EXPLORING PARTICIPATION IN INDIVIDUALS WITH GLAUCOMA

by

Heather Michelle Livengood

MS in Occupational Therapy, Shenandoah University, 1999

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This dissertation was presented

by

Heather Michelle Livengood

It was defended on

February 4, 2015

and approved by

Richard A. Bilonick, PhD, Assistant Professor, Department of Ophthalmology

Ian P. Conner, MD, PhD, Assistant Professor, Department of Ophthalmology

Michael McCue, PhD, Professor and Vice Chair, Department of Rehabilitation Science and Technology

Elizabeth Skidmore, PhD, OTR/L, Associate Professor, Department of Occupational Therapy

Chair: Nancy Baker, ScD, MPH, OTR/L, Associate Professor, Department of Occupational Therapy

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Heather Michelle Livengood, PhD, OTR/L

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Glaucoma is a progressive, chronic optic neuropathy and a leading cause of blindness in the United States. It is an asymptomatic disease that affects an estimated 2.7 million Americans, of whom only half know they have the disease. As glaucoma severity progresses, people often experience changes in their abilities to engage in social life situations, have reduced confidence and/or avoid situations they once deemed important and pleasurable, and they may alter how they are able to accomplish roles and routines they want to or need to do.

Historically the effects of glaucoma on people's daily living have been measured in research by vision-specific quality of life (VSQoL), a measure of people's own perceptions of how glaucoma affects their health, well-being, and quality of living. In vision rehabilitation, one measure of the effect of an ocular disease on people's abilities to accomplish daily living is participation. Participation is involvement in social life situations. Yet little research has focused on participation as an outcome measure for people with glaucoma. Therefore, the objective of this study was to explore participation in individuals with glaucoma to better understand the relationship between severity of vision loss and the degree to which participation was associated with glaucoma severity.

The aims of this study were to: 1) explore the association between participation and glaucoma severity, 2) explore the relationship between participation and VSQoL, and 3) compare the relationship between participation and VSQoL as each related to glaucoma severity.

We performed correlation analyses and found that participation had a fair association with glaucoma severity and a moderate association with VSQoL. In multiple regression analyses, findings suggested that for individuals who on average had early stage glaucoma, participation and VSQoL were each statistically significant, incremental indicators of glaucoma severity after controlling for covariates. Exploring the effects of glaucoma on participation will inform our understanding of the effects of glaucoma on function and vision-related disability. A unique contribution of this research is its focus on participation and the exploration of participation as a potential indicator of severity of vision loss for people who may be at risk for disability.

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PREFACE

I would like to express my gratitude to all those whose help was instrumental to the conduct and completion of this research project. A special thank you to my mentor and committee chair Nancy Baker, ScD, MPH, OTR/L for her dedication to mentorship, guiding me through professional development from clinician to research scientist. Thank you to my other committee members, Richard A. Bilonick, PhD, Ian P. Conner, MD, PhD, Michael McCue, PhD, and Elizabeth Skidmore, PhD, OTR/L, for their expert contributions and collaboration to the design and implementation of this research project. I also would like to thank Kaley Miller, OTS, for her contributions to various aspects of this project. Most especially, heartfelt gratitude to my family for their unconditional love and support.

1.0 INTRODUCTION

Loss of vision has a statistically significant association with disability, as indicated through loss of personal independence, impaired mobility and falls, depression, transportation challenges, difficulties maintaining employment, and placement in long-term care (Campbell & Crews, 2001; de Boer et al., 2004; Desrosiers, Wanet-Defalque, et al., 2009; Haymes, Johnston, & Heyes, 2002; Jones, Crews, & Danielson, 2010; Lord, 2006). As people's vision worsens, their psychological burden increases along with a fear of blindness and social withdrawal (Chang-Quan et al., 2010; Jampel et al., 2007; McDonnall, 2009; Ramulu, Maul, et al., 2012; Skalicky & Goldberg, 2008; Stelmack, 2001). Our daily living involves complex, skilled actions guided by vision. Vision drives people's decision making and contributes to anticipating and planning responses, interpreting social situations, aiding in information processing, and dictating motor actions (e.g., postural control). People with glaucoma are at risk for progressive loss of vision, often unaware of changes in their vision in the early stage of the disease. Since those changes are progressive and not abrupt, people likely adapt or unknowingly modify how they accomplish daily living. For this research study, we explored the association between individuals' involvement in life situations (i.e., participation) and severity of vision loss as a result of glaucoma.

1.1 SIGNIFICANCE

1.1.1 Glaucoma

Glaucoma is a progressive, chronic optic neuropathy that may result in a functional loss of vision (i.e., visual impairment); it is the second leading cause of blindness worldwide and a leading cause of blindness in the United States (U.S.; National Eye Institute, n.d.; Quigley & Broman, 2006). Glaucoma is typically characterized by increased intraocular pressure, retinal nerve fiber and optic nerve damage, and progressive loss of visual fields (Anderson, 2006; Cassin & Rubin, 2006). It is usually an asymptomatic disease, referred to as the 'silent thief of sight.' Glaucoma affects an estimated 2.7 million Americans, a number that is projected to increase to 4.2 million by 2030 (National Eye Institute, n.d.). Of the estimated 2.7 million Americans who have glaucoma, only half know they have the disease (Friedman et al., 2004; National Eye Institute, 2013).

People with a familial history of glaucoma are among the most at risk for developing the disease. Race and age are statistically significant risk factors, particularly for African Americans aged 40 years and older and Hispanics and Mexican Americans aged 60 to 65 years and older. Glaucoma is most prevalent in China, India, and Europe (Quigley & Broman, 2006). Additional risk factors strongly associated with severity of glaucoma include myopia, hyperopia, cardiovascular disease, diabetes, eye injury, and the use of cortisone steroids (Dahl, 2013; Schuman, 2008).

People with glaucoma demonstrate characteristic behavior that is the consequence of both changes in vision and of the increased effort to overcome challenges in daily living in order to maintain their independence. It is important to recognize that people are typically unaware of changes in their vision as the result of glaucoma until later stages in the disease progression, a

point at which permanent vision loss has already occurred. We must consider then that some of the challenges in daily living for people with undiagnosed or early stage glaucoma may be subtle or hidden; people may naturally manage those challenges through adaptation or by using compensatory methods. For example, people may successfully accomplish their daily living but modify the way they accomplish tasks or how frequently they engage in tasks. They generally do not perceive that those modifications indicate any level of difficulty with task accomplishment.

As reported in the quality of life (QoL) research, driving, mobility, involvement in the community (e.g., crossing the road, reading street signs), reading, adjusting to different levels of illumination, judging distances, contrast sensitivity, and peripheral vision-dependent tasks were affected by glaucoma (Goldberg et al., 2009; Hochberg et al., 2012; Kuyk, Elliott, & Fuhr, 1998; Nelson, Aspinall, & O'Brien, 1999; Nelson, Aspinall, Papasouliotis, Worton, & O'Brien, 2003; Ramulu, 2009; Ramulu, Maul, et al., 2012; Ramulu, van Landingham, et al., 2012; Spaeth, Walt, & Keener, 2006; Turano, Rubin, & Quigley, 1999; Viswanathan et al., 1999). Changes in mobility were characterized by slower ambulation and reaction times, impaired perception of motion, and bumping into objects located in the periphery (Kuyk et al., 1998; Turano et al., 1999; Viswanathan et al., 1999). Because of these changes in behavior, people had reduced confidence in their abilities which led to avoidance of those situations they deemed important and pleasurable (Gilhotra, Mitchell, Ivers, & Cumming, 2001; Hartmann & Rhee, 2006; McGwin et al., 2004).

The least difficult tasks people with glaucoma felt able to manage were looking after their appearances and visiting family and friends. The most important tasks (for which they had difficulty) were near vision tasks and mobility outside the home while the least important were bumping into objects, the impact of glare, and performing household chores. Considering involvement in the life situations (i.e., participation) that were the most difficult to manage, people

with glaucoma were generally more independent with basic self-care activities, such as grooming, and were more dependent with complex instrumental activities of daily living, for example community mobility (Hochberg et al., 2012). This is likely because basic self-care management over time becomes a rote activity that does not require extensive visual skill. Of note, people with severe glaucoma attached greater importance to the integrity of their central vision in the advanced stages of the disease than they did in the early stages of the disease (Spaeth et al., 2006). This reflects the physiological progression of the disease; the central visual field is generally not compromised until the advanced stages.

1.1.1.1 Visual Sensory Perception The functional limitations common for people with glaucoma directly relate to sensory perception. Glaucoma preferentially affects rod dominated areas of the retina resulting in peripheral visual field defects, often sparing the central visual field until late stages of the disease. When there is structural impairment to the retina and/or optic nerve, information is not sent along the visual pathway for cortical processing. It is estimated that up to 50% of retinal ganglion cells are damaged or permanently lost before current diagnostic techniques detect structural damage to the retina (Anderson, 2006; Bullimore, Wood, & Swenson, 1993; Canadian Ophthalmological Society Glaucoma Clinical Practice Guideline Expert Committee, 2009). The lost ability to process visual input at the level of the retina disrupts cortical sensory perception of motion and thus peripheral awareness (Wolfe et al., 2012). Peripheral vision is linked to the cortical processing of spatial information that relates to posture, balance, and stability during motion.

Motion perception is a mechanism for judging self-motion, reaction responses, postural control, and navigation in the environment (Bullimore et al., 1993; Karwatsky, Bertone, Overbury, & Faubert, 2006; Shabana, Pérès, Carkeet, & Chew, 2003; Wu, Coffey, Reidy, & Wormald, 1998).

People with glaucoma demonstrated higher motion thresholds to detect items in the peripheral environment than did people with normal vision (McKendrick, Badcock, & Morgan, 2005). This finding suggested that people with glaucoma may have greater difficulty processing complex visual tasks (e.g., navigation) than could be predicted merely from their visual field loss. It is typically at the moderate or severe stages of glaucoma when people begin to perceive peripheral vision loss. Therefore, changes in behavior that may occur in the early stage of the disease could be the consequence of loss of visual sensory information.

1.1.1.2 Medical Evaluation and Interventions for People with Glaucoma The current medical management of glaucoma focuses on maintaining the integrity of eye function and structure through early diagnosis and treatment of the signs of the disease to prevent vision loss. Common objective clinical measures of vision for people with glaucoma are intraocular pressure, visual acuity, visual field, thickness of the retinal nerve fiber layer, and contrast sensitivity (see Table 1; Black, Wood, & Lovie-Kitchin, 2011; Jampel et al., 2002; Kulkarni, Mayer, Lorenzana, Myers, & Spaeth, 2012; Lamoureux et al., 2007; Ramulu, Maul, et al., 2012; Ramulu, van Landingham et al., 2012; Richman et al., 2010; Viswanathan et al., 1999).

Table 1. Clinical Measures of Vision for the Medical Evaluation for Glaucoma

Vision term	Definition	Measure
Contrast sensitivity	The ability to detect detail having subtle gradations in luminance or color between a target and its background	Pelli-Robson contrast sensitivity chart
Intraocular pressure	The fluid pressure inside the eye	Tonometry
Retinal nerve fiber layer	The layer of retinal ganglion cells of the retina that receive visual information from photoreceptors	Optic coherence tomography
Visual acuity	The ability to distinguish detail and shape clearly	Early Treatment Diabetic Retinopathy Study (ETDRS) acuity charts or Snellen charts
Visual field	The extent of the area people are able to see when the eye is fixated straight ahead	Automated perimetry

Note. Optical coherence tomography is a high resolution imaging technique used to take cross-sectional images of the thickness of the retina to measure the structural neural integrity of the retinal nerve fiber layer and other layers of the retina.

The severity of visual field loss is the benchmark measure for quantifying the severity of glaucoma. The emphasis on visual field is related to the neural mechanisms underlying visual sensory perception and the preferential loss of peripheral vision. Optical coherence tomography is used clinically to measure the thickness of the retinal nerve fiber layer and the vertical cup/disc ratio, a measure of the pathological cupping of the optic disc as a result of glaucoma. These measures, retinal nerve fiber layer thickness and vertical cup/disc ratio, are also used in addition to visual field to classify severity of glaucoma. Physicians and researchers may categorize people along a continuum of disease severity based on the degree of visual field loss described by a staging system (See Table 2; Mills et al., 2006).

Table 2. Exemplars for Staging Severity of Glaucoma

Stage of glaucoma	Mean deviation
Humphrey Visual Field	
Stage 0 – Ocular hypertension/earliest glaucoma	> 0.00
Stage 1 – Early glaucoma	-0.01 to -5.00
Stage 2 – Moderate glaucoma	-5.01 to -12.00
Stage 3 – Advanced glaucoma	-12.01 to -20.00
Stage 4 – Severe glaucoma	≤ -20.01
Stage 5 – End stage glaucoma	No Humphrey Visual Field (worse-seeing eye)
Octopus Visual Field	
Stage 0 – Ocular hypertension/earliest glaucoma	≤ -0.80
Stage 1 – Early glaucoma	-0.70 to 4.40
Stage 2 – Moderate glaucoma	4.50 to 9.50
Stage 3 – Advanced glaucoma	9.50 to 15.30
Stage 4 – Severe glaucoma	15.40 to 23.10
Stage 5 – End stage glaucoma	≥ 23.20
American Glaucoma Society	
Mild	No measurable visual field loss but evidence of pathology on clinical examination OR optical coherence tomography
Moderate	One hemifield with visual field loss in one or both eyes, not within 10˚ of fixation
Severe	Both hemifields with visual field loss in one or both eyes OR involving the central 10˚ of visual field in either eye

Note. From Mills et al. (2006) and physician report.

The medical interventions for glaucoma include: eye drops to control intraocular pressure, oral medication (in lieu of or in conjunction with eye drops) to control intraocular pressure, laser trabeculoplasty to improve the eye's drainage system for the flow of aqueous fluid, laser iridotomy to create an opening through the iris to manage aqueous fluid flow, trabeculectomy in which a

passage is created in the sclera to drain excessive eye fluid, implantation of glaucoma drainage device, and cyclodestructive surgery which is a laser to destroy parts of the ciliary body. Potential side effects of commonly prescribed medications include eye discomfort such as burning, stinging, tearing, and dry/itchiness (Lee et al., 1998; Lopez, Karaca, Ekici, Waisbourd, & Spaeth, 2014). Additional side effects of medication may include blurred vision, headaches, and shortness of breath. Potential side effects from laser or surgical procedures include infection, blurred vision, fluctuating eye pressure, and pain. These laser or surgical-related symptoms are generally short term, enduring through the post-operative recovery phase. Eye procedures do not guarantee people will no longer require the use of oral or topical medications.

1.1.1.3 Vision Rehabilitation Evaluation and Interventions for People with Glaucoma

A goal of vision rehabilitation is for individuals to learn to maximize the use of their remaining vision (i.e., usable vision) to develop and/or optimize their abilities to live as independently as possible to engage in their roles and routines. Occupational therapists are trained in evaluating and treating the interaction between individuals and their environments, contexts and occupations, and how those interactions influence individuals' abilities for independence and maintaining function. Direct outcomes evaluated in vision rehabilitation are measured most often by individuals' abilities to execute a task or action (i.e., activity) and to accomplish a life situation (i.e., participation). Given what is known about the effects of glaucoma on function and disability, that people are generally more independent with basic self-care and more dependent with complex and dynamic tasks (Hochberg et al., 2012), it is at the level of participation that we should evaluate people who are at risk for or diagnosed with glaucoma.

The American Occupational Therapy Association recently published practice guidelines for working with older adults with low vision (Kaldenberg & Smallfield, 2013). The guidelines

summarize the common intervention approaches used by occupational therapists with people with visual impairment and the scientific evidence that supports the interventions. The intervention approaches commonly used with people with glaucoma include sensory substitution, organization and environmental adaptation, driving and community mobility, visual skills training, problem solving and self-management, and advocacy (see Table 3). Refer to Livengood (2014) for a review of the role of occupational therapy in vision rehabilitation for people with glaucoma.

Table 3. Vision Rehabilitation Intervention Approaches Common for People with Glaucoma

Intervention approach	Description	Example
Sensory substitution	Use of alternate senses to compensate for vision loss	Use of hearing via a smartphone application where the smartphone takes a picture of an object and speaks what object is in the picture
Organization and environmental adaptation	Use of techniques to systematically modify and/or arrange items in an orderly fashion; increase lighting and contrast within the environment	Optimize ambient lighting (proper illumination) to reduce shadows in the home environment for safe mobility
Driving and community mobility	Alternative driving/transportation techniques; safety with community mobility	Education on driving cessation and other alternative transportation options (including accessibility)
Visual skills training	Use of techniques to maximize awareness of visual field	Visual scanning strategies to increase awareness of the environment (e.g., purposefully turning the head side-to-side to increase field of view)
Problem solving and self-management	Techniques to facilitate participation in daily living	Facilitate the process of working through details of a problem to reach a solution
Advocacy	Identify support networks (e.g., education, community resources, referral to appropriate services) to optimize function and participation	Education on the short- and long-term implications of glaucoma on participation; how to access community resources to support independence and safety

1.1.2 Societal and Individual Burden of Vision Loss

Understanding glaucoma and its effect on people's daily living, we can consider the significance of the overall burden of vision loss. An estimated 285 million people worldwide have a visual impairment that results from limitations of the eye and/or visual system; more than 80% of those visual impairments are moderate to severe (World Health Organization [WHO], 2014). Currently, there are approximately 3.4 million people in the U.S. aged 40 years and older who are blind or have a visual impairment (Friedman et al., 2004). Americans aged 80 years and older were members of the fastest growing segment of the population between 2000 and 2010 (Werner, 2011) and had the highest rates of visual impairment (Chou et al., 2013). Several factors associated with visual impairment include age, gender, race/ethnicity, socioeconomic status, duration of visual impairment, location of visual field loss, and multiple comorbidities (Rubin et al., 1997; Schuman, 2008; Ulldemolins, Lansingh, Valencia, Carter, & Eckert, 2012).

With increasing age, the prevalence of visual impairment increases and is most dramatic after age 75; 1 in 6 people aged 70 years and older has a visual impairment (Dillon, Gu, Hoffman, & Ko, 2010). Visual impairment is more prevalent in women. People of particular ethnicities have a higher risk of certain types of eye diseases; age-related macular degeneration is more prevalent among Caucasians while glaucoma is more prevalent among African Americans.

There is a link between socioeconomic status and visual impairment, but the underlying mechanism has not been determined. Suggested determinants of visual impairment associated with socioeconomic status are people's access to health and eye care and their level of education. Reasons people do not seek out eye-care services include cost, lack of insurance, and the perception they have nothing wrong with their vision that requires examination (Chou, Sherrod, & Zhang, 2011; Centers for Disease Control, 2011; Saaddine et al., 2008). Given these reasons that

people do not seek out eye-care services, less than half of people who are eligible for eye examinations access vision services. Approximately 40% of working-aged adults have no vision insurance and 30% have no vision insurance when they have general health insurance (Li, Xirasagar, Pumkam, Krishnaswamy, & Bennett, 2013). Those who have vision insurance are twice as likely to receive eye care in the past 12 months (Li et al., 2013).

Another factor associated with visual impairment is the location of visual field loss. The location of visual field loss and specific patterns of vision loss vary depending on the type and progression of the eye disease and can differentially affect people's abilities to accomplish tasks associated with daily living (Eichenbaum, 2012; Kotecha, O'Leary, Melmoth, Grant, & Crabb, 2009; Merigan & Maunsell, 1993; Milner & Goodale, 1995; Patino et al., 2010). Loss of inferior visual fields is associated with increased postural sway to a greater extent than loss of superior visual fields (Black et al., 2011) and adults with central and/or inferior visual field loss have poorer mobility (Lovie-Kitchin, Mainstone, Robinson, & Brown, 1990; Turano et al., 2004). Inferior visual field loss is a predictor of lower independence. Similarly, the challenges in managing daily living for people with peripheral visual field loss (e.g., glaucoma) are likely to be different from those challenges for people with central visual field loss (e.g., age-related macular degeneration; (Eichenbaum, 2012; Kotecha et al., 2009; Merigan & Maunsell, 1993; Milner & Goodale, 1995; Patino et al., 2010).

Comorbidities common among people aged 65 years and older who report vision loss include: breathing problems, depression, emotional distress, diabetes, heart problems, hearing impairment, hypertension, joint problems, low back pain, and stroke (Cardol et al., 2002; Crews, Jones, & Kim, 2006; Desrosiers et al., 2006; Lamoureux, Hassell, & Keeffe, 2004; Werner, 2011). Each of these conditions is associated with poorer quality of life outcomes and influences people's

abilities to accomplish their typical roles and routines. Dual sensory loss, such as visual impairment combined with hearing impairment, leads to a greater perceived visual impairment and diminished participation in daily living (Crews et al., 2006; Lin et al., 2004).

Visual impairment is among the top 10 disabilities among adults aged 18 years and older and is among the most common chronic conditions that contribute to people aged 70 years and older requiring assistance in daily living activities (Warnecke, 2003). The population of older Americans continues to grow, with older adults at greatest risk of experiencing a disability as the result of visual impairment. The combination of visual impairment with other co-existing conditions may exacerbate the effect of vision loss more than any one condition alone (Crews et al., 2006; Horowitz, Reinhardt, & Kennedy, 2005; Jones, Rovner, Crews, & Danielson, 2009; Leske et al., 2001; Mukesh, McCarty, Rait, & Taylor, 2002; Schuman, 2008). Disability related to visual impairment accounted for approximately 18.8% of the total disabled in 2013 (Institute on Disability, 2014). Of the working-aged adults with a visual impairment, approximately 34.7% are employed (Brault, 2010).

1.1.3 Economic Burden of Vision Loss

Among Americans aged 40 years and older, the annual federal total direct cost of blind and vision disorders is an estimated $13.7 billion (Prevent Blindness America, 2007). An additional annual $16 billion financial burden is estimated on individual, caregiver, and non-governmental healthcare payers (Frick, Gower, Kempen, & Wolff, 2007). The U.S. healthcare expenditure for glaucoma is approximately $2.9 billion annually (Fiscella, Lee, Davis, & Walt, 2009; Rein et al., 2006). For Medicare beneficiaries aged 65 years and older, the medical costs for an event directly related to vision loss are approximately 90% non-eye related medical care (e.g., a hip fracture from

a fall that was related to poor vision; Javitt, Zhou, & Willke, 2007); the estimated cost of glaucoma care is $748 million (Quigley et al., 2013). Recognizing the burdens associated with vision loss, initiatives such as Healthy People 2020 have called for evidence-based evaluations and interventions to preserve sight and prevent blindness through early detection and timely treatment of eye diseases, including vision rehabilitation services (U.S. Department of Health and Human Services, 2014). An informed awareness of the consequences of vision loss on daily living and disability and its burden on society will direct public health policy to promote education and research to improve access to preventative care, evaluation, and interventions.

1.2 SUMMARY

The effect of glaucoma on people's daily living has justifiably received increased attention in regard to increasing public health awareness of glaucoma. As the Baby Boomer generation ages, the percentage of the total population aged 65 years and older will increase as will the prevalence of age-related eye diseases such as glaucoma. The majority of the people with ocular diseases will have secondary chronic conditions that also affect their occupational performance. Decreased independence related to vision loss can result in a number of disabling consequences, including increased likelihood of falls and automobile accidents (Coleman et al., 2004; Haymes, LeBlanc, Nicolela, Chiasson, & Chauhan, 2007; Hu, Trumble, Foley, Eberhard, & Wallace, 1998; Lamoureux et al., 2008; McGwin et al., 2005; Owsley, McGwin Jr, & Ball, 1998), decreased ability to manage daily living (Freeman, Munoz, West, Jampel, & Friedman, 2008; Jones et al., 2009; Nelson et al., 2003; Parrish et al., 1997; Ramulu, West, Munoz, Jampel, & Friedman, 2009; West et al., 2002), and avoidance of or social withdrawal from life situations once deemed

important and/or pleasurable (Gilhotra et al., 2001; Hartmann & Rhee, 2006). Factors such as general health, socio-economics, mood, and coping strategies also influence how an ocular condition affects people's daily living (Rovner, Casten, Hegel, & Tasman, 2006; Warrian, Spaeth, Lankaranian, Lopes, & Steinmann, 2009).

People who lose vision because of glaucoma may attempt to conceal it or, given the asymptomatic progression of the disease that generally is not abrupt, they may not be aware of subtle changes in their vision. They may naturally adapt over time to the gradual, progressive changes in their vision. For example, they might change how frequently they do a task or use some type of compensatory strategy. Vision loss is often a hidden disability, more often overlooked during healthcare evaluations than physical impairments. Behavior that results because of vision loss may be attributed to other client factors, particularly when behavioral adaptations due to changing vision are not intuitive based on standard vision evaluations. Thus, healthcare providers, and rehabilitation specialists in particular, need to be aware of what may be subtle signs of behavior associated with visual impairment versus physical impairment. The healthcare attitude towards people with glaucoma is transitioning from reactive to proactive in regard to identifying people at risk for disability (Fried, Herdman, Kuhn, Rubin, & Turano, 1991; Higgins, Janelle, & Manini, 2013; West et al., 2005).

The need to better understand the consequences of glaucoma on disability is imperative to public health initiatives. Physicians and vision specialists increasingly acknowledge that research on how glaucoma affects people's daily living is as important as research on its effects on the structural integrity of the eye. The U.S. Department of Health and Human Services has fronted several programs directly related to vision health. The Centers for Disease Control created the Vision Health Initiative to provide guidance in the promotion of vision health, to enhance public

health surveillance of visual impairment and eye health in the U.S. (Centers for Disease Control, 2011). Healthy People 2020 strategic plans include programs for prevention, early detection, treatment, and vision rehabilitation. Recognizing the effect of glaucoma on people's daily living is an important component of the broader healthcare process for healthcare providers, particularly when people with glaucoma receive services for a condition other than vision (e.g., joint replacement). With many types of vision loss, people must learn to cope with the fact that their vision loss is likely permanent and adapt to how changes in vision affect their daily living. Vision science and rehabilitation researchers and clinicians are important in this realm, to help people learn to cope with and adapt to their changes in vision, given their expertise in the evaluation of human behavior and task analysis.

As glaucoma can negatively affect people's daily living and research priorities include identifying indicators of the early stage of the disease process for earlier diagnosis and intervention, we designed this research study to look at the association between people's involvement in life situations (i.e., participation) and severity of vision loss due to glaucoma. The physical detection (medical perspective) and conscious recognition (individual perspective) of vision loss as a result of glaucoma occur at a point in the disease process at which permanent vision loss has already begun. The more advanced the disease process when glaucoma is detected, the more likely there is irreversible vision loss. People are often unaware of subtle changes to their vision and the consequences of those changes in the early stage of glaucoma because of the asymptomatic progression of the disease. Earlier detection could allow earlier initiation of care. For example, early medical treatment can slow or prevent continuing visual field loss by lowering intraocular pressure (Adatia & Damji, 2005; Advanced Glaucoma Intervention Study Investigators, 1998; Glacuoma Laser Trial Research Group, 1995; Heijl et al., 2002; Lichter et al.,

2001; Miglior et al., 2005; Yumori & Cadogan, 2011; Zhao, Jia, Sui, & Ellwein, 1998). Changes in participation may eventually be used to identify those at an early stage of glaucoma due to the consequences of vision loss. However, first we need to establish that participation is independently associated with glaucoma severity.

Historically, research measured the effects of glaucoma on people's daily living using QoL (i.e., people's perceptions of their well-being; Goldberg et al., 2009; Hochberg et al., 2012; Kuyk et al., 1998; Nelson et al., 1999; Nelson et al., 2003; Ramulu, Maul, et al., 2012; Ramulu, van Landingham, et al., 2012; Turano et al., 1999; Viswanathan et al., 1999). Changes in behavior and diminished QoL were associated with the disease progression of glaucoma. In vision rehabilitation, one measure of the effect of glaucoma on people's abilities to accomplish daily living situations is participation. Yet, little research has specifically focused on measuring participation as a direct outcome for people with glaucoma. In this research study, we explored the concept of participation because it is the immediate focus for vision rehabilitation evaluation and intervention. We contend that QoL (WHO Quality of Life Group, 1993; WHO, 2001) and participation (Fougeyrollas, Cloutier, Bergeron, Cote, & St-Michel, 1999; WHO, 2001) are two conceptually separate constructs and each contributes uniquely to our understanding of the effect of glaucoma on daily living. Yet, the distinction between QoL and participation as measures of the effect of glaucoma is ambiguous in vision research. Of the little research that studied participation in people with a visual impairment, most research studied participation as the dependent variable and found that factors such as impaired cognition, impaired physical ability, and medical comorbidities were indicators or predictors of participation. In this research study, however, we were interested in whether or not participation was an indicator (i.e., independent variable) of severity of glaucoma. While there is little research about participation of people with glaucoma, we know that because

of the effect of vision loss on visual sensory perception, the consequence of early stage vision loss on daily living may not align with clinical measures of visual impairment.

1.3 PURPOSE OF STUDY

The objective of this research study was to explore participation to better understand its relationship with severity of vision loss related to glaucoma. In this study, participation referred to the frequency of participation, participation accomplishment, and satisfaction with participation.

1.3.1 Aim 1: Explore the Association between Participation and Severity of Glaucoma

The primary aim of this study was to explore the association between participation (frequency, accomplishment, and satisfaction) and severity of glaucoma. We hypothesized that participation would have at least a moderate association with severity of glaucoma (i.e., lower participation for people with worse severity of glaucoma) after controlling for covariates.

1.3.2 Aim 2: Explore the Relationship between Participation and Vision-Specific Quality of Life

The second aim of this study was to explore whether there was a relationship between participation and vision-specific quality of life (VSQoL). We hypothesized that participation would have a positive correlation (rho $\geq$ .40) with VSQoL.

1.3.3 Aim 3: Compare the Relationship between Participation and Vision-Specific Quality of Life as They Each Related to Severity of Glaucoma

The third aim of this study was to compare the association between participation and severity of glaucoma to the association between VSQoL and severity of glaucoma to explore whether participation had a more robust association with severity of glaucoma. We hypothesized that participation would have a stronger association with severity of glaucoma than VSQoL.

2.0 QUALITY OF LIFE AND PARTICIPATION IN VISION RESEARCH

Over the past several decades, healthcare has influenced outcomes research. Specifically, the introduction of patient-reported outcomes (Glickman & Peterson, 2009) were integrated as primary measures in vision research. Patient-reported outcomes measure whether or not services provided by healthcare providers improved patients' health and well-being, as perceived by the patients themselves. Patient-reported outcomes are any statement or measure of health reported by a patient, without any interpretation given by a clinician or researcher, to quantify people's perceptions of their health (Denniston, Kyte, Calvert, & Burr, 2014; Meadows, 2011). Patient-reported outcomes are used to assess performance and to determine the comparative effectiveness of interventions, linking reimbursement to the evidence of the effectiveness of interventions.

Historically, quality of life (QoL) has been the most common patient-reported outcome measure of health, in regard to function and disability, used by both healthcare providers and vision researchers. However, QoL is a multidimensional construct. As such, it may not be fully sensitive to the effects of disease on specific aspects of function and disability, specifically with regard to identifying areas of people's daily living most affected by a disease or health condition. In vision rehabilitation, participation is a measure of function and disability specific to people's involvement in life situations. Despite the fact that participation is one measure used in vison rehabilitation, distinct measures of participation have not been integrated into research until recently. While it appears there are conceptual similarities and differences between QoL and participation, variability in definitions, applications, and interpretations of each contribute to ambiguity in the vision science literature. Arguably, participation is one component included within the broader conceptualization of QoL.

The purpose of this chapter is to describe the state of the science in regard to the conceptualization of QoL and participation in vison research, specifically in regard to glaucoma. We describe a theoretical framework to characterize glaucoma and its association with function and disability and apply the framework to current evaluation methods for both medical management and vision rehabilitation of people with glaucoma.

2.1 THEORETICAL FRAMEWORK

Two common theoretical frameworks used in vision science and rehabilitation research are the Disability Creation Process (DCP; Fougeyrollas et al., 1998) and the International Classification of Functioning, Disability and Health (ICF; Leissner, Coenen, Froehlich, Loyola, & Cieza, 2014; World Health Organization [WHO], 2001). In 1980 the WHO published the International Classification of Impairments, Disabilities and Handicaps (ICIDH) to conceptualize between biological, functional, and social consequences of trauma and disease (WHO, 1980). The DCP originated from the Quebec Committee on the ICIDH and was a revision based on the ICIDH (Fougeyrollas, Cloutier, Bergeron, Cote, & St-Michel, 1999). The DCP model is based on the interaction between individuals (i.e., personal factors) and their environment (see Figure 1A). The ICF was the direct revision of the ICIDH adopted by the WHO and was developed from a biopsychosocial perspective, which recognizes the interaction between physical, psychological, and social factors on health (WHO, 2001). This perspective also recognizes the importance of people's perceptions of their health and well-being.

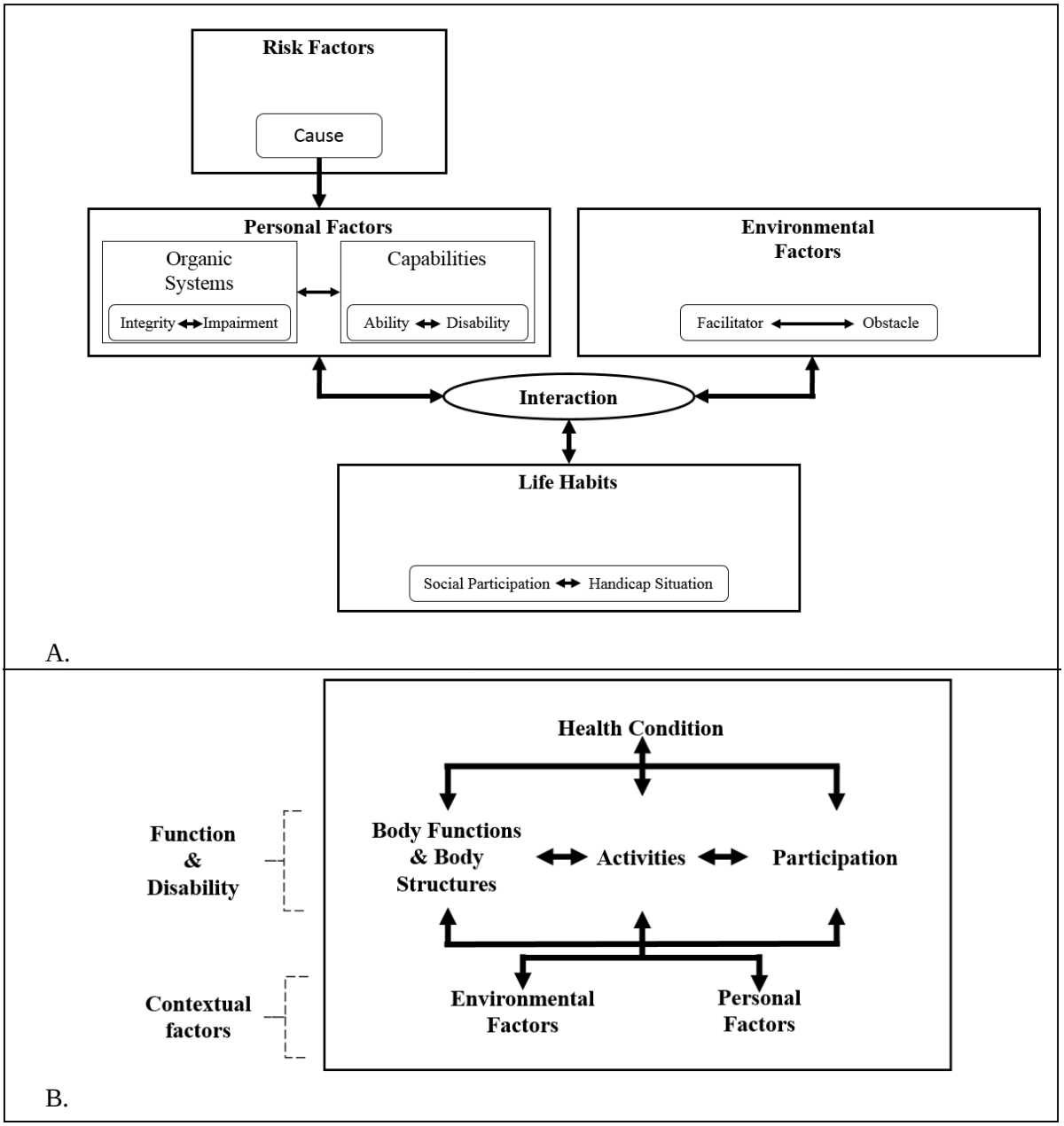


Figure 1. Theoretical frameworks used in vision research. (A) Disability Creation Process (Fougeyrollas & Noreau, 2003) and (B) International Classification of Functioning, Disability and Health (World Health Organization, 2001).

The most common theoretical framework used in the United States is the ICF. The ICF is a model intended to provide a globally accepted, standard language and framework to describe

health as an interactive process between health conditions and contextual factors mediated by three components of function and disability: 1) body functions and body structures, 2) activities, and 3) participation (see Figure 1B). Body functions are the physiological functions of body systems and body structures are the anatomical parts of the body such as organs. Activity is the execution of a task or action by an individual. Participation is the involvement in a life situation. In this framework, function is an overarching term that encompasses all body functions and structures, activities, and participation. Disability is an overarching term for any problems in body functions or body structures (impairments); difficulties people experience in the execution of a task or action (activity limitations); and difficulties in the involvement of a life situation (participation restrictions). For example, glaucoma is a health condition that often presents with visual field loss (impairment) that may affect an individual's ability to drive (activity limitation) which in turn may affect successful employment (participation restriction). To better understand the distinction between QoL and participation for this study, we review the two constructs according to the ICF.

For this research study, we used the ICF as the theoretical framework to specify the constructs of QoL and participation. The objective of this study was to explore participation in individuals with glaucoma to better understand its association with severity of glaucoma. We designed the study to include QoL even though our primary focus was on participation. We included QoL as a comparison variable to participation because (1) QoL is a measure so often used in vision research and its interpretation is familiar to researchers and clinicians and (2) we contend there are conceptual distinctions between the two outcomes. Participation has been used less frequently in vision research so its measurement may be less understood. Therefore, the two constructs that were of greatest importance in this study were QoL and participation.

2.1.1 Quality of Life: Conceptual Definition

Over the past 15 years, in addition to reports of medical advancements in glaucoma care, glaucoma research has steadily yielded more published articles to describe the lived experiences of people with glaucoma. The most common primary outcome measured was the effect of glaucoma on QoL, more specifically the effect of glaucoma on vision-specific quality of life (VSQoL). Within research and clinical practice QoL is an overall global measure of people's perceived quality of their daily life (i.e., well-being). In this study, we refer to QoL from the perspective of VSQoL, which refers to the effect of ocular conditions and changes in function related to vision on people's health and well-being.

The WHO Quality of Life Group (1993) defined QoL as individuals' perceptions of the quality of their life in the context of the culture and value system in which they live. Simply stated, QoL is an individual's subjective well-being (WHO, 2001). It is an important distinction to note that QoL is multidimensional in that it measures several areas of life domains: physical health, psychological health, level of independence, social relationships, the environment, and personal beliefs (see Figure 2). Because QoL is a multidimensional construct that conceptually encompasses multiple domains in the ICF framework, it is not directly represented in the ICF model as a single domain (see Figure 1B). There are multiple conceptual models of QoL and the definitions and measurement of QoL in research have been elusive (Moons, Budts, & De Geest, 2006). The discrepancies in the definitions, applications, and interpretations of QoL make it an ambiguous concept. The lack of conceptual clarity also results in operational disparities for instrument design and outcome measurement. The validity of an instrument is compromised when the underlying construct for which it is designed to measure is not well specified. In this study, we defined QoL as conceptualized by the ICF and WHO.

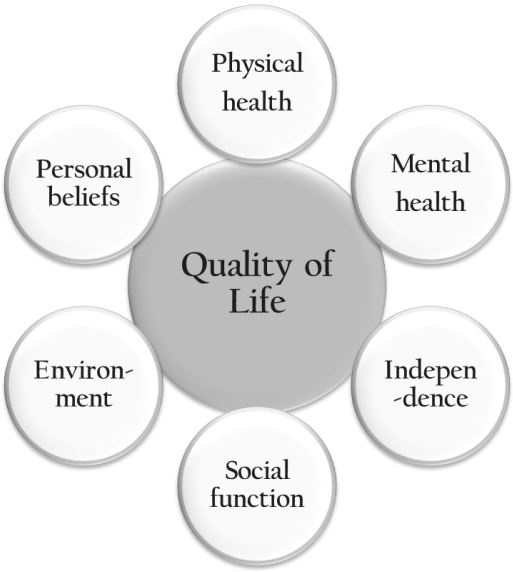


Figure 2. Conceptual Representation of Quality of Life published by the World Health Organization Quality of Life Group (World Health Organaization Quality of Life Group, 1993).

2.1.1.1 Vision-Specific Quality of Life: Measurement Understanding how QoL is conceptualized, we can better understand how it is measured. Over the past decade, there was a paradigm shift in outcome measurement focused on QoL (Carr, Gibson, & Robinson, 2001); researchers in vision rehabilitation developed instruments and studied how to best measure VSQoL. VSQoL instruments are primarily self-report questionnaires by which respondents are typically asked to rate their perceived level of difficulty to complete specific tasks. In addition to rating the level of difficulty to complete a task, respondents may also be asked to indicate the importance of completing such tasks.

There are numerous QoL and VSQoL questionnaires available and used in glaucoma research which vary in their emphasis; for example, health-related QoL versus glaucoma-specific QoL. Several of the most common questionnaires used in glaucoma research are the Medical Outcomes Study Short Form Health Survey-36, Glaucoma Quality of Life-15, Impact of Vision

Impairment, and National Eye Institute Visual Function Questionaire-25 (see Table 4; Hamzah, Burr, Ramsay, Azuara-Blanco, & Prior, 2011; Severn, Fraser, Finch, & May, 2008; Spaeth, Walt, & Keener., 2006; Vandenbroeck, De Geest, Zeyen, Stalmans, & Dobbels, 2011).

Table 4. Quality of Life and Vision-Specific Quality of Life Instruments used with People who have Glaucoma

Instrument	Number of items	Domains
SF-36	36	Physical function
		Bodily pain
		Role limitations
		Emotional well-being
		Social function
		Energy/fatigue
		General health
GQL-15	15	Near vision
		Peripheral vision
		Outdoor mobility
		Dark adaptation
IVI	32	Leisure and work
		Consumer and social interaction
		Household and personal care
		Mobility
		Emotional reaction to vision loss
VFQ-25	25	General health
		General vision
		Ocular pain
		Near vision
		Distant vision
		Vision-specific social functioning
		Vision-specific role difficulties
		Vision-specific mental health
		Vision-specific dependency
		Driving
		Peripheral vision
		Color vision

Note. SF-36 = Medical Outcomes Study Short Form Health Survey-36; GQL-15 = Glaucoma Quality of Life-15; IVI = Impact of Vision Impairment; VFQ-25 = Visual Function Questionnaire-25.

The Medical Outcomes Study Short Form Health Survey-36 is an example of a health-related QoL instrument. It is a reliable and validated 36-item instrument that demonstrated discriminate validity between people with and without glaucoma (Wilson et al., 1998). However, it has correlated weakly to measures of visual impairment such as visual field and visual acuity (Parrish et al., 1997). The Medical Outcomes Study Short Form Health Survey-36 was mostly used prior to the emergence of VSQoL instruments. The Glaucoma Quality of Life-15 questionnaire is an example of a glaucoma-specific instrument (Nelson, Aspinall, Papasouliotis, Worton, & O'Brien, 2003). It is a reliable and validated 15-item instrument. However, it only queries activity limitations and focuses on the physical effects of the disease process (Khadka et al., 2013).

The Impact of Vision Impairment questionnaire is one example of a VSQoL instrument (Weih, Hassell, & Keeffe, 2002). It is a reliable and validated 32-item instrument; however, when evaluated using Rasch analysis the instrument had poor targeting (Lamoureux et al., 2007). Poor targeting suggested the items that comprised the scale did not span the full range of person abilities of people with glaucoma. Additionally, in people with glaucoma the Impact of Vision Impairment questionnaire did not correlate statistically significantly with visual impairment (e.g., visual field). Across several studies, the construct measured by the Impact of Vision Impairment questionnaire was described as both a measure of QoL and a measure of participation, the terms used interchangeably (Lamoureux, Hassess, & Keeffe, 2004; Noe, Ferraro, Lamoureux, Rait, & Keeffe, 2003).

The most frequently used measure of VSQoL is the National Eye Institute Visual Function Questionniare-25 (VFQ-25; Dougherty & Bullimore, 2010; Mangione et al., 2001; Marella et al., 2010; Massof, 2002; Revicki, Rentz, Harnam, Thomas, & Lanzetta, 2010; Suner et al., 2009). It is a reliable and validated instrument (Dougherty & Bullimore, 2010; Mangione et al., 2001). We

included the VFQ-25 in this research project as the measure of VSQoL. The psychometric properties of the VFQ-25 have been evaluated in people with various eye conditions, including age-related macular degeneration, age-related cataracts, glaucoma, diabetic retinopathy, and cytomegalovirus retinitis. A consistent trend in the relationship between VFQ-25 scores and visual field loss was reported in the literature: lower VFQ-25 scores for people with visual field loss than for people without visual field loss. This relationship between VFQ-25 scores and visual field loss indicated greater visual disability and poorer QoL (Gutierrez et al., 1997; Jampel et al., 2002; Kulkarni, Mayer, Lorenzana, Myers, & Spaeth, 2012; McKean-Cowdin et al., 2008; Richman et al., 2010). A large effect on VSQoL was demonstrated in people with both central and peripheral visual field loss, a moderate effect was demonstrated in people with binocular peripheral visual field loss, and a small effect was demonstrated in people with a monocular peripheral visual field loss (McKean-Cowdin et al., 2008).

The popular use of the VFQ-25 in studies of people with glaucoma is likely related to its statistically significant correlation with visual field staging systems and its fair correlation with visual impairment outcomes (Altangerel, Spaeth, & Rhee, 2003; Jampel et al., 2002; Kulkarni et al., 2012). The status of the better-seeing eye demonstrated a closer relationship with VFQ-25 total scores than the status of the worse-seeing eye (van Gestel et al., 2010). The degree of binocular visual field loss and the status of the visual field of the better-seeing eye most accurately predicted functional ability and VSQoL (Kulkarni et al., 2012; Richman et al., 2010).

While glaucoma-specific questionnaires may be more sensitive to the effects of disease and course of treatment, clinically more relevant, and narrower in scope, their psychometric rigor requires further validation. The current glaucoma-specific VSQoL instruments (e.g., Glaucoma Quality of Life-15) tend to measure only one aspect of the broad conceptualization of QoL (e.g.,

symptoms related to interventions or satisfaction with interventions; Khadka et al., 2013). Additionally, they often have an insufficient number of items which results in inadequate measurement precision when evaluated for psychometric rigor using Rasch analysis. Rasch analysis is the theoretical method advocated by vision science researchers for instrument development and for testing the psychometric properties of ordinal-scaled instruments (Massof, 2002).

When using and interpreting VSQoL data, we need to take into account not only the effect of the progression of visual field loss as it relates to functional abilities but also recognize that different patterns of visual field loss have different effects on functional abilities. For example, VSQoL was more affected by the presence of binocular defects in the inferior visual field than by defects in the superior visual field (van Gestel et al., 2010). It is important to take into consideration that the consistency of people's ratings and meaningfulness attached to those ratings may shift over time and alter by circumstance (Levasseur, Desrosiers, & St-Cyr Tribble, 2008). For example, having had glaucoma surgery resulted in lower VSQoL scores related to post-surgical symptoms. Likewise, the side effects of glaucoma medications negatively influence VSQoL. Notably, poorer VSQoL was also attributed to merely having a diagnosis associated with visual impairment, the inconvenience and burden of treatment regimens, and the cost of treatment (Iester & Zingirian, 2002). Thus, VSQoL is multidimensional and measures several areas of life domains and is affected by environmental and psychosocial factors.

2.1.2 Participation: Conceptual Definition

Participation is a core concept in the ICF model to measure function and disability. Conceptually, participation is defined as individual's involvement in life situations. There are nine domains that

comprise the taxonomy for participation in the ICF: 1) learning and applying knowledge, 2) general tasks and demands, 3) communication, 4) mobility, 5) self-care, 6) domestic life, 7) interpersonal interactions and relationships, 8) major life areas, and 9) community, social, and civic life. In vision rehabilitation, the effects of glaucoma on individuals' daily living are measured by participation (i.e., abilities to accomplish life situations). Therefore, it becomes evident that participation is a direct outcome (i.e., mechanism of change) for the goals that are a part of the plan of care for intervention in vision rehabilitation. However, in research, there is no consensus on a criterion standard for defining and measuring participation (Levasseur, Richard, Gauvin, & Raymond, 2010).

Despite the wide adoption of the ICF, there is a lack of conceptual clarity in regard to defining and distinguishing mutually exclusive taxonomies between the activity and participation constructs (Whiteneck & Dijkers, 2009). While activity and participation are two separate constructs in the ICF, they share the taxonomy that includes the aforementioned nine domains (see Table 5). The ICF offers four options to distinguish activity from participation and recommends that users should individually decide which option to choose. However, there is no consensus in the scientific literature as to which recommendation is the best distinction. Because of this conceptual ambiguity, researchers have recommended alternative conceptualizations of and differentiation between activity and participation (Badley, 2008; Nordenfelt, 2003; Whiteneck & Dijkers, 2009).

Table 5. The International Classification of Functioning, Disability and Health Taxonomy for Activities and Participation

Domains
1) Learning and applying knowledge
2) General tasks and demands
3) Communication
4) Mobility
5) Self-care
6) Domestic life
7) Interpersonal interactions and relationships
8) Major life areas
9) Community, social and civic life
Recommendations
1) Mutually exclusive sets of activities domains and participation domains
2) Partial overlap between sets of activities and participation domains
3) Detailed categories within domains classified as activities and broad categories within domains as participation, with or without overlap
4) Use of the same domains for both activities and participation

Note. From World Health Organization (2001).

In regard to the conceptualization of activity differentiated from participation, a review of the literature suggested the distinction that activity is performance at the individual level of function and participation is performance at the societal level of function (WHO, 2001; Whiteneck & Dijkers, 2009). Simply stated, we can interpret this conceptual distinction as activity is done alone and participation is done in the company of or for others (i.e., social situations). Participation therefore, may better embrace the complexity and dynamic nature of human function better than activity as the solitary execution of a task (Desrosiers, Noreau, & Rochette, 2004; Levasseur et al., 2008). As with QoL, the conceptual ambiguity for participation also results in operational disparities for instrument design and outcome measurement (Resnik & Plow, 2009). While minimizing activity limitations tends to be the typical intervention goal in traditional medical

rehabilitation settings, reducing participation restrictions may be the ultimate goal of vision rehabilitation given the effects of glaucoma on daily living and the relationship between participation and social role performance of people with glaucoma.

In this study, we distinguished participation from activity as described by Whiteneck and Dijkers (2009) by stating that participation requires a social context involving other people and is more complex than activities, in that participation broadly encompasses a combination of several activities. We used the method to distinguish the activities and participation taxonomy into distinct sets of activity domains and participation domains with no overlap (WHO, 2001). Participation in this study is defined by the following three distinct ICF domains: 1) interpersonal interactions and relationships, 2) major life areas, and 3) community, social, and civic life.

2.1.2.1 Disability Creation Process While the ICF is the theoretical framework for operationalizing QoL and participation for this research project, we used a participation instrument, the Assessment of Life Habits, which is based on the DCP model. Therefore, recognizing the similarities and differences in their theoretical conceptualization of participation is important for understanding the application and interpretation of the Assessment of Life Habits. The underlying conceptualization of participation is critical in the process of defining what constitutes a participation situation.

In the DCP model, participation is defined by life habits, which are defined as regular activities and social roles that ensure people's survival and well-being in society throughout their lifespan (Fougeyrollas & Noreau, 2003). The term in the DCP model 'capabilities' is equivalent to 'activities' in the ICF model, not to be confused with the DCP term 'regular activities' used to define life habits (see Figure 1A). There are 12 domains of life habits in the DCP model. When the DCP model was compared to the ICF model, there are six life habits (DCP) that are similar to

the conceptualization and operationalization of participation (ICF) previously described: 1) interpersonal relationships, 2) education, 3) employment, 4) community life, 5) recreation, and 6) responsibilities (see Table 6; Levasseur, Desrosiers, & Tribble, 2007). Therefore in this study, we analyzed only the six life habits (i.e., social roles) on the Assessment of Life Habits instrument that are equivalent to the conceptualization of participation in the ICF.

Table 6. Participation versus Activities: Similarities between the International Classification of Functioning, Disability and Health and the Disability Creation Process Models

ICF	DCP (Life habits)
Activities	Regular activities
Learning and applying knowledge	
General tasks and demands	
Communication	Communication
Mobility	Mobility
Self-care	Personal care
	Fitness
	Nutrition[a]
Domestic life	Housing
	Nutrition[a]
Participation	Social Roles
Interpersonal interactions and relationships	Interpersonal relationships
Major life areas	Education
	Employment
Community, social, and civic life	Community life
	Recreation
	Responsibilities

Note. ICF = International Classification of Functioning, Disability and Health; DCP = Disability Creation Process. Participation is delineated from activities as suggested by Whiteneck & Dijkers (2009).

[a]Nutrition in the DCP relates to both self-care and domestic life in the ICF.

2.1.2.2 Participation: Measurement Participation can be measured in terms of frequency of participation, participation accomplishment, and satisfaction with participation. Because of the conceptual ambiguities surrounding the distinction between activities and participation, participation is an evolving outcome in rehabilitation and the best methods for measuring participation are yet unclear.

Multiple questionnaire-based instruments have been developed to measure participation, though the psychometric rigor of the newer instruments is not well established. Yet, despite existing participation instruments and the ultimate goals of vision rehabilitation to maximize participation in meaningful occupations, few studies on participation have been conducted with people with glaucoma. The number of studies on participation of people with glaucoma is likely to increase due to recent efforts to develop and/or modify existing instruments that distinguish the construct of participation from other constructs (e.g., QoL and activities) in response to the growing focus on participation as a measure of function and disability. A limitation of existing participation instruments is that several are designed for specific populations (e.g., brain injury), which may limit the instruments' measurement of people's abilities across a range of tasks with different complexities for different diagnostic populations. Few instruments have been used with or developed for people with glaucoma. Several participation instruments potentially relevant to use with people with visual impairment or glaucoma are the Impact of Participation and Autonomy, Participation Assessment with Recombined Tools-Subjective, Participation Assessment with Recombined Tools-Objective (PART-O), and Assessment of Life Habits (LIFE-H; see Table 7).

Table 7. Instruments used to Evaluate Participation in Rehabilitation

Instrument	Number of items	Domains
IPA	32	Autonomy indoors
		Family role
		Autonomy outdoors
		Social life and relationships
		Work and education
PART-S	11	School and other opportunities to learn
		Paid and unpaid work
		Having/raising children
		Housekeeping and other activities to keep the home in good order
		Relationships: spouse or significant other
		Relationships: family and relatives
		Relationships: friends and acquaintances
		Public and private transportation
		Participation in religious services and functions
		Activities in organizations or community
		Recreation and leisure
PART-O	24	Productivity
		Social relations
		Out-and-about in the community
LIFE-H	77	Nutrition
		Fitness
		Personal care
		Communication
		Housing
		Mobility
		Responsibilities
		Interpersonal relationships
		Community life
		Education
		Employment
		Recreation

Note. IPA = Impact on Participation and Autonomy; PART-S = Participation with Recombined Tools-Subjective; PART-O = Participation Assessment with Recombined Tools-Objective; LIFE-H = Assessment of Life Habits.

The Impact on Participation and Autonomy is a reliable and validated 32-item instrument developed to measure people's perceptions of their participation (i.e., how likely they will be able to participate) and autonomy (i.e., how disability effects their ability to participate; Magasi & Post, 2010; Sibley et al., 2006). It has been used with people across a wide spectrum of rehabilitation diagnoses and healthy adults, though not with people with visual impairment. It was developed based on the ICIDH-2 model. We did not use the Impact on Participation and Autonomy because our research questions were about how frequently and how individuals accomplished life situations and the research questions did not focus on the concept of autonomy.

The Participation Assessment with Recombined Tools-Subjective was developed to measure people's perceptions of their satisfaction for how they participate in home and community tasks. It is a separate scale from the Participation Assessment with Recombined Tools-Objective (PART-O). Its psychometric properties have not yet been published (Whiteneck et al., 2011). It has 11 domains of participation for which respondents rate the importance of each domain and their level of satisfaction with their participation in each domain area. It was developed based on the ICF model. We did not use the Participation Assessment with Recombined Tools-Subjective since its psychometric properties have not been reported.

The PART-O is a reliable and validated 24-item instrument developed to measure the frequency of participation (Whiteneck et al., 2011). We included the PART-O in this research study as the measure of frequency of participation. The psychometric properties of the PART-O were evaluated using Rasch analysis in people with brain injury, spinal cord injury, stroke, and people in the general population with and without a disability. The instrument is unidimensional (i.e., measures one underlying construct). Reliability and validity values are within acceptable ranges for the Rasch model. The PART-O was developed within the past 5 years and only cross-

sectional studies describing the instrument, mainly for its validation, were located in the published literature. It was developed based on the ICF model.

The Assessment of Life Habits (LIFE-H) is a reliable and validated 77-item instrument developed to measure both participation (i.e., accomplishment) and satisfaction with participation (Fougeyrollas et al., 1998; Noonan, Miller, & Noreau, 2009; Noreau et al., 2004). We included the LIFE-H in this research project as the measure of participation accomplishment and satisfaction with participation. It demonstrated low ceiling and minimal floor effects (Magasi & Post, 2010). The LIFE-H is divided into 12 domains of life habits: 6 regular activities and 6 social roles. The psychometric properties of the LIFE-H accomplishment scale have been evaluated in diverse populations of people with varying conditions, including visual impairment, multiple sclerosis, spinal cord injury, stroke, older adults with disability, amputation, coronary disease, rheumatic disorders, and healthy people. The LIFE-H was used in a study of older adults with and without visual impairment and the study reported statistically significant differences in participation in regular activities and social roles between the two groups (Desrosiers, Wanet-Defalque, et al., 2009). In the same study, the instrument demonstrated good reliability and weak to strong validity. Depressive symptoms and perceived quality of distant vision were the strongest correlates that together explained greater than 65% of the variance in the participation scores of people with visual impairment. It was developed based on the DCP model.

Reliability and validity of the LIFE-H satisfaction with participation scale was studied separate from the LIFE-H accomplishment scales since it has its own score. A study of people described as having functional limitations explored the relationship between levels of participation and satisfaction with participation; the satisfaction with participation scale had a statistically significant and fair, positive association with the regular activities domains and total score (Poulin

& Desrosiers, 2009). In the same study, the satisfaction scale did not have a statistically significant association and only had a weak association with the social roles domains. Overall, the satisfaction scale had a moderate correlation with the participation accomplishment domain scales. The test-retest reliability of the satisfaction scale was good for the regular activities domains, social roles domains, and the composite score. The satisfaction scale also had a stronger correlation to the Quality of Life Index than to the participation accomplishment domain scales, suggestive that satisfaction with how people were able to participate in everyday roles and routines was associated more with QoL than with performance.

2.2 SUMMARY

Over the past 15 years, glaucoma research has advanced. Healthcare now includes patient-reported outcomes to measure whether or not provided services improved patients' perceptions of their health and well-being. Patient-reported outcomes are increasingly used with the focus on client-centered care. Globally, vision science and medical care management included patient-reported outcomes that measured QoL as a means to understand the lived experiences of people with glaucoma in regard to their overall health and well-being (Labiris, Giarmoukakis, Larin, Gkika, & Kozobolis, 2012). A consistent trend in the literature is that VSQoL decreased as the severity of glaucoma increased and there were differences in the VSQoL of people with glaucoma compared to people without glaucoma (Freeman, Munoz, West, Jampel, & Friedman, 2008; Gutierrez et al., 1997; Jampel et al., 2002; McKean-Cowdin et al., 2008). Additionally, there were perceived differences in VSQoL for people with mild stage glaucoma than those with severe stage glaucoma.

Recently, with an increased awareness of the role of and effectiveness of vision rehabilitation (i.e., evaluation and interventions), there is an increased focus on understanding the effects of glaucoma as they relate to function and disability. Participation is one outcome used in vision rehabilitation to measure the effects of vision loss on function and disability. The conceptualizations of both QoL and participation, however, have been ambiguous in the scientific literature. We described the conceptualization of QoL and participation as defined by the ICF to interpret the outcomes of this research project. In addition, we briefly described the current evaluation instruments used in both the medical and the rehabilitation management for people with glaucoma to summarize the state of the science in regard to glaucoma research and how the science is interpreted and applied clinically.

While VSQoL has been a primary outcome in vision science to measure the effect of glaucoma on people's daily living, we suggest that participation (the primary outcome measure used in vision rehabilitation to directly evaluate the effect of vision loss due to glaucoma on individuals' abilities to accomplish social life situations) should be included in vision research. Yet, participation has not been well studied in people with glaucoma. We also contend that VSQoL and participation are two distinct constructs that can be used to measure the effect of glaucoma on people's daily living, and that each contributes uniquely to our understanding of function and disability. Additionally, given there are conceptual similarities and differences between QoL and participation, arguably participation is one component included within the broader conceptualization of QoL (see Appendix A). Therefore, we designed this research project to explore participation in individuals with glaucoma, including a comparison to VSQoL, to better understand the association between participation and severity of glaucoma.

3.0 EXPLORING PARTICIPATION IN INDIVIDUALS WITH GLAUCOMA

3.1 INTRODUCTION

In health care and in research, there is an emerging focus to understand how glaucoma affects people's abilities in regard to the accomplishment of roles and routines in daily living. Historically, research focused on how glaucoma affected the structure and function of the eye and the effect of glaucoma on people's vision-specific quality of life (VSQoL). In recent years, the healthcare model of care shifted to a client-centered model where the client is encouraged to be an active stakeholder and their individual experiences are considered as integral to part of the care process. Vision rehabilitation services emerged in the forefront as part of the care process to meet individuals' eye care needs.

A primary goal of vision rehabilitation is for people to maximize the use of their remaining vision to live as independently as possible to engage in their chosen roles and routines. One outcome in rehabilitation that can be used to measure individuals' accomplishment of roles and routines is participation. Clinically, rehabilitation specialists evaluate and develop intervention programs targeted toward maximizing participation when individuals experience disability related to vision loss. Participation is used to measure people's responses to and the success of intervention. Yet, little vision research has focused on participation as a distinct outcome measure of function and disability in people with glaucoma; rather, the research to date focused primarily on VSQoL (see Section 2.0). Participation is an evolving outcome measure in rehabilitation research. How to best measure participation is still in developmental stages and, as previously described in Section 2.1.2, there are ambiguities in regard to the conceptualization of participation.

Participation in meaningful roles and routines is an important aspect of health, health management, and quality of life (Ellexson, 2004; Sørensen, Axelsen, & Avlund, 2002; Stevens-Ratchford, 2010). The concept of participation, as taking part in doing something, is threaded throughout the gerontology literature. Studies explored how people engaged in tasks and how their engagement influenced successful aging; developmental theories suggest that participation patterns change across the lifespan, most especially among older adults (Bath & Deeg, 2005; Christiansen, Baum, & Bass-Haugen, 2005; Maier & Klumb, 2005; Sørensen, Axelsen, & Avlund, 2002).

3.2 PARTICIPATION: NORMAL AGING

It is well documented that participation decreases with normal aging (Levasseur, Desrosiers, & St-Cyr Tribble, 2008; Perlmutter, Bhorade, Gordon, Hollingsworth, & Baum, 2010; Sørensen et al., 2002) and is more restricted by disabilities in older age (van Campen & Iedema, 2007). Participation in instrumental activities of daily living, leisure, and social activities were facilitators for remaining involved with families, communities, and social networks; sustaining health; and aging successfully (Glass, Seeman, Herzog, Kahn, & Berkman, 1995; Marsiske, Klumb, & Baltes, 1997; Stevens-Ratchford, 2005). The presence of a disease, activities limitation, or participation restriction may alter people's abilities to maintain their roles and routines; and in adapting to such changes, people may either cease engagement in a situation or change their level of engagement. Either way, there are changes in participation over time. For older adults, these changes in participation may lead to an inability to age in place and result in placement in long-term care facilities (Schoessow, 2010).

Limiting factors beyond age that influenced health and participation were decreased cognition and depression; each factor was associated with changes in participation (Perlmutter et al., 2010). Depressive symptoms or emotional distress were among the strongest correlates of lower participation in studies of people with physical and functional disability (Cardol et al., 2002; Desrosiers et al., 2006). As the Baby Boomer generation ages, the total percentage of the population aged 65 years and older will increase. Understanding the normal conditions of aging and how those conditions are managed will help direct resource utilization to support people's involvement in social roles and routines (i.e., participation). However, while it is common to associate decreased levels of participation with normal aging, vigilance is warranted to discriminate when in fact the sequela of a chronic disease, such as glaucoma, is the true limiting factor of participation (Maier & Klumb, 2005; Mendes de Leon, 2005).

3.3 PARTICIPATION: VISION LOSS

For people with vision loss, their perceptions of their abilities to accomplish and 'do' a task (i.e., be involved in a life situation) was more important than the amount of their remaining vision that was still usable (severity of vision loss; Nelson, Aspinall, & O'Brien, 1999; Noe, Ferraro, Lamoureux, Rait, & Keeffe, 2003). The following determinants of participation were reported for people with vision loss: age, physical fitness, helplessness, social network size, and the personal value attached to participation (Alma, Van der Mei, Groothoff, & Suurmeijer, 2012). A point of interest from that study was that visual acuity, a measure of impairment, was not a determinant of participation. Visual acuity is often a benchmark measure used to indicate the presence of a visual impairment. In adults with chronic conditions, mobility and balance were indicators of

participation and characteristics such as age, depression, and comorbidities were not indicators of participation (Anaby et al., 2009). These findings contribute to the discussion that changes in participation may not be influenced by severity of impairment alone.

Vision loss often co-occurs with other sensory conditions and the combination of conditions was associated with greater limitations on people's abilities than either condition alone (Crews, Jones, & Kim, 2006). Dual sensory loss (e.g., the combination of vision and hearing loss) was present in 8.6% of older adults (Crews & Campbell, 2004) with 23% of adults aged 81 years and older having had some degree of dual sensory impairment that likely affected participation (Bergman & Rosenhall, 2001). The elderly who reported vision problems had a higher number of comorbidities compared to people without vision problems (Desrosiers, Wanet-Defalque, et al., 2009). Studies of people with vision loss have identified associations between visual impairment and frequency of participation and mobility restrictions and visual field loss (Desrosiers, Wanet-Defalque, et al., 2009; Noe et al., 2003). Decreased distant vision was associated with changes in participation and was a factor that influenced health and participation (Perlmutter et al., 2010). Overall, people with vision loss had statistically significant lower participation scores than people without vision loss (Desrosiers, Wanet-Defalque, et al., 2009; Renaud et al., 2010).

People with glaucoma demonstrate characteristic behavior that is the consequence of both changes in vision and of the increased effort to overcome challenges in order to maintain independence in daily living. We know that gradual deterioration in vision may result from changes occurring in the body functions and the body structures of the eye that are not recognized until there is a degree of severity of change that is detectable by medical technologies. These initial, undetectable changes affect visual sensory perception and likely have subtle effects on higher level cortical sensory processing that may affect our abilities (e.g., motion perception for mobility and

driving). As previously stated, participation may be influenced by more than severity of impairment. Therefore, we asked the question whether or not participation would be an indicator of severity of vision loss independent of clinical measures of visual impairment.

It is possible that people can fully compensate for a decline in clinical visual function by using strategies such as low vision aids or by doing tasks differently before they are diagnosed with an eye condition. These people may exhibit indicators for being at risk for disability, a functional state in which they are still able to accomplish daily roles and routines but they are changing the frequency or modifying the way in which they complete the tasks (Fried, Herdman, Kuhn, Rubin, & Turano, 1991; Higgins, Janelle, & Manini, 2013; West et al., 2005). This implies that these people with vision loss may be at risk for disability, but they do not perceive difficulties due to their use of compensatory strategies. For people with vision loss, participation may be an indicator of their risk for disability, demonstrating limitations in participation but not the lack of independence.

The effect of glaucoma on people's daily living and functional independence has justifiably received increased attention in regard to public health awareness. The prevalence of glaucoma in adults aged 40 years and older is increasing (Friedman et al., 2004). Participation is recognized in rehabilitation as a primary measure of the effect of impairment or disability on people's accomplishment of their roles and routines. Yet despite the fact that a primary clinical goal of vision rehabilitation is to promote health through participation, by evaluating the effects of glaucoma on people's abilities, participation has not been sufficiently studied. Moreover, the conceptual ambiguity surrounding the definition of participation (e.g., participation distinguished from activities) has received little attention in the design and interpretation of study results reported in the literature.

Based on the conceptualization of participation (i.e., a social context involving other people) previously described for this study, participation relates to more complex behavior than the execution of a singular task (i.e., activities). Glaucoma is associated with disability and loss of personal independence. Many of the effects of glaucoma on function and disability described in the literature are at the level of participation. Therefore, it is at the level of participation that may be most critical to evaluate in people with glaucoma to recognize behaviors that may be associated with severity of vision loss.

The objective of this study was to explore participation in individuals with glaucoma to better understand the relationship between severity of vision loss related to the disease process and the degree to which participation was associated with severity of glaucoma. We currently know that participation decreases with the natural progression of aging and that it may also decrease in the presence of a health condition or disease. For individuals with glaucoma, we don't know what participation is relative to the progression of the disease. This study aimed to explore the association between participation (frequency of participation, participation accomplishment, satisfaction with participation) and severity of glaucoma. We hypothesized that participation would have at least a moderate association with severity of glaucoma.

3.4 METHODS

3.4.1 Design

A cross sectional design was used to examine the relationship between participation and severity of glaucoma.

3.4.2 Participants

We recruited participants from the University of Pittsburgh Medical Center (UPMC) Eye Center(s) in Pittsburgh, PA from November 2013 to August 2014. Two methods were used for recruitment: 1) clinical appointments at the UPMC Eye Center(s) and 2) the UPMC Eye Center Registry (a research registry of individuals who consented to be contacted about vision-related research conducted by the University of Pittsburgh). We directed our recruitment procedures to the patients of the physicians who were glaucoma specialists, including the clinical staff (e.g., fellows) under the physicians' supervision. Patients were eligible to enroll in the study if they met the following criteria: 1) community-dwelling adult or older adult, 2) age 50 years or older, 3) medically diagnosed with glaucoma (not restricted by a specific type of glaucoma), and 4) best-corrected visual acuity (BCVA) of 20/200 or better in at least one eye. Patients were excluded from eligibility if they: 1) had a diagnosis of optic neuropathy or pathology other than glaucoma that was visually significant, 2) had a medical condition with subsequent vision loss, 3) were non-English speaking, or 4) had a cognitive impairment (defined by either a medical diagnosis or a Telephone Interview for Cognitive Status-modified [TICS-m] score ≤ 27).

3.4.2.1 Modified Eligibility Criteria We conducted two planned interim analyses of data in the early stages of our study to examine how the estimates that informed the statistical analysis plan were supported by our data. The first analysis was based on the first 15 enrolled participants with complete data; the second analysis was based on 51 enrolled participants. Per recommendation following the first analysis, the dissertation committee agreed to two eligibility criteria modifications. We modified the original inclusion criterion BCVA of 20/200 or better in both eyes to 20/200 or better in at least one eye. The rationale for this change was to minimize

the exclusion of individuals with more advanced glaucoma, who otherwise qualified for the study, and to potentially improve the distribution of the sample in regard to the spectrum of disease severity. We also modified the exclusion criterion for cognitive impairment defined by a TICS-m score ≤ 31 to cognitive impairment defined by either a medical diagnosis or a TICS-m score ≤ 27. The criterion change was supported by published research that reported individuals who scored as mild cognitive impairment (TICS-m score range 28 to 31) were accurate self-reporters. The University of Pittsburgh Institutional Review Board approved these changes, at which point 36 participants were enrolled. No changes in study criteria were made after the second interim analysis.

3.4.3 Instruments

We used two procedures to screen for eligibility: 1) an electronic medical record (EMR) review and 2) an interview to screen cognition using the TICS-m. The descriptive and outcome assessments included: 1) EMR review, 2) Humphrey Visual Field Analyzer, 3) a demographic questionnaire, 4) the Participation Assessment with Recombined Tools-Objective (PART-O), and 5) the Assessment of Life Habits (LIFE-H), version 3.1.

3.4.3.1 Screening Instruments

Electronic medical record review checklist. We created an EMR review screening checklist to screen patients' medical records for eligibility for this study. The checklist included a yes/no response format as to whether the following information was recorded in the medical record: date of birth, living situation, medically diagnosed glaucoma, Humphrey Visual Field Analyzer test and mean deviation (MD) scores, BCVA, comorbidities with subsequent vision loss, diagnosed optic

neuropathy or pathology other than glaucoma, diagnosed cognitive impairment, English-speaking, and the date of the last clinical vision appointment (within 9 months of potential enrollment to the study). During an initial review of the EMR, yes/no was checked as to whether or not the information found in the EMR met the eligibility criteria for potential enrollment and whether the information was within the 9 month time parameter for eligibility for this study. The checklist is completed during an EMR review prior to any encounter with a patient (see Appendix B).

Telephone Interview for Cognitive Status-modified. The TICS-m is a 13-item instrument developed to screen adults and older adults for cognitive impairment (see Table 8; de Jager, Budge, & Clarke, 2003). The TICS-m is a reliable and validated instrument (de Jager et al., 2003). TICS-m scores had a weak, inverse correlation with age, moderate correlation with the Mini-Mental State Examination, and moderate correlation with the Cambridge Cognitive Examination. The normal distribution of TICS-m scores suggested it was less constrained by ceiling effects than both the Mini-Mental State Examination and the Cambridge Cognitive Examination, which each had skewed distributions. The TICS-m demonstrated 94% sensitivity and 100% specificity for grouping individuals as either normal cognition or impaired cognition (Martin-Khan, Wootton, & Gray, 2010). The memory tasks consist of higher item difficulty than other screening instruments; thus, it is a more discriminative test across the range of cognitive performance than the Mini-Mental State Examination and the Cambridge Cognitive Examination.

Table 8. Domains of the Telephone Interview for Cognitive Status-modified

Domains	Number of items
Orientation	3
Registration/free recall	1
Attention/calculation	2
Comprehension, semantic and recent memory	5
Language/repetition	1
Delayed recall	1

The maximum total score for the TICS-m is 39; a higher score indicates better cognitive function. A score of 31 or less is the optimal cut point to separate individuals with normal cognition from those with mild cognitive impairment; a score of 27 or less is the optimal cut point to separate individuals with mild cognitive impairment from those with dementia (Knopman et al., 2010). Patients were excluded from this study if they scored at or below 27. We chose to use the TICS-m to screen for cognitive impairment because it can be completed in 5 to 10 minutes either face-to-face or via the telephone.

3.4.3.2 Descriptive and Outcome Instruments

Electronic medical record review checklist. We again used the EMR review screening checklist during a second review of the EMR after patients signed their consent to enroll in the study. We recorded the following information on the checklist: date of birth, mean deviation (MD) scores from the Humphrey Visual Field Analyzer test, clinical interpretation of the Humphrey Visual Field Analyzer test, BCVA, diagnosed comorbidities not indicated on the demographic questionnaires, and the date of the last clinical vision appointment.

Humphrey Visual Field Analyzer. The primary outcome variable for this study was the severity of glaucoma, defined by the MD of the better-seeing eye, measured by the Humphrey Visual Field Analyzer using the standard threshold 24-2 visual field test. The MD is a measure of visual field sensitivity through threshold testing using an automated perimeter; the measure is the deviation from the expected threshold value for a person of the same age and ethnicity. Individuals who are able to see dimmer thresholds than others of the same age and ethnicity have positive scores, while those individuals who require brighter threshold stimuli have negative scores. The mean deviation of the better-seeing eye is just as useful as more complicated strategies for staging the severity of glaucoma (Kulkarni, Mayer, Lorenzana, Myers, & Spaeth., 2012). The Humphrey Visual Field Analyzer is a threshold perimetry test developed to detect intensity of brightness respondents can see within the central 24 degrees of their visual fields. The Humphrey Visual Field Analyzer is considered the gold standard automated perimeter for the diagnosis and measurement of severity of glaucoma (Foster, Buhrmann, Quigley, & Johnson, 2002). Individuals who are able to see dimmer thresholds than others of the same age and ethnicity have positive scores (no or little impairment), while those individuals who require brighter threshold stimuli have negative scores (more severe impairment; see Table 2). MD scores for reliable tests range from 2 dB to -30 dB. The MD scores were dated within 9 months of enrollment to the study.

We chose MD of the better-seeing eye for the measure of severity of glaucoma based on published research that reported the status of the better-seeing eye most accurately predicted functional ability, disability, and quality of life in individuals with glaucoma (Arora et al., 2013; Kulkarni et al., 2012).

Demographic Questionnaire. The demographic questionnaire, developed specifically for this study, is comprised of three sections: 1) 12-items designed to collect background information

and eye and medical histories, 2) the Glaucoma Symptom Scale (GSS), and 3) the Patient Health Questionnaire-9 (PHQ-9). It can be self-administered or interview-administered in less than 5 minutes (see Appendix B).

The GSS is a 10-item instrument developed to measure visual problems experienced by respondents in the past 4 weeks; each eye is assessed separately (see Table 9; Lee et al., 1998). The GSS demonstrated discriminant validity between individuals with and without glaucoma, fair to moderate correlations with the National Eye Institute Visual Function Quationnaire-25 ocular pain subscale, and good internal consistency (Lee et al., 1998). Responses are rated on a 5-point categorical scale ranging from 0 (yes, very bothersome) to 4 (no, absent). The score for each item is transformed to a 0 to 100-point scale and the total score is the average of all 10 items; the score is reported for each eye individually or as an average for both eyes. A high score indicates no ocular complaints.

Table 9. Visual Problems Assessed by the Glaucoma Symptom Scale

Burning, smarting, stinging
Tearing
Dryness
Itching
Soreness, tiredness
Blurry/dim vision
Feeling of something in your eye
Hard to see in daylight
Hard to see in dark places
Halos around lights

The PHQ-9 is a 9-item instrument developed to screen respondents for depressive symptoms experienced in the past 2 weeks (Kroenke, Spitzer, Williams, & Lowe, 2010; Lamoureux et al., 2009; Zhang et al., 2013). The PHQ-9 is a reliable and validated instrument (Gilbody, Richards, Brealey, & Hewitt, 2007; Kroenke, Spitzer, & Williams, 2001; Wittkampf, Naeije, Schene, Huyser, & van Weert, 2007). For individuals with vision loss, the PHQ-9 had no statistically significant deviation from the Rasch model and it was unidimensional (Lamoureux et al., 2009). Responses are rated on a 4-point categorical scale ranging from 0 (not at all) to 3 (nearly every day). The maximum total score is 27; a high score indicates the presence of greater depressive symptomology (see Table 10). The PHQ-9 includes a global rating of functional impairment (i.e., whether the symptoms identified make everyday activities difficult) which is not factored into the total score. The minimum recommended cut point to refer an individual for further formal testing for depression is 10 (Kroenke et al., 2001). At a score of 10 or greater, the PHQ-9 demonstrated 88% sensitivity and 88% specificity for identifying major depression; individuals with major depression were 7 times more likely to have a score of 10 or greater.

Table 10. Interpretation of the Patient Health Questionnaire-9 Scores

< 5	No depressive symptoms
5 - 9	Mild depressive symptoms
10 - 14	Moderate depressive symptoms
15 - 19	Moderately severe depressive symptoms
≥ 20	Severe depressive symptoms

Advantages of the PHQ-9 over other measures to screen for depressive symptoms include: shorter administration time; it consists of the actual nine criteria from the Diagnostic and Statistical

Manual of Mental Disorders for which the diagnosis of depressive disorders is based; performance by respondents was similar regardless of the method of administration; it performed similarly across sex, age, race, and ethnicity; and it was sensitive to clinically meaningful change (Kroenke et al., 2010).

Participation Assessment with Recombined Tools-Objective. The PART-O is a reliable and validated 24-item questionnaire developed to measure frequency of participation in regard to respondents' function in the household, family, and community and wider society (Whiteneck et al., 2011). It is divided into three areas of functioning: productivity, social relations, and out-and-about in the community. Refer to section 2.1.2.2 for a brief description of the instrument's psychometric properties.

Assessment of Life Habits. The LIFE-H, version 3.1, is a reliable and validated 77-item questionnaire developed to measure: 1) how a respondent accomplishes regular activities and social roles (participation accomplishment) and 2) satisfaction with how regular activities and social roles are accomplished (satisfaction with participation; Fougeyrollas et al., 1998; Noonan, Miller, & Noreau, 2009; Noreau et al., 2004; Noreau, Fougeyrollas, & Vincent, 2002). Regular activities and social roles are life habits that are valued by people and ensure their survival and well-being in society throughout their lifespan (Fougeyrollas & Noreau, 2003). We used only the domains of life habits for social roles for this study because their meaning parallels the conceptualization of participation used for this study (see Table 6). There are six domains of life habits for social roles: 1) responsibilities, 2) interpersonal relationships, 3) community life, 4) education, 5) employment, and 6) recreation (see Table 11). Refer to section 2.1.2.2 for a brief description of the instrument's psychometric properties.

Table 11. Social Roles Domains of the Assessment of Life Habits

Domain	Taxonomy
Responsibility	Financial responsibility
	Civil responsibility
	Family responsibility
Interpersonal relationships	Sexual relationships
	Affective relationships
	Social relationships
Community life	Community participation
	Spiritual life and religious practice
Education	Pre-school
	Academic education
	Occupational training
	Other training
Employment	Guidance
	Job search
	Paid occupation
	Unpaid occupation
Recreation	Sports and games
	Arts and culture
	Socio-recreational activities

Note. From Fougeyrollas, Cloutier, Bergeron, Cote, & St-Michel (1999).

The participation accomplishment scale measures the level of difficulty and type(s) of assistance that are required to accomplish task performance (i.e., accomplishment; see Table 12); responses are rated on categorical scales. Respondents rate the level of difficulty and type(s) of assistance on categorical scales and the responses are converted to a 0 to 10-point scale (using a weighted formula) for each domain of life habits. A score of 0 indicates social roles are not accomplished and a score of 10 indicates social roles are performed without difficulty or assistance. The composite score for the participation accomplishment scale is the average of the

normalized scores for each domain of life habits. High scores indicate accomplishment of tasks with little or no difficulty and/or with few or no types of assistance.

Table 12. Score Categories for the Assessment of Life Habits

Participation accomplishment (/10)		Satisfaction with participation(/5)
Level of difficulty	Type(s) of assistance	Level of satisfaction
No difficulty	No assistance	Very satisfied
With difficulty	Assistive device	Satisfied
Accomplished by a proxy	Adaptation	More or less satisfied
Not accomplished	Human assistance	Dissatisfied
Not applicable		Very dissatisfied

Note. Assistive device = non-human support to assist in the accomplishment of a life habit (e.g., visual aid); adaptation = any modification to an individual's environment to facilitate accomplishment of a life habit (e.g., lighting modifications); human assistance = a person assisting in the accomplishment of a life habit (includes supervision).

The satisfaction with participation scale measures how satisfied individuals are with how they are able to accomplish task performance. Respondents rate their satisfaction with participation on a 5-point categorical scale ranging from 1 (very dissatisfied) to 5 (very satisfied). The domain score for each life habit is the average of all the items rated for that domain. The composite score for the satisfaction with participation scale is the average of all the domain scores. High scores indicate a high level of satisfaction with participation.

The LIFE-H can be self-administered or interview-administered in approximately 40 minutes. We chose the LIFE-H as a measure of participation accomplishment and satisfaction with participation based on its psychometric properties, clear distinction of the concept of participation versus activity, item content, and prior use with individuals with visual impairment (see Appendix B).

3.4.4 Procedure

The study was approved by the University of Pittsburgh Institutional Review Board. We used two resources from which to screen potential participants: 1) we reviewed the clinical appointments scheduled for the glaucoma specialists at the UPMC Eye Center(s) and 2) we used the UPMC Eye Center Registry (see Figure 3). For patients scheduled for clinical appointments with the glaucoma specialists at the UMPC Eye Center(s), the primary investigator screened the patients' EMRs using the EMR review checklist to identify any scheduled patients who potentially qualified for the study based on the eligibility criteria. This EMR review was conducted prior to a patient's encounter with the physician. For those patients identified as potentially eligible for the study, a verbal permission form to allow the primary investigator to speak with patients to discuss the study was attached to their registration paperwork. Physicians then, at the conclusion of the patient's appointment, verbally introduced the study to those patients who were earmarked potentially eligible for the study. The physicians completed the verbal permission forms by indicating (yes/no) whether or not the patients were interested in speaking with the primary investigator about the study.

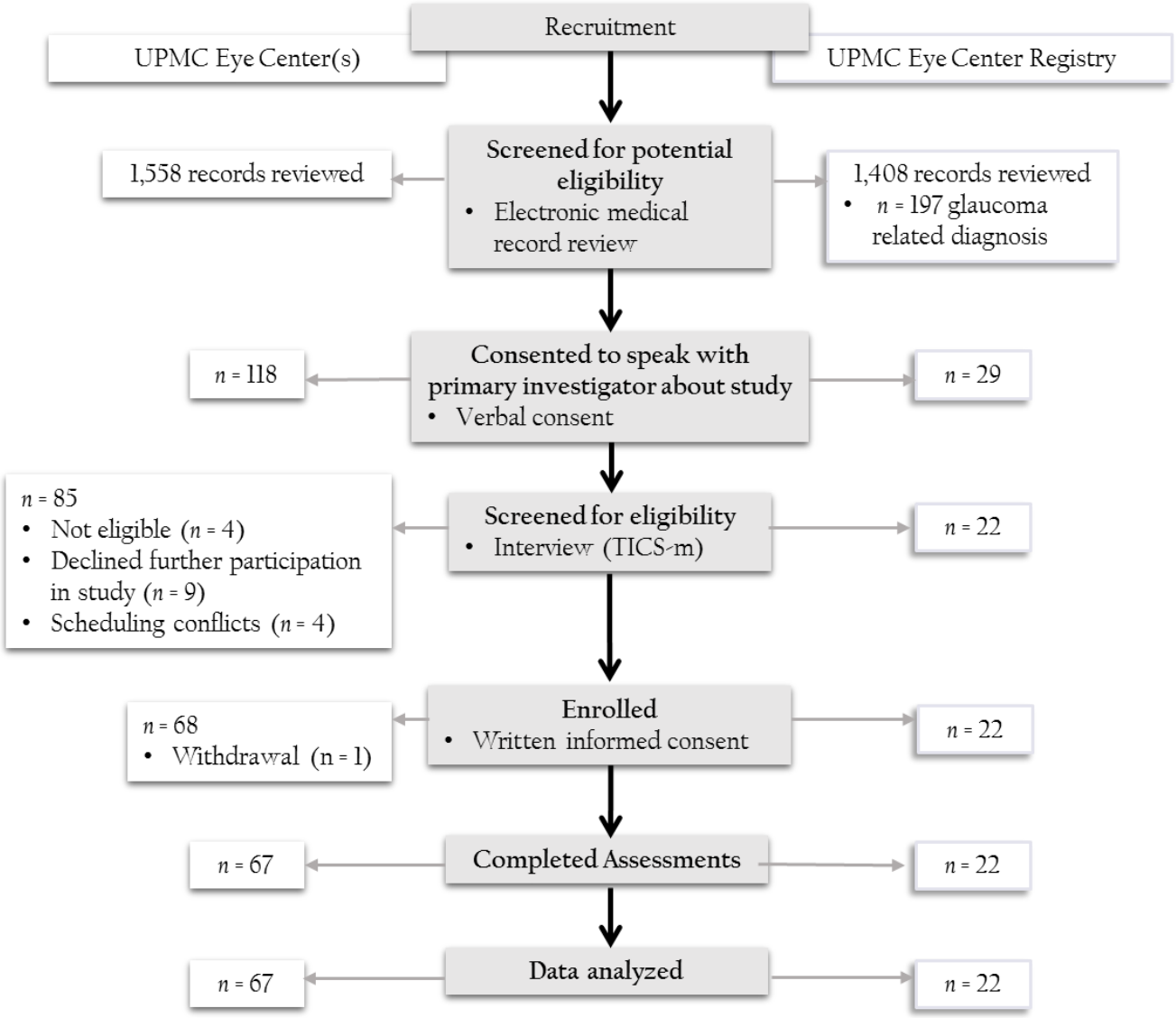


Figure 3. Study Flow Diagram.

For patients enrolled in the UPMC Eye Center Registry, a list of their names was provided to the primary investigator. All patients younger than age 50 years were removed from the list and the remaining names were then randomized using a random number generator. Screening procedures for the EMR review were conducted for only those patients who were diagnosed with glaucoma. Per UPMC Eye Center Registry protocol, the patients who met the eligibility requirements were contacted about the study via telephone.

The TICS-m was administered by the primary investigator to all patients who met the eligibility criteria following the first EMR review screening and who verbally expressed to the physician and/or primary investigator an interest in the study. After patients met the TICS-m eligibility criterion, their consent was obtained prior to administration of descriptive and outcome assessments per Institution Review Board protocol. Consent and assessment procedures were conducted either on the same day the patient was deemed eligible for the study or an appointment was scheduled to complete the assessments at a future date. Data were collected at the UPMC Eye Center(s), in participants' homes, or at the University of Pittsburgh School of Health and Rehabilitation Sciences. The primary investigator administered, in order, the demographic questionnaire, PART-O, and LIFE-H per protocol. Testing took an average of 45 to 60 minutes to complete. After participants completed all the outcome assessments, the primary investigator performed a second review of the participants' EMRs to document the testing results of their most recent clinical visual evaluations.

3.4.5 Data Processing

The Snellen BCVA scores that were recorded from the EMR to the EMR review checklist were transformed to logarithm of the minimal angle of resolution (logMAR) scale. We then relabeled the logMAR scores from 'right eye' and 'left eye' to the 'better-seeing eye' and 'worse-seeing eye.' The better- and worse-seeing eye designation for any variable was defined as such according to the eye with better BCVA (better-seeing eye) and worse BCVA (worse-seeing eye). The MD scores were also relabeled from 'right eye' and 'left eye' to 'better-seeing eye' and 'worse-seeing eye.' As a result of the multicollinearity diagnostic analyses (Cohen, Cohen, West, & Aiken, 2013; Field, 2009), we excluded reporting associations related to the MD and BCVA of the worse-seeing

eye. We transformed the comorbidity variable from yes/no, as to whether each comorbidity was present, to the total number of comorbidities participants indicated on the demographic questionnaire.

For this analysis, participation accomplishment and satisfaction with participation were both measured by the LIFE-H. Each variable (participation accomplishment and satisfaction with participation) is measured by a separate scale and validated as separate measures of participation. Specifically, we reported the results for the domains of life habits that comprise the social roles scale (responsibilities, community life, interpersonal relationships, employment, and recreation). The meaning of these life habits, defined by the Disability Creation Process, are similar to the International Classification of Functioning, Disability and Health conceptualization of participation described for this study (see Table 6). We do not present data in regard to the education domain since this domain refers to current involvement in high school and entry-level training education programs which were not applicable to the participants in this study.

We tested for violations of the assumptions of our variables for our statistical analyses (Field, 2009; Osborne & Waters, 2002). Multicollinearity was evaluated by examining the correlation among variables measuring a similar attribute; selection of those variables most appropriate to the interpretation of our results based on our objective were selected and results were reported based on theory and previously reported recommendations in the literature (Kulkarni et al., 2012; Richman et al., 2010; van Gestel et al., 2010). As a result of a bivariate analysis between composite scores and subscale scores for each participation measure, we performed our primary statistical analyses using the composite scores due to the multicollinearity between the composite scores and subscale scores. The distribution of the residuals for our outcome variable, severity of glaucoma (MD of the better-seeing eye), was not normally distributed (see Appendix

C). To address this violation, we transformed our data (Cohen et al., 2013; Field, 2009; Kleinbaum, Kupper, Muller, & Nizam, 1997). We adjusted the scale for MD scores so all scores were positive, severe glaucoma was still indicated by a low score and early glaucoma was indicated by a high score. We then transformed the variable using the fourth power transformation; normality was analyzed with P-P and Q-Q plots of the residuals, kurtosis and skewness, and a histogram. We analyzed the linear relationships of the standardized residuals and homoscedasticity with scatterplots. Our errors in the regression were independent (Durbin-Watson = 1.8; Field, 2009). All other assumptions were met within recommended parameters (Field, 2009; Osborne & Waters, 2002).

3.4.6 Statistical Analysis

Data were entered, maintained, and analyzed using SPSS software, version 22 (IBM Corp., Armonk, NY). All data were de-identified and personal information was stored separately to ensure confidentiality in compliance with the standards of the University of Pittsburgh Institutional Review Board. Descriptive statistics were computed for participant demographics with means (*M*) and standard deviations (*SD*) for continuous variables and frequencies and percentiles for categorical variables.

The level of significance was set at $\alpha = .05$ for all statistical tests. The strength of the correlation coefficients was interpreted where a Spearman rho coefficient value less than .25 indicates little or no correlation, between .25 to .49 indicates a fair correlation, between .50 to .74 indicates a moderate to good correlation, and a value of .80 or greater indicates a good to excellent correlation (Cohen et al., 2003; Portney & Watkins, 2009). The magnitude of the importance of the standardized beta ($\hat{\beta}$) was interpreted where a value less than .20 indicates no to little

importance, between .20 to .49 indicates a minimal importance, between .50 to .79 indicates a moderate importance, and greater than .79 indicates a large importance (Ferguson, 2009).

The aim was to explore the association between participation and severity of glaucoma (see Figure 4). To address this aim, we first performed a bivariate correlation analysis with the Spearman rho correlation coefficient, based on nonparametric variables, to explore the relationships between each measure of participation (frequency of participation, participation accomplishment, satisfaction with participation) and severity of glaucoma. We included in the correlation analysis demographic and clinical characteristics (covariates) to identify the variables that had at least a fair correlation (rho $\geq$ .25) and/or were statistically significant ($p \leq .05$) with each measure of participation.

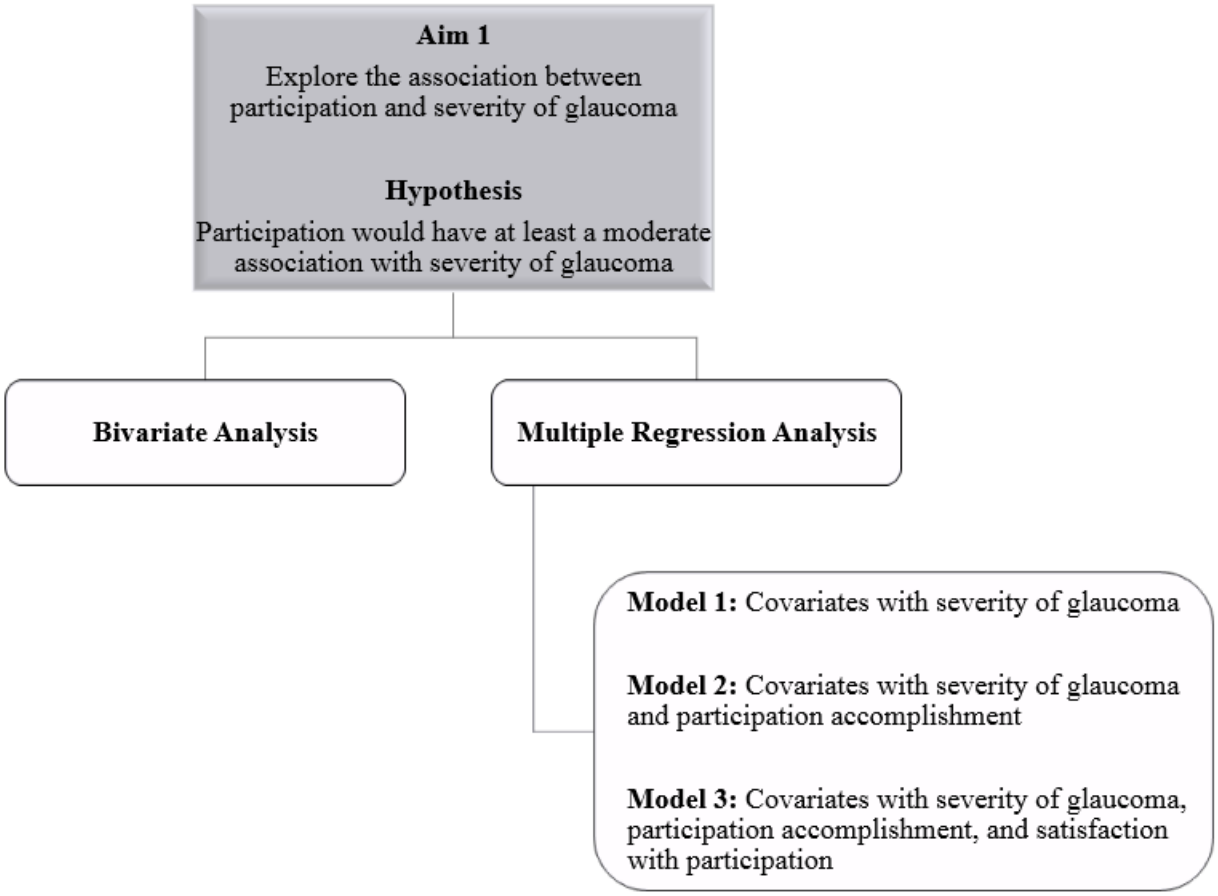


Figure 4. Statistical analyses to explore the association between participation and severity of glaucoma.

To estimate to what extent participation was an indicator of severity of glaucoma, controlling for covariates, we performed a multiple regression analysis. Variables that had at least a fair correlation (rho ≥ .25), were statistically significant ($p \leq .05$), and/or are known to associate with severity of glaucoma based on previous research were identified in the correlation analysis and included in the regression model. We initially proposed to perform the multiple regression analysis with each measure of participation entered individually for each model. However, frequency of participation did not qualify for nor contribute to our regression models in explaining the variance in severity of glaucoma so only participation accomplishment and satisfaction with participation were included in the regression models.

To test our hypothesis, we explored multiple regression models where severity of glaucoma was the dependent variable. Model 1 explored the relationship among covariates as indicators of severity of glaucoma. Model 2 explored the association between participation accomplishment, controlling for covariates, as an indicator of severity of glaucoma. Model 3 explored both participation accomplishment and satisfaction with participation, controlling for covariates, as indicators of severity of glaucoma. Covariates and participation measures were entered in a hierarchical order and based on the logic of our research; confounding variables were removed (Cohen et al., 2003).

3.4.6.1 Sample Size A sample size analysis conducted a priori determined that we needed to enroll 52 participants to achieve adequate power (80%, $\alpha = .05$) to detect at least a fair to moderate effect size (rho $\geq .40$) explaining a fair amount of variance in severity of glaucoma ($R^2 = .40$, $\widehat{\boldsymbol{\beta}} \geq .40$). Because there are a limited number of studies of participation for people with visual impairment, fewer yet for people with glaucoma, we referenced both the ranges of the correlation and linear association between vision-specific quality of life and severity of glaucoma reported in the literature. The rationale for this was twofold: 1) there was a lack of scientific data in regard to participation of people with visual impairment or glaucoma from which to generalize with robust confidence our predicted outcomes, and 2) our initial estimates were based on similar trends extrapolated from the literature between participation and quality of life in other populations in regard to severity of disability. We used data from published research based on the

National Eye Institute Visual Function Questionnaire-25 and MD of the better-seeing eye as the point of reference to estimate the relationship between participation and severity of glaucoma.

3.5 RESULTS

The objective of this study was to explore participation of individuals with glaucoma to better understand the relationship between severity of vision loss related to the disease process and the degree to which participation was associated with severity of glaucoma.

3.5.1 Descriptive Data

3.5.1.1 Participant Characteristics A total of 90 participants enrolled in this study; 1 participant withdrew from the study due to personal reasons prior to completing the assessments. Sixty seven participants were recruited from the UPMC Eye Center(s) and 22 were recruited from the UPMC Eye Center Registry. Participants were on average 68 years of age (ranging between 50 and 89 years), predominantly female (67%) and Caucasian (78%), and nearly half (43%) had a graduate-level education (see Table 13, see Appendix D).

Table 13. Participants' Demographic and Descriptive Characteristics

Characteristic	*M*	*SD*	Range	*n*
Age, years	68.0	9.2	50-89	89
Length of glaucoma diagnosis, months	109.0	113.7	2-492	87
Total number of comorbidities	1.8	1.5	0-7	89
	Frequency			
Gender				
Male	33%			29
Female	67%			60
Race				
Asian	3%			3
Black or African American	19%			17
Caucasian	78%			69
Other	2%			2
Ethnicity				
Hispanic or Latino	1%			1
Not Hispanic or Latino	99%			88
Marital status				
Married	64%			57
Divorced	17%			15
Widow/er	10%			9
Single	9%			8
Living situation				
Alone	26%			23
With spouse/partner	64%			57
Other	10%			9
Caregiver assistance	3%			3

Table 13 (continued)

Characteristic	Frequency	*n*
Highest level of education		
Elementary	1%	1
Secondary	9%	8
Post high school	47%	42
Graduate school	43%	38
Annual income		86
<$20,000	19%	16
$20,000-$39,000	22%	19
≥$40,000	59%	51
Received glaucoma treatment	96%	85
Topical medication	86%	73
Oral medication	1%	1
Laser	54%	46
Other	38%	32

Note. Other = implant surgery, trabectome, electrical brain stimulation, trabeculectomy, laser procedure prior to glaucoma diagnosis, canaloplasty.

The average length of time since participants were diagnosed with glaucoma was 9 years. Participants had approximately 2 other medical conditions in addition to glaucoma (ranging between 0 and 7), with hypertension (38%), arthritis (31%), and respiratory conditions (21%) being the most common. Sixteen percent of participants reported having a hearing disorder.

The severity of glaucoma (mean deviation [MD] of the better-seeing eye) on average was early stage (M = -4.25 dB, SD = 6.67 dB) and the average Snellen best-corrected visual acuity (BCVA, better-seeing eye) was approximately equivalent to 20/27 (M = 0.124 logMAR, SD = 0.136 logMAR; see Table 14). Participants experienced symptoms associated with their glaucoma (GSS) but the symptoms were generally not bothersome (M = 76.1, SD = 18.8); the most bothersome problems were dryness in the eye and hard to see in dark places (see Appendix E). Participants on average did not experience many depressive symptoms (M = 2.7, SD = 3.4). The

most frequently reported depressive symptoms were trouble falling or staying asleep or sleeping too much (39.4%) and feeling tired or having little energy (53.9%).

Table 14. Participants' Clinical Characteristics

			95% CI		
Characteristic	*M*	*SD*	*LL*	*UL*	*n*
Clinical characteristics					
MD better seeing eye, dB[a]	-4.25	6.67	-5.66	-2.85	89
MD worse seeing eye, dB[a]	-8.24	7.62	-9.89	-6.60	85
BCVA better seeing eye, logMAR[b]	0.124	0.136	0.096	0.153	89
BCVA worse seeing eye, logMAR[b]	0.268	0.266	0.210	0.326	84
Glaucoma symptoms (/100)[a]	76.12	18.77	72.17	80.08	89
Depressive symptoms (/27)[b]	2.67	3.43	1.95	3.40	89
Participation measures composite scores					
Frequency of participation (/3.17)[c]	2.08	0.47	1.98	2.18	89
Participation accomplishment (/10)[c]	9.29	0.76	9.13	9.45	89
Satisfaction with participation (/5)[c]	4.50	0.60	4.37	4.62	89

Note. MD = mean deviation; dB = decibel; BCVA = best-corrected visual acuity; logMAR = logarithm of the minimal angle of resolution.
[a]High score = less severe impairment. [b]High score = more severe impairment. [c]High score = greater participation.

3.5.2 Participation

For our sample, participants' scores on each of the three participation measures on average were high. The average score for frequency of participation (PART-O) was 66% of the maximum total score (*M* = 2.08, *SD* = 0.47; see Table 14). In regard to the subscales for frequency of participation, out-and-about in the community had the highest average score (*M* = 2.37, *SD* = 0.63; see Appendix F). Within this subscale, participants were most likely to travel beyond their block or neighborhood (96.6%) and get out of their homes and go someplace 7 days per week (58.4%). In a typical month,

participants were least likely to go to a movie (52.8%) or attend a sports event as a spectator (74.2%) and more likely to attend spiritual or religious services (66.3%).

Participants on average had little to no difficulty accomplishing tasks and required little assistance (i.e., assistive device, environmental modification, human assistance) to participate in life situations (i.e., participation accomplishment [LIFE-H]; *M* = 9.29, *SD* = 0.76; see Table 14). Similarly, participants on average were satisfied with how they were able to accomplish life situations (i.e., satisfaction with participation [LIFE-H]; *M* = 4.50, *SD* = 0.60).

3.5.2.1 Recreation and Employment The domains of life habits that were the most difficult for participants to accomplish, required some type(s) of assistance to accomplish, and/or participants were least satisfied with were recreation and employment (see Table 15). In regard to the recreation domain, a majority of participants actively participated in: sporting or recreational activities (e.g., sports, games; 86.5%), tourist activities (84.3%), and artistic or cultural events (e.g., concerts; 80.9%; see Appendix F). Of these three areas of recreation, participants had less difficulty or required little if any assistance going to artistic or cultural events (*M* = 8.14, *SD* = 1.56), while they had more difficulty and required some assistance participating in sporting or recreational activities (*M* = 7.69, *SD* = 2.07). In regard to satisfaction with participation, participants were most satisfied with how they accomplished attending artistic or cultural events (*M* = 4.43, *SD* = 0.89) and least satisfied with sporting or recreational activities (*M* = 4.04, *SD* = 1.11). The areas of the recreation domain for which the fewest number of participants participated in were going to sporting events as a spectator (51.7%) and taking part in outdoor activities (e.g., camping; 48.3%).

Table 15. Participants' Domain Scores for the Assessment of Life Habits

	Participation accomplishment				Satisfaction with participation			
			95% CI				95% CI	
Domain	*M*	*SD*	*LL*	*UL*	*M*	*SD*	*LL*	*UL*
Responsibilities	9.47	0.58	9.34	9.59	4.59	0.59	4.47	4.71
Interpersonal relationships	9.72	0.50	9.61	9.82	4.63	0.55	4.52	4.75
Community life	9.26	0.80	9.10	9.43	4.51	0.68	4.37	4.65
Employment	8.86	1.43	8.56	9.17	4.43	0.77	4.26	4.59
Recreation	8.68	1.88	8.29	9.07	4.20	0.96	4.00	4.40

In regard to the employment domain, a majority of participants actively participated in: unpaid activities (e.g., volunteering; 61.8%), getting to a principal place of occupation (e.g., work, volunteer location; 68.5%), and entering and moving around in a principal place of occupation (67.4%). Of these three areas of employment, participants had less difficulty or required little if any assistance moving around in a principal place of occupation ($M = 8.57$, $SD = 0.62$), while they had more difficulty and required some assistance taking part in unpaid activities ($M = 8.27$, $SD = 1.35$).

The same pattern was observed for satisfaction with participation: participants were most satisfied with how they accomplished moving around in a principal place of occupation ($M = 4.58$, $SD = 0.72$) and least satisfied with how they accomplished unpaid activities ($M = 4.42$, $SD = 0.90$). The areas of the employment domain for which the fewest number of participants participated in were choosing a career or profession (16.9%) and seeking employment (12.4%). Most participants were either well established in their careers or retired. However, for those participants who were seeking employment, approximately 36.4% experienced difficulty participating in this role and 45.5% required some assistance.

3.5.2.2 Interpersonal Relationships and Responsibilities The domains of the life habits that were the least difficult for participants to accomplish, required few if any assistance, and participants were the most satisfied with were interpersonal relationships and responsibilities (see Table 15). In regard to interpersonal relationships, a majority of participants actively participated in: maintaining friendships (100%), maintaining social relationships (98%), and maintaining close relationships with other members of their family (94%; see Appendix F). Participants had less difficulty or required little if any assistance maintaining friendships (M = 8.83, SD = 0.41), while they had more difficulty and required some assistance maintaining close relationships with other members of their family (M = 8.63, SD = 1.11). The same pattern was observed for satisfaction with participation: participants were most satisfied with how they accomplished maintaining friendships (M = 4.66, SD = 0.62) and least satisfied with how they accomplished maintaining close relationships with other members of their family (M = 4.56, SD = 0.78).

In regard to responsibilities, a majority of participants actively participated in every area except ensuring the education of children and taking care of children. The area that participants had less difficulty or required no or little assistance was assuming personal or familial responsibilities (M = 8.72, SD = 0.56), while they had more difficulty and required assistance with making purchases (M = 8.34, SD = 1.07). In regard to satisfaction with participation, participants were most satisfied with how they accomplished their responsibilities towards others and society (e.g., voting; M = 4.72, SD = 0.56) and least satisfied with managing their budgets/meeting financial obligations (M = 4.47, SD = 0.79).

3.5.3 Aim 1: Explore the Association between Participation and Severity of Glaucoma

3.5.3.1 Bivariate Correlation Analysis The following covariates had at least a fair correlation and/or were statistically significant with frequency of participation, participation accomplishment, or satisfaction with participation: race, marital status, annual income, MD of the better-seeing eye, BCVA of the better-seeing eye, glaucoma symptoms, depressive symptoms, frequency of participation, participation accomplishment, and satisfaction with participation (see Table 16). Based on the covariates known to associate with participation from previous research, we included in the correlation analysis age, length of glaucoma diagnosis, and total number of comorbidities. Participation was not associated with age, length of glaucoma diagnosis, or the total number of comorbidities. Having a self-reported hearing disorder was statistically significant with participation accomplishment (rho = -.22, p = .04) but was not reported separately since it was included in the total number of comorbidities variable (see Appendix G).

Table 16. Correlation Analysis (Spearman rho) between Participation and Covariates

	Frequency of participation			Participation accomplishment			Satisfaction with participation		
		95% CI			95% CI			95% CI	
Characteristic	Spearman rho	*LL*	*UL*	Spearman rho	*LL*	*UL*	Spearman rho	*LL*	*UL*
Demographic									
Age, years	.03	-.18	.24	.08	-.13	.28	.01	-.20	.22
Length of glaucoma diagnosis	-.01	-.22	.20	-.08	-.29	.13	-.15	-.35	.06
Total number of comorbidities	-.09	-.29	.12	-.04	-.25	.17	-.17	-.37	.04
Race	.35***	.15	.52	-.05	-.26	.16	-.08	-.28	.13
Marital status	-.33**	-.50	-.13	-.06	-.26	.15	-.10	-.30	.11
Annual income	.48***	.30	.63	.25**	.04	.44	.21	-.00	.40
Clinical									
MD better-seeing eye, dB	.17	-.04	.37	.28**	.08	.46	.25*	.05	.44
BCVA better-seeing eye, logMAR	-.16	-.36	.05	-.28**	-.46	-.08	-.28**	-.46	-.08
Glaucoma symptoms	.03	-.18	.24	.22*	.01	.41	.38***	.19	.55
Depressive symptoms	-.21*	-.40	-.00	-.26*	-.44	-.06	-.46**	-.61	-.28
Frequency of participation				.22*	.01	.41	.16	-.05	.36
Participation accomplishment							.60***	.45	.72

Note. MD = mean deviation, dB = decibel; BCVA = best-corrected visual acuity; logMAR = logarithm of the minimal angle of resolution.

*$p \leq .05$. **$p \leq .01$. ***$p \leq .001$.

Demographic Characteristics. Race and marital status had statistically significant, fair correlations with frequency of participation (rho = .35 and -.33, $p < .01$, respectively). There was little correlation between race and marital status with participation accomplishment and satisfaction with participation (rho $\leq$ -.05, $p \geq .34$). Annual income had a statistically significant, fair correlation with both frequency of participation and satisfaction with participation (rho = .48 and .25, $p \leq .05$, respectively), but had little correlation (rho = .21, $p = .06$) with participation accomplishment. The majority of participants who reported an annual income of at least $40,000 were Caucasian (90%). Notably, 64% of participants were married. Additionally, 76% of participants with either a post high school or graduate education were Caucasian. The relationship between frequency of participation and annual income was distinctly higher than that between satisfaction with participation and annual income.

Clinical Characteristics. Impairment-based clinical measures of visual function (MD of the better-seeing eye, BCVA of the better-seeing eye, glaucoma symptoms) did not strongly correlate with frequency of participation (absolute rho $\leq .17$, $p \geq .11$) but rather had fair (absolute rho = .25 to .38) and/or statistically significant ($p \leq .05$) correlations with participation accomplishment and satisfaction with participation. In regard to glaucoma symptoms of the better-seeing eye, as previously stated the most bothersome problems were dryness in the eye and difficulty seeing in dark places. Dryness in the eye had little correlation (absolute rho $\leq .15$, $p \geq .15$) with any participation measure. Difficulty seeing in dark places had a fair and stronger correlation with satisfaction with participation (rho = .40, $p < .01$) than with participation accomplishment (rho = .23, $p = .03$). In general, the GSS composite score for the better-seeing eye had a fair correlation with satisfaction with participation (rho = .33, $p < .01$) but little correlation

with frequency of participation (rho = -.02, p = .85) or participation accomplishment (rho = .17, p = .12).

Participants on average had no depressive symptoms, yet depressive symptoms had a fair and/or statistically significant relationship with each measure of participation. Further analysis indicated that participants who had depressive symptoms (PHQ-9 score < 5) participated less frequently in participation situations, accomplished participation with more difficulty and/or required some assistance, and were less satisfied with their participation compared to participants without depressive symptoms. The correlation between depressive symptoms and satisfaction with participation (rho = -.46, p < .01) was distinctly greater than the correlations with frequency of participation (rho = -.21, p = .04) and participation accomplishment (rho = -.26, p = .01).

3.5.3.2 Multiple Regression Analysis We performed a multiple regression analysis to test our hypothesis (see Table 17). The following variables were associated with severity of glaucoma, determined based on a correlation analysis, and included in the regression analysis: BCVA of the better-seeing eye, glaucoma symptoms, gender, participation accomplishment, and satisfaction with participation (see Appendix G). The following covariates, previously identified in the literature to associate with severity of glaucoma, did not substantially contribute to our regression models from which we determined the parsimonious models: age, length of glaucoma diagnosis, and total number of comorbidities (see Appendix H). Frequency of participation also did not contribute to our models for our analysis. The negative $\widehat{\boldsymbol{\beta}}$ for BCVA indicated that individuals with better BCVA had less severe glaucoma.

Table 17. Multiple Regression Analysis Models for Indicators of Severity of Glaucoma (Covariate and Participation Independent Variables)

	Model 1			Model 2				Model 3			
Variables	$\hat{\beta}$	R^2	Adjusted R^2	$\hat{\beta}$	R^2	Adjusted R^2	ΔR^2	$\hat{\beta}$	R^2	Adjusted R^2	ΔR^2
BCVA, logMAR	-.31**	.27	.25	-.21*	.34	.31	.06*	-.21*	.36	.32	.02
Glaucoma symptoms	.27**			.23*				.28**			
Gender	.23*			.20*				.23*			
Participation accomplish-ment				.28**				.37**			
Satisfaction with participation								-.20			

Note. BCVA = best-corrected visual acuity of the better-seeing eye; logMAR = logarithm of the minimal angle of resolution.
*$p \leq .05$. **$p \leq .01$. *** $p \leq .001$.

Regression Model 3 indicated the greatest proportion of the total variance in severity of glaucoma was explained by the independent variables included in the model ($R^2 = .36$; see Table 17). However, based on the adjusted R^2, which represents a chance-adjusted value for R^2 for the number of predictors included in a model (Portney & Watkins, 2009), Model 2 was the most parsimonious model which indicated that 31% of the variance in severity of glaucoma was explained by BCVA of the better-seeing eye, glaucoma symptoms, gender, and participation accomplishment. Participation accomplishment was a statistically significant, independent indicator of severity of glaucoma and had the largest magnitude of importance ($\hat{\beta} = .28$, $p < .01$) among all the variables in Model 2. However, the addition of satisfaction with participation in Model 3 did not produce a statistically significant R^2 change ($\Delta R^2 = .02$). Satisfaction with participation was not a statistically significant indicator ($p = .09$) and was associated with the lowest magnitude of importance in Model 3 ($\hat{\beta} = -.20$, $p = .09$). All measures of impairment and

gender (covariates) were statistically significant and independent indicators of severity of glaucoma (Model 2) when participation was included in the model. We were unable to support our hypothesis that participation would have at least a moderate association with severity of glaucoma.

3.6 DISCUSSION

This research study aimed to explore the association between frequency of participation, participation accomplishment, and satisfaction with participation with severity of glaucoma. The demographic of our sample did not reflect the demographic for people who are most at risk for glaucoma (e.g., African Americans aged 40 years and older). However, the sample did reflect the demographic of the greater Pittsburgh area and Allegheny County, Pennsylvania, in regard to gender, race, ethnicity, and level of education.

Our findings were logical in that individuals who on average had early stage glaucoma and less severe impairment had high participation accomplishment and satisfaction with participation. Our findings suggested that while our participants were highly independent, a degree of that independence was achieved by using some type(s) of assistance (i.e., assistive device, environment or task adaptation, and/or human assistance). We found that frequency of participation had little correlation with severity of glaucoma and the relationship was not statistically significant. There was a stronger relationship between participation accomplishment and severity of glaucoma. This may be due to the fact that how often a person participates in selected life situations varies based on several factors other than glaucoma severity. In contrast, how someone accomplishes participation in life situations (i.e., through the use of compensatory methods) may be related to glaucoma severity. Our findings support the importance of recognizing that people who on average

had early stage glaucoma and less severe vision loss demonstrated participation among the incremental indicators of severity of glaucoma. Therefore, given these results, we suggest that participation may provide healthcare providers useful information and perspective about whether or not glaucoma is affecting patients' accomplishment of everyday tasks even in the early stages of disease severity. This perspective may influence how general health care is evaluated and delivered in regard to the effect of disease on everyday living in addition to the effect of disease on the structure and function of the body.

Our findings also support that subtle changes in people's abilities to engage in daily living, roles, and routines may be affected by visual sensory perception which likely occurs in the early stage of glaucoma (Anderson, 2006; Bullimore et al., 1993; Canadian Ophthalmological Society Glaucoma Clinical Practice Guideline Expert Committee, 2009; Karwatsky, Bertone, Overbury, & Faubert, 2006; McKendrick, Badcock, & Morgan, 2005; Shabana, Pérès, Carkeet, & Chew, 2003; Wolfe et al., 2012; Wu, Coffey, Reidy, & Wormald, 1998). We know that at the time of diagnosis, permanent vision loss has already occurred. Individuals who modify the way they complete tasks, but are still able to accomplish what they need to or want to do, may not perceive compensatory strategies as indicators of risk for a visual disability. The effects of glaucoma on function is often a hidden disability. We suggest that modifying the method to accomplish tasks may be an indicator of being at risk for disability (Fried et al., 1991; Higgins et al., 2013; West et al., 2005). Rodakowski (2014) demonstrated that preclinical disability measured by performance-based tasks distinguished between older adults with normal cognitive function and older adults with mild cognitive impairment. Our findings suggest further study of the assessment of how people with glaucoma participate, as measured through self-report, and whether participation may discriminate between adults with and without vision loss.

In rehabilitation, clinicians evaluate how a health condition affects individuals' abilities to accomplish their daily living. Participation is a level at which clinicians evaluate the interaction between individuals, the roles and routines they want to or need to do, and the contexts in which those roles and routines are performed. How that interaction influences individuals' abilities for independence in regard to participation is the focal point for intervention. Yet little research has focused on describing participation in people with glaucoma. We found that participation was an independent incremental indicator of severity of glaucoma after controlling for covariates, which included clinical measures of visual impairment and gender. Specifically, participation accomplishment had a stronger association with severity of glaucoma than did satisfaction with participation. It is noteworthy that age and hearing loss (i.e., dual sensory loss) did not correlate strongly with severity of glaucoma in our sample.

Participation may change over time; while some changes may result from normal aging, other changes may be due to health conditions, activity limitations, and/or participation restrictions. Our data suggest that even mild vision loss was associated with subtle adaptations in participation accomplishment. Without norms, it is difficult to comment on whether these adaptations are normal or indicators of decline. Certainly other studies report that vision loss has been associated with changes in participation (Desrosiers, Wanet-Defalque, et al., 2009; Hochberg et al., 2012; Noe et al., 2003; Perlmutter et al., 2010). That said, participation is an important component of the rehabilitation process when developing evaluation and intervention strategies. Additionally, we suggest an awareness that subtle changes in the methods people use to complete a task may be indicators of yet undetected or undiagnosed vision loss. This is important for specialists working in the broader healthcare process with people for whom vision loss may not be the primary reason for referral to their services.

Our study contributes to the current literature in that it is important to recognize and to further explore these factors in people with glaucoma to identify opportunities for prevention of the onset of disability. Currently, referral to vision rehabilitation for people with glaucoma typically occurs after there is significant, irreversible vision loss that already affects participation.

Interestingly, frequency of participation had stronger correlations with socio-demographic variables (race, marital status, annual income) than the other indices of participation. Our sample on average participated more frequently than what was reported in published studies of patients with physical disabilities who participated in a hospital rehabilitation program and individuals 1 year post traumatic brain injury with or without depression (Bogner et al., 2011; Hart et al., 2011). Although our sample did on average have lower frequency of participation compared to the general population with or without a disability (Bogner et al., 2011), our finding suggested that frequency of participation in individuals who on average had early stage glaucoma may relate more to socio-demographic status and having the opportunity to engage in participation situations than to function and disability.

Further exploring participation, we found that participants were more satisfied when they accomplished their life habits with little to no difficulty and with little if any type(s) of assistance. This is consistent with previous research that reported participants who performed better were more satisfied with their social participation (Levasseur, Desrosiers, & Noreau, 2004; Renaud et al., 2010). Desrosiers, Robichaud, et al. (2009) reported that older adults without a disability demonstrated decreased participation over time but no change in regard to their satisfaction with participation. Nelson, Aspinall, and O'Brien (1999) reported that loss of confidence in performing some routine daily tasks may actually precede self-reported vision-specific visual disabilities. These reports suggest that future study should incorporate measures of both participation

accomplishment and satisfaction with participation to understand the broader perspective of participation. Satisfaction with participation has been a determinant of overall participation in social roles (Alma et al., 2012).

In this study, the life habits that were the most difficult for participants to accomplish and/or required some if any assistance were employment and recreation; the least difficult were responsibilities and interpersonal relationships. The same pattern was observed for satisfaction with participation. In previously reported studies of people with visual impairment, a similar trend was reported for recreation, responsibilities, and interpersonal relationships for participation accomplishment (employment was not included in the studies; Desrosiers, Robichaud, et al., 2009; Desrosiers, Wanet-Defalque, et al., 2009; Levasseur et al., 2004). Also, our results align with a previous study that reported employment challenges for people with vision loss and that only approximately 40% of working-aged adults with a visual impairment were employed (Bramley, Peeples, Walt, Juhasz, & Hansen, 2008). While the majority or our participants were not employed or were retired, of those who were seeking employment approximately 35% to 45% experienced difficulty and/or required some type(s) of assistance.

Based on our participants who on average had early stage glaucoma, we suggest that responsibilities and interpersonal relationships are less dynamic and visually challenging, as they occur in more controlled and standard environments, than are employment and recreation, which occur in less controlled and shifting environments. We found that of the five participation life habits, only recreation and responsibilities were statistically correlated with severity of glaucoma. This finding highlights that people with glaucoma may verbalize or demonstrate different patterns of participation in social life situations at the time of their diagnosis or during early stages of the

disease that intuitively may not be expected to relate to vision loss based on clinical testing (Janz et al., 2001a).

3.6.1 Conclusion

We found that participation accomplishment was an independent incremental indicator of severity of glaucoma, after controlling for covariates and clinical measures of visual impairment. We also found that satisfaction with participation was reliably correlated with severity of glaucoma; individuals with more severe glaucoma had less satisfaction with their participation than those individuals with less severe glaucoma. Additionally, it may be less important to focus on frequency of participation of individuals with early stage glaucoma as a measure of severity of vision loss. These findings support that participation contributes to our understanding of function and disability of people with glaucoma. Our findings also provide evidence for further exploration as to how and whether or not individuals with glaucoma compensate for their vision loss by using strategies such as low vision aids or by changing the methods in which they complete tasks. While participation may change over time as a result of normal aging, we provided evidence of incremental indicators of severity of glaucoma associated with participation and that the patterns of participation may not be intuitive based on clinical testing and/or recognized during people's engagement in daily living tasks.

4.0 PARTICIPATION AND VISION-SPECIFIC QUALITY OF LIFE RELATED TO SEVERITY OF GLAUCOMA

4.1 INTRODUCTION

The World Health Organization (WHO) stated that "health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (WHO, 2003). Since that conceptualization of health by the WHO, the effects of a disease and its influence on people's daily living have increasingly been measured in research by the construct of quality of life (QoL). QoL is a multidimensional construct defined by the International Classification of Functioning, Disability and Health (ICF) as individuals' subjective well-being in several areas of life domains (physical health, psychological health, level of independence, social relationships, the environment, and personal beliefs; WHO Quality of Life Group, 1993).

In vision rehabilitation, the effects of a disease on individuals' abilities to accomplish daily life situations are clinically measured by participation, not by QoL. Participation is considered a unidimensional construct of function and disability in the ICF, defined as an individual's involvement in life situations. Historically, glaucoma research included vision-specific quality of life (VSQoL; i.e., the effect of ocular conditions and changes in function related to vision on health and well-being) as the primary construct used to both describe the experiences of people with glaucoma and to measure the effectiveness of vision rehabilitation (Labiris, Giarmoukakis, Larin, Gkika, & Kozobolis, 2012). Consequently, participation has not been directly measured as a primary construct, but rather described through the lens of QoL. Vision research only recently

began to include measures specific to participation in study designs to parse participation from within the multiple domains within VSQoL.

4.1.1 Participation of People with Vision Loss and Glaucoma

Refer to Sections 3.3 and 3.5 for a discussion of participation of people with vision loss and glaucoma.

4.1.2 Vision-Specific Quality of Life of People with Glaucoma

There is now a growing body of scientific literature to describe the unique experiences and the functional manifestations of vision loss of people with glaucoma as they relate to VSQoL. VSQoL was poorer as the severity of glaucoma worsened; VSQoL was statistically significantly different between the mild and severe stages of glaucoma while the moderate stage of glaucoma was generally not significantly distinct from either the mild or severe stages (Freeman, Munoz, West, Jampel, & Friedman, 2008; Goldberg et al., 2009; Gutierrez et al., 1997; Iester & Zingirian, 2002; Jampel et al., 2002; McKean-Cowdin et al., 2008; Nelson, Aspinall, & O'Brien, 1999; Nelson, Aspinall, Papasouliotis, Worton, & O'Brien, 2003). Factors associated with VSQoL of people with glaucoma included older age, a greater number of comorbidities, visual acuity of the better- and worse-seeing eyes, mean deviation (MD), difficulty using eye drops and adverse drug effects, perception of worsening health, and depressive symptoms (Freeman et al., 2008; Mangione et al., 2001; Nassiri, Mehravaran, Nouri-Mahdavi, & Coleman, 2013).

The progression of visual field loss that was associated with increasing severity of glaucoma has been shown to predict people's functional abilities as measured by VSQoL (Iester & Zingirian, 2002; Qiu, Wang, Singh, & Lin, 2014; van Gestel et al., 2010). Additionally, research

reported that different patterns of visual field loss had more or less and different functional repercussions (Black, Wood, & Lovie-Kitchin, 2011; Lovie-Kitchin, Mainstone, Robinson, & Brown, 1990; Turano et al., 2004; van Gestel et al., 2010). The effects of glaucoma influenced VSQoL through both changes in vision (i.e., deterioration) and by the glaucoma treatment itself (Janz et al., 2001b; Nordmann, Auzanneau, Ricard, & Berdeaux, 2003). For example, having had a surgical procedure for medical management of glaucoma resulted in poorer VSQoL due to post surgical symptoms. People with glaucoma who respond similarly in regard to quantifying their VSQoL may differ in the severity of their glaucoma, their confidence in performing routine daily tasks, or how satisfied they feel about how they are able to accomplish their meaningful roles and routines.

In this research study we specifically evaluated both participation and VSQoL. Because VSQoL has been well studied in people with glaucoma, we included a measure of VSQoL to compare our results to those published in the literature and as a point of reference to better understand and interpret the meaningfulness of our results in regard to participation. In the ICF model, QoL is not represented as a single construct of function and disability because it is multidimensional. Therefore, in regard to the relationship between severity of glaucoma and its effect on daily living, VSQoL is confounded by its multidimensional context that includes several areas of life domains. Participation is represented as a unidimensional construct of function and disability. Therefore, participation may be an indicator the severity of disease in regard to life situations affected by glaucoma, and less influenced by other confounding factors (see Appendix A). We contend that since participation is a primary measure used in vision rehabilitation to evaluate individuals' abilities and to design intervention programs, participation should be studied

in glaucoma research to better understand disability and who is at risk for disability related to severity of vision loss.

At the point at which people are diagnosed with glaucoma, structural and functional changes of the eye have already occurred. Because of what we know about visual sensory perception (see Section 1.1.1.1), people may have subtle differences in their abilities to accomplish daily living situations (i.e., participation) even in the early stage of glaucoma. People may still accomplish what they need to or want to do at some level of independence but they may establish different patterns of participation relative to decline in visual function by using strategies such as low vision aids or by doing tasks using a different method (Fried, Herdman, Kuhn, Rubin, & Turano., 1991; Higgins, Janelle, & Manini, 2013; West et al., 2005). Additionally, people may report that having some level of difficulty accomplishing a task affects their VSQoL. Therefore, we designed this study to compare participation and VSQoL.

There is a need to better understand disability related to severity of vision loss. While the distinction between QoL and participation may not appear at first of consequence, their distinction is important. Arguably, VSQoL and participation are indeed two different constructs being blurred together to interpret research outcomes for clinical application. This trend may be related to the lack of instruments developed to measure well-defined constructs that parallel clinical practice, resulting in over-interpretation of data to compensate for measurement limitations. An increasing awareness of the blurred representation and whether or not it would be beneficial to distinguish between VSQoL and participation is needed to move vision science and practice forward to advance research and discriminately measure the constructs of VSQoL and participation.

We designed this study to include data collection of VSQoL, an established evidence-based variable, to compare the relationship between participation and VSQoL as they each related to

severity of glaucoma. In most vision research designs, studies analyzed what factors were indicators or predictors of participation and VSQoL. In this research study, however, we were interested in whether or not participation and VSQoL were indicators of severity of glaucoma. We designed the study as such because research has suggested that the consequence of early stage vision loss on daily living may not align with (be predicted by) clinical measures of visual impairment (e.g., visual field), yet people who are diagnosed or at risk for disability may report subtle differences in their participation or QoL. For example, more severe visual field loss was a predictor of poorer VSQoL. Conversely, poorer VSQoL was associated with visual disability. Therefore, this study extends current research to specifically explore participation and VSQoL as indicators of severity of glaucoma.

We measured participation in three ways: frequency of participation, participation accomplishment, and satisfaction with participation. Our intent was to explore participation since participation is the focal point for rehabilitation specialists to evaluate function and disability and develop intervention strategies. Knowledge of when and how disability occurs in people with glaucoma will inform medical care, improve patient safety in terms of treatment and prevention, and inform referral to vision rehabilitation. VSQoL was measured using a vision-specific instrument, the National Eye Institute Visual Function Questionairre-25 (VFQ-25). We hypothesized that participation would have a positive correlation (rho $\geq$ .40) with VSQoL, and that participation would have a stronger association with severity of glaucoma than VSQoL with severity of glaucoma.

4.2 METHODS

4.2.1 Design

A cross sectional design was used to examine the relationship between participation (frequency of participation, participation accomplishment, satisfaction with participation), VSQoL, and severity of glaucoma.

4.2.2 Participants

We recruited participants from the University of Pittsburgh Medical Center (UPMC) Eye Center(s) using two methods: 1) patients scheduled for clinical appointments with glaucoma specialists at the UPMC Eye Center(s) and 2) the UPMC Eye Center Registry. We sought the patients of physicians who were glaucoma specialists. Refer to Section 3.4.2 for a description of the recruitment methods and eligibility criteria.

4.2.3 Instruments

We used two procedures to screen for eligibility for this study: 1) an electronic medical record (EMR) review and 2) an interview to screen cognition using the Telephone Interview for Cognitive Status-modified (TICS-m). The descriptive and outcome assessments included: 1) EMR review, 2) Humphrey Visual Field Analyzer, 3) a demographic questionnaire, 4) the Participation Assessment with Recombined Tools-Objective (PART-O), 5) the Assessment of Life Habits (LIFE-H), version 3.1, and 6) the VFQ-25.

4.2.3.1 Screening Instruments Refer to section 3.4.3.1 for a description of the following screening instruments: electronic medical record review checklist and TICS-m.

4.2.3.2 Descriptive and Outcome Instruments Refer to section 3.4.3.2 for a description of the following outcome instruments: electronic medical record review checklist, Humphrey Visual Field Analyzer, demographic questionnaire, PART-O, and LIFE-H. In addition to these instruments, we included in this study the VFQ-25.

National Eye Institute Visual Function Questionnaire-25. The VFQ-25 is a 25-item questionnaire developed to measure VSQoL. It was developed by RAND with funding from the National Eye Institute and is the most frequently used measure of VSQoL. The VFQ-25 is divided into 12 subscales (see Table 19). Refer to Section 2.1.1.1 for a description of the psychometric properties of the VFQ-25.

Table 18. Subscales of the Visual Function Questionnaire-25

Subscales	Number of items
General health	1
General vision	1
Ocular pain	2
Near vision	3
Distant vision	3
Vision-specific social functioning	2
Vision-specific role difficulties	2
Vision-specific mental health	4
Vision-specific dependency	3
Driving	3
Peripheral vision	1
Color vision	1

Note. General health is not included in the 25-item composite score.

Responses for the VFQ-25 are either dichotomous (yes/no) or rated on scales that range from 3 to 6 categories. Each item score is transformed to a 0 to 100-point scale. The scores within each subscale are averaged for a subscale score and each subscale is subsequently averaged for a composite score; a high score indicates better visual function and VSQoL. The general health subscale is not included in the composite score. The VFQ-25 can be self-administered or interview-administered in approximately 10 minutes (de Boer et al., 2004; see Appendix B).

4.2.4 Procedure

This study was approved by the University of Pittsburgh Institutional Review Board. We screened potential participants who were scheduled for clinical appointments at the University of Pittsburgh Medical Center (UPMC) Eye Center(s) with the glaucoma specialists and who were enrolled in

the UPMC Eye Center Registry. Refer to Section 3.4.4 for a description of the recruitment and enrollment processes.

4.2.5 Data Processing

We transformed the Snellen best-corrected visual acuity (BCVA) scores to logarithm of the minimal angle of resolution (logMAR) scale and the comorbidity variable from yes/no, as to whether each comorbidity was present, to the total number of comorbidities participants indicated on the demographic questionnaire. We relabeled the logMAR scores and mean deviation (MD) scores from 'right eye' and 'left eye' to the 'better-seeing eye' and 'worse-seeing eye.' Refer to section 3.4.5 for a detailed description of these data transformations.

For this analysis, participation accomplishment and satisfaction with participation were both measured by separate scales on the LIFE-H, which was developed based on the Disability Creation Process. We reported the results for the domains of life habits that comprise the social roles domains (responsibilities, community life, interpersonal relationships, employment, and recreation) because the meaning of these life habits are equivalent to the ICF conceptualization of participation described for this study (see Section 2.1.2.1). We do not present data in regard to the education domain of life habits since this domain was largely not applicable to the participants in this study.

In regard to testing for violations of the assumptions of our variables for our statistical analyses, refer to section 3.4.5 for details in regard to multicollinearity diagnostic analyses and data transformation for our dependent variable (MD of the better-seeing eye) due to non-normally distributed residuals (Field, 2009; Osborne & Waters, 2002). Because of the multicollinearity between composite scores and subscale scores for each participation measure and the VFQ-25, we

performed our primary statistical analyses using the composite scores (Kulkarni, Mayer, Lorenzana, Myers, & Spaeth, 2012; Richman et al., 2010; van Gestel et al., 2010). We excluded reporting correlations based on the MD and BCVA of the worse-seeing eye. Our errors in the regression were independent (Durbin-Watson = 1.8; Field, 2009). All other assumptions were met within recommended parameters (Field, 2009; Osborne & Waters, 2002).

4.2.6 Statistical Analysis

Refer to section 3.4.6 for a description of our data entry and data processing procedures. Descriptive statistics were computed for participant demographics with means (*M*) and standard deviations (*SD*) for continuous variables and frequencies and percentiles for categorical variables.

4.2.6.1 Aim 2: Explore the Relationship between Participation and Vision-Specific Quality of Life

The first aim of this study was to explore the relationship between participation (frequency, accomplishment, satisfaction) and VSQoL. We hypothesized that participation would have a positive correlation (rho $\geq$ .40) with VSQoL. To address this aim, a bivariate correlation analysis was performed with the Spearman rho correlation coefficient, based on nonparametric variables, to explore the relationship between each measure of participation and VSQoL (see Figure 5).

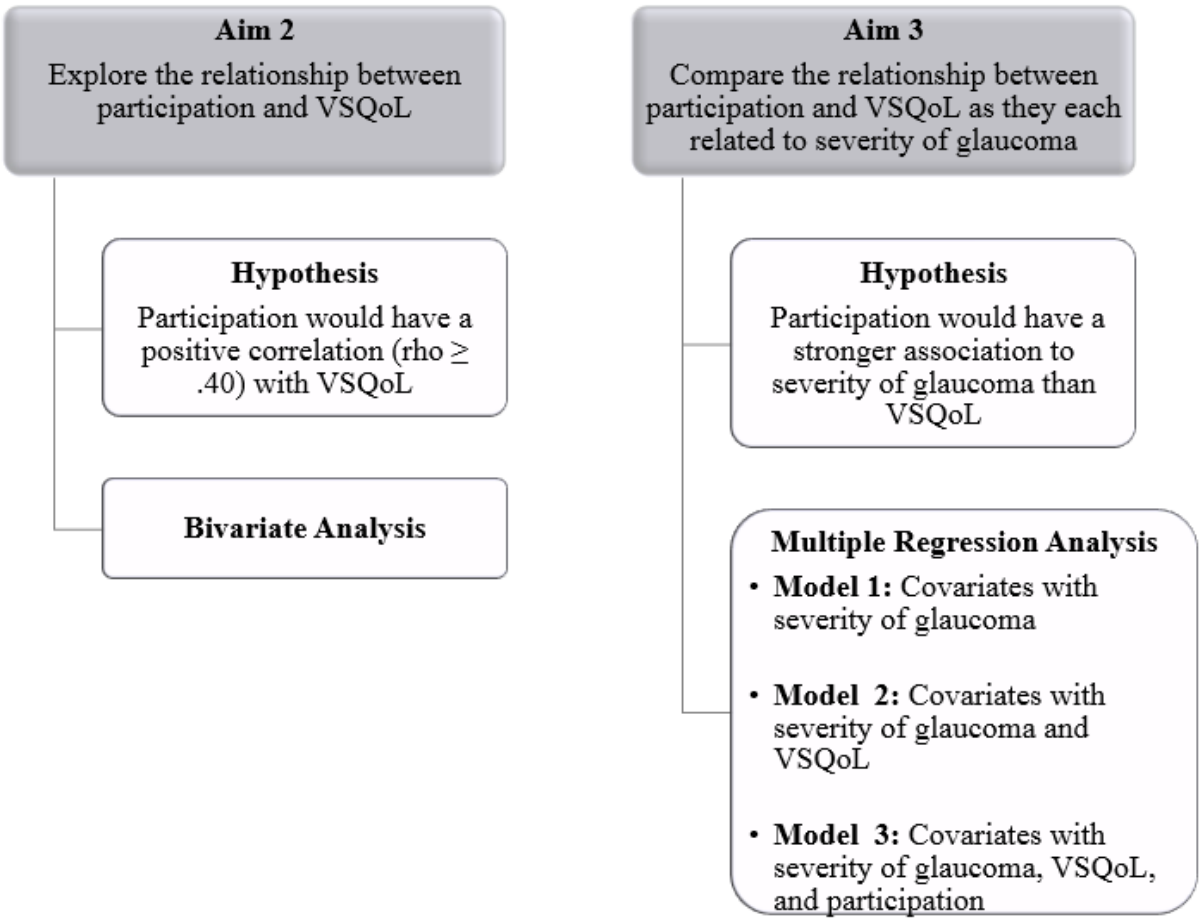


Figure 5. Statistical analyses to explore the relationship between participation (frequency, accomplishment, satisfaction) and vision-specific quality of life (VSQoL).

4.2.6.2 Aim 3: Compare the Relationship between Participation and Vision-Specific Quality of Life as They Each Related to Severity of Glaucoma

The second aim for this study was to compare the relationship between participation and VSQoL as they each related to severity of glaucoma. We hypothesized that participation would have a stronger association to severity of glaucoma than VSQoL to severity of glaucoma. A bivariate correlation analysis was performed with the Spearman rho correlation coefficient, based on nonparametric variables, to explore the relationships among demographic and clinical characteristics (covariates), participation, VSQoL,

and severity of glaucoma to identify the variables that had at least a fair correlation (rho ≥ .25) and/or were statistically significant ($p \leq .05$) with severity of glaucoma.

To estimate to what extent participation and VSQoL were indicators of severity of glaucoma, controlling for covariates, we performed a multiple regression analysis (see Figure 5). Specifically, we were interested in the comparison of the relationship between participation and VSQoL as they each related to severity of glaucoma. Variables that had at least a fair correlation, were statistically significant, and/or are known to associate with severity of glaucoma (based on previous research) were identified and were included in the regression models.

To test the hypothesis that participation would be a better indicator of severity of glaucoma than VSQoL, we explored regression models where severity of glaucoma was the outcome variable. Model 1 explored the relationship among covariates as indicators of severity of glaucoma. Model 2 explored the association between VSQoL and severity of glaucoma, controlling for covariates, and Model 3 explored each measure of participation and VSQoL, controlling for covariates, to compare their association as indicators of severity of glaucoma. We used the same decision process described in Section 3.4.6 to determine which variables to include in our regression models.

4.2.6.3 Sample Size A sample size analysis conducted a priori determined that we needed to enroll 37 participants to achieve adequate power (80%, $\alpha = .05$) to detect a rho = .40 between participation and VSQoL. Using the same assumptions, we needed to enroll 67 participants to detect a rho = .30. Because there are a limited number of studies of participation of people with visual impairment and people with glaucoma, we used the ranges of the correlations between VSQoL and severity of glaucoma reported in the literature for our sample size analysis. The rationale for this was twofold: 1) there was a lack of scientific data in regard to participation (of

individuals with visual impairment or glaucoma) from which to generalize with confidence our predicted outcomes, and 2) we based our initial estimates on similar trends extrapolated from the literature between participation and QoL in other populations with chronic diseases in regard to severity of disability. We used data from published research based on the VFQ-25 and MD of the better-seeing eye as the referent to estimate the relationship between participation and VSQoL. Due to the limited scientific literature from which we predicted our outcomes, our power analysis was vulnerable.

4.3 RESULTS

The objective of this study was to explore participation in individuals with glaucoma to better understand the relationship between participation and severity of vision loss related to glaucoma and to explore the relationship between participation and VSQoL as they each related to severity of glaucoma.

4.3.1 Descriptive Data

4.3.1.1 Participant Characteristics A total of 90 participants were enrolled in this study, 1 participant withdrew from the study due to personal reasons prior to completing the assessments. Participants were recruited from both the UPMC Eye Center(s) and the UPMC Eye Center Registry. Participants were on average 68 years of age, predominantly female and Caucasian, and nearly half had a graduate-level education. The severity of glaucoma (mean deviation [MD] of the better-seeing eye) was early stage. Refer to Section 3.5.1 for more detail

in regard to the demographic characteristics (see Table 13) and the clinical characteristics (see Table 14) of the participants in this study.

4.3.1.2 Participation We used two instruments to measure three components of participation: the PART-O measured frequency of participation and the LIFE-H measured participation accomplishment and satisfaction with participation. Refer to section 3.5.2 for a detailed description and interpretation of participation data for the participants in this study. Frequency of participation was greatest for community engagement. Participants were most likely to travel beyond their block or neighborhood (96.6%) and least likely to attend a sports event as a spectator (74.2%).

Participants on average had no difficulty accomplishing tasks and required little assistance to participate in life situations (M = 9.29, SD = 0.76; see Table 14), and were satisfied with how they were able to accomplish life situations (M = 4.50, SD = 0.60). Types of assistance to accomplish tasks are described by the LIFE-H as assistive devices, environmental or task modifications, and human assistance (see Table 12). Participants had the most difficulty accomplishing and were the least satisfied with how they accomplished recreation and employment domains of life habits, requiring some assistance. The domains of life habits that were the least difficult for participants to accomplish and participants were the most satisfied with how they were able to accomplish a life situation were interpersonal relationships and responsibilities, requiring little if any assistance.

4.3.1.3 Vision-Specific Quality of Life The average VFQ-25 composite score for our sample indicated that participants who on average had early stage glaucoma had very good VSQoL (M = 84.0, SD = 13.2; see Table 20). On average, participants rated their overall general

health (not included in the VFQ-25 composite score) good (*M* = 63.8, *SD* = 23.8) and general health was the lowest rated VFQ-25 subscale. In addition to general health, the following subscales had the lowest average scores (poorer VSQoL): general vision (scores indicated fair eyesight with correction when used [*M* = 75.1, *SD* = 15.2]), distant vision (scores indicated a little difficulty [*M* = 78.4, *SD* = 18.9]), and driving (scores indicated a little difficulty [*M* = 79.0, *SD* = 17.7]). The subscales with the highest scores (better VSQoL) were color vision (*M* = 95.7, *SD* = 11.5), vision-specific dependency (*M* = 93.7, *SD* = 13.5), and vision-specific social functioning (*M* = 93.0, *SD* = 13.3). All VSQoL indices were anchored by relatively small confidence intervals.

Table 19. Participants' Scores for the Visual Function Questionnaire-25

			95% CI		
	M	*SD*	*LL*	*UL*	*n*
General health	63.8	23.8	58.7	68.8	89
General vision	75.1	15.2	71.9	78.3	89
Ocular pain	82.2	16.3	78.7	85.6	89
Near vision	79.2	20.0	75.0	83.4	89
Distant vision	78.4	18.9	74.5	82.4	89
Vision-specific social functioning	93.0	13.3	90.2	95.8	89
Vision-specific role difficulties	83.9	21.3	79.4	88.3	89
Vision-specific mental health	80.9	20.8	76.5	85.2	89
Vision-specific dependency	93.7	13.5	90.9	96.6	89
Driving	79.0	17.7	75.0	83.0	77
Peripheral vision	84.3	20.4	80.0	88.6	89
Color vision	95.7	11.5	93.3	98.2	88
Composite score	84.0	13.2	81.3	86.8	89

Note. High score (/100) indicates better vision-specific quality of life.

4.3.2 Aim 2: Explore the Relationship between Participation and Vision-Specific Quality of Life

We performed a bivariate correlation analysis to test the hypothesis that participation would have a positive correlation (rho ≥ .40) with VSQoL. There was little correlation between frequency of participation and VSQoL (rho = .17, p = .11; see Table 21). Further exploring the relationship between frequency of participation and VSQoL subscales, productivity (i.e., home and work-related roles) had a fair correlation with general health (rho = .25, p = .02). Additionally, out-and-

about in the community had fair and/or statistically significant correlations with general vision, vision-specific dependency, and peripheral vision (rho = .27, .21, and .23, $p \leq .05$, respectively).

Table 20. Correlation Analysis (Spearman rho) between Covariates, Participation, and Vision-Specific Quality of Life

	Frequency of participation			Participation accomplishment			Satisfaction with participation			VSQoL		
		95% CI			95% CI			95% CI			95% CI	
Characteristic	rho	*LL*	*UL*	rho	*LL*	*UL*	rho	*LL*	*UL*	rho	*LL*	*UL*
Demographic												
Age, years	.03	-.18	.24	.08	-.13	.28	.01	-.20	.22	.09	-.12	.29
Length of glaucoma diagnosis	-.01	-.22	.20	-.08	-.29	.13	-.15	-.35	.06	.04	-.17	.25
Total number of comor-bidities	-.09	-.29	.12	-.04	-.25	.17	-.17	-.37	.04	-.10	-.30	.11
Race	.35***	.15	.52	-.05	-.26	.16	-.08	-.28	.13	.03	-.18	.24
Marital status	-.33**	-.50	-.13	-.06	-.26	.15	-.10	-.30	.11	-.06	-.26	.15
Annual income	.48***	.30	.63	.25**	.04	.44	.21	-.00	.40	.25*	.04	.44
Clinical												
MD better-seeing eye, dB	.17	-.04	.37	.28**	.08	.46	.25*	.05	.44	.48***	.30	.63
BCVA better-seeing eye, logMAR	-.16	-.36	.05	-.28**	-.46	-.08	-.28**	-.46	-.08	-.39***	-.55	-.20
Glaucoma symptoms	.03	-.18	.24	.22*	.01	.41	.38***	.19	.55	.60***	.45	.72
Depressive symptoms	-.21*	-.40	-.00	-.26*	-.44	-.06	-.46**	-.61	-.28	-.35***	-.52	-.15
Frequency of participation				.22*	.01	.41	.16	-.05	.36	.17	-.04	.37
Participation accomplish-ment							.60***	.45	.72	.58***	.42	.70
Satisfaction with participation										.62***	.47	.73

Note. VSQoL = vision-specific quality of life, MD = mean deviation, dB = decibel; BCVA = best-corrected visual acuity; logMAR = logarithm of the minimal angle of resolution.
*$p \leq .05$. **$p \leq .01$. ***$p \leq .001$.

There were positive, moderate correlations between participation accomplishment and satisfaction with participation with VSQoL (rho = .58 and .62, $p < .001$, respectively). Exploring the relationships among the VFQ-25 and LIFE-H subscale scores indicated that VSQoL had statistically significant, fair to moderate correlations with nearly every LIFE-H subscale. The exceptions included (1) general health with the participation accomplishment subscales (rho $\leq .23$) and (2) the VFQ-25 subscales with participation accomplishment of interpersonal relationships. Vision-specific social functioning (among the areas with the highest VFQ-25 scores) and general vision and near vision (among the areas with the lowest VFQ-25 scores) had the strongest correlations with participation accomplishment and/or satisfaction with participation.

Participants' responses indicated that recreation and employment were the two domains of life habits which were the most difficult to accomplish, required some assistance, and/or participants were the least satisfied with how they were able to accomplish them (see Table 15). In regard to participation accomplishment and satisfaction with participation, both recreation (rho = .58 and .65, $p < .01$, respectively) and employment (rho = .31 and .48, $p < .01$, respectively) had fair to moderate correlations with VSQoL. For recreation, the strongest correlations for participation accomplishment were with general vision and near vision (rho $\geq .56$, $p < .01$), and for satisfaction with participation were general health and near vision (rho $\geq .61$, $p < .01$). For employment, the strongest correlations for participation accomplishment were with general vision and peripheral vision (rho $\geq .33$, $p < .01$) and for satisfaction with participation were with near vision and driving (rho $\geq .47$, $p < .01$).

4.3.2.1 Covariate Sub-Analysis The following covariates had at least a fair correlation and/or were statistically significant with participation and/or VSQoL: race, marital status, annual income, MD of the better-seeing eye, BCVA of the better-seeing eye, glaucoma symptoms

(Glaucoma Symptom Scale [GSS]), depressive symptoms (Patient Health Questionnaire-9 [PHQ-9]), frequency of participation (PART-O), participation accomplishment (LIFE-H), satisfaction with participation (LIFE-H), and VSQoL (VFQ-25; see Table 21). Neither participation nor VSQoL were associated with age, length of glaucoma diagnosis, or the total number of comorbidities.

Race and marital status had little correlation with VSQoL (absolute rho $\leq .06$, $p \geq .57$). Annual income had a fair correlation with VSQoL (rho = .25, $p = .02$); notably, 64% of participants were married. The correlation between annual income and frequency of participation was distinctly stronger (rho = .48, $p < .001$) than the relationship between annual income and VSQoL.

Impairment-based clinical measures of visual function (MD of the better-seeing eye, BCVA of the better-seeing eye) had a fair correlation with VSQoL (rho = .48 and -.39, $p < .001$, respectively) and indicated that participants with better visual function had better VSQoL. In regard to impairment-based clinical measures of symptoms (glaucoma and depressive symptoms), VSQoL had a moderate correlation with glaucoma symptoms (rho = .60, $p < .001$); which indicated that participants with fewer symptoms had better VSQoL. The most bothersome symptoms were dryness in the eye and hard to see in dark places (see Appendix E). Further exploring the relationships between these two symptoms, participation, and VSQoL, dryness in the eye had a fair correlation with only VSQoL (rho = .29, $p < .01$) while hard to see in dark places had fair to minimal correlations with participation accomplishment (rho = .27, $p = .01$), satisfaction with participation (rho = .43, $p < .001$), and VSQoL (rho = .52, $p < .001$). There was a pattern among MD of the better-seeing eye, BCVA of the better-seeing eye, and glaucoma symptoms in that these variables each had distinctly stronger correlations with VSQoL than with each of the three participation measures. Participants on average had no depressive symptoms, yet depressive

symptoms had a fair correlation with VSQoL (rho = -.35, p = .001). The correlation between depressive symptoms and VSQoL indicated that participants with fewer depressive symptoms had better VSQoL.

Based on the 95% confidence intervals (see Table 20), our findings provide support for our hypothesis that participation would have a positive correlation (rho ≥ .40) with VSQoL for measures of participation accomplishment and satisfaction with participation but not for frequency of participation.

4.3.3 Aim 3: Multiple Regression Analysis

We performed a multiple regression analysis to test the hypothesis that participation would have a stronger association to severity of glaucoma than VSQoL with severity of glaucoma (see Table 21). Based on our correlation analysis, the following variables had at least a fair correlation and/or were statistically significant with severity of glaucoma: BCVA of the better-seeing eye, glaucoma symptoms, gender, participation accomplishment, satisfaction with participation, and VSQoL (see Appendix G). The following covariates associated with participation and VSQoL previously identified in the literature did not substantially contribute to our regression analysis for which we determined the parsimonious regression models: age, length of glaucoma diagnosis, and total number of comorbidities (see Appendix H). Frequency of participation also did not contribute to our models for our analysis. The negative $\hat{\beta}$ indicated participants with better BCVA had less severe glaucoma, and participants who reported greater satisfaction had less severe glaucoma.

Table 21. Multiple Regression Analysis Models for Indicators of Severity of Glaucoma (Covariates, Vision-Specific Quality of Life, and Participation Independent Variables)

	Model 1			Model 2				Model 3			
Variables	$\hat{\beta}$	R^2	Adjusted R^2	$\hat{\beta}$	R^2	Adjusted R^2	ΔR^2	$\hat{\beta}$	R^2	Adjusted R^2	ΔR^2
BCVA, logMAR	-.31**	.27	.25	-.20*	.34	.31	.06**	-.16	.40	.35	.06*
Glaucoma symptoms	.27**			.12				.17			
Gender	.23*			.18*				.21*			
VSQoL				.33**				.33*			
Participation accomplish-ment								.25*			
Satisfaction with participation								-.29*			

Note. BCVA = best-corrected visual acuity of the better-seeing eye; logMAR = logarithm of the minimal angle of resolution, VSQoL = vision-specific quality of life.
*$p \leq .05$. **$p \leq .01$. *** $p \leq .001$.

The regression results indicated that 40% of the variance in severity of glaucoma was explained by the variables in Model 3 (see Table 21). Based on the adjusted R^2, which represents a chance-adjusted value for R^2 for the number of predictors included in a model (Portney & Watkins, 2009), Model 3 was also the most parsimonious model which indicated that 35% of the variance in severity of glaucoma was explained by BCVA of the better-seeing eye, glaucoma symptoms, gender, VSQoL, participation accomplishment, and satisfaction with participation. When participation accomplishment and satisfaction with participation were added to Model 3, the impairment-based clinical measures were no longer statistically significant indicators of severity of glaucoma. The R^2 change between each model, while small, was statistically significant and indicated that the additions of VSQoL, participation accomplishment, and satisfaction with

participation were statistically significant contributors to understanding the variance in severity of glaucoma. Therefore, Model 3 was the most parsimonious model.

VSQoL, participation accomplishment, and satisfaction with participation were each statistically significant ($p \leq .04$) indicators and had the largest magnitude of importance ($\hat{\beta}$ = .25 to .33) among all the variables in the model; VSQoL had the largest magnitude of importance ($\hat{\beta}$ = .33). However, the distinction in regard to the magnitude of importance between VSQoL, participation accomplishment, and satisfaction with participation was not large. Although based on the correlation analysis we identified at least a fair correlation between severity of glaucoma and the covariates BCVA of the better-seeing eye and glaucoma symptoms, these covariates were not statistically significant indicators of severity of glaucoma when regressed with participation measures and VSQoL. Comparing Models 2 and 3 in the regression analysis, the magnitude of the importance of VSQoL did not change relative to whether or not participation was included.

Overall, this clearly indicates no great distinction between participation and VSQoL and the strength of their associations with severity of glaucoma were modest. Although these results indicated that participation did not have a stronger association to severity of glaucoma than VSQoL (our hypothesis), the strengths of the correlations were similar.

4.4 DISCUSSION

This research study aimed to: 1) explore the relationship between participation and VSQoL and 2) compare the relationship between participation (frequency of participation, participation accomplishment, satisfaction with participation) and VSQoL as they each related to severity of glaucoma. Our findings overall were logical in that for individuals who on average had early stage

glaucoma, they had high participation and VSQoL. We found that VSQoL and participation (accomplishment and satisfaction) had fair to moderate correlations with severity of glaucoma (see Appendix G). VSQoL, participation accomplishment, and satisfaction with participation were each independent incremental indicators of severity of glaucoma and similarly associated with severity of glaucoma. Previous studies reported that participation contributed to QoL (Ellexson, 2004; Levasseur, Desrosiers, & Noreau, 2004; Levasseur, Desrosiers, & St-Cyr Tribble, 2008; Sørensen, Axelsen, & Avlund, 2002; Stevens-Ratchford, 2005), satisfaction with participation contributed to social participation (Alma et al., 2012), and severity of vision loss was associated with QoL (Gutierrez et al., 1997; Iester & Zingirian, 2002; McKean-Cowdin et al., 2008; Parrish et al., 1997; van Gestel et al., 2010).

4.4.1 Aim 2: Explore the Relationship between Participation and Vision-Specific Quality of Life

We found positive, moderate correlations among VSQoL, participation accomplishment, and satisfaction with participation. These correlations suggested that for social life situations accomplished with little to no difficulty and with few if any type(s) of assistance, participants were satisfied with how they accomplished life situations and they reported greater perceptions of their well-being. These results are consistent with previous research that reported fair to moderate relationships between participation and VSQoL (Desrosiers, Wanet-Defalque, et al., 2009; Levasseur et al., 2004; Renaud et al., 2010). Similar to published studies, we found that individuals with worse severity of glaucoma reported lower VSQoL (Goldberg et al., 2009; Gutierrez et al., 1997; Hyman, Komaroff, Heijl, Bengtsson, & Leske, 2005; Jampel et al., 2002; Labiris et al., 2012; McKean-Cowdin et al., 2008; Nelson et al., 2003; Richman et al., 2010; Ringsdorf, McGwin Jr, & Owsley, 2006; Suzukamo et al., 2005; van Gestel et al., 2010; Wren et al., 2009). In this study, our

finding that recreation (a life habit that was the most difficult for participants to accomplish, required some assistance to accomplish, and participants were the least satisfied with how they accomplished it) had the strongest correlation with VSQoL corroborated our previous suggestion that a more visually challenging task may be an important, early indicator of severity of vision loss. This finding in regard to a more visually challenging task also suggests that people's decreased abilities to accomplish a life situation (i.e., recreation) may not be evident during visual testing but may become evident when evaluating participation.

In our sample of individuals who on average had early stage glaucoma, our findings of the areas of better and worse VSQoL were consistent with previous research of people with glaucoma with the exception that our study participants reported worse VSQoL for distant vision while the majority of previous research reported instead vision-specific role difficulties (Hyman et al., 2005; Labiris et al., 2012; Lee et al., 1998; McKean-Cowdin et al., 2008; Nassiri et al., 2013; Parrish et al., 1997; Ringsdorf et al., 2006). Interestingly in this study, peripheral vision was not the most frequently reported vision-related difficulty, even though loss of peripheral vision is one of the hallmark characteristics ascribed to glaucoma to explain how glaucoma may first begin to affect function and behavior. This finding again emphasizes that people with glaucoma may verbalize or demonstrate visual-related behavior prior to their diagnosis or during the early stage of the disease that may not be detected through traditional clinical testing (Janz et al., 2001a). Mental versus physical indicators of QoL were scored lower on the VFQ-25 by people with glaucoma compared to people with other ocular conditions (Evans, Law, Walt, Buchholz, & Hansen, 2009).

In general, the clinical measures of visual function (impairment) had stronger correlations with VSQoL than with participation. We suggest that knowledge about impairment affected participants' perceptions of their state of health and well-being. Since physicians educate their

patients about changes in vision and severity of vision loss indicated by test results, patients' perceptions' about their state of health and well-being may be influenced by knowing glaucoma results in permanent loss of vision. Since testing rarely includes evaluation of patients' accomplishment of daily living situations, people may tend to associate clinical symptoms of impairment more strongly with their state of health and well-being than with how they accomplish daily living situations. As impairment worsens, psychological burden increases together with a growing fear of blindness, social withdrawal, and depression (Janz et al., 2007; Ramulu, van Landingham, et al., 2012; Skalicky & Goldberg, 2008), all of which are recognized to affect VSQoL.

Also in regard to impairment, glaucoma symptoms had a distinctly stronger correlation with VSQoL than with participation. Participants' reports of difficulty seeing in dark places was consistent with previous literature which reported that people with glaucoma had difficulty adapting to sudden changes in light or darkness and had sensitivity to varying contrasts (Nelson et al., 1999; Nelson et al., 2003; Ramulu, 2009; Spaeth et al., 2006). Even though our sample overall had no depressive symptoms, depressive symptoms had, not surprisingly, stronger correlations to satisfaction with participation and VSQoL than with participation accomplishment.

Frequency of participation had a weak correlation with VSQoL and stronger correlations to socio-demographic variables (race, marital status, annual income) than to clinical measures of visual impairment. This relationship was similar to what we reported in the previous chapter. Measures of visual impairment more strongly correlated with participation accomplishment, satisfaction with participation, and VSQoL than with frequency of participation. Therefore, frequency of participation may relate more to socio-demographic status and having the opportunity to engage in participation situations than to function and disability.

4.4.2 Aim 3: Compare the Relationship between Participation and Vision-Specific Quality of Life as They Each Related to Severity of Glaucoma

Gender (female), VSQoL, participation accomplishment, and satisfaction with participation were indicators of severity of glaucoma. These findings are of particular interest since measures of clinical visual impairment such as visual acuity and glaucoma symptoms were not indicators of severity of vision loss for individuals who on average had early stage glaucoma. Our findings in regard to participation and measures of impairment were consistent with previous, yet limited research (Alma et al., 2012). We hypothesized that participation would have a stronger association with severity of glaucoma than did VSQoL, after controlling for covariates, but we did not find this result. However, our findings are important in that participation accomplishment, satisfaction with participation, and VSQoL were similar in regard to the strength of their association with severity of glaucoma. We suggest, therefore, that participation be further studied during routine medical care to elucidate whether or not participation is sensitive to identify vision-related deficits in patients' accomplishment of daily living situations. Participation measures may be applied during a routine medical examination more so than a vision-specific measure.

It is recognized that people with similar disease states such as glaucoma likely rate the effects of the disease on their QoL differently. When interpreting research that used self-report instruments to measure the effects of glaucoma on VSQoL, the consistency of self-report ratings and meaningfulness attached to ratings may shift over time and alter by circumstance (Levasseur et al., 2008), evidence of the multidimensional nature of VSQoL. Subjective measures can be influenced by people's physical health, psychological health and coping strategies, social relationships, personal and cultural beliefs, personal expectations, socio-economic factors, value of the importance of roles and routines, and the environment (Meadows, 2011; Rovner, Casten, Hegel, Hauck, & Tasman, 2007; Warrian, Spaeth, Lankaranian, Lopes, & Steinmann, 2009).

People are also likely to have different patterns of impairment based on the combination of the various eye functions and structures affected by glaucoma which affects function differently (Black et al., 2011; Eichenbaum, 2012; Kotecha, O'Leary, Melmoth, Grant, & Crabb, 2009; Lovie-Kitchin et al., 1990; Merigan & Maunsell, 1993; Milner & Goodale, 1995; Patino et al., 2010; Turano et al., 2004). We contend that participation may be less influenced by the variety of these factors since it is a unidimensional measure of what people are or are not able to do and, therefore, should be included in vision research.

Vision loss is a major determinant of poorer VSQoL but ocular surface discomfort, psychosocial factors, and social constraints also contribute to disease burden. The clinical measures of visual function (e.g., visual acuity, contrast sensitivity, visual fields) facilitate the monitoring of disease severity but do not capture the perceived or actual effect of eye conditions on the accomplishment of people's daily living situations. Participation, on the other hand, is a direct measure of function and disability to evaluate the effect of glaucoma on people's accomplishment of social life situations.

4.4.3 Conclusion

While a majority of vision science research has focused on QoL as a primary outcome, few studies included a distinct measure of participation as a potential determinant of disability and disease severity for people with visual impairment or glaucoma. Rehabilitation specialists evaluate how vision loss affects individuals' abilities to accomplish daily life situations they want to or need to do using participation. The outcomes of the evaluations serve as the basis for intervention strategies. Therefore, it is important that we understand how glaucoma affects participation. Currently, there is little scientific data in regard to participation of individuals with glaucoma while

there is extensive research in regard to how VSQoL is affected by glaucoma. The results of this study provided a unique perspective of participation to influence the care of people with glaucoma.

This study was novel in that we provided evidence that both participation accomplishment and satisfaction with participation were independent incremental indicators of severity of glaucoma, when controlling for VSQoL, and these participation measures and VSQoL had similar associations with severity of glaucoma. This finding supports that participation as an outcome in vision research contributes to our understanding of the effects of glaucoma on daily living. Rehabilitation specialists who receive a referral to provide service to people with a condition other than vision loss need to be aware that vision loss can affect participation, especially since vision loss is often a hidden disability. Many people with vision loss can still accomplish their daily living tasks, roles, and routines that they need to or want to do. However, they may begin to change the frequency or the methods to accomplish such tasks which may be potential indicators of risk for disability and/or indicator of early disease.

5.0 CONCLUSION

People with glaucoma often experience changes in their abilities to engage in social life situations and change how they accomplish daily living tasks, roles, and routines that they want to or need to do. As a result of the effects of glaucoma on their function, psychological burden often increases along with a fear of blindness. While historically the effects of glaucoma on people's daily living were measured by people's perceptions of their health and well-being (vision-specific quality of life [VSQoL]), their abilities to participate in social life situations as influenced by glaucoma has not been frequently measured in research and is an essential missing component to the overall understanding of the life experiences of people with glaucoma.

We explored the concept of participation because it is the immediate focus for vision rehabilitation goals and interventions to maximize people's use of their remaining vision. Although it is important to consider the conceptual differences between participation and VSQoL, we can't ignore that participation is correlated with quality of life (QoL), likely because QoL is a multidimensional construct. Therefore, VSQoL measures can be helpful in studying participation. This research study sought to explore participation in individuals with glaucoma to better understand the relationship between severity of vision loss related to the disease process and the degree to which participation was associated with severity of glaucoma.

5.1 SPECIFIC AIMS

This project had three specific aims:

1. To explore the association between participation and severity of glaucoma,
2. To explore the relationship between participation and VSQoL, and
3. To compare the relationship between participation and VSQoL as they each related to severity of glaucoma.

5.2 SUMMARY OF FINDINGS

To address these aims, Chapter 2 described the theoretical framework used to define the major constructs for this study (i.e., QoL and participation) and the current state of the science for vision research, including the evaluation of vision loss and its effects on function and disability. A review of the scientific literature indicated that VSQoL was the primary outcome measure used in vision research to describe the experiences of people with glaucoma in regard to the situations that most and/or least affected their health and well-being because of severity of vision loss related to glaucoma. Although clinically participation is measured in vision rehabilitation to evaluate the effects of glaucoma on function and disability, the focus on participation in vision research has only recently emerged. A limitation to existing research is that there is no consensus as to the best conceptualization of participation or how to best measure it.

Chapter 3 addressed the first specific aim of this study by exploring participation of individuals with glaucoma. It is well documented that participation decreases with normal aging, yet we do not know how participation may change relative to the progression of glaucoma and how that differs from normal aging. We explored participation from three perspectives: frequency of participation, participation accomplishment, and satisfaction with participation. We found that for individuals who on average had early stage glaucoma, participation accomplishment (the level

of difficulty to accomplish a social situation and whether or not assistance was required to accomplish a social situation) was a statistically significant and independent incremental indicator of severity of glaucoma after controlling for other covariates. Exploratory analyses revealed that frequency of participation was more strongly correlated to socio-demographic variables (having the opportunity and resources to engage in participation situations) while participation accomplishment and satisfaction with participation were more strongly correlated to clinical measures of vision. These results support that participation is an important measure of function and disability; further study should explore the sensitivity of changes in participation over time to identify whether or not people with glaucoma may be at risk for vision-related disability (having restrictions in participation but not the lack of independence).

Chapter 4 addressed Aims 2 and 3 for this study by exploring the relationship between participation and VSQoL and comparing the relationship between participation and VSQoL as they each related to severity of glaucoma. This chapter expanded on the findings from Chapter 3 which described participation patterns of individuals who on average had early stage glaucoma. We found that participation accomplishment, satisfaction with participation, and VSQoL each had a similar association with severity of glaucoma when controlling for covariates. Also, each aforementioned measure was a statistically significant and independent incremental indicator of severity of glaucoma after controlling for covariates. Frequency of participation was not an indicator of severity of glaucoma. Additionally, the findings support that participation is a separate and meaningful construct from VSQoL. Given that participation is a clinical measure used directly in vision rehabilitation to evaluate the effects of glaucoma on function and disability and the effectiveness of interventions for each individual patient, we suggest that further exploration of

participation may elucidate whether or not participation can be a measure to identify people who may be at risk for disability because of their vision loss.

Overall, these findings suggest that participation accomplishment, satisfaction with participation, and VSQoL are related. At the same time, participation accomplishment and satisfaction with participation contributed uniquely as incremental indicators of severity of glaucoma which, after further study, may inform public health awareness for the prevention of visual disability. Given that people with glaucoma are at risk for lower participation than people without glaucoma, examining their participation patterns as well as exploring the factors that lead to these patterns becomes critical.

5.3 SIGNIFICANCE

The prevalence of glaucoma increasingly affects a larger portion of the adult and older adult populations in the United States as the Baby Boomer generation ages and the economic impact of vision problems on individuals, caregivers, and non-healthcare related services will continue to grow. Closing the gap between people's perceptions of their experiences and members of the eye care teams' perceptions of patients' experiences is a priority; failing to recognize this gap we provide suboptimal care. The care process for the medical management of glaucoma is early diagnosis and treatment to minimize the progression of glaucoma and irreversible visual loss that results from damage to the structure and function of the eye. Clinical measures of visual impairment facilitate the monitoring of disease severity but do not capture the perceived or actual effect of eye conditions on people's accomplishment of their daily tasks, roles, and routines. In vision rehabilitation, on the other hand, participation is directly measured to evaluate the effect of

eye conditions on people's accomplishment of life situations. As the goals of medical management and vision rehabilitation continue to shift towards client-centered care and prevention of disability by early recognition of the causes of disease and disability, understanding participation in people with vision loss becomes increasingly important and participation may be a potential method of identifying early vision loss. The findings of this study contribute to the current vision science literature that participation is an independent indicator of and is associated with severity of glaucoma and is a measure distinctly separate from VSQoL.

5.4 LIMITATIONS

There are several limitations to the conduct and results of this study. The design was cross-sectional which did not include any comparisons of participation of age-matched people without glaucoma or without a visual impairment. While the design is appropriate to the exploratory aims of this study, it does not allow for study of changes in vision related to glaucoma and participation that may occur over time. We can make no inference as to whether or not there is a pattern of participation change relative to deterioration in the structure and/or function of the eye captured by clinical measures of vision.

Overall, our participants had on average early stage glaucoma and high participation scores. The modest correlations found in this study between participation and glaucoma severity may be attributed to the restricted range of glaucoma severity of our sample which did not reflect the full spectrum of glaucoma severity in the population. In regard to the average participation scores, without norms for comparison it is difficult to comment on whether the compensatory

methods used by our participants are normal or indicators of decline. Our data merely describe associations between participation and severity of glaucoma.

The dependent variable for this study was a measure of visual fields for severity of glaucoma. There are other components of vision, such as contrast sensitivity, that are affected by glaucoma for which we did not measure for our data collection nor could we control for their effects in our analyses. Additionally, with some measures such as the Glaucoma Symptom Scale, people who have no usable vision in one eye may respond to questions indicating that a symptom or problem is not present in that specific eye (because they have no vision in their eye) the same as people with intact vision and no symptoms or problems.

The assessment instruments used in this study relied heavily on self-report. Since all the questionnaires were subjective measures, they carry with them several limitations. Bias is introduced by participants' knowledge of their disease, the clinical significance of the differences in self-report scores is unclear, and life situations that are not accomplished or given up may not be adequately classified in terms of the inability to engage in a social situation versus desire to no longer engage in the social situation.

Volunteer bias is a limitation to consider as those people who tend to voluntarily participate in research studies who receive no compensation may possess different characteristics than people who elect not to participate in research. Additionally, the method of our recruitment may have a bias in regard to which of the University of Pittsburgh Medical Center Eye Center(s) and which physicians who are glaucoma specialists for which we targeted our recruitment procedures.

It is recognized that people with similar disease states such as glaucoma may rate the effects of the disease on their QoL differently since subjective measures can be influenced by factors such as people's emotional well-being, social relationships, and financial constraints. In addition,

people who rate their QoL similarly may differ in how satisfied they are with how they are able to accomplish social situations. The strengths of the self-report questionnaires include capture of participants' perceptions of their lived experiences and they are simple to administer and complete.

We recognize that our study results are likely influenced by measurement error due to the presence of distorting influences on our assessments (e.g., errors in participant self-recording responses, reliability, participants' personal distractions or clinical situational distractions). Measurement error is uncorrelated with the true scores of our assessment and treated as random error. When independent variables are measured with distorting influences, the estimates of our regression coefficients and their standard errors for each independent variable are biased. One method to address measurement error for future study is to perform reliability testing on the assessment instruments with larger samples of people who have glaucoma. Estimates of reliability based on small samples will often be too high or too low and may produce estimates of correlations between true scores that are inaccurate. Choosing the most reliable measure of a construct will minimize bias due to measurement error. The ambiguity among the constructs used in this study increases our risk for bias. Using multiple methods to measure a single construct is another strategy to address measurement error. When designing future studies, an a prioi statistical plan to adjust for measurement error would include structural equation modeling.

A unique contribution of this research to vision science is its focus on participation, though the measurement of this construct is still early in its development. Most instruments that measure participation are self-report measures versus performance-based, objective measures. The difficulty for an objective measure of participation is developing an instrument that is specific to the conceptualization that participation occurs in a social environment with or for other people. Designing an instrument that unidimensionally captures participation is challenged by the

standardization of social environments that are true-to-life; such environments are often not the typical research or clinical setting.

5.5 FUTURE RESEARCH

Participation is an evolving measure in vision rehabilitation and how to best measure participation is still in a developmental stage. Participation is an ambiguous construct for which there is little consensus in regard to its measurement or conceptualization and the majority of existing participation instruments are self-report. Future research should continue to evolve self-report measures of participation and distinguishing the construct from that of activities or other constructs, yet research should also develop objective measures of participation given the limitations of self-report instruments previously discussed.

Participation in people with glaucoma should be further explored in a sample that reflects a more even distribution of severity across the spectrum of the disease (i.e., later stages of glaucoma). Given that a majority of our participants were in the early stage of glaucoma, further analyses of this data set could explore whether dichotomizing the sample by age and/or severity would result in delineation of different types of patterns of participation. Additionally, further exploration is warranted as to whether or not the location of visual field loss (i.e., superior versus inferior visual field and peripheral versus central visual field) had any differentiating effects on participation. Increasingly, there is research designed to study the effects of visual field loss on effective visual search to locate near objects which demonstrated slower search times for people who had glaucoma versus age-similar controls who had no vision loss (Smith, Crabb, & Garway-Heath, 2011).

As discussed in Chapters 3 and 4, participation may be an indicator to identify whether or not people may be at risk for visual disability and this relationship warrants further investigation. Describing disability in people with glaucoma may improve earlier evaluation, diagnosis, and intervention. By exploring participation in people without glaucoma or without visual impairment, comparing their participation to people with glaucoma across the spectrum of the disease severity, and incorporating longitudinal data of participation, a better understanding of participation patterns will help inform the standard of care for glaucoma prevention and management. Once participation is better understood for people with vision loss, we can better research effective interventions that directly target successful engagement in social life situations.

APPENDIX A

SIMILARITIES AND DIFFERENCES BETWEEN CONCEPTUAL MODELS OF QUALITY OF LIFE AND PARTICIPATION

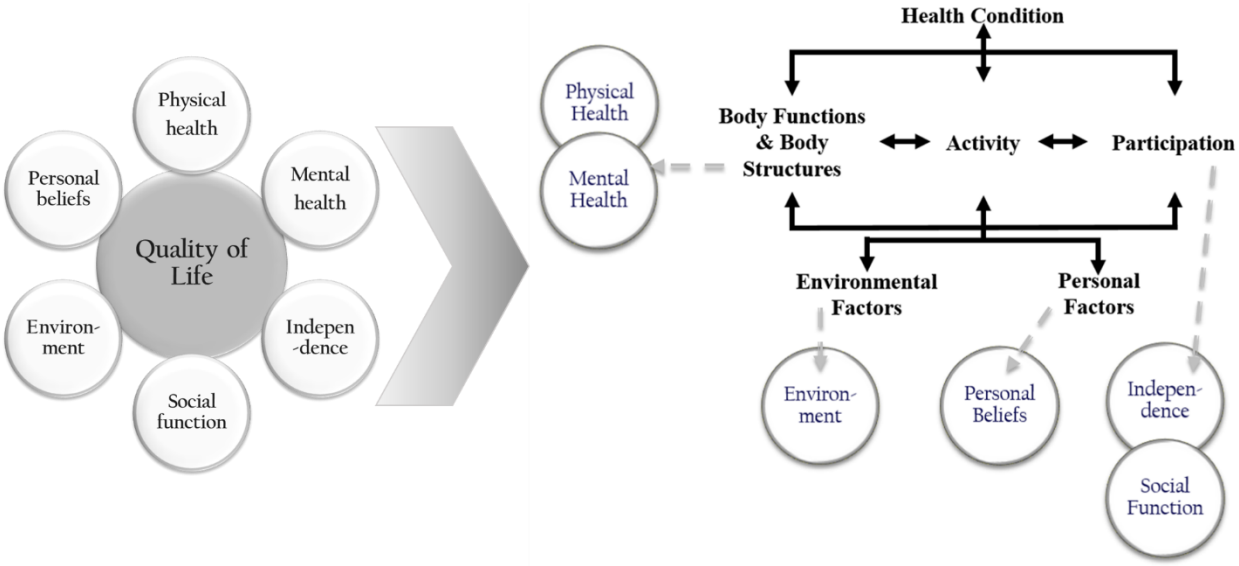


Figure 6. Similarities and differences between conceptual models of quality of life (World Health Organization Quality of Life Group, 1993) and participation (World Health Organization, 2001).

APPENDIX B

OUTCOME ASSESSMENT EXEMPLARS

B.1 ELECTRONIC MEDICAL RECORD REVIEW CHECKLIST

Screening: Medical Record Review

Subject's Name:_____Date:_____Reviewer's Initials:

Subject's Phone Number:_____☐ Enrolled ☐ Not Enrolled

Meets medical record review eligibility criteria: ☐ Yes ☐ No

Eligibility Criteria (options in ALL CAPS mean not eligible for study)	Reviewed *(check box)*
Date of birth:_____Age ≥ 50: Yes NO	☐
Community-dwelling: Yes NO Other:_____	☐
English-speaking: Yes NO	☐
Medically diagnosed glaucoma: Yes NO Mean deviation score: OS:_____OD:_____	☐
Date of last clinical vision evaluation:_____ Within 9 months of potential enrollment: Yes NO	☐
Best-corrected visual acuity: OS:_____OD:_____ 20/200 or better in at least one eye: Yes NO	☐
Medical history/comorbidities Optic neuropathy/ocular pathology other than glaucoma: YES No If yes, describe:_____ Diagnosed cognitive impairment: YES No End-stage organ disease with subsequent vision loss: YES No (*circle*: diabetes, heart disease, cerebrovascular disease, renal disease, central nervous system disease)	☐

B.2 DEMOGRAPHIC QUESTIONNAIRE

Demographic Questionnaire

Subject ID:_____ Date: ____/____/____ Rater Initials:_____

Please check the appropriate number or fill in the blank.

A. Background Information

1) Gender
   - ☐ Male
   - ☐ Female

2) Ethnicity
   - ☐ Hispanic or Latino
   - ☐ Not Hispanic or Latino

3) Race (choose all that apply)
   - ☐ Asian
   - ☐ Black or African American
   - ☐ Caucasian
   - ☐ Other

4) What is your current marital status?
   - ☐ Married
   - ☐ Divorced
   - ☐ Widow/er
   - ☐ Single

5) What is your current living situation?
   - ☐ Alone
   - ☐ With spouse or partner
   - ☐ With caregiver
   - ☐ Other:_____

6) Do you receive caregiver assistance?
   - ☐ Yes
   - ☐ No

Subject ID:_____

7) What is your highest level of education?

- ☐ Elementary
- ☐ Secondary
- ☐ Post high school
- ☐ Graduate school

8) What is your annual income?

- ☐ < $20,000
- ☐ $20,000 - $39,000
- ☐ ≥ $40,000

9) How long has it been since you were diagnosed with glaucoma?_____

B. Medical History

Please check all the boxes that apply, fill in the blank, or circle the appropriate number.

10)
- ☐ Diabetes
- ☐ Heart disease
- ☐ Cerebrovascular disease
- ☐ Hypertension
- ☐ Stroke
- ☐ Renal disease
- ☐ Respiratory condition/asthma
- ☐ Depression
- ☐ Chronic fatigue
- ☐ Musculoskeletal disorder
- ☐ Arthritis
- ☐ Neurological disease (Please list your diagnosis): _____
- ☐ Eye condition(s) other than glaucoma (Please list): _____
- ☐ Hearing disorder: Do you use a hearing aid (circle one)? Yes | No

11) Do you currently receive treatment or have you received a surgical procedure to treat your glaucoma? ☐ Yes ☐ No

12) If you indicated yes to question 11, please indicate what treatment you currently receive or have received to treat your glaucoma.

- ☐ Topical medication
- ☐ Oral medication
- ☐ Laser surgery
- ☐ Other (please indicate treatment):_____

Subject ID:_____

C. Glaucoma Symptom(s)

Have you experienced any of the following problems in the last 4 weeks in your left eye? If yes, indicate how bothersome the problem has been.

	Yes, Very bothersome	Yes, Somewhat bothersome	Yes, A little bothersome	Yes, Not at all bothersome	No, Absent	Score
1) Burning, smarting, stinging	0	1	2	3	4	
2) Tearing	0	1	2	3	4	
3) Dryness	0	1	2	3	4	
4) Itching	0	1	2	3	4	
5) Soreness, tiredness	0	1	2	3	4	
6) Blurry/Dim vision	0	1	2	3	4	
7) Feeling of something in your eye	0	1	2	3	4	
8) Hard to see in daylight	0	1	2	3	4	
9) Hard to see in dark places	0	1	2	3	4	
10) Halos around lights	0	1	2	3	4	

Subject ID:_____

Have you experienced any of the following problems in the last 4 weeks in your right eye? If yes, indicate how bothersome the problem has been.

	Yes, Very bothersome	Yes, Somewhat bothersome	Yes, A little bothersome	Yes, Not at all bothersome	No, Absent	Score
1) Burning, smarting, stinging	0	1	2	3	4	
2) Tearing	0	1	2	3	4	
3) Dryness	0	1	2	3	4	
4) Itching	0	1	2	3	4	
5) Soreness, tiredness	0	1	2	3	4	
6) Blurry/Dim vision	0	1	2	3	4	
7) Feeling of something in your eye	0	1	2	3	4	
8) Hard to see in daylight	0	1	2	3	4	
9) Hard to see in dark places	0	1	2	3	4	
10) Halos around lights	0	1	2	3	4	

Subject ID:_____

D. **Patient Health Questionnaire (PHQ-9)**

Over the last 2 weeks, how often have you been bothered by any of the following problems?

(circle your answer)	Not at all	Several days	More than half of days	Nearly every day
1) Little interest or pleasure in doing things	0	1	2	3
2) Feeling down, depressed, or hopeless	0	1	2	3
3) Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4) Feeling tired or having little energy	0	1	2	3
5) Poor appetite or overeating	0	1	2	3
6) Feeling bad about yourself or feeling that you are a failure or have let yourself or your family down	0	1	2	3
7) Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8) Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9) Thoughts that you would be better off dead, or thoughts of hurting yourself	0	1	2	3
			Total score	

10) If you circled any problems, how *difficult* have these problems made it for you to do your work, take care of things at home, or get along with other people?

- ☐ Not difficult at all
- ☐ Somewhat difficult
- ☐ Very difficult
- ☐ Extremely difficult

B.3 PARTICIPATION ASSESSMENT WITH RECOMBINED TOOLS-OBJECTIVE

B.3.1 Exemplar Questions

- In a typical week, how many days do you get out of your house and go somewhere? It could be anywhere-it doesn't have to be anyplace "special."

  Response Options:

  0 None
  1 1-2 days
  2 3-4 days
  3 5-6 days
  4 7 days

- In a typical month, how many times do you do volunteer work?

  Response Options:

  0 None
  1 One time
  2 Two times
  3 Three times
  4 Four times
  5 Five or more times

- In a typical month, how many times do you attend sports events in person, as a spectator?

  Response Options:

  6 None
  7 One time
  8 Two times
  9 Three times
  10 Four times
  11 Five or more times

B.4 ASSESSMENT OF LIFE HABITS, VERSION 3.1

B.4.1 Exemplar Areas of Life Habits

Employment

- Holding a paid job
- Taking part in unpaid activities (volunteering)
- Getting to your principal place of occupation (work, school, volunteer center, etc.)
- Entering and moving around in your principal place of occupation (work, school, volunteer center, etc.)

Recreation

- Participating in sports or recreational activities (walking, sports, games, etc.)
- Participating in artistic, cultural or craft activities (music, dance, woodworking, etc.)
- Going to sporting events (hockey, baseball, etc.)
- Using your neighborhood recreational services (library, municipal recreational center, etc.)

Note. From "Assessment of Life Habits: General short form," by P. Fougeyrollas and L. Noreau, 2003. Copyright 2005 by INDCP. Reprinted with permission.

B.5 VISUAL FUNCTION QUESTIONNAIRE-25

B.5.1 Exemplar Questions

In general, would you say your overall health is:

1 Good
2 Very good
3 Good
4 Fair
5 Poor

At the present time, would you say your eyesight using both eyes (with glasses or contact lenses, if you wear them) is excellent, good, fair, poor, or very poor or are you completely blind?

1 Excellent
2 Good
3 Fair
4 Poor
5 Very poor
6 Completely blind

How much of the time do you worry about your eyesight?

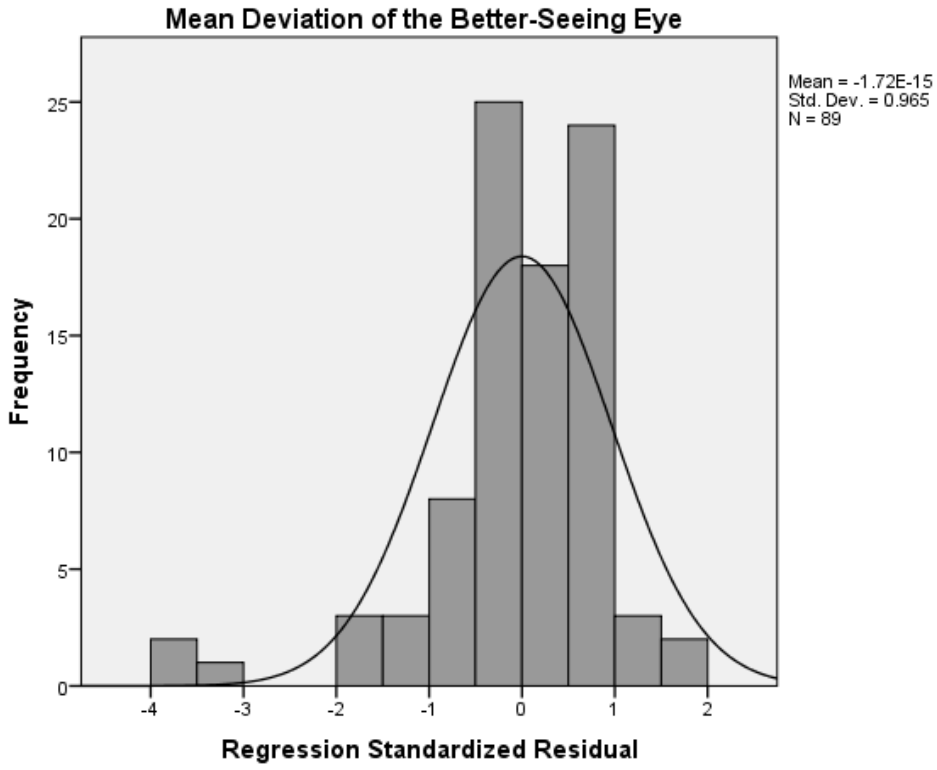
1 None of the time
2 A little of the time
3 Some of the time
4 Most of the time
5 All of the time

APPENDIX C

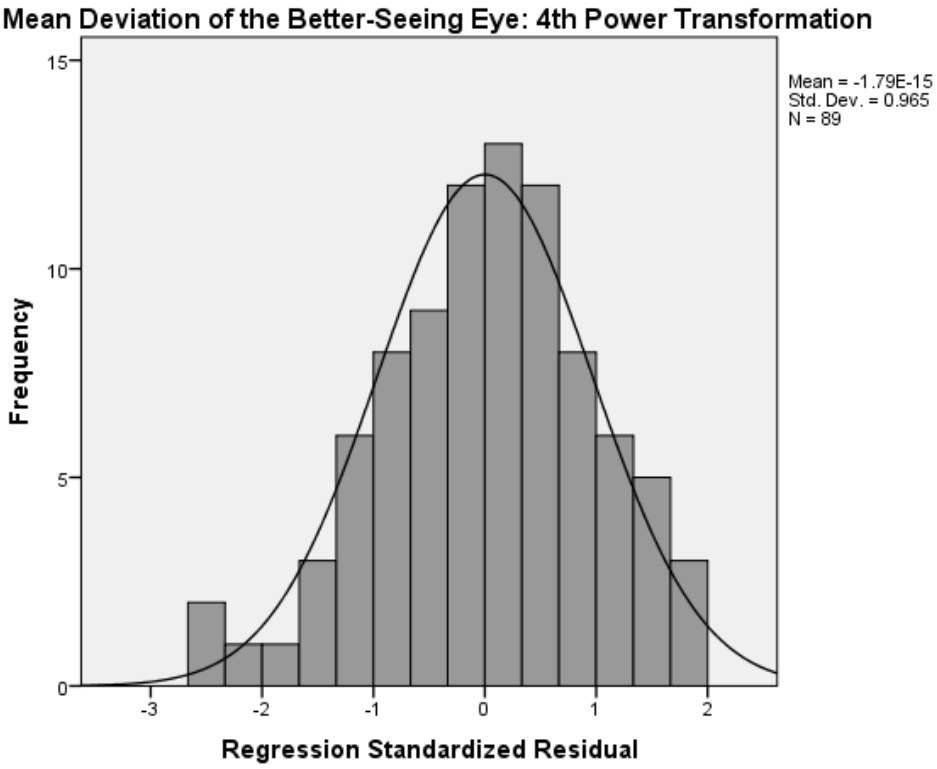
CHECKING THE ASSUMPTIONS OF THE DATA AND DATA TRANSFORMATIONS

C.1 NORMAL DISTRIBUTION OF THE DEPENDENT VARIABLE: MEAN DEVIATION OF THE BETTER-SEEING EYE

C.1.1 Before Transformation

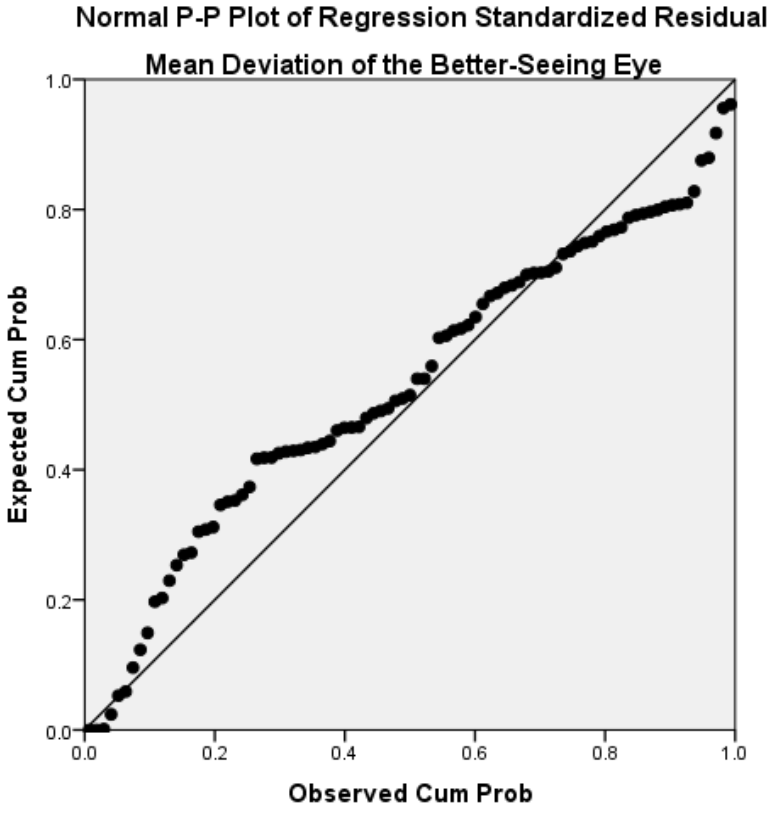


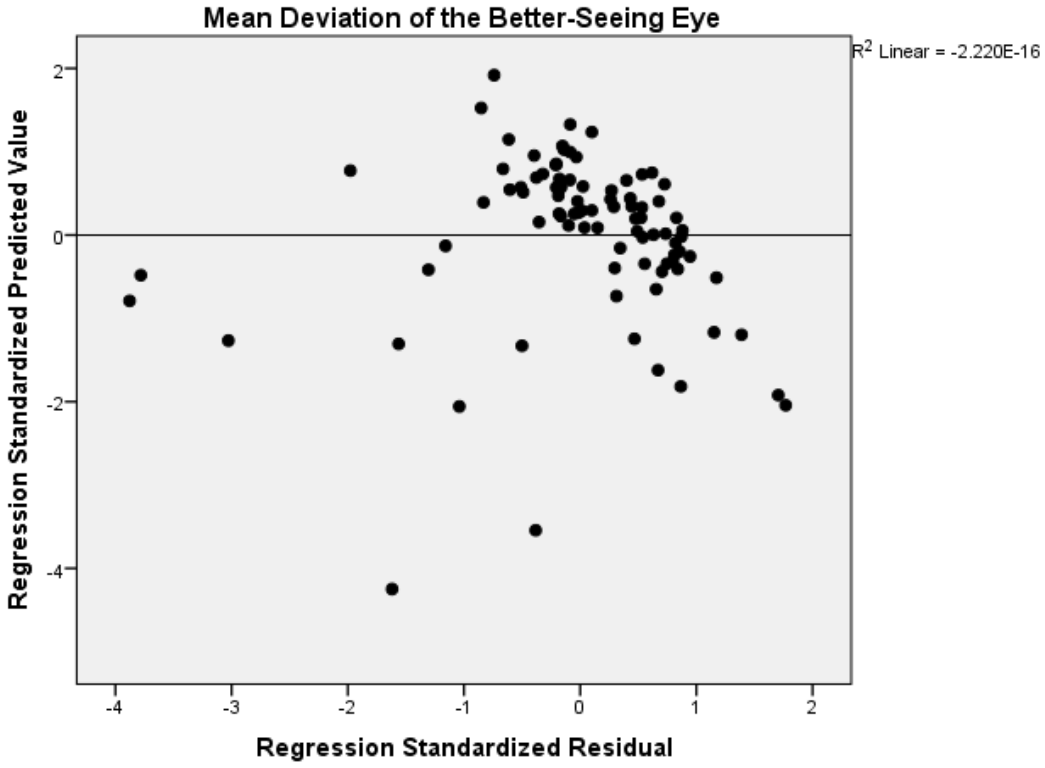
C.1.2 After Transformation



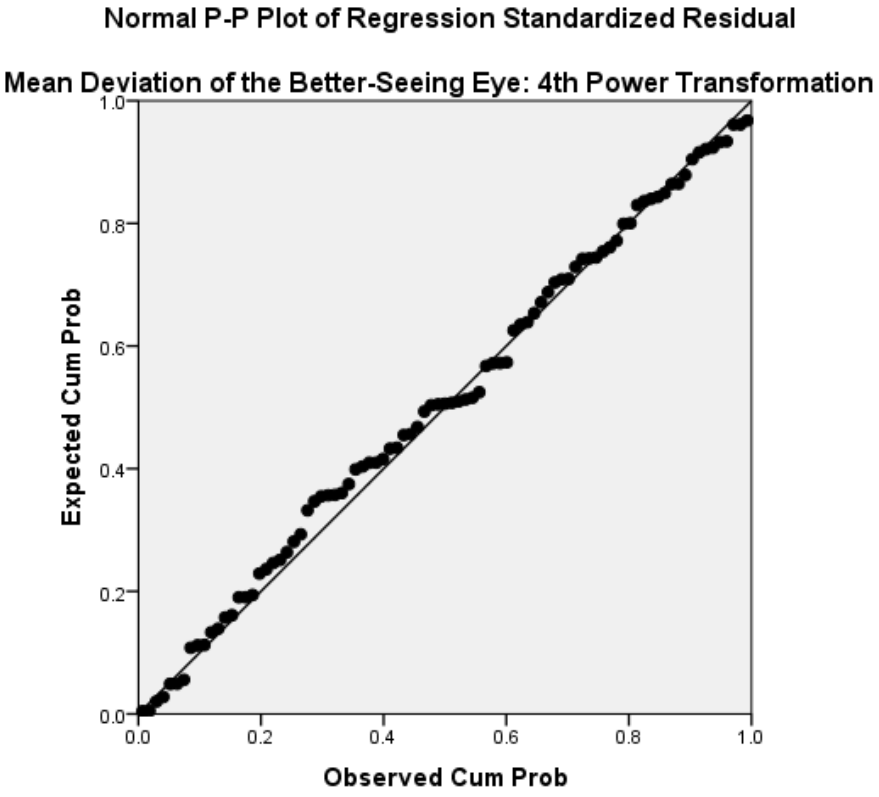
C.2 HOMOSCEDASTICITY OF THE RESIDUALS OF DEPENDENT VARIABLE: MEAN DEVIATION OF THE BETTER-SEEING EYE

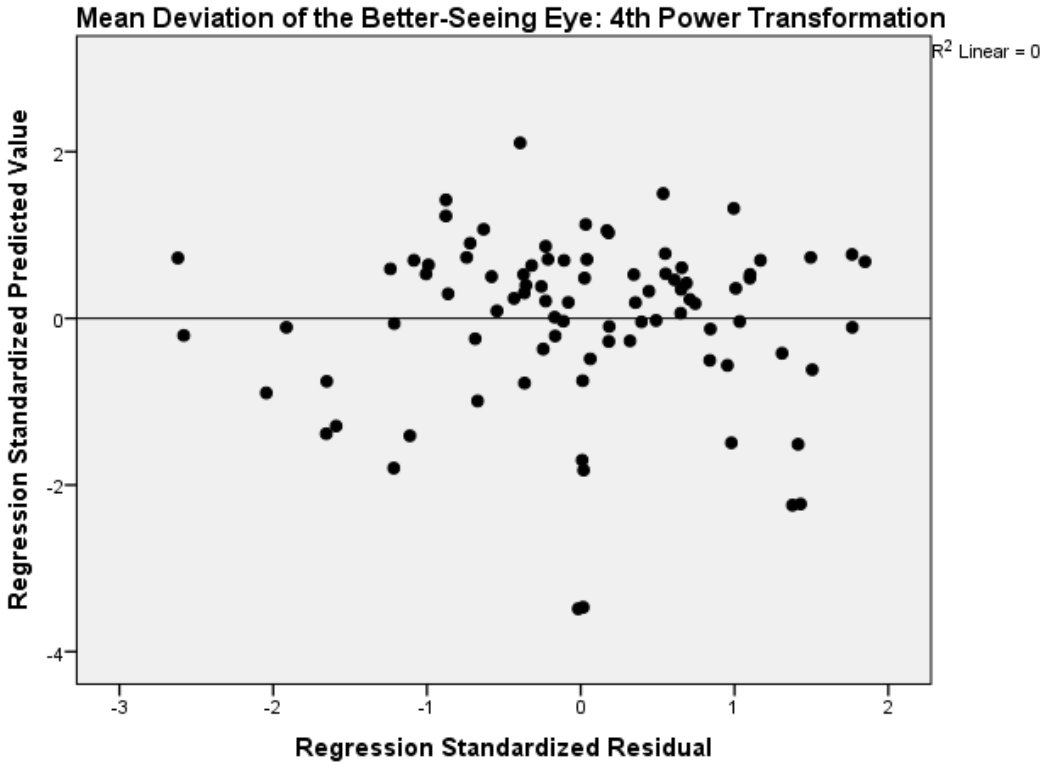
C.2.1 Before Transformation




Mean Deviation of the Better-Seeing Eye
R2 Linear = -2.220E-16
Regression Standardized Predicted Value
2
0
-2
-4
-4
-3
-2
-1
0
1
2
Regression Standardized Residual

C.2.2 After Transformation




Mean Deviation of the Better-Seeing Eye: 4th Power Transformation
R2 Linear = 0
Regression Standardized Predicted Value
2
0
-2
-4
-3
-2
-1
0
1
2
Regression Standardized Residual

APPENDIX D

COMPARISON OF PARTICIPANT DEMOGRAPHICS TO ALLEGHENY COUNTY, PA DEMOGRAPHICS

Table 22. Comparison of Participant Demographics to Allegheny County, PA Demographics

	Frequency (%)	
Participant characteristic	This study	Allegheny County
Gender (female)	67	51.9
Race		
Asian	3	3.2
Black or African American	19	13.3
Caucasian	78	81.3
Other	2	1.9
Not Hispanic or Latino	99	98.2
Education (secondary or higher)	99	92.6

APPENDIX E

GLAUCOMA SYMPTOM SCALE

Table 23. Participants' Scores for Glaucoma Symptoms of the Better and Worse-Seeing Eye

	Better-seeing eye				Worse-seeing eye			
			95% CI				95% CI	
Symptoms	*M*	*SD*	*LL*	*UL*	*M*	*SD*	*LL*	*UL*
Burning, smarting, stinging	77.8	30.3	71.4	84.2	75.0	31.3	68.4	81.6
Tearing	84.0	24.8	78.8	89.2	78.7	30.7	72.2	85.1
Dryness	71.1	32.4	64.2	77.9	65.7	34.8	58.4	73.1
Itching	76.4	28.5	70.4	82.4	73.9	31.7	67.2	80.6
Soreness, tiredness	77.3	29.6	71.0	83.5	75.6	32.0	68.8	82.3
Blurry/dim vision	73.6	33.8	66.5	80.7	68.3	33.9	61.1	75.4
Feeling of something in your eye	82.6	28.1	76.7	88.5	76.7	30.6	70.2	83.1
Hard to see in daylight	84.6	27.3	78.8	90.3	80.3	29.5	74.1	86.6
Hard to see in dark places	71.3	34.2	64.1	78.6	65.5	34.6	58.1	72.7
Halos around lights	82.3	30.9	75.8	88.8	82.0	29.7	75.8	88.3
Composite score	78.1	19.3	74.0	82.2	74.2	21.0	69.7	78.6

Note. LL = lower limit; UL = upper limit.

APPENDIX F

SUMMARY PARTICIPATION ASSESSMENT SCORES

F.1 PARTICIPATION ASSESSEMENT WITH RECOMBINED TOOLS-OBJECTIVE

Table 24. Participants' Subscale Scores for the Participation Assessment with Recombined Tools-Objective

Subscale	*M*	*SD*	*n*
Productivity	1.37	0.52	89
Social relations	2.18	0.83	89
Out-and-about in the community	2.37	0.63	89

F.2 ASSESSMENT OF LIFE HABITS

Table 25. Participants' Domain Scores for the Assessment of Life Habits

	Participation accomplishment		Satisfaction with participation		
Domain of life habit	*M*	*SD*	*M*	*SD*	*n*
Responsibilities					
Recognize/use correct value of money	8.56	0.89	4.66	0.62	89
Use bank card/automatic teller machine	8.41	0.93	4.58	0.73	78
Make purchases	8.34	1.07	4.53	0.74	89
Plan/execute budget	8.36	0.86	4.47	0.79	88
Assume responsibilities towards others and society	8.70	0.46	4.72	0.56	89
Personal or familial	8.72	0.56	4.62	0.73	89
Child education	8.88	0.34			16
Child care	8.80	0.41	4.93	0.26	15
Interpersonal relationships					
Partner	8.84	0.45	4.74	0.54	62
Children	8.78	0.51	4.75	0.60	73
Parents	8.76	0.56	4.53	0.62	17
Other family members	8.63	1.11	4.56	0.78	84
Friendships	8.83	0.41	4.66	0.62	89
Other individuals	8.72	0.77	4.61	0.71	87
Intimacy	8.79	0.59	4.63	0.84	57
Employment					
Choose a career	8.13	2.30	4.60	1.06	15
Seek employment	6.64	3.04	3.91	1.38	11
Maintain job	7.46	2.72	4.33	1.10	46
Unpaid activities	8.27	1.35	4.42	0.90	55
Get to place of occupation	8.51	0.77	4.54	0.83	61
Enter place of occupation	8.57	0.62	4.58	0.72	60
Use services at place of occupation	8.49	0.66	4.64	0.61	47
Homemaking	8.41	0.81	4.43	0.79	54
Recreation					
Sports (participant)	7.69	2.07	4.04	1.11	77
Art, culture, crafts (participant)	8.10	1.40	4.41	0.97	58
Sports (spectator)	7.80	2.04	4.20	1.20	46
Art, culture (spectator)	8.14	1.60	4.43	0.89	72
Tourist activities	7.75	2.01	4.16	1.10	75
Outdoor activities	7.77	2.11	4.23	1.15	43
Neighborhood recreational services	8.03	1.86	4.38	0.93	61

APPENDIX G

BIVARIATE CORRELATION ANALYSIS

Table 26. Bivariate Correlation Analysis (Spearman rho) between Covariate, Participation, and Vision-Specific Quality of Life Variables

		1	2	3	4	5	6	7	8	9
1	MD	1.00	-.13	-.13	-.04	-.01	.10	-.09	.05	**-.09*** **
2	Age	-.13	1.00	.10	.17	.11	.04	**.22***	-.05	-.04
3	Length of dx	-.013	.10	1.00	-.13	.08	-.03	.01	.14	.06
4	Co-morbid	-.04	.17	-.13	1.00	**.32****	-.10	.07	-.11	.01
5	Hearing disorder	-.01	.11	.08	**.32****	1.00	.12	.03	.13	-.04
6	Race	.10	.04	-.03	-.10	.12	1.00	-.23*	**.38*** **	-.14
7	Marital status	-.09	**.22***	.01	.07	**.03**	**-.23***	1.00	**-.45*** **	.00
8	Annual income	.05	-.05	.14	-.11	**.13**	**.38*** **	-.45	1.00	-.04
9	BCVA	**-.39*** **	-.04	.06	.01	-.04	-14	.00	-.04	1.00
10	GSS	**.36*** **	.04	.08	-.14	-.04	-.12	.09	.02	**-.29****
11	Gender	**.28****	.03	**-.31****	.00	**-.23***	-.08	.19	-.12	-.04
12	PHQ-9	.07	-.14	-.25*	.15	.01	.05	.11	**-.29****	-.06
13	PART-O	.17	.03	-.01	-.09	-.06	**.35*** **	**.48*** **	**-.33****	-.16
14	LIFE-H accomp	**.28****	.08	-.08	-.04	**-.22***	-.05	-.06	.21	**-.28****
15	LIFE-H sat	**.25***	.01	-.15	-.17	-.14	-.08	-.10	.25	**-.28****
16	VFQ-25	**.48*** **	.09	.04	-.10	-.08	.03	-.06	.25*	**-.39*** **

Note. MD = mean deviation of the better-seeing eye; dx = diagnosis; Comorbid = comorbidities; BCVA = best-corrected visual acuity of the better-seeing eye; GSS = Glaucoma Symptom Scale (glaucoma symptoms); PHQ-9 = Patient Health Questionnaire-9 (depressive symptoms); PART-O = Participation Assessment with Recombined Tools-Objective; LIFE-H accomp = Assessment of Life Habits participation accomplishment; LIFE-H sat = Assessment of Life Habits satisfaction with participation; VFQ-25 = Visual Function Questionnaire-25 (vision-specific quality of life).

*$p \leq .05$. **$p \leq .01$. ***$p \leq .001$.

Table 26 (continued)

		10	11	12	13	14	15	16
1	MD	**.36*** **	**.28** **	.07	.17	**.28** **	**.25***	**.48*** **
2	Age	.04	.03	-.14	.03	.08	.01	.09
3	Length of dx	.08	**-.31** **	**-.25***	-.01	-.08	-.15	.04
4	Co-morbid	-14	.00	.15	-.09	-.04	-.17	-.10
5	Hearing disorder	-.04	**.23***	.01	-.06	**-.22***	-.14	-.08
6	Race	-.12	-.08	.05	**.35*** **	-.05	-.08	.03
7	Marital status	.09	.19	.11	**-.33** **	-.06	-.10	-.06
8	Annual income	.02	-.12	**-.29** **	**.48*** **	**.25** **	.21	.25*
9	BCVA	**-.29** **	-.04	-.05	-.16	**-.28** **	**-.28** **	**-.39*** **
10	GSS	1.00	-.09	**-.35*** **	.03	**.22***	**.38*** **	**.60*** **
11	Gender	-.09	1.00	.11	.04	.12	.12	.12
12	PHQ-9	**-.355*** **	.11	1.00	**-.21***	**-.26***	**-.46*** **	**-.35*** **
13	PART-O	.03	.04	**-.21***	1.00	**.22***	.16	.17
14	LIFE-H accomp	**.22***	.12	**-.26***	.22*	1.00	**.60*** **	**.58*** **
15	LIFE-H sat	**.38*** **	.17	**-.46*** **	.16	**.60*** **	1.00	**.62*** **
16	VFQ-25	**.60*** **	.12	**-.35*** **	.17	**.58*** **	**.62*** **	1.00

Note. MD = mean deviation of the better-seeing eye; dx = diagnosis; Comorbid = comorbidities; BCVA = best-corrected visual acuity of the better-seeing eye; GSS = Glaucoma Symptom Scale (glaucoma symptoms); PHQ-9 = Patient Health Questionnaire-9 (depressive symptoms); PART-O = Participation Assessment with Recombined Tools-Objective; LIFE-H accomp = Assessment of Life Habits participation accomplishment; LIFE-H sat = Assessment of Life Habits satisfaction with participation; VFQ-25 = Visual Function Questionnaire-25 (vision-specific quality of life).

*$p \leq .05$. **$p \leq .01$. ***$p \leq .001$.

APPENDIX H

H.1 COMPARISON MULTIPLE REGRESSION ANALYSIS MODELS WITH COVARIATE, PARTICIPATION, AND VISION-SPECIFIC QUALITY OF LIFE (INDEPENDENT VARIABLES) FOR INDICATORS OF SEVERITY OF GLAUCOMA

Table 27. Multiple Regression Analysis Models with Covariates, Participation, and Vision-Specific Quality of Life (Independent Variables) for Indicators of Severity of Glaucoma

	Model 1			Model 2				Model 3				Model 4				Model 5			
Variables	$\hat{\beta}$	R^2	Adj R^2	$\hat{\beta}$	R^2	Adj R^2	ΔR^2	$\hat{\beta}$	R^2	Adj R^2	ΔR^2	$\hat{\beta}$	R^2	Adj R^2	ΔR^2	$\hat{\beta}$	R^2	Adj R^2	ΔR^2
Age, yr	-.09	.30	.24	-.15	.38	.32	.08**	-.17	.39	.33	.02	-.18*	.47	.40	.07**	-.18*	.47	.40	.00
Length of diagnosis, mo	-.13			-.14				-.12				-.16				-.15			
Number of comorbidities[a]	-.04			-.01				-.01				-.06				-.05			
BCVA, logMAR	-.28**			-.14				-.12				-.09				-.09			
Glaucoma symptoms	.29**			.14				.17				.20				.20			
Gender	.20*			.14				.14				.18*				.18*			
VSQoL				.38**				.26				.43**				.43**			
Participation accomplishment								.18				.29*				.28*			
Satisfaction with participation												-.39**				-.38**			
Frequency of participation																.05			

Note. Adj = adjusted, BCVA = best-corrected visual acuity of the better-seeing eye; logMAR = logarithm of the minimal angle of resolution, VSQoL = vision-specific quality of life.

[a]Number of comorbidities not including glaucoma.

*$p \leq .05$. **$p \leq .01$. *** $p \leq .001$.

APPENDIX I

MEAN DEVIATION CORRELATIONS WITH PARTICIPATION AND VISION-SPECIFIC QUALITY OF LIFE

Table 28. Correlation Analysis (Spearman rho) for Mean Deviation Scores of the Better-Seeing Eye with Participation and Vision-Specific Quality of Life Subscale Scores

	Participation subscale scores												
	Productivity	Social relations	Out-and-about	Comp score									
PART-O	.10	.15	.13	.17									
	Responsibilities	Interpersonal relationships	Community life	Employment	Recreation	Comp score							
LIFE-H accomp	.24*	.03	.20	.18	.36***	.28**							
LIFE-H satisfy	.17	-.01	.14	.20	.27**	.25*							
	Vision-specific quality of life subscale scores												
	General health	General vision	Ocular pain	Near vision	Distant vision	Social funct	Role diff	Mental health	Depen-dency	Driving	Periph vision	Color vision	Comp score
VFQ-25	.10	.48***	.23*	.46***	.38***	.35***	.43***	.42***	.41***	.15	.35***	.34***	.48***

Note. PART-O = Participation Assessment with Recombined Tools-Objective (frequency of participation); LIFE-H accomp = Assessment of Life Habits participation accomplishment; LIFE-H satisf = Assessment of Life Habits satisfaction with participation; VSQoL = vision-specific quality of life; VFQ-25 = Visual Function Questionnaire-25; Comp = composite; funct = functioning; diff = difficulties; Periph = peripheral.

*$p \leq .05$. **$p \leq .01$. ***$p \leq .001$.

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