vision loss as well.



The dynamic of trust that was required for this type of research and for this personal of a topic should not be understated. Participants in this study had to feel that I was a trustworthy individual who would use the information in a way that would benefit and support others as they experience vision loss. Due to my current employment as a university instructor and my extensive network of professionals and students who work directly with people who have lost vision, participants in this study could also feel that I had the ability to use and disseminate information to a wide audience.

As a university instructor, I am versed in the literature and what it says about the stages of grieving due to vision loss. In this study, I made no assumptions about the experiences that individual participants may or may not have had with depression or other emotions that are considered typical in the process to adjustment to vision loss.

As a researcher, I also became aware that the stages of adjusting to vision loss were normed on white men in the 1950s and 1960s. I did interview one white man, and I was curious if there may be a variation in what my Hispanic, African American, and white female interview respondents reported compared with the experiences as reported in the textbooks.

### **Impact of Researcher's Experiences**

Through the years, I became aware that individuals who had lost vision came from all walks of life, and that there could be no common denominator to represent a likelihood or propensity for experiencing vision loss. Regardless of how vision was lost, the end results were very much the same. A person who lost vision in the war had the same functional losses that a person who lost vision due to disease or accident. Some

individuals lost their jobs; some had lost their spouse. Most lost the ability to read. All lost the ability to drive.

Regardless of how the vision was lost, and regardless of the person's background, race, religion, class status, or other demographic measure, two things were also true. Individuals who lost vision were caught unaware that vision loss would happen to them, and when it did happen, the rehabilitation intervention strategies used to rehabilitate a functional loss are relatively universal. There are, however, no distinct strategies to help people or their families to overcome the emotional aspects of vision loss.

This knowledge resonated deeply within me because the only assumption that could be proffered is that vision loss could happen to anyone at any time, and that emotional adjustment was dependent upon the individual. Functional losses could be restored, but only if awareness of the rehabilitation possibilities exist, and only if the person is able to accept the rehabilitation.

I, therefore, used this knowledge to try to bring awareness of vision loss and disability to the general public. If anyone could lose vision, and if, as per my experience, most people are not aware of available services for the visually impaired at the time that their vision was lost, then a gap between accepting rehabilitation could occur. I hoped to bridge the knowledge gap between what is known by rehabilitation specialists and what is known by the general public. I also sought to understand why such pertinent knowledge so often remains hidden.

My hypothesis of the rationale for hiding disability and blindness stems from the current and historical presumptions of the inability for persons with disabilities to be able

to be rehabilitated or to function independently in society. This hypothesis is influenced heavily by critical disability theory.

Critical disability theory “identifies, describes, and analyzes the subsumed or hidden origins of social and political culture, discourses, and institutions” (Hall, 2019). Moreover, critical social theory attempts to help people gain autonomy and participation in society (Hall, 2019).

As a rehabilitation specialist, university instructor, and researcher on behalf of people who are visually impaired, I hoped that, through research, an understanding of the experiences that individuals face when they lose vision would start a conversation about how to help individuals to know what to expect and how to seek help. The result, if successful, may lead others to increase their autonomy and participation in society by finding their voice. Increased participation in society may also allow for members of the general public to observe persons with a disability as successful and independent, which may help to change existing societal perceptions.

Certainly, the existing societal perception that disability equates to inability creates inherent barriers to independence as well. The intersection of disability, societal misperceptions, and race is further addressed by Critical Disability Theory as follows:

Critical disability theorists argue that racism and ableism operate jointly, intensifying and borrowing from each other. These phenomena, along with other forms of oppression, thus call for intersectional analysis. This requires the simultaneous investigation of the multiple, intersecting power relationships that affect whole persons through pathologization, stigma, and exclusion. (Hall, 2019)

Understanding Critical Disability Theory and the intersectionality of power relationships between ability and disability may be used to substantiate that the disability of vision loss is confounded by misperceptions of blindness and inaccessibility in society. The theory also supports that inaccessibility and perceived inferiority are side effects of the “pathologization, stigma, and exclusion” that are affiliated with vision loss, blindness, and disability in general (Hall, 2019; Schulz, 1980). Worse still, the power structures currently in operation may intentionally or unintentionally produce oppression for people who have disabilities due to the presumption of inability. The presumption, therefore, begets inaccessibility.

My awareness of these concerns and the cyclical nature of the dilemma prompted my research to begin to investigate experiences of vision loss as an avenue towards alleviating oppression. When voices are silenced, either by choice or by force, they cannot be heard. Using this platform, I am actualizing a step toward having important, never-before-heard voices, heard.

When the voices can be heard, the assumption reconnects to the Transtheoretical Model as described in Chapter II. In that theory, individuals may resist change due to the internal barrier of an unwillingness to self-identify as a person with a disability. Persons are reluctant to claim such identity due to shameful societal stigmas (Goffman, 1963; Siebers, 2011). Changing societal perceptions and creating awareness of rehabilitation success may reduce the negative effects of such stigmas.

## **CHAPTER V**

### **Findings**

This qualitative phenomenological study made inquiry into the lives of four adventitiously blinded individuals. The purpose of the study was to learn how these individuals experienced vision loss.

While all four participants in this study each experienced vision loss in different ways, there were similar themes that emerged from among those experiences. This chapter explores the participants' demographics, and the major themes that were derived through analysis of their interviews.

The major themes are Medical Dysfunction, Others' Reactions, Ancillary Losses, Rehabilitation, Sensory Enhancements, Benefits of Vision Loss, and Participants' Advice. In relaying the participants' experiences, all quotes are left in the participants' phrasing, and pseudonyms are used to protect their identities.

#### **Participants' Demographics**

Of the four participants of this study, three participants lived on the East coast of the United States, and one participant lived in Southwest United States. Three participants were female and one participant was male. Two participants were white, one participant was Hispanic, and one participant was African American. The participants'

current ages ranged between 42 and 63 with a mean age of 54.

Two participants were veterans, and two were not. All participants were heterosexual, cisgender, and Christian. Three participants were married living with a spouse, and one was single living with a dependent. Three participants had bachelor's degrees, and one participant had a GED. One participant was gainfully employed, one participant was working from home or occasionally out of the home, one participant was unemployed, and one participant was retired. All four participants attributed their working or non-working status to their vision loss.

Two participants lost vision in the third decade of life, one lost vision in the fifth decade of life, and one lost vision in the sixth decade of life. All participants faced some degree of incremental vision loss leading to legal blindness or total blindness. At the time of the interviews, two participants were legally blind, and two participants were totally blind. Participants were declared legally blind or totally blind between 1.5 and 19 years ago with a mean length of 8.6 years ago. Participants' vision ranged in visual acuity between 20/60 with a field restriction of 20 degrees to No Light Perception.

### **Medical Dysfunction**

The first commonality among all participants began with a medical concern leading to a medical diagnosis. For Joanie, the experience of vision loss began like this:

When I was in the military, I first actually experienced my blindness in one of my eyes—the left eye—and it was a, like, a gray patch. After, like, a very long day of being out in the sun, the very next day, this patch appeared, like a gray spot. So it wiped out my whole [left] vision; basically grayed it out in a matter of week.

This manifestation was later determined to be a rare condition called Devic's Syndrome, but Joanie also had experienced complications in addition to the sudden onset of blindness in the left eye:

The Devic's Syndrome happened to also attack, it attacked my central nervous system. So on top of also being blind, I also was, like, paralyzed from the chest down. So I was in a wheelchair, so I had to go through rehab.

While in the rehabilitation center learning how to walk again, Joanie then lost the vision in her right eye. She said, "Oh my gosh! Can it get worse?"

Charles also first had trouble with his left eye when his left retina began detaching. Even though the doctors had tried to reattach it through surgery, the retina would not stay attached, and the eye ultimately died. It was causing a great deal of pain, and the doctors had recommended the eye to be removed. Charles knew that living in pain was not what he wanted to do, so he said, "OK. Let's remove it!" The doctor agreed and made an appointment to surgically remove the left eye.

After the eye was removed, the socket had to heal for about two months before it could be fitted with a prosthesis. As Charles recalled:

It was the Sunday before the Monday I was supposed to go back to have the [prosthetic] eye fitted and put in. I had a stroke in the right eye, and it was due to the pressure in my right eye from not having the left eye. The pressure had built up, had nowhere else to go. And, so, it caused an eye stroke, and it took the remaining of my good vision [in the right eye]."

Amanda was born with reduced vision and weakened retinas due to a condition called Retinopathy of Prematurity (ROP), but she was not legally blind. Amanda could still see well enough to function without any accommodations such as magnifiers, and she could still drive. It wasn't until recently that Amanda experienced a significant reduction in vision and became legally blind.

During the transition from having vision that was slightly impaired to having vision that is severely impaired, Amanda visited the doctor when “floaters” or “smudgies” began to block her vision in ways that made it impossible for her to read or drive. As she recalled, “from a very young age, I was told that there was a high probability of the retina detaching [due to ROP].” To help prevent a detachment, “in 1976, I had cryo-surgery where they went around and they tacked the edges of the retina to keep it from detaching.” Now, according to the doctor, “what's happening is, because of hardening of the arteries, the, the scar tissue around the cryo places is dying and sloughing off into the eye.”

Unfortunately, Amanda had to visit three different doctors before gaining an understanding of what had occurred. The floaters and, as she called them, “smudgies,” have been determined to be remnants of the scar tissue that are now blocking her ability see. Because her retinas are already so weak, however, the doctor is not recommending any additional surgery.

Maria also had gone to the doctor when something wrong was suspected. Initially, Maria had not lost vision, but she had experienced runny, watery eyes along with significant migraines.



In August, my eyes just start running, but like, I had headaches and stuff like that. And I was telling my doctor, I said, 'I'm having headaches all the time.' I said, 'Something wrong.' I said, 'Can you test me? Do some tests on me?' I said, 'Something wrong. I don't know what it is, but something wrong.'

The doctor unfortunately never tested Maria for her eye pressure, nor did the doctor honor Maria's in-office request to be referred to a neurologist for follow-up. Instead, the doctor sent her to a rheumatologist and made a decision to increase the magnification strength of her reading glasses.

Less than 6 weeks after visiting the doctor and asking for help, Maria was totally blind. "I was just taking a bath, and all of a sudden it seemed dark. And I said, 'Why is the light off? Why all of a sudden the light off?'" Maria soon realized that the light was on. When she looked up at the lightbulb, she saw purple.

Just a few nights before, Maria had been watching a medical program on the television, and she recalled hearing that "if you look at the light, and the light is purple, you have a tumor." Immediately, Maria realized, "Oh, I got to go back to the hospital. I got to go to the hospital."

At the hospital, Maria was determined to have pseudotumor cerebri, a type of superficial tumor. She was admitted for surgery, and she said at the time, "I thought things was going to get better" and that her vision would be restored, but it wasn't.

These stories of losing vision may be scary to read, because in all examples, one

day, participants could see, and then the next day, they could not. There is currently no cure for blindness, and so understanding these experiences may be helpful to alleviate some fears and make adjustment easier.

### **Others' Reactions**

Participants shared that when their vision was lost, the loss impacted people around them as well. The vision loss touched the lives of those with whom they lived, worked, or were otherwise acquainted through friendship or in public spaces. Sometimes the effect on others was psychological, and it caused others to feel bad or sorry for the person who is visually impaired. Sometimes other people were asked to contribute more to assist the person who now is unable to perform tasks such as driving. The combination of taking these requests along with the other person's psychological response created varying situations.

Amanda noted that she had to stop driving when her vision got worse due to "the smudgies." "I'd be driving down the road with these smudgy places [in my vision] thinking, you know, I can't see!" She, therefore, asked her husband to do the driving for her. Amanda credits her husband as being "fairly tolerant about hauling me around places," but she still feels like a burden on him.

When asking for help with other tasks within the general public, Amanda will say, "I don't see very well; can you help me do such and such?" Amanda believes that most people are open to assisting her, more because of her age than her visual impairment. Amanda said she feels they help her "because they treat you differently 'cause you're retired, and you're grey-headed, and you're old."

Of her friends, Amanda said that sometimes, her friends “forget” that she is legally blind, and they will buy her print copies of books. “This one lady in particular, she's given me two books in the last four months!” Amanda said that she wishes “to finally say to my friends, you know, it's really not helpful bringing me a book!”

When Joanie lost her vision, she said that her friends and family members became overprotective. They would not take her to places she wanted to go, and they would not allow her to do things alone, without her husband. Joanie said, however, that she would ask her husband to take her places, and he would refuse.

Joanie, believed that her first marriage ended because of her vision loss, due to her husband's inability to see her as an independent woman. She said, “in my first marriage, you know, he eventually just was like, well, I'm just a caregiver; you don't understand.”

Joanie recalled, “I also had a friend—a really good friend of mine at the time—who, like, would be like, ‘Hey, are you going to bring somebody with you [to help you]?’ Like, almost like I need to be babysat.” She remembered thinking, “I kinda lost friends because of that, because of the blindness, so that, that's also sad. I really wanted to do something other than just, you know, stay at home.”

Charles' family had offered him a place to live when he started to lose his vision, and Charles moved in with his son while he was undergoing treatment for the enucleation of the left eye. After losing his vision completely, however, Charles reported that now his family generally feels bad for him. “Everybody's, ‘Well, oh, I'm sorry.’ I'm, you

know, I'm like, 'Well, you know, it's...it is what it is,' you know? And, you know, they, they seem truly sorry.'

Charles said he thinks the reason everyone feels so sorry for him is that "a lot of the people's got the misconception that because you're blind, you're crippled," but Charles definitely knows he isn't crippled. After receiving rehabilitative training in orientation and mobility through an American veteran's hospital, Charles travels quite readily on his own. In so doing, Charles shared some interesting interactions he has had with the public:

A lot of people, you know, they assume when you're blind and you can't see, they come to you, and they start almost hollering when they're talking to you. No, no, I'm not Deaf, I just can't see! Yeah, I don't hear with my eyes! Sitting in the bus station, a guy comes up and says [slowly and loudly] 'Hey, are you okay? Do you need some help?' Look! No! But if you keep hollering at me, you will!

Charles shared another story of when he was at a roadside park:

I'm just standing there, listening to the traffic, trying to decide which way I want to head, because I'm just out scouting around, you know. This guy who's out there comes walking up, and he says, 'Say, are you lost?' I'm like, 'No.' 'Well, what are you doing out here?' 'Cause he seen my cane. I said, 'I'm just looking around.' He didn't say anything for a few minutes, and then he says, 'Okay, asshole.'

Charles recounted one morning, while he was having a cup of coffee in a public space, someone came up to him and handed him \$5.00. Charles is aware that there is a

perception that people who are blind are beggars who are in need of charity, but that is not the situation for Charles. Charles told the generous man, “If you wanna give your money to me, that's really nice of you, but I'm just gonna give it to this [homeless] guy.”

Public responses to blindness can be hard to predict, but Maria had even more unusual reactions happen to her within her own family, including from her twin sister. The events helped Maria to learn about her sister in a way that she did not understand before:

I've learnt so much about her that people been trying to tell me for years that I just couldn't, I just wouldn't receive it because I didn't understand it. Like I told you earlier, certain things that I guess I have trouble processing if I don't understand why. So I didn't understand that my sister would be jealous, was jealous of me because I was always the one who worked and drove. I had a car and stuff. She didn't do none of that. And so, when I lost my physical sight, my spiritual sight was able to catch on, and then blind people pay attention to details. I started paying attention to a lot of stuff, and I started seeing them for—people—who they really are, and my sister was my number one enemy!”

During a heart to heart with her sister some time later, Maria's twin sister opened up a little. “She said, ‘When I look at you, when I see you like this, reality really hit me,’ and something. But I said, ‘Well, don't let it be harder for you than it is for me.’”

Other members of Maria's family interpreted the news of Maria's blindness to mean that since “[Maria] can't see, she don't know what's going on.” Maria also recalled one of her cousins saying, “I can't believe she let herself go blind like that,” and

all types of stuff.” Maria expressed how hurt she was over the incidents. “Yeah, that part, it was hurtful, hearing some of the stuff, and them making their judgments.”

Maria believes, however, that her son may have been hurt the most. She said, “He don't even really like to hear the word blind. He don't really like, he don't like when I'm telling people I'm blind. He, he...it still bother him.”

Maria suspects that her son went into a depression from which he hasn't fully recovered:

My youngest son was just this angel. He did so good in school. I had no complaints. He was always respectful. Yeah, he was a very good young man. He would just do anything for me; he would cook and all that. When I lost my vision a couple of months later, he changed to a whole totally different child.

Maria explained some of the ways in which her son changed after she lost her sight. “He went from honor roll to getting his first failing grade, to then all of his grades going down to failing.” She said that, “He went into depression, but he went about it the wrong way. He act out. He start taking advantage of me being blind. Because it's just me and him now, but he has taken total advantage of the blindness.”

Maria did not elaborate on the ways in which she felt that her son tried to take advantage of her. Regardless, she stays close with her son, and she tries to help him.

Maria said she went up to the school so often to ensure her son was successful, the school wanted to give her mother of the year award. Fortunately, Maria's son did graduate, but she said, “It was challenging. It was hard.”

### **Ancillary Losses**

Participants in this study shared that when they lost their vision, they lost more than just their eye sight. Losing friends or family members, independence, confidence, a sense of identity, the ability to read, drive, or maintain employment were among the ancillary losses cited by participants.

Maria had experienced negative interactions from her family and friends in response to her blindness, and Maria felt forced to cut those ties. “Believe it or not, everybody that I considered close to me, I no longer consider close.” Maria believes she found this strength through her blindness:

Being blind helped me to detach [from people]. Because if you’re no good for me while I’m with my sight, imagine how you would be without my sight? So yeah, it’s taught me to detach myself. You don’t need these people. You don’t have to have these people in your life.

Maria found out the hard way that staying away from people and circumstances that are negative is important. “I have to protect myself,” she said. “Your mind is not built to constantly take in negative, negativity. It’s just not. Your mind is not strong enough.” If that means “staying away from you and your verbal abuse, then I will.”

Maria said that she was not always as strong as she is now. “It took me a while to get there. It did. It took me a while to get there. It took me a good while.” Now, however, there is no hesitation:

If it even a chance it ain’t good, then there’s no need for me to deal with you.

Yeah. And that's when we get caught up in the title: sister, brother, mother, and all that. It don't matter. If they're no good for you, then since it's not good for you, you got to let it go.

Joanie indicated that she initially lost pieces of her identity by not being able to work in the career she had chosen. Joanie had been serving in the military when she lost her vision, and she was forced into a medical retirement. Joanie admitted:

Well, that was devastating. I'm not going to lie to you about that because I was going to do, I was going to do my, a career out of it. So I was going for, I was going to try to be commissioned. I had gotten the paperwork to apply to become, like, a physician assistant. I wanted to be a doctor. I wanted to be all these things that, obviously, the blindness just stopped me from doing. And so yeah initially that was devastating to lose that part of my life that I loved—the military. I loved being in the military, so that in itself was very much just, just a big blow to, to just who I was.

The Devic's Syndrome not only took her vision, her career in the military, her ability to walk for a short time, and her ability to go out independently, moreover, Joanie and her first husband filed for divorce. These losses were overwhelming. “Every night, I, initially, I would cry when I was in the hospital. I would cry because I was like, ‘Oh my God! What am I going to do? I can't walk, I can't see!’”

Joanie recalled how she was feeling in those times:



Just six months ago I could walk; I had 20/20 vision, you know? So it was like, and all of a sudden, I just can't do anything. I couldn't even—it felt like, and I'll be honest—I couldn't even go to the bathroom, you know? Like, it was, it was so bad!

Other thoughts that Joanie experienced were reflective of her concerns:

Like, honestly it's just not seeing [the faces of] the people that you love, you know. That, that was something that was also, would make me sad. And, you know, am I going to be able to, to go to work? Or am I going to be able to be able to do things, you know, to, to just live life? I guess initially that's kind of how I felt, which I know, you know, it's obviously yes, you can! But that's just the initial thought is I felt that, you know, what's my life going to be like now that I can't see? It's like, how am I going to... Am I going to be able to do anything for myself? Am I going to be able to be, you know, a productive person? Or, you know, just, just stuff like that I guess is what I felt."

While Joanie was in the midst of having doubts, Joanie befriended a soldier who was in the same military hospital that she was in:

There was a soldier there that I would watch him, and he was always, like, just such a positive person. He was in a wheelchair, right? And so, I was always even afraid to, like, come up and talk to him.

After some time, he said hi to her:

He's like, he kind of said hi to me, and I was like, 'hi'. And then, then I had the courage to finally talk to him. And, you know, I was like, you know, 'Can I ask you something?' I would ask him, like, how is he doing it? How is he always so

positive, and how is he—I know he's always smiling, and he's always, like, happy. And, and, he is like—and he really told me the truth—like, he's like... So what had happened to him is, like, his parachute failed when he did a jump, and he is lucky he's alive. But he's like, 'Let me tell you. I was 8 months in a bed where I couldn't move from my neck down.' And, he said, 'And then I've had all these surgeries, and then I was able to get back my upper body.' He still couldn't walk; he said he didn't think he'd ever be able to walk and stuff like that, but the fact that he has the ability to roll around in a wheelchair and able to do things versus being in a bed? He's like, it's, it was, like, so much better, you know? And I was like, okay, yeah! I, I, yeah! Completely! And he's like, you know, 'Yes, I wish I could get up and walk.' I wish I could do this, but, you know, at least I have this, and I'm going to make the best of it. And so, so, that kinda helped me.

When Joanie began to get her physical strength back, if she had friends who were negative, Joanie became emotionally strong enough to intentionally walk away. When things got bad, Joanie said,

Well, so, you know. I just stopped, honestly. I just stopped engaging. And I think eventually people just get the point, or they just don't really call you, or whatever. Because I just had to stop engaging because they would make me feel bad, or I would feel a certain way, and I just don't think they cared enough about me to, you know. And if they did, they would have reached out or they would have said, 'Hey, let's talk about it,' or let's... you know what I mean? If someone really did care, I feel like they would really make an effort, or they would really

do this and that. And they did, like I said. They shared, hey, well, you know, it's a lot to deal with you or some... you know? And so, when I saw their mindset, then I was like, you know what? I just don't think that this is a healthy relationship to be with. You know, because if they see you this way, if they—even though you're independent—you know what I mean? Like, you know, I'm not asking you to help me wipe my butt when I go to the bathroom! You know, I mean, it's like, come on. I am not a child. And it's like, but if you find that a burden to help me to locate where the bathroom is, then it's like, I don't know if you're really that good of a friend, you know? So it's like, I would do that to you, for you, even if you could see! Like, so, I was just kind of like, uh, maybe I should really think about this relationship with this person, you know?"

Amanda, who was born with a mild visual impairment, recalled that her family has been concerned from the time she was very young that she would lose more vision and not be able to function. As Amanda increased vision loss, however, she admits, "Well, so far, nothing's happened in terms of my being able to care for myself."

Amanda used the words, "so far" because Amanda faces a perpetual fear that total blindness will develop. The fear is stronger now that she has crossed the threshold to legal blindness. "So, it's kind of like, here's something [total blindness] I've dreaded my whole—oh, I'm gonna start crying—my whole life, and, but, here it is imminent, you know?"

Living with the fear of becoming totally blind has taken some of Amanda's

happiness and left her with doubts. For example, Amanda and her husband recently moved into a new house. She wonders, “Will I have time to figure out my way around in it before I can't see anymore?”

Despite the fear, Amanda believes that the loss of driving is the worst of her losses so far. Amanda expressed that she has “a lot of grief about losing the independence.” She does ask her husband to help her to get around to places, but now, Amanda stated, even grocery shopping is something she would rather not do. Amanda said that negotiating the space inside the store is challenging, and it takes so much effort and time to try to see or read anything, she has found it easier to stay home. As a result, of choosing to stay home, she said, “It's kind of like the, the world is getting smaller.”

Charles' experiences with vision loss, he felt, required that he would put on a façade of strength. He said,

I had to put up a strong front, you know? I didn't want, I wanted to set an example, I guess, for other people, you know? And you've got lots of peers, and sometimes you've even got peers that are in the shadows, you know? People that are watching you—don't even know that are watching you—from a distance, you know? And, you know, like, younger members of your family or friends, you know, their children, or something, you know? And you got to always be on your toes about how you carry yourself and about the comments you make. And, you know, I've always felt you need to project yourself as a strong person, you know? You know, we all let things get to us sometimes. I mean, it's human nature. But I felt, you know, I had to project myself as being a very strong person. And, you

know, you can overcome anything—you can—but it's how you overcome that it makes the difference.”

When describing how he really felt about his vision loss, Charles confessed, “If I was anything, and I had to describe it, I guess disappointed and sad. Disappointed because I didn't feel I'd fulfilled everything I ever want to do sighted, and sad because I couldn't...” Here Charles trailed off and did not complete his thought.

Continuing, he said,

No, I don't know. I really don't know how to put how I felt into words. I was, I don't know, maybe disappointed? I don't know. You know, it's one of those things you take for granted, having vision. You know, because I've done lots of artwork and logo designs, wrote commercial ads, wrote advertisement, you know, everything that is visually needed for a job. And then, all of a sudden, you can't do it. I've done mechanic work, I done carpentry work, I done custom flower beds, you know, and all of a sudden I can't do any of that anymore, you know. Driving! That's another thing. I mean, I mean, I literally had to quit driving overnight, and I drove all my life. You know, I'm 58 years old, and I've been driving since I was a young teenager. And, so, just suddenly, you know, it's like going into a world where vehicles don't exist, or they exist for everybody but you, so. You know, I'd say that was the hardest part, because I love vehicles. And, you know, then not being able to see, like, my grandkids or my mother or my kids, you know?

And friends! You know, I know in my mind what they look like, and I'm not totally blind. I do have lights and shadows, you know, that I can see, and, but I can't see well enough to make out somebody's face. You know, once I put a voice to that, to that shadow, then I, you know, I know who it is, and I can remember kind of what they looked like.

Charles didn't mention it directly as a loss, but Charles also lost his house when he moved to Oklahoma to live with his son. "I went to stay with my son and his wife, and their kids to get the help. I was going to move back to Texas, and then I just sold the house I had there, back to my brother." Charles felt that he needed to move in with his son, because it was not safe for him to live alone:

The reason—the whole reason—I moved to Oklahoma wasn't so much that I lost the vision in my left eye, but it was the fact that I couldn't see to draw out my medication for my insulin, you know. And, and I couldn't read my pill bottles. I didn't have a pill reader—I didn't even know they existed. And I didn't have the pens—insulin pens—I use now. I had a needle syringe and a bottle of insulin. And, you know, I wasn't able to see the side of the syringe to know how many milligrams per deciliter I was pulling up. And, so, that's kind of dangerous.

Another powerful loss for Charles was his ability to complete art work:

Well, you know, I, (big sigh) I didn't see myself doing art work anymore, and that was that was who I was, a lot, you know. I've got art work scattered from South Texas all the way to North Dakota, and from Europe to Korea! I mean, I've got artwork all over the world, literally, and, you know, and I just didn't see me doing

this anymore. And it was such a part of me, that, you know, that's how a lot of people knew me was from my artwork. I'd sit in a restaurant, and I would bring my sketchpad, and I'd always do sketches, you know—real detailed sketches—and leave them for the waitresses. Or I'd do a charcoal, you know, and I'd always leave my artwork behind everywhere I ever went.”

Charles shared that in addition to sketches and drawings, he also made dream catchers. Charles further revealed that he made art for other people at least as much as he was making art for himself. “I'd make dream catchers, and I'd leave dream catchers—a trail of dream catchers—you know, everywhere. But when I lost my vision, you know, that's... *In the times when I was by myself*, I had my art work, you know. And that was a lot of times.”

### **Rehabilitation**

All four participants were eligible to receive professional rehabilitation services for their functional losses options because all four participants are legally blind or totally blind. Two participants were eligible to receive training from the Veteran's Administration (VA), and two participants were eligible to receive services through their respective states. Three of the four participants at the time of this study already graduated from rehabilitation programs, and one participant had only recently become eligible for services and is now seeking an evaluation. All participants learned about services from their doctor or by a rehabilitation professional.

Participants who had already completed rehabilitation shared that rehabilitation was a significant part of adjusting to the losses described above. Those who lost jobs

were able to regain employment skills. Those who lost the ability to read were able to use computer technology and audio resources to access books and other printed material. Individuals who had only known visual ways of completing household tasks were able to adopt non-visual strategies for cooking, home maintenance, and even recreation.

When Joanie was first pursuing physical rehabilitation to regain her ability to walk, Joanie had still lost vision in only one eye. Having lost vision in one eye did not initially make her legally blind, so she was not receiving services for the blind at that time. To be declared legally blind, the vision in the both eyes must meet the criteria for legal blindness; therefore, Joanie did not qualify for blind rehabilitation services until she had lost vision in both eyes.

When Joanie did lose vision in the second eye, it still retained some acuity at 5/200. Joanie was not totally blind. She explained, “I was legally blind. I could see shapes, and a little bit of color. So things were blurred, but it was... I felt like I could get around a little.”

As Joanie was being released from physical rehabilitation, she was scheduled to meet with a vocational counselor to help identify a new career. Joanie didn't realize at that time that after losing so much vision, she would have to “learn how to blind,” before going back to school or work. “That's just lack of me knowing anything about blindness,” she said.

Joanie described her first meeting with the vocational counselor:

I went there at the time with my husband. He took me to the VA, and I did, like, a vocational rehabilitation assessment with the counselor. And when she sees that



I'm [legally] blind, you know, like, she's, I guess read my file, and I'm telling her what happened. She's like, 'Well, you need to learn to be blind first,' you know. And I was, like, 'Well, yeah!' Because I was ready to, like, okay, I want to go to college, and, you know, I was just, like, 'I know I need to do this,' 'cause that was my goal was to get my bachelor's degree. And so she was like, 'Well, I think you need to learn to be blind first.'

Once the vocational counselor shared that Joanie needed blind rehabilitation in order for Joanie to be able to accomplish her goals, they worked together to find the retraining that she needed to meet those goals. "And so that, that was kind of the beginning of being, you know, going into the blind rehab knowledge of, of what's out there."

Joanie said that the rehabilitation processes took about three years. During that time, she said, "The rehabilitation experts had to kind of show me, like, OK. This is this is how you're going to do it, you know, and be successful. So I thought that that was, that was good."

After being fully "rehabbed," Joanie took her first job. In that job, however, Joanie admitted that she had been uncomfortable to use her cane at her work:

I should have used my cane, but I didn't do it because I was more so protecting... I wanted to be employed, you know. So I want to be employed. I don't want to be a liability. I don't want them to, I don't want the, the, obviously, the customers to take advantage and then just, you know, steal, and then, you know. And then

they'll just say, 'Well, she really can't do the work,' or something. So I kind of did it for those reasons. And so that's the only time I didn't though.

From the time when Joanie took her first job, she has since lost the remainder her vision. Using the cane is no longer optional. Joanie has had to learn to accept herself and her strengths as a woman who is totally blind. Joanie would say that rehabilitation had a lot to do with that:

Rehabilitation is a lifelong process, and, and it just helps you just feel good about yourself. Like, I feel like I've had really good goals that I've set, and I think I've accomplished most of them. And so, you know, we'll see, you know. I'm not done!

Like Joanie, Charles also had initially lost vision in only one eye. For a time, he, too, was not legally blind. When he lost the vision in the second eye due to the eye stroke, he became legally blind. When that occurred, a regional VA eye care provider told him, "Your vision now is as good as it's ever going to be. Tomorrow, it's as good as it's going to be. Every day that you get up that you can see, it's as good as it's gonna be." Charles accepted what his doctor said. Charles knew, "I mean, I'm going to be blind, and that's a fact. But I had to learn how to be blind."

Charles' doctor referred him to a blind rehabilitation center (BRC) for veterans where he would be able to receive training. Once there, members of the VA staff commended Charles for attending the BRC so quickly after losing vision. One woman had told him directly:

She said that, you know, she was surprised that I was there as soon as I was after losing my sight because a lot of people, you know. They, they wait a long time before they try to get any training, you know, because they're adjusting and trying to, and they're stubborn, you know. Most men. And, so, but I thought, no. I gotta, I got to move on. So I gotta learn how to move on and, so, I went there as quick as I could.

Charles described some of the training he received at the BRC:

When I went to the blind rehabilitation center, I found that there was definitely things I could still do, you know. I'd done sketches, I'd done drawings... I done all kinds of stuff that I didn't think I'd do again, and just for the need to do them, you know. I guess, you know, I was... I don't know how to put it, but I found a way to make people happy again, and I thought I'd try to sketch. And when I was in the crafts room, I was working on a leather project which is, it was simple. It was just lacing it together, you know, and, so, it's not rocket science. And they had a big sketchpad in there, and I asked if I could use it. And they said, 'Yeah, use it all you want!'

Charles also explained some of the devices that he received:

They gave me equipment to help me in my day to day life, you know. Like the iPhone I use. The VA give me that with the blind apps on it. You know what I'm talking—they use it—and then they added programs on there like Seeing AI where the phone will actually read whatever you point it at, pretty much, as long as it's

typed out, not handwritten. And then they give me a machine—I don't even know the name of it—where you, it'll read your mail. I don't know what it's called. It's got a little tower, and it's got a camera at the top of that tower. It's got a flatbed, like a scanner type thing, and you just lay it on that flat bed, and it takes a picture of it.

Charles continued to excitedly tell me about devices that he received:

Yeah, and then the Victor Reader. I use, I use it a lot, then the book reader from Library of Congress, you know. And then we've got, of course, the Apple TV. And we've got Xfinity, you know, Comcast. And then I've got the glasses—NuEyes. Yeah, I got the NuEyes from Comcast!

Charles said that the NuEyes device from Comcast was significant to him because it enabled him to get back into art. Using NuEyes, “I was able to start a new painting. And then I was going to put it into the Creative Veteran's Art Competition this year!”

Charles further shared that before he lost his vision, he was an avid walker. “There was days I was doing three to five miles every day, you know, walking.” After he lost his vision, however, Charles was mostly afraid to go out by himself at all. Charles told a story of when he was visiting his girlfriend before he finished the training:

The first time I come up, I stayed at [my girlfriend's] apartment. I never left in that 10 days, unless I left with her and her cousin or someone, you know. I stayed right there in her apartment the whole time that she was at work.

Now that Charles knows how to use his cane and the iPhone, Charles is a lot more comfortable with navigating independently:

Getting out by myself, you know, and, and walking, and not being worried about where I was going, you know? Having the iPhone, I feel that real significant for anybody who's blind. And being able to ask, 'Siri, what is my location,' you know? 'Cause, you know. You can, you can walk and just walk and walk and not really pay attention to where you're going—because you can't see—and make sure you're going in the right direction. You know, I think having the iPhone is a real real milestone compared to just going out walking, you know. You know, and not being afraid to go out and start walking.

Overall, Charles said that he has rebuilt his life after vision loss, and he said he owes all of it to the rehabilitation training and devices he received. Despite his extensive training, however, he feels that people still have “a misconception about the blinded. I mean, yeah, there's a lot of things we need help with. It's, they're really worried when it comes to stairs, you know. But I took my training, and I use my cane.”

When Maria lost her vision so suddenly, she said one of her first thoughts was that she wished she had had more time to prepare to live as a person who is blind. She stated,

If you think about something that happens that you never ever would have thought would happen, you know what I'm saying? I've never ever thought I would have went totally blind. Never. Not even halfway blind. Maybe if I could have prepared for it or something? I don't know. If I had time to prepare and look around and see this and that, and then practice, or something? I ain't even

have a chance to prepare or nothing. I was, I had no time. So I ain't even had the chance to get ready, to prepare to being blind. It was just, like, unbelievable.”

Without any preparation, training, or adaptive devices of any kind, Maria was at a loss for several months prior to when her rehabilitation program began. Maria had even found herself to be homeless. “Yeah, I was homeless twice, and it was only because I didn't find a house by the time my lease was up. So that's why. And my kids, they're not that responsible, so them looking...it was just a challenge.”

Maria had tried to rely on her children to find suitable housing. She needed them, in addition to finding the house, to also “move furniture, and get a U-Haul, and put stuff in storage...it was a lot.” “But,” she says, “I wasn't in the shelter long. I was in there about three weeks. But they kept applauding me. They say, ‘You do more than we ever seen any of these babies in here do.’”

Meanwhile, while she waited for rehabilitation services to begin, Maria spent a lot of time questioning herself. She would ask, “‘How did this [blindness] happen?’ I'm going over how this happened. ‘What did I miss?’ And stuff like that. That's what I was, that's where I was at.”

Other people were questioning Maria's blindness, too.

I'd had people say to me, ‘but you're a nice person! How can that happen to you?’ I'm like, ‘Fool, this could happen to anybody.’ Like, my twin sister said, when it first happened, she said, ‘Did you ask God why did this happen to you?’ I said, ‘No, I didn't ask him *why*, because everybody has to go through something.’

I say, 'I asked him why the blindness'—I didn't understand the blindness. I never thought I would be blind.

When finally, Maria was admitted to the blind rehabilitation program in her state, Maria expressed, “That's what helped me to start to begin to heal. You can put that as a milestone. When I went to [rehabilitation], that's what helped me to start my healing process. When I went to [rehabilitation], and being around other blind people.”

At the rehabilitation center, Maria learned how to use computers that had assistive technology programmed onto them, but Maria was not given a computer to take home. Maria did not receive expensive devices such as a free iPhone or scanning software to help convert printed papers into text that can be read aloud in the way that the veterans had received from the VA. Maria did receive a white cane and training on how to use it. Maria also learned strategies to help maintain her independence, including Braille and labeling, and she learned responsibilities that go along with managing a home.

With the training that Maria received from her State service provider, Maria learned how to keep the house clean, and she learned how to take care of herself. She currently maintains a gym membership, takes vitamins, and is always looking for ways to improve her health.

Because of rehabilitation, Maria is able to get on her personal computer and research health and other topics that interest her. She is also able to independently use her cell phone. Lately, since she is not working, Maria has been researching volunteer opportunities in her area, including ways to better advocate for her son who still lives at home, herself, and others.

Amanda has not yet participated in rehabilitation. Although she has been visually impaired all her life, she was not aware that she is now eligible for blind rehabilitation services. She told me, “I don’t qualify for a lot of services. I have a little too much vision.”

Amanda was using information she had received in the 1970s to make the self-determination that she did not qualify for services now. She shared, “I was evaluated at the state—whatever the agency for the blind was—when I was in college. They just looked at my vision information and said that I wasn’t eligible for services because I was too high functioning.”

It was true that Amanda was predominately able to function visually up until a year and a half ago. It was a year and a half ago when Amanda became legally blind. At that time, Amanda had to resign from driving. The same is true of reading print textbooks and novels. Up until a year and a half ago, Amanda was able to read visually with regular sized print. When she became legally blind, now Amanda no longer is able to read print books.

As Amanda remembered, she used regular sized print text book for most of her primary and secondary education. “The school ordered large print books for me for first and second grade, and then they kinda figured out I could get along without it.”

Amanda indicated that using regular sized print through school was not without its challenges. “Whenever our teacher gave us something to read, I was always the last one finished. And, um, if... if I took home to a book to read, a lot of times my mother would read it aloud to me.”



By college, Amanda had developed a secondary visual condition called nystagmus. She noted,

When I went to college, you know, the reading was much worse. The school librarian helped me get signed up with Recordings for the Blind [and Dyslexic], so, I was able to get books on tape through them for undergraduate and then, my masters in seminary.

After college, however, Amanda still read novels and books for leisure in print. Now that Amanda is legally blind, Amanda is unable to read print, and she is unable to drive. Amanda is still able to see shapes and colors, but to be safe, Amanda would like to start to use a cane when travelling outside, especially in a new or unfamiliar area.

Another problem I have is tripping because if the, which I'm sure when you were talking about the cane, that would probably be helpful. But, you know, if there's *this much* change in the floor or sidewalk [indicated small distance with fingers]...

I fell once in August and twice in September, always outside, you know. Once was going down a sidewalk, but the other two times were back here [at home]. But, you know, if there's a hole or whatever, I don't necessarily see that. So, I mean, I'm sure that if it was a cane, then it would be out in front.

Amanda has difficulty in other areas of her daily living as well. For Amanda, she said that living with vision loss means "there's a lot of stuff I'm just kinda skimming around the surface on instead of really doing." Amanda mentioned that she can't see the controls on her oven, and that "it takes too much effort" to try to set it exactly, so "I guess

at it.” Amanda now has realized that, because she is legally blind, she can qualify for state services. She said, “I want an evaluation for my vision–Low Vision.”

### **Sensory Enhancements**

Three of four participants suggested their other senses have enhanced due to vision loss. According to Maria, who is now totally blind, she said,

Like, it is automatic. It’s just, like, automatic. Like, say, like, you listen for certain things. This your ears just going to automatic listen because you can't see. It's just automatic, like turns on to listen, just to hear. It just, all the time is listening, there is a listening. But yeah. And smell? Yeah. You're smelling, you're walking through stuff, and you can smell wheat bread in the grocery aisle and different stuff. The smell and the hearing, your ears enhance.”

Joanie who also is totally blind similarly highlighted enhancements in her hearing and her smell:

I feel like my hearing is sharper; my sense of smell is very sharp. So I feel like those two are just a lot, you know, sharper on when it comes to, I guess, yeah. I'm able to hear things a lot more acute. And just smells definitely. Yeah. I guess those two.”

Joanie described how she uses her enhanced senses:

Well, I have to listen for things, for, because I can't, you know, I can't see it. So I gotta really pay attention to sound. Like, when something drops, you know. You really need to locate where that is by listening to it. Smelling, I can find things when, ‘Oh! Smells like,’ for instance, ‘a cafeteria! Smell the food!’ But

sometimes I'm able to pick it up sooner, or even anything dangerous, you know.

Like, 'There's smoke! Hey, I smell something!'

Charles stated that his two most improved senses are smell and taste. "I think certain, certain seasonings I taste better—stronger—[laughing] like when you [accidentally] put chili powder on Cornflakes!" His hearing, he said, was damaged in the war, and so his hearing is probably not ever going to get any better.

Amanda stated that her hearing is getting progressively worse as she ages, but that she hasn't noticed any marked improvements or changes in the way that she uses any of her other senses, other than her intuition. Now that she can't see well, she said, "There's a lot of things that my brain kind of fills in the blanks."

### **Benefits of Vision Loss**

Participants shared that losing vision and living without vision has not been without benefits, positives, or advantages. Initially, however, when reflecting on positives, Amanda could not think of any. "No," she said. "Not in the last year and a half, nope. I'm trying to think...positive...no."

When imagining how her life would have been different had she had vision all of her life, Amanda realized,

Part of my call to ministry had to do with being thankful for the vision I had when so many others are left, you know—Retinopathy of Prematurity people—didn't have any [vision]. So why was I spared? So what was I going to do with what I was given? And so, OK.

Having recognized that her life choices and trajectory may be different if had not

been for having a visual impairment, Amanda continued:

I've always wondered, you know, could I have done more? Could I have accomplished more if I was fully sighted, you know, but I never knew what to, what to credit not being able to see? With, you know? Could, am I not doing as well at X because I can't see, or because I'm just not as good at that? And so what to think?

Having made it to retirement age, Amanda is glad that she was able to retire:

It was a big relief to retire because I, you know, I didn't, it wasn't as big a deal whether I got through the mail or not, and it wasn't as big a deal whether I could see who was there on Sunday morning and who wasn't. It wasn't, you know? I just, just this big relief, you know, that's just always been trying to keep up with what everybody else did.

Unfortunately, Amanda became concerned that becoming legally blind was a punishment for retiring:

I did retire at 62. I had enough years to be full, full retirement. That might turn out to be a good deal. But, you know, part of me thinks, well, you know, here you're retired now, and you get to—you can go and do all these things, but oh well, now your vision's worse. And, so, I don't know. Should I be thankful that it, well, at least it waited until I was retired, or should I be mad because... Did you give me that good of vision all those years because I was serving You, and now I'm not, so I don't have it anymore? I don't need it anymore?

In summary, Amanda seems to have mixed feelings about her vision loss. She believes that if she had not been visually impaired all her life, she may not have become a minister, but she also struggles with the notion that retiring has brought on a punishment from God. Still, Amanda “enjoyed” her life, and she is working toward fully accepting the losses she now has. “It [acceptance] is a work in progress,” she said.

As a positive, Amanda does not feel that her vision loss will impede her from doing all of the things she would like to do in retirement. “I’d like to write a book,” she said, and “I want to travel more.” Finally, she said, “There’s a lot of novels and things that I would like to read.” She said, in the case of reading, it’s not vision loss that is holding her back. She said, “It’s a matter of getting to it instead of being distracted by Facebook!”

Maria expressed that “being blind can be peaceful, more peaceful than having your eyesight.” Maria explained,

To me, it's like being in another world. I mean, you can't see, but certain things that remind you that you are here, but you can feel like it's a totally different world. But peace, you have peace. It's, it's...you're not worried about a lot of the things you would worry about if you had your sight. A lot of things that I thought were important are not important. I probably haven't used papers, or pictures—you know what I'm saying—that you might have held onto and stuff. You probably don't know. You even begin to hold on to the stuff because you think it's so important, and it's not as important. And definitely, far as the worry, you don't

worry about as many things as you used to. So to me, it's a little bit more peaceful.

The losses that Maria experienced that made her life more peaceful can be regarded as positives. Maintaining a positive attitude is something that Maria credits with her belief and trust in God. Until she lost her vision, Maria remarked “I've always known God, but I didn't have the relationship or the connection that I needed.” Maria felt that losing her job is what gave her more time to connect with the Lord:

When I lost my vision, and I got the audio Bible, because I had more time on my hands, because I worked a lot. So, I had more time on my hands to go through that Bible over and over again and just get an understanding. Just go through different things.

Since then, Maria has learned to trust, pray, and be thankful. “I pray because that's all I know is to pray, and to pray to God. That's where my help come from.” Through prayer and constant communication with God, she is able to understand the messages that God sends to her, and she is able to discern when others' ideas need to be ignored:

When it's your story, no matter what their perspective is or what it is, when God tells you something, if they ain't in alignment with what God is telling you, then I don't listen. I don't pay them no mind.

This mindset of faith has brought Maria through the losses of her vision, her job, the ability to drive, and the individuals to whom she was close at one time. Some people may be devastated to experience any one of these events, but Maria is not. She said,

And I didn't know why I noticed...there's a lot of blind people that are depressed. That's why I thank God that he strengthens my mind because...And I'm blind, but I see a lot of other blind people are depressed and emotional. And also, they almost feel like victims.

Maria herself does not identify as a victim. She would not even reverse God's decision if she could. "I wouldn't change it. People say, 'Well, if you could take it back, would you change?' No, I wouldn't. It happened, and it's taught me. It's taught me."

Joanie, who initially had lost her career with the military, her relationship with her husband, and several friends, now has a life that she enjoys very much. She explained, "Initially, I think there's stages [to acceptance], you know what I mean? Like, initially, sure. I was like, 'I'm probably going to die a lot sooner.' And, you know, I was just like, it was just a little more gloomier than now. Now I feel like, nope! I think I'm going to live a good, long, productive life. I don't feel any, any less. In fact, I feel like the blindness has allowed me to do more things. I almost consider it now, a different, like, a blessing than I did before because I have met so many awesome people because of it. I've been able to do so many really cool things because of it, you know? It's allowed me a lot of different opportunities that I probably wouldn't have had had I not lost my sight. So, so I, I don't see it negative now."

Joanie said she didn't always recognize losing vision as a positive, but she realized the positives more readily when the right job came along:

I want to say, maybe when I started working for [a blindness agency]. I just got all these awe, awe, awesome opportunities because of them, you know. Like, I don't know. Going to inaugural balls, going to the White House, going to just really different things that you would never have easier access to, I guess. You know what I mean? I don't know. It's like, so I feel like, because of that, or be, because of the—or just, just like, ‘Wow! I just did that with my eyes closed!’ I tell people that all the time, you know? Like, I'm like, ‘Hey! I go skiing with my eyes closed,’ you know? And then they're like, ‘That's actually pretty true!’ You know, like, I mean, I just feel like, I feel like, since I've been with [the blindness agency] more. Because I've been more involved with the blind rehabilitation stuff—and them as well. I want to say even before, a little before [working for the blindness agency], but certainly that has helped me. Being with, with other blind individuals, it's not so bad, you know?

Joanie said that losing vision has also helped her to become more adventurous, and that she now is looking forward to retirement so that she can enjoy more exciting adventures such as these:

I think I became more of a risk taker, and I think more adventurous and more daring than what I was before I couldn't see because I, I just, I don't know. I guess because I feel, like, because of the disability that I've had, or this condition, you know, that life can be short, I don't know. I was like I, I'm not, you know, I'm not promised tomorrow. So I feel like I've become more risky in taking risks and in doing more adventurous things, and why not? Let's try it! You know, stuff



like that. Not risk in a negative way. Not, you know, don't get me wrong. I'm not going to, like, do foolish things, but I am going to do more like, hey, you know, yeah! Let's go skiing, or let's, you know, let's try this thing that I would have probably not tried in the past, you know. And then I realized how much I love, like, adrenaline. Oh my gosh, like, I'm a—I want to say, I feel like I'm an adrenaline junkie now—and I love frickin' fast! You know, I love the downhill skiing, and I love, you know, just doing things that are, like, exciting.

Charles' attitude about vision loss remains in the acceptance of what you can't control. He shared, "It is what it is." He has only been blind for three years, and he admits that he is still adjusting. If he were to identify positives, however, Charles said, "I think my outlook is broader, you know? I tend to think in dimensions rather than anything else, you know. I look at things a lot more different ways, you know."

One way in which Charles adjusted his thinking was related to trust in other people:

It [losing vision] made me more aware, you know, and, in some ways, more trusting, in some ways less trusting, you know. I mean, it depends on the circumstance. I find that I have to trust people, you know, to a certain extent, you know."

Finding trust in people now that he has lost vision is an improvement. He said, "I used to not trust anybody, you know."

Part of his new attitude toward people helped Charles to meet his wife. “I wouldn’t have met her had I not lost my vision!” Because of the rehabilitation and the support that he gets from her, he said,

We live by ourselves, and we cook our own meals. We order groceries, you know. We don't actually go out grocery shopping—we order through Peapod and other delivery services—but we do put everything away, and we do cook our own meals, you know. We do our own laundry. For the most part, we keep our house clean, but we have a housekeeper we hire, and she comes in once every two weeks to do maintenance, you know. And, so, no, we still do everything.

Charles said, too, that he has always kept a can-do attitude, and this has carried forward with him through vision loss. “I just, I just don't quit and don't give up, you know. My demeanor has not changed. I’m the same person I was before I went blind.”

### **Participants’ Advice**

The participants in this study have each lived with vision impairment, and they have adjusted to their lives in various ways. They adjusted emotionally, spiritually, physically, and psychologically to the challenges that vision loss can bring, but each maintains hope and optimism. Maria shared, “If you lose it [vision], it is not as hard as it may seem. It's not as hard as it may seem. It's not as hard as it may seem.” Maria also suggested:

You got to be careful for what you say, because I remember one day I was at work, and I was like, ‘Damn, I'm tired. I need a break.’ I was like, ‘I'm tired. I'm tired of driving.’ So, now I can't drive!

Joanie recalled reading a survey where it asked respondents to rate the worst possible events that could happen to a person. The results showed that death was the worst, and blindness was the second worst. Joanie said, “And I feel like, ugh, you know? You, you've gotta change that mentality! But it is because of the lack of knowledge and the lack of things” that people find blindness to be “a death sentence.”

Amanda admitted, too, that she doesn't share many of her feelings about vision loss with others “because the trust is difficult. Because, for one thing, it's ‘cause people don't understand!” Moreover, Amanda doesn't “look blind,” so when she is not using her cane, “most people don't realize that there is anything wrong.” Amanda also finds that her vision loss, which has left her with the ability to see some things sometimes, is confusing for others, including the doctors. As a result, she has resigned to “making it on my own.”

Amanda admitted that she does not like to use her cane because it does reveal her visual impairment, but that it is, in fact, helpful:

And so far I haven't, you know, seen a great need to announce things, but as I get where trip hazards and falling are more problematic, you know, more fraught with danger, then I think, you know, something like a cane or something might be helpful just so other people would know that there's issues here.

Joanie had learned as well that “this [the cane] isn't just for your safety; it's also for people to know that you're blind.” However, even when having the cane, mishaps can occur. People may know that you are blind and still not be helpful or informative.

Joanie shared a story of when she was walking with a family member at Christmas in an unfamiliar house. Her aunt had been guiding her through the house, but she did not tell Joanie that there was a flight of stairs heading down to the basement.

My aunt just didn't really know how to guide me and just didn't think, 'Hey, I should warn her about that whole flight of stairs,' you know what I mean? So as soon as I kind of slightly turned, I stepped right into the stairwell. And she didn't even mention it, you know what I mean? So it's like I trusted her, but I really, you know, and it's not her fault. She's not used to guiding me, but I just thought, 'Oh my gosh!' Like, it's just lack of her knowing [that] I fell down that whole flight of stairs. Lucky I didn't break anything!

Joanie and Amanda both lamented the fact that the general public, family members, and even doctors are not knowledgeable about what vision loss is, how it can affect people, and how to help beyond the diagnosis.

Joanie shared another story about a doctor she had met at a conference:

I saw this ophthalmologist, and he was like, you know, 'I want to tell you,' he's like, 'you're an impressive young lady.' Just, and this was, he's like, he was telling me, 'I've been an ophthalmologist for 30 plus years.' He's like, 'and I had never really genuinely grasped the concept of blindness even though I dealt with people losing their sight' and this, till he went to a *Dining in the Dark*. He said, 'I just went to that this past summer.' And he's like, 'and it was so difficult, so challenging, which made me really focus, like, really, it brought to fruition what it was to be losing your sight, what a blind person really can go through.' And, like,

he's like, and 'until now!' Like, and I'm, he's like, 'I'm ashamed to say that.' He was like, 'here I am an ophthalmologist,' you know, 'an expert on eyes, and I never really understood how much until I went to that and experienced that—experiencing being blind,' you know. And, so, he's like, 'and oh my gosh!' He was like, 'just how difficult it is just to eat! It's challenging! It's like, oh my God!' He's like, 'It was so frustrating,' you know? And I was just like, yep!"

If even doctors who diagnosis blindness and who are "experts on eyes" can't understand what it may actually be like to be blind, how might they and the general public become better informed? How might society overcome, as Charles identified, "the misconception that because you're blind you're crippled?"

Charles hopes that people will know that people who are blind are still able to do the things they did before, "only a lot more careful." Maria acknowledged the shock that others may feel when somebody they know loses vision. "You see somebody driving, then the next day, they in the hospital and they blind. That is, that is something!"

Finally, Joanie expressed her desire for society to be re-designed with accessibility in mind, where the consideration of disabilities was a fore-thought and not an afterthought. "When you make things accessible for everybody, then it just makes the world even a better place, right?"

## **CHAPTER VI**

### **Conclusion**

#### **Introduction**

This was a qualitative phenomenological study about four adults who adventitiously lost their vision in adulthood. Participants were asked to share their personal experiences from when they became blind. All interviews were conducted and recorded with the participants' consent.

A literature review resulted in very limited information on the lived experience of adventitiously blind adults. The purpose of this research was to better understand the lived experiences of adventitiously blinded individuals for the benefit of updating the limited existing research on this topic. Another purpose of this research was to increase the knowledge base for both practitioners as well as individuals who lose vision.

#### **Methodology**

The design of the study was descriptive phenomenology. The ideology behind the approach was Husserlian. The researcher did not attempt to interpret the participants' story; the researcher allowed the participants to tell their own story by using direct quotes to support underlying themes in the findings.

While analyzing the data, the researcher bracketed her 10 years' experiences of working as a rehabilitation practitioner for adventitiously and congenitally blinded adults and children. The researcher analyzed each interview individually and collectively to establish themes from the experiences that participants shared using a whole-parts-whole approach to reading as suggested by Vagle (2018, p. 98).

### **Participants**

The four individuals who participated in the study ranged in ages between 42 and 63 years, had educational attainment ranging from a GED to a master's degree, had visual acuity between 20/60 with a field restriction of 20 degrees to No Light Perception, and they were declared legally blind or totally blind between 1.5 and 19 years ago.

Two participants were White, one participant was Black, and one participant was Hispanic. Three participants were female, and one participant was male. All participants were from different states or parts of the country.

### **Findings**

Despite the heterogeneous nature of the participants themselves and the individual experiences they had with blindness, seven themes emerged. The major themes were: Medical Dysfunction, Others' Reactions, Ancillary Losses, Rehabilitation, Sensory Enhancements, Benefits of Vision Loss, and Participants' Advice.

**Medical Dysfunction.** The loss of sight in the cases of each participant was secondary to a medical condition and associated diagnosis. The participants in this study were diagnosed with Devic's Syndrome, Diabetes, Pseudotumor Cerebri, and

Retinopathy of Prematurity. Each condition led to blindness or legal blindness as a result.

**Others' Reactions.** Participants shared the reactions of those around them, including their friends, family, or members of the general public. Common reactions from family, friends, or members of the general public indicated that they did not understand blindness, such as when a stranger spoke slowly and loudly to Charles at the bus station. Other persons may also be unsure of how to help, such as when Amanda's friends bought her print books to read. In some cases, people did not want to help, such as when Joanie's family refused to take her out. Some individuals even became judgmental, as was the situation for Maria.

**Ancillary Losses.** Participants shared that consequent to vision loss, they lost their jobs, the ability to read, the ability to drive, and experienced other losses of independence such as the ability to perform grocery shopping or set an oven. Personal losses included losses in confidence, loss of identity, as well as loss of loved ones who could not be depended upon for support or assistance.

**Rehabilitation.** All four participants were eligible for blind rehabilitation services. Two participants were eligible for federal services through the Veteran's Administration, and two participants were eligible for state services.

Three of the four participants had already graduated from a rehabilitation program, and one was actively seeking an evaluation. The three participants who already experienced rehabilitation agreed that rehabilitation was needed in order to live



successfully as a person who is blind; prior to rehabilitation, they did not know “how to be blind.”

**Sensory Enhancements.** Three of the four participants experienced enhancements to their other senses, including taste, smell, and hearing. No participant indicated that their sense of touch became more pronounced. One participant stated that her intuition was the only sense that has increased since experiencing vision loss.

**Benefits of Vision Loss.** Participants overwhelmingly shared that their lives would not be as they are had they not lost their vision, but only three of the four participants stated they would not undo the blindness that was given to them. Participants further indicated that appreciating blindness as a blessing was not immediate.

Interestingly, the participant with the most vision is the most fearful of total vision loss. Participants who have total vision loss have expressed their lives have improved because of vision loss. Maria felt that she learned about people, Joanie was given opportunities and experiences she would not have had, and Charles met his wife.

**Participants’ Advice.** All participants in this study have experienced vision loss, and they have been adapting for at least 1.5 years. Participants were able to reflect on ideas that may be helpful for other individuals who may experience vision loss as an adult. As Maria stated, “It’s not as hard as it may seem.”

## **Conclusions**

In the time of Father Carrol (1961) and Louis Cholden (1958), blindness and vision loss most likely was more debilitating than it may be today. In the 1960’s the

university training programs were only just beginning, and resources were not as plentiful and readily available as they are now.

Up until a few years ago, only Braille, cane skills, and audio books were available as the dominant intervention tools for people who are blind. Today, a plethora of assistive devices and technologies exist to help people who are blind to live independently. Charles in particular liked the iPhone that he was given from the VA, but Joanie and Maria liked the computer and screen reading technologies that brought their independence to a new level.

Participants were able to receive their training through a combination of state and federal agencies. The rehabilitation specialists who staff those facilities are trained at universities where specific blind interventions skills such as orientation and mobility can be learned. These university trained blind rehabilitation specialists and their respective training universities however did not always exist.

The first university to offer orientation and mobility as a career training program was at Boston College in 1960 (Wiener & Siffermann, 2010, p. 487). Prior to 1960, orientation and mobility specialists for civilians did not exist. Today, many individuals who are blind or low vision receive orientation and mobility and other independent living training. This type of training is what enables individuals who are blind or low vision complete their education and go to work.

When a person loses vision, as Joanie found out, before going to school or being able to work, one must “learn to be blind first.” “Learning to be blind” is rehabilitation.

During modern day rehabilitation, individuals are shown how to use talking technology such as talking telephones and talking computers, as well as a variety of gadgets and apps that can read money, read the mail, identify colors, or indicate if a light is on or off. Maria, Joanie, and Charles all graduated from a rehabilitation training program and now live independently.

Skill sets for independent living can be learned through modern rehabilitation, but in the 1960s, only Braille, canes, and audio books were used. Even modern day conveniences such as washing machines, cars, electricity, refrigeration, and indoor plumbing also were not as accessible nor convenient as they are today. Some modern day conveniences that we use today did not exist at that time at all such as microwaves, Instantpot, or GPS. Not even public school accepted children who were blind at that time, neither did accommodations exist to help people maintain employment.

Based on the absence of so many modern conveniences and technologies for people who are blind at that time, the loss of vision was likely to present greater challenges to independent living than it does today. This may help to further explain the importance of psychological evaluations that were required of persons who wished to receive training or evaluations at that time.

When looking at the emotional adjustment of individuals who lost their vision, the literature suggested that individuals who lose vision experience shock, denial, depression, coping, and change. I found that was mostly true even today.

Participants were not able to prepare for if or when legal blindness or total blindness would occur in their lives. When it happened, each had to react to an

unplanned situation. Maria had to go to the hospital, Joanie was already in the hospital, and Charles was preparing to go the hospital for surgery as well. Amanda had been aware of the risk of vision loss due to ROP, but she could not have known what it would be like once the vision loss occurred.

Participants did indicate periods of shock or depression following the initial surprise. To say however that participants were immobilized (Cholden, 1958, p. 73) is not completely accurate. The participants of this study were actively problem solving and adapting to the situation by seeking rehabilitation and arranging their lifestyles to make that happen. Participants needed help to accomplish tasks such as travel, getting to the store, and getting to doctors' appointments, but the human and professional resources were there.

Had our participants lost their vision in the 1960s, those same resources would not have been available, and participants would very likely have been far more immobilized psychologically—as well as lacking in transportation options—than they are in 2020. The changes in rehabilitative options, availability, and funding from then until now are significant because the options for rehabilitation and public social services are much greater than ever before.

In 1958, Dr. Louis Cholden expressed that when he saw patients who lost their vision, their depressive symptoms included self-pity, and suicidal thoughts. Dr. Cholden (1958, p. 75) perceived this as a time of mourning for their “dead eyes.” Mourning was likely to be more significant when there were very few options for living independently as a person who is blind.

Today, with modern rehabilitative options available such as technology, participants did still experience a time of mourning, each in his or her own way. Maria's mourning period included questioning herself and blaming herself. Charles' mourning period was for his art work and other hobbies. He thought that those things defined who he was, and he thought that he had lost those things.

Joanie, too, felt that she lost her identity when she was unable to work in her chosen career, and she mourned her career. Amanda, who lost vision the most recently and has not yet participated in rehabilitation, may still be in her mourning period. Interestingly, the mourning period for each participant was experienced prior to the discovery that rehabilitation services even existed and the time when rehabilitation began.

Similar to Joanie's reaction when she first lost vision, Amanda asked "How will I live?" It is fair to question and to even fear how one will live when one does not know that rehabilitation exists and what it can do. Joanie stated it is "because of the lack of knowledge and the lack of things" that people find blindness to be "a death sentence."

Moving forward toward participating in rehabilitation could be more difficult when fear is present. "For each individual who takes his first steps as a blind person, the most immediate hindrance is fear" (Chevigny & Braverman, 1950, p. 230). Additionally, Chevigny and Braverman (1950, p. 233) suggested that "Before he can reorganize, he may need to adjust first to the need to reorganize."

Unlike Chevigny and Braverman's assumption that participants needed to "adjust first to the need to reorganize," participants of this study seemed to relish the opportunity for rehabilitation once it was offered to them. The fear of not knowing how to live

subsided in the knowledge that the blind rehabilitation services would help them to meet their goals and their needs.

When discovering rehabilitation options were available, participants wanted to go “the next day” or “as soon as possible.” No participant denied services when they were offered to them, but, also, no participant previously knew about the existence of services for the blind, the names and types of services available, or how to contact the agencies that provided the services.

Seemingly, participants needed to be more aware of rehabilitation services for the blind and how to access them. Perhaps if such services were more advertised, the fears of “How will I live” would subside, and people may instead think, “I need to call the blindness agency for help.” Having a greater awareness of resources throughout the general public has the potential to reduce depression, doubt, and fear, not only in the lives of people who lose vision, but also for people who are acquainted with people who lose vision.

Without knowing of even the existence of rehabilitation services for people who are blind ahead of time, however, participants deeply felt the emotional effects of their losses. Moreover, persons in the general public and others maintained the false belief that services for the blind are not available, and therefore, that people who are blind are treated “different from others in a less than desirable way.” (Goffman, 1963, p. 3).

In the literature, following shock and depression is coping and change (Cholden, 1958, p. 20). Rehabilitation represents the coping and change stage that follows after

shock and depression have subsided (Cholden, 1958, p. 20). Rehabilitation is useful for participants and others to recover from their ancillary losses.

The skills that are addressed in modern day rehabilitation programs focus more upon a person's functional losses rather than their psychological losses. The rehabilitation programs however offer significantly more training opportunities than only the cane, or Braille. Training programs now include assistive devices and talking computers and phones, bringing independence to new heights.

While rehabilitation interventions have changed significantly from the 1950s and 1960s until now, what hasn't changed significantly are the perceptions of society toward visual impairment. Society remains largely undereducated about the rehabilitative options that are available for people who are congenitally or adventitiously blind.

If society in general is uneducated, then when a member of society loses vision, a phenomenon that is increasing at exponential rates worldwide (The World Health Organization, 2018), panic and malaise can set in. The questions and doubts of "How will I live", and "How will I function" can and will be pervasive without proper information being made to the public, including to doctors. Should the awareness of blind rehabilitation options be better advertised, and if blindness as a topic was more discussed, society may find that the negative and hurtful stereotypes of "beggar" and "punished by God" are false. Moreover, the mourning period may be lessened.

### **Implications for Practitioners**

When participants in this study were asked to describe their experiences with vision loss, participants shared feelings and experiences that they, in some cases, had not

told anyone, or that they had only told very few people. As a practitioner, it will be important to be aware that the experience of vision is traumatic, and that great trust is necessary for individuals to open up about experiences of vision loss.

The findings in this study support the importance of individual's ability to share their experience with a knowledgeable professional or person who has lived through the same or similar phenomenon. Individuals may be able to rehabilitate their functional skills without fully emotionally accepting the condition. Having others to talk to and to be around who also are visually impaired is helpful if not critical to feel "normal."

Practitioners might seek to establish connections through Facebook resources, in-person support groups, or state and national level organizations. Being well versed in options for support groups will prove useful in connecting people to the resources they need in others. Should a person not have access to the resources that they need, then I would believe Cholden's (1958, p. 52) determination that a person who has a disability "becomes a *different person* from his former self." Based on the experiences of the successfully rehabilitated persons in this study, however, persons who lost their identity in work or hobbies never lost their core identities and values.

Because blindness may result due to a medical dysfunction, blindness may be best seen as a medical condition, rather than a condition fit for charity (Barasch, 2001, p. 92; Cholden, 1958, p. 21). The rehabilitation of blindness also is completed by trained therapists, sometimes in clinical settings. Doctors, therapists, and society may well become aware that persons who are blind can be successfully rehabilitated, which may ease the fears and doubts surrounding blindness and vision loss. Acceptance of self may



come more easily as well when rehabilitation has been successful (Carroll, 1961, Tuttle & Tuttle, 2004).

### **Implications for Adventitiously Blinded Adults**

The trauma of vision loss may be overwhelming to begin with, but the participants in this study show that they were able to recover, at times, even when they did not have significant support. Losing vision made them realize who was and was not important to have in their lives, and those kinds of determinations made them stronger in their resolve to be successful on their own if need be.

Each step forward after vision loss is post-traumatic growth, and there is no established timeline for that. Participants shared that rehabilitation and adjustment can occur over a lifetime. The events of shock, depression, coping, and change were experienced by all.

Denial did not have as much relevance in this study; one participant who shared that she believes her vision may come back would not be characterized as operating in a state of denial. Denial would function as a barrier to acceptance; however, all participants in this study seemed to have accepted blindness as part of their lives and are able to count blessings for having vision loss.

The doctors who were mentioned in this study by participants predominately were up front with their patients about vision loss. The referrals for rehabilitation services also came from the doctors. Therefore, it would seem that, unlike doctors in the 1960's who were not honest with their patients, doctors today may be somewhat better informed.

For individuals who find that a doctor or professional has not made a referral for services, knowing that every state has an agency for the blind will be useful.

Unfortunately, because a national level, unified registration for people who are blind does not currently exist, each state agency has a unique name and department. Often times, these may be best located by contacting a state division on aging.

Due to the circumstance that the world's population is aging rapidly and that the probability to lose vision increases with age, many state agencies are currently experiencing funding crises. Some states already have more cases of blindness than they can accept with state funding.

In situations where state agencies may not be able to assist, non-profit agencies such as an area Lighthouse for the Blind also serve people who have visual impairments free of charge. The services are free due to charitable donations, but services are also subject to available funding.

Services for veterans are not subject to available funding and are guaranteed through VA healthcare. Like Joanie and Charles, the integrated healthcare assures the appropriate referrals and services. Persons who are veterans also will be trained the equipment that they will receive at the conclusion at the training.

Persons who are served by the state or non-profit agencies may receive training, but they are often expected to purchase their own equipment to use at home. If employed, persons who are returning to work may ask their employer to purchase equipment for them under "reasonable accommodations."

### **Recommendations for Future Research**

As evidenced by the stories of participants who shared that doctors did not make initially make correct diagnoses or where doctors were unable to understand what it means to live as a person who is blind, doctors could learn more about rehabilitation strategies and outcomes. A broad survey of optometrists and ophthalmologists might gauge current feelings about blindness and their understanding of blind rehabilitation.

A similar study may be useful to administer to other professionals within varying fields such as business, education, political science, or law. Ignorance of blindness, its effects, and the ability of rehabilitation to mitigate the perceived negatives of visual disability could have direct ramifications on public access to business or education. Moreover, continued ignorance of blindness could directly impact facets of inclusion and recognition within the political and legal spheres.

Participants who were willing to share experiences for the purpose of this research can in no way represent the experiences of all individuals who have experienced vision loss. Continuing to investigate experiences with vision loss and rehabilitation would be interesting to discover the factors that may cause individuals to deny rehabilitation, rather than accept it. Individuals who deny rehabilitation will allow a closer look into the Transtheoretical model of change and its implications for adjustment.

Approaching the discussion from other theoretical lenses may also prove beneficial. One example may connect aspects of Axel Honneth's recognition theory to disability theory and the quest for an esteemed identity. Van Leeuwen argued:

The logic of recognition of cultural identity also demands a non-evaluative recognition, namely a respect for difference. Difference-respect is formal because it is a recognition of the value of a particular culture not “for society” or “as such”, but for the social group involved. Yet, although it is formal, difference-respect cannot be reduced to respect for personal autonomy and its preconditions... This kind of respect entails a separate register of formal recognition with a corresponding concept of personal identity and a parallel category of social disrespect. (2007, p. 280)

One last recommendation for future research is the implication that providing a national level registry for blindness may have. If all optometrists and ophthalmologists were to register their patients as blind, complete with the eye condition and prognosis, blindness could be better tracked. Moreover, the national registration might be linked directly to rehabilitative service centers that would enable the provision of information about rehabilitation services immediately.

Because of the current funding crises in state agencies where some individuals who lose vision are turned away or placed on a waiting list, by including vision loss as a covered benefit on general insurance policies may provide supplemental funding that could ensure all persons who need equipment and training would receive it. A national registry, coupled with integrated healthcare for civilians and veterans alike, might guarantee services and equipment for all persons who are blinded in America.

## **Epilogue**

This research as well as the suggestions for future research represented in this study are breaking new ground to shift what is currently known and accepted as true for visual impairment. Because of technology, the rehabilitative outcomes and potential outcomes already are far greater than ever had been imagined during the time when rehabilitative services began and when university textbooks were written.

Technology continues to change the face of society in surprising and awe-inspiring ways. Emails and text messages can be sent and read. Banking can be done online. Bills can be paid electronically. Groceries can be ordered online and delivered on demand. Any product from Amazon can be purchased and delivered. Uber inexpensively takes passengers door to door and can be accessed through an app on a smartphone. Facebook connects people around the world. Alexa eases the lives of many. Google classrooms and Zoom allow education to occur remotely.

What isn't well known is that all of the modern conveniences just mentioned are completely accessible to people who are blind. What also is not well known is that training exists for how to use all of these things. Moreover, what is not well known includes who must be contacted to get the services? What are the services called? How is the computer used to look up information if vision is suddenly lost? If the reader of this epilogue is unable to answer the questions, my assumption is proven that society needs to be better educated about options and services for people who are blind.

Throughout the interviews, participants shared in every instance that societal barriers and misperceptions were challenging to them. Throughout the review of

literature, even in the 1800s with Newell Perry, the suggestion that societal barriers and inaccessibility were more limiting than blindness itself remained constant.

As Joanie had commented in her interview, if everyone thought about accessibility when the products were being made, then everyone's lives would be improved. More than ever, people who are blind are wanting to have their voices heard. I have found that people who are blind throughout the world, no matter where they are from, or where they are living now, have a very important story to tell about their blindness. My hope is to take the voices that have spoken through this dissertation and use the dissertation as a platform to share and connect people with visual impairments globally. I hope to use research to help break barriers of inaccessibility and end the silence and fear around blindness for the betterment of society.

## References

- Aliyu, B., Abdulraheem, M., & Abdulkabir, A. (2014). The Sokoto blind beggars: Causes of blindness and barriers to rehabilitation services. *Middle East Journal of Ophthalmology*, 21(2), 147-154.
- American Foundation for the Blind (2013). Special report on aging and vision loss. Retrieved February 24th 2019 from <http://www.afb.org/info/blindness-statistics/adults/special-report-on-aging-and-vision-loss/235>
- American Foundation for the Blind (2018). Facts and figures on adults with vision loss. Retrieved February 15th 2019 from <http://www.afb.org/info/blindness-statistics/adults/facts-and-figures/235>
- American Foundation for the Blind (2020). Low vision and legal blindness terms and descriptions. Retrieved February 12th 2020 from <https://www.afb.org/blindness-and-low-vision/eye-conditions/low-vision-and-legal-blindness-terms-and-descriptions>
- American Foundation for the Blind (2020). Reviewing the disability employment research on people who are blind or visually impaired: Key takeaways. Retrieved April 17<sup>th</sup>, 2020 from <https://www.afb.org/research-and-initiatives/employment/reviewing-disability-employment-research-people-blind-visually>

- Barasch, M. (2001). *Blindness: The history of a mental image in Western thought*.  
New York, NY: Routledge.
- Barraga, N. C., & Erin, J. N. (1992). *Visual handicaps & learning*. (3rd ed.). Austin, TX:  
Pro-Ed.
- Bentz, V. M., & Rehorick, D. A. (2008). Transformative phenomenology: A scholarly  
scaffold for practitioners. In D. Allan, & V. M. Bentz (Eds.), *Transformative  
phenomenology: Changing ourselves, lifeworlds, and professional practice* (pp.  
3-31). Lanham, MD: Lexington Books.
- Bergmann, K., Schubert, A.-L., Hagemann, D., & Schankin, A. (2016). Age related  
differences in the P3 amplitude in change blindness. *Psychological Research*, 80,  
600-676.
- Blank, H. R. (1957). Psychoanalysis and blindness. *The Psychoanalytic  
Quarterly*, 26(1), 1-24.
- Bourne, R. A., Flaxman, S. R., Braithewaite, T., Cicinelli, M. V., Das, A., Jonas, J. B.,  
Keefe, J., Kempen, J. H., Leasher, J., Limburg, H., Naidoo, K., Pesudovs, K.,  
Resnikoff, S., Silvester, A., Stevens, G. A., Tahlan, N., Wong, T. Y., & Taylor, H.  
R. (2017). Magnitude, temporal trends, and projections of the global prevalence  
of blindness and distance and near vision impairment: A systematic review and  
meta-analysis. *The Lancet*, 5, 888-897.
- Bruce, S. M. (2005). Visual impairment across the life span. In C. B. Fisher, & R. M.



Lerner (Eds.), *Encyclopedia of applied developmental science* (pp. 1126-1130). Thousand Oaks, CA: Sage Publications, Inc.

Calhoun, L. G., & Tedeschi, R. G. (2006). The foundations of posttraumatic growth: An expanded framework. In L. G. Calhoun & R. G. Tedeschi (Eds.), *Handbook of posttraumatic growth: Research and practice* (pp. 1-23). Mahwah, NJ: Erlbaum.

Carroll, T. J. (1961). *Blindness: What it is, what it does and how to live with it*. Boston, MA: Little, Brown and Company.

Centers for Disease Control and Prevention. Vision Health Initiative (VHI). (2015). *Common eye disorders*. Retrieved December 28<sup>th</sup> from <https://www.cdc.gov/visionhealth/basics/ced/index.html>

Center for Substance Abuse Treatment. (1999). *Enhancing motivation for change in substance abuse treatment* (Publication No. 99-3354). Retrieved from <https://www.ncbi.nlm.nih.gov/books/NBK64967/>

Cherry, K. (2018, November 19). The 6 stages of behavior change: The transtheoretical or stages of change model. *Verywell Mind*. Retrieved November 27<sup>th</sup> 2018 from <https://www.verywellmind.com/the-stages-of-change-2794868>

Chicago Lighthouse for the Blind. (2020). *Commentary: Is blindness really that scary?* Retrieved January 16<sup>th</sup> 2020 from <https://chicagolighthouse.org/sandys-view/commentary-is-blindness-really-that-scary/>

Cholden, L. (1954). Some psychiatric problems in the rehabilitation of the blind. *Bulletin of the Menninger Clinic*, 18(3), 107-112.

- Cholden, L. S. (1958). *A psychiatrist works with blindness*. New York, NY: American Foundation for the Blind, Inc.
- Chevigny, H., & Braverman, S. (1950). *The adjustment of the blind*. New Haven, CT: Yale University Press.
- Colorado State University (2018, Jan 30). Student Disability Center. Disability Legislation History. A Brief History of Legislation. Retrieved from <https://disabilitycenter.colostate.edu/awareness/disability-history/>
- Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Creswell, J. W., Hanson, W. E., Clark, V. L., & Morales, A. (2007). Qualitative research designs: Selection and implementation. *The Counseling Psychologist*, 35(2), 236-264.
- Cutsforth, T. D. (1951). *The blind in school and society: A psychological study*. New York, NY: American Foundation for the Blind, Inc.
- Dahlberg, K., Dahlberg, H., & Nyström, M. (2008). *Reflective lifeworld research* (2nd ed.). Malmö, Sweden: Holmbergs.
- Dobson, J. (1975). *What wives wish their husbands knew about women*. Carol Stream, IL: Tyndale House Publishers, Inc.
- Du Pré, E. (2018, April 25). What is vision rehabilitation? Part 1. *Florida agencies serving the blind*. Retrieved February 12th, 2020 from <https://beyondvisionloss.org/blog/vision-rehabilitation/what-is-vision-rehabilitation-part-1/>

- Eisenhart, M. A., & Howe, K. R. (1992). Validity in educational research. In M. D. LeCompte, W. L. Millroy, & J. Preissle (Eds.), *The handbook of qualitative research in education* (pp. 643-680). San Diego, CA: Academic Press, Inc.
- Ferguson, R. J. (2007). *The blind need not apply: A history of overcoming prejudice in the orientation and mobility profession*. Charlotte, NC: Information Age Publishing.
- Frankl, V. E. (1969). *The will to meaning: Foundations and applications of logotherapy*. Cleveland, OH: The New American Library, Inc.
- Freeman, M., deMarrais, K., Preissle, J., Roulston, K., & St. Pierre, E. A. (2007). Standards of evidence in qualitative research: An incitement to discourse. *Educational Researcher*, 36(1), 25-32.
- Giorgi, A. (1997). The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. *Journal of Phenomenological Psychology*, 28(2), 235-260.
- Giorgi, A. (2009). *The descriptive phenomenological method in psychology*. Pittsburgh, PA: Duquesne University Press.
- Goetz, J. P., & LeCompte, M. D. (1984). *Ethnography and qualitative design in educational research*. New York, NY: Academic Press.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York, NY: Simon & Schuster.
- Graetz, F., & Smith, C. T. (2010). Managing organizational change: A philosophies of change approach. *Journal of Change Management*, 10(2), 135-154.

- Hackman, M. (2014, January 6). American Foundation for the Blind. *Why do people fear the blind?* Retrieved from <https://www.afb.org/blog/entry/why-do-people-fear-blind>
- Hall, M. C. (2019, September 23). Stanford Encyclopedia of Philosophy. *Critical disability theory*. Retrieved from <https://plato.stanford.edu/entries/disability-critical/>
- Heidegger, M. (2010). *Being and time*. Albany, NY: State University of New York Press.
- Hibbs, T., & Pothier, D. (2006). Post-secondary education and disabled students: Mining a level playing field or playing in a minefield? In D. Pothier, & R. Devlin (Eds.), *Critical disability theory: Essays in philosophy, politics, policy, and law* (pp. 195-219). Vancouver, BC, Canada: UBC Press.
- Husserl, E. (1983). *Ideas pertaining to a pure phenomenology and to a phenomenological philosophy. Book I*. (F. Kersten, Trans.). The Hague, NL: Martinus Nijhoff.
- Husserl, E. (2014). *Ideas for a pure phenomenology and phenomenological philosophy. First book: General introduction to pure phenomenology*. (D. Dahlstrom, Trans.). Indianapolis, IN: Hackett Publishing Company.
- Janoff-Bulman, R. (1992). *Shattered assumptions: Toward a new psychology of trauma*. New York, NY: Free Press.
- Jernigan, K. (n.d.). Blindness—concepts and misconceptions. Retrieved from <https://www.nfb.org/images/nfb/publications/convent/blndnesc.htm>
- Jose, R., & Sachdeva, S. (2010). Community rehabilitation of disabled with a focus on

- blind persons: Indian perspective. *Indian Journal of Ophthalmology*, 58(2), 137-145.
- Keys, T., & Resnikoff, S. (2012). Future trends in global blindness. *Indian Journal of Ophthalmology*, 60(5), 387-395.
- King, T. (2020, January 8). 3 tricks: How to permanently delete/erase files from USB drive. *EaseUS*. Retrieved January 25<sup>th</sup> 2020 from <https://www.easeus.com/partition-manager-software/permanently-delete-files-from-usb.html>
- Kleinschmidt, J. J. (1999). Older adults' perspectives of their successful adjustment to vision loss. *Journal of Visual Impairment & Blindness*, 93(2), 69-81.
- Koestler, F. A. (1976). *The unseen minority: A social history of blindness in the United States*. New York, NY: David McKay Company, Inc.
- Kritsonis, A. (2004-2005). Comparison of Change Theories. *International Journal of Scholarly Academic Intellectual Diversity*, 8(1), 1-7.
- Kyuk, T., Elliott, J. L., Wesley, J., Scilley, K., McIntosh, E., Mitchell, S., & Owsley, C. (2004). Mobility function in older veterans improves after blind rehabilitation. *Journal of Rehabilitation Research and Development*, 41(3), 337-346.
- Kyuk, T., Liu, L., Elliott, J. L., Grubbs, H. E., Owsley, C., McGwin, G., Griffin, R. L., & Fuhr, P. S. (2008). Health related quality of life following blind rehabilitation. *Quality of Life Research*, 17, 497-507.
- Lam, J., Robertson, K., Robertson, W., Bernstein, R. (2015). Improving access to vision

care for people who are homeless through eyeglasses recycling. *Journal of Health Care for the Poor and Underserved*, 26(4), 1359-1367.

LaMorte, W. W. (2018). Behavioral Change Models. *Boston University School of Public Health*. Retrieved November 27<sup>th</sup> 2018 from [http://sphweb.bumc.bu.edu/otlt/MPH-Modules/SB/BehavioralChangeTheories/BehavioralChangeTheories\\_print.html](http://sphweb.bumc.bu.edu/otlt/MPH-Modules/SB/BehavioralChangeTheories/BehavioralChangeTheories_print.html)

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications.

Lumbres, J. (2018). Why nonprofit advertising is important. *Elevate*. Retrieved August 11<sup>th</sup> 2019 from <https://www.elevateclicks.com/the-nonprofit-marketing-blog/why-nonprofit-advertising-is-important>

Matthews, L. T., & Marwit, S. J. (2006). Meaning reconstruction in the context of religious coping: Rebuilding the shattered assumptive world. *Omega*, 53, 87-104.

National Academies of Sciences, Engineering, Medicine. (2016). Meeting the challenge of vision loss in the United States: Improving diagnosis, rehabilitation, and accessibility. In S. M. Teutsch, M. A. McCoy, R. B. Woodbury, & A. Welp (Eds.), *Making eye health a population health imperative: Vision for tomorrow* (pp. 381- 425). Washington, DC: The National Academies Press.

National Federation of the Blind. (2018). *Statistical facts about blindness in the United States*. Retrieved February 15<sup>th</sup> 2019 from <https://nfb.org/blindness-statistics>

Neimeyer, R. A., Keesee, N. J., & Fortner, B. V. (2000). Loss and meaning

- reconstruction: Propositions and procedures. In R. Malkinson, S. Rubin, & E. Witztum (Eds.), *Traumatic and non-traumatic loss and bereavement* (pp. 197-230). Madison, CT: Psychosocial Press.
- Nelson, K. A., & Dimitrova, E. (1993). Severe visual impairment in the United States and in each state. *Journal of Visual Impairment & Blindness*, *87*, 80-85.
- Margrain, T. H. (1999). Minimizing the impact of visual impairment. *British Medical Journal*, *318*(7197), 1504.
- Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: SAGE Publications, Inc.
- Omvgig, J. H. (2009). Why use the word “blind”? *Braille Monitor*, *52*(1). Retrieved from <https://www.nfb.org/sites/www.nfb.org/files/images/nfb/publications/bm/bm09/bm0901/bm0901.htm>
- Onderko, K. (2019). Trauma defined. *Integrated listening systems*. Retrieved from [https://integratedlistening.com/what-is-trauma/?utm\\_source=bing&utm\\_medium=cpc&utm\\_campaign=what-is-trauma&utm\\_term=trauma&msclkid=b700de30892c15d718908076591c5c45](https://integratedlistening.com/what-is-trauma/?utm_source=bing&utm_medium=cpc&utm_campaign=what-is-trauma&utm_term=trauma&msclkid=b700de30892c15d718908076591c5c45)
- Park, C. L. (2005). Religion as a meaning-making framework in coping with life stress. *Journal of Social Issues*, *61*, 707-729.
- Pashmdarfard, M., Amini, M., & Amini, M. (2016). Review paper: Rehabilitation of blind people and people with low vision in Iran. *Iranian Rehabilitation Journal*, *14*(2), 77-84.

- Patton, M. Q. (2015). *Qualitative research and evaluation methods: Integrating theory and practice* (4th ed.). Thousand Oaks, CA: SAGE Publications, Inc.
- Powell, S. (2017, February 10). The psychological impact of blindness. *Optometry today*. Retrieved from <https://www.aop.org.uk/ot/science-and-vision/research/2017/02/10/the-psychological-impact-of-blindness>
- Pro-Change Behavior Systems, Inc. (2018). *The Transtheoretical Model*. Retrieved November 27<sup>th</sup> 2018 from <https://www.prochange.com/transtheoretical-model-of-behavior-change>
- Prochaska, J. O., Norcross, J. C., & DiClemente, C. C. (2013). Applying the stages of change. *Psychotherapy in Australia, 19*(2), 10-15.
- Rapaport, L. (2015, September 17). Vision impairment linked to worse quality of life. *Reuters*.
- Roman, L., & Apple, M. (1990). Is naturalism a move away from positivism? Materialist and feminist approaches to subjectivity in ethnographic research. In E. Eisner & A. Peshkin (Eds.), *Qualitative inquiry in education: The continuing debate* (pp. 38-73). New York, NY: Teachers College Press.
- Sassani, J. W. (1995). A history of low vision and blind rehabilitation in the United States. *Documenta Ophthalmologica, 89*, 145-152.
- Schulz, P. J. (1980). *How does it feel to be blind?* Van Nuys, CA: Muse-Ed Company.
- Scott, R. A. (1969). *The making of blind men: A study of adult socialization*. New York, NY: Russell Sage Foundation.
- Siebers, T. (2011). *Disability Theory*. Ann Arbor, MI: University of Michigan Press.



- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretive phenomenological analysis: Theory, method, and research*. Thousand Oaks, CA: SAGE Publications, Inc.
- Stevens, G. A., White, R. A., Flaxman, S. R., Price, H., Jonas, J. B., Keeffe, J., Leasher, J., Naidoo, K., Pesudovs, K., Resnikoff, S., Taylor, H., & Bourne, R. R. A. (2013). Global prevalence of vision impairment and blindness: Magnitude and temporal trends, 1990-2010. *The American Academy of Ophthalmology*, *120*(12), 2377-2384.
- Strawbridge, W. J., Wallhagen, M. I., & Shema, S. J. (2007). Impact of spouse vision impairment on partner health and well being: A longitudinal analysis of couples. *The Journals of Gerontology: Series B*, *62*(5), S315-S322.
- Stroupe, K. T., Stelmack, J. A., Tang, C., Reda, D. J., Moran, D., Rinne, S., Mancil, R., Wei, Y., Cummings, R., Mancil, G., Ellis, N., & Massof, R. W. (2008). Economic evaluation of blind rehabilitation for veterans with macular diseases in the Department of Veterans Affairs. *Ophthalmic Epidemiology*, *15*, 84-91.
- Tuttle, D. W., & Tuttle, N. R. (2004). *Self-esteem and adjusting with blindness: The process of responding to life's demands*. (3rd ed.). Springfield, IL: Charles C. Thomas Publisher, Ltd.
- United States Department of Commerce. Census Bureau. (2017). *The nation's older population is still growing, Census Bureau reports*. Retrieved from <https://www.census.gov/newsroom/press-releases/2017/cb17-100.htm>
- United States Department of Health and Human Services. Centers for Disease Control

and Prevention. National Center for Health Statistics (2016). *National Health Interview Survey*. Retrieved from:

[ftp://ftp.cdc.gov/pub/Health\\_Statistics/NCHS/Dataset\\_Documentation/NHIS/2015/srvydesc.pdf](ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/Dataset_Documentation/NHIS/2015/srvydesc.pdf)

United States Department of Health and Human Services. National Institutes of Health.

United States National Library of Medicine. Medline Plus. (2020). *Blindness and vision loss*. Retrieved from <https://medlineplus.gov/ency/article/003040.htm>

United States Social Security Administration. (2019). *Meaning of terms: Aged, blind, or disabled individual*. Retrieved from

[https://www.ssa.gov/OP\\_Home/ssact/title16b/1614.htm](https://www.ssa.gov/OP_Home/ssact/title16b/1614.htm)

Vagle, M. D. (2014). *Crafting phenomenological research*. Walnut Creek, CA: Left Coast Press.

Vagle, M. D. (2018). *Crafting phenomenological research* (2nd ed.). New York, NY: Routledge.

van Leeuwen, B. (2007). A formal recognition of social attachments: Expanding Axel Honneth's Theory of Recognition. *Inquiry: An Interdisciplinary Journal of Philosophy*, 50(2), 180-205.

van Manen, M. (1990). *Researching lived experience*. Albany, NY: State University of New York Press.

van Manen, M. (2016). *Researching lived experience*. New York, NY: Routledge.

van Manen, M. (2014). *Phenomenology of practice: meaning-giving methods in*

*phenomenological research and writing*. New York, NY: Routledge.

Varma, R., Vajaranant, T. S., Burkemper, B., Wu, S., Torres, M., Hsu, C., Choudhury, F., & McKean-Cowdin, R. (2016). Visual impairment and blindness in adults in the United States: Demographic and geographic variations from 2015 to 2050.

*Journal of the American Medical Association Ophthalmology*, 134(7), 802-809.

VisionAware (2020). A definition of vision rehabilitation therapy. Retrieved February 12<sup>th</sup>, 2020 from <https://www.visionaware.org/info/everyday-living/essential-skills/vision-rehabilitation-services/vision-rehabilitation-therapists/a-definition-of-vision-rehabilitation-therapy/12345>

Welsh, R. L. (2010). Psychosocial dimensions of orientation and mobility. In W. R. Wiener, R. L. Welsh, & B. B. Blasch (Eds.), *Foundations of orientation and mobility* (3rd ed., Vol. 1) (pp. 173-210). New York, NY: AFB Press.

Welsh, R. L., & Tuttle D. W. (1997). Congenital and adventitious blindness. In J. E. Moore, W. H. Graves, & J. B. Patterson (Eds.), *Foundations of rehabilitation counseling with persons who are blind or visually impaired* (pp. 60-79). New York, NY: AFB Press.

Werdel, M. B., & Wicks, R. J. (2012). *Primer on posttraumatic growth: An introduction and guide*. Hoboken, NJ: John Wiley & Sons, Inc.

Whitson, H. E., & Lin, F. R. (2014). Hearing and vision care for older adults: Sensing a need to update Medicare policy. *Journal of the American Medical Association*, 312(17), 1739-1740.

Wiener, W. R., & Siffermann, E. (2010). The history and progression of the profession of

orientation and mobility. In W. R. Wiener, R. L. Welsh, & B. B. Blasch (Eds.), *Foundations of orientation and mobility* (3rd ed., Vol. 1) (pp. 486-532). New York, NY: AFB Press.

World Health Organization. (2018). *Blindness and visual impairment*. Retrieved February 24, 2019 from <https://www.who.int/news-room/fact-sheets/detail/blindness-and-visual-impairment>

Yong, V. K., Morgan, W. H., Cooper, R. L., Shaw, M., Bremner, A. P., Bulsara, M., & Yu, D-Y.(2006). Trends in registered blindness and its causes over 19 years in Western Australia. *Ophthalmic Epidemiology*, 13, 35-42.

## **APPENDIX A**

### **Consent Letter**

Hello,

If you are a person who used to have vision and then you have lost your vision, you are invited to participate in a research study on what it is like to lose your vision. This study is being conducted by a doctoral student and professor at Stephen F. Austin State University in Educational Leadership and Visual Impairment Studies. This research is asking for people who once had vision and then who lost their vision, to tell their story and share the experiences of what it was like, how you felt, and what were the experiences you had when you lost vision. Only people who have had vision and then lost vision are being asked to share their story for this opportunity.

The benefit of this research is to help tell your story about true experiences of vision loss. This subject is not frequently discussed, even in private life. Sharing your personal story may not only help you to process some feelings or thoughts, it may also help others such as professionals or other people who are newly blind to learn from you and gain sensitivity or insight into your experiences.

Participating in this research is voluntary, and there are a few options of ways to participate. You may answer questions from an email survey online, participate in a telephone call, have a 1:1 interview and discussion with the researcher, or meet in a group with other people who have lost vision and share stories in a group.

All answers will be recorded on a digital recorder and then transcribed.

Information from the research could be used in the doctoral dissertation, but no real names or personal identifiers will be used. All answers will be completely anonymous.

Any recordings that are made will be confidentially stored in a locked filing cabinet in the researcher's private office at Stephen F. Austin State University for a minimum of five years. During this time, only the researcher will have access to those files. After five years, the recordings may be destroyed, or they may be offered for review by other professionals who are studying adjustment to vision loss. Please check this box if you would like for other professionals in the field of blindness to be able to review the recordings after 5 years

At any time, if you have any questions or concerns about this process, you may contact the Office of Research and Graduate Studies at Stephen F. Austin State University at 936 468 6606. The chair of the dissertation, Pauline Sampson, is available for questions at 936 468 2807 or email [sampsonp@sfasu.edu](mailto:sampsonp@sfasu.edu) You may also contact the moderator/researcher at any time: Jennifer Perry 936 468 5511 or email [perryjn1@sfasu.edu](mailto:perryjn1@sfasu.edu)

Please enter your name and contact information, including information for a legal guardian, if applicable, and you will be contacted to set up a time to meet either in person, or in a group if possible. If not possible to meet in person, we can talk over the phone or you may type your answers. The entire process should take 1-2 hours.

Name: Click or tap here to enter text.

Legal Guardian: Click or tap here to enter text.

Date: Click or tap here to enter text.

Email: Click or tap here to enter text.

Phone: Click or tap here to enter text.

Thank you!

## **APPENDIX B**



### Interview Questions

How did you find out that you were going to lose your vision?  
Where were you?  
What was your reaction?  
How do you think that your reaction might have changed had you found out differently?  
What did you do?  
Why did you pick that?  
What were you thinking about?  
What were you sharing with others?  
Was there anything you were keeping to yourself?  
In what ways did you seek help?  
In what ways were you getting help?  
What did you continue to do for yourself?  
Was there anything you did that you felt that you should not have done?  
How were others reactions to you?  
How did you decide who to trust?  
Was trust difficult? How so? How not?  
How did you find yourself again?  
Did you change in any way?  
What about your dreams?  
What about your core being? Did it change?  
When it first happened, did you believe your vision would return?  
Did any of your other senses become stronger?  
How did you come to start to use them more?  
How has your outlook on life been affected?  
Was there anything positive that came from losing vision?  
When did you recognize it?  
Have you accepted your vision loss? Yourself?  
What would you describe as your milestones in recovery?  
Has anything NOT changed because of vision loss?  
Did you get what you needed out of this focus group today?  
Is there anything still to clarify, or share?

## VITA

Jennifer N. Perry graduated from Gaylord High School in 1993. She attended Grand Valley State University, and received her Bachelor of Science degree in Criminal Justice in 2000. She began working using her Bachelor's degree in a variety of private and professional security firms in Michigan, before deciding in 2005 to pursue a career change. In 2009, Jennifer graduated from Western Michigan University with Masters degrees in Orientation and Mobility (O&M) and Vision Rehabilitation Therapy (VRT). Jennifer then became a nationally certified direct service provider of both O&M and VRT. In 2017, after eight years of helping individuals who are blind or visually impaired to achieve rehabilitation, Jennifer began working as a clinical instructor in the Visual Impairment Preparation Program at Stephen F. Austin State University (SFA) where she took on the challenge of preparing new professional blind rehabilitation specialists in orientation and mobility. Jennifer was soon accepted into the SFA 2017 Doctoral Cohort of Educational Leadership. In May 2020, Jennifer completed the Doctorate of Education and accepted her first tenure track position as the lead O&M at Shawnee State University in Portsmouth, OH.

Permanent Address: 1839 Coles Blvd, Portsmouth, OH, 45662

Style Manual designation: *Publication Manual of the American Psychological Association, Sixth Edition.*

Typist: Jennifer N. Perry