12-2015

A Descriptive Case Study of Individuals with Presumed Ocular Histoplasmosis Syndrome Utilizing a Facebook Support Group

Lisa Aimee Thompson
University of Arkansas, Fayetteville

Recommended Citation

Thompson, Lisa Aimee, "A Descriptive Case Study of Individuals with Presumed Ocular Histoplasmosis Syndrome Utilizing a Facebook Support Group" (2015). *Theses and Dissertations*. 1374.
http://scholarworks.uark.edu/etd/1374

A Descriptive Case Study of Individuals with Presumed Ocular Histoplasmosis Syndrome
Utilizing a Facebook Support Group

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctorate in Philosophy in Rehabilitation

by

Lisa A. Thompson
New College of California
Bachelor of Arts in Humanities, 1993
University of Arkansas
Master of Science in Rehabilitation, 2011

December 2015
University of Arkansas

This dissertation is approved for recommendation to the Graduate Council.

_____
Dr. Brent Williams
Dissertation Director

_____   _____
Dr. Mary Ramey   Dr. Kristin Higgins
Committee Member   Committee Member

_____
Dr. Ron Freeman
Committee Member

Abstract

This dissertation describes the experiences of people diagnosed with presumed ocular histoplasmosis syndrome as they participate in an online peer-support group on Facebook. This is a descriptive case study of factors related to adjustment, treatment, emotional distress, access to services, and online peer support. Participants were interviewed and observed, and documents were collected to describe this phenomenon.

Acknowledgement

Hardship often prepares an ordinary person for an extraordinary destiny.
—C. S. Lewis

I am very grateful for the opportunities I have received at the University of Arkansas. My chair, Dr. Brent Williams, provided me with guidance and encouragement during my studies, delivering these gifts with wit and sensitivity. I am very grateful to my committee for agreeing to join me on this journey. Dr. Ron Freeman always offered a listening ear from contemplation to completion, as I ultimately tamed the beast known as dissertation. Dr. Mary Ramey worked diligently with me in my qualitative coursework to guide me to a better understanding of this amazing process. Dr. Kristin Higgins inspired me with her dedication to the field of counseling and her detailed notes for the original draft of this document. Thank you all very much for your efforts and support!

Dedication

       I dedicate this dissertation to my loving family. I also acknowledge my canine companion. Good dog.

Table of Contents

List of Tables

List of Figures

I.   Introduction

Organization of the Chapter

Chapter 1 begins with an introduction to the topic. Presumed ocular histoplasmosis syndrome (POHS) is a rare condition that can result in disability. The unpredictability of this eye disease contributes to various difficulties facing individuals with POHS when seeking appropriate medical and vocational services. Next, I describe the background of the study, followed by the statement of the problem, purpose of the study, and the research question. Then I present the significance of the study, followed by the theoretical framework. A conceptual design will provide the reader with a visual concept of how the study was conducted. Theoretical sensitivity, including professional experience, personal experience, knowledge of the literature, and analytic rigor are explained. The next section includes the parameters of the study, definitions of terms, and limitations. Finally, a summary and the organization of the dissertation completes the chapter.

Introduction

This dissertation concerns the medical disease of POHS. POHS is both a medical condition and a rehabilitation-counseling issue. Rehabilitation counselors adhere to the biopsychosocial model, regarded as a holistic perspective. The biopsychosocial model includes person-first language and a focus on reasonable accommodation as a means of inclusion. The biopsychosocial model does not encourage perpetuation of stereotypes of people with disabilities (Michigan Disability Rights Association, 2015). Much of the literature reviewed for this dissertation was derived from sources that ascribe to the medical model. In reporting on the literature findings, every effort has been put forth to use person-first language and represent

people with disabilities in a dignified manner, which includes careful attention to using person-first language.

The topic of person-first language is addressed in the definition of terms. Person-first language is essential when discussing people with disabilities and their concerns. The words people use and the order in which they phrase them greatly informs the images created about individuals with disabilities and the negative or positive impressions that result (Blaska, 1993). Identifying the person first, before the person's disability, is an immediate and important reminder that disability is not an identity. The danger in not using person-first language is that it denotes the person is a disability and focuses inordinately on their real or imagined limitations.

POHS is a rare eye disease that causes people in the prime of their vocational lifespan to lose their vision, resulting in disability. Researchers and healthcare professionals know little about effective treatment interventions; currently available treatments may increase vision damage and result in unknown and further debilitating side effects. Researchers have conducted few studies of POHS and none explored the individual experience of having such an unmanageable disorder and the process by which people are able to cope with the associated emotional distress and adjust to their changed lives.

Access to peer support and relevant medical advisement is limited primarily to an individual's retina specialist and familial-support system. Individuals with this rare disorder strive to adjust to a disability that may be a vocational inhibitor, expensive, and inconsistent in response to treatment, as well as alarmingly irregular in its course of visual symptomology. The ramifications of vision loss significantly affect these individuals' abilities to remain in the workforce. Lack of medical information and supportive-counseling resources are apparent, due

to the many unknown components of this disease, which may leave people vulnerable to emotional distress and severe vocational constraint.

Social networking is becoming a reliable and consistent means for individuals to relate over shared topics of interest. People in online peer-support groups can source information and shared concerns regarding rare diseases easily and privately synchronously or asynchronously, as well as through archived materials (Huber et al., 2010). Facebook offers users many topics related to health concerns through its group options. Guidance on how to navigate these groups, including how to better understand the administration of a group, is available to participants on the Facebook website.

This descriptive case study of an online Facebook group focuses on peer-support for people with POHS. It is an important step in the needed discovery of what transpires in this cyberspace venue. By revealing the experiences of these individuals through the process of online peer support, I illuminate the possible benefits of medical providers and other points of contact, recommending these online peer-support groups as a means of closing the wide gaps in services provided to people with POHS.

Background

Histoplasmosis is a disease that manifests when a person inhales the airborne spores of the fungus *histoplasma capsulatum* into the lungs, the primary infection site (Smith, 1997). This microscopic fungus is found throughout the world in North America, Asia, and Africa. In the United States, the fungus is prevalent in the Ohio-Mississippi River Valley region and in soil where bird and bat droppings accumulate. *Histoplasma capulatum* are primarily released into the air when plowing fields, sweeping chicken coops, or digging holes, resulting in disturbing histo rich soil or aviary feces. Individuals who are infected but do not come from endemic regions

may have participated in caving, military service in endemic regions, or have been exposed

through contact with garments worn by others who work in the factory fowl industry. Depending

on the location, 60–90% of the adult population living in the region (called the Histo Belt) will

have been exposed to this fungus (National Eye Institute, 2015). This systemic fungal exposure

causes small areas of inflammation and scarring of the retina, called *histo spots* (Sinha, Raju,

Garg, Venkatesh, & Talwar, 2007).

Although individuals with this disability tend to be sensitive to the histoplasm skin test,

Woods and Wahlen (1960) posited that this disease resulted from a systemic infection with

Histoplasma capulatum (Ganley, Smith, Knox, & Comstock, 1973). Not every individual with

this disease reacts to the histoplasm skin test and some persons are not from endemic areas.

Therefore even though researchers have not illustrated a definitive causative relationship

between *Histoplasma capulatum* exposure and POHS, the ocular lesions are presumed to be the

result of previous exposure to *Histoplasma capulatum* (Crum-Cianflone, 2010). Consequently

this disease is referred to as "presumed" ocular histoplasmosis syndrome.

Typically this fungal exposure results in mild symptoms and individuals may believe they

have the common cold or a mild case of the flu. Infection is often asymptomatic and fewer than

1% of people exposed develop a clinical illness 7 to 21 days after exposure (Crum-Cianflone,

2010). For many individuals, this is the extent of their illness: a simple exposure with mild

symptoms and resulting histo spots that never become active. Exposure does not affect their

general health or vision.

For a small percentage of the population, even a mild case of histoplasmosis can later

cause a serious eye disease: POHS, resulting in a significant loss of vision for often young and

otherwise healthy individuals (University of Iowa Healthcare, 2008). Choroidal

neovascularization (CNV) is typically diagnosed in patients with POHS between 30 and 50 years of age. Individuals with active POHS develop visual symptoms due to the manifestation of CNV at the site of the choroidal scars. These new blood vessels can hemorrhage, causing impaired central vision (distorted vision and blind spots), leading to vision loss greater than 20/200. The criterion for a diagnosis of blindness is central vision acuity of 20/200 or less in an individual's better eye, with correction (National Federation of the Blind, 2015).

Presumed ocular histoplasmosis is a clinical diagnosis based on a constellation of ocular findings that occur after exposure. POHS may result from an autoimmune trigger that is spurned by the presence of the infectious organism (Cohen & Graff, 2008). Although POHS may be contracted in childhood, it typically does not manifest symptoms in individuals until their 30s, 40s, and 50s, which may be considered the prime of a person's career trajectory.

POHS is a relatively rare eye disease. Treatment options are few and limited in their effectiveness. Several treatments are unapproved by the Federal Drug Administration and require the person receiving treatment to sign a waiver before being administrated treatment. Few clinical trails are available, frustrating these individuals, as the typical time it takes from the onset of the disease to visual impairment or blindness can be rapid in duration without treatment.

The very rarity of the disorder creates a void in support and treatment interventions. Additionally, POHS is an unpredictable disease in onset timing; speed of visual acuity demise and even response to treatment varies from individual to individual (Dickinson, Melberg & Thomas, 1996). The unpredictable and erratic nature of the disease may put the individuals who have it in a continuous state of adjustment to their disability that demands modification of their daily lives, as well as those of their families.

Statement of the Problem

Individuals with rare, progressive, and unpredictable eye diseases may find it difficult to combat and adjust to the sudden or gradual onset of visual loss. Online support groups, through social-networking outlets such as Facebook, may be an effective medium for people with POHS to participate in a forum that can be tailored to the needs of the group. Identifying and describing the experiences of individuals as they adjust to a progressive and rare eye disease in an online forum may offer peer support and resources that are of benefit to this population.

In identifying the difficult decisions that individuals with POHS face regarding work, family life, and treatment, the unique value of online peer support may be revealed. Additionally, newly diagnosed individuals with POHS may be encouraged to participate in online support groups. The benefit of online peer support may offset the lack of disease-specific resources and counseling they would receive from traditional counseling venues or medical providers. Individuals with rare or emerging disorders commonly experience isolation, prolonged adjustment to disorder symptoms, and cultural dissonance due to the obscurity of their disease.

Purpose of the Study

Currently, little research addresses the experience of participants of an online social-networking support group for POHS and the potential supplemental benefits of the peer support they receive. Under the larger disability umbrella of low vision/blindness, persons with progressive and rare diseases face additional psychosocial challenges as they pursue unchartered territory in treatment options with unknown side effects and outcomes (Dickinson, Holekamp, Thomas &Valluri, 1997). The purpose of this study is to identify significant variables that POHS impacts and describe the experiences of active participants in a social-networking support group as they navigate treatment, work, and family life.

Research Question

Researchers found that current social-media sites offer various benefits to users with chronic illnesses (Greene, Choudhry, Kilabuk, & Shrank, 2010; Lasker, Sogolow, & Sharim, 2005). For individuals with rare diseases, the Facebook platform offers numerous peer-support groups. Active participants are able to navigate, personalize, and participate in peer group support with whatever level of participation they choose. Given the current popularity of social media and the paucity of literature available regarding individuals with POHS, the following research question warrants investigation: What are the experiences of active participants in an online Facebook peer-support group for POHS? This study examined this research question to gain a deeper understanding of the unique experiences of an online support group for individuals with POHS.

Significance of Study

The intent of the study was to learn about the experiences of participants of an online peer-support group for people with POHS, and subsequently to identify how participating in an online peer-support group affects family, work, and treatment. In identifying the decisions these individuals faced regarding work, family, and treatment, the unique value of online peer support was revealed; consequently, newly diagnosed individuals may be encouraged to participate. The benefit of online peer support may offset the lack of disease-specific resources and counseling they would receive from traditional counseling venues and medical professionals.

Currently, little research addresses the experiences of participants of an online social-networking support group for POHS and the potential supplemental benefits of the peer support they receive. Additionally, individuals with rare or emerging disorders commonly experience isolation, prolonged adjustment to disorder symptoms, and cultural dissonance due, to the

obscurity of their disease. Under the larger disability umbrella of low vision/blindness, persons with progressive and rare diseases face additional biopsychosocial challenges as they pursue unchartered territory in treatment options with unknown side effects and outcomes. The purpose of this study was to identify quality-of-life variables that POHS impacts and describe the experiences of active participants in a social-networking support group as they navigate family life, work, and treatment.

Conceptual and Theoretical Framework

Researchers use a descriptive-research design to describe different characteristics of a phenomenon. The goal of a descriptive-research design is to describe the features, context, and process of a phenomenon, which in this case is a group (unit) of individuals with POHS participating in a Facebook peer-support group. The case study is a preferable approach to research when studying a contemporary event (Yin, 2011, p. 7). "A qualitative case study is an intensive, holistic description and analysis of a single instance, phenomenon or social unit" (Merriam, 2009, p. 21). Individuals with chronic rare disorders may go without the level of support they need, to reach a state of stasis. In examining the phenomenon of participants in a Facebook peer-support group, the description of the occurrence may clarify the experience. Figure 1, Conceptual Designs for the Study, provides information about how the study was conducted.

Theoretical Sensitivity

Theoretical sensitivity comprises the ability to understand and identify what is relevant in data. Theoretical sensitivity is the researcher's professional experience, personal experience, analytic rigor and knowledge of the literature (Lincoln & Guba, 1985). By informing the reader

of the researcher's position as the research instrument, the researcher acknowledges their

potential bias (Patton, 2014). Sources of theoretical sensitivity follow.

Step 1 Topic of research	Experiences of Facebook peer-group members with POHS
Step 2 Review literature	Clarify research topic
Step 3 Identify data collection method and participants	FTF interviews, documentation collection and observation of three to four active participants
Step 4 Ethics approval	Apply for IRB approval through the University of Arkansas, Fayetteville
Step 5 Data collection	Coding of data
Step 6 Analyze data	Analysis begins from the first moment of data collection. Theory emerges from the data and is reported
Step 7 Write research report	

Figure 1. Conceptual design for the study.

Professional Experience

As a certified rehabilitation counselor and a practicing licensed associate counselor, I

have extensive experience and training related to disability and counseling. In working with

individuals who have chronic illnesses, I have developed counseling skills suited to identifying

and supporting issues of adjustment and emotional distress. My educational background supports

my professional skills by having provided a thorough and deep knowledge base.

Personal Experience

As a woman with POHS and a member of the online support group, I am uniquely

sensitized to the experiences of the participants. The challenges that face individuals with the

diagnosis of POHS are my own. While navigating work, school, and family life, I have sought

treatment and support for this rare disease. Often, I am working to accommodate my own POHS-

related limitations and working with a certain urgency to complete tasks before my vision

inhibits my progress.

Analytic Rigor

A qualitative study contains a large collection of data that could have multiple meanings.

Researchers collect these data at the individual and social levels. Researchers work to manage

the words, language, and meanings implied by the data, and glean, from its rich descriptions,

understandings of what is being studied (Miles & Huberman, 1994). As the researcher partitions

the data to classify it, themes from the concepts and fresh descriptions emerge. By using coding,

the data are divided into smaller bits of information that are then compared and categorized with

identifying codes (Patton, 2014). The researcher collects and analyzes the data using this

constant-comparative method in an ongoing process throughout the study.

Knowledge of the Literature

Although researchers and healthcare providers know very little about POHS, the National

Eye Institute (2015) stated that "ocular histoplasmosis syndrome is a leading cause of vision loss

in Americans ages 20 to 40" (p. 69). Additionally, the Review of Optometry (2007) reported, for

CNV associated with POHS, the classic treatment is laser photocoagulation; however, the

treatment itself is destructive, producing an absolute scotoma at the site where the laser is applied. Essentially, the process stops the bleeding but the scar it produces damages the individual's vision.

Definition of Terms

In the following section, I define specific terms used throughout this dissertation. I define these specific terms for the benefit of clarity, as some are less common medical terminology and others are general terms for which the reader needs to know the specific meaning of the term as it applies in this instance. I present these definitions, which may be construed as a body of general knowledge, to be transparent.

Terms

Biomedical model. Traditionally the biomedical model of clinical medicine focuses on pathology. This model gives no merit to the idea that social, psychological, and behavioral aspects interplay to create the dimensions of an illness. The biomedical model is the dominant model of disease today (Michigan Disability Rights Coalition, 2015).

Biopsychosocial approach. The biopsychosocial approach considers biological, social, and psychological factors and their interaction to understand illness (Engel, 1977). This approach highly esteems humanistic values and treatment modalities are multidimensional. The biopsychosocial model posits that natural and social sciences are basic to medical practice.

Choroidal neovascularization (CNV). CNV is the creation of fragile new blood vessels in the choroid layer of the eye. CNV membranes break through the barrier between the choroid and the retina. The bleeding that occurs when they rupture in the retina can cause vision loss (Postelmanns, Pasteels, Coquelet, Caspers, & Verougstraete, 2004).

Histo spots. Histo spots are small circular punched-out spots in the retina that result from the initial infection sites of ocular histoplasmosis (Oliver, Ciulla, & Comer, 2005). Histo spots can be inactive or active. Many individuals with histo spots never experience symptoms of POHS.

Person-first language. Person-first language demonstrates respect for people with disabilities by referring to them first as a person. The focus is on the individual's ability and the reference to disability is only used when necessary (Blaska, 1993). Person-first language is beneficial because it promotes inclusion by acknowledging subtleties of language that may promote stereotypes.

Presumed ocular histoplasmosis syndrome (POHS). POHS is a disease affecting the eye in which peripheral atrophic scars on the retina result in atrophy or scarring near the optic disc and maculopathy occurs (Lewis, Van Newkirk, & Gass, 1980). CNV causes the loss of vision associated with POHS. Although various treatment options are available, this illness is considered incurable at this time.

Social-networking site (SNS). SNSs are websites created for the purpose of interactions between people online. For the purpose of this study, I refer to a social networking site entitled Facebook. Facebook is a site through which users can create online communities in which they can share ideas, personal messages, and other content (Ross et al., 2009).

Limitations

A descriptive single case study has slight generalizability value (Yin, 2008). The limitations of this study are the size of the sample, which was limited to three participants, and that it was not open to all manner of people with low vision or blindness. The study was limited to members of a group that have POHS, which is a rare disease. The results are not transferable

to the general public and are also inapplicable to other Facebook support groups or people who are seeking general counseling. This study is still a most worthy endeavor in that researchers have not performed a descriptive case study with this population. Furthermore, this underrecognized group deserves a voice, especially due to the possibility that this is a underreported, untreated illness for some marginalized populations. Prior to this study, it was unknown if or how online peer-support works and what individuals with POHS are experiencing in this type of group.

Chapter Summary

Individuals with rare, progressive, and unpredictable eye diseases may find it difficult to combat and adjust to the sudden or gradual onset of visual loss. Symptoms associated with POHS can negatively affect quality of life for individuals with this rare disease. Online support groups, through social networking outlets such as Facebook, may be an effective medium for people with POHS to participate in a forum that can be tailored to the needs of the group. Identifying and describing the experiences of individuals as they adjust to a progressive and rare eye disease in an online community can offer peer support and resources that may be beneficial to this population.

This descriptive case study of a Facebook peer-support group used by individuals with POHS describes the experiences of a sample of the participants. By collecting and examining the acquired data with careful adherence to ethical standards, it was my intention to gain a better understanding of this phenomenon. Researchers using a descriptive-research design work to describe different characteristics of a phenomenon. The goal of descriptive-research design is to describe the features, context, and process of a phenomenon, which in this case is a group (unit) of individuals with POHS participating in a Facebook peer-support group.

Organization of the Dissertation

The dissertation is displayed in five chapters. The first chapter provided an introduction to the study. Chapter 2 is the literature review. In Chapter 3, I describe the methods used to conduct the study. In Chapter 4, I present the data. Finally, Chapter 5 includes the conclusions and recommendations to the field of vocational rehabilitation and to future researchers.

II.   Review of the Literature

Organization of the Chapter

Chapter 2 begins with an introduction followed by the search strategy used to define and discuss POHS. In the next section, I describe treatment options that are currently available. Following that is a section addressing the adjustment to disability. Next, I discuss emotional distress, showing stress, grief process, and emotional well-being issues. The need for support and the use of online support groups is the next focus. Finally, the chapter ends with a summary.

Introduction

POHS is a rare eye disease that causes people in the prime of their vocational lifespan to lose their vision and become a person with a disability. Little is known in the way of effective treatment interventions and currently available treatments may increase vision damage and result in unknown and further debilitating side effects. No studies of the experience of individuals with this disease emerged in a search of the literature. None to date have explored the individual experience of participants in an online support group regarding having such an unmanageable disorder and the process by which people are able to manage emotional distress and adjust to their changed lives.

Access to peer support and relevant medical advisement are limited primarily to the individual's retina specialist and familial-support system. Individuals with this rare disorder may have difficulty adjusting to an illness that is a vocational inhibitor, expensive, inconsistent in response to treatment, and alarmingly irregular in its course. Ramifications of the loss of vision significantly affect these individuals' abilities to remain in the workforce if they do not have adequate accommodations. Lack of information and supportive counseling resources are

apparent, due to the many unknown components of this disease, which may leave people vulnerable to emotional distress and vocational constraint.

As computers have become more accessible to the general population and vision-related technology has advanced, online support groups have become more accessible to people with disabilities. Issues such as transportation, distance, privacy, and time restrictions can impede people from using face-to-face peer support. Consequently, online peer-support groups may provide a valuable alternative for people with relatively rare diseases (Lasker et al., 2005).

This descriptive case study of an online Facebook group focuses on peer support for people with POHS. It is an important step in the needed discovery of what transpires in this cyberspace venue. By revealing the experiences of these individuals through the process of online peer support, I may illuminate the possible benefits of primary medical and counseling points of contact, recommending these online peer-support groups as a means of closing the wide gaps in services provided to individuals with rare diseases.

Search Strategy

The search strategy for this literature review included using the terms; "presumed ocular histoplasmosis syndrome," "ocular histoplasmosis," "POHS," "*histoplasma capulatum,*" "vision loss," "low vision," "degrees of visual disability," "treatment for choroidal neovascularization," "treatment for POHS," "adjustment to disability," "adjustment to disability related to vision loss," "adjustment to rare and debilitating diseases," "online support groups," and "Facebook and peer support." Search engines used included EBSCO*host* academic, ProQuest, ProQuest dissertations, JSTOR, Google Scholar, and the National Institutes of Health. Given two schools of thought regarding the use of the term "presumed" in the name of this syndrome, I employed both presumed ocular histoplasmosis and ocular histoplasmosis in this search.

Presumed Ocular Histoplasmosis Syndrome

POHS is described in this section using peer-reviewed literature. To assist the reader in

understanding the articles reviewed, they appear in table format for easy access. Table 1,

Presumed Ocular Histoplasmosis Syndrome, shows the literature reviewed for this section.

Table 1
Presumed Ocular Histoplasmosis Syndrome

Authors	Methods	Conclusions
Ala-Kauhaluoma, Ahi, Ristola, & Karma (2010)	Case report	Intraocular dissemination of histoplasmosis
Amaro, Muccioli, & Abreu (2007)	Institutional prospective study	POHS described in nonhistoplasmosis patients
Crum-Cianflone (2010)	Case study	Early exposure to *histoplasma capsulatum*
Ganley et al. (1973)	Clinical study of characteristics of people with peripheral atrophic scars	The presence of pulmonary calcification increases the likelihood of peripheral atrophic scars developing into macular disease.
Hawkins (2005)	Clinical case study evaluation of treatment	Symptoms of POHS
Hernandez, Munoz-Cadavid, Hernandez, Montoya, & Gonzalez (2012)	Case report	Shows diagnostic tools
Kim (2015)	Physician description of disease process	POHS disease entity and etiology
McCann (2009)	Interview	Describes POHS as a hidden fungi in the lung (reanimated over time)
McCluskey, Bourgeois, & Harbison (2013)	Case Report	Discusses the misdiagnosis of POHS
New Jersey Department of Health and Senior Services (2014)	Public Employees Occupational Safety and Health Program	Identifies health risks to workers related to bird and bat droppings

Table 1

Presumed Ocular Histoplasmosis Syndrome (Cont.)

Authors	Methods	Conclusions
Ongkosuwito et al. (1999)	Diagnostic case study	Triggering factors where described and better diagnostic criteria determined
Rappleye & Goldman (2007)	Review	Defines successful mechanisms employed by fungi
Reid, Schere, Herbut, & Irving (1942)	Review	First scientific discovery of histoplasmosis
Sinha et al. (2007)	Case study	Determines how to identify new cases
Smith (1997)	Commentary	Late onset of macular disease due to POHS
Spitz & Schwartz (1953)	Review	Discusses new cases in nonendemic regions
Suttorp-Schulten, Bollemeijer, Bos, & Rothova (1997)	Retrospective clinical picture	Fungus is not in this location but the diagnosis is increasing
Trevino & Salval (2006)	Clinical background	Identification of risk factors
Woods & Wahlen (1960)	Review	First discovery of ocular histoplasmosis

Note. POHS = presumed ocular histoplasmosis syndrome.

Review of the Literature for Presumed Ocular Histoplasmosis Syndrome

The first description of an ocular abnormality associated with histoplasmosis was published in 1942 by Reid et al., based on the observation of a person dying of acute disseminated histoplasmosis. In 1960, Woods and Wahlen described a clinical symptom of great significance at the Wilmer Ophthalmological Institute. They reported the existence of benign systemic histoplasmosis and identified it as responsible for "a peculiar and consistent pattern of ocular lesions" (p. 212). Today these lesions are referenced as histo spots and can manifest as the source of CNV and subsequent "bleeds" that can compromise an individual's vision, rapidly resulting in vision loss. Currently, no known cure for POHS exists; consequently, individuals

who have the active manifestation of the disease experience vision loss and become a person with a visual disability.

According to Hernandez et al. (2012), "*histoplasma capsulatum* is the causative agent of histoplasmosis—one of the most important endemic mycosis in the Americas." Ocular histoplasmosis is a noteworthy cause of vision loss in young and middle-aged adults because it is incurable. Available treatments result in inconsistent outcomes and vision loss can be sudden and unpredictable. Additionally, the age groups most commonly affected by this disease are in their vocational prime.

The literature related to the cause of POHS is fraught with controversy, due to the ongoing debate regarding how to create a conclusive test for this disease. At this time, physicians diagnose the syndrome based on the presenting character traits of the disease. The four primary manifestations of POHS are maculopathy, histo spots, peripapillary pigment changes, and clear vitreous fluid (McCluskey et al., 2013). The majority of research points to the overwhelming correlation between histoplasmosis and POHS. However, in an aetiological study of presumed ocular histoplasmosis in The Netherlands, authors Ongkosuwito et al. (1999), reported, "The direct role of *H. capsulatum* in the pathogenesis of presumed ocular histoplasmosis has not been clearly demonstrated, hence the prefix 'presumed'" (p. 536). The Ongkosuwito et. al account of the relationship was based on epidemiological studies and other risk factors, such as autoimmunity, may also play an aetiological role in this syndrome. At this time skin tests are not consistently accurate and The Netherlands study points to the possibility POHS could also represent an autoimmune inflammatory reaction triggered by certain organisms including *histoplasma capsulatum* (Kim, 2015).

Additionally, medical researchers have described a syndrome that shares the same clinical features in areas where histoplasmosis is virtually nonexistent in parts of western Europe (Suttorp-Schulten et al., 1997). A study conducted by Amaro et al. (2007), concluded, "clinical findings of histoplasmosis were described in non-histoplasmosis patients" (p. 577). The study went on to suggest other etiological agents might be involved. Epidemiologic studies have statistically confirmed a relationship between POHS and exposure to the histo organism determined by skin tests (Smith, 1997). Because inconsistencies still exist in testing in nonendemic regions, further investigation is warranted.

Cases exist of the transfer of *histoplasma capsulatum* spores from clothing, and veterans have contracted the disease while on deployment. In a case reviewed by Spitz and Schwartz (1953), veterans did not have to reside for long periods of time in endemic areas and the known duration of exposure for one solder who qualified for the study was "only a few hours" while passing through Oklahoma. Sinha et al. (2007) conducted a case study in India of three individuals from nonendemic areas that fit the criteria for POHS. Sinha et al. (2007) noted the patients met the criteria for POHS but skin tests were not performed, based on prior research that the skin test had been found to reactivate the fungus and was contradictory to treatment protocol (Ganley et al., 1973). This aspect further complicates the diagnosis process for people with this rare disease.

On one point the majority of experts can agree: the initial point of infection takes place in the pulmonary system. The origin of the offending microorganism is found on the feathers of pigeons, chickens, and blackbirds as well as the droppings of infected bats and the aforementioned fowl. McCluskey et al. (2013) reported *histoplasma capsulatum* can also be found in demolition sites of old buildings. The New Jersey Department of Health and Senior

Services Public Employees Occupational Safety and Health Program (2014) provides a booklet

published by the Division of Epidemiology, Environmental and Occupational health to provide

guidelines for people in the workplace who may come in contact with high-risk environments.

Under the heading "histoplasmosis" it states, "Once airborne, spores are carried easily by wind

currents over long distances. Such contaminated airborne dusts can cause infections not only in

persons at a work site but also in others nearby" (U.S. Department of Labor, 2015). The

guidelines report that The National Institute of Health has described a potentially blinding eye

condition referred to as POHS that may result from the contact with the fungus.

Somewhat incomplete information available in EyeWiki (Kim, 2015) reported the fungi

histoplasma capsulatum is yeast. A better explanation of *histoplasma capsulatums'* origin and

nature can be found in an feature article by McCann (2009): "Histoplasma are a special kind of

fungus: they're dimorphic, meaning they can grow in two forms." McCann explained that in the

soil, histoplasma grows like a mold, but when dispersed through the air and consequently inhaled

by a host, the histoplasma grow rapidly like yeast. The mold *histoplasma capsulatum* uses one

set of genes to survive in the soil and another to survive as yeast in human cells.

The spread of the infection can occur after inhalation, at which time the fungi are able to

hide in immune cells in the lung (Rappleye & Goldman, 2007). After inhalation, the organism

spreads hematogenously to the choroid, which causes an inflammatory reaction leading to a

chorioretinal scar (Kim, 2015). These scars can look like stars in a night sky during an eye

examination. The spread of *histoplasma capsulatum* to the choroid causes an inflammatory

reaction with a resulting scar. The choroid is a layer of blood vessels that provide blood and

nutrients to the retina. The retina is the light sensitive layer of tissue that lines the back of the

eye. POHS develops when fragile blood vessels grow underneath the retina. The lesion the vessel

forms is the CNV. CNV potentially results in vessel leakage into the macula, which is damaging to central vision.

Various researchers estimated that 60–90% of the adult population in an endemic region tests positive to histoplasma by skin antigen test with only 1.5% of that positive group demonstrating the typical chorioretinal lesions (Kim, 2015; McCann, 2009). Significantly, the diagnosis of histoplasmosis may be quite difficult, according to the case report by Ala-Kauhaluoma et al. (2010): "Cultures can remain falsely negative" and "no single test exhibits high sensitivity" (p. 495). What typically brings a person with POHS into the ophthalmologist's office is either CNV or hemorrhagic retinal detachment. These events present as symptoms that manifest as metamorphosia, blurred vision, or a loss in central vision (Hawkins, 2005).

Histoplasmosis is endemic to the midwestern and southwestern United States as well as many parts of Central America, Asia, and Africa. In a case report by Ala-Kauhaluoma et al. (2010), "in a immunocompetent person, acute pulmonary inflection is usually self-limited" (p. 493). The manifestation of "punched out" chorioretinal scars often refers to histo spots, thought to be lesions caused by the dissemination of *histoplasma capsulatum* to choroidal circulation.

Notable professor and chair of Microbiology and Immunology at University of North Carolina at Chapel Hill, Goldman (2007, as cited in McCann, 2009) referred to cells in the lungs called macrophages, which act as the body's first defense against bacterial and fungal invaders. Histoplasma can control these cells and hide in them in tiny sacks, emerging decades later "reactivated" and capable of manifesting into POHS. "Very few patients with ophthalmoscopic evidence of POHS develop visual symptoms" (Crum-Cianflone, 2010, p. 422). The initial infection is more often asymptomatic and less than 1% of people exposed develop a clinical

illness 7 to 21 days after exposure; 1–5% of residents in highly endemic areas commonly display

atropic choroidal scars and these scars do not become active. The disciform macular scarring

associated with POHS leads to loss of central vision (Trevino & Salvat, 2006). The pathogenesis

of POHS and its association with histoplasmosis are still unclear. Some researchers have

proposed it may be an immunological response to deposited fungal antigens (Crum-Cianflone,

2010).

Summary of Presumed Ocular Histoplasmosis Syndrome

Clearly, POHS is a rare disease causing disability that requires diligence in treatment and

education for individuals to maintain the highest possible level of functioning. POHS is

unpredictable, difficult to manage, and can run a potentially damaging course. Finding answers

for patients' questions about the etiology of this disease may be a time consuming and difficult

endeavor. Figure 2 depicts the eye of an individual with POHS showing peripheral atrophic

chorioretinal scars, atrophy, or scarring adjacent to the optic disc and maculopathy. Histo spots

are small circular punched out spots in the retina that result from initial infection sites of POHS.
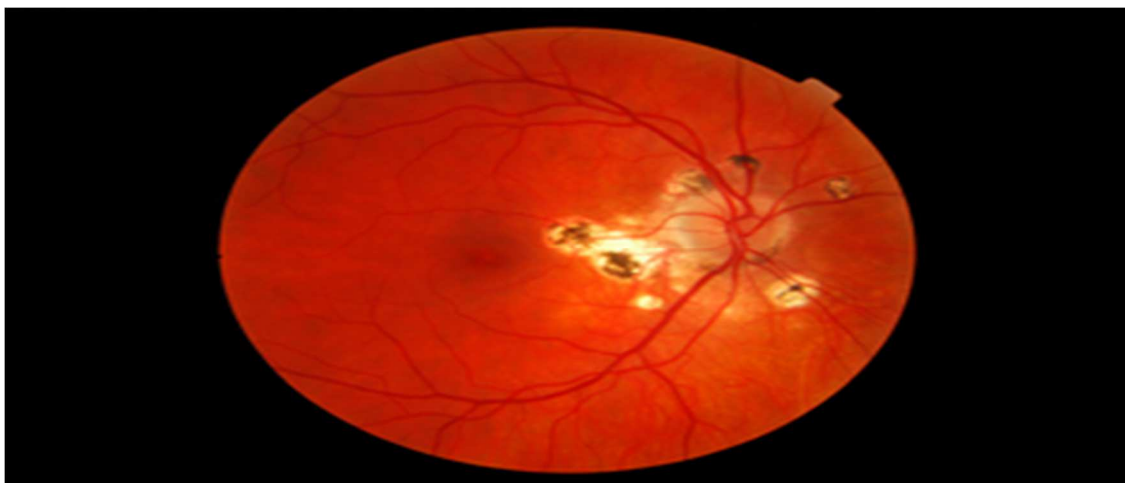
Figure 2. Picture of the eye with histo spots.

Treatment for Presumed Ocular Histoplasmosis Syndrome

In this section, I present treatment options available for POHS. Table 2 describes the

literature associated with treatment options for POHS gleaned from peer-reviewed literature and

websites created by medical experts. To assist the reader in understanding the articles reviewed,

they appear in table format for easy access.

Table 2

Treatment for Presumed Ocular Histoplasmosis Syndrome

Authors	Methods	Conclusions
Bennett & Bloom Eye Center (2015)	Review	Treatment options for POHS
Hawkins et al. (2004a)	Treatment study group	Results show treatment help with symptoms but did not alleviate disease
Holekamp, Thomas, Dickinson, & Valluri (1996)	Retrospective study	Surgical removal of subfoveal choroidal neovascularization, suggests encouraging results
Lewis et al. (1980)	Follow up study	Evaluation of new macular scars after 5.5 years
McGee, Dean, & Danesh-Meyer (2002)	Review	Benefits and risks
Melberg, Thomas, Dickinson, & Valluri (1996)	13-month follow up study	No improvement after surgery
Oliver et al. (2005)	Review	Treatment: subfoveal localization
Postelmanns et al. (2004)	Evaluation of treatment	PDT can be beneficial but not curative
Ramaiya, Blinder, Ciulla, Cooper, & Shah (2013)	Review	Ranibizumab versus photodynamic therapy
Rechtman et al. (2003)	Retrospective analysis	Defining what treatments are safe although not completely effective
Saperstein et al. (2002)	Safety assessment	Results indicate no systemic or ocular adverse events
Schadlu et al. (2008)	Retrospective chart Review	May have sight improvements but no lasting improvements
Whoriskey, & Keating (2013)	Review	Expensive treatments help with some symptoms but do not treat
Williamson Eye Institute (2015)	Review	Review of treatments

Note. POHS = presumed ocular histoplasmosis syndrome; PDT = photodynamic therapy.

Review of Literature for Treatment of Presumed Ocular Histoplasmosis Syndrome

The treatment for POHS currently consists of multiple options including observation, corticosteroids, laser photocoagulation, photodynamic therapy, vascular endothelial growth factor inhibitors, and submacular surgery (Williamson Eye Institute, 2015). No treatment at this time results in a cure. "Controversy seems to be an essential part of the presumed ocular histoplasmosis syndrome (POHS). Its cause continues to be debated, its prevalence estimates vary considerably, its pathophysiology has never been completely understood, and its therapeutic regimens are constantly evolving" (Oliver et al., 2005, p. 160). An intense effort at identifying the most beneficial therapeutic treatments for POHS has resulted in some large studies, although to date the disease still remains incurable.

The detection and diagnosis of POHS is achieved during a dilated-eye examination. Three key attributes of the disease are (a) the presence of peripheral histo spots, which indicate a history of exposure; (b) atrophy or thinning of the retina around the optic nerve; and (c) swelling of the retina, which indicates the growth of new abnormal blood vessels. The next step in the diagnostic process is a procedure called fluorescein, in which the ophthalmologist injects dye into the individual and photographs the affected eye. The dye enables a clearer view of the CNV to trace the extent to which it has spread. The location of the bleed is important, especially if it is near the fovea (Williamson Eye Institute, 2015).

The initial treatment for inactive or successfully treated histo spots is observation. Using an Amsler grid, the physician can provide accurate and consistent observation. The Amsler grid is a card that shows a grid pattern that is viewed several times a day to check vision. If a wavy or blurred line or a black or blurry spot appears on the grid, it is imperative the individual contact their retina specialist immediately to determine if they have a CNV (Eye Center, 2015). The

subfoveal and juxtafoveal neovascularization is the most significant of symptoms exhibited by POHS; consequently almost all research has focused on finding the optimal treatment to address this issue. Daily use of the Amsler grid enables people with POHS to determine if they need immediate medical attention to treat a visual distortion caused by fluid or blood leaking in the eye.

Figure 3, the Amsler grid, shows the pattern of the grid. The Amsler grid is a test for identifying distortions in central vision that individuals can use on their own. By gazing at the center black dot in a fixed manner a person can identify any wavy lines or missing lines that would indicate a problem with their vision. If the individual identifies an area of concern, the person would then mark the area on the grid and bring it to their physician for confirmation and treatment.
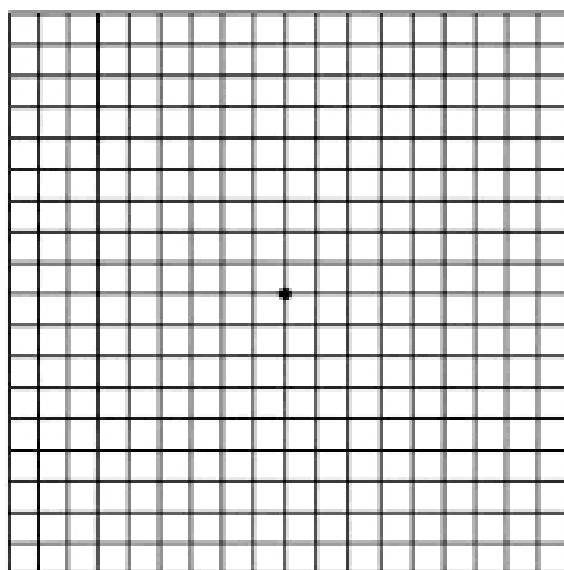
Figure 3. The Amsler grid.

In the early stages of ocular disease, corticosteroids can be an effective immunosuppressive therapy. Physicians widely used regimens of systemic corticosteroids, often recommended at the first symptoms of possible recurrence (Oliver et al., 2005). However, once a

hemorrhage has occurred, because the membrane of Bruch is disrupted and CNV has ensued, the immune response is no longer the primary factor that must be addressed. Currently, medical researchers are readdressing corticosteroids for their ability to combat inflammatory cells that participate in the neovascular response. Intravitreal Kenalog is a steroid that physicians inject into the white of the eye and deep into the vitreous cavity. It has shown promise for its action against blood vessel growth and retinal swelling (Williamson Eye Institute, 2015). However, the inherent risks of periocular injection of steroids, and the availability of comparable or superior methods of application, conscript this treatment to situations of immediate necessity, such as use as a postoperative anti-inflammatory (McGee et al., 2002).

Photodynamic therapy (PDT) is a treatment option with few side effects, often used in the treatment of CNV related to myopia. Postelmanns et al. (2004) reviewed the results of a study of various treatment modalities including PDT for a small number of individuals with POHS. Results indicated that photodynamic treatment of the subfoveal classic CNV associated with POHS seemed to be beneficial. Saperstein et al. (2002) endorsed the positive effects of PDT after reviewing the results of a 1-year uncontrolled case series, which combined the use of a nonthermal long-wave-length laser with an infusion of a photosensitive drug. The laser was used to activate the drug, resulting in the occlusion of CNV (Saperstein et al., 2002). Researchers indicated that the scarring left after laser treatment is only somewhat less egregious than the initial visual obstruction. Laser treatment of subfoveal CNV destroys the fovea and researchers do not recommend its use in treating POHS (Melberg et al., 1996; Rechtman et al., 2003). Although persons with POHS may benefit from the stopping of an active bleed, thermal laser treatment use should be limited a tendency to cause scotoma (Schadlu et al., 2008).

Antivascular endothelial growth factor therapy inhibitors Macugen, Avastin, and Lucentis are a class of potent medications that prevent CNV from growing and leaking. Researchers have studied these inhibitors extensively in patients with POHS. The drug Avastin was originally approved by the Federal Drug Administration for treatment of colorectal cancer. Considered an experimental drug at this time in its ocular use, it requires a signed release and is commonly not covered by insurance. The cost of Avastin is approximately $50.00 per injection, whereas the drug Lucentis costs about $2,000 per injection. According to *The Washington Post,* doctors choose the more expensive drug more than half a million times a year. In contrast, many ophthalmologists are skeptical that Lucentis provides any added value over the less expensive alternative (Whoriskey & Keating, 2013).

A retrospective study showed that if untreated or treated with only observation, macular CNV results in a visual acuity of 20/200 or worse in up to 58% of individuals with POHS (Lewis et al., 1980; Ramaiya et al., 2013). In an authored manuscript for the National Institutes of Health, Hawkins (2005), as part of a 10-person writing committee for submacular surgery trials, addressed the issue of whether vision-targeted quality of life improved after submacular surgery versus only observation. Researchers found a small possible benefit from the surgery (Hawkins et al., 2004a). This study was an examination of a surgical intervention as compared to a nontreatment modality. Furthermore, recurrence of neovascularization is a common outcome with surgical intervention (Holekamp et al., 1996). Melberg et al. (1996) acknowledged the need to manage recurrent CNV after subfoveal surgery.

Summary of Treatment

Treatment options for POHS are improving through research and the dedication of physicians who treat these individuals. As a result people may be able to preserve their vision as

long as they have access and the means to afford treatment. Acquiring current information about treatment modalities and understanding the associated risks of treatment are challenging for individuals with rare and chronic diseases. Beyond the services received during an office visit, getting information and support appears to be very limited.

Emotional Distress

This section describes the emotional distress individuals may experience when they have a chronic illness that manifests in vision loss. Table 3 lists the literature discussed in this section. To assist the reader in understanding the articles that will be reviewed, they are in table format for easy access.

Review of Literature for Emotional Distress

Adjusting to vision loss may entail a certain degree of suffering. "Suffering can be defined as a state of distress that occurs when a person's integrity or life plan is threatened, disrupted, or burdened" (Hayeems et al., 2005, p. 615). Emotional distress, caused by functional decline, contributes to depressive symptoms in the visually impaired population (Rees et al., 2010). Patients with visual impairment are a group that is least likely to have their depression recognized by a primary-care physician and subsequently may often go untreated (Rees et al., 2010).

Physicians encourage individuals with POHS to seek treatment in a timely manner and to practice self-observation to preserve their vision. People who are depressed may not seek eye care when experiencing visual difficulties (X. Zhang et al., 2013). Furthermore, "they may also not realize, unless asked, they even have difficulties with their vision" (X. Zhang et al., 2013, p. 579). For those with diagnosed eye conditions, depression may cause poor adherence to treatment, which may in turn hasten vision loss (X. Zhang et al., 2013). Empirical evidence

consistently confirmed difficulties in emotional functioning among visually impaired people

(Burmedi et al., 2002). Moreover, depressive symptoms were at least twice as prevalent as in the

general population.

Table 3
Emotional Distress

Authors	Methods	Conclusions
Bergeron & Wanet-Defalque (2013)	MANCOVA	People with visual impairment engage in an adaptive coping style to address their situation
Burmedi, Becker, Heyl, Wahl, & Himmelsbach (2002)	Journal review	Emotional consequences of age-related low vision and visual impairment
Dreer et al. (2008)	Cognitive appraisals	Appraisal of a person's ability to cope with vision loss
Fenwick, Lamoureux, Keeffe, Mellor, & Rees (2009)	Focus groups	An attempt to improve depression management
Fitzgerald, Ebert, & Chambers (1987)	4-year Study	Reactions to blindness
Hawkins et al. (2004b)	Interviews	Assessment of visual acuity
Hayeems, Geller, Finkelstein, & Faden (2005)	Model of Adjustment	Development of a model of adjustment based on qualitative research.
Marques-Brocksopp (2011)	Emotional well-being review	Ways to promote emotional well-being
Moschos (2014)	Quantitative survey	Psychological aspects of depression
Rees et al. (2010)	Cross-sectional study	Assessment of ways to cope with depression and vision loss
Thurston, Thurston, & Mcleod (2010)	Semistructural interview	How people adjust to the socio-emotional transition to vision loss
X. Zhang et al. (2013)	Review of the NHANES survey	Using the NHANES to look at depression and vision loss

Note. MANCOVA = Multivariate analysis of covariance; NHANES = National Health and Nutrition Examination Survey.

Informants described a lack of emotional understanding and support from healthcare

professionals they encountered at the time of receiving a diagnosis (Thurston et al., 2010).

During diagnosis, people need to make sense of their sight loss on several levels: intellectually,

practically, and emotionally. That goal has not yet been accomplished. The experience of sight

loss was "a fundamental challenge to a sense of self" and "a profound sense of loss" (Thurston,

Thurston & Mclead, 2010, p. 105).

In a sample of people with acquired blindness, Fitzgerald et al. (1987) endorsed the

presence of depressed mood in 90% of cases and, in a 4-year follow-up study, noted persistence

of depressive symptoms in more than 50% of cases, indicating the initial crisis had not been

resolved. The psychopathological picture may be worse for individuals with partial sight,

signifying gradually deteriorating sight, posing greater problems than adaption to total, definite

loss (Moschos, 2014). "Findings illustrate that cognitive appraisals of the degree to which

individuals can tolerate vision loss and how interfering vision loss is on everyday living are

major factors associated with emotional distress" (Dreer et al., 2008, p. 455). As a result, distress

may predict vision-related disability independent of the level of actual impairment.

Vision loss is a substantial predictor of emotional distress (Fenwick et al., 2009).

Healthcare workers in settings serving individuals with vision impairments need to be trained to

distinguish depression from normal emotional response to vision loss. In a study by Fenwick et

al. (2009) participants revealed a range of factors aligned with the onset of emotional distress.

The degree and impact of vision loss and persons understanding of their condition were factors

associated with depression, as well as visual functioning and lack of coping strategies. Lack of a

clear referral pathway for treatment and poor communication between all levels of staff were

barriers to depression management (Fenwick et al., 2009). These service provider failures

combined with the aforementioned possible tendency of people with depression to not actively

seek consistent medical intervention set the stage for this population to acquire additional

disability.

Occupational constraint, due to the onset of POHS between the ages of 30 and 50, puts individuals with POHS at further risk for emotional distress. People with POHS are not only at jeopardy for loss of vision but also experience the loss of work all together, or at least separation from their usual occupations (Hawkins, 2005). As a consequence of the increased research on this topic, an increasing awareness is emerging of the importance of preventing negative mental health outcomes and promoting emotional well-being (Marques-Brocksopp, 2011) The diagnosis of a chronic health condition such as POHS that results in loss of vision is often the beginning of emotional and physical losses (Bergeron & Wanet-Defalque, 2013).

Summary of Emotional Distress

Emotional distress often accompanies POHS due to the visual losses associated with this disease progression, but also with the lack of information given to persons with POHS at the time of diagnosis. Individuals with vision loss may experience a degradation of psychological well-being. In addition, medical interventions do not currently include any assessment or referral system to address the marked emotional needs of these individuals as they attempt to navigate their care in relation to this rare disorder.

<div align="center">

Adjustment to Disability

</div>

In this section, I present the difficulty for persons with POHS to adjust to disability. Table 4 shows the literature evaluated for adjustment to disability and describes the literature reviewed in this section. To assist the reader in understanding the articles reviewed, they are in table format for easy access.

Table 4
Adjustment to Disability

Authors	Method	Conclusions
Ben-Zur & Debi (2005)	Regression Analysis	Benefits of optimism and social comparisons in relation to rehabilitation
Boerner, K. (2004)	Hierarchical regression of coping and disability	Findings indicate that addressing disability poses a serious mental health risk in late adulthood
Cooper, Collier, James, & Hawkeye (2010)	Qualitative review	Beliefs of personal control and self-management issues
deRidder, Geenen, Kuijer, & van Middendor (2008)	Review of reports from the last decade regarding the psychological adjustment to chronic illness	Patients who find healthy ways to address chronic disease are more successful adjusting to disability
Hayeems et al. (2005)	Focus groups and interviews, cross-sectional sample.	Eye doctors need to understand what patients are going through and help them cope with vision loss
Irvine, Davidson, Hoy, & Lowe-Strong (2009)	Phenomenological analysis	Identifying coping strategies helps people better deal with disability
Jang, Mortimer, Haley, & Graves (2004)	Cross-sectional study	The role of social engagement
Mpofu & Bishop (2006)	Review of literature	Value of change theory development
Murray, McKay, & Nieuwoudt (2010)	Phenomenological case study	Grief and visual impairment
Nyman, Dibb, Victor, & Gosney (2012)	Meta-analysis	Qualitative research reveals more information concerning quality-of-life measure
Reinhardt, Boerner, & Horowitz (2009)	Interviews	Adapting through acceptance
Senra, Aragao, & Leal (2011)	Semistructured interview	Milestones in adjustment
Tabrett & Latham (2012)	Quantitative study	Factors associated with adjustment
Trillo & Dickinson (2012)	Journal article	Quality of life and adaptation
Tunde-Ayinmode, Akande, & Ademola-Popoola (2011)	Cross-sectional descriptive study	More education can help with coping strategies

Review of Literature for Adjustment

Vision loss may be feared more than other physical impairments because it is regularly associated with a state of dependence and helplessness (Boerner, 2004). Vision loss has numerous implications for an individual's daily living and functioning Vision loss may provide a potential cause for other individual losses such as stopping driving, working, reading, writing, learning, memory processing, and spatial representation (Ben-Zur & Debi, 2005; Senra et al., 2011). However, with appropriate rehabilitation interventions, individuals can maintain independence.

Because POHS requires such vigilance on the part of the individual and the physician to curb its potentially damaging effects on vision, they require a strict adherence to a disease-management regimen. Although malaise and behavioral inactivity associated with a typical illness is considered adaptive, these same adaptive devices can negatively impact those with chronic illness and can become obstacles to psychological adjustment (deRidder et al., 2008). Additionally, given the earlier mentioned issue of observational vigilance, they can be detrimental to positive disease-management outcomes for people with POHS.

Nyman et al. (2012) suggested that "the emotional needs of those with visual impairment should not be neglected, particularly those recently diagnosed" (p. 971). deRidder et al. (2008) affirmed this view: "after the medical diagnosis of chronic illness, patients are confronted with new situations that challenge their habitual coping strategies" (p. 246). Consequently, chronic illness has the potential to induce profound changes in a person's life, resulting in negative effects on their well-being (deRidder et al., 2008). Irvine et al. (2009) emphasized that, "the resolution of an identity crisis that accompanies diagnosis requires changes in values and belief systems" (p. 7). Mpofu and Bishop (2006) concurred, identifying the "process of reorganizing or

adjusting one's value system" (p. 147) as a means of adapting to the psychosocial disturbances that may relate to chronic-illness adjustment.

Personal and social resources deserve more attention as factors that can alter the disability process (Jang et al., 2004). A significant change in visual acuity has also been associated with social issues such as lack of acceptance and difficulty in sustaining relationships. Furthermore, social resources play an important role in the process of adapting to chronic impairment such as vision loss (Reinhardt et al., 2009). Researchers suggested that personal and social resources may deserve greater attention as factors that can alter the disability process (Jang et al., 2004). Individuals' adaption to and acceptance of their visual loss may influence their reactions to rehabilitation (Trillo & Dickinson, 2012). Consequently, addressing the significant issue of social isolation affecting people with low vision may improve adjustment to vision loss and enhance rehabilitation.

Tunde-Ayinmode et al. (2011) related a different finding, asserting that most participants in their cross-sectional descriptive study with visual disabilities were reasonably adjusted in social interactions and poorly adjusted to the areas of education, vocational training, employment, and mobility. Cultural differences between Nigeria and the United States may have influenced results. Culture and financial affluence may impact people in these nations in different ways.

Senra et al. (2011) stated, "After vision loss people show different kinds of adjustment courses and achieve different levels of rehabilitation outcomes. Therefore, the personal experience of vision loss has aroused interest in some authors, especially those using qualitative studies" (p. 1141). Murray et al. (2010) asserted the findings of their study on grief and needs of adults with visual impairments that these needs are "dynamic, chronic and recurrent but episodic

processes rather than linear and resolved processes" (p. 87). It has been purported that adjusting

to a vision loss may follow the initial stages of mourning and bereavement but may be a

continual process rather than one with a definite endpoint (Tabrett & Latham, 2012). Researchers

emphasized that reconciling the uncertainty and unpredictability of life with chronic illness may

be a key aspect of adjustment. Although specific symptoms and episodes of chronic illness may

be unpredictable, illness itself may become predictable (Cooper et al., 2010).

Summary of Adjustment

Aspects of chronic illness, such as often-resulting social isolation, may negatively

influence the process of adjustment. The unpredictable qualities of POHS in progression and

symptomology may influence the outcomes of rehabilitation. Some level of adaption appears to

be required for individuals to move forward in a restorative manner.

Online Peer-Support Groups

This section describes the literature for online support groups. Table 5 shows the

literature review for this section. To assist the reader in understanding the articles reviewed, they

are in table format for easy access.

Table 5

Online Peer-Support Groups

Authors	Method	Conclusions
Ahmed, Sullivan, Schneiders, & McCrory (2010)	Journal article	Support networking sites
Bittner, Edwards, & George (2010)	Focus-group study	Finding support for coping with loss of vision
Dibb & Yardley (2006)	Journal article	Social comparison of self-help groups
Forest & Wood (2012)	Meta-analysis	Mixed responses from Facebook regarding disclosure
Gray, Annabell, & Kennedy (2010)	Survey	Facebook as a learning platform can be challenging
Greene et al. (2010)	Qualitative evaluation	Risks associated with a lack of accountability and checks for authenticity
Huber et al. (2010)	A mixed-methods approach	Online support group for cancer patients
Kurtz (1997)	Book	Handbook to help professional with support groups
Lasker et al. (2005)	Content analysis	Internet-based group for people with rare diseases
Letourneau et al. (2012)	Review	Social isolation and loneliness reduced through online support
Molinari, Nelson, Shekelle, & Crothers (1994)	Journal article	Support groups for older people
Newman, Lauterbach, Munson, Resnick, & Morris (2011)	Qualitative analysis of online health communities	Exploration of the issues facing various users online in pursuit of support for health-related issues
Ralph, Berglas, Schwartz, & Brindis (2011)	Journal article	Using social networking sites for support
Spiegel, Bloom, Kraemer, H & Gottheil (1989)	Journal article	Effects of treatment and social concerns
Sugimoto (2013)	Dissertation	Social support on the Internet for people with depression
White & Dorman (2001)	Meta analysis	Communication difficulties arising from lack of visual and aural cues found in traditional support groups

Table 5

Online Peer-Support Groups (Cont.)

Authors	Method	Conclusions
Woolley & Peterson (2012)	Online questionnaire	The effectiveness of Facebook for health-information seeking
Y. Zhang, Tang, & Leung (2011)	Factor and regression analysis	Gratifications and psychological traits related to Facebook use

Review of Literature for Online Peer-Support Groups

Upon developing a chronic illness, more and more individuals are turning to a growing list of self-help groups (Dibb & Yardley, 2006). Numerous studies have suggested that support groups may provide valuable social support (Molinari et l., 1994; Spiegel et al., 1989). Newman et al. (2011) studied how and why people shared information with others online regarding health concerns or chronic illness: "In relation to health concerns our participants reached out to others for emotional support, motivation, accountability and advice" (p. 247).

In recent years, the Internet has played a popular role in providing health-related content due to its accessibility, speed, and availability (Woolley & Peterson, 2012). However, "online support groups also presents challenges when compared to traditional face-to-face group communication. Communication difficulties may arise from lack of visual and aural cues found in traditional face-to-face communication" (White et al., 2001, p. 693).

Other studies focused on research related to SNSs in providing guidance and connecting individuals to resources (Ahmed et al., 2010; Ralph et al., 2011). People with diseases with few treatment options and unclear etiology may be more likely to search for answers and support online (White & Dorman, 2001). Two major reasons people use the Internet for health-related concerns emerge from reviews conducted by Lasker et al. (2005): first, to find biomedical

knowledge and second, to interact with others who have like conditions to share experiences and emotional support.

Bittner et al. (2010) studied retinitis pigmentosa (RP), another disease leading to blindness. The authors found that "part of the coping process that has been helpful for many RP patients has involved social support and communicating with others who have RP" (p. 466). Many participants in focus groups indicated that people without vision loss may not fully understand what it is like to be blind or have a debilitating eye disease. In a mixed-methods study by Sugimoto (2013), the author suggested that, for chronic depression, "results indicated that users sought various types of emotional support, coaching support and social companionship. Users not only sought listening ears, but also practical advice to cope with situations they were going through" (p. 68). Individuals with POHS commonly have emotional distress related to many aspects of their disease process. Consequently, they may benefit in a similar fashion from SNSs and groups that offer peer support to their members. As an SNS designed to enhance social interaction, Facebook allows users to express emotions openly by encouraging a wide range of interactions including posting pictures and indicating the like button on posts and threads (Y. Zhang et al., 2011).

The web brings people together across vast distances to share their experiences and health questions. These self-help groups may be described as change-oriented organizations (Kurtz, 1997). With over 500 million active users, Facebook is currently the most widely used social-networking platform across the globe (Facebook, 2015). Originally created as a method of social communication for college students, Facebook is now the best known SNS. Facebook's features make it easy for users to set up personal profile pages, connect to and remark on the pages of other individuals and groups, as well as publish content and participate in groups (Gray

et al., 2010). "An interesting aspect of Facebook is that it allows people's disclosures to reach a wide audience including people with whom the discloser has an emotionally close relationships and people whom the discloser barely knows" (Forest & Wood, 2012, p. 296). This aspect of Facebook may cast a wide net of sorts to broaden subject-specific connections that may widen the individuals' support network.

Several disease-specific information exchanges now exist on Facebook. A study conducted by Greene et al. (2010), suggested tentative support for the proposed public health benefits of social networking in the management of a chronic disease such as diabetes. Individuals with severe allergies and difficult-to-control asthma also benefit from SNSs as they may remediate issues of social and geographic isolation (Letourneau et al., 2012). Individuals with POHS may also benefit from similar social-networking usage.

Summary of Online Peer-Support Groups

Issues regarding diagnosis, treatment, adjustment, and emotional distress may be appropriate courses of discussion for individuals with POHS in a Facebook support group. Given the rarity of POHS and the general lack of consistent medical information available, individuals may benefit from having access to the online option of peer support. Online peer support may serve as a central contact for resources and support.

<div align="center">

Chapter Summary

</div>

The tables provided in Chapter 2 describe the six major headings related to this dissertation topic. Researchers provided information about what is known about POHS, vision loss, treatment, adjustment to visual disability, emotional distress, and online support groups. The comprehensive nature of this literature review clearly reveals a gap in research with regard to experiences of individuals with POHS who participate in online peer-support groups. Missing

from the literature is information that would inform rehabilitation practice and address the support needs of people with POHS.

Researchers have not yet clearly identified issues related specifically to individuals with rare eye diseases. Consequently, interventions are not readily available to practitioners or rehabilitation recipients. Identifying and describing the experiences of individuals as they adjust to a progressive, rare, and debilitating eye disease in an online community setting can offer a view to the reader of online peer support that may be beneficial to people with POHS.

In this descriptive case study of a Facebook peer-support group used by individuals with POHS, I describe the experiences of a sample of participants. By collecting and examining the acquired data with careful adherence to ethical standards, it was my intention to gain a better understanding of this phenomenon. In this qualitative research inquiry, I sought to address unanswered questions regarding the experiences of individuals with POHS who are active participants in an online peer-support group.

III.   Methodology

Organization of the Chapter

Chapter 3 includes the following. First, I discuss the focus of the study and the research question. After that, I discuss theoretical sensitivity and follow that with my research design and timeline. Site and sample selection will be next, followed by a clear description of participants. Then, I explain research ethics, followed by depth versus breadth and the theoretical framework. Next, I describe data-collection methods used: interviews, observation, and document collection. Then, I discuss the topic of my role, followed by information regarding the management and recording of data. The next section includes the topic of trustworthiness including prolonged engagement, persistent engagement, triangulation, peer debriefing, member checks, and an audit trail. Finally, I provide a chapter summary.

Introduction

POHS is a rare eye disease that causes people in the prime of their vocational lifespan to lose their vision. Little is known in the way of effective treatment interventions and currently available treatments may increase vision damage and result in unknown and further debilitating side effects. Researchers have conducted few studies of POHS and none to date explored individual experiences of having such an unmanageable disorder or the process by which people are able to manage emotional distress and adjust to their changed lives through participation in a Facebook online peer-support group.

Individuals have limited access to peer support and relevant medical advisement, provided primarily by the individual's retina specialist and familial-support system. Individuals with this rare disorder struggle to adjust to a disability that is a vocational inhibitor, expensive, and inconsistent in responding to treatment, as well as alarmingly irregular in its medical course.

The ramifications of vision loss significantly affect these individuals' abilities to remain in the work force. Lack of medical information and supportive counseling resources are apparent, due to the many unknown components of this disease, which may leave people vulnerable to emotional distress and severe vocational constraint.

This descriptive case study of an online Facebook group focused on peer-support for people with POHS. This research is an important step in the needed discovery of what transpires in this cyberspace venue. By revealing the experiences of these individuals through the process of online peer support, I illuminated the possible benefits of medical providers and others recommending these online peer-support groups as a means of closing the wide gaps in services provided to individuals with POHS.

<div style="text-align:center">**Social-Networking Sites**</div>

SNSs are becoming a reliable and consistent means for individuals to relate over shared topics of interest. People in online peer-support groups can source information and share concerns regarding rare diseases easily and privately synchronously or asynchronously, as well as through archived materials (Huber et al., 2010). Given their significant rise in popularity, it is not surprising they receive significant attention from researchers as they try to define the impact they have on individuals' daily lives (Hargittai & Hsieh, 2010). SNSs are forms of electronic communication through which users create online communities. For this study, the SNS described is Facebook.

Description of Facebook

Facebook is a computer-networking SNS launched in 2004. The initial purpose of Facebook was to provide university students the means to create and maintain social ties that were relevant to their collegiate experience (Ross et al., 2009). Creator of Facebook Zuckerburg

initially launched the site while attending Harvard University. In its original form, Facebook was restricted to users with an .edu e-mail address (Joinson, 2008). After extending to the general public, Facebook became progressively more popular and currently has approximately 728 million users logging in on a daily basis (The Next Web, 2015).

Facebook provides a series of formatted, interrelated web pages to individuals who sign up for its free services. These profile pages are the starting point from which they can link their own profile to others (Wilson, Gosling, & Graham, 2012). The profile page can be filled in with a considerable amount of information about the user and provides a point of jurisdiction from which users can navigate privacy options and general usage preferences (Walther, Van Der Heide, Kim, Westerman, & Tong, 2008).

Major features that promote communication include a private messaging system, a "wall" page that provides the opportunity for friends who have permission to post various forms of communication including videos, messages, photographs, and links; a "news feed" page that displays the activities of friends, which may include photographs, befriending new people, and written messages on others' walls; and a "homepage" page that serves as a central hub, displaying information specific to each user (Wilson et al., 2012). The home page incudes a news feed feature that displays recent content submitted by friends in chronological order.

Facebook allows individuals to control their information and who sees it. Users can modify the settings for privacy on their account and determine which groups or individuals have access to information (Zhao & Grasmuck, 2008). For this study, I focused on the means of functioning and usage of a Facebook group. The moderator of each Facebook group sets the parameters of the group with a statement on the top of the homepage. This description of the

groups' premise and activities provides a snapshot for the potential user to decide if they want to join. This specific proclamation generally describes the group's content.

Facebook Groups

Several months after the inception of Facebook, designers added an important feature called "groups." This feature was added for the convenience of sharing similar topics of interest among members (Xia, 2009). Upon joining Facebook, any member can start a group and invite members who are either in the moderator's network or global members. The group wall is available for all members to read, and display individual posts, pictures, and videos. The Facebook group that was the setting for this descriptive case study was created by its moderator to provide support to individuals with rare eye diseases and is a global group with members added on a regular basis from the general public.

Wilson et al. (2012, p. 212) stated "the sharing of content and personal information on Facebook comes with certain potential privacy risks, including unintentional disclosure of personal information." Participants of groups are made aware of risks by a declarative statement on the groups' wall. By joining a group, participants imply they take responsibility for complying with the group policies and guidelines. For groups focused on an illness, the posted declaimer indicates that group postings are not a substitute for professional medical advice.

<div align="center">

Focus of the Study

</div>

For this research study, I used a qualitative methodology. A case study is an illustrative variation that studies a phenomenon (the "case") in its real world context. It is well suited to a contemporary view of real life such as a specific group of individuals participating in an online peer-support group. Because the individuals participating in this online peer-support group are in a unique and extreme situation, a descriptive case study is an appropriate design. The type of

case study is intrinsic. Stake (1995) used the term *intrinsic* to suggest the researcher who has a genuine interest in the case should use this approach when the intent is to better understand the case. As a classification of a case, intrinsic studies are exploratory in nature, and do not seek to extend a theory or redraw generalizations (Yin, 2011).

Individuals with rare, progressive, and unpredictable eye diseases may find it difficult to combat and adjust to the sudden or gradual onset of visual loss. Symptoms associated with POHS can negatively affect family life, work, and treatment for individuals with this rare disease. Online support groups through social-networking outlets such as Facebook may be an effective medium for people with POHS to participate in a forum that can be tailored to the needs of the group. Identifying and describing the experiences of individuals as they adjust to a progressive and rare eye disease in an online community can offer peer support and resources that may be beneficial to this population.

In identifying the difficult decisions these individuals face regarding work, family life, and treatment, the unique value of online peer support may be revealed. Consequently, support personnel may encourage newly diagnosed individuals to participate. The benefit of online peer support may offset the lack of disease-specific resources and counseling they would receive from more traditional counseling venues or medical providers. Individuals with rare or emerging disorders commonly experience isolation, prolonged adjustment to disorder symptoms, and cultural dissonance due to the obscurity of their disease.

Research Question

Researchers found that current social-media sites offer various benefits to their users with chronic illnesses (Greene et al., 2010 ; Lasker et al., 2005). For individuals with rare diseases, numerous peer-support groups are available on the Facebook platform. Active participants are

able to navigate, personalize, and participate in peer-group support at whatever level of participation they choose. Given the current popularity of social media and the paucity of literature regarding individuals with POHS, the following research question warrants investigation: What are the experiences of active participants in an online Facebook peer-support group for POHS? This study examined this research question to gain a deeper understanding of the unique experiences of an online support group for individuals with POHS.

Theoretical Sensitivity

When the researcher acts as the research instrument, the "objectivity and the sensitivity" to the research and the data "necessary for making the discoveries" (Strauss & Corbin, 1998, p. 43) must be maintained. The researcher's personal qualities influence the theoretical sensitivity of the researcher, contributing to their understanding of the subtleties in the meaning of the data. Sensitivity "refers to their attributes of having insight, the ability for assigning meaning, the capacity to understand, and the capability to separate the pertinent from that which isn't" (Strauss & Corbin, 1998, p. 42). See Table 6 for the timeline of this study.

Research Design and Timeline

Table 6
Research Design and Timeline

Proposal	May 2015
IRB application and data collection	May–August 2015
Writing Chapter 4 and 5	August 2015
Defend dissertation	November 24, 2015

Note. IRB = Institutional Review Board.

Site and Sample Selection

I chose a homogenous sample because the main research question addressed is specific to the characteristics of this particular group (unit). Subsequently, this group of interest was

examined in detail. A homogenous sample is considered a purposive sample, which could be considered at high risk for researcher bias (Patton, 2014). However, the judgmental, subjective component of purposeful sampling is only a major disadvantage when such judgments are ill conceived or poorly considered (Patton, 2002). This research study used participants selected with a clear criteria. Most compelling, each participant carried the specific diagnosis of the rare disorder, POHS, and was an active participant in the Facebook peer-support group. Knowledge integration in a holistic design requires a synthesis process, which is informal (avoiding reductionism and elementalism), empathic, and largely intuitive (Scholz & Tietje, 2002); consequently, the dissertation is narrative and descriptive in nature.

Participants

The online Facebook peer-support group from which the sample was selected was entitled Presumed Ocular Histoplasmosis POHS Support Group and was comprised of 343 members. Primary sources were secured through this existing online social-networking support group in which the investigator maintains membership. Recruitment was achieved through a moderator and an Institutional Review Board (IRB) approved statement I posted to the Facebook site. The statement was pinned on the site until recruitment was accomplished.

I chose individuals who met the criteria based on being the first responding members of the group. I limited participation to three. The sample was comprised of active participants ranging in age from 20 to 60. I selected this site because participants actively contribute to an online dialog and I was added as a member.

The individuals who participate in the group by posting to the site were qualified to answer the research question because they were currently describing experiences online to each other about having POHS. By studying these individuals with POHS, I fully developed a

description of their experiences and conveyed them to the reader. Through document collection, interviews, and pictures, the research question was answered as the process of identifying themes unfolded.

Research Ethics

The rules and regulations of the University of Arkansas IRB were honored and followed at all times during this study. To gain and hold the trust and respect of all participants engaged in the study, the researcher must maintain a high degree of ethical conduct. From the onset of the study, all participants were fully informed of the nature, purpose, and scope of the study. Each participant signed a form to verify informed consent and willing participation. I clarified the right to withdraw from the study at any time to participants. All data collected were kept in a private and secure place at all times.

Depth Versus Breadth

The qualitative concept of depth versus breadth involves the development of thick, rich description. The presentation of a rich and extensive set of details about methodology and context that describe a study enables the reader to judge its believability, and consequently, the value of the study's findings (Denzin, 2001). Readers can learn vicariously from an encounter with the case if the researcher's narrative description (Stake, 2005) is adequately filled with sufficient detail to take the reader into the setting being described. The goal was to ensure that what I learned and reported from conducting this study would add value to the field, as the knowledge gained could be transferred to and used in similar situations (Erickson, 1986).

Data Collection

The data-collection techniques associated with this study included structured interviews, observations (including participatory observation), and document analysis. I conducted

interviews with participants in person, in a discreet and private location of participants'

choosing. I interviewed three participants for approximately 60 minutes each on three separate

occasions.

Interviews. Face–to-face interviews are characterized by synchronous communication.

Social cues such as voice, intonation, and body language can be highly beneficial to the

observant interviewer in gathering data about an individual's experience of a social context.

Consequently, I conducted face-to-face interviews with participants to ensure I captured the

physical and environmental nuances for the reader. Keeping a record of the interview is an

important skill in qualitative research. Preserving the data and meanings on tape and combining

transcription with preliminary analysis greatly increases the effectiveness of data analysis

(Marshall & Rossman, 2006). I comprised a written record of the interview to capture key ideas

(Stake, 1995).

I conducted interviews in person at a private and secure location of participants'

choosing. Conducting interviews with participants included offering any modifications required

to accommodate any visual impairment that may have impacted the individual's ability to

participate. Anticipated examples of accommodations included providing transportation or

ensuring a service animal would be able to enter the venue. Immediately following the interview,

I secured sufficient time and an appropriate setting to document the field notes and make entries

in the research journal (Stake, 1995).

Using open-ended, descriptive questioning enabled participants to speak about

experiences that were important to them, as well as the meanings they attached to these

experiences (Taylor & Bogdan, 1998). I devised interview questions to illicit views and opinions

of participants through the unstructured and straightforward components they contain (Creswell,

2014). "The opportunity to learn about what you cannot see and to explore alternative explanations of what you do see is the special strength of interviewing in qualitative inquiry" (Glesne, 2006, p. 81). Construction of the questions was influenced by the experience of learning as a participant observer, because construction often precedes the interview.

Observation. I captured participants' online interactions on the Facebook site in screen shots. These screen shots contained original posts and responses to these posts as well as instances when the "like" button had been clicked, which would be considered part of the "action" taking place. This type of "purposeful" observation is important to capture as it provided information that added to the study (Wolcott, 2008). I examined and interpreted posts made by individuals as the interactions between or among people (Yin, 2011). I describe these posts detail to provide vicarious experiences for the reader and give the reader the sense of being in a virtual world with participants (Stake, 1995). Additionally, in establishing the credibility of the setting (Facebook), I described the participants and themes in vivid detail. By providing vivid detail, readers can better understand that the account is credible (Creswell & Miller, 2000).

Document collection. At times, individuals may post pictures of reactions they are having to medical procedures directly to the Facebook site, in addition to links and articles that reference issues of interest to group members. I captured these documents, photographs, and articles through screen shots, downloading, and copying. The document analysis comprised website information, individual posts and responses, as well as any available medical records and photographs participants provided. I obtained access to participants' medical records with a signed medical release. I showed and explained a Federal Health Insurance Portability and Accountability Act of 1996 form to participants (Salick & Auerbach, 2006).

Researcher's Role Management

In a unique way, because the observer becomes participant in what is observed, I adopted the path of vulnerable observation (DeWalt, DeWalt, & Wayland, 1998). The participant-observer becomes as fully involved as possible in a social situation where people know they are being studied and understand the agenda. However, "it is not the researchers' perception or perspective that matters but rather how research participants see events or happenings" (Strauss & Corbin, 1998, p. 47). Because the researcher is an observer of actions and behaviors, a certain distance persists between them and those they observe. DeWalt et al. (1998) defined "complete observation" as the instance in which the observer is or becomes a member of the group that is being studied (p. 263)

I am an active participant in this online peer-support group. Having been diagnosed with POHS in 2006 at the age of 43, I have first-hand knowledge of the treatment and adjustment issues related to the loss of visual acuity from POHS. "Past experiences with the research problem or with the participants help the reader understand the connection between the researcher and the study" (Creswell, 2014, p. 188). The strength of the participant-observer's role is that it can provide the researcher with previously unknown information and enhances insight into contexts, relationships, and behavior. The weaknesses are that it is time consuming and requires a conscious effort at objectivity because the method is inherently subjective. I was fully aware of the need to remain objective as I took on the role of participant observer.

Managing and Recording Data

Names of participants, names of any persons mentioned in conversation, as well as names of places were changed to protect participants' identities and maintain confidentiality. Although I include direct quotation from participants in the final report, I continue to protect their identities.

Supervisors and peers will not have access to any documented data that would in any way reveal participants' identities. Original recordings are stored on my computer hard drive, which is password protected. Subsequent to publication of this study, recordings used to collect data will be destroyed.

The nature of the data-collection site is private to a degree. The site has a participant/moderator who accepts requests from individuals who want to join the online group. This group leader has the power to deny membership or to rescind membership at any time, as it is a privately held and moderated group, referenced as a "closed" group on the Facebook social-networking site. Consequently, the group moderator has a displayed post on the front page of the site listing the guidelines members need to abide to continue membership.

Trustworthiness

Prolonged Engagement

Prolonged engagement involves spending adequate time observing various aspects of a setting, speaking with a range of people, and developing relationships and rapport with members of the culture. Prolonged engagement enables researchers to build trust, rise above their own preconceptions, detect and account for distortions in the data, and orient to the situation so they understand the context.

Persistent Engagement

Persistent engagement is accomplished by employing negative case analysis. In brief, negative case analysis eliminates anomalies and selects relevant data through a logical process of elimination. Inferences supported by patterns in data are separated from those that do not. Researchers discuss and dismiss anomalies as random rather than patterned information (Lincoln

& Guba, 1985). To maintain focus on the overarching view of participants' experiences, researchers seek all data; not just the data that make sense.

Triangulation

Triangulation is the use of multiple data sources (Cookingham, 2004). For this study, I observed, structured interviews, and collected documents. Triangulation is critical because it "draws on other types and sources of data and observation, to gain a deeper and clearer understanding of the setting and people being studied" (Taylor & Bogdan, 1998, p. 80). From the multimethod perspective, researchers must use genuinely different methods of data collection independently. The use of different methods in concert compensates for their individual limitations and exploits their respective benefits (Lincoln & Guba, 1985).

Member Checks

A member check is a researcher tests data, interpretations, and conclusions with the research participants from which the data originated. Participants clarified statements and checked to ensure the data collected reflected what they intended to say. Member checks are both formal and informal and take place continually to provide respondents the opportunity to clarify and expand, check data for accuracy of meaning, and confirm the communicants' intentional connotation.

Peer Debriefing

Creswell and Miller stated (2000), "a peer review or debriefing is the review of the data and research process by someone who is familiar with the research or the phenomenon being explored" (p. 129). Due to the obscurity of the research topic, opportunities for scrutiny of the project by disinterested peers were sought for debriefing, as they could provide uncensored responses while protecting the identity of all places and research participants. I engaged in

collaborative sessions to discuss alternative approaches, discuss any flaws related to a course of action, and help me recognize my own biases and preferences.

Audit Trail

An audit trail can add methodological rigor to a study (Wolcott, 2001). For this study, I maintained a record or log of processes that contained all field notes, reflections, questions, and issues. An audit trail is a rendering of how researchers conduct their studies. It is a running record that any observer could use to follow the trail of research, verify the rigor of fieldwork and ensure the confirmability of the data collected to minimize bias and maximize accuracy (Patton, 2014).

<div align="center">

Chapter Summary

</div>

Individuals with rare, progressive, and unpredictable eye diseases may find it difficult to combat and adjust to the sudden or gradual onset of visual loss. Symptoms associated with POHS can negatively affect quality of life for individuals with this rare disease. Online support groups through social-networking outlets such as Facebook may be an effective medium for people with POHS to participate in a forum that can be tailored to the needs of the group. Researchers provided information about what is known about POHS, vision loss, treatment, adjustment to visual disability, emotional distress, and online support groups. The comprehensive nature of the literature review clearly reveals a gap in research with regard to experiences of individuals with POHS who participate in online peer-support groups. Missing from the literature is information that would inform rehabilitation practice and address the support needs of people with POHS.

In this descriptive case study of a Facebook peer-support group used by individuals with POHS, I describe for the reader the experiences of a sample of participants. Researchers found

that current social-media sites, specifically Facebook, offer various benefits to its users with disabilities. Active participants are able to navigate, personalize, and participate in peer-group support at whatever level of participation they choose. Given the current popularity of social media and the paucity of literature available regarding individuals with POHS, the following research question warrants investigation: What are the experiences of active participants in an online Facebook peer-support group for POHS? This study examined this research question to gain a deeper understanding of the unique experiences of an online support group for individuals with POHS.

IV.   PRESENTATION OF THE DATA

Organization of the Chapter

In this chapter, I present the data collected and a description as well as a discussion of those findings. The chapter begins with an introduction followed by an explanation of how I transcribed the interviews. Next, I address the participants, followed by data analysis. I describe open coding along with a matrix of the open codes that led to the axial codes. The presentation of the axial codes follows and subsequent to that a concluding chapter summary.

Introduction

The purpose of this study was to describe the experiences of active participants in an online Facebook peer-support group for POHS. The intent of this study was to describe the prevailing themes contained in the participants' narratives to clarify the needs of this population from a rehabilitation perspective. Asking questions that would answer the study's guiding research query completed the process.

Given the current popularity of social media and the paucity of literature available regarding individuals with POHS the following research question warrants investigation: What are the experiences of active participants in an online Facebook peer support group for POHS? I examined this research question to gain a deeper understanding of the unique experiences of an online support group for individuals with POHS.

I selected this Facebook group because the participants actively contribute to an online dialog and I was added as a participating member. The online Facebook peer-support group from which the sample was selected is entitled Presumed Ocular Histoplasmosis POHS Support Group, comprised of 343 members. The sample comprised participants ranging in age from 20 to 60. Primary sources were secured through this existing online social-networking support group.

The individuals who participate in the group by posting to the site are qualified to answer the research question because they are describing their own experiences online to each other about having POHS. By studying these individuals with POHS, I was able to fully develop and convey a description of their experiences to the reader. Through document collection, interviews, and observations, I answered the research question as the process of identifying themes unfolded.

Researchers found that current social-media sites offer various benefits to their users with chronic illnesses (Greene et al., 2010 ; Lasker et al., 2005). For individuals with rare diseases, the Facebook platform provides numerous peer-support groups. Active participants can navigate, personalize, and participate in peer-group support at whatever level of participation they choose.

Interviews were the primary source of data used in this study. I used standardized open-ended questions approved by the IRB in an informal interview format. The voluntary participants read, understood, and signed the provided informed consent. I also obtained data through observations and document collection. Document collection comprised screen shots of current and archived posts from the Facebook group, subsequently employed to provide additional data for the study and enable the triangulation procedure. In addition, I include photographs posted to the site appropriately as observation material because I was a participant observer.

Transcribed Interviews

Upon receiving approval for the formal proposal to complete this qualitative case study, I contacted and arranged interviews with participants. I interviewed three participants in the Facebook online peer-support group and transcribed the findings. All three participants seemed comfortable and willing to describe their experiences in detail. All expressed support for the study and enthusiasm at having the opportunity to have their voices heard. Interviews took place

in venues of participants' choosing with careful attention placed on accessibility for service animals, if applicable.

I extracted the resulting data from the interviews conducted for this study, then immediately transcribed them. When transcribing the interviews, I made certain the recordings captured the exact words of participants and that their statements and comments were accurate. Participants spoke in an informal and relaxed manner and consequently the wording in the quoted passages was informal and, at times, communicated in incomplete sentences. The transcript depicts casual conversation and includes pauses and repetitive terms throughout. These aspects of verbal communication are indicative of informal interviewing (Patton, 2015, p. 438).

Participants

I report participants' original unaltered words in this dissertation by means of in-paragraph quotations and block quotations. I cite the material with notation of participants' pseudonyms in addition to the page number from the transcribed data. I assigned pseudonyms to participants to protect their identities.

Table 7 depicts the demographic characteristics of participants and the method used to cite their direct quotations from the data. I used the pseudonyms Emily, Penny, and Maggie, in conjunction with page numbers in parenthesis to indicate the location of the quote in the data, to provide clarity and accountability.

Table 7
Pseudonyms of Participants and Audit Trail

Name	Age	Cite
Emily	31	Emily/page number
Maggie	53	Maggie/page number
Penny	46	Penny/page number

Data Analysis

A qualitative study contains a large collection of data that could have multiple meanings. The researchers' challenge, then, is to manage the words, language, and meanings implied by the data and glean from them rich descriptions and understandings of what is being studied (Miles & Huberman, 1994). I employed grounded theory as the basis for how I collected and analyzed data from the case study. Grounded theory is a research method that enables the researcher to develop theories that offer an explanation about the concerns of the population being studied. Several stages are involved in grounded theory including data collection, coding, and sorting.

Developing a manageable classification or coding scheme is the first step in data analysis. Content analysis involves identifying, coding, classifying, and labeling primary patterns in the data (Patton, 2015). Although no set guidelines exist for coding data, I followed some general procedures (Creswell, 2012). By using coding, the data are divided into smaller bits of information that were then compared and categorized with identifying codes (Patton, 2015). I collected and analyzed the data using this constant-comparative method in an ongoing process throughout the study.

The object of the coding process was to make sense out of text data by starting with broad themes. Coding is an inductive process that eventually leads the researcher to reduce overlap and redundancy and reveal emic themes of the study (Marshall & Rossman, 2006). By adhering to the structures of grounded theory the researcher is able to produce theories that are grounded in the data.

Open Coding

Open coding, or first-level coding, yields meaning based on labeling the data. Researchers chunk items together based on the meaning that emerges and record examples of

participants' words establishing the properties of each code. The open codes are the participants own words, verbatim, taken from the transcribed data while the axial codes are themes derived from the categories that emerge. Grouping concepts and organizing them into categories further reduces open codes. Researchers identify and examine the relationships between open codes. Figure 4 provides the reader with a matrix showing how the data were analyzed. The first row of Figure 4 indicates the axial codes (themes). Each column of terms under the axial code is a sample of the open codes, which are the participants' own words.

Medical	Distress	Traditional Support	Loss and Isolation	Online Peer Support	Adjustment	Rehab
Distrust of Medical Professionals	Devastated	Positive Thinking	Lost Friendship	Encourage Someone Else	Not Life Ending	Lost My Job
Conflicting Medical Information	Depressed and Suicidal	We Will Get Through This	Afraid to Go Out	Usually the Answer Is There	Adjust My Expectation	Stressed with the Work
Experimental Treatment	Help Now with PTSD	Invisible Disability	Can't Begin New Relationship	I'm Not Alone	You Just Get on with It	People Ask What You Do
Injections into Eye	Counseling is Nonexistent	Fear and Confusion	I'm Going to Go Blind	Ask for Help	Accept the Worst Possibility	I don't have a lot of Options

Figure 4. Matrix of axial codes with sample of open codes.

Presentation of the Axial Codes

  Medical intervention. The first axial code is entitled medical intervention. What qualifies medical intervention as an axial code is that the data referred to it specifically as the beginning of the experience of having POHS. Participants related common themes to medical intervention including diagnosis and self-advocacy, treatment and injections, decision making, medical rapport, and issues related to the rarity of POHS.

Participants achieved diagnosis over time and with multiple medical professionals. Optometrists, ophthalmologists, infectious-disease specialists, and retinal specialists were all points of contact for participants as they sought a definitive diagnosis for symptoms that included blurred vision, distortion, and spots. Here they describe their experiences leading to their diagnosis of POHS.

Emily described the first time she was told about POHS by her eye doctor:

It was a normal eye exam and my eye doctor said there was scarring old scars. Basically he mentioned histoplasmosis. I didn't know what it was and he said it's always there and if they looked it would be in your tissue. And, um, that I just had to watch it over time or be careful over time but he didn't tell me exactly what to watch out for. (Emily/1)

Emily further stated,

The initial bleed, ya uh huh, so I had, um, I just noticed this small distortion that didn't go away and so I just remembered back to when, what that doctor had said that and well, ok, so I forgot, so you know so like last year I was having flashing in my peripheral vision and I went to the eye doctor and had to do brain scans and stuff. But basically but nothing was ever determined during that period of time. (Emily/3)

Penny shared a similar story and described her diagnosis**:**

I was first diagnosed in 2003. It took a lot of visits to a lot of different doctors because no one could understand what histoplasmosis was, so when I finally did find a specialist, the only treatment at that time was steroid tablets, so I went onto high-dose steroids, 60 milligrams of prednisone a day, and that is how we treated it for the first 5 years. (Penny/1)

Penny also indicated that after the identification of scars, a diagnosis was offered:

At first I was told that I had scars on my eyes they were bleeding a bit and nobody knew what it was at all but it was just one histo spot then another histo spot and then I finally saw the retinal specialist that I'm with now, um, and it was him that made the diagnosis. (Penny/1)

Penny further described her physicians approach to her diagnosis:

I mean, medical wise I can't complain. He was actually good enough to, um, when I was first diagnosed and he said I think you've got this, in fact I'm sure you've got this, um, except its very, very rare and there is only one other person in this area that has seen it, um, so I'm going to send you to him for a second opinion, and because I want you to be

as sure as I am sure. So he actually sent me to a different doctor in a different hospital to confirm his diagnosis. (Penny/17)

Maggie's explained her experience with her diagnosis in an emergency-room setting:

I went to the emergency room in Florida. We had no idea what was wrong. Well, they sent in five doctors and they couldn't diagnose it. In fact they accused me of trying to get a medical marijuana card because it had just come out and glaucoma people could get medical marijuana cards. So they kept accusing me of that and, um, I kept telling them no and, um, and they told me when I got back home to have another doctor look at it then, well, so that was like 4 days, 5 days, and as the days went by it got worse and worse, but it was finally diagnosed when I got back. (Maggie/1)

After the initial diagnosis Maggie, Penny and Emily described seeking further

confirmation of the diagnosis and more information about the health affects they could expect.

Maggie stated,

I went to a infectious disease doctor and he didn't believe me that I had histo because he couldn't see it and it didn't show up on a blood test. But then I found a doctor that is a DO and he is a cross between a holistic doctor and a regular doctor and he completely understands. And so he understood and he has been a God send. He even listens to my natural cures and he says right, that's right, and any other doctor looks at me like hippy chick get out of here. But thank God I found a doctor that understands me. I went through every doctor on my insurance list to find him. (Maggie/9)

Penny stated,

Health issues like the lung spots. I never had my lungs checked so I had to go to my doctor and show them the article and, um, and she was like, oh great. She was absolutely clueless and it kind of annoys me they don't go look it up so they can tell me what's wrong and help me, rather than me going to find these things out and but she did a lung function test and a full range of blood tests to check on the organs and all sorts of things but I had to take the information to her. (Penny/11)

Emily also saw a specialist and stated,

I went to the, what's the word, infectious-disease doctor and it didn't show up in my blood work and so then I think because I wasn't having any symptoms and then because it wasn't, they looked for it in my blood and then couldn't see it, which I guess is very common and then so because I wasn't having any lung issues, they determined I didn't need the chest x-ray. (Emily/9)

Some participants expressed their ideas about how they think they contracted POHS.

Emily asserted,

I mean I grew up in Ohio in an endemic area and I traveled extensively and, you know, they talk about caves and dirt and, you know, travel, and I grew up in a house that was built in 1912 and I've been, you know, I have family in Oklahoma. I've been in the chicken houses. Just there is just no telling. (Emily/7)

Emily went on to express her feelings about "not knowing," (Emily/17) "I just wanted to know what to expect" (Emily/11) and Penny stated, "nobody could explain how I had contracted this" (Penny/2), and, "I had been in the military and was stationed in various locations but I just don't know" (Penny/2). Emily stated,

Not knowing how it was contracted, even if you could just have that, even if it is false belief that maybe an anti-inflammatory diet or limiting sugars. Um, I just think that because of the nature of the disease not being understood and there not being a lot of information and your doctors are not even agreeing. (Emily/17)

Limited information and conflicting treatment approaches appeared to influence the participants' need to advocate for themselves. Maggie stated she pushed for answers because "Doctors make mistakes" (Maggie/6) and "What makes you think Doctors are infallible?" (Maggie/6). Emily expressed "If I don't push things I don't get an adequate answer" (Emily/16). Emily further stated,

Like I left the doctor without really any information even like, um, I remember, like, asking so many questions and thinking you should be covering this and I am just going to go ahead and ask. Oh my gosh and I am not very assertive to begin with, so what if someone is less assertive or what if someone is more nervous. (Emily/18)

Penny expressed her frustration by stating, "It kind of annoys me they don't go look it up so they can tell me what's wrong" (Penny/11) and Emily confirmed an issue with physicians not being informed. She stated,

I don't know if it was, I think it was last year when I had the flashing issue and I mentioned to my doctor that just my primary-care physician, just that I had been diagnosed with POHS and like he started asking me about if I have cats, which we have always had like encountering a lot of misinformation like the cat thing, but just people just not knowing. (Emily/8)

Moreover, Emily asserted, I thought I would be getting pertinent information because I am an informed patient" (Emily/16) and "you just think they are the professionals and even if you are intelligent and you know you and you care you can advocate for yourself but you don't because they are they experts" (Emily/18).

Additionally, the rarity of the syndrome and consequent lack of information appeared to inhibit communication between the individual and the medical provider, as the participants sought medical care. Emily and Penny's statements show how the conversation was cut short by the doctors' lack of familiarity with POHS.

Emily stated,

He wasn't trying to be dismissive. It just seemed like he, I don't know, like maybe he didn't understand the magnitude or didn't think it would, you know, and it was just combined with seeing it, um, and I remember I still had questions but I didn't know what to ask." (Emily/1)

The issues with seeing a general practitioner with a rare condition are many, as Penny confirmed:

You see your doctor for about 5 or 10 minutes and then you come out and none of the nursing staff had ever heard of histoplasmosis and my general practitioner still doesn't know anything about it. My normal doctor, she knows nothing. My general practitioner, they knew nothing about it. If I go and see somebody for any reason, they know nothing about it. Um, I had to go and get, oh what was it that I had? Oh, it was a mole I had taken off my back by the dermatologist and he says "oh what's that?" and I said you are a dermatologist; you should know these skin eye body things. He had never heard of it and I tell him about the bat poop thing and they look at me like, oh, she is one of those that is stark raving mad. (Penny/17)

Maggie added, "I should not have to educate my doctor I mean that is scary as hell to me to have a dumb blonde come in and to tell you" (Maggie/5).

Another concern of participants that became apparent during the interviews was the issue of systemic POHS and the limited medical information available to them about how POHS can

affect their general health. They expressed concern and a certain lack of confidence in their

physicians' knowledge about POHS.

> I told someone whose ex husband who she was really close with had it and but it was more of a systemic thing and but she said he was so sick but its ok because they finally figured it out and gave him antifungal and he is doing much better. So its just (voice rises) that I kind of feel like I have to continually readjust my expectations like, oh, is that what I need to do? Why didn't anyone tell me. (Emily/8)

Emily further stated,

> What was more confusing for me is the flashing in my eye that was unresolved and several years ago I had a series of very serious throat infections like I had this thing called pseudomonas that you're not supposed to get unless you are immune compromised and then an elevated staff infection. So anyways, for me, you know, it was more like so a lot of people have this and nothing ever happens and so what is wrong with me? (Emily/8)

Penny stated,

> My specialist said this can travel and I had initially noticed problems with my vision with vertical double vision and bending of the lines and it was treated as a squint to start off with so I had prisms for a squint and obviously eventually it went on as soon as I was fanatical with doing an Amsler grid near on every day. (Penny/6)

Participants described their apprehension regarding making medical decisions about

treatment approaches. "I mean my ophthalmologist never said you should really see a retinal

specialist" (Emily/18). Emily identified the fears participants shared about making informed

medication choices with limited and, at times, contradicting information.

> What has been confusing also is that it seems like different doctors treat it like the ophthalmologist said you are going to come back two more times for shots but when I got to the retinal specialist he was like, no, we are going to check on you and if you need a shot then, you need it. So that was very confusing too and of course everyone has their own preference. You know, it just goes to show how little it is understood. They can have very wildly different approaches regarding what they think is the best approach. It was hard to switch from the first opinion of the doctor I saw to the specialist because I was like, well, I don't want to just wait and see. I want to but on the other hand, you are the specialist and I want to trust your opinion about this. (Emily/15)

Maggie asserted,

They said to me, Well, this doctor is really good and I said, Have you even been listening to me? I told you the last injection I had I was blinded for 90 seconds. He did that last injection, so I left there completely losing my mind and had to go doctor shopping and these doctors had no idea, like, why won't your eye doctor give you this and he seriously sent me into a mental roller coaster and I finally got another doctor and so my eye doctor doesn't know I am prescribed valium. (Maggie/6)

Maggie went on to state,

These little girls are telling me "bleh bleh bleh" and I'm like, you have no idea what I am going through. You sit in this chair and let him do this to you. Because doctors made major mistakes and that is why I am blind in this eye. So I ended up with worse vision than I had before. (Maggie/6)

Emily also revealed another issue that impacted the treatment decision-making process:

the limited time and surrounding sense of urgency the participants described. A distortion in an

individual's vision can be an indication that a histo spot has become active and is bleeding.

Emily reported her doctor told her "make sure if you have distortion you have to call me"

(Emily/3).

Emily explained,

One time I saw the specialist and I told him, ok, so I'm going out of town and if something happens, do I call you or what do I do or do I need a list of people or do I go to the nearest? What is the procedure, you know, trying to be proactive and, you know, the answer was sort of like, oh its not a big deal. Emily/17)

Emily also expressed her concern about getting pregnant and how that would impact

treatment. She was the only participant who was considering starting a family. Emily described

the risks involved in treatment. Emily stated,

My doctor told me if I was potentially pregnant at any time that I could have treatment and that's all we talked about, so it just felt like, when you are pregnant your body is under a lot of stress and the autoimmune part is so confusing. I don't understand that. But it felt at first like, oh, that is something I am going to have to think about. I would have to choose, like choose between having a baby and risking it all. (Emily/13)

A diagnosis of POHS is often quickly followed by treatment. Maggie stated she was,

"diagnosed and surgery the next day" (Maggie/6). Penny and Maggie were both diagnosed

before the newer more effective injectable treatments became available to the public. Initially,

steroids and surgery were the only options and the results were not always beneficial, as

indicated by Maggie in this statement,

> Usually they can fix it by a laser by just tacking it down, but mine was directly above my ocular nerve and so if they hit it with a laser it was going to kill my ocular nerve all together, so I needed to come in and actually have surgery where they removed my eye, they opened it up and took out all the vitreous jelly out. They did real surgery with stitches, then they did laser surgery, and then they put back in a gas bubble and put it back in and told me to look down from anywhere from 2 weeks to 4 months, and the idea of that was that the gas bubble as I was looking down would rise up and press my retina back into the right place, but it didn't work. (Maggie/2)

Penny asserted,

> When it started, when it started the injections were not available and so I was back on the steroids, which I found horrific to take. Um, I really did not agree with them and they did not agree with me. Um, I still go on them every now and then when he thinks I have swelling at the back of my eye which doesn't warrant an injection but that he wants us to try and get the swelling down. (Penny/7)

As new medications became approved for treatment, the drugs continued to carry inherit

risks, either because they were not FDA approved or the procedure for administration carried the

risk of injury or infection. Participants explained in vivid details trauma related to treatment and

a sense of desperation related to being in uncharted medical territory. Emily described her

experience as follows:

> About a year later and I noticed distortion that was not going away and so I, I called into the office. And they got me in and then it was, it was a bleed and so I had to have a shot. I had Avastin. Just had the shot. I remember getting the paperwork on the medication and it was a big deal to me and I read it. It was business as usual to them but to me it was like this big deal because it was, I was having a bleed for the first time. (Emily/3)

Emily continued,

> I want to read the paper, I want to make a phone call and, you know, I want to all these things that they act is wasting their time, but this is normal. It is what everyone should do and, you know, I don't know. I feel like just talking. (Emily/16)

Emily further explained,

I have this distrust of the medical professional and the medications and, you know, I just don't want to go there and so it was hard for me to accept the treatment and then, and then hard to understand it too because, yeah, they were telling me, you know, this isn't going to affect your heart because it is such a minute amount; its just going into your eye. But then telling me you can't do this when you are having a baby. So what is that? It doesn't make any sense, you know? (Emily/14)

Maggie described her experience:

They have been injecting it and it has got better and in fact I had lost the top right corner of my vision and after the injection it came back. And I've been getting injections ever since. I have had both Avastin and Lucentis and, um, I'm not sure which one, oh, that's right, on my first injection of Avastin. 15 people in my area got blinded by the exact same bottle as I got but I didn't get blinded. They had contaminated the shots when they divided them into doses so everybody else that used my exact same medicine got blinded except for me. (Maggie/2)

Maggie further explained,

The day I went in for the shot, my vision was so distorted. I mean people's faces were stretched and it was like looking at a scary movie. I went into the little room and I was white as a ghost and I headed out of the office to call my mom and then I came back in. (Maggie/10)

Penny described the procedure as follows:

I got an injection into my eye and they kind of look at you and you say well, they have to inject it into the eye and I said, you can't blink, and they actually peel your eye open with a metal clamp and they have the clamp to hold your eye open and you can't move. You have to freeze. (Penny/11)

Penny described her treatment:

So I managed to get into a study, a drug trial, and they used me as a case study for the first injections of Avastin, um, simply because of my age and so I did get two or three injections before it was released to the general public for macular degeneration. (Penny/1)

Penny further stated,

I was on the steroids for a year constant, and it was horrific. It was a necessary evil at the time. I had to just do it or suffer the consequences, but I was so glad when the injections came in, until I got the first one (laughs) and it is quite funny because I go for my injections and they have all the patients there with the age-related macular degeneration and we all go up to the operating theatre and he has a small room there for where he does the injections and they all walk up and back down again, but I get a special chair for after

because I get so dizzy afterwards because I'm such a wimp. So there I am with all these 80 year olds having to walk (laughs). (Penny/12)

Participants described concerns about receiving treatment. These concerns included cost, fear of pain or injury, mistrust of their treatment provider, and an obvious lack of information on the part of the medical community. Maggie described her experience of being uninsured and seeking treatment:

Terrifying! Both times I had surgery and when this eye started to go and they said, "ok, well, you are going to need this shot and it is 1000.00," ok, well, I will go home and figure out how to get the money and they said, "you don't understand. You have to get this shot." So I was flipping out and didn't have any insurance at that time either and so I had to pay for it out of my pocket which I'm so proud that I did and you know I knew I never wanted to piss off any eye doctor. (Maggie/10)

Emily explained her feelings about acknowledgement from her treatment providers:

At the office it was just like you know medical. I just wish that, like, if I could change things and that just it maybe would have been acknowledged that it was a difficult moment because even though it's not like learning you have a terminal illness, you know, but just, I think just anything that happens medically, like that no matter how big or small is a big shift in reality being just like someone asking how are you doing or even just the acknowledgement of it being difficult, I think would have been really helpful. (Emily/5)

She went on to say,

It just always feels so hurried and they are so busy. It always feels like I'm trying to ask questions, I just never feel the gravity of it is considered. And even, like, I remember one time I had a persistent specific floater and which is fine because I know you get a lot of those but the reason, well, I noticed that for about a month, but I didn't say anything and then I was like, ok, this is everyday but then I noticed the distortion. I told them I still have that same floater that I had before and it is very specific and always there and before that preceded my distortion so I felt it was significant and his response was, "yeah, well, you know that's our gift in our thirties, we get floaters" and its like, well, ok. (Emily/15-16)

All three participants had problems with the support they received from their medical providers. "Medical Support was terrible" (Maggie/9). Emily followed by saying,

I think just anything that happens medically like that, no matter how big or small, is a big shift in reality being just like someone asking how are you doing or even just the acknowledgement of it being difficult I think would have been really helpful. (Emily/5)

Emily went on to say,

> There's just really conflicting information and I think talking to my coworkers who were very supportive as well and I told someone whose exhusband who she was really close with had it and but it was more of a systemic thing and but she said he was so sick but its ok because they finally figured it out and gave him antifungal and he is doing much better. (Emily/8)

Summary of medical intervention. It's clear from all three participants that medical intervention was difficult. Making a diagnosis was slow and the doctors seemed to have trouble knowing how to treat the problem. All three participants felt they had no support from medical professionals who seemed to know little about their condition.

Distress. The second axial code was entitled distress. Study participants revealed they experience distress related to fear, grieving, mental illness, and physical pain. Their experiences of distress are evident in the following data.

Fear, as it relates to dependence and being unaccepted, was prevalent in the data provided by Maggie. Fear was a dominant theme in her story. She stated, "So I was flipping out. I was so scared, so terrified, it makes me cry now thinking about it" (Maggie/10) and "I don't like being completely dependent. I'm terrified the way I am now" (Maggie/14). Maggie continued to explain,

> Like, why wouldn't I be scared? Why on earth and now that I have fought for so long I need anxiety medication everyday. I mean driving in the passenger seat of the car, that is scary. I hated flying that way and I hate driving that way. I'm a backseat driver. (Maggie/9)

Maggie also reported she has fears related to other online peer-support group members:

> I worry about the other people on there. I am so far into it sometimes, I am afraid to tell them what I've been through because it will scare them. Sometimes people need to not think about it and my story is kind of tragic, I think, with how bad it went. (Maggie/13)

Maggie stated,

> To just even explain the vitreous buckle that they did, you know, that's more than a horror story. I wouldn't want to listen to somebody say it. I would be screaming at them

"shut up, shut up." You don't want to freak people out completely. Its just too scary. (Maggie/13)

In contrast, Emily talked about reading things online that frightened her about POHS. She

stated,

> I just don't even, you know, I should probably encourage someone else but, you know, I kind of felt like I don't know. Like, I was into it during the critical time but I think if I looked at it everyday or posted more, I don't think it would be supportive and, like, it would be when I need it but, um, just day to day maybe other people can balance it well but for me it's to easy for me to become anxious and scared and I don't want to live in fear so I think that. (Emily/12)

Emily expressed more about her fear about having POHS and the affect it has on her health:

> You know it was more like, so a lot of people have this and nothing ever happens and so what is wrong with me that, and it was very terrifying, like, why is this affecting me and then this confusion? (Emily/8)

Participants talked about struggling with mental illness. Penny and Maggie reported they

had no history of mental illness before they began to experience POHS and the related distress.

Maggie talked about her anxiety as follows: "I was ready to call it quits" (Maggie/7). Maggie

continued,

> I have anxiety hugely and, um, I didn't have it before this. I didn't have it before but now anxiety can really get, and I'm even learning I can calm that, and that is psychological too. It's like, calm it down, calm it down. So but I do and I can mark every one of them with a stressful situation. (Maggie/13)

Maggie further stated,

> I went to two mental hospitals and saw psychologists and then diagnosed me as PTSD but they wouldn't give me any medication unless I stopped smoking pot, but that was the only thing that calmed me down so they just didn't see that I was a different case. It was abuse and I was losing my mind. (Maggie/9).

"And I ended up in the psychiatric ward and there is no help here unless you are a threat to

yourself" (Maggie/6).

Penny talked about her depression,

Um, because before it was like, ok, she's got a problem with her eyes but she's alright. She stills drives and she still working and that it sort of a traditional Scottish thing: you have it and you get on with it and that's what we are very much like as a family. You don't make a meal of it and you don't feel sorry for yourself; you just get on with it. So it wasn't really until then when it was having an impact on work and I was having to stop work and I went into this really bad depression that they really knew that this was severe; it was life changing; it was going to be changing everything I do how I do it and it. (Penny/13)

Penny stated, "I very much want to know why and how did I get this. I still do. Um, it because I had just admitted that I worked through the depression and I was like, ok, we have a problem here (Penny/9). Penny added that "You could be killing yourself inside but you've got good face on" (Penny/15). Penny described in hindsight how her mental illness affected her life, "Not realizing it back then but now I think I have some PTSD for sure. Um yeah, I'm very weary" (Penny/11). Penny continued,

You see a lot more help now for PTSD. Um, because it think they need to realize that the emotional part of it is just as bad as the disease bit of it, um, if not worse. Sometimes, plus the fact that if you don't really know what you've got, you have all these issues going on with your work and your partner and your family; the emotions can I mean. I never thought I as a depressive person. I've never been on antidepressants or anything, so when I hit this kind of wall, I don't know I can't really say the difference between a mental break down and a emotional breakdown, but I hit something and it just shattered me and people don't realize when you're at that stage that it's hard to get you out of it. It's not just something you can snap out of it. You have to go through, it's almost a grieving process. (Penny/18)

POHS is a relatively pain-free illness with the exception of headaches related to eyestrain and the pain resulting from treatment. Pain related to treatment was distressing to participants. Recovery from medical procedures contributed to distress as well.

Maggie stated,

I seriously could have committed suicide because, well, not from the surgery but from the recovery because you had to keep your head down and it hurt so bad and its so hard to sleep because if you sleep face down in a pillow you smother and it would suffocate you and this was when they had not figured out anything about sleeping on a massage table. (Maggie/7)

Emily also experienced pain as distressing. She stated,

It went fine but I remember being, like, you not being able to see from the injection being in a lot of pain, you know, physically and psychologically, and it being really emotional. I know after they left me in the other room I was just crying from just realizing everything. I was just in tears and no one ever addressed it. (Emily/4)

"I just felt like so alone and so devastated" (Emily/2).

Emily went on to say,

I think, too, like the first few days were so traumatic because it was, like, you know, for me, the emotional part was worse but it was exacerbated by this physical pain and so to wake up in the morning in pain, it being sore and itchy, and then, you know, when you wake up after you lose somebody or some other sort of grieving, you are in the grieving process and you know you forget for a minute and then you remember. (Emily/10)

Emily and the other participants described their feeling of grief over the change they

experienced in their health related to having POHS. Additionally, they described not feeling

supported to experience their feelings in the medical facility.

Emily expressed,

That was just fine but no one checked it out and I remember standing at the counter making my next appointment, crying and just feeling like so alone and just feeling so devastated. but the world was just going on like usual. (Emily/4)

Emily went on to say,

I felt like I was walking out of this and I felt like I was in a different world, like an alternative universe, and I'm walking around the office and I'm wanting someone to notice that and or something and wanting some comfort but knowing that no one would even know that I needed it. Like, I just wish that, like, if I could change things and that just it maybe would have been acknowledged that it was a difficult moment. (Emily/5)

Emily further stated,

I know after they left me in the other room, I was just crying from just realizing everything. I was just in tears and no one ever addressed it. That was just fine, but no one checked it out and I remember standing at the counter making my next appointment crying and just feeling like so alone and just feeling so devastated but the world was just going on like usual, you know. It was a devastating moment and a confusing moment and felt this like childlike, like; I was just trying to fend for myself. (Emily/5)

Emily described her recovery at home:

The first few days were like similar experiences of actual grieving: you wake up and you remember, you know, it's a new thing and you wake up and actively remember and, oh yeah, this happened and this is different and then it would hurt and you look awful and so I'd just cry. (Emily/10)

Emily continued,

It was again one of those things where I felt like, you know, when I was in the initial darkness, like, I'm going to go blind. I will never have babies and I will never travel again, so that was the other thing with my friends and stuff when I would describe it and be really real with them. I would say, ok, this is what is happening and you know I am grieving because this is its going to mean this for my life and then just trying to describe, like, how it just makes you aware of all these limitations that you didn't have before. (Emily/17)

Emily described the realization that her life had changed:

I first realized that it felt to me that I would have to chose, like, chose between having a baby and risking … like, everything is a risk and it was just, like, that is a horrible thing, like, that is the most horrible thing I ever heard (laughs), like, I don't want to just it just at this time in my life, it made me feel really broken. (Emily/13–14)

Emily added to her description of distress as it relates to having people be aware of her situation:

It just makes me feel like the feelings I have with my friends, like, you know, if I have a moment, were I'm like when I think about it again and I, it makes me sad or something, that its, like, its not a visible thing. Its not a everyday struggle but for right now anyways but so I was just thinking how I want it to be remembered and regarded as a big deal and so I just feel like sort of like involving people, it's, like, to me it has been and to everyone it's a traumatic thing. (Emily/14)

Penny describes how the distress increased over time,

I didn't know at that stage how bad it was going to be, um, just the constant visits. I was going in every month for an injection and each and every month I was on the steroids I had work asking "when are you coming back to work. We are really short staffed." I was stressed with the eye thing, I was stressed with the work thing, and I was stressed because I couldn't drive. (Penny/7)

Penny went on to describe her distress related to navigating her life:

I just had a near miss yesterday where a guy almost ran me over and he yelled, "are you efing blind" and I shouted back "yes, I am." And he kinda looked at me and I said "just because I don't have a white stick doesn't mean I can see your car coming." (Penny/8)

Summary of distress. Each participant sensed a lack of understanding from family, friends, and the medical community. They all felt as though POHS was causing them much more loss than people understood and that they needed people who understood what they were going through. The loss each felt and the distress over their future caused them considerable pain and emotional trauma.

Traditional support. This axial code emerged from the stories participants told about family, friends, and the community, and their response to the participants' need for support. The experiences they described at times were contradictory, as though their own perceptions of getting support needs met was still developing.

Emily described her family's support this way:

> My experience with my family was really great. We are very close and loving. I was definitely very coddled and, you know, it was just the right way. You, we just cried a lot and just, you know, you know, my fiancé bought me a (laughs), he went to the store and my sister picked me up, you know, 'cause I realized I couldn't drive, so they both came and she got my car and he went to the store. I was so paranoid about it. (Emily/5)

Even though her family is confused and frightened, she described them as, "cocooning her in love" (Emily/6). Emily continued,

> I have a mother and a sister and they were, like, "we are here for you. We are going to pray over you and love you and its going to be fine" and even if this happens, my sister said you could get a seeing-eye pony, a cane one day, if you need it, like listing the option so you know its just made it, like, in moments where I felt more stable. I'm very fortunate that I was just cocooned in love and they were scared too, you know. It was a lot of as far as their support and there was a lot of confusion about what it all is. (Emily/6)

Maggie described her sister's bravery, but also described her difficult relationship with her spouse as follows:

> My sister was very good to me and brave because I cannot image seeing what she saw. I really, my eye looked like hamburger meat but I wasn't really around a lot of family. Then she came to me and at that time I was married to a guy that was kind of crazy and we built hang gliders so we flew, and they didn't like him and at that time he had a brain injury, so I was having to deal with him. He was like a 2-year old. (Maggie/7)

Maggie described her current relationship as "not supportive" and her family's lack of

understanding as a barrier to support. Maggie stated,

> Not much family support. They didn't understand. It scared them, um, and, like I say, its easy to forget something is wrong because I don't look like something is wrong, so I can't blame them, but my boyfriend was absolutely not supportive and in fact I think he took advantage of it and stressed me out more. But getting to the doctor every 3 months is hard. It's in the middle of my boyfriend's day and I try to drive myself. The worst part is driving in the city. (Maggie/6–7)

Maggie questioned her family's values when describing her brother's statement that giving her

heart to Christ may have prevented her illness. Maggie stated,

> I had a very yelling family and they look at me like I'm a '60s hippie. That is just crazy as can be. They are very Bible belt. Speaking of family support, my little brother told me that if I had just given my heart to Christ I would never have gotten this disease. Isn't that something? I'm thinking in my mind, ok, so at St. Jude's children's hospital you don't think those parent haven't given their heart to the lord begging for mercy? You don't think and how could a child die then? (Maggie/12)

Maggie found comfort in the words of a stranger in her doctor's office who reassured her before

treatment. She stated,

> I headed out of the office to call my mom and when I came back in there was a man in the waiting room. He was from the islands or someplace and he said, "sit down here with me" and this is hard to say because it was so sweet (voice catches) and he said to me "when I came to this doctor I was totally blind" and he looked at me and he goes, but let me tell you that "you have long blonde hair" and I just said "thank you, thank you," because that meant he could see me and that one human being that I will never see again in my life and I don't even know his name, I probably would have gone blind that day because I wouldn't have gotten the shot because I was so freaking scared. That helped me so much. (Maggie/10)

Maggie described the practical support she received from her friends,

> Friends were ok but I didn't involve them. I mean, they helped a lot but at the time I was living in a place that had a lot of chicken poop and so I needed a place to stay and really back then they didn't know that had anything to do with it. But did stay with some friends and they got me that massage table and their kids got me a little TV and they put it on the ground and they got me a aquarium hose that I could smoke cigarettes through (laughs) and then would take me out and I would have to look down the whole time and they kinda did get a kick out of it. Looking ridiculous and ordering beer with a straw (laughs) I got to know all my friends by their shoes. (Maggie/8)

Emily described getting a mixed reaction from her friends related to support:

Ok, so I also have a lot of really wonderful friends but I have more frustration with that piece of it because I felt like, um, because its not understood. I felt like I had to convey the seriousness of it while not wanting to feel whiney, you know, but it's like not like anything did anything wrong and I have fantastic friends but because, yes, it's not known and understood that some of them took it really seriously because of my fears and others took it seriously but, um, said "well that's good they have medication for it" or "that's good that they can give you a shot." (Emily/7)

Penny also described her family as being very inexperienced:

Nobody's ever been in an accident, had a major surgery, a dramatic illness like a cancer. We've never had that so its with, like, my brother and I have never lost a parent. His parents are still there so its not something we had ever gone through where we thought, ok, this is really bad but we will get through it. (Penny/18)

Emily continued and talked about what she wants by way of support:

I just feel like sort of, like, involving people, it's like to me it has been and to everyone it's a traumatic thing and to realize that you have this impairment and what it could mean but it's not like you want people to make a fuss over you. Just want it to be, um, you know, deemed important. (Emily/15)

I felt like I was walking out of this and I felt like I was in a different world like an alternative universe and I'm walking around the office and I'm wanting someone to notice that and or something and wanting some comfort but knowing that no one would even know that I needed it. (Emily/5)

Penny reported a lack of community support,

And even then back in 2003–2006 there was nothing. There were no support groups, um, there was not a huge amount of information on the Internet. Counseling is nonexistent here. Um, there were no support groups, none at all. (Penny/2)

Additionally, Penny relayed a lack of information as a barrier to support:

Allister the consultant and he said that there was a charity there that day that dealt with blind people and that I could go and talk to the volunteer that was there so it wasn't until I was there and she was asking all these questions, because she had never, she didn't know anything about it and I thought, well I don't know the answer to half these questions and I'd only recently started using Facebook. (Penny/9)

Next Penny talked about her experience of family support:

I can watch the television but I can't see anything that needs dusting, as my father likes to point out. He asked, "when is the last time you dusted your TV" and I said "I don't

know" and he says "well, do you watch it?" and I said "yeah, but I'm used to watching it in my way, which isn't the same amount of focus that you would look at it" (laughs) and he said "yeah, well I don't really understand that." So I said "hang on a minute" and I showed him the photographs and he said, "oh, that's what it's like?" and it's been so hard to describe it. (Penny/10)

A lack of understanding support is evident in this statement from Penny:

Friends support was kind of difficult because they hadn't heard of it and because I was quite young at the time. Um, I didn't know anybody that was in a situation like that. Support in general was quite difficult because there's nothing they can do really. You don't know what's happening so you can't tell them what's happening and then and I didn't know enough to explain. It was just like, oh, I got this weird thing in my eye that comes from bat poop. (Penny/12)

Maggie also described a lack of understanding: "If you look at me, you know, if you look

people say to me it looks like you're seeing better today. What does that mean? I … what does

that mean? how can you know what I am seeing? (Maggie/5).

Penny described understanding and distance as barriers to support:

Very difficult. My friends didn't understand it and my work friends looked at it as a clinical issue and they'd never heard of it and we didn't have a lot going on with eyes apart from the diabetic retinopathy. Um, so they didn't really understand it and my family didn't understand it at all. Um, I joined the Navy when I was 18, so I've lived away from home quite a while in various parts of the world. My mum and dad, I see them in the summer because they have a camper and I see then probably once a month for 6 months and otherwise we talk on the phone, but by that stage I didn't feel comfortable to do the 4-hour drive there and 4 hours back so it was very difficult. I don't it was only when I lost central sight in my left eye that they really understood what was happening with it. (Penny/12–13)

Maggie reported distance from her family as a factor when she stated,

And when it first happened, I told you it was like a '60s trip. I mean, so I would just close one eye while I drove and the person next to me would freak about it. I'm getting so I don't get to see my family but twice a year because they live 6 hours away. I mean I might have more support if they were closer. (Maggie/8)

Penny brought up issues around culture and support when she stated,

It's all unknown how long, what vision I have is going to last, how long this going to be a problem for. I could be completely blind in 3 months. I could be completely blind at 83. Um, its very difficult to explain and being traditional Scottish people they are not if you ask them for the help they'll give it but they are not the give me a cuddle or this kind of

thing to make a person now that they see I'm not working, they can see, or the house dust or we go to a restaurant and I take a photograph of the menu. (Penny/13)

Penny described having a supportive partner:

Its been really hard because people don't know what you are talking about and they don't understand the affect it has on you and I think having someone to talk to makes a big difference, whatever it is. I was lucky enough I had a partner that supported me. (Penny/15)

Penny referred to her dog Daisy as a therapy dog when she stated,

Getting Daisy, getting the dog. We don't have kids so by choice. But having her, she makes me get out everyday. I mean pet therapy, but she is a bit too excitable at this age, but just having company in the house, just something to talk in the house besides. (Penny/18)

Summary of traditional support. All three participants felt they had support from their family, even though they experienced a lack of understanding regarding treatment and prognosis. Family members were supportive but did not understand what the treatment process entailed. Additionally, friends and family members did not understand that the treatments available did not cure POHS. Participants identified driving and mobility related to completing their activities of daily living as difficult. They acknowledged the effort they needed to exert to complete these tasks as taxing on their energy. Family and friends had a difficult time understanding the extent of their vision loss and consequently did not always provide appropriate support.

Loss and isolation. The data revealed a significant experience of loss on the part of the participants. Additionally, participants' feelings of isolation were quite apparent in the data. Here they described their experiences of loss and isolation.

Maggie expressed her isolation by identifying her isolation related to having POHS: "I don't know anyone at all who goes through what I go through" (Maggie/5); and Penny stated, "I felt very isolated" (Penny/2). Maggie described her lack of peers:

I really haven't talked to anyone outside of posting and reading the group. I was a virgin until now really (laughs). You are the first person I've spoken to. I have never met or

spoken to anyone that has gone through anything close to something like this. You know, its all old people in my doctor's office. They are lined up getting their diabetes shots or macular shots. (Maggie/11)

Emily described wanting to be alone:

The first week, like, I avoided people's expressions, like, I think all except my family and fiancé who were present, I think. I don't think I saw anybody else that week I was just so devastated, like I just stayed in my bed or on my couch then. (Emily/10)

Participants described their awareness of losing their independence and how that has

affected their relationships. Finding new friends and maintaining relationships was an issue of

concern for participants. Maggie described her concerns about new relationships:

I don't walk into store with, like, the things that stick out (fixtures). I cannot be around that. I need guidance so, like, trying to make a new friend is like, you wonder if you say that the burden right there scares them into thinking OMG, I don't want to watch her go through the rest of this. You know, it's kind of like knowing someone who is dying. It's like, can I actually handle going through this with them and I couldn't imagine trying to start a new relationship or something, you know dating wise, you know it's only fair to pretty soon, you know, tell them. (Maggie/13–14)

Penny described a feeling of standing still as others are moving forward in their lives:

You can keep in touch with people from work. I had considered them friends (laughs). They obviously didn't there. Life went on and mine kind of stopped, um, so I didn't just lose my job; it was my self-respect, my pride, um, my friends, my social life. It was really really difficult. See, I wanted to the study because I thought, well, maybe when I do get to the stage and I can go to college. I'd like to be a counselor. (Penny/14)

Participants described their experiences of being unable to participate in activities they

could do prior to having POHS. Activities such as shopping, driving, and merely leaving the

house became difficult and this increased their experience of isolation. Penny explained,

I left the house. I was crying and I wouldn't go out because I would see people that I knew and they'd think I was being stuck up and not speaking to them. Um, I couldn't go to the shops because I couldn't see. (Penny/8)

Penny shared how people treated her differently:

I might be blind but I am not deaf. Um, and just because I can't see, I can still hear (laughs). It's quite funny because you tell people you are partially sited or you are

partially blind and they start talking to you like you're 90 years old, so it was then that it hit me. It was very invisible. People don't know. (Penny/8)

Maggie described her lack of mobility,

So my family, they wouldn't ride with me. I mean they new I couldn't drive very well. I mean nighttime was out of the question. I drive very seldom now; it is so nerve racking that I pretty much stay at home. Which has quarantine me in a way. The bright lights hurt and the sun, I mean. (Maggie/7)

Emily revealed her thoughts about reading the stories of others:

People are like, yeah, I remember when I could drive. I had to change careers. I mean, yeah, what do you do. I, they need I mean especially in these horrible scenarios they need to express that and it is not their fault, but it is like, yeah. I don't know, just the realization of how bad it can get. (Emily/17)

Emily described her feelings of having limitations:

But that was a whole other thing because I like to be in the, in the dirt and be in places where I'm way out there and it was again one of those things where I felt like, you know, when I was in the initial darkness like, I'm going to go blind. I will never have babies and I will never travel again, so that was the other thing with my friends and stuff when I would describe it and be really real with them, I would say "ok, this is what is happening and you know I am grieving because this is its going to mean this for my life" and then just trying to describe like how it just makes you aware of all these limitations that you didn't have before. (Emily/17)

Maggie spoke about her history of feeling isolated with POHS:

I'm getting so it has just completely slowed me down now, so I don't get to see my family but twice a year because they live 6 hours away. You are the first person I have ever spoken to who has this disease and I have had it for over 20 years, since 1994. You are the first person. (Maggie/8)

Maggie described feeling dependent on others: "I'm completely dependent on my boyfriend and,

bless his heart, he takes care of me but I don't like being completely dependent. I'm terrified the

way I am now. I want to be making friends but I mean" (Maggie/14).

Penny explained how she felt her health was significantly altered:

I get very bad headaches and I think it's the stage my eyes are at or I think it's the fact that I'm trying to compensate. She thinks is probably the mental effort that I am having to put into things and that I can only work like that for so long and then I need to rest. I find that I need to sleep for about 2 hours in the afternoon to function in the evening and when

I say I get tired, its not like I just get tired. I get like a painful achy tired and I just can't, just can't function after that period of time. Um, certainly I have glasses for distance and short site and contact lens and my reading glasses. I have three things going on at the minute and bifocals and trifocals I just don't have the balance for that. Um, I was in a car crash so I have a kind of numb right leg and I kind of tend to trip up over that or anything. (Penny/21–22)

Emily conveyed similar sentiments about her health:

I'm in a place of gearing up for new beginnings and I'm already broken, like I feel old or like I feel just like my health I wrecked, which it's not, but there is just, like, this weird thing, this very serious caveats that no one your age has or is dealing with you and that you are in that place of planning your family. (Emily/14)

Penny spoke about preserving her sight:

I could do to protect them. I was, I was very much aware if something happened to that one, then I was jiggered. Yeah, it was always in the back of my head. As soon as it hit my left eye, that was me, really. A real downslope then because I thought, oh crap, here it goes and it then became much more real because where the left eye had been covering the right eyes issues, if the left eye had a spot in the place, that was it, it was gone. (Penny/6–7)

Penny expressed her feelings about losing her central vision:

You can't snap out of it. You have to go through it. It's almost a grieving process and you have to go through it before I came out the other side and it was very much almost to the extreme that a close person had died. (Penny/18)

Penny described the isolation she experienced:

The other thing that made a huge difference was getting Daisy. Getting the dog. We don't have kids so by choice. But having her, she makes me get out every day. I mean pet therapy, but she is a bit too excitable at this age. But just having company in the house, just something to talk in the house besides the walls. She makes me go out of the house. I used to stay in for 7–10 days because it's so easy. I could do everything—Internet shopping—and never leave the house and get things online and just sit in your own wee world. (Penny/18—19)

Summary of loss and isolation. The axial code loss and isolation revealed the state of mind of the participants after they received a POHS diagnosis. As the gravity of their situation unfolded, they had a deep sense of loss and isolation. All three participants felt concern for every part of their lives.

Online peer support. The fifth axial code is online peer support. The data revealed a sense of community, access to information, and shared experience were vital components to the participants when using online peer support.

Emily and Maggie spoke about their feelings of not being alone:

Honestly, like, the support group was very helpful in just seeing, you know, like basics, like knowing I wasn't alone knowing other people were living with far worse conditions, you know, and knowing other people knew what it was like. (Emily/9)

Maggie agreed, saying, "just reading what people say helps me a lot just to know I'm not alone" (Maggie/11).

Participants talked about what made them seek out online support and how they ended up in the group. Penny and Emily were trying to find answers online. Emily expressed her reason for getting involved:

I would say once a month, but initially it was like 10 times, immediately it was like instant support, which is comforting, and also kind of alarming. I mean because I was just trying to determine like how big of a deal it was, um, so I guess 'cause my first, like the reason I became involved, was because I had my first bout of activity in my eye so I had to get a shot so, um, it was upon it sort of becoming so more real that it and I felt like the response was just, yeah, just supportive. (Emily/2)

Maggie stated, "Medical Support was terrible and that is why I looked for this group" (Maggie/9). Penny added, "So I was basically just looking up things on the Internet and answering things myself" (Penny/2). After Penny found the online peer-support group she stated,

So I find that the groups, I feel so much better knowing I can put something on Facebook and knowing I will get a response or reply almost automatically. I may be on the computer at 1, 2, 3 o'clock here and, um, but there is always someone says something and even if it's I agree and I went through something like that, it makes you feel better. I think having someone to talk to makes a big difference, whatever it is. (Penny/15)

Maggie stated just reading the posts alleviates her feelings of isolation:

After I found this group it was such a blessing and it was a good year after I started getting my second eye taken care of that my boyfriend accidently found it and I was like, "you are kidding! Thank you." You know, some outlet to, you know, like I said, just reading what people say helps me a lot just to know I'm not alone and to see how quickly

answers do come up. You know what I mean? They will divulge the information. They are so helpful. (Maggie/11)

Emily concurred that using the online peer-support group abated her feelings of being

alone:

> Honestly, like, the support group was very helpful in just seeing, you know, like basics. Like, knowing I wasn't alone. Knowing other people were living with far worse conditions. You know, and knowing that other people knew what is was like to get the injections. You know, like, that was just really, really helpful. (Emily/2)

Emily stated she felt online peer support provided more access to information than her medical

provider:

> I remember that, you know, I had a pretty significant bleed and I remember, like, eventually I called my doctor and, you know, they were nice and I texted a picture to whoever was on call and they were helpful in that way, but during that time it was the online group that felt a lot more accessible than the doctor office. Like I had, like, 80,000 questions that were not answered at the doctor that I think what was most helpful about the group at that time was that I could go in and say, "hey, ok, should this happen or what do you think about this or was this your experience" or, um, just like logistical. You know, it was like that for what to expect and what's normal. (Emily/9–10)

Maggie talked about how responsive the group was to questions:

> I do see that people get rapid responses and I like that. I mean if it wasn't that the answer has already been given, I would, but I think I am an extreme case and I think I could help people a lot but in general they have already gotten it covered already. I haven't asked anything but I have posted and there are people out there with worse. I guess I don't want to be redundant. (Maggie/11)

Maggie continued,

> But in general, I don't see any cases that are worse than mine, so I just keep an eye on them like a momma would. Until there is a question I need to answer, I just read the posts to see where I can answer and I'm sure I have answered a couple times. But pretty much I read it. (Maggie/12)

Maggie described how immediacy of access is a helpful aspect:

> I respect it and have never seen a troll on there. You know, you can have to wait until Monday to talk to your doctor and with this, people can say this is happening and this is happening and they can read it and reread it. I think I will start writing more because I worry about the other people on there. I am so far into it sometimes, I am afraid to tell them what I've been through because it will scare them. (Maggie/13)

Penny agreed, pointing out the notification feature on Facebook:

I definitely visit the group probably every 2 or 3 days. I've got it set up so I get a notification. If anything new gets posted, I pop on and have a look. Um, it's given me so much information just in the last 6 months of joining the group because I have only been on the group for 6 months, if that I've learned so much more. I am constantly asking questions. (Penny/4)

Emily pointed out another aspect of the notification system on Facebook:

Its really like, yeah, if those things come, you deal with it, but you don't know how to prepare 'cause you don't want to be in denial. I have notice at times when I haven't thought about it as much. If I see a notification or something (laughs) on my Facebook feed its like, ahh, oh, you know, hmmm, you reminded me. (Emily/11–12)

Penny further explained how she can gather information and also give information to

other members:

I was thinking about things and how I was going to explain it and I thought, I'm going to see if there are any face groups and Facebook groups on it and that's when I found the one we are on and another one here are two histo ocular histoplasmosis groups and so I joined both of them and it's basically been so enlightening and it's been so rewarding as well in a way because people are in the same situation I was in 10 years ago and they're just coming up to the stage where they're having to stop work and things like that. It's great that I can get advice but it's also great that I can give it. (Penny/9)

Emily also viewed the experience of other members as beneficial and stated,

And there not being a lot of information and your doctors are not even agreeing and I think the fact that you can crowd source and just kind of survey and have a community is essential. Like, I don't know what I would have done without, you know, just the frame of reference and just experiences and encouragement and, um, even just referrals. I mean my ophthalmologist never said you should really see a retinal specialist. I thought, shouldn't I be? I don't know that I would have known to do that. I wouldn't have known all kinds of things. (Emily/18)

Penny described the benefit of sharing the information from the sight with her dad:

It's also the pictures that people post. Um, somebody put up a post about what it looks like for a person with histo to look at things and it was blurry pictures and it was great because I could download them and I could show my other half and my mum and dad see that's what I see when I look at things and they had never really understood because none of them have partial vision or blindness or anything like that. They don't understand that I can and what I can't see. (Penny/10)

Penny talked about posting to the group,

Some of them are big long chatty posts and some of them are a lot of information in them but you always get something. I've looked at photographs. I've looked at chats. Sometimes there is no answer but I would say nine out of 10 times there is, or there is something you can follow, um, at least a lead that you follow. I haven't done a huge amount in the archive search but it is definitely a resource I can look through if I have any questions. (Penny/21)

Penny acknowledged her experience might help others:

Basically been so enlightening and it's been so rewarding as well in a way because people are in the same situation I was in 10 years ago and they're just coming up to the stage where their having to stop work and things like that it's great that I can get advice but its also great that I can give it to people who are just coming through the things that I had to go through. And I had such a hard time with it. I'd like to think that hopefully I'd like to think it would help them get through it quicker and easier than I did. (Penny/9–10)

Penny continued and added her thoughts on group members who are at different stages of having

POHS:

Posting in the group, I always find really good. I always get a good response. I always get a varied response. I get some short answers, some long answers. Um, I think it's really, it depends what stage your disease is at. Um, if someone hasn't experienced that then they will say, "well, I'm sorry about that. I hope it gets better" and even that's nice; the fact that they have taken time out of their day to do that. They just say they hope it gets better and that's a really good thing in and of itself. Um, but the posts that I find have been very supportive have been always said, "come back and let us know how you get on" and reciprocate and you feel you are helping someone as well. (Penny/21)

Emily spoke about the down side to being at a different stage and how it can be

confusing:

I'll say that the hard part about the support group was it made it more confusing for me to categorize it or frame it because I felt like, you know, there were some people where it was like, you know, like people who were living and doing fine and it wasn't really that, you know, it didn't interrupt much and then it felt like there were these people who were blind. (Emily/10)

Emily continued on the topic of different stages of POHS:

People are, like, yeah, I remember when I could drive. I had to change careers, I mean, yeah, what do you do? I, they need, I mean especially in these horrible scenarios, they need to express that and it is not their fault but it is like, yeah. I don't know, just the realization of how bad it can get. But then its like you don't want to live in fear of that because it might not happen. (Emily/17)

Emily further stated,

> If I see a notification or something (laughs) on my Facebook feed its like, ahh, oh, you know, hmmm, you reminded me and it's like, oh, but its like that thing when I almost felt like to be a friend that was using a friend. (Emily/12)

Maggie agreed and added her thoughts about the difficulty with posting:

> I don't post often at all but I read it all the time and usually the answer is there; that the answer I would get has already been given. The advice is there and one of the reasons for that is that it is so hard for me to type. You know what I mean? I have such poor vision, it's hard for me to do all the typing. (Maggie/3)

Penny addressed how she handles eye fatigue when using the site:

> I enjoy it so I do it but it's a bit like on the computer, the more intensely I am focusing on reading, like, if I'm reading a document, I can only go for so long, whereas if I'm just flicking through pages, I can go longer. (Penny/22–23)

Penny expressed her experience of being able to give back to the online group:

> Because of the histo site I gave something to somebody else who thought they had lost something they loved through the Facebook site. So it's very much, it's not necessarily limited to people with histoplasmosis and I think we've got a really elderly population there and eye issues. (Penny/24)

Emily described how she uses the group strategically to meet her needs for support:

> When I was in the depths of despair, I was posting all the time and I needed input and I needed comfort and then now I just don't even, you know, I should probably encourage someone else, but you know I kind of felt like I don't know, like I was into it during the critical time but I think if I looked at it everyday or posted more, I don't think it would be supportive. (Emily/12)

Emily described getting some insight into her process of using the online support:

> The first time after I posted that someone I remember it was after I came out of the initial darkness and you know, and I remember it seemed so desperate and so desperate and so, so sad and I remember feeling a lot of compassion for her and it was just so interesting because it showed me what it looked like when I did that. (Emily/12)

All the participants agreed the online peer support group was beneficial:

> Its essential to have something like this for something that is so misunderstood. I mean that is really amazing and that just gives you hope for just that you can have fortitude and that, and that, yeah, at least people are on there. It's very humbling. (Emily/19)

Penny agreed and added,

Facebook has become very important to me because of that, because I have no facility to ask people the questions here. I felt so isolated with this. Nobody had heard of it and nobody had it and I think more than anything I appreciate the support there. (Penny/24)

Penny added,

I may be on the computer at 1, 2, 3 o'clock here and, um, but there is always someone says something and even if it's I agree, and I went through something like that, it makes you feel better because you don't feel so alone. (Penny/14)

Summary of online peer support. The participants all found value in having a place where they would learn, find information, share experiences, and have support from others who were dealing with POHS. Using Facebook as a tool to locate others with POHS and learn about shared experiences was helpful to the participants.

Adjustment. The sixth axial code is adjustment. I identified adjustment because the participants described moments of adjustment that were pivotal in how they experienced their world. Physical and emotional adjustment manifested for participants differently.

Maggie protected the stability of her vision with her consistent self-care routines and she reported,

I actually haven't gotten a injection now in, its probably been 7 months, maybe even longer, that it is starting to hold its own and I can attribute every bleed to stress. A very stressful event will happen and if I get way stressed out it starts doing it. Since then I've gone on to study yoga and mediation and I can identify my triggers but, um, I'm in a relationship and there's triggers there (laughs). He hasn't studied any of the meditation for himself, but yes I've learned my triggers and how to calm it down and how to get my breathing and stress level down. (Maggie/2)

Penny also explained how she protects her vision and uses an Amsler grid to be aware of any active histo spots.

I was fanatical with doing an Amsler grid near on every day or at least I made up one as a template and I would check it every day, um, and then do a blank one every week. Um I was much more conscientious of what I was doing and wearing safety glasses and doing like [do it yourself] at home, putting up a picture things. I was wearing my glasses more whereas before I wouldn't do, that if I was just hammering a nail in. So certainly things

like that, anything that I could do to protect them, I was, I was very much aware. (Penny/6)

Emily also described her experience of having her vision stabilize**:**

I felt like, oh, ok, so people are living and going on so this is not life ending or anything and, um, I don't know, just not knowing on that scale and still, um, and now it has been stable for so long I kind of forget about it. I just don't think about it everyday. (Emily/11)

Maggie described her use of assisted technology:

It is so hard for me to type, you know what I mean? I have such poor vision, it's hard for me to do all the typing and stuff. Um, I use voice to text sometimes but I always forget to use it. My boyfriend got me a bigger phone so I can blow up the screen and my text letters are huge, so but I'm doing it but seeing the actual keys. Well, that doesn't change, but I can see, but it's funny to see one of my texts. You can only see but two letters at a time and I assume it doesn't go out that way and it's just that I see it that way. (Maggie/3)

Emily shared her experience of using her mobile phone, like Maggie:

I don't see everything, like on a piece of paper, they've taught me with my mobile phone, take a photo and then expand it and so when I go to a restaurant now I take a picture of the menu and I can actually see the menu and it works for a lot of other things as well, so technology is definitely coming more of a friend than an enemy, but I had a terrible time with my work, although I was a podiatrist, a lot of it was inputting into the computer as well and that was the first thing I found I really struggled with was typing. (Penny, 3–4)

Maggie talked about preparing for her vision to get worse:

I tried to actually prepare myself for if and when this one does go, you know, that I would be a little more prepared, but I don't think you can prepare for that. I really don't think there is a way to do it and by doing that it messes with my positive thinking, that it's not ever going to happen. You know, the more you think about it, the more I think it can happen. I really do. In fact, when I first had it happened in this eye, everyone flipped out and I said luckily I still have this I and I said and I told myself, I know when the other eye starts going they are going to have come up with something and no doubt they did just shortly before this eye started messing up. (Maggie/3–4)

Emily also described how she deals with the uncertainty of her illness:

So I was just trying desperately to understand and there is no, there wasn't a standard at all, and so I was or had a very difficult time adjusting, like what do I expect. You know, you just want to know, ok, I have to deal with this so how do I prepare myself for and what do I expect from now on? What is my reality going to be and that's an impossible one, so I just, um, at first it felt like I had to accept the worst possibility. (Emily/11)

Emily continued,

Like, the first week I was just absolutely certain that it would only be a matter of years before I lost my vision and then talking to people it was like, oh, this could be the worst of it which, you know, I didn't, it was like that was so relieving, like, that conversation was the first peace I felt that whole week. (Emily/11)

Emily described her experience of adjusting to her medical treatment:

'Cause I kinda felt like I just had to be tough. I just felt kinda, like, I just had to stop crying. Like, we are about to do this thing and it was all very urgent. Yeah, just, yeah, there wasn't a lot of time to adjust to it. (Emily/5)

Emily further stated,

That I kind of feel like I have to continually readjust my expectations. Like, oh, is that what I need to do? Why didn't anyone tell me and actually I don't know if it was, think last year when I had the flashing issue and I mentioned to my doctor. (Emily/8)

Emily talked about her experience of the reality of having a chronic illness:

To realize that you have this impairment and what it could mean. Its not like you, you want people to make a fuss over you, you just want it to be, um, you know deemed important. (Emily/15)

Penny shared the rarity of the syndrome:

I didn't know that only 5% of people who get histoplasmosis get ocular histoplasmosis so now I've got something that I don't know how I got and I only had a 5% chance of catching something I never should have caught and you think how lucky am I (laughs). But, um, I've learned more and more. (Penny/5)

Emily added, "It just makes you aware of all these limitations that you didn't have

before" (Emily/17).

Penny shared her experience of adjusting to working with her illness:

But along a similar vein, I definitely read all the posts and replies. Yes, both eyes. Started in the right eye and then about 5 years later it was in the left. Um, my central vision is gone in both eyes I was very protective. Having found out it was caused by a fungus of the right eye, I went from being and I became extremely cautious being around a fungus or a potentially fungus nail. Um, it was my good eye which covered the right one, um, so I would be extra careful with the drilling and the filing. I'd be wearing a mask for a longer period. You used to just wear your mask while you were doing the treatment but then you would take it off when you were finished 'cause obviously you can't talk, you the patient, very well with it on. Um, but then I started wearing it whilst I was cleaning up and things. (Penny/6)

Penny continued,

> We had a treatment chair in the room and then we had a computer further over and the cleaners would come in and dust the computer, but we would clean the medical equipment and so it became standard for me to use an alcohol wipe to clean the computer and all the desk and everything as well. Just more for myself than I was much harder on my colleagues or any students that we had through for not wearing their masks. (Penny/6)

Penny talked about adjusting to the idea of having a disability:

> I didn't want to go to services for the blind to start off with because I felt it was kind of admitting defeat and the disease had given me a disability and I don't I mean I have medical conditions but I don't consider myself disabled because I have always been taught, where there is a will there is a way, and so I should just do things differently. (Penny/3)

Penny explained how she is adjusting to low vision:

> I can't type anymore because I can't see the keyboard. I can't see the letters on the keyboard so I do everything on my tablet. Um, I find that it is quite hard to focus on the screen because I don't see the whole screen and, um, its very hard for my eyes to take in all the information and I actually get quite bad headaches now if I'm trying to do something that requires concentration. I don't do much on the computer anymore. I like to focus on the things I can do now rather than the things I can't. So I have a couple of [Facebook] groups I'm on. (Penny/3)

Penny described how she accommodates her low vision**:**

> I have to peer at the top of my glasses to read. Yes, I read more posts than I write for sure. Um, I'm still just going through the process of adjusting to being partially sited so, well, I'm figuring it out. (Penny/5)

Penny continued, describing how someone taught her to use her phone as a reading device:

> I don't see everything, like, on a piece of paper. They've taught me with my mobile phone take a photo and then expand it and so when I go to a restaurant now I take a picture of the menu and I can actually see the menu and it works for a lot of other things as well so technology is definitely coming more of a friend than an enemy, but I had a terrible time with my work, although I was a podiatrist, a lot of it was inputting into the computer as well and that was the first thing I found I really struggled with was typing. (Penny/3–4)
>
> **Summary of adjustment.** As participants learned more about the effects of having

POHS, they also learned more about the related issues that caused their limitations. These

limitations create a need to adjust to their situation and change the way they do things. Two of

the three participants acknowledged they struggled with their adjustment to POHS.

     Vocational rehabilitation. The seventh axial code is vocational rehabilitation. This

theme was primarily recognizable for its absence. For these respondents, rehabilitation has been

an uninitiated process. By there own efforts, they have begun the process, but they remain

largely unaware or unable to qualify for services. This minimal achievement has come about

essentially from each individual's determination to, in the words of Penny, "think outside the

box." Maggie reported some progress after her vision had stabilized and stated, "Since then I've

gone on to study yoga and mediation" (Maggie/2). Vocationally, two of the three participants

were out of the workforce and none were receiving any type of benefits or retraining.

     Maggie described her previous work life:

     I go blind in one eye so who the heck is going to buy planes from us. I can't land it and
     he can't say it (laughs), so we lost everything. It was really weird! Everything got taken
     away that we ever wanted in our lives and we had done that for 18 years and traveled all
     over the world. I traveled with a professional hang-gliding team with 36 single guys and I
     traveled around doing competitions and shows and stuff but it took all that away. With
     that went a lot of friends, too, but the drinking buddies stuck around (laughs), but they
     would take me out and help me out. (Maggie/8–9)

     Penny also described what work was like for her:

     I loved my job. I used to do all the training courses and learning new things and being
     this, I did all the acupuncture and things and I always kind of leaned to the holistic side. I
     liked to use essential oils, tea tree oil, um, marigold acupuncture rather that the surgical
     thing, so now it's almost like something is being taken away but something is possibly
     being given and that's always what my grandmother, she was always my best pal. I was
     raised by her in a wee village. She was always very much, oh, I loved her to bits. Every
     cloud has a silver lining and that's the way I have always looked at life and it's like, ok,
     you might have that but. (Penny/14)

Penny continued to reveal her challenges with employment:

     I always think, because I have my practical head on as well, I think I can't really, well, I
     don't have a lot of options of what I can do. I can't work in a shop because I can't see the
     till. I can't type in an office because I can't see the typewriter. You, its, I liked being a
     podiatrist because I could work for myself or I could work for somebody else, um, and it,

I think it would give me a lot as well as giving someone else a lot. Its really funny because I had always thought I almost chose counseling as a career. (Penny/14)

Maggie expressed pride in her career achievements:

And when it first happened, I told you, like a '60s trip so I would just close one eye. We were designers of hang gliders. We were in big magazines and we designed the first amphibious ultra light airplane ever to be built. (Maggie/8)

Maggie continued and explained why she feels unable to work:

With my anxiety from all this I just can't see myself working a regular schedule. Because it's on and off and the brightness is difficult and the darkness is hard, so what can I do. It's a shame because I want to work with people. I used to be such a people person. In hang gliding, I travel with a lot of people, you know, and we traveled all over. (Maggie/14)

Emily expressed her concerns about not knowing what to do:

I don't think about what a person is supposed to do if they don't have vision and that is really alarming and humbling and convicting to me, like, that needs to be considered but if you don't struggle with it you don't consider it and there are so many things that are a huge impediment, um, so that's something too. (Emily/19)

Emily continued to describe how she doesn't know how to prepare herself for the future:

I felt like, oh, ok, so people are living and going on, so this is not life ending or anything and, um, I don't know, just not knowing on that scale and still, um, and now it has been stable for so long, I kind of forget about it. I just don't think about it everyday. Some people talk about changing jobs and that they can't drive anymore and I can't and its really like, yeah, if those things come, you deal with it but you don't know how to prepare 'cause you don't want to be in denial. (Emily/11)

Emily continued,

It gives you hope that they are on there even when they have changed careers or something. Like, this person is using this filter or this person is using technology. I mean that is really amazing and that just gives you hope for just, that you can have fortitude and that and that, yeah, at least people are on there. It's very humbling but I still even, given my job, have not given a lot of thought to resources for people with disabilities before or ever, ever, and I come from a social work background where I am more likely too, but still I never think about that. I don't think about what a person is supposed to do if they don't have vision and that is really alarming. (Emily/19)

Penny also discussed her lack of preparation:

I could have been medically discharged out of my job but instead they sacked me under the disciplinary act for absence at work, which meant I didn't get a pension I didn't know at that stage how bad it was going to be, um, just the constant visits. I was going in every month for an injection and each and every month I was on the steroids I had work asking, "when are you coming back to work. We are really short." (Penny/7)

Penny continued,

I was off work for quite awhile. By that stage I had stopped night driving and I really didn't like to drive anywhere because I was conscious that even though I was still legal, I was knew that I had a blind spot. I was off work for quite a while with work-related stress because I knew that I was struggling to see for any fine detail. They did not help at all. (Penny/7)

Maggie reported her experience of not working and trying to make friends:

I want to be making friends but I mean the first question people ask is, "what do you do?" and of course I have to come up with some clever answer or thing that I can say that doesn't make me seem just worthless. (Maggie/14–15)

Emily stated she still works, "I am a intelligent person and I am a professional"

(Emily/16) and "I mean I am still paying the bills but I have insurance and a good paying job"

(Emily/18). Emily continued to express her concern about having an "impairment":

Its not a visible thing. It's not a everyday struggle but for right now, anyways, but so I was just thinking how I want it to be remembered and regarded as a big deal, and so I just feel like, sort of like involving people, its like to me it has been and to everyone it's a traumatic thing and to realize that you have this impairment (Emily/14)

Emily observed other people's experiences and stated,

Yes (laughs) people are like, yeah, I remember when I could drive. I had to change careers. … I mean, yeah, what do you do? I, they need I mean especially in these horrible scenarios, they need to express that and it is not their fault. (Emily/17)

Penny described her struggle to use assistive devices and what they mean to her:

I have thought about a cane it had been suggested to me. Um, I don't know, but in certain areas, to me it just feels as though I'm screaming, victim. Almost it's like "come and mug me. I'm an easy target." (Penny/8)

Penny described going about her hobbies in a different way:

I love craft. I love craft and anything crafty. I used to crochet and make cards and scrap book and I've been doing it for years and, um, I've had to work it a different way of doing it, but I'm still doing it. (Penny/22)

Penny continued to express her enjoyment of crafting:

I can't see that so I can't do that anymore, but I have a cutting machine and I just do it different and it's the same with the crochet. I love to crochet but I can't focus on each stitch so whatever the pattern is, I have to go for the ones with the big holes so I'm going into the ones with the big holes and stitch but, so, I find if I do it that way, I can still do it, so I have loads of things that are made with big holes and circles and squares but I enjoy it so I do it, but it's a bit like on the computer: the more intense, like if I'm reading a document, I can only go for so long. (Penny/22)

Penny described another hobby she enjoys:

I could quite easily go through 10 or 15 audio books in a month and I just thank God for Amazon: they do a yearly subscription, that is 24 books for a year, and I do that every 6 months and whenever anyone says, "what do you want for your Christmas" or "your birthday" or whatever I just say, get me Amazon vouchers for the audio because that is me still reading and still doing something that I like to do. (Penny/23)

Penny described her philosophy of how she has improved her quality of life:

You have to … to have any quality of life, you have to, you must think outside the box. You have to think of someway of doing it. You might not do it the same way you did, but you can work something out and that is what I find about the group. The group is very much a lot of people saying "I can't do this but I can do that" which you think, oh, I never thought of that. You see, they were talking about knitting and crochet. (Penny/23)

Penny talked about helping others maintain their lifestyle:

There is a knitting group and a sewing group and I'm half blind and I can't knit and I can't sew anymore. Um, so I'm wanting to do, I'm wanting to do a craft class for people with low vision because I think you have to keep your brain going. Yeah, and it's all because of the group experience on Facebook and now I don't sit there and say I can't do it. I say I want to do it and I just need to figure out a way to go around it. And if nobody on there can help, then I have a troll through YouTube and look at other groups and just see what they have, but, have there. (Penny/24)

Penny explained how she shared her abilities with peers:

So because of the histo site, I gave something to somebody else who thought they had lost something they loved through the Facebook site. So it's very much, it's not necessarily limited to people with histoplasmosis and I think we've got a really elderly population there and eye issues for the people who come through the clinic. (Penny/24)

Summary of vocational rehabilitation. All three participants talked about the work they had done in the past and how POHS has affected their ability to continue in that position, as well as leisure activities. They lack vocational-rehabilitation services or even considering how those services could help them. The frustration of addressing the unpredictable aspects of POHS forced them to find other ways of participating in work and leisure activities.

Summary of Chapter 4

Chapter 4 presented the data. Three participants answered the interview questions. Their responses were recorded and transcribed word for word. Then the data was coded with open and axial codes, searching out themes in the data. Seven themes were identified: medical intervention, distress, traditional support, loss and isolation, online peer support, adjustment, and vocational rehabilitation. Chapter 5 continues with selective codes, development of theories, interpretation of the data, answering the research question, and suggestions for further research.

V.   Results and Conclusions

Introduction

This dissertation addressed a medical condition, POHS, which is considered a medical illness and a rehabilitation-counseling issue. POHS is a rare eye disease that causes people in the prime of their vocational lifespan to lose their vision, resulting in disability. Few researchers have conducted studies on POHS and none have explored the individual experience of having such an unmanageable disorder and the process by which people are able to cope.

This descriptive case study of an online Facebook group focused on peer support for people with POHS. This research provided important information about what transpires in a cyberspace venue that offers online peer support. By revealing the experiences of these individuals through the process of online peer support, I illuminated wide gaps in services provided to people with POHS.

Organization of the Chapter

First, I offer a thorough definition and description of grounded theory. Next, I discuss how I analyzed the data and how this process allowed theories to develop. Thereafter, I describe the experience of myself as research instrument and how that process operated. An explanation of the theories that developed from the data follow. After that is an interpretation of the data, a review of the research question, recommendations to the field, and suggested future research with the conclusion of this dissertation.

Grounded Theory

This study sought to generate theory about the experience of active participants using Facebook online peer support. To accomplish this end, I employed grounded theory. According to Strauss and Corbin (1990) "Grounded theory is a general methodology for developing theory

that is grounded in data systematically gathered and analyzed. Theory evolves during actual research and it does this through continuous interplay between analysis and data collection" (p. 274).

A qualitative study contains a large collection of data that could have multiple meanings. Researchers collect these data at the individual and social levels. Researchers' challenge is to manage the words, language, and meanings implied by the data and glean from it rich descriptions and understandings of what is being studied (Miles & Huberman, 1994). As researchers partitions the data to classify it, they devise themes from the concepts and provide fresh descriptions. By using coding, researchers divide the data into smaller bits of information that they then compare and categorize with identifying codes (Patton, 2015). Researchers collect and analyze the data using this constant-comparative method in an ongoing process throughout the study.

Codes

Open Code

Open coding is the first stage of data analysis. Each transcribed interview is broken down into pieces, or open codes, in order for the researcher to identify relationships, similarities, and differences. "Open coding and its characteristics of making use of questioning and constant comparisons enable investigators to break through subjectivity and bias" (Corbin & Strauss, 1990, p. 423). Breaking up the data forces examination of preconceived concepts and beliefs by judging these against the data collected.

Axial Codes

Grouping concepts and organizing them into categories then further reduces open codes. Researchers identify and examine relationships between open codes; then reassemble the

dissected data to develop and relates categories that result in axial codes. To clarify, "in axial coding categories are related to their subcategories and these relationships tested against data" (Corbin & Strauss, 1990, p. 40). Bohm further enumerated (2004), "for theory formation what is of particular importance is the development of relationships between the axial categories and the concepts that are related to them in terms of their formal and content aspects" (p. 272).

Selective Codes

Selective coding is the last phase of coding in grounded theory, focused on linking and integrating codes. Researchers reread transcripts and selectively code data as they relate to a previously identified core variable. Strauss and Corbin (1994) supported identification of categories as variables: "Categories are essentially variables because they represent dimensions of concepts or conceptual classificatory schemes" (p. 843). Researchers then further analyze the collected data to identify answers to the main research question, synthesizing this information to form a comprehensive understanding of the central phenomenon through description and thematic development (Creswell, 2012).

Intra-analysis revealed seven axial codes or themes, each supported by several open codes. By using grounded theory, these seven axial codes were revealed as follows: (a) medical intervention, (b) distress, (c) traditional support, (d) loss and isolation, (e) online peer support, (f) adjustment, and (g) rehabilitation. The identification of these axial codes then led to identification of the most prevalent and pertinent of selective codes, which were as follows:

1. Medical Intervention

2. Online Peer Support

3. Rehabilitation.

DeWalt and DeWalt (2010) referenced participant observation as a unique way for the researcher to "know," because the observer becomes a "participant in what is observed" (p. 263). As the research instrument, I engaged in almost everything the participants were doing as a means of learning the culture of the online peer-support group. This activity, in turn, enabled me to transport the "data from transcript to theory" (Walker & Myrick, 2006, p. 549). "Analysis is the interplay between researchers and data. It is both science and art" (Strauss & Corbin, 1998, p. 13). This interplay allowed my observation of the group online dynamic and activity, combined with copious reading of group members' postings, to complete the triangulation process of the data. The consequence of that effort unfolds as three final theories that capture the experience of these participants using online peer support, as revealed in this descriptive case study. Each theory represents the voices of the participants and describes their experiences as they were captured in their words.

Discussion

Discussion of Theory 1: Medical Intervention

As discussed in the initiation of this dissertation, rehabilitation counselors adhere to the biopsychosocial model, which can be regarded as a holistic perspective. The dominant model of disease today, however, is biomedical, which, by the definition asserted by Engel (1977, p. 379), "Leaves no room for the social, psychological and behavioral dimensions of illness." The biomedical model subscribes to a body–mind dualism and is physicalistic in nature, as discorded somatic processes are viewed purely from the perspective of chemistry and physics. Although the biomedical approach has its merits, it is not a complete explanation or description of the experience of individuals with disabilities. It falls short particularly in reference to rare disorders or emerging disabilities.

Participants in this study described emotional trauma and social barriers that were exacerbated and at times caused by their medical providers' adherence to the biomedical model. The emotional needs of the participants were predominately overlooked. In other instances specific actions on the part of medical providers caused further psychological injury. Communication inhibited or circumscribed by lack of knowledge, also was prevalent among care providers. This culture of misinformation or limited information that surrounds treatment for POHS goes beyond the allowances warranted for rare disorders. Participants experienced this limited information as disempowering and disorienting.

Medical decisions of significant importance, that in some cases heavily impacted treatment outcomes, were shifted into the arena of what benefited the providers' schedule. Supportive counseling was never provided or suggested, nor were alternative treatments, referrals to other medical specialists, or medical resources.

> Early diagnosis of CNV in the second eye should be followed by referral for low vision or other professional counseling. In addition, ophthalmologists should be aware of the possibility of poor mental health in these patients and should consider referral for psychiatric examination and management when depression is suspected." (Hawkins, 2005, p. 10)

Schmidt (2012) reports, "They try to explore diseases, effects of medications and correlations between parts of the body as if these were neutral objects or entities, existing independently of a particular context" (p. 606) By subscribing entirely to the biomedical model, treatment providers miss the context in which treatment consumer exists.

Discussion of Theory 2: Online Peer Support

Social networking is becoming a reliable and consistent means for individuals to relate about shared topics of interest. People in online peer-support groups can source information and share concerns regarding rare diseases easily and privately in current time as well as through archived materials (Huber et al., 2010). Some have suggested that individuals managing diseases

with few treatment options and unclear etiology are more likely to search for help online (Culver, Greer, & Frumkin, 1997; Ferguson, 1997) Facebook offers users many topics related to health concerns through its group options. Guidance on how to navigate these groups, including a better understanding of how the administration of a group works, is available to participants on the Facebook website.

Participants indicated that social identification through group membership could provide a basis for social support. Collective coping strategies were identified as a beneficial result of membership as well as timely medical advice based on personal experience, research resources, linkage to services, compassionate support, camaraderie, and social interaction. Participants reported using the group to aid in making difficult medical decisions. Social-support groups offer a holistic and cooperative approach to meeting cultural and social needs, resulting in a sense of empowerment (Braithwaite, Waldon, & Finn, 1999). The data revealed that participants concurred with these sentiments. A holistic approach was missing from participants' experiences of the biomedical model; consequently, it is of great significance that they are able to access this approach online with their peers.

Participants also reported limitations of online support, including receiving notification of a post when the participant was not receptive to interaction. One participant described being able to put the disease out of her mind and then being reminded of it by receiving a notification, negatively impact her emotionally. Another individual thought some comments disturbed her positive thinking and stress-reduction strategy. Controlling the content and timing of support appeared to be a minor concern compared to the benefits, but still needs to be acknowledged.

Discussion of Theory 3: Rehabilitation

The data revealed that access to support and services was limited primarily to the participant's retina specialist and familial-support system. The data suggested neither of these points of contact were viable mechanisms for the provision of sufficient support or linkage to services that help these individuals initiate the process of rehabilitation. Individuals with this rare disorder strive to adjust to a disability that is a vocational inhibitor, costly, and inconsistent in response to treatment, as well as alarmingly irregular in its progression. In addition, a significant reason for the lack of services the participants receive aligns with the criteria they must meet for state rehabilitation or for services for the blind. For state vocational rehabilitation to open a case for an individual with low vision, the individual must have another disability listed as primary and low vision is relegated as secondary. If the individual does not have documentation supporting a different disability, services can be delayed or unavailable.

To receive assistance from services for the blind when the individual is not yet legally blind or totally blind, the person must meet the following criteria for visual impairment, listed on the humanservices.arkansas.gov (2015) website:

> "A progressive visual condition with a visual acuity of 20/50 in the best eye after correction which may result in total or legal blindness or there is imminent danger that the individual may become totally or legally blind as documented by a physician who is skilled in diseases of the eye. (para #4)

What is problematic about these criteria for services, as the data indicated, is that for these individuals to remain in the workforce, service agencies must intervene sooner. By the time the second eye is involved for individuals with POHS, they are often at high risk of losing their employment or career, not merely due to the issue of inhibited visual acuity in the workplace, but from the time and trauma associated with their treatment.

Traditional vocational-rehabilitation services also offer very limited resources and services to individuals with POHS or low vision. The only obvious services listed in the Arkansas Department of Human Services policy manual, in Section 6, page 45, indicates services for blindness are limited to glasses and artificial eyes. It is understandable that the policy for Arkansas Rehabilitation Services (ARS) would require that rehabilitation counselors refer clients with blindness to services for the blind, but the statutes do not mention services for people with significant low vision (Arkansas Department of Human Services, 2015). Although ARS is limited by policy, they partner with other agencies. However, federal monitoring would question any duplication of services, which would be problematic during an audit of their services.

Services for the blind and ARS have inadvertently solved their dilemma of duplicated services by offering no easily accessible services to the population of people who are visually impaired enough to need significant accommodation and advocacy, but do not meet the implicit criteria for the agencies definition of visual impairment. The only avenue for services for individuals with visual disabilities who do not meet the definition of visual impairment is the clause for exceptions, which requires the intervention of district managers. The language presents a vague and unpublished process for the public at large.

In a recent study, rehabilitation professionals confirmed the belief that most employers exhibit negative attitudes toward this population, in part because "performance on the knowledge instrument indicated that overall most employers are very limited in their knowledge about how someone who is blind or visually impaired can perform specific functions" (McDonnall, O'Mally, & Crudden, 2013, p. 222). This finding is not altogether surprising, considering the relatively small number of people with a visual impairment in the labor force. It is not surprising that employers who do not know how a person with low vision or blindness can work would

look upon this population unfavorably in terms of hiring them. The cycle of ignorance ensures people with visual impairments remain underemployed or out of the workforce entirely.

The ramifications of vision loss significantly affect these individuals' abilities to remain in the workforce. The data indicate a lack of supportive counseling available in the communities in which these individuals reside. Mobility and limited travel access inhibited entry to support of every kind. Participatory losses were gradual in nature, but the data indicated mental discord and isolation motivated the individuals to come out of denial and try to find a new way to participate in life. Medical resources are limited due to the many unknown components of this disease, which leave people at increased risk for co-occurring mental health issues, which further causes vocational constraint.

Qualifying for retraining and job-placement services is challenging for individuals with low vision. The data suggested these individuals want to receive services, but family support and medical providers lack awareness, necessitating they orchestrate their lives without them. Awareness of services was generally low, however participants acknowledged the mindset of thinking creatively, helping them move forward in their lives. Access to professionals trained in mobility, accommodations, and job placement has been sufficiently absent so these individuals have often decided to take responsibility independently.

Summary of the Findings

The dominant biomedical practice is not addressing or serving the needs of individuals with rare progressive eye diseases. Limited information and medically focused communication between medical providers and participants has not addressed issues of vital importance to this population such as alternative treatments, supportive counseling or community support, barriers

to services, and social isolation. Consequently, medical intervention is only addressing the disease process; other important aids in healing are overlooked.

The data reveal online peer support offers users the opportunity to remedy issues of isolation, distress, education for family support, adjustment, and resources leading to rehabilitation. The significant issue of inhibited mobility is addressed by the benefits of online accessibility. Participants were able to use online peer support to crowd source current medical research, experience a sense of community, and pursue alternative forms of treatment, should they be so inclined. The ability to check in at any time and get feedback from other members regarding treatment and resources was of significant benefit to the participants.

Rehabilitation and services for those who are blind were revealed as unfamiliar areas that participants identified as an option only in the event they became completely blind. The role of these agencies with regard to advocacy, work-place accommodations, and assistive technology was only marginally familiar to participants. This lack of awareness, combined with the unwieldy criteria they must meet to be eligible for services, further demonstrates the likelihood that this population will remain underserved and consequently fall out of the workplace at a significant rate.

Interpretation of the Data

During comprehensive interviews, the research findings this chapter reports are based on analysis of the following data sources: semistructured interviews, screen-captured posts by participants, and researcher observations as a participant observer (group member). The data suggest that online peer support is filling a gap in service that is systemic in the nature of the prevailing medical system and localized in their communities.

Through the data-analysis process of the interviews, which included open and axial coding, major themes or selective codes emerged. These three selective codes—medical, online peer support, and rehabilitation—strongly indicated that individuals with POHS have problems in several areas as they maneuver through the healthcare and services system. The discussions of each of the three emergent categories/theories provide answers to the research question: What are the experiences of active participants in an online Facebook peer-support group for POHS?

After the initial onset of symptoms, participants struggled to connect to the appropriate medical provider to get a diagnosis and begin treatment. In part, this process was a consequence of limited research, treatment options, and lack of familiarity of medical staff with POHS. The data revealed every participant was required to see numerous physicians and specialists before an accurate diagnosis was made, which increased the individual's chance of incurring further visual damage. In addition to these obstacles to timely and accurate diagnosis, one participant reported her vision was significantly worse after treatment, whereas another reported the side effects of her course of treatment were intolerable.

None of the participants were provided adequate support or referral to any support or vocational services during their contact with their medical providers. Consequently, the process of adjustment was circumscribed and the data revealed the individuals became increasingly distressed. The data revealed participants became highly anxious and began to grieve the life they knew before the onset of symptoms in that a significant change had occurred. They were unable to return to their former lives.

The data revealed that the initial contact made by participants to online peer support was to clarify or seek further medical intervention. The secondary motivation was to become reconciled to the experience of having a rare visual disorder by participating in a venue that

reduced their feelings of loss, isolation, and confusion related to having POHS. The data

revealed that participants, contributing at their chosen level of participation on Facebook, were

provided relief from the pervasive frustration they felt with the medical support they received

and the lack of services and information they experienced. The data further revealed a

contributing factor to participants' distress was their experience of having an invisible disability.

The data indicated that the online peer-support group provided the restorative function of

allowing participants to become visible to a community of peers and to share and gather

information they needed to work toward a state of adjustment through shared experience.

Services such as vocational rehabilitation and supportive counseling were somewhat

outside the awareness of the participants. One participant worked in the field of mental health

and still did not have any sense of what vocational rehabilitation might have to offer a person in

her circumstances. Although several participants sought mental health treatment, they stated it

fell short and vocational treatment was not offered to them at any point. The data revealed that

these individuals were in a very real sense becoming disconnected from the world and only

through their own tenacity were able to find resources to improve their circumstances.

Clearly the data indicated a void in services and support for individuals with rare and

chronic visual disabilities. Any intervention that took place was poorly timed to occur after the

person had left the work force. Providing services for people with POHS requires early

intervention to offset their immediate need for accommodation in the workplace, retraining,

emotional support, and subsidized treatment options.

Research Question

Researchers found that current social-media sites offer various benefits to users with

chronic illnesses (Greene et al., 2010; Lasker et al., 2005). For individuals with rare diseases,

numerous peer-support groups are available on the Facebook platform. Active participants are able to navigate, personalize, and participate in peer-group support with whatever level of participation they choose. Given the current popularity of social media and the paucity of literature available regarding individuals with POHS, the following research question warranted investigation: What are the experiences of active participants in an online Facebook peer-support group for POHS? This study examined this research question to gain a deeper understanding of the unique experiences of an online support group for individuals with POHS.

Recommendations to the Field

The following recommendations are for the field of vocational rehabilitation, services for the blind, and medical providers:

1. The biopsychosocial model focuses on reasonable accommodation as a means of inclusion. The integration of the biopsychosocial model into the current biomedical-model structure would be advantageous for people with rare diseases such as POHS. Integration of these models would require cross training between agencies and medical facilities and could be initiated by vocational rehabilitation as in-service trainings for staff and case managers.

2. Limited mobility is a difficult extenuating circumstance for people with visual disabilities when they attempt to obtain support of any kind. The data revealed that online peer support was an accessible and immediate asset for individuals who have limited access to transportation. Consequently medical providers must consider these benefits and link their medical-care recipients to online support to assist them in beginning the rehabilitation process.

3. Online peer support offers users a broad spectrum of information including holistic interventions that reflect the biopsychosocial model. Alternative therapies and social support combine with shared experiences of psychological trauma related to treatment, reducing social isolation. For the benefit of those under their care, medical providers must expand their knowledge beyond the dominant biomedical model and engage with the broader healing community to meet the needs of people with POHS.

4. Service criteria must be adjusted sufficiently to include individuals with low vision and rare medical conditions that wax and wane such as POHS. Rigid service criteria have become gatekeepers and consequently certain populations of people with visual disabilities are not receiving timely interventions that could keep them in the job force. Retraining to improve job skills and self-advocacy skills must be addressed early in the disease process for people with POHS to prepare for their medical outcome.

5. Medical providers must participate in studies that would identify and potentially rectify shortcomings in their services by actively seeking feedback and dialog from the recipients of services. Additionally, medical providers must be responsive and implement policy changes to address the shortfalls brought to their attention.

Recommendations for Future Research

The following recommendations are for future researchers:

1. Additional qualitative studies of online peer support and the apparent benefits it offers people with rare visual disorders are needed. In addition I would suggest the merits of real-time chats with group participants as an expanded contact forum for group

members. The exploration of expanding online peer-support access is warranted, as evidenced by the data from this study.

2. A further examination of preventative measures and identification of risk factors associated with POHS are needed. Additionally, a public-service campaign for individuals in at-risk populations, endemic regions, and high-risk occupations is necessary. Information about POHS needs to be disseminated broadly to educate as yet unknown categories of people who may unwittingly be at risk for contracting this disease.

3. An increased identification of currently in use technology and the identification of its cross purpose for people with visual impairments is needed. In addition to developing new technology, the increased availability of personal-use technology such a mobile phones and applications specifically or adaptively made available to persons with low vision would be beneficial. Additional training on devices would be warranted.

4. The identification of and development of cross-disorder support in medical venues would aid in avoiding a silo system of treatment and education. Although POHS is a rare disorder, the resulting disability is common with other populations that have age-related macular disease, diabetes, retinitis pigmentosa, and eye injury. Broadening support to capture this population in its totality would be beneficial for people with POHS who tend to be lost in the myriad of more prevalent diseases, gaining them more attention and support.

5. Ophthalmologists and retinal specialist must engage in early intervention practices for emotional distress and adjustment issues identified in their patients at the point of diagnosis and beyond. Because these medical professionals are not trained to identify

early signs of mental illness, a mental status questionnaire would be beneficial as an in-office diagnostic tool for this population. A supportive counseling referral should be made for all patients, should it be warranted, and identification of problematic symptoms should be addressed intermittently for persons experiencing chronic illness.

Conclusion

For this population, the moment of diagnosis and treatment is the point at which services must be brokered to reduce the likelihood of individuals dropping out of the workforce. Retraining efforts must be initiated swiftly to prevent these individuals from becoming underemployed or relegated to dependence on family, friends, or public benefits. These individuals are at increased risk of falling into poverty and social isolation, and experiencing comorbid mental illness. People with chronic illness can benefit from knowing how others have adapted and this knowledge is available in online peer support. "It has been noted that chronic illness has distinct features from acute illness. People with chronic illness are often not deemed disabled enough to trigger some of the disability solutions, yet they may need more structured support" (Beatty, 2012, p. 197).

Robust research methods and high-quality reporting are necessary to advance understanding of how rehabilitation services can best help people with a visual impairment. The data exposed in this descriptive case study offered important discoveries of what the experience of people with POHS has been and how their lives can be improved, increasing access to early interventions that align with the biopsychosocial model. A holistic approach to services will enable more discoveries and improvements, as knowledge of this population can inform how best to service their unmet vocational, emotional, and social support needs.

References

Ahmed, O. H., Sullivan, S. J., Schneiders, A. G., & McCrory, P. (2010). iSupport: Do social networking sites have a role to play in concussion awareness. *Disability and Rehabilitation, 32,* 1877–1883. doi:10.3109/09638281003734409

Ala-Kauhaluoma, M., Ahi I., Ristola, M., & Karma, A. (2010). Involvement of intraocular structures in disseminated histoplasmosis. *Acta Ophthalmologica, 88,* 493–496. doi:10.1111/j.1755-3768.2008.01454.x

Amaro, M. H., Muccioli, C., & Abreu, M. T. (2007). Ocular histoplasmosis-like syndrome: A report from a nonendemic area. *Arquivos Brasileiros de Oftalmologia, 70,* 577–580.

Arkansas Department of Human Services. (2015). *Vocational rehabilitation.* Retrieved July 27, 2015, from http://www.human.services.gov/ardhs.sharepoint.net

Braithwaite, D. O., Waldon, V. R., & Finn, J. (1999). Communication of social support in computer-mediated groups for people with disabilities. *Health Communication, 11,* 123–151. doi:10.1207/s15327027hc1102_2

Beatty, J. E. (2011). Career barriers experienced by people with chronic illness: A U.S. study. *Employment Response Rights Journal, 24,* 91–110. doi:10.1007/s10672-011-9177-z

Bennett & Bloom Eye Center. (2015). *Ocular histoplasmosis.* Retrieved January 3, 2015, from http//:www.eyecenters.com/what-you-should-know-about-ocular-histoplasmosis.html

Ben-Zur, H. & Debi, Z. (2005). Optimism, social comparisons, and coping with vision loss in Israel. *Journal of Visual Impairment and Blindness, 99,* 151–164. Retrieved from http://files.eric.ed.gov/fulltext/EJ683482.pdf

Bergeron, C. M., & Wanet-Defalque, M. C. (2013). Psychological adaptation to visual impairment: The traditional grief process revised. *British Journal of Visual Impairment, 31,* 20–31. doi:10.1177/0264619612469371

Bittner, A. K., Edwards, L., & George, M. (2010). Coping strategies to manage stress related to vision loss and fluctuations in retinitis pigmentosa. *Optometry, 81,* 461–468. doi:10.1016/j.optm.2010.03.006

Blaska, J. (1993). The power of language: Speak and write using "person first." In M. C. Nagler (Ed.), *Perspectives on disability* (2nd ed., pp. 25–32). Palo Alto: CA Health Markets Research.

Boerner, K. (2004). Adaptation to disability among middle-aged and older adults: The role of assimilative and accommodative coping. *Journal of Gerontology, 59,* P35–42. doi:10.1093/geronb/59.1.P35

Bohm, A. (2004). Theoretical coding: Text analysis in grounded theory. In U. Flick, T. Kardorff, & I. Steinke (Eds.), *A companion to qualitative research* (pp. 270–275). London, England: Sage.

Burmedi, D., Becker, S., Heyl, V., Wahl, H. W., & Himmelsbach, I. (2002). Emotional and social consequences of age related low vision. *Visual Impairment Research, 4,* 47–71. doi:10.1076/vlmr.4.1.47.15634

Cohen, A. W., & Graff, J. M. (2008). *Presumed ocular histoplasmosis.* Retrieved October 27, 2015, from http://webeye.ophth.uiowa.edu

Cookingham, F. G. (2004). *Triangulation as a strategy for increasing rigor, breadth, depth.* Retrieved from http://evalfrank.com/wp-content/uploads/2013/08/Tool-triangulation.pdf

Cooper, J. M., Collier, J., James, V., & Hawkey, C. (2010). Beliefs about personal control and self-management in 30–40 year olds living with inflammatory bowel disease: A qualitative study. *International Journal of Nursing Studies, 47,* 1500–1509. doi:10.1016/j.ijnurstu.2010.05.008

Corbin, J., & Strauss, A. (1990). Grounded theory research: Procedures, canons and evaluative criteria. *Qualitative Sociology, 13,* 3–21. doi:10.1007/BF00988593

Creswell, J. W. (2012). *Planning, conducting, and evaluating quantitative and qualitative research.* Boston, MA: Pearson.

Creswell, J. W. (2014). *Research design* (4th ed.). Thousand Oaks, CA: Sage.

Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory Into Practice, 39,* 124–130. doi:10.1207/s15430421tip3903_2

Crum-Cianflone, N. F. (2010). The eyes: A window into the past. *Cleveland Clinic Journal of Medicine, 77,* 422–424. doi:10.3949/ccjm.77a.09157

Culver, J. D., Greer, F., & Frumkin, H. (1997). Medical information on the Internet: A study of the electronic bulletin board. *Journal of General Internal Medicine, 12,* 466–470. doi:10.1046/j.1525-1497.1997.00084.x

Denzin, N. K. (2001). *Applied Social Research Methods Series: Vol. 16. Interpretive interactionism* (2nd ed.). Thousand Oaks, CA: Sage.

deRidder, D., Geenen, R., Kuijer, R., & van Middendor, H. (2008). Psychological adjustment to chronic disease. *The Lancet, 372,* 246–255. doi:10.1016/S0140-6736(08)61078-8

DeWalt, K. M., & DeWalt, B. R. (2010). *Participant observation: A guide for fieldworkers.* Plymouth, England: AltaMira Press.

DeWalt, K. M., DeWalt, B. R., & Wayland, C. B. (1998). Participant observation. In H. R. Bernard (Ed.), *Handbook of methods in cultural anthropology* (pp. 259–300). Walnut Creek, CA: AltaMira Press.

Dibb, B., & Yardley, L. (2006). How does social media comparison within a self-help group influence adjustment to chronic illness? A longitudinal study. *Social Science & Medicine, 63,* 1602–1603. doi:10.1016/j.socscimed.2006.03.031

Dreer, L. E., Elliot, T. R., Berry, J., Fletcher D. C., Swanson, M., & McNeal, J. C. (2008). Cognitive appraisals, distress and disability among persons in low vision rehabilitation. *British Journal of Health Psychology, 13,* 449–461.

Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science, 196,* 129–136. doi:10.1126/science.847460

Erickson, F. D. (1986). Qualitative methods in research on teaching. In M. C., Wittrock (Ed.), *Handbook of research on teaching* (3rd ed., pp. 119–161). New York, NY: MacMillan.

Eye Center. (2015). *Treatment.* Retrieved January 3, 2013, from http://www.eyecenter.com

Facebook. (2015). *Home.* Retrieved February 17, 2015, from http://www.facebook.com/statistics on February 17, 2015.

Fenwick, E. K., Lamoureux, E. L., Keeffe, J. E., Mellor, D., & Rees, G. (2009). Detection and management of depression in patients with vision impairment. *Optometry and Vision Science, 86,* 948–954. doi:10.1097/OPX.0b013e3181b2f599

Ferguson, T. (1997). Healthcare in cyberspace: Patients lead a revolution. *The Futurist, 31*(6), 29–34.

Fitzgerald, R.G., Ebert, J. N., & Chambers, M. (1987). Reactions to blindness: A four-year follow-up study. *Perceptual and Motor Skills, 64,* 363–378. doi:10.2466/pms.1987.64.2 .363

Forest, A. L., & Wood, J. V. (2012). When social networking is not work: Individuals with low self-esteem recognize but do not reap the benefits of self-disclosure on Facebook. *Psychological Science, 23,* 295–302. doi:10.1177/0956797611429709

Ganley, J. P., Smith, R. E., Knox, D. L., & Comstock, G. W. (1973). Presumed ocular histoplasmosis. *Archives of Ophthalmology, 89,* 116–119. doi:10.1001/archopht .1973.01000040118011

Glesne, C. (2006). *Becoming qualitative researchers* (3rd ed.). Boston, MA: Pearson.

Gray, K., Annabell, L., & Kennedy, G. (2010). Medical students' use of Facebook to support learning: Insights form four case studies. *Medical Teacher, 32,* 971–976. doi:10.3109 /0142159X.2010.497826

Greene, J. A., Choudhry, N. K., Kilabuk, E., & Shrank, W. (2010). Online social networking by patients with diabetes: A qualitative evaluation of communication with Facebook. *Journal of General Internal Medicine, 26,* 287–392. doi:10.1007/s11606-010-1526-3

Hargittai, E., & Hseih, Y. P. (2010). Predictors and consequences of differentiated practices on social network sites. *Information, Communication & Society, 4,* 515–536. doi:10.1080 /13691181003639866

Hawkins, B. S. (2005). Health and vision related quality of life among patients with ocular histoplasmosis or idiopathic choroidal neovascularization at enrollment in a randomized trail of submacular surgery. *Archives of Ophthalmology, 123,* 78–88. doi:10.1001 /archopht.123.1.78

Hawkins, B. S., Bressler, N. M., Bressler, S. B., Davidorf, F. H., Hoskins, J. C., Marsh, M. J. … Submacular Surgery Trials Research Group. (2004a). Surgical removal vs. observation for subfoveal choroidal neovascularization, either associated with the ocular histoplasmosis syndrome or idiopathic: I. Ophthalmic findings from a randomized clinical trial: Submacular surgery trials (SST) Group H Trial: SST Report No. 9. *Archives of Ophthalmology, 122,* 1597–1611. doi:10.1001/archopht.122.11.1597

Hawkins, B. S., Miskala, P. H., Bass, E. B., Bressler, N. M., Childs, A. L., Mangione, C. M., … Submacular Surgery Trials Research Group. (2004b). Surgical removal vs. observation for subfoveal choroidal neovascularization, either associated with the ocular histoplasmosis syndrome or idiopathic. *Archives of Ophthalmology, 122,* 1616–1628. doi:10.1001/archopht.122.11 .1616

Hayeems, R. Z, Geller, G., Finkelstein, D., & Faden, R. R. (2005). Now patients experience progressive loss of visual function: A model of adjustment using qualitative methods. *British Journal of Ophthalmology, 89,* 615–620. doi:10.1136/bjo.22003.036046

Hernandez, J. M., Munoz-Cadavid, C. O., Hernandez, D. L., Montoya, C., & Gonzalez, A. (2012). Detection of *histoplasma capsulatum* DNA in peripheral blood from a patient with ocular histoplasmosis syndrome. *Medical Mycology, 50,* 202–206. doi:10.3109 /13693786.2011.593050

Holekamp, N. M., Thomas, M. A., Dickinson, J. D., & Valluri, S. (1996). Surgical removal of subfoveal choroidal neovascularization in presumed ocular histoplasmosis. *Ophthalmology, 104,* 22–26. doi:10.1016/S0161-6420(97)30367-4

Huber, J., Ihrig, A., Peters, T., Huber, C., Kessler, A., Hadaschik, B., … Hohenfellner, M. (2010). Decision-making in localized prostate cancer: Lessons learned from an online support group. *BJU International, 107,* 1570–1575. doi:10.1111/j.1464-410X.2010 .09859.x

Irvine, H., Davidson, C, Hoy, K., & Lowe-Strong, A. (2009). Psychosocial adjustment to multiple sclerosis: Exploration of identity redefinition. *Disability and Rehabilitation, 9,* 599–606. doi:10.1080/09638280802243286

Jang, Y., Mortimer, J. A., Haley, W. E., & Graves, A. R. (2004). The role of social engagement in life satisfaction: Its significance among older individuals with disease and disability. *Journal of Applied Gerontology, 23,* 266–278. doi:10.1177/0733464804267579

Joinson, A. N. (2008). 'Looking at,' 'looking up' or 'keeping up with' people? Motives and uses of Facebook. *CHI 2008 Proceeding,* 1027–1036. doi:10.1145/1357054.1357213

Kim, J. E. (2015). *Presumed ocular histoplasmosis syndrome.* EyeWiki. Retrieved January 26, 2015, from http://eyewiki.org/Presumed_Ocular_Histoplasmosis_Syndrome

Kurtz, L. F. (1997). *Self-help and support groups: A handbook for practitioners.* Thousand Oaks, CA: Sage.

Lasker, J. N., Sogolow, E. D., & Sharim, R. R. (2005). The role of an online community for people with a rare disease: Content analysis of messages posted on a primary biliary cirrhosis mailing list. *Journal of Medical Internet Research, 7*(1), e10–e26. doi:10.2196/jmir.7.1.e10

Letourneau, N., Stewart, M., Masuda, J., Anderson, S., Cicutto, L., McGahn, S., & Watt, S. (2012). Impact of online support for youth with asthma and allergies: Pilot study. *Journal of Pediatric Nursing, 27,* 65–73. doi:10.1016/j.pedn.2010.07.007

Lewis, M. L., Van Newkirk, M. R., & Gass, J. D. (1980). Follow-up study of presumed ocular histoplasmosis syndrome. *Ophthalmology, 87,* 390–399. doi:10.1016/S0161-6420(80)35226-3

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry.* Thousand Oaks, CA: Sage.

Marques-Brocksopp, L. (2011). The broad reach of the wellbeing debate: Emotional wellbeing and vision loss. *British Journal of Visual Impairment, 30,* 50–55. doi:10.1177/0264619611428244

Marshall, C. Y., & Rossman, G. B. (2006). *Designing qualitative research* (4th ed.). Thousand Oaks, CA: Sage.

McCann, J. (2009). *The pharaoh's curse.* Retrieved December 13, 2014, from http://endeavors.unc.edu/fall2009/the_pharaohs_curse.php

McCluskey, J., Bourgeois, M., & Harbison, R. (2013). A case of mistaken identity ocular histoplasmosis in Florida. *Clinical Toxicology, S5,* 7–10. doi:10.4172/2161-0495.S5-007

McDonnall, M. C., O'Mally, J., & Crudden, A. (2014). Employer knowledge of and attitudes toward employees who are blind or visually impaired. *Journal of Visual Impairment and Blindness, 108,* 213–225.

McGee, C. N. J., Dean, S., & Danesh-Meyer, H. (2002). Locally administered ocular corticosteroids: Benefits and risks. *Drug Safety, 25*(1), 33–55. doi:10.2165/00002018-200225010-00004

Melberg, N. S., Thomas, M. A., Dickinson, J. D., & Valluri, S. (1996). Managing recurrent neovascularization after subfoveal surgery in presumed ocular histoplasmosis syndrome. *Ophthalmology, 103,* 1064–1068. doi:10.1016/S0161-6420(96)30566-6

Merriam, S. B. (2009). *Qualitative research.* San Francisco, CA: Jossey Bass.

Michigan Disability Rights Coalition. (2015). *Models of disability.* Retrieved April 27, 2015, from www.mymdrc.org/leadership/models-of-disability

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis* (2nd ed.). Thousands Oaks, CA: Sage.

Molinari, V., Nelson, N., Shekelle, S., & Crothers, M. K. (1994). Family support groups of the Alzheimer's Association: An analysis of attendees and nonattendees. *Journal of Applied Gerontology, 13,* 86–98. doi:10.1177/073346489401300107

Moschos, M. M. (2014). Physiology and psychology of vision and its disorders: A review. *Medical Hypothesis, Discovery & Innovation Ophthalmology Journal, 3*(2), 83–90. Retrieved from http://mehdijournal.com/index.php/mehdiophthalmol/article/view/174/81

Mpofu, E., & Bishop, M. (2006). Value change and adjustment to disability: Implications for rehabilitation education practice and research. *Rehabilitation Research, Policy, and Education, 20,* 147–161. doi:10.1891/088970106805074412

Murray, S. A., McKay, R. C., & Nieuwoudt, J. M. (2010). Grief and needs of adults with acquired visual impairments. *British Journal of Visual Impairment, 28,* 78–89. doi:10 .1177/0264619609359388

National Eye Institute. (2015). *Facts about histoplasmosis.* Retrieved January 27, 2015, from http://www.nei.nih.gov/health/histoplasmosis/histoplasmosis

National Federation of the Blind. (2015). *Blindness statistics.* Retrieved January 27, 2015, from http://nfb.org/blindness-statistics

New Jersey Department of Health and Senior Services. (2014). *Public employees occupational safety and health program.* Retrieved February 12, 2015, from http://www.nj.us/health/eoh/peoshweb/pigeon.pdf

Newman, M. W., Lauterbach, D., Munson, S. A., Resnick, P., & Morris, M. E. (2011). "It's not that I don't have problems, I'm just not putting them on Facebook": Challenges and opportunities in using online social networks for health. *Proceedings of the ACM Conference on Computer Supported Cooperative Work* (pp. 341–350). New York, NY: ACM. doi:10.1145/1958824.1958876

The Next Web. (2015). *Facebook officially passes 1 billion monthly active users.* Retrieved February 20, 2015, from http://www.thenextweb.com/facebook/-hits-1-billion-active-users/

Nyman, R. L., Dibb, B., Victor, C. R., & Gosney, M. A. (2012). Emotional well-being and adjustment to vision loss in later life: A meta-synthesis of qualitative studies. *Disability and Rehabilitation, 34,* 971–981. doi:10.3109/09638288.2011.626487

Ocular histoplasmosis. (2007). *Review of Optometry, 144* 44A-46A Retrieved from http:www.ebscohost.com.library.uark.edu

Oliver, A., Ciulla, T. A., & Comer, G. M. (2005). New and classic insights into presumed ocular histoplasmosis syndrome and its treatment. *Current Opinion in Ophthalmology, 16,* 160–165. doi:10.1097/01.icu.0000161228.21797.d9

Ongkosuwito, J. V., Kortbeek, L. M., Van der Lelij, A., Molicka, E., Kijlstra, A., de Smet, M. D., & Suttorp-Schulten, M. S. A. (1999). Aetiological study of the presumed ocular histoplasmosis syndrome in The Netherlands. *British Journal of Ophthalmology, 83*, 535–539. doi:10.1136/bjo.83.5.535

Patton, M. Q. (2002). *Qualitative research and evaluation methods.* Thousand Oaks, CA: Sage.

Patton, M. Q. (2014). *Qualitative research and evaluation methods.* Thousand Oaks, CA: Sage.

Patton, M. Q. (2015). *Qualitative research and evaluation methods: Integrating theory and practice.* Thousand Oaks, CA: Sage.

Postelmanns, L., Pasteels, B., Coquelet, P., Caspers, I., & Verougstraete, C. (2004). Photodynamic therapy for subfoveal classical choroidal neovascularization related to punctate inner choroidopathy (PIC) or presumed ocular histoplasmosis-like syndrome (POHS-like). *Ocular Immunology and Inflammation, 13,* 361–366. doi:10.1080 /09273940590951124

Ralph, L., Berglas, N., Schwartz, S., & Brindis, C. (2011). Finding teens in their space: Using social networking sites to connect youth to sexual health services. *Sexuality Research and Social Policy*, 8(1), 38–49. doi:10.1007/s13178-011-0043-4

Ramaiya, K. J., Blinder. K. J., Ciulla, T., Cooper, B., & Shah, G. K. (2013). Ranibizumab versus photodynamic therapy for presumed ocular histoplasmosis syndrome. *Ophthalmic Surgery, Lasers and Imaging Retina, 44,* 17–21. doi:10.3928/23258160-20121221-07

Rappleye, C. A., & Goldman, W. E. (2007). Fungal stealth technology. *Trends in Immunology, 29,* 18–24. doi:10.1016/j.it.2007.10.001

Rechtman, E., Allen, V. D., Danis, R. P., Pratt, L. M., Harris, A., & Speicher, M. A. (2003). Intravitreal triaminolone for choroidal neovascularization in ocular histoplasmosis syndrome. *American Journal of Ophthalmology, 136,* 739–741. doi:10.1016/S0002 -9394(03)00389-1

Rees, G., Tee, H. W., Marella, M., Fenwick, E., Dirani, M., & Lamoureux, E. L. (2010). Vision-specific distress and depressive symptoms in people with vision impairment. *Investigative Ophthalmology & Visual Science, 51,* 2891–2896. doi:10.1167/iovs.09 -5080

Reid, J. D., Schere, J. H., Herbut, P. A., & Irving, H. (1942). Systemic histoplasmosis diagnosed before death and produced experimentally in guinea pigs. *Journal of Laboratory Clinical Medicine, 27,* 419–434.

Reinhardt, J. P., Boerner, K., & Horowitz, A. (2009). Personal and social resources and adaptation to chronic vision impairment over time. *Aging & Mental Health, 13,* 367–375. doi:10.1080/13607860902860912

Ross, C., Orr, E. S., Sisic, M., Arsemeault, J. M., Simmering, M. G., & Orr, R. R. (2009). Personality and motivations associated with Facebook use. *Computers in Human Behavior, 25,* 578–586. doi:10.1016/j.chb.2008.12.024

Salick, E. C., & Auerbach, C. F. (2006). From devastation to integration: Adjusting to and growing from medical trauma. *Qualitative Health Research, 16,* 1021–1037. doi:10 .1177/1049732306292166

Saperstein, D. A., Rosenfeld, P. J., Bressler, N. M., Rosa, R. H., Sickenberg, M., Sternberg, P., … Reaves, T. A. (2002). Photodynamic therapy of subfoveal choroidal neovascularization with verteporfin in the ocular histoplasmosis syndrome. *Ophthalmology, 109,* 1499–1505. doi:10.1016/S0161-6420(02)01103-X

Schadlu, R., Blinder, K. J., Shah, G. K., Holekamp, N. M., Thomas, M. A., Grand, M. G., … Sheybani, A. (2008). Intravitreal bevacizumab for choroidal neovascularization in ocular histoplasmosis. *American Journal of Ophthalmology, 145,* 875–878. doi:10.1016/j.ajo .2007.12.030

Schmidt, J. M. (2012). The biopsychosocial model and its potential for a new theory of homeopathy. *Homeopathy, 101,* 121–128. doi:10.1016/j.homp.2012.02.001

Scholz, R. W., & Tietje, O. (2002). *Embedded case study methods.* Thousand Oaks, CA: Sage.

Senra, H., Aragao, R., & Leal, I. (2011). From self-awareness to self-identification with visual impairment: A qualitative study with working age adults at a rehabilitation setting. *Clinical Rehabilitation, 25,* 1140–1151. doi:10.1177/0269215511410729

Sinha, R., Raju, S., Garg, S. P., Venkatesh, P., & Talwar, D. (2007). Presumed ocular histoplasmosis syndrome in India. *Ocular Immunology and Inflammation, 15,* 315–317. doi:10.1080/09273940701375428

Smith, R. E. (1997). Commentary on histoplasmosis. *Ocular Immunology and Inflammation, 5,* 69–70. doi:10.3109/09273949709085053

Spiegel, D., Bloom, J. R., Kraemer, H. C., & Gottheil, E. (1989). Effect of psychosocial treatment on survival of patients with metastatic breast cancer. *The Lancet, 2,* 888–891. Retrieved from http://empresa.rediris.es/pub/bscw.cgi/d4565558/Spiegel-Effect _psychosocial_treatment_survival_metastatic_breast_cancer.pdf

Spitz, L. J., & Schwartz, B. (1953). Histoplasmosis in non-endemic regions. *American Journal of Medicine, 14,* 624–632. doi:10.1016/0002-9343(53)90151-X

Stake, R. E. (1995). *The art of case study research.* Thousand Oaks, CA: Sage.

Stake, R. E. (2005). *The art of case study research*. Thousand Oaks, CA: Sage.

Strauss, A., & Corbin, J. (1994). *Grounded theory an exploration of process and procedure.* Thousand Oaks, CA: Sage.

Strauss, A., & Corbin, J. (1998). *Basics of qualitative research* (2nd ed.). Thousand Oaks, CA: Sage.

Sugimoto, S. (2013). *Support exchange on the Internet: A content analysis of an online support group for people living with depression* (Doctoral dissertation). University of Toronto, Toronto, Canada.

Suttorp-Schulten, M. S. A., Bollemeijer, J. G., Bos, P. J. M., & Rothova, A. (1997). Presumed ocular histoplasmosis in the Netherlands—An area without histoplasmosis. *British Journal of Ophthalmology, 81,* 7–11. doi:10.1136/bjo.81.1.7

Tabrett, D. R., & Latham, K. (2012). Adjustment to vision loss in a mixed sample of adults with established visual impairment. *Investigative Ophthalmology & Visual Science, 53,* 7227–7234. doi:10.1167/iovs.12-10404

Taylor, S. J., & Bogdan, R. (1998). *Introduction to qualitative research methods.* New York, NY: John Wiley Sons.

Thurston, M., Thurston, A., & Mcleod, J. (2010). Socio-emotional effects of the transition from sight to blindness. *British Journal of Visual Impairment, 28,* 90–112. doi:10.1177 /0264619609359304

Trevino, R., & Salvat, R. (2006). Preventing reactivation of ocular histoplasmosis: Guidance for patients at risks. *Optometry, 77,* 10–16. doi:10.1016/j.optm.2005.09.004

Trillo, A. H., & Dickinson, C. M. (2012). The impact of visual and nonvisual factors on quality of life and adaptation in adults with visual impairment. *Investigative Ophthalmology & Visual Science, 53,* 4234–4241. doi:10.1167/iovs.12-9580

Tunde-Ayinmode, M., Akande, T. M., & Ademola-Popoola, D. S. (2011). Psychological and social adjustment to blindness: Understanding from two groups of blind people in Ilorin, Nigeria. *Annals of African Medicine, 10,* 155–164. doi:10.4103/1596-3519.82073

University of Iowa Healthcare. (2008). *Presumed ocular histoplasmosis(POHS): 30-year-old male with blurred central vision.* Retrieved March 7, 2015, from http://www.eyerounds.org/cases/83-Presumed-Ocular-Histoplasmosis-POHS.htm

U.S. Department of Labor, Occupational Safety & Health Administration. (2015). *Control of health hazards associated with bird and bat droppings.* Retrieved February 28, 2015, from http://www.state.nj.us/health/eoh/peoshweb

Walker, D., & Myrick, F. (2006) Grounded theory: An exploration of process and procedure. *Qualitative Health Research, 16,* 547–559. doi:10.1177/1049732305285972

Walther, J. B., Van Der Heide, B., Kim, S. Y., Westerman, D., & Tong, S. T. (2008). The role of friends' appearance and behavior on evaluations of individuals on Facebook: Are we known by the company we keep? *Human Communication Research, 34,* 28–49. doi:10 .1111/j.1468-2958.2007.00312.x

White, M., & Dorman, S. (2001). Receiving social support online implications for health education. *Health Education Research, 16,* 693–707. doi:10.1093/her/16.6.693

Whoriskey, P., & Keating, D. (2013). An effective eye drug is available for $50 but many doctors choose $2,000 alternative. *The Washington Post.* Retrieved December 13, 2014, from http://www.washingtonpost.com

Williamson Eye Institute. (2015). *Presumed ocular histoplasmosis.* Retrieved January 3, 2015, from http://www.williamsoneyeinstitute.com

Wilson, R. E., Gosling, S. D., & Graham, L. T. (2012). A review of Facebook research in the social sciences. *Perspectives on Psychological Science, 7,* 203–220. doi:10.1177 /1745691612442904

Wolcott, H. F. (2001). *Writing up qualitative research.* Thousand Oaks, CA: Sage.

Wolcott, H. F. (2008). *Ethnography: A way of seeing*. Walnut Creek: CA: AltaMira Press.

Woods, A. C., & Wahlen, H. E. (1960). The probable role of histoplasmosis in the etiology of granulomatous uvetis. *American Journal of Ophthalmology, 49,* 205–220. doi:10.1016 /0002-9394(60)91515-4

Woolley, P., & Peterson, M. (2012). Efficacy of a health-related Facebook social network site on health seeking behaviors. *Social Marketing Quarterly, 18*(1), 29–39. doi:10.1177 /1524500411435481

Xia, Z. D. (2009). Marketing library services through Facebook groups. *Library Management, 30,* 469–475. doi:10.1108/01435120910982159

Yin, R. K. (2008). *Qualitative research from start to finish.* New York, NY: The Guilford Press.

Yin, R. K. (2011). *Qualitative research from start to finish.* New York, NY: The Guilford Press.

Zhang, X., Bullard, K. M., Cotch, M. F., Wilson, M. R., Rovner, B. W., McGwin, G., … Saddine, J. B. (2013). Association between depression and functional vision loss in persons 20 years of age or older in the United States, NHANES 2005–2008. *JAMA Ophthalmology, 131,* 573–581. doi:10.1001/jamaophthalmol.2013.2597

Zhang, Y., Tang, L. S. T., & Leung, L. (2011). Gratifications, collective self-esteem, online emotional openness and trait like communication apprehension as predictors of Facebook uses. *Cyberpsychology, Behavior, and Social Networking, 14,* 733–739. doi:10.1089 /cyber.2010.0042

Zhao, S., & Grasmuck, J. M. (2008). Identity construction on Facebook: Digital empowerment in anchored relationships. *Computers in Human Behavior, 24,* 1816–1836. doi:10.1016/j .chb.2008.02.012

Appendix A: Informed Consent

Project Title: A Descriptive Case Study of Presumed Ocular Histoplasmosis Syndrome
                      Patients Utilizing a Facebook Support Group
Investigator: Lisa Thompson, Principal Researcher
College of Education and Health Professionals
Rehabilitation, Human Resources and Communication Disorders

████████████████████████
████████████████

Purpose: The purpose of this study is to identify and describe the experiences of
                      individuals with Presumed Ocular Histoplasmosis Syndrome as they
                      participate in an online peer-support group. Individuals with rare,
                      progressive and unpredictable eye diseases do not get sufficient support to
                      adjust to the sudden or gradual onset of visual loss. Symptoms associated
                      with POHS may affect family, work and treatment for individuals with
                      this rare disease. Online support groups through social networking outlets
                      such as Facebook can be an effective medium for people with POHS to
                      participate in a forum that can be tailored to the needs of the group.

Procedures: You are invited to participate in a series of three interviews of
                      approximately 60 minutes in duration in a private and secure venue of
                      your choosing. Interview questions will cover topics such as peer support,
                      medical interventions, work, family relationships and adjustment to
                      disability. Your interview will be audio taped with a digital voice recorder
                      with your permission and transcribed for the purpose of accuracy. You
                      will receive a copy of the transcript so you may verify that your words
                      have been captured correctly. The interviewer will also take written notes
                      during the interview. You may also be asked to permit the researcher to
                      observe you during a typical day in your life involving work, family time
                      or leisure.

Risks of Participation: There are no known risks associated with this study that are greater than
                      those encountered in daily life.

Benefits: No direct benefits are associated with this project. However, the results
                      may help identify the need for social networking peer support groups for
                      individuals with rare eye diseases to supplement current available care.

Confidentiality: Names of participants, the names of any persons mentioned in
                      conversation and the names of places will be changed to protect
                      participant identity and maintain confidentiality. Direct quotes by you may
                      be included in the final report but your identity will be protected.
                      Supervisors and peers will not have access to any documented data that

would in any way reveal your identity. Original recordings will be stored on Lisa Thompson's computer hard drive, which is password, protected. After recordings have been used for the purpose of data collection they will be destroyed.

Compensation: No compensation will be offered for participating in this study.

Contacts: For questions about this study, contact Lisa Thompson, Principal Researcher, College of Education and Health Professionals, Rehabilitation, Human Resources, and Communication Disorders, Graduate Education Building, ███████████████████████ ███████████████████████

For concerns about this research study, contact Brent Williams PhD Program Coordinator, Dissertation Chair and Faculty Advisor in the Department of Rehabilitation, College of Education and Health Professionals, Rehabilitation, Human Resources, and Communication Disorders, ██████████████████████████████ ██████████████████████████

For information on subjects rights, contact Iroshi Windwalker, Compliance Coordinator, █████ ████████████████████████████

Participant's rights: As a participant in this research study you are entitled to know the nature of my project. You are free to decline to participate, and you are free to stop the interview or withdraw from the study at any time. No penalty or risks are associated with withdrawing your participation. Feel free to ask any questions at any time about the nature of the study and the methods I am using.

Signatures: I have read and fully understand the consent form. I signed freely and voluntarily. A copy of this form has been given to me.

_____   _____
Signature of Participant   Date

I certify that I have personally explained this document before requesting the participant sign it.

_____   _____
Signature of Principal Researcher   Date

Appendix B: IRB Approval

UNIVERSITY OF ARKANSAS

<div align="right">
Office of Research Compliance
Institutional Review Board
</div>

June 9, 2015

MEMORANDUM

TO:	Lisa Thompson Brent T. Williams
FROM:	Ro Windwalker IRB Coordinator
RE:	New Protocol Approval
IRB Protocol #:	15-05-751
Protocol Title:	*A Descriptive Case Study of Individuals with Presumed Ocular Histoplasmosis Syndrome Utilizing a Facebook Support Group*
Review Type:	☐ EXEMPT ☒ EXPEDITED ☐ FULL IRB
Approved Project Period:	Start Date: 06/09/2015 Expiration Date: 06/07/2016

Your protocol has been approved by the IRB. Protocols are approved for a maximum period of one year. If you wish to continue the project past the approved project period (see above), you must submit a request, using the form *Continuing Review for IRB Approved Projects*, prior to the expiration date. This form is available from the IRB Coordinator or on the Research Compliance website (https://vpred.uark.edu/units/rscp/index.php). As a courtesy, you will be sent a reminder two months in advance of that date. However, failure to receive a reminder does not negate your obligation to make the request in sufficient time for review and approval. Federal regulations prohibit retroactive approval of continuation. Failure to receive approval to continue the project prior to the expiration date will result in Termination of the protocol approval. The IRB Coordinator can give you guidance on submission times.

This protocol has been approved for 3 participants. If you wish to make *any* modifications in the approved protocol, including enrolling more than this number, you must seek approval *prior to* implementing those changes. All modifications should be requested in writing (email is acceptable) and must provide sufficient detail to assess the impact of the change.

If you have questions or need any assistance from the IRB, please contact me at 109 MLKG Building, 5-2208, or irb@uark.edu.