Optical Device Use: Exploring Its Impact on Participation in Daily Living Activities of Older Adults with AMD

Lily Perete Orticio
University of Miami, August2@aol.com

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UNIVERSITY OF MIAMI

OPTICAL DEVICE USE: EXPLORING ITS IMPACT ON PARTICIPATION IN DAILY LIVING ACTIVITIES OF OLDER ADULTS WITH AMD

By

Lily Perete Orticio

A DISSERTATION

Submitted to the Faculty of the University of Miami in partial fulfillment of the requirements for the degree of Doctor of Philosophy

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OPTICAL DEVICE USE: EXPLORING ITS IMPACT ON PARTICIPATION IN
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Lily Perete Orticio

Approved:

_______________________________  ______________________________
Doris N. Ugarriza, Ph.D. ARNP  M. Brian Blake, Ph.D.
Professor of Nursing  Dean of Graduate School
and Health Studies

_______________________________  ______________________________
Victoria B. Mitrani, Ph.D.  Linda Liska Belgrave, Ph.D.
Professor of Nursing and  Associate Professor of Sociology
and Health Studies

_______________________________
Karina Gattamorta, Ph.D.
Research Assistant Professor of Nursing
and Health Studies
Age-related macular degeneration (AMD) is the leading cause of blindness among older adults in the United States. The purpose of this study was to explore the experiences of older adults with vision impairment from AMD in managing participation in daily living activities with the use of assistive optical devices and arrive at a substantive theory that captured the essence of these phenomena. Barriers to optical device use that may result in abandonment and differences between individuals who find the devices useful and those who have abandoned using them were also explored.

The sample consisted of 18 older adults, ages 75 to 96 years, 6 males and 12 females who were diagnosed with AMD and recruited during their scheduled appointments at the Retina clinic of an eye specialty hospital. The better seeing-eye had a diagnosis of dry AMD and visual acuity that ranged from 20/50 to 20/200. All participants were fluent in English and acquired their low vision optical devices (LVODs) not less than six months prior to the start of the study. Data were collected from a triangulation of sources that included semi-structured interviews, demographic survey, medical records review, and literature review. The constant comparative method and theoretical sampling of Grounded Theory methodology were used to collect and analyze data from the research question “What are the experiences of older adults with AMD in losing vision and using LVODs?”
Findings revealed the Theory of Doing the Best You Can, a process that includes categories of discovering optical devices where individuals start acquiring LVODs for their changing vision, losing sight from AMD when they first experience the disease, living with AMD that includes the experiences of treatment and the devastating effects of AMD on their daily life patterns, and using LVODs as different factors affect decisions on using, semi-using, or abandoning the optical device. The common thread that weaves through the process is discovering magnifiers as individuals keep looking for devices that will optimize their residual vision.

New findings on signs of AMD and depth and space perception were revealed that have not been cited in the literature and should guide the health practitioners’ assessment of older adults with AMD. More than 50% of the participants had incidence of falls. Three user types were identified: Users, Semi-users, and Abandoners. Users used their LVODs more than once a day, had worse visual acuities, experienced AMD longer, had their LVODs for a shorter period of time, and had the most sources of help. Semi-Users used their LVODs once or less daily and sporadically the past three months, had better visual acuities, were younger, were all females, and took more medications daily. Abandoners had not used their LVOD the previous three months, were older, had their LVODs for a longer period of time, and took the least number of medications. None of the participants were referred for low vision assessment or training and none of the LVODs were prescribed.

Reading disability, facial recognition disability, giving up driving, and dependence on others were found to severely impact daily lives. The treatment of wet AMD with intra-vitreal injections of anti-vascular endothelial growth factor is a difficult
repetitive regimental procedure that has varying outcomes. Results indicate that accepting AMD and vision impairment is complex, however the participants were socially mobile and engaged in activities outside the home. Barriers to LVOD use included factors that involve physicians, the individual with low vision, the device, and service delivery.

The findings have important implications for nursing practice and research and for other disciplines. *Doing the Best You Can* has the rudiments of a middle-range theory that need to be refined by future research to mature and secure its place among established nursing theories.
DEDICATION

To the participants of the study who willingly shared their experiences of vision impairment and are *doing the best they can*,

To those who continue their unwavering passion and vision of conquering blindness,

And

To my mother Elizabeth, my first and lasting teacher, who conquered unbelievable storms.
ACKNOWLEDGEMENT

My journey to finishing my dissertation took twists and turns and I owe gratitude to many individuals who continued to believe in me. My deep appreciation to my committee chair Dr. Doris Ugarriza, who answered my questions and listened. I wish to thank the members of my dissertation committee, Dr. Victoria Mitrani, Dr. Karina Gattamorta, and Dr. Linda Belgrave for their valuable input.

To Dr. William Smiddy, Dr. Zayna Nahas, and Sandra O’Mallen for their enormous help in recruiting participants and Kenya Barr for locating medical records, my sincerest thanks. I am grateful to Dr. Mary Lou Lewis, retired retina specialist from Bascom Palmer Eye Institute for her critical review of the earliest draft and to Dr. Paul Gartner, low vision optometrist who patiently explained the basics of magnification. To the ophthalmologists, optometrists, nurses, technicians, coordinators, and patient access representatives of the Retina Clinic at Bascom Palmer Eye Institute in Miami, I wish to thank them for welcoming me and allowing my study to be a part of their daily routine.

To my brother Mon (Engr. Ramon P. Orticio) who readily understood the theoretical framework of Doing the Best You Can and did all the diagrams, thank you for saving me. To my friends Cora, Josie, Merly, Jay, Myrna, Eileen, and Julia thank you for being present in my life, otherwise who would I call to vent in times of need? To my Bascom Palmer family with whom I spent 30 years of my nursing career, thank you for your support and sharing the profession of caring. I will always cherish the good times. We did the best we could. And to Georgia, my furry dear friend, who witnessed my jubilations and frustrations throughout this life event, thank you for always being there.
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"LVOD" stands for Low Vision Optical Device.
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Chapter 1

Introduction

Age-related macular degeneration (AMD) is the leading cause of irreversible blindness among older adults (65 years old and older) in industrialized countries affecting 30-50 million people worldwide and is the third leading cause of worldwide legal blindness after cataract and glaucoma (World Health Organization, 2012). In the US, AMD is the leading cause of vision impairment among individuals 75 years old and older, and the number one cause of new cases of vision impairment among those older than 65 (Prevent Blindness America, 2008; The Eye Diseases Prevalence Group, 2004). More than eight million older Americans have the intermediate form of the disease and the advanced and late form of AMD affects 1.8 million (The Eye Disease Prevalence Group, 2004). Advanced AMD is expected to affect more than 3.5 million persons by 2030, and more than five million persons by 2050; California, Florida, New York, Texas, and Pennsylvania are the leading states with the highest number of cases (Prevent Blindness America, 2012).

According to the most recent statistics, there are over 40.3 million Americans aged 65 years old or older, an increase of 15% or 5.3 million from 2000 (US Census Bureau, 2011). The increase corresponds to about 13%, or one in every eight Americans. This group has an estimated life expectancy of an additional 19 years and is expected to increase in number by 55 million in 2020, 72 million by 2030, and 88.5 million by 2050 (Administration on Aging, 2011; US Census Bureau, 2011). The fastest growing cohort is the 85 years and older cohort with a projected increase from 5.5 million in 2010 to 6.6 million by 2020 (US Census Bureau, 2011). This population is most affected by AMD.
The Administration on Aging (2011) reported that 87% of the older adult population relies on Social Security benefits and about 3.5 million are below the poverty line. About 485,000 65 years old or older, have primary responsibility for their grandchildren who live with them, while about 10.5 million live alone, and 3.7 million receive care at home. In this age group, women outnumber men and 40% of the women tend to be widows. The individuals identified in population studies in this cohort are most likely in their retirement years and live with the general health consequences of aging. Based on a national health and retirement study (Cigolle, Langa, Kubeto, Tian, & Blaum, 2008), those with vision age-related disease such as AMD experience the additional subsequent critical disabling effects of visual impairment on independent functioning and participation in daily living activities.

Vision impairment from AMD affects central vision that is required for the execution of a variety of everyday tasks necessary for a meaningful daily life. Disruptions or loss of central visual acuity (VA) primarily affects visually intensive tasks like reading and the ability to recognize faces and images, but with progressive visual loss mobility activities are also impaired (West et al., 2002). Reading disability in itself involves a myriad of losses. Not only is the pleasure of reading lost, but also more profoundly, the disability affects participation in performing activities that maintain the person’s safety and connectedness to daily living and to the larger society (Horowitz, Brennan, Reinhardt, & MacMillan, 2006).

The inability to read medication labels may lead to under or over dosage of regularly taken medications imposing health safety risks. Activities, such as reading current events in newspapers, paying bills, reading prices while shopping in a
convenience store, reading menus while with a group of friends or relatives, or reading Psalms and prayers while in religious gatherings, are activities that elicit active participation and give meaning to daily living. Thus, losing the ability to read is considered by older adults as one of the most devastating effects of vision impairment (Ryan, Anas, Beamer, & Bajorek, 2003).

Low vision optical devices (LVODs), such as handheld or stand magnifiers optimize residual functional vision through increased magnification thereby enabling individuals with AMD to perform daily tasks. The ability to continue participation in daily activities through LOVD use has been shown to decrease disability and depression (Horowitz et al., 2006; Stelmack, Stelmack, & Massof, 2002), however lack of knowledge and proper training have been cited as barriers to optimal device use (Casten, Maloney, & Rovner, 2005; Copolilo & Tietelman, 2005; MacLahlan, Rudman, & Klinger, 2009). Little is known about how visually impaired individuals with AMD perceive their own realities of using assistive devices to manage aspects of their daily living activities independently.

The purpose of this study was to explore the experiences of older adults diagnosed with age-related central vision impairment such as in AMD, in managing participation in daily living activities with the use of assistive optical devices. Barriers to optical device use that result in abandonment and differences between individuals who find LVODs useful and those who have abandoned using them were explored. Capturing the essence of the experiences of visually impaired individuals with AMD in optimizing their residual vision with the use of LVODs is essential in gaining insight to the nurse’s role in providing care to this patient population.
**Background**

**AMD.** AMD is a progressive bilateral ocular condition that results in the deterioration of the macula, the central area of the retina responsible for central vision (see Figure 1.1). Based on anatomical and physiological functions, the macula is only 6 mm in diameter but accounts for 10% of the visual field (Alfaro et al., 2006). The central region called the fovea has the highest concentration of cone photoreceptor cells that is mainly responsible for photopic vision. The deterioration of photoreceptor cells in the macula results in scarring and to the gradual formation of scotomas or blind spots that have reduced sensitivity to light leading to impaired vision.

**Figure 1.1. Central location of the macula and fovea in ocular anatomy**


Hyaline deposits, called drusen beneath the retinal pigment epithelium are believed to be the precursors of AMD (Alfaro et al., 2006). There are two types of AMD: atrophic or dry and exudative or wet. Atrophic AMD starts from blurred vision and can slowly progress to severe loss of vision and to wet AMD. The advanced stage of dry AMD is called geographic atrophy. The exudative or wet form is characterized by the
proliferation of new vessels in the deeper layers called choroidal neovascularization that results in greater risk of permanent and more rapid loss of central vision. Due to neovascularization, exudative AMD is also called neovascular AMD. Majority of AMD cases are the dry form, but wet AMD causes the more severe cases of vision loss (Kellner, Kellner, & Weinitz, 2010; Schmucker, et al., 2011).

The focus of medical treatment in AMD is to prevent, stop, or retard the progress of the foveal cellular destruction that causes the formation of an organized fibrous scar that results to central scotoma or irreversible blind spot (Prasad, Schwartz, & Hubschman, 2010) shown in Figures 1.2, 1.4, and 1.5. Serial intravitreal injection of vascular endothelial growth factor (VEGF) inhibitors, also called anti-VEGF, is the current trend in the pharmacologic management of exudative or wet AMD patterned after the cellular growth inhibition paradigm of anti-neoplastic drugs (Gher, Anderson, Johnson, & Hageman, 2006; Prasad et al., 2010). Randomized trials of anti-VEGF using Ranibizumab monthly treatments resulted in 95% of patients having stable vision for one year and 40% of treated patients had 20/40 vision or better (Brown et al., 2006; Rosenfeld, et al., 2006). Currently, the trend is to treat with a monthly dose as it could yield almost 4 letters, not even a line in the eye chart, but has a clear impact in reading (Velez-Montoya et al., 2012).

In spite of the beneficial effects of VEGF inhibitors, patients go for repeated treatments due to recurrence that expose individuals to adverse reactions including increased intraocular pressure, cell atrophy, infection, and inflammation and exposure to the risks of compounding drugs (Velez-Montoya et al., 2012). Another concern is that the long term effects of angiogenic agents such as VEGF inhibitors are not well known,
especially among the elderly population. Comparatively, the promising effects of the use of antioxidants and nutritional supplements in atrophic AMD is estimated to prevent more than 300,000 cases of advanced wet AMD over the next 5 years (95% CI, [158,000-487,000]) signifying a public health impact (Bressler, et al., AREDS, 2003). The most recent reports indicate that among 3,549 individuals no significant reduction was seen in the progression of dry AMD with the use of Vitamins C and E, β carotene, and Zinc [(p=.93); (OR, 1.02; 95% CI, 0.71-1.45)], but was significant in the risk of developing advanced AMD [(p=.001); (OR 0.66, 95% CI, 0.53-0.83)], and the development of neovascular AMD [(p=.001); (OR, 1.02; 95% CI, 0.71-1.45)] over a ten-year period (Chew, et al., AREDS, 2013).

Pooled findings of large epidemiological cohort studies indicate that one out of almost every three persons over the age of 70 has early forms of AMD (Smith et al., 2001). The incidence of the more severe stages of the disease increases from less than 1% among individuals under 65 years of age, to over 25% among the 90 year-old and older group. The rates of progression of AMD from early stage to the advanced neovascular stage over a 5 year period was reported as 20.2% with an annual rate of 4% (AREDS, 2001). The most current data indicate that the odds ratio for developing neovascular AMD over a five year period was 0.64 (95% CI, 0.50-0.82; p=0.001) as reported by Chew, et al., (2013). Reported risk factors for AMD were advanced age, white race, smoking, diabetes (Clemons, Milton, Klein, Seddon, & Ferris, 2005; Smith et al., 2001) and family history (Raptrapriya, & Chew, 2013; Ting, Lee, & MacDonald, 2009). Cardiovascular disease, hypertension, and hyperlipidemia have also been reported as risk factors (Chakravarthy, et al., 2010; Munch, Linnenberg, & Larsen, 2013).
**Disabling effects of AMD.** The presence of a scotoma alters the view of letters and images resulting in difficulty for individuals with AMD to accurately read, recognize faces, or interpret their surroundings. In AMD, scotomas are identified by their location either at the center of the macula in the fovea (central scotoma), or outside of the fovea (paracentral scotoma) but within the central 20 degrees of the visual field (Rowe, 2006). A central scotoma appears as a blind spot in the fovea that blocks the central visual field. To test macular function and presence of scotoma within the central 20 degrees of the visual field, an Amsler grid is used. This grid consists of horizontal and vertical lines and individuals being tested are asked at normal reading distance to fix their gaze at the central dot and check if the lines are seen as all straight, without distortion, and no spots or any part of the grid is missing. Figure 1.2 is an illustration of the visual representation of a picture as seen by an individual with a central scotoma. Figure 1.3 is a visual representation of the Amsler grid with a normal macula and a macula with distortion due to a paracentral scotoma found in patients with AMD.

As the disease progresses, the scotoma increases in size resulting in severe restrictions in visual functions such as reading, contrast sensitivity, color perception and depth perception. Scanning, spotting focusing, and tracking that are important in mobility and distance viewing are also severely affected (Park, 1999). Figures 1.4 and 1.5 are further illustrations of the visual disabling effects of AMD that affect driving and recognizing faces.

The visual restrictions due to scotoma formation in the central visual field limit older individuals with AMD to independently function and participate in their various daily activities. Personal care activities, such as bathing, toileting, or eating and tasks
**Figure 1.2.** Visual Representation of a Central Scotoma in AMD

Note: Adapted from “New independence for older persons with vision loss in long term care facilities” by M. Duffy & M. Bileveau-Tobey, 1992, Copyright by AWARE.

**Figure 1.3.** Normal View of Amsler Grid versus Grid Distortion from AMD

Note: Adapted from “Macular Degeneration Photo Galleries” by the National Eye Institute, National Institutes of Health, 2012, Reference #EC03 & EC04. Retrieved from http://www.nei.nih.gov/photo
such as reading, writing checks, reading mail, and dialing the telephone that are normally performed independently become activities that are difficult to perform and may require assistance. Visual field loss and effects on depth and space perception that can lead to critical problems with mobility and physical safety may be so profound that older adults can be at risk for falls or may give up driving a vehicle or their leisure activities further negatively impacting their quality of life.

**Figure 1.4.** The Visual Disabling Effects of Central Scotoma in AMD

![Normal visual field and Abnormal visual field](image)

Note: Adapted with permission from “A Guide to the Human Eye” by Merck Pharmaceuticals. Copyright 1993 by Tim Peters & Company.

**Figure 1.5.** The Visual Disabling Effects of Central Scotoma in AMD

![Normal Vision and Age-related Macular Degeneration](image)

Note: Adapted from “Macular Degeneration Photo Galleries” by the National Eye Institute, National Institutes of Health, 2012, Reference # ED04 & ED05. Retrieved from [http://www.nei.nih.gov/photo](http://www.nei.nih.gov/photo)
As shown by Figures 1.2, 1.4 and 1.5, in AMD, the areas surrounding the scotoma are areas with functional vision. Diverting focus away from the non-functioning scotoma in the macula to an adjacent retina locus that allows vision is called eccentric viewing (Palmer, Logan, Nabili, & Dutton, 2010). The retinal locus that allows the best vision that an individual with AMD usually uses whether consciously or unconsciously is called preferred retinal locus and is closest to the fovea (Vukicevic & Fitzmaurice, 2009). The preferred retinal locus is a “trained” area of the macula and the position or angle of reading above or below text due to the scotoma is “eccentric”. Eccentric viewing skill may develop intuitively but training is offered by low vision rehabilitation agencies. LVODs maximize the remaining vision potential through magnification so individuals with AMD can better read or view objects at near or far distances. Mastery of regained visual skills through the use of LVODs can mean regaining the ability to read which has numerous implications in daily activities. Learning to master these skills requires reinforcement and support until an independent level of functioning is achieved.

**Activities and Participation (WHO-ICF, 2001)**

The World Health International Classification of Functioning, Disability and Health (WHO-ICF, 2001) provides a standard unifying language for describing the health-related components of functioning and disability. First classified in 1980, WHO-ICF (2001) was a result of nine years of international collaboration among different countries aimed at providing a universal language to promote communication among users, comparison and exchange of data, and a coding scheme for health information systems globally. The classification is currently used by WHO member countries and translated to several languages (WHO, 2013).
The framework is structured around health components including body function and structure, activities and participation, and environmental factors. This classification is a comprehensive taxonomy of the different dimensions of functioning and disability such as learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal relationships, major life areas, and community, social, and civic life. Therefore, vision-related functioning and disability are conceptualized in the context of complex interactions between the individual’s health-related conditions and personal characteristics and the environment (Hendershot, Placek, & Goodman, 2006). Although there are controversies in the definition of disability within the rehabilitation and quality of life (QOL) research community, the WHO ICF (2001) concepts of functioning and disability were used in this study due to the global collaboration in establishing their definitions and global application in health and research.

In the WHO-ICF (2001) nomenclature, activity is the execution of a task and participation is the involvement in a life situation. These concepts are expressed as functioning and are not separate entities. The execution of a task leads to involvement in a life situation and is an example of functioning. Activity limitations are the difficulties encountered in executing tasks. Participation restrictions are the problems experienced in becoming involved with life situations. These items are expressed as disability. Activity limitations and participation restriction are likewise not separate entities as the difficulties in executing tasks result in participation restriction that contributes to disability. Functioning is identified as positive and disability as negative depending on the capacity and performance of an individual.
The state of functioning or disability of individuals is a dynamic interaction between their health conditions and factors in their personal lives and an environment that can either serve as a facilitator or barrier. Impairment is a deviation or incongruence from a normal function that can be temporary, permanent, progressive, regressive, intermittent, continuous, static, slight, or severe that may fluctuate over time. The degree of functioning and disability in impairment is determined by the interaction of the individuals’ health conditions, personal factors, and the environment.

Age-related vision impairments such as AMD limit the participation of older individuals in daily life situations due to visual field defects from a central or paracentral scotoma and a diminished VA. The impaired vision limits their independent execution of personal care tasks and instrumental tasks that constitute their daily activities. In a self-rated performance survey, \((n=173)\) older visually impaired persons rated themselves as participating less in life situations such as household \((p=.001)\), hobbies \((p=.030)\), socializing \((p=.002)\), and leisure activities \((p=.05)\) than their peers (Alma et al., 2011).

**Daily living activities (DLA).** Independent functioning is expressed as the successful execution of skills that are performed to meet the individual’s everyday needs also called daily living skills (WHO-ICF, 2001). Daily living skills are classified as either activities of daily living (ADL) or instrumental activities of daily living (IADL). Basic activities such as bathing, toileting, dressing, or eating are classified as ADL and more complex activities such as preparing a meal, reading, house chores, handling money, or taking medications are classified under IADL. For the purposes of this research, daily living skills will be referred to as daily living activities (DLA).
ADLs except for taking care of one’s appearance and feeding one’s self, are associated more with health problems other than visual function deficit while IADLs such as picking out and identifying clothing, food, and money, or taking medications are more related to vision impairment (Travis, Boerner, Reinhardt, & Horowitz, 2004). LVODs such as hand held, or stand magnifying lenses are prescribed by low vision specialists to assist individuals to perform a variety of DLA. The most frequently reported DLA in using LVOD for close, intermediate, and distance reading involve tasks such as reading large and fine print, labels, handwritten material, medications, or menus (Stelmack, Rosenbloom, Brennerman, & Stelmack, 2003) that fall under IADL.

The independent execution of DLA is associated with visual function. When age related impairments such as vision impairment are present there is a risk for DLA disability that becomes more pronounced in the presence of other health problems or age related impairments (Berger & Porell, 2008; Cigolle et al., 2008). Independent functioning can be facilitated by the use of assistive devices such as LVODs. The ability to successfully execute DLA that enable individuals to actively participate and regain a certain degree of independent functioning distances the older visually impaired adult from disability.

**Classification of Vision Impairment**

The assessment of the different functions of the eye, such as, near and far VA, contrast sensitivity (dark/light adaptation), stereopsis (depth perception), visual fields, accommodation, color vision, brightness acuity, macular function, and presence of refractive errors constitute a comprehensive low vision assessment (Park, 1999). The degree of visual deficit determines the type of rehabilitation from which the visually
impaired individual may benefit. According to the Salisbury Eye Evaluation (SEE) project (Muñoz, et. al, 2000; West et. al., 2002; West, et. al., 1997) persons with visual impairment are disabled when they have a VA measure of worse than 20/200 or contrast sensitivity loss of 0.9 log units. For intensive visual tasks like reading, a VA level worse than 20/30 or contrast sensitivity worse than 1.4 log units is disabling.

The classification of impaired vision in Table 1.1 is an illustration of the diagnostic grouping based on VA or visual field radius by WHO International Classification of Diseases (WHO ICD-10, 2008). Other visual functions, such as, (a) contrast sensitivity, (b) brightness acuity, (c) stereopsis, or (d) the presence of refractive errors, are not included as defining factors of visual impairment in this classification. It is important to differentiate visual function from functional vision. Visual function includes VA, contrast sensitivity, and other parameters that are included in an ophthalmic assessment, while functional vision refers to how an individual performs in activities that require the use of vision (Berger & Porell, 2008). Visual function loss leads to functional vision impairment.

According to Table 1.1, an individual with low vision has a BCVA that can range from less than 20/70 to 20/400, and an individual who is blind can have a VA of less than 20/400 to no light perception or a visual field radius of 10 degrees to less than five degrees. Therefore, blindness does not necessarily mean the inability to perceive light.

An individual may have the ability to count fingers, perceive hand movement, perceive light, or may be completely unable to detect light. One common misconception is that blind persons no longer have the power of visualization and are in a state of complete and continuous darkness. In a qualitative study of 12 older individuals, Mogk
Table 1.1. Categories of Vision Impairment

<table>
<thead>
<tr>
<th>Classification &amp; Category of Visual Impairment</th>
<th>Best Corrected Visual Acuity (BCVA)</th>
<th>Or Central Visual Field*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low vision 1</td>
<td>Maximum (less than) 6/18, 3/10, 20/70</td>
<td>Minimum (equal to or better than) 6/60, 1/10, 20/200</td>
</tr>
<tr>
<td></td>
<td>6/60, 1/10, 20/200</td>
<td>3/60, 1/20, 20/400</td>
</tr>
<tr>
<td>Blindness 3</td>
<td>3/60, 1/20, 20/400</td>
<td>1/60 (finger count at 1 meter)</td>
</tr>
<tr>
<td></td>
<td>1/60 (finger count at 1 meter)</td>
<td>1/50, 5/300 (20/1200)</td>
</tr>
<tr>
<td></td>
<td>1/50, 5/300</td>
<td>Light Perception</td>
</tr>
<tr>
<td></td>
<td>No light perception</td>
<td>≤10 degrees but &gt; 5 degrees</td>
</tr>
<tr>
<td></td>
<td>Undetermined or unspecified</td>
<td>≤ 5 degrees</td>
</tr>
</tbody>
</table>

*Visual field restriction criteria applicable even if VA is better than the category of visual impairment


(2008) found that legally blind individuals also do not consider themselves as blind persons because doing so would be “claiming a hardship that they are not actually experiencing” (p.12). They continue to see themselves as sighted in spite of the visual disabilities that they experience because being blind is considered as being older and in need of help in the society’s cultural context (Mogk, 2008; Orticio, 1994).

According to Dandona & Dandona (2006) the WHO ICD-10 definitions of visual impairment (Table 1.1) underestimate worldwide prevalence rates of visual impairment as they have been in use for more than 30 years and are no longer relevant to current data. The authors proposed low vision categories of mild visual impairment (less than 20/40 to 20/60 or better), moderate visual impairment (less than 20/60 to 20/200 or better), and three categories of blindness starting from less than 20/200 to no light perception. In the
US, low vision is defined as best corrected vision worse than 20/40 in the better-seeing eye and blindness as equal to or worse than 20/200 in the better-seeing eye (National Eye Institute, 2012). One is legally blind if the best seeing eye has a central VA of 20/200 or worse or a VA of better than 20/200 with a concurrent visual field limitation of 20 degrees or less. The 20/200 VA category for legal blindness is based on the Social Security Act of 1935 criteria for disability benefits (Social Security Administration, 2012).

The VA of 20/40 demarcation for low vision is based on the criterion for unrestricted driver’s license in most US states (Wilkinson, 2006). Rehabilitation specialists, however, define low vision as a permanent visual impairment that interferes with normal everyday activities and is not correctable with refractive, medical or surgical intervention (Copolillo & Titleman, 2005; Horowitz, 2004).

**Statement of the Problem**

Vision impairment is a sensory deprivation that critically decreases an individual’s independence, self-care, and autonomy. To older adults who have functioned independently most of their lives and look forward to their retirement years, visual deficit from age-related diseases such as AMD means a critical threat to the loss of these functions. The number of older individuals affected with all forms of AMD is compelling. Equally compelling are the devastating effects of visual impairment that are indicators for healthcare assessment in older individuals with AMD.

Currently, there is no permanent cure for AMD. Treatments available on the wet form, the more debilitating and rapidly progressive form of the disease, although having shown vision improvement, do not have lasting effects and individuals require repeated
injections that can have adverse effects. Nutritional supplements, such as high dose anti-oxidants and zinc only delay the progression of the wet form of the disease to its advanced stages. Vision rehabilitation plays a major role in managing and living with AMD-related vision impairment. The goal is to improve visual function capacity in near or distance vision through the use of vision enhancement LVODs (spectacles, magnifiers, telescope, prism lenses, and closed circuit television), non-optical devices (reading books, large print materials, and talking devices) and environmental modification (lighting) for the successful completion of DLA.

The general goal of vision rehabilitation is to bring the abilities of visually impaired individuals up to a level at which they approach the independent functioning of their non-impaired counterparts in society. Regaining the ability to recognize faces, enjoy television, dial the telephone, read menus and price labels, or write a check can restore the ability to function independently. The use of LVODs is a restorative process of gaining back a certain degree of independent functioning to increase participation in DLA; however, there exists a lack of knowledge and training for these assistive devices (Copolilo & Teitelman, 2005; MacLahlan et al., 2009). Furthermore, the costs of LVODs are not included under Medicare or any other insurance coverage which means denying beneficiaries completion of the goals of vision rehabilitation (Center for Medicare Advocacy, 2007; Morse, et al., 2012).

The care of visually impaired individuals with age-related diseases such as AMD is a shared domain among healthcare professions. Rehabilitation is not confined to low vision impairment specialists, occupational therapists, or behavioral specialists. The older adult who is visually impaired is a patient in all healthcare settings where a nurse
practices. Therefore, gaining insight and understanding of the experiences of older adults with AMD in managing their participation in DLA with the use of optical devices is essential in delivering care. The use of assistive optical devices optimizes residual vision so individuals with vision impairment can, to some extent, continue to independently participate in performing daily living activities. However, barriers to its optimal use that can result in abandonment need to be explored. Furthermore, the paucity of nursing literature on independent functioning and vision impairment is compelling, further supporting the need for this research.

**Significance**

Strong evidence exists that AMD diminishes the QOL of older adults. However, individuals affected by AMD were not included as a target population in the summary measures of achieving healthy vision in the vision goals of Healthy People 2010, a federally supported program to increase the quality of healthy life and elimination of health disparities among Americans (US Department of Health and Human Services, 2004). AMD was included the summary measures for Healthy People 2020 (US Department of Health and Human Services, 2010) therefore addressing the needs of Americans with AMD was just recently recognized.

The older adult population is projected to increase and so will the consequences of age-related diseases that result in vision impairment such as AMD. Medicare or other insurance plans do not include reimbursement for LVODs and the coverage for low vision rehabilitation visits is also limited. As 87% of the older adult population relies on Social Security benefits and about 3.7 million are below poverty line (Administration on Aging, 2011), these direct costs may considerably add to the financial constraints of
affected individuals. Evidence to support improved QOL of visually impaired older adults as a result of low vision device utilization is imperative to bolster the enactment of a nation-wide implementation of 3rd party and Medicare reimbursement on low vision services and LVODs. The inadequate service programs for this underserved sector of the population and the paucity in nursing literature on age-related vision impairment research further support the need for this research.

**Statement of Purpose**

The purpose of this study was to explore the experiences of older adults diagnosed with age-related central vision impairment in managing participation in daily living activities with the use of assistive optical devices. Barriers to optical device use that result in abandonment and differences between individuals who find LVODs useful and those who have abandoned using them were explored. Capturing the essence of the experiences of visually impaired individuals with AMD in optimizing their residual vision with the use of LVODs is essential in gaining insight on the nurse’s role in providing care to this patient population. Using Grounded Theory methodology, the PI conducted in-depth interviews, a demographic survey, reviewed of the participants’ medical records, and literature review that elicited answers to the research question “What are the experiences of older adults with AMD in losing vision and using LVODs?”

**Key Substantive Variables Explored**

Figure 1.6 is an illustration of key substantive variables that the PI explored from the life events of visually impaired older adults with AMD in managing their participation in DLA by using assistive optical devices as time evolves. LVOD use, diagnosis of AMD, participation in DLA, and LVOD abandonment share a common
relationship with vision loss. There are no other established relationships between the substantive variables as no assumptions were made at the start of the study.

**Figure 1.6.** Key Substantive Variables Explored in the Study
Chapter 2

Literature Review

The Impact of AMD

Depression. The physical, functional, emotional, and social dimensions of health are empirical referents of QOL. The research data on the effects of visual impairment on the health-related QOL of older individuals with AMD is robust. In a cross-sectional data analysis (Brody, et. al., 2001) of a randomized trial of 151 individuals (mean age = 80, $SD = 5.79$) with advanced AMD, depression was twice the rate as compared to those observed among their community dwelling counterparts without AMD ($p<.010$). The greatest predictor of depression among older adults with AMD-related visual impairment is non-acceptance of vision loss ($p<.001$) and was found to be comparable to that found among those with life-threatening conditions such as cancer and cardiovascular disease. In a cross-sectional study (Tolman, Hill, Klenschmidt, & Gregg, 2005) of 144 legally blind participants with AMD 65 to 95 years of age the investigators found that non-acceptance of vision loss was the strongest predictor of depression among older adults with AMD ($p<.001$). Depression was likewise correlated with relationships with family and friends ($r = .40$, $p<.001$) and attitudes towards compensatory behavior ($r = .34$, $p < .001$) indicating the connection to perceived intrapersonal and interpersonal adaptation. There was a notable decreased use of rehabilitation services ($r = - .43$, $p<.001$) with increased depressive symptomatology.

In a prospective cohort study of 51 older adults (mean age 81 years, $SD = 6.4$) with recent onset bilateral AMD, 33% were depressed at baseline and had worse VA ($p=.040$), greater vision-specific disability ($p=.030$), and general physical disability
than the non-depressed participants with AMD (Rovner, Casten, & Tasman, 2002). Hence, depression in older adults with AMD also results in a decline in activities that require vision and in general physical functioning. Activity loss and dissatisfaction with performance of valued activities lead to depression among older individuals with AMD (Rovner and Casten, 2002). On the same participants (n=51) the authors found that more than 70% of the participants reported activity loss as a result of visual impairment and that these activities were greatly missed (Rovner & Casten, 2002). The activities that were reported as frequently given up were reading (87.5%), driving (33.3%) crafts (29.2%) and watching television (12.5%).

In another study by Casten, Rovner & Edmonds (2002) among 114 participants with AMD (mean age = 80.4, SD = 6.4) depression was highly correlated not only to VA ($r = .31, p<.001$), but also to physical function ($r = .29, p<.001$). Since those who are depressed tend to use rehabilitation services less frequently (Tolman et al., 2005) there is a potential for a reciprocal relationship between visual disability and depression (i.e. depression may lead to disability).

Rovner, Casten, Hegel, Hauck, and Tasman (2007) also reported that among 206 individuals (mean age = 81) with exudative AMD in one eye and pre-existing AMD in the fellow eye, those dissatisfied with their valued activity performance ($n = 71$) were found to be twice as likely ($OR=2.41; [95\% \text{ CI}, 1.02 -5.65], p=0.044$) to become depressed in two months than the satisfied participants ($n = 135$) independent of baseline VA, visual function, and medical comorbidity. The findings also indicated that AMD as a diagnosis alone irrespective of its visual impairment consequences or of other co-existing diseases can cause depression.
Depression can lead to suicide. Most individuals who commit suicide late in life suffer from depression and those who are visually impaired are more at risk (Waern, Rubenowitz, Runeson, Skoog, Wilhelmson, & Allebeck, 2002). In a case control study on the burden of illness and suicide in elderly people, the authors interviewed the relatives of 85 consecutively selected individuals who died from committing suicide (Mean age = 75, SD = 8) and 153 randomly selected living control individuals with serious illnesses and disability (Mean age = 79, SD = 8). Visual impairment (OR = 7.0, 95% CI = 2.3 to 21.4) and major depression (adjusted OR = 11.4) were found to be associated with increased risk for suicide. The ophthalmic conditions were not reported however, considering the ages of the subjects, age-related visual impairment such as AMD would be a likely ophthalmic diagnosis.

**Falls.** A risk that LVOD use may not have direct impact on, but is important to identify, is the risk of individuals with AMD for falls. Fall prevention is a vital part of promoting safety in a home environment. Reaching a place where one can comfortably sit and read, do knitting, watch television or perform any other activity requires safe navigation in the home environment. Ivers, Cumming, Mitchell, & Attebo (1998) examined the results of the Blue Mountain Eye Study, a population based assessment of vision impairment and common eye diseases among 3,654 individuals aged 49-97. The researchers found that adults 75 years old and older with a VA worse than 20/30 (OR = 1.9, 95% CI, 1.2 -3.0) and poor contrast sensitivity (OR = 1.2, 95% CI, 1.1-1.3) are more likely to experience multiple falls. The data suggest that contrast sensitivity is a factor to consider in assessing independent function in AMD. Visual acuity (p<.010), contrast sensitivity (p<.01), and depth perception (p<.010) were also reported as predictors of
multiple falls among community-dwelling older individuals \((n=148, \text{mean age}=76.5, SD=5.1)\) by Lord and Dayhew (2001). Older women with AMD were identified to be more at risk for falls than those without AMD (Szabo, Janssen, Khan, Potter, & Lord, 2008. Among 115 women with AMD (mean age = 81.30, \(R=70-92\)) and 54 women without the disease (mean age = 77.5, \(R=71-88\)), the fall risk index score for the AMD cohort was statistically significantly higher \((p<.001)\) and increased with age.

**Measuring QOL in AMD.** Among vision specific instruments, the National Eye Institute Visual Function Questionaire-25 (NEIVFQ-25, 2000) is the most commonly used to measure health-related QOL in visually impaired individuals. In a cross-sectional study (Scilley, DeCarlo, Wells, & Owsley, 2004) of 127 individuals with AMD, the investigators found that the measures that had the significant deficits were general vision \((p<.010)\), near vision \((p<.001)\), distance vision \((p<.001)\), driving \((p<.001)\), color vision \((p<.010)\), role difficulties \((p<.005)\), social functioning \((p<.001)\), and mental health \((p<.050)\). In a cross-sectional study by Brody et al. (2001) with 151 participants, the authors also found that the subscales that were most affected were general health \((p<.001)\), ocular pain \((p<.001)\), near vision \((p<.050)\), distance vision \((p<.010)\), social functioning \((p<.001)\), mental health \((p<.001)\), role difficulties \((p<.001)\), and dependency \((p<.001)\). The results of these studies reveal the physical, functional, psychosocial impact of visual impairment from AMD.

The significant relationship between progressive visual loss related to AMD and QOL is well established. Sahel et al. (2007) in a cross-sectional, prospective, observational study of 360 individuals with AMD (mean age = 77, \(SD=8\)) among 22 centers in three countries in Europe found that the National Eye Institute Visual Function
Questionnaire-25 (NEIVFQ-25) global score decreased with VA severity from 67 to 40.7 (highest score = 100). The decrease in global score was related to VA best estimates ($p<.001$) and worst estimates ($p<.050$), indicating that quality of life decreases with progression of visual impairment.

Results of the AREDS population study (Clemons, Chew, Bressler, & McBee, 2003) indicate that among 4,119 individuals with different stages of AMD, progressive VA loss was significantly related to decreased QOL as measured by NEIVFQ-25 ($t = 16.2, p<.001, ES=0.74$). The mean change ranged from 11 to 25 points in the subscales of (a) general vision, (b) near and distance visual activities, (c) social functioning, (d) mental health, (e) role difficulties, (f) dependency, and (g) driving. In a cross-sectional study of 219 older adults with AMD (mean age = 82.8, $SD = 12.9$), VA was significantly associated with participation restriction as shown by the decrease in total Impact of Vision Impairment scores in emotional, mobility, and reading subscales, [$F(2, 216) = 23.4, p<.001$] (Lamoureaux, Palliant, Tenant, O’Connor, & Keefe, 2008).

Among qualitative studies, in an analysis of diaries completed by 226 individuals with AMD (mean age = 81.62) the researchers found that the main themes experienced in AMD-related visual impairment were (a) loss of independence, (b) personal safety, (c) social interaction and isolation, (d) support mechanisms, (e) effect of AMD on mood, (f) effects of negative media reporting, and (g) psychosocial adaptation (Stanford, Waterman, Russel, & Harper, 2009). Findings from a focus group of 34 older adults (Mean age = 78) with age-related vision loss were that the impact of vision loss included discontinuity in occupation, loss of roles, and threat to independence (Girdler, Packer & Boldy, 2008).
Living with a pervasive sense of fear was a common theme found among 16 urban (mean age = 80.75, SD = 6.99) and 18 rural (mean age = 82.9, SD = 6.50) dwelling adults with age-related vision loss, and this fear reduced their participation in various forms of activities (Rudman & Durdle, 2009). Among older men with AMD, themes identified related to understanding the lived experience with visual impairment included (a) activity limitations, (b) cherishing independence, (c) creation of strategies, (d) acknowledgement of visual impairment progression, (e) confrontation of uncertainties, and (f) persistent hope, and optimism (Moore & Miller, 2003).

**LVOD Use in AMD**

Low vision optical devices such as stand and handheld magnifiers, telescopic-mounted spectacles, prism spectacles, video magnifiers, and closed circuit television, enhance residual vision and offer a potential for independence and improved quality of life. However, there is scant research on the efficacy of LVOD use in independent functioning in daily living and impact on the quality of life of individuals with AMD or with other age-related visual impairment.

To determine the effectiveness of prism spectacles for image relocation, a double masked placebo controlled study among 225 participants with AMD fitted with spectacles and randomized into three groups was conducted (Smith, Dickinson, Cacho, Reeves, & Harper, 2005). Participants in the first group were fitted with bilateral prisms customized for preferred power and base direction, the second group with standard bilateral prisms, and the third with placebo spectacles without prisms. The researchers found that after three months there were no significant differences among the three groups in distance VA ($p=.63$) reading speed ($p=.580$), and critical print size ($p=.270$).
No significant differences in self-assessed visual function were found as shown by Rasch item analysis (NEIVFQ-25 \( p=.310 \)), ADL (Melbourne Low Vision ADL part 2 \( p=.910 \)), or in observed performance on tasks dependent on vision (Melbourne Low Vision ADL part 2 \( p=.110 \)). The results of the study failed to establish prism lenses as an effective device for enhancing image relocation or preferred retinal locus in AMD.

Al-Karmi & Markowitz (2006) however, reported that individuals with AMD who use prism for image relocation have a more sizeable improvement in BCVA. A five-year review of 77 individuals with AMD who underwent low vision assessment that included identification of preferred retinal locus was undertaken by the researchers. Sixty three participants had prism added to their prescription distance spectacles and 14 did not have prisms as it was deemed not beneficial. Results indicated that both sets of individuals achieved significant improvement in BCVA for image relocation with prism \( t(63) = 9.5, p<.001 \) and without prism \( t(14) = 2.25, p=.04 \). Although participants using prisms showed a more sizeable improvement, the sample size of the non-users was comparatively smaller and the outcome measures were limited to VA.

**LVOD use and depression.** The greater use of optical devices such as magnifiers or telescopes is associated with fewer depressive symptoms and less disability. Interviews with of 438 older adults with age-related visual impairments (69.7 % with AMD) who were enrolled in rehabilitation training and receiving training on the use of optical devices such as magnifiers, telescopes, or special sunglasses were conducted (Horowitz et al., 2006). The use of optical devices at 6 month follow-up was negatively correlated with depression \( (r = -12, p<.050) \) and functional disability \( (r = -.30, p<.001) \). LVOD use was associated with a decline in functional disability after adjusting
for depression and baseline results (Older American’s Resources and Services Multidimensional Functional Assessment Questionnaire Total $R^2 = .696; p<.001$). Optical device use was also associated with fewer depressive symptoms after adjusting for disability and baseline results at 6 months follow-up (Center for Epidemiologic Studies-Depression Scale Total $R^2 = .465; p<.001$). Greater use of the device negatively correlated with less disability at both baseline ($r =-.29, p<.001$) and 6 months ($r =-.30, p<.001$) strongly supporting the efficacy of optical device use.

**Degree of visual impairment and LVOD use.** The impact of visual impairment severity on optical device use was studied in 803 participants with AMD (Schmier, Halpern, Covert, Delgado, & Sharma, 2006). These participants (Mean age = 73) were surveyed with AMD Health and Impact Questionnaire and Daily Living Tasks dependent on Vision (DLTV) questionnaire. Visual acuity was estimated using scores from the DLTV. Although the greatest use of low vision spectacles and handheld and stand magnifiers among the participants was in the range of 20/50 to better than 20/150 visual acuities, the total impact of visual impairment to optical device use was significant ($p<.001$). The results also indicate there is a high prevalence of specific optical device and use in specific visual impairment levels. A significant use of spectacles ($p <.001$), handheld magnifiers ($p <.001$), closed circuit television (CCTV) ($p <.001$), and telescopic lenses ($p <.001$) in all VA acuity levels ranging from 20/30 to worse than 20/250 was found. Most notable was the use of handheld magnifiers among those with VA of 20/50 to better than 20/80 (67.4%) and 20/80 to better than 20/150 (66.4%). The use of optical devices declined in the far advanced stages of the disease for those participants with visual acuities beyond 20/150 (40%). Therefore, the recovery of functional vision
through optical device use as the study results indicate is most beneficial for patients with visual acuities better than 20/150. The authors also found significant relationships between VA and falls ($p<.050$) and taking the wrong medication ($p<.050$) indicating the heightened health risks of older adults with AMD.

Older individuals with AMD use LVODs more than those whose visual impairment involves non-central visual field loss such as glaucoma or diabetic retinopathy. In a recent study on LVOD abandonment in an outpatient population, Dougherty et al. (2011) found that non-central vision loss is associated with low usage rates the past three months ($p=.049$, abandonment $OR= 4.97$; $n= 8$, Mean age=77, $SD=17$) confirming a significant LVOD use rate among older adults with AMD. The authors also found that LVOD abandonment was not associated with age ($p=.863$), time since prescription ($p=.125$), or type of LVOD ($p=.412$). Of the 119 devices handheld magnifiers (49%) and stand magnifiers were the most prescribed LVODs. The results were similar to a previous study by Watson, De L’aune, Stelmack, Maino, & Long (1997) among 200 veterans (mean age = 67.4, $SD=11.6$). Of the 740 prescribed LVODs 36.9% were stand or handheld magnifiers that were used mainly for reading (82%). The typical veteran identified receiving low vision services was an elderly Caucasian male with AMD and VA of approximately 20/200.

**LVOD and training.** Proper training on the use of LVODs resulted in improved ability to read prescribed medication labels from a baseline of 58% to 94% among 57 visually impaired adults (Median age = 80) 78% of whom have AMD (Markowitz, Kent, Schuchard & Fletcher, 2008). The participants were asked to rate their ability to read the labels of their prescribed medications as to unable = 0, partially able but without
confidence =1, and able to read accurately and reliably = 2. At initial evaluation 58% of
the participants were unable to read (rating = 0), 40% were able to read but without
confidence (rating = 1) and 2% were able to read accurately (rating = 2). After low vision
assessment and training in reading and use of appropriately prescribed LVODs, 94 % of
the participants were able to read the labels of their prescribed medications (rating = 2).

A two-week supervised training in the use of optical device was effective in
achieving maximum reading rates (Cheong, Lovie-Kitchin, Bowers, & Brown, 2005).
Thirty-two participants with AMD (mean age = 80.3, SD=4.4) who were using stand
magnifiers for the first time were randomly assigned to three groups. All participants
received standard training that included optical device use and reading training in the
office for two weeks. The first group received standard training in the use of stand
magnifiers. The second group was given additional large print books to read at home.
The third group was given additional large print books to read at home but used a stand
magnifier with a smaller field view to simulate a reduced field view. Results indicated
that a two week-training improved reading rates of persons with AMD over time (p=.020)
but additional home reading of large print did not yield any reading improvement
(p=.090). Over time, the maximum reading rate with the LVOD was equivalent to a large
print reading rate that it was not significantly different (p=.110).

**LVOD acquisition and access to low vision care.** Lack of LVOD use may be
attributed to the low referral rate from ophthalmologists and ophthalmic specialists.
Eighty individuals with AMD (Mean age = 82.5, SD=5.2) were questioned about their
awareness and interest in services for vision rehabilitation (Casten, et al., 2005). Only
24% were aware of the program with 83% expressing their desire to enroll. Although
100% were aware of magnifiers and 81% used them, only 6% had devices that were prescribed by an ophthalmologist or optometrist. The majority of the users purchased their devices from a pharmacy or the devices were given to them by relatives. Therefore, the majority of the participants were not trained on the proper use of the optical device. Supporting the previously cited study of Schmeir, et al. (2006), the researchers also reported that the participants with worse vision were more likely to use magnifiers than those with better vision.

Results about understanding the decision making process of acquiring LOVDs, among 15 visually impaired older adults indicated that non-referral to low vision rehabilitation, lack of knowledge, the limitations of the device, and poor adjustment to low vision disability were barriers to LVOD use (Copolilo & Teitelman, 2005). Satisfactory experiences with low vision personnel, existence of a well-established network of individuals with low vision, and being savvy at negotiating prices for LVODs were reported as characteristics leading to successful LVOD use. The authors also cited the importance of a trial period when individuals can experience using the LVOD and the need for a supportive transfer of learning from the clinic setting to the home for more positive outcomes.

In a phenomenological study, four visually impaired older women ages ranging from 69 to 77 years described the experience of living with low vision as keeping with life while managing risk, coming to terms with vision loss, depending on others while maintaining a sense of independence, and avoiding formal low vision training (MacLahlan et al. 2009). The participants also revealed a low level of awareness as a reason of poor access to rehabilitation services. A recurrent theme of non-acceptance of
vision impairment emerged as the underlying cause of non LVOD use and understanding the complexity of acceptance of vision impairment was presented as a vital aspect of care management.

The paucity of nursing literature on age-related visual impairment should be noted. In a review of literature on visual impairment among mid-life and older adults, Sharts-Hopko (2009) concluded that the dearth of nursing research showed a void in understanding holistic care frameworks on age-related visual impairment and the need for evidence-based practice as related to age-related eye diseases. The lack of nursing literature may contribute to a knowledge deficit among nurses that can impose subsequent limitations to accessibility to low vision care and accommodations needed by visually impaired individuals and additionally, the low vision needs of the aging nursing workforce.

**Summary**

The chapter was an overview of the robust literature on the devastating impact of AMD on the physical, functional, emotional, and social dimensions of QOL among visually impaired older adults. The scant literature found on the effects of LVOD on QOL indicated improved outcomes in performance of daily living activities, fewer depressive symptoms, and less disability. Lack of knowledge of low vision services, low rate of referrals to rehabilitation services, advancing visual impairment, and perceptions of blindness were identified as possible causes of decreased use of LVODs. The paucity in the literature of optical device use among individuals with AMD supports the need for this research.
Chapter 3

Methods

Statement of Purpose

The purpose of this study was to explore the experiences of older adults with vision impairment from AMD in managing participation in daily living activities with the use of assistive optical devices and arrive at a substantive theory that captured the essence of these phenomena. Barriers to optical device use that result in abandonment and differences between individuals who find LVODs useful and those who have abandoned using them were also explored. Capturing the essence of the experiences of visually impaired individuals with AMD in optimizing their residual vision with the use of LVODs is essential in gaining insight of the health practitioners’ role in providing care to this patient population.

Design

A qualitative design was used to capture the essence of vision impairment as experienced by individuals with AMD in managing their daily living activities with the use of optical devices. An interpretive approach is necessary for discovering how it is to lose sight and come to a resolution to use or not use a device that might assist in recovering a certain degree of independence in performing sighted activities necessary for daily function and the enjoyment of life. The Grounded Theory research method is the qualitative method selected to arrive at a substantive theory that conceptualizes this experience. The literature review has revealed paucity in nursing research on vision impairment, AMD, and LVOD use. When little is known or has been done on a research
area of interest the Grounded theory research method is appropriate to use (Glaser & Straus, 1967).

**Grounded theory methodology.** Glaser and Strauss (1967) believed that the interpretive focus of Grounded theory is analyzing actual daily realities (substantive area) and the interpretations of the individuals participating in them. Corbin and Strauss (2008) further noted that in conducting the Grounded theory process, there is not one reality waiting to be discovered but multiple realities. Gathering the interpretations of the daily realities of losing sight and using or not using devices that enhance residual vision from each participant, then analyzing the differences and similarities of these interpretations is the focus of this study to arrive at discovering a substantive theory or theories.

Although Glaser and Strauss (1967) established the foundations of Grounded theory as a social inquiry research methodology, their interpretations of its implementation later diverged and two schools of thought emerged: Classic or Glaserian positivistic grounded theory and the more pragmatic interactionist Straussian grounded theory that were reflective of the ontology adopted by the institutions where they were trained. As social scientists adopted and adapted the Glaserian and Straussian models, the interpretive attribute of grounded theory was more articulated and refined. The limited social constructionism laid by Glaser and Strauss in their original work came into focus and gained recognition from the works of social scientists such as Charmaz (2006). The emphasis of the constructionist approach is on the critical role of researchers as participants and contributors in theory building. As active participants, researchers participate by building theories that are constructed from their own past and present
involvements, interactions, perspectives, and research practices and this contribution becomes integrated with the data being collected and analyzed (Charmaz, 2006).

In this study the Straussian model was used as it affords more clarity in giving credence to gaining insight from a review of literature, stating a research question, and use of unstructured interviews (Corbin & Strauss, 2008; Streubert & Carpenter, 2011). However, the commonalities between both approaches that were based from their original work were also used to acknowledge the shared origins. The PI also adopted the perspectives of Charmaz (2008, 2006) who trained under Strauss, the qualitative interviewing approach to “hearing” data (Rubin & Rubin, 2005) and active interviewing of older people (Holstein & Gubrium, 1995; Russel, 1999; Wenger, 2002) and works of others who have made contributions to the articulation of Grounded Theory implementation. This synthesis of the scholarly interpretations and articulations of Grounded Theory reflects the true emergence of a theory from data analysis and upholds the philosophical foundations of Grounded Theory (Chen & Boore, 2009).

In Grounded Theory, the research question is used to identify and clarify the phenomenon of interest that is poorly understood or is conceptually underdeveloped through engaging in the why, what and how of social inquiry (Charmaz, 2008, 2006; Corbin & Strauss, 2008). The research question of the study is “What are the experiences of older adults with AMD in losing vision and using LOVDs?” The PI explored (a) how the vision loss began, (b) reaction to the diagnosis of AMD, (b) how LOVD was obtained, (c) how it feels to use LVODs for the first time, the succeeding times, and at present (d) difficulties encountered with using LVODs, and (e) DLA most and least helped by LVODs, and (e) when why LOVDs were abandoned. The PI also explored
similarities and differences between participants who continue using their LVODs and those who abandoned using them. Little is known about LVOD abandonment among older adults with AMD.

**Key characteristics of grounded theory.** According to Glaser and Strauss (1967), the focus of Grounded theory is to explore social processes for the purpose of developing a theory where (a) constant comparison, (b) theoretical sampling, (c) coding and categorizing data, (d) memos and diagrams, (e) theoretical sensitivity, (f) theoretical integration, and (g) theoretical saturation are key. These key characteristics embody the simultaneous data collection and analysis that are conducted in Grounded Theory.

**Constant comparison.** In constant comparison, after data are collected from interviewing the first participant, the properties of the substantive areas of interest are coded and analyzed. This systematic process is an inductive analysis and is the first step of theory generation.

**Theoretical sampling.** The decision on what data to collect next from the succeeding research participant is based on the emerging theory and theoretical connections being constructed. This process embodies the deductive analysis of theoretical sampling in grounded theory. Glaser and Strauss (1967) assert that in theoretical sampling the researcher continues to seek new data to clarify or support the previously discovered concept and how they are related, or establish another newly discovered concept or concepts. This process allows the researcher to explore the phenomenon of interest by proceeding with an undetermined number of participants and sampling new data at the start of the inquiry to continue constructing the developing theory.
Theoretical sampling further involves filling out the categories with coded data that will define its properties or attributes, examining gaps within and between categories, seeking more properties, establishing relationships, and finding relevance until no new properties emerge and a substantial understanding of the phenomenon is achieved (Charmaz, 2006; Corbin & Strauss, 2008).

**Coding, categorizing.** Coding and categorizing and examining relationships among the emerging properties (sorting) central to living with loss of sight are key stages in formulating theory. As more data are collected, additional properties are identified that define categories. Charmaz (2006) identifies the process as non-linear and reflexive due to the flexibility of the researcher to go back to previous implicit data that may be made explicit by current data being coded, categorized, or sorted to refine the emerging theory in theoretical sampling.

**Writing memos and drawing diagrams.** Writing memos and diagrams are used by researchers in constructing data into concepts as these actions record thoughts, ideas, abstractions, or questions that occur at any stage of data gathering and analysis. The use of memos and diagrams help clarify, substantiate, connect, integrate, and direct data analysis during coding, theoretical sampling, categorizing, and sorting (Charmaz, 2006; Corbin & Strauss, 2008; Glaser & Strauss, 1967). Charmaz (2006) explains that this process explicates the critical role of the researcher in building the theoretical properties of the phenomenon as pointed out by the constructionist approach. The researcher is an active participant and contributor to the data being analyzed through his/her own values, experiences and critical thought.
**Theoretical sensitivity.** Theoretical sensitivity is the process of acquiring meaning through immersion in the data collected where the researcher posits questions and identifies possibilities and connections in the theory formulation (Charmaz, 2006; Corbin & Strauss, 2008; Glaser & Strauss, 1967). Corbin and Strauss (2008) point out that theoretical sensitivity can be derived from the researcher’s professional or personal experience or expertise in the phenomenon being explored or from review of literature.

**Theoretical integration.** Linking codes, concepts, categories, memos, and diagrams to arrive at a central core or central category that embodies the emerging theme from data collected describes the process of theory integration (Corbin and Strauss, 2008). The emerging theory has distinct characteristics and dimensions.

**Theoretical saturation.** Theoretical sampling ceases when after close examination, no additional or new properties emerge and all concepts are defined, hence theoretical saturation is reached (Glaser & Strauss, 1967). Theoretical saturation determines the number of participants necessary to establish the construct validity of the theory. Glaser and Strauss (1967) stressed that no limits are set on the number of participants because it is impossible to know beforehand where the emerging concepts will lead and when theoretical saturation will be reached.

**Sample size and theoretical saturation.** As data establishes theoretical saturation and theoretical saturation determines the sample size, the question on how much sample size is adequate to reach theoretical saturation in qualitative research is impossible to establish a priori. However, some researchers have alluded to a sample size of 25 to 30 as adequate based on the obtained Mean of sample sizes from different qualitative studies reviewed (Mason, 2010; Thomson, 2004). Other qualitative
researchers relied on their research experience and suggested starting at 10 or 12 participants and then adding three or extending up to 20 participants (Adler & Adler, n.d.; Guest, Bunce, & Johnson, 2006). To establish coherence on the subject, Baker & Edwards (n.d.) asked 15 renowned social scientists and five early career social science researchers to answer the question, “How many interviews is enough?”

From the submitted essays of the respondents, the authors concluded that the collective answer was “it depends” (p. 42). There is no rule of thumb or a universal system of determining when it is time to end a qualitative study other than when the researcher is not learning anything new anymore, which is not dependent on a precise number. According to the social scientists, the researcher’s decision to end a study does not depend on the number of participants, but on whether the research question has been answered with the type of evidence that will be satisfactory to the epistemic community comprised of the researcher’s scholarly mentors, peers, and readers. Therefore the critical factor is not the number of participants, but the rigor of the study because the goal is to gather sufficient appropriate data that will fully describe the substantive area under scrutiny and ensure the depth of analysis (Fossey, Harvey, McDermott, & Davidson, 2002).

**Rigor in Grounded Theory methodology.** Validity and reliability are the essential criteria in determining rigor in quantitative research. In qualitative studies rigor is determined by establishing trustworthiness, the soundness and adequacy of methodology (Holloway and Wheeler, 2010). As a different research paradigm, the qualitative researcher’s means of establishing validity and reliability is by removing bias and fostering trustworthiness (Golafshani, 2003). According to Lincoln and Guba (1985),
the criteria for trustworthiness are: (a) credibility, (b) transferability, (c) dependability, and (d) confirmability.

**Credibility.** Credibility is the confidence in the “truth” of the findings and is corollary to internal validity (Lincoln & Guba, 1985, Thomas & McGilvy, 2011). Credibility is established when a researcher’s interpretation of an experience evokes an instant recognition from readers who share the same experience, as if it was their own (Beck, 1993; Guba and Lincoln, 1985; Krefting, 1991).

Corbin and Strauss (2008) assert that credibility is integrated in the theory formulation process of simultaneous data collection and analysis where constant comparison, theoretical sampling, coding, sorting, integration, memo writing, and diagramming result in adding, trimming, and discarding of data units or codes as categories emerge to define the theory. Using multiple data sources in exploring a phenomenon to warrant a comprehensive and robust interpretation of an experience is called triangulation that Lincoln and Guba (1985) contend as means of establishing credibility in qualitative research. Shenton (2004) pointed out that multiple data sources such as use of background information from supporting documents can further elucidate a behavior or experience and verify the details of the data gathered from participants, thereby enriching a deeper understanding of the subject of inquiry.

**Transferability.** Lincoln and Guba (1985) compare transferability to external validity which according to Beck (1993) means that the findings are applicable in other situations or milieu in such a way that the interpretation have meaning to others in similar circumstances. A “thick description” of the phenomenon is vital to transferability and pertains to the sufficient detail of the experience where the researcher makes explicit the
theoretical constructs and conclusions drawn which others may use in their own settings, situations, or cultural patterns (Holloway & Wheeler, 2010; Lincoln & Guba, 1985). The sufficiency of the details allows the “transfer” of the experience, behavior, or phenomenon described in the study to others who may find that they are in the same situation.

**Dependability.** Dependability is consistency and repeatability of findings that Lincoln and Guba (1985) refer to as corresponding to reliability. To meet this criterion, Holloway and Wheeler (2010) maintain that the researcher’s documentation of data and decisions during the research process serves as an audit trail that is open to scrutiny. An audit evaluates the accuracy of findings and determines if interpretations are supported by data. Readers are able to verify the adequacy of the findings by following the decision making process of the researcher. In this regard, Cooney (2011) asserts that memos should sufficiently document the details of the methodological and analytical decisions of the researcher to serve as an audit trail.

**Confirmability.** Confirmability refers to the degree to which the participants shaped the findings or emerging theory without researcher bias (Lincoln and Guba, 1985). Corbin and Strauss (2008), emphasize the importance of reflexivity where researchers bring into the open their own personal assumptions, experience, insights, values, and biases and how these factors may influence theory development. According to Thomas & McGilvy (2010) during the course of the interview, the researcher should make a conscious effort to follow the leads of the participants by asking for clarifications of words or figures of speech used by the participant to ensure capturing the essence of
the participant’s story. Lincoln and Guba (1985) cite audit trail, triangulation, and reflexivity as methods of establishing confirmability.

**Protection of Human Subjects**

Approval to conduct the study was obtained from the University of Miami Institution Review Board (IRB) following the guidelines set by the Human Subjects Committee. The Informed Consent (Appendix D) followed the required elements that included (a) the title of the study and an explanation of its purpose/s, (b) the procedure that detailed the duration and process of the telephone interview and a possible follow-up call for clarification, (c) a statement on accessing the individual’s medical records and the pertinent information that will be obtained, (d) a statement that no direct benefits can be promised for participation, (e) explanation of possible risks, (f) any compensation given to the participants (g) measures taken to protect confidentiality of the participant and the information obtained, (h) right of the participant to decline or withdraw at any time without any change in their care in the University of Miami, and (i) contact information for questions and concern.

There was no compensation given or direct benefits offered to the participants. However, the participants were informed that the results of the study may help health practitioners further understand the needs of individuals with vision impairment from AMD. Possible risks that were explained to the participants included interruption of their daily routine so the PI asked for the best time to call. The participants were also told that they may find the interview tedious or experience emotional discomfort when telling their story about their vision loss. Should this transpire they were reassured that the PI would stop the interview momentarily or reschedule at a later time.
All forms and questionnaires were assigned numbers to maintain data confidentiality. Confidentiality and HIPPA regulations were followed when reviewing medical records. All forms were kept in a secure locked filing cabinet and all computer files had a security password code accessed only by the PI and her dissertation chair. All records and audio and computer files were kept and destroyed according to the University of Miami protocol. Further discussions of ensuring protection of human subjects are discussed in the sections of recruitment and obtaining informed consents.

Prior to the start of the study the PI was granted approval by the Department of Ophthalmology Chairman and by the Retina faculty of Bascom Palmer Eye Institute (BPEI). All retina coordinators and staff were also informed of the study and the PI addressed any questions or concerns. BPEI is a renowned research facility so the PI did not find difficulty in obtaining approval and explaining the study and its requirements for protecting human subjects to the staff.

**Recruitment and the Screening Process**

**Participants.** Participants were recruited from the waiting areas of the Retina clinics on the first floor of the Bascom Palmer Eye Institute (BPEI) in Miami during patients’ scheduled clinic appointments. BPEI is the Department of Ophthalmology of the University of Miami Miller School of Medicine, the leading ophthalmologic institution in the country (US News & World Report, 2012) that sees more than 2,000 patients with retina problems monthly (P. Lee, financial analyst, personal communication, November 16, 2012).

Table 3.1 and Table 3.2 list the inclusion and exclusion criteria of the purposive sample. Participants with primary diagnosis of dry AMD in the better eye also included
those who have converted from wet AMD to dry AMD. Better seeing-eye is the eye with a better VA. If both eyes have the same VA, the better seeing-eye is both eyes, but the eye with dry AMD met the inclusion criteria. The VA range of 20/50-20/200 was based from the findings of Schmeir et al., (2006) that identified BCVA of 20/50 to better than 20/150 as benefitting the most from handheld LVOD use. The VA 20/200 end range was used to follow the definition of moderate low vision impairment by Dandona and Dandona (2006) that was also used by Stelmack et al. (2012) in determining the effectiveness of low vision rehabilitation.

Table 3.1 Study Inclusion Criteria

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<td>65 year-old or older</td>
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<td>English speaking</td>
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<tr>
<td>Primary eye diagnosis of dry AMD in better seeing-eye</td>
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<tr>
<td>BCVA 20/50-20/200 in better seeing-eye</td>
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<tr>
<td>Purchased handheld, stand, and/or portable video magnifier prior to July 1st, 2012</td>
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Table 3.2. Study Exclusion Criteria

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<th>Exclusion criteria</th>
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<td>No telephone access</td>
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<tr>
<td>Non-English speaking</td>
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<tr>
<td>Uncorrected hearing impairment</td>
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<tr>
<td>Hand restrictions</td>
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<tr>
<td>Cognitive impairment</td>
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<td>Nursing home resident</td>
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Distance VA measurement with glasses was used as BCVA when refraction was not available in the ophthalmic evaluation data, and was based on reading a complete line from the Snellen chart. Having purchased handheld, stand, and/or portable video magnifiers prior to July, 1st 2012 ensured that participants had experienced using LVOD for at least six months prior to the start of the study.

The exclusion criteria included (a) no telephone access (b) non-English speaking, (c) nursing home residents (d) uncorrected hearing impairment (e) hand restrictions, and (f) cognitive impairment that were identified during the recruitment process and review of medical history.

**LVODs for handheld use.** The LVODs for handheld use vary in sizes, shapes, types, and prices. The more common ones which the participants used are presented in Figures 3.1 and 3.2. A discussion of the principles of magnification is in Appendix A.

Handheld magnifiers and stand magnifiers are similar except that the stand magnifiers are mounted on a “stand” that gives height to the magnifier (see Figure 3.1). There are several kinds of handheld magnifiers in the market: there are smaller round ones with or without a handle or light, can hang around the neck, and some are rectangular shaped that vary in sizes that slide across a page. Handheld LVODs are portable and can be used to carry out other tasks such as reading menus in a restaurant or price labels while shopping. Stand magnifiers are specifically used for stationary reading only. The height of the stand magnifier allows for a constant focal length making it more convenient to simply slide the device across the span of reading material.
Portable video magnifiers or electronic magnifiers are the newest addition in handheld optical device technology. They offer an adjustable range in magnification, viewing modes to adjust for contrast and brightness, a freeze frame for fixed viewing, a larger field of view, a camera, and have an option for use in a writing position. Portable video magnifiers can also easily fit in pockets or purses like the handheld magnifiers. This type of LVOD is more expensive. Some models can be connected to the television for increased magnification. Figure 3.2 shows models of portable video magnifiers.

**Recruitment.** Recruitment was done at the Retina clinics of Bascom Palmer Eye Institute in Miami. Letters explaining the study and importance of notifying the PI of eligible participants were sent by the PI to retina specialists and coordinators (see Appendix B). The PI also met with the Retina coordinators to determine preliminary eligibility, explain the study and address questions and concerns. A post-card sized summary of the study that included the study title, purpose, eligibility criteria and the PI’s telephone number was given to each Retina coordinator and also placed at their working
areas as reminders (see Appendix C). After being informed by the ophthalmologists and/or coordinators, the PI approached the potential participants to discuss the study and the person’s possible participation. As clinic visits include multiple staff and practitioner encounters, the PI approached the participants inside the clinic rooms before or after they were seen by the ophthalmic technician or ophthalmologist, or while they were waiting in the waiting areas.

The PI initially asked the potential participants if they would be interested in joining a study of patients with macular degeneration who use optical devices. Upon signifying interest, if the participants were inside the clinic room the PI proceeded with the screening and to explain the study in detail. If the participants were in the waiting areas, the PI escorted them to a private area of the Retina Clinic. After determining eligibility, the PI obtained an informed consent (see Appendix D) and Health Information Portability Accountability Act (HIPAA) authorization (see Appendix E).

The PI scheduled a telephone interview within a few days that would be convenient for the participant. The PI then proceeded to collect demographic data using the Demographic Survey in Appendix F. If time was limited and did not allow for the
demographic data collection, the PI collected the data during the scheduled telephone interview.

**Obtaining informed consent and explaining the interview process.** The PI explained the study in detail including the purpose, procedure, risks, benefits, confidentiality, and right to withdraw at any time without jeopardizing care. The PI also asked permission to access the participants’ medical records to obtain information that would be used in the study and have the participant sign the HIPAA authorization form.

The PI informed the potential participants that she will conduct a recorded telephone interview where they will be asked how it is to experience losing sight from AMD and using LVODs in their daily activities. Recorded telephone interviews were selected in lieu of face to face interviews as it afforded more privacy and the participants could be uncomfortable receiving guests in their home or have no means of transportation in meeting at a different location. The PI informed the participants that the interview could last up to one hour where the participants would talk about their story at their own pace and that the PI may call back to clarify a few aspects of the prior interview as needed. The PI also apprised the potential participants that after the interview the she will listen to the conversation word for word and the information obtained will be combined with the other information gathered from other participants of the study.

The PI answered all questions, addressed concerns and reassured the potential participants and their family or significant other that confidentiality will be maintained at all times: (a) their names or any names or places recorded during the interview will be removed and will not appear in the written version, (b) any record will not bear their name, (c) the informed consent will be separated from the interview records to maintain
anonymity, and (d) the audio digital file will be erased after the study is completed. Participants who preferred to read the Informed consent at home or have a family member read it prior to signing were asked for their mailing addresses so the Informed consent and HIPPA consent could be mailed to them with an enclosed return self-addressed stamped envelope. Two participants requested their consents to be mailed and one participant requested to be interviewed in the clinic room as he had a long wait for his treatment. Both requests were granted.

Data Collection and Analysis

 Obtaining demographic data. Descriptive demographic data were obtained using the Demographic Survey Form in Appendix F. Descriptive demographic variables include age, gender, marital status, ethnicity, income and source of income, educational attainment, primary language spoken, whether they have insurance, whether living alone, source of help, activities of interest and hobbies, type/s of LOVDs being used, how long ago LVOD was purchased, frequency of use, and if they have used the LVOD the past three months, whether the participants are still driving, source of transportation, and whether they have incidences of falling the past year. The demographic data were obtained during the telephone interview if the participant requested to do so due to a lengthy clinic visit. Ophthalmic and medical profile demographic data (see Appendix G) were also obtained from the participants’ medical records that included distance VA with glasses, BCVA when available, duration of AMD, ophthalmic and medical comorbidity/ies, and current medications taken.

 The interview process. Using responsive and active interviewing, the PI conducted in-depth interviews to activate participant narratives that addressed what it is it
like to lose vision and use an optical device. In responsive interviewing, the interviewer is bound by ethical obligations in the relationship that is formed with the individual being interviewed (Rubin & Rubin, 2005). In active interviewing, where and how the interview unfolds and gives meaning to the phenomenon under consideration is as critical as what is being articulated and conveyed (Hosltein & Gubrium, 1995). Researchers are more sensitive to the nuances of the interactive interview process and their active role in eliciting a substantive response.

The PI called each participant at home for the scheduled interview except for one participant who requested to be interviewed in the clinic room due to his long wait during the visit. At the start of the interview the PI reminded each participant that the interview would be recorded. The PI then asked the participants to tell their stories beginning with the question “Tell me, when and how did losing good vision begin for you?” Additional questions guided the interview process to explore and clarify the concepts being introduced by the participant during the course of each interview. Obtaining the depth and detail of concepts is crucial and made possible by additional questions that may also help the researcher in eliciting more nuanced answers (Rubin & Rubin, 2005).

The PI explored the key substantive areas of LVOD use, vision loss, AMD, participation in DLA, and LVOD abandonment by asking the following questions: (see Interview Guide in Appendix H).

1. Tell me how you felt when you were told you have AMD?

2. How was it like to use your ___________ (type/s of LOVD) the first time? the succeeding times? now?
3. What activities do you find __________ (type/s of LVOD) useful?
   less useful?

4. What made it easier for you to use your ________ (type/s of LVOD)?

5. What hindered you from using __________ (type/s of LVOD?)

Utilizing the constant comparison and theoretical sampling process as previously discussed in this chapter guided the need for modifications of the guide questions or supplementing additional probe questions in the succeeding interviews. As the data collection progressed, the guide questions were supplemented with the additional probe questions. Appendix I indicates the additional questions and the dates they were added. These supplemental probe questions allowed the PI to capture a more far reaching account of the participants’ experience with vision loss, diagnosis of AMD, LVOD use, participation in DLA, and LVOD abandonment as time evolved.

The additional supplemental probe questions included questions on:

(a) actual visualization – Please describe what is wrong with your sight
(b) obtaining information about AMD – What questions did you ask? How did you find information about AMD?
(c) biggest change in life – Living with AMD, what was the biggest change in your life? What activities do you miss because of poor vision?
(d) driving – How did you feel when you could no longer drive? Or, if still driving, how would things change in your daily life if you are no longer able to drive?
(e) falls – When you are walking are you afraid that you might fall? How about taking the stairs? Describe to me how you see the steps.
(f) advice – What advice would you give to someone who is just starting to use a magnifier? To someone who has just been diagnosed with AMD?

During the interview, the term “magnifier” was used instead of LVOD as this is a term that the participants could easily understand and relate to. Abandonment was defined as not using LVOD for three months (Dougherty, et al., 2011) hence participants were designated as either Users or Abandoners. However, a new group emerged during data collection: those that used their LVODs sporadically the past three months and were using it once or less a day. This group was called as Semi-users.

**The constant comparison process of analyzing data.** After each interview, the digital audio file was initially transcribed using Dragon Premium™ speech recognition software that was judged to be with 99% accuracy by consumer reviews (Consumer Search, 2012). However, the researcher found that the transcription was extremely inaccurate due to the software’s inability to discriminate different accents. Therefore, the digital audio file was transcribed word for word by the PI directly as she played back and listened to the interview.

The PI used two Olympus WS-710M® digital voice recorder that has features of slowing speed down to different levels during playback which helped the ability to capture the spoken words easier. All names of persons, places, and events or any other word/s that identified persons, places, or events were deleted to ensure anonymity and confidentiality.

In using the constant comparison and theoretical sampling process (Glaser & Strauss, 1967), data analysis drives data collection and places the researcher centrally and intricately connected to the data, thus enabling the data to shape the researcher and
inversely, the researcher to shape the data (Corbin & Strauss, 2008). Due to the immersion of the researcher in the data being simultaneously collected and analyzed, Corbin & Strauss (2008) outlined important characteristics that the researcher needs to strictly follow to arrive at a discovery devoid of pre-conceived concepts or structured designs. These characteristics include (a) stepping back to critically analyze each situation, (b) recognition of tendency towards bias, (c) abstract thinking, (d) flexibility and openness to criticisms, (e) sensitivity to the words being said by each participant, and (f) sense of absorption and devotion to the process (p.7). Rubin & Rubin (2005) also placed emphasis on the systematic examination of the actual transcribed words and warned against depending on intuition and memory of any aspect of the interview. The PI followed these steps by asking follow up questions during the interview and by conducting follow-up telephone calls for clarification of parts of the interview that were not clear to the PI. The PI also reviewed the transcription of the interview word for word while playing back the audio digital file in the slowed speed and regular speed to ensure the accuracy of the transcribed interview. The PI had a close communication with her adviser for feedback and critique that were vital in the data collection and analysis stages of the study.

After the first interview was completed and precisely transcribed, the PI began the data analysis prior to proceeding to any succeeding interviews. The PI analyzed the entire transcript line by line and initiated coding that included the open and axial coding process (Corbin & Strauss, 2008) or initial and focused coding as termed by Charmaz (2006). During the open or initial coding the PI examined the transcript line by line and recognized words, phrases, or sentences that share common characteristics or meaning,
grouped them, and assigned a code or label. Hence, codes were derived concepts and
were the basic data units of the analysis. Cutting and pasting and marking the segments of
the transcription pages were ways of literally identifying the data units to easily group the
data units.

As this process continued, the properties (characteristics) and dimensions (span
or range) of the concepts were identified until the entire transcript was thoroughly
examined and analyzed. Coding line by line helped the PI make decisions on what data
to collect next and identify processes that are responses to problems, situations, or events
(Corbin & Strauss, 2008). This was evident on the addition of supplemental question in
Appendix I.

Critical questions that the PI asked at this stage included (a) What process is at
issue here? (b) Under which conditions does this process develop? (c) How does the
research participant/s think, feel, and act while involved in this process?
(d) When, why, and how does the process change? and (e) What are the consequences of
the process? (Charmaz, 2006). Notes or written answers to these questions were
embodied in memos and/or diagrams. In memo writing, the three groups were color
coded to differentiate their interview narratives. The users’ responses were colored black,
semi-users brown, and abandoners purple.

Consequently, the large quantity of codes required sorting. During the sorting
phase, the axial or focused coding process started. The numerous concepts identified in
open coding were examined and concepts that share common properties were grouped
into categories, sub-categories, items, and sub-items. This phase was the next higher step
of sorting in the data analysis of substantive areas explored that were cited in Figure 1.6.
The PI closely examined the characteristics of categories and sub-categories to determine which could be combined, collapsed, or modified to arrive at a more precise and complete description of phenomena that may explain the impact of optical device use on participation in DLA of older adults with AMD. The PI re-examined prior code or statements within narratives that were previously identified as not relevant data but surfaced as having a relationship to the emerging concepts.

During the coding process the PI recorded thoughts in memos and drew diagrams to capture ideas about emerging relationships of concepts, categories, or sub-categories. These memos were marked with the interview and page number to designate the specific interview where the thought occurred. Memo keeping was important because it focused analysis on the theoretical properties of the emerging theory. Hence, probe questions were added to the interview guide on the succeeding interviews of participants. Coding continued until all the data were coded and no new categories were substantiated.

Comparison of all categories reduced the number of categories and defined the properties of each category and sub-category. Sorting of the categories and memos allowed the PI to use constant comparison and identify what theoretical and substantive relationships the categories bear to each other. Irrelevant properties were discarded. The PI repeated this process after each interview and prior to each succeeding interviews.

A taxonomy was constructed to illustrate the categories, sub-categories, items and sub-items within the emerging theory. When no new additional properties emerged that give meaning to the category, theoretical saturation is reached and data collection ceases (Glaser & Strauss, 1967). Theoretical saturation was reached after 12 participants were interviewed. However, the PI continued data collection to determine if new data would
emerge. The data collection ended at 18 participants after theoretical saturation was confirmed.

**Trustworthiness of the Study**

The rigorous method of simultaneous comparative data collection and analysis and theoretical sampling is the built-in credibility of the Grounded methodology (Corbin & Strauss, 2008). This was evident in the resulting modification of guide questions during the inductive and deductive process of the study. The purpose of the additional probe questions was to capture a more far reaching description of optical device use in participation in DLA of older adults with vision loss from AMD. The triangulation of data sources that included 18 interviews, demographic survey, ophthalmic and medical profile obtained from review of medical records, and literature review further established the credibility and confirmability of the study. To obtain a “thick description” for transferability, data collection and analysis and theoretical sampling continued until 18 participants were enrolled, although theoretical saturation was reached after 12 interviews. Inquiry audit was reflected by the multiple discussions between the PI and her Committee Chair at the different phases of the study either by telephone, e-mails, and face-to-face meetings and the critical input of the other Dissertation Committee members. The Committee chair also verified the data collected by the researcher. An IRB audit also confirmed the procedural integrity of the study.

**Summary**

The purpose of this study was to explore the experiences of older adults diagnosed with age-related central vision impairment such as in AMD, in managing participation in daily living with the use of assistive optical devices. Barriers to optical
device use that may result to abandonment and differences between individuals who find the devices useful and those who have abandoned using them were explored.

The inclusion criteria were 65 year old or older individuals with primary diagnosis of macular degeneration in the better seeing-eye, BCVA 20/50-20/200 in the better seeing-eye, English speaking, and have purchased their prescribed LVODs prior to July 1st, 2012 to ensure at least 6 months of LVOD use prior to the start of the study. Individuals with no telephone access, did not speak English, had uncorrected hearing impairment, had hand or cognitive impairments, or were nursing home residents were excluded. The PI recruited potential participants from the Retina Clinics of BPEI following strict compliance in obtaining informed consents, HIPPA authorization, and maintaining confidentiality and record safe-keeping.

The PI interviewed participants by telephone using responsive and active interviewing techniques that elicited answers to the research question “What are the experiences of older adults with AMD with losing vision and using LVODs?” Following Grounded Theory methodology data collection analysis utilized the inductive and deductive approach of comparative analysis and theoretical sampling to arrive at core categories or themes that emerged from the verbatim transcripts of the participants’ experiences with optical device use and vision impairment. No new or additional properties emerged and theoretical saturation was reached after 12 interviews. However, to confirm that no new data emerged 18 interviews were conducted. Trustworthiness of the study was supported by the intrinsic simultaneous data collection and analysis and theoretical sampling of Grounded Theory methodology, the triangulation of data sources, and the confirmation of theoretical saturation after 18 interviews.
Chapter 4

Results

The purpose of this study was to explore the experiences of older adults with vision impairment from AMD in managing participation in daily living activities with the use of assistive optical devices and arrive at a substantive theory that captured the essence of these phenomena. Barriers to optical device use that may result in abandonment and differences between individuals who find the devices useful and those who have abandoned using them were also explored.

The constant comparative method and theoretical sampling of Grounded theory methodology were used to collect and analyze data that addressed the research question “What are the experiences of older adults with AMD in losing vision and using LVODs? A Theory of “Doing the Best You Can” (see Figure 4.1) emerged from a triangulation of data sources that included 18 recorded interviews, 18 demographic surveys, 18 ophthalmic and medical profile reviews of participant’s medical records, and literature review. Tables 4.1 to Table 4.6 describe the characteristics of the sample.

Sample

Forty-two potential participants were approached and 24 were enrolled. Of the 18 potential participants who were not enrolled, nine were not interested in participating, and nine participants who expressed interest did not meet the inclusion criteria. Nineteen participants were interviewed from the 24 participants who were enrolled and six participants were dropped. Five of the six enrolled participants who were withdrawn from the study were not interviewed: (a) two had changes in their schedule and were going out of town (b) one was upset about the income bracket question as being too intrusive, (c)
one had advanced glaucoma per medical records review and (d) one had a VA change of 20/60 to 20/40 in the better seeing-eye from an intra-ocular lens implant cataract surgery. One participant had to be dropped after being interviewed because the PI misread her VA as 20/200 instead of 2/200.

**Sample Characteristics.** Twelve participants were females (66.6%), six were males (33.3%) and age range was 75-96 years with a mean age of 86 years (see Table 4.1). Ethnicity was mainly white (100%) with 12 European (66.6%) and six of Hispanic descent. Eight participants were married (44.4%), eight participants were widowed (44.4%) and two participants (11.1%) were divorced. The sample was well educated with 10 participants (55.5%) having college degrees and six (33.3%) with advanced degrees (four Masters and two Doctorate degrees). Only one participant (5.5%) finished 6th Grade and one participant (5.5%) finished High School. Although all participants were retired from their previous occupations, three participants (16.6%) were still working in their private businesses part time.

Five (27.7%) participants opted not to answer the income bracket question and two participants (11.1%) did not answer source of income. Eight participants (44.4%) received $50,000 or less, and two receive more than $150,000 per year. Only three participants (16.6%) relied on Social Security and seven (38.8%) relied on Social Security plus retirement. Six (33.3%) had additional income sources and one (5.5%) participant resided outside of the US did not receive any Social Security. The majority of the participants had Medicare and supplemental insurance ($n=14, 77.7 \%) . One non-US resident had no health insurance and was self-pay (5.5%).
<table>
<thead>
<tr>
<th>Variable</th>
<th>Characteristic</th>
<th>n</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>Female</td>
<td>12</td>
<td>66.6</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>6</td>
<td>33.3</td>
</tr>
<tr>
<td>Age</td>
<td>71 – 75 years</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>76 – 80 years</td>
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<td>22.2</td>
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<td></td>
<td>81 – 85 years</td>
<td>3</td>
<td>16.6</td>
</tr>
<tr>
<td></td>
<td>86 – 90 years</td>
<td>6</td>
<td>33.3</td>
</tr>
<tr>
<td></td>
<td>91 – 95 years</td>
<td>3</td>
<td>16.6</td>
</tr>
<tr>
<td></td>
<td>96 - 100 years</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>Range = 75-96 years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital Status</td>
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<td>8</td>
<td>44.4</td>
</tr>
<tr>
<td></td>
<td>Divorced</td>
<td>2</td>
<td>11.1</td>
</tr>
<tr>
<td></td>
<td>Widow</td>
<td>8</td>
<td>44.4</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>White, Caucasian</td>
<td>12</td>
<td>66.6</td>
</tr>
<tr>
<td></td>
<td>White, Hispanic</td>
<td>6</td>
<td>33.3</td>
</tr>
<tr>
<td>Primary language</td>
<td>English</td>
<td>12</td>
<td>66.6</td>
</tr>
<tr>
<td></td>
<td>Spanish</td>
<td>6</td>
<td>33.3</td>
</tr>
<tr>
<td>Educational level</td>
<td>Primary</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>High School</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>College</td>
<td>10</td>
<td>55.5</td>
</tr>
<tr>
<td></td>
<td>Masters</td>
<td>4</td>
<td>22.2</td>
</tr>
<tr>
<td></td>
<td>Doctorate</td>
<td>2</td>
<td>11.1</td>
</tr>
<tr>
<td>Annual gross income</td>
<td>&lt; $25,000</td>
<td>4</td>
<td>22.2</td>
</tr>
<tr>
<td></td>
<td>$ 25 – 50,000</td>
<td>4</td>
<td>22.2</td>
</tr>
<tr>
<td></td>
<td>$ 51 – 75,000</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>$ 75 – 100,000</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>$ 101-125,000</td>
<td>0</td>
<td>----</td>
</tr>
<tr>
<td></td>
<td>$ 126 – 150,000</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>&gt; 150,000</td>
<td>2</td>
<td>11.1</td>
</tr>
<tr>
<td></td>
<td>Refused to Answer</td>
<td>5</td>
<td>27.7</td>
</tr>
<tr>
<td>Source of income</td>
<td>Social Security only</td>
<td>3</td>
<td>16.6</td>
</tr>
<tr>
<td></td>
<td>Social Security plus retirement</td>
<td>7</td>
<td>38.8</td>
</tr>
<tr>
<td></td>
<td>Social security plus retirement plus other</td>
<td>5</td>
<td>27.7</td>
</tr>
<tr>
<td></td>
<td>Retirement plus other</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>Refused to answer</td>
<td>2</td>
<td>11.1</td>
</tr>
<tr>
<td>Health insurance</td>
<td>Medicare only</td>
<td>2</td>
<td>11.1</td>
</tr>
<tr>
<td></td>
<td>Medicare/Medicaid</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>Medicare plus Supplemental private</td>
<td>14</td>
<td>77.7</td>
</tr>
<tr>
<td></td>
<td>Self-pay</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td>Retired</td>
<td>Retired from full time job</td>
<td>18</td>
<td>100.0</td>
</tr>
<tr>
<td></td>
<td>Working retiree</td>
<td>3</td>
<td>16.6</td>
</tr>
</tbody>
</table>
Thirteen participants (72.2%) did not live alone and lived with their spouse or partner (n=9), family (n=3), or employed a 24 hour Nursing Assistant 7 days a week (n=1) as seen in Table 4.2. Five participants (27.7%) lived alone and four expressed that they have no sources of help but did not need help. The participant who needed help employed a Nursing Assistant during the day.

In Table 4.2, social connectedness is shown as visiting family or friends and by favored leisure activities outside of their homes. Seventeen participants (94.4%) visited their families and/or friends two or more times the previous month. One participant, who did not go out of her home explained that she was a winter resident of Florida, but she is accustomed to visiting her friends in the North.

Of the hobbies listed 11 were out of home activities further indicating the social mobility of the participants. Some of the activities were shopping (n=9, 50%), going to music performances (n = 7, 38.8 %), travel (n=4, 22.2 %), going to the movies or the theatre (n=4, 22.2%), and going out to exercise (n=4, 22.2%). The home bound favored leisure activities cited by the majority of the participants were reading (n=12, 66.6 %) and watching the television (n=12, 66.6%). Other favored homebound activities included gardening (n=6, 33.3%), listening to the news or audio books (n=3, 16.6%) doing crossword puzzle (n=2, 11.1%), and watching the stock market (n=2, 11.1%). Listening to audiobooks were compensatory mechanisms used in lieu of reading.

Majority of the participants had maintained their independence by continuing to drive. Table 4.3 indicates that 11 participants (61.1%) still drive, however seven (38.8%) drive ten miles or less to and from their homes, one drives 11-20 miles when needed, and
Table 4.2. Home Situation, Social Connectedness, and Hobbies

<table>
<thead>
<tr>
<th>Variable</th>
<th>Characteristic</th>
<th>n</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home situation</td>
<td>Lives alone</td>
<td>5</td>
<td>27.7</td>
</tr>
<tr>
<td></td>
<td>Has help</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No help</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Does not live alone</td>
<td>13</td>
<td>72.2</td>
</tr>
<tr>
<td></td>
<td>Lives with spouse/partner</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lives with family</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Nursing Assistant 24/7</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Visited family/friends</td>
<td>3 times or more</td>
<td>15</td>
<td>83.3</td>
</tr>
<tr>
<td>the past month</td>
<td>2 times</td>
<td>2</td>
<td>11.1</td>
</tr>
<tr>
<td></td>
<td>does not go out*</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td>Hobbies</td>
<td>Reading</td>
<td>12</td>
<td>66.6</td>
</tr>
<tr>
<td></td>
<td>Watching television</td>
<td>12</td>
<td>66.6</td>
</tr>
<tr>
<td></td>
<td>Shopping</td>
<td>9</td>
<td>50.0</td>
</tr>
<tr>
<td></td>
<td>Gardening</td>
<td>6</td>
<td>33.3</td>
</tr>
<tr>
<td></td>
<td>Going to music performances</td>
<td>7</td>
<td>38.8</td>
</tr>
<tr>
<td></td>
<td>Travel</td>
<td>4</td>
<td>22.2</td>
</tr>
<tr>
<td></td>
<td>Going to movies/theatre</td>
<td>4</td>
<td>22.2</td>
</tr>
<tr>
<td></td>
<td>Exercise</td>
<td>4</td>
<td>22.2</td>
</tr>
<tr>
<td></td>
<td>Gym</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Swimming</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Walking</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Listening to news/Audiobooks</td>
<td>3</td>
<td>16.6</td>
</tr>
<tr>
<td></td>
<td>Crossword puzzle</td>
<td>2</td>
<td>11.1</td>
</tr>
<tr>
<td></td>
<td>Going to sports events</td>
<td>2</td>
<td>11.1</td>
</tr>
<tr>
<td></td>
<td>Watching stock market</td>
<td>2</td>
<td>11.1</td>
</tr>
<tr>
<td></td>
<td>Dining out with friends</td>
<td>2</td>
<td>11.1</td>
</tr>
<tr>
<td></td>
<td>Going to political events</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>Play sports</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>Dancing</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>Visiting the farm</td>
<td>1</td>
<td>5.5</td>
</tr>
</tbody>
</table>

*Winters in Florida (“snow bird”)

Three participants could drive more than 20 miles as necessary, but not on a regular basis. Five of the participant drivers preferred not to drive at night time and four were afraid that they will not be able to drive the next six months due to poor vision. Of the seven participants who no longer drive (38.8%), two participants still have licenses, but voluntarily gave up driving due to their failing vision, two never drove, six have
Table 4.3. Driving and Incidence of Falls

<table>
<thead>
<tr>
<th>Variable</th>
<th>Characteristic</th>
<th>n</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Driving</td>
<td>Still drives</td>
<td>11</td>
<td>61.1</td>
</tr>
<tr>
<td></td>
<td>less than 5 miles</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5-10 miles</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>11-20 miles</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&gt;20 miles</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Does not drive at night</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Afraid won’t be able to drive in 6 months</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Does not drive</td>
<td></td>
<td>7</td>
<td>38.8</td>
</tr>
<tr>
<td></td>
<td>Still have license</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Never drove</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Has transportation help</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Takes bus or taxi</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Fallen the past the past 12 months</td>
<td>Has fallen</td>
<td>10</td>
<td>55.5</td>
</tr>
<tr>
<td></td>
<td>Fallen 1 time</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Fallen 2 times</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Injured</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Has not fallen</td>
<td>8</td>
<td>44.4</td>
</tr>
<tr>
<td></td>
<td>Fallen the previous years</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tripped a few times</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

transportation help from either family or friends, and three have taken buses or taxis when no one was available to take them where they wanted to go.

More than half of the participants have fallen the past year (n=10, 55.5%) and six sustained injuries. From those who have not fallen the past year (n=8, 44.4%), one participant had fallen “several times” previously and another had “tripped a few times”, but was able to brace herself each time and prevented the fall. Per review of the medical history of the 18 participant’s medical records, comorbidities and number and form of medications taken are listed in Table 4.4. More than half of the participants have hypertension (n=11, 61.1%), half have high cholesterol (n=9, 50%), and a third (n=6,
### Table 4.4 Comorbidities and Medications

<table>
<thead>
<tr>
<th>Variable</th>
<th>Characteristic</th>
<th>n</th>
<th>Percent</th>
</tr>
</thead>
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<tr>
<td>Comorbidities</td>
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<td>11</td>
<td>61.1</td>
</tr>
<tr>
<td></td>
<td>High cholesterol</td>
<td>9</td>
<td>50.0</td>
</tr>
<tr>
<td></td>
<td>Cardiovascular</td>
<td>6</td>
<td>33.3</td>
</tr>
<tr>
<td></td>
<td>Asthma</td>
<td>3</td>
<td>16.6</td>
</tr>
<tr>
<td></td>
<td>Prostate problem (Males = 6)</td>
<td>3</td>
<td>50.0</td>
</tr>
<tr>
<td></td>
<td>Thyroid</td>
<td>3</td>
<td>16.6</td>
</tr>
<tr>
<td></td>
<td>Cancer survivor</td>
<td>3</td>
<td>16.6</td>
</tr>
<tr>
<td></td>
<td>Spinal stenosis</td>
<td>2</td>
<td>11.1</td>
</tr>
<tr>
<td></td>
<td>Diabetes</td>
<td>2</td>
<td>11.1</td>
</tr>
<tr>
<td></td>
<td>Depression/anxiety</td>
<td>2</td>
<td>11.1</td>
</tr>
<tr>
<td></td>
<td>Vertigo</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>Osteoporosis</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>Arthritis</td>
<td>2</td>
<td>16.6</td>
</tr>
<tr>
<td>Number of medications taken daily</td>
<td>1-5 kinds</td>
<td>5</td>
<td>22.2</td>
</tr>
<tr>
<td></td>
<td>6-10 kinds</td>
<td>11</td>
<td>66.6</td>
</tr>
<tr>
<td></td>
<td>11-15 kinds</td>
<td>2</td>
<td>11.1</td>
</tr>
<tr>
<td></td>
<td><strong>Range=1-12 kinds</strong></td>
<td></td>
<td><strong>Mean = 6.6 kinds</strong></td>
</tr>
<tr>
<td>Form of medication</td>
<td>Tablets</td>
<td>106</td>
<td>88.3</td>
</tr>
<tr>
<td></td>
<td>Eye drops</td>
<td>12</td>
<td>10.0</td>
</tr>
<tr>
<td></td>
<td>Inhaler</td>
<td>2</td>
<td>.01</td>
</tr>
</tbody>
</table>

33.3%) have cardiovascular disease. These comorbidities are risks for AMD. Two participants (11.1 %) suffered from depression and three were (16.6%) cancer survivors. Eleven participants (61.1%) take 6 to 10 different medications daily, five participants (27.7%) take 1 to 5 different medications, and two participants (11.1%) take 11-15 different medications daily. Eighty-eight per cent of the medications taken were in the form of tablets (n=106) 10% were eye drop medications (n=12) and 0.01% were inhalers (n=2). The medications included medicines for their comorbidities, vitamins, and dietary supplements.
The ophthalmic profile in Table 4.5 indicates that the range of VA in the better seeing-eye is 20/50 to 20/200 with seven of the participants (38.8%) seeing at 20/50, the best VA in the range. One participant was legally blind (20/200). The other eye however, has a wider range of 20/50 to hand motion and eleven participants (61.1%) have 20/200 to hand motion.

Fifteen participants (83.3%) have both forms of AMD. The better seeing-eye has dry AMD and the other eye has the wet form that currently or in the past has been treated with intra-ocular injections. The better seeing-eye may also have converted from wet to dry due to the effects of the repeated injections. Only three participants (16.6%) have mainly dry AMD in both eyes.

Seven participants (38.8%) have had AMD longer than 10 years, six (33.3%) have had the disease for 1 to 5 years, and five participants have had AMD for 6 to 10 years (27.7%). Cataract was the number one eye comorbidity (n=15, 83.3%). Eleven participants (61.1%) had their cataracts removed and replaced with an implanted intraocular lens, four participants have cataracts but did not require surgery yet (22.2%) and one participant refused to have surgery because she “does not need it” and can still read. Four participants have glaucoma (22.2%) and one participant has diabetic retinopathy. Although these eye comorbidities are contributory to vision impairment, the symptoms of central vision loss are distinct to AMD. No measurements for contrast sensitivity or entries for referral for low vision assessment or to the Lighthouse for the Blind were found.
Table 4.5. Ophthalmic Profile

<table>
<thead>
<tr>
<th>Variable</th>
<th>Characteristic</th>
<th>n</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visual acuity better-seeing eye</td>
<td>20/50</td>
<td>7</td>
<td>38.8</td>
</tr>
<tr>
<td></td>
<td>20/60</td>
<td>5</td>
<td>27.7</td>
</tr>
<tr>
<td></td>
<td>20/70</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>20/80</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>20/90</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>20/100</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>20/125</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>20/200</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td>Visual acuity other eye</td>
<td>20/50</td>
<td>2</td>
<td>11.1</td>
</tr>
<tr>
<td></td>
<td>20/60</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>20/80</td>
<td>3</td>
<td>16.6</td>
</tr>
<tr>
<td></td>
<td>20/100</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>20/200</td>
<td>4</td>
<td>22.2</td>
</tr>
<tr>
<td></td>
<td>20/250</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>20/400</td>
<td>2</td>
<td>11.1</td>
</tr>
<tr>
<td></td>
<td>20/500</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>8/200E</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>2/200E</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>Hand Motion</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td>AMD diagnosis</td>
<td>Dry one eye, wet other eye</td>
<td>15</td>
<td>83.3</td>
</tr>
<tr>
<td></td>
<td>Dry both eyes</td>
<td>3</td>
<td>16.6</td>
</tr>
<tr>
<td>Duration of AMD</td>
<td>1-5 years</td>
<td>6</td>
<td>33.3</td>
</tr>
<tr>
<td></td>
<td>6-10 years</td>
<td>5</td>
<td>27.7</td>
</tr>
<tr>
<td></td>
<td>&gt; 10 years</td>
<td>7</td>
<td>38.8</td>
</tr>
<tr>
<td>Other eye condition</td>
<td>Cataract, had lens implant</td>
<td>11</td>
<td>61.1</td>
</tr>
<tr>
<td></td>
<td>Cataract no surgery required</td>
<td>4</td>
<td>22.2</td>
</tr>
<tr>
<td></td>
<td>Refused cataract surgery (&quot;doesn’t need&quot;)</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>Glaucoma</td>
<td>4</td>
<td>22.2</td>
</tr>
<tr>
<td></td>
<td>Diabetic Retinopathy</td>
<td>1</td>
<td>5.5</td>
</tr>
</tbody>
</table>

Data on LVOD acquisition and frequency of use are outlined in Table 4.6. All participants owned several handheld magnifiers (100%) and only one (5.5%) supplemented the handheld with a stand magnifier. One participant purchased a portable video magnifier from the internet but the device was not included as he has not used it for 6 months. The magnifiers were purchased from the local stores listed (n=9, 50%), from
an optical shop or the Lighthouse (n=2, 11.1%), from the internet (n=1, 5.5%), from a catalogue (n=1, 5.5%), and from a beauty salon (n=1, 5.5%). Others had received them as gifts (n=6, 33.3%), or were previously owned by deceased family members (n=3, 16.6%), or were free samples from commercial companies (n=3, 16.6%). None of the magnifiers were prescribed devices including those purchased from an optical shop or the Lighthouse for the Blind.

**Table 4.6. LVOD Type, Acquisition, and Frequency of Use**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Characteristic</th>
<th>n</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>LVOD Type</td>
<td>Handheld</td>
<td>18</td>
<td>100</td>
</tr>
<tr>
<td></td>
<td>Stand</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>Portable video</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>How acquired</td>
<td>Purchased from store</td>
<td>9</td>
<td>50.0</td>
</tr>
<tr>
<td></td>
<td>Radio Shack</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Walgreens</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>CVS</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Home Depot</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Kmart</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ten cent (Dollar) store</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Art store</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Office supply</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Purchased from optical shop/</td>
<td>2</td>
<td>11.1</td>
</tr>
<tr>
<td></td>
<td>Lighthouse</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Purchased from internet</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>Purchased from catalogue</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>Purchased from beauty salon</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>Sample from commercial company</td>
<td>3</td>
<td>16.6</td>
</tr>
<tr>
<td></td>
<td>Handed down from family</td>
<td>3</td>
<td>16.6</td>
</tr>
<tr>
<td></td>
<td>Given by relatives/friends</td>
<td>6</td>
<td>33.3</td>
</tr>
<tr>
<td>How long acquired</td>
<td>&gt;6 months &lt;1 year</td>
<td>1</td>
<td>5.5</td>
</tr>
<tr>
<td></td>
<td>1-5 years</td>
<td>10</td>
<td>55.5</td>
</tr>
<tr>
<td></td>
<td>6-10 years</td>
<td>4</td>
<td>22.2</td>
</tr>
<tr>
<td></td>
<td>&gt;10 years</td>
<td>3</td>
<td>16.6</td>
</tr>
<tr>
<td></td>
<td>Range = 8 months to 30 years</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Median = 7.7 years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency of use</td>
<td>Users = &gt; once per day</td>
<td>9</td>
<td>50.0</td>
</tr>
<tr>
<td></td>
<td>Semi-users = once per day or less &amp;</td>
<td>5</td>
<td>27.7</td>
</tr>
<tr>
<td></td>
<td>sporadically the past 3 months</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Abandoners = not used for ≥ 3</td>
<td>4</td>
<td>22.2</td>
</tr>
<tr>
<td></td>
<td>months</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
More than 50% \((n=10, 55\%)\) of the participants acquired their magnifiers for 1 to 5 years, four participants \((16.6\%)\) owned them for 6 to 10 years and three participants \((1.6\%)\) for more than 10 years. Only one participant purchased his magnifier for less than a year \((5.5\%)\). The range for how long the participants had acquired their LVODs was from 8 months to 30 years with a Mean of 7.7 years. The frequency of use determined the types of users. As defined by this study, Users were participants who used their LVODs more than once a day \((n=9, 50\%)\), Semi-users used their LVODs once or less a day and sporadically the past three months \((n=5, 27.7\%)\), and Abandoners had not used their LVODs for three months or longer. None of the participants’ LVODs were prescribed.

**Theory of Doing the Best You Can**

The substantive theory that emerged from analyzing the data was that of *Doing the Best You Can* (see Figure 4.1). As the PI collected demographic data, interviewed the participants on their experience of using magnifiers and with vision impairment, and reviewed their ophthalmic and medical histories, the theory began to develop from the comparative and theoretical sampling process. The theory of *Doing the Best You Can* is a process that describes what people do when their vision starts to change, and as time evolves they discover that they are losing sight from a progressive age-related eye disease that has devastating consequences in their daily life. Imbedded throughout this process is using an optical device that can enhance their enjoyment and use of their residual vision.

Older individuals who are losing sight from AMD go through *Doing the Best You Can* where they “do their best” in discerning what is most helpful for their own specific situations. The theory is a dynamic life event process that is supported by four categories.
Discovering magnifiers is the category where individuals start acquiring LVODs for their changing vision, Losing sight is when they first experience the signs of the disease, Living with AMD that includes the experiences of treatment and the devastating effects of AMD on their daily life patterns, and Using magnifiers is where different factors affect decisions on using, semi-using, or abandoning the optical device. The common thread that weaves through the process is discovering magnifiers where individuals keep looking for devices that will optimize their residual vision.

The theory emerged from the substantive areas explored that include vision loss, diagnosis of AMD, LVOD use, participation in DLA, and LVOD abandonment (Figure 1.6, p. 20). Figure 4.1 illustrates the taxonomy of the Doing the Best You Can. The theory was derived from the narratives of the participants to the probe questions on losing sight, using magnifiers, significant life changes brought about by AMD, and giving advice to those who have been recently diagnosed with AMD and those who are using magnifiers for the first time

The title was lifted from the narrative of a 96 year-old participant who, in spite of having severe visual impairment from AMD, spoke of an extremely optimistic outlook:

“My attitude is fantastic. I’ll try to make the best of it as long as I can. I’m very, very happy… I refuse to let it change my life, and I’m going to do the best I can until God takes me.”
The Process

In discussing the process of the theory of *Doing the Best You Can* direct excerpts from interview transcripts are represented by indented single-spaced paragraphs that are in smaller font where square brackets ([   ]) are information added by the PI and ellipses (…) denote parts deleted for conciseness. To identify the narratives of each type
of user, the font color coding used in memo writing was retained: black font for Users, brown for Semi-users, and purple for Abandoners.

**Category 1: Discovering magnifiers.** Discovering magnifiers is the first category of the process and has a direct relationship with the other categories. As individuals age, their vision change and they start acquiring simple to more complex magnifiers and learning how to read with the device as reading instruments. This category weaves through and is imbedded in the other three categories because as time evolves progressing vision loss compel individuals to look for and try different types of assistive devices that enhance vision from an array of optical devices introduced by the advances in technology.

Discovering magnifiers (see Figure 4.2) entails two sub-categories that are the initial experiences of participants to acquire, select, test, and use LVODs. In *Acquiring magnifiers* the participants obtained their magnifiers from the different sources outlined in Table 4.6 and if purchased, cost can be a determining factor. Reading with magnifiers is the period where individuals start to adapt to optical devices by getting used to them and discover the value of lighting and experimenting. As new technology was introduced in the market the participants learned how to adapt to instruments that are specific or non-specific for low vision use. Discovering magnifiers was captured from the responses of the participants to the probe questions “Please tell me about your experience with using your magnifier?” “What was it like to use the first time?” the succeeding times?”

*Acquiring magnifiers.* Discovering magnifiers begins when individuals want to address their difficulty of reading small print in spite of their eyeglasses. Table 4.6 indicates how the participants easily acquired their magnifiers.
Sources. They were purchased from local stores that they ordinarily shop, received as samples, given by family members, or inherited from deceased relatives. The ease of acquiring magnifiers is evident in the narratives of the different participant user-type who have acquired the devices from various sources.
My grandma have some, my father have some. We’re used to it, so it’s nothing that special (...) [(I also bought it)] from art stores (...) I am pretty sure one or two [(are)] still from Europe, from my father’s, from may be 80 years ago.

I did not buy it, may be that was my husband’s. I just don’t know. My husband used that (...) It’s funny it’s probably one of those samples, because in the handle it says Roxanne, for some kind of hair problem.

[It was] given by the bank (...) [I also got it when] I was in the hair salon, they were selling a pocket magnifier which was the size of a credit card..

[I] probably bought it from a ten cent store, those little round things.

I got another one too, as a present (...)This one you can only get through the computer but they are much better than the ones you can get from any one of the stores around… I got it through the internet (...) have bought some more at OfficeMax and ah, Office Depot.

In purchasing LVODs from the internet, one User participant pointed out that the internet is not an ideal avenue for acquiring LVODs:

They [(internet)] have magnifiers you know (...) but you cannot touch them, you cannot prove, this is good for me, or this is not, this is the size that I want, and this is the price, things like that.

Cost. Simple magnifiers cost a few dollars but as low vision features of magnification are added, the devices become more expensive. Currently, the market has a wide array of LVODs that use new technology. Cost is a determining factor in the decision to buy the kind of magnifier suitable for the individual’s needs, considering that Medicare and third party insurers do not cover the cost of LVODs. From the different narratives, some participants were content with their inexpensive magnifiers, others had tried different kinds, and some wished they could afford the more expensive ones.

He showed many to the people, many magnifiers. The biggest one cost about three thousand dollars, the smallest one he said “this is eighty five dollars”. ...

I said okay I’ll take it. It cost me ten dollars (...)
If you have the money, have a good magnifier at home so that you can see whatever you need.

I bought it for ten dollars. They got it all way up till three hundred.

My cousin who had both eyes with the worst kind of macular degeneration (…) He had all kinds of inventions, wants to watch television, a big one to see something … One to four thousand, so many dollars at a time. He was a doctor himself. So he had means but I don’t have those means so I cannot even think of getting anything like that. I just have to read what I can when I can. That’s all. The best will have to be ordered when I can, but I can’t.

**Reading with magnifiers.** Once the LVOD is acquired, the device becomes a reading instrument. How to read with a magnifier is reflected in this sub-category.

Participants also found ways of enhancing their reading experience with using magnifiers that include lighting and experimenting with the device/s. Participants articulated how easy it was to use the magnifiers including changing batteries for the LVODs with light features. The apparent intuitive method of using the device is evident in their narratives.

I can read with that very well back and forth. It has the power to increase according to different levels.

All I have to do is focus it (…) Just pick it up and get used to it.

Nothing was difficult with using it.

[It] has two triple A batteries which is much easier to get and easy to put in, until it wears out, you just buy a pile of them.

One participant who is near-sighted finds her spectacles bothersome when she reads using her magnifier.

I have this progressive glasses which I really don’t care for. When I read I have to take my glasses off, because I am nearsighted.

**Lighting.** Participants found that lighting was important in improving their reading when using magnifiers. Participants have purchased special lighting and lamps in their homes to make their using the magnifiers when reading more effectively.
I do have reading lights all over the place. Yes…: I have to have [light] on the object which I am going to read. And then I can read. Not just regular light in the, in the environment (…) I have a lamp by the bed (…) In the computer room, I have two very powerful lights there. I have lights no question about it. I have collected all kinds of lights. And I keep looking for different lights, but that is to illuminate the item I am reading or looking at whatever it is.

When I have to read, when I have to look at [things] I have to get closer or use more light.

I used to have the Magna-lite™. And I always used it.

Experimenting. Experimenting with different ways on how to use a magnifier for reading better was found by some participants to work for them. Some closed their worse eye so they could concentrate on using their better seeing-eye, hold the device at a different angle, attach the device on a table, or experiment with different powers that they find suitable for reading small print easier. Others have new glasses prescribed by their ophthalmologists to use with their magnifiers.

I close the left eye when I read. I read with my right eye (…) You have to experiment which position and good light (…) That’s important. I think everybody has to experiment. Sometimes I have to hold it different (…) I just play around with it when I need and I get the best result.

[I] have one that is screwed on the table that you can move around.

You have to have it close and sometimes like I am reading [a] material [with] something like the fine print I get a magnifier 3X or 4X whatever, and I put it there.

I can read with that very well back and forth. It has the power to increase according to different levels (…) [I] need extra power magnified, multiplied.

[My] doctor prescribed new glasses.

Using new technology. Some of the participants have discovered using new technology in reading, such as using the magnification feature of computer software, accessing the internet, and using notebooks like Kindle™ and IPad™. Their joy at being
able to read entire books was evident in their narratives. The oldest participant (96 years old) expressed her regret at not being able to access new technology.

(...) I got an IPad for Christmas from my daughter and grandchildren. And the letters are half an inch big and then I can read that (...) I listen to books only before, but with the IPad I can read it and I like reading books, because it is different than listening to books.

What I have found very, very helpful is the Kindle book (...) I have the big one not the small one. And it enlarges the type. And interestingly I am reading more than six years ago.

(...) My computer, I have set [it] up. I have larger letters. I can read it so I don’t need the light (...) I just looked up something about magnifying glasses on the computer.

If I want a word defined I go to the internet

They have a lot of things in the computer, but I don’t know how to work the computer… anybody who know [s] how to work the computer can have a much easier time.

**Category 2: Losing sight.** This category is a description of the participants’ experiences of how they became aware that they have AMD, their reactions to the diagnosis, search for information about the disease, and decisions on the plan of care.

Their initial emotional reactions to a devastating disease are captured in this category. Losing sight has two sub-categories that emerged from the probe questions “Please tell me how and when you noticed that you were losing sight? How did you feel when you were told you have AMD?

*Discovering signs and reacting to diagnosis.* In this sub-category, participants find that there is something wrong with their vision and learn that their condition is urgent. After a comprehensive examination, AMD is confirmed by the ophthalmologist and patients are informed of the diagnosis. They are confronted with the reality of the threat of losing sight and express their initial reactions. In Seeking information, participants become more aware of AMD and they start to ask questions and search for
information to learn about more about the disease including connections of the disease in their family, and find the best health care. The individual learns of the difficult treatment regimen for wet AMD and the non-availability of current established treatment for dry AMD.

**Figure 4.3.** Category 2: Losing Sight
Signs. There were different presentations of the signs and symptoms of AMD among the participants. Some participants were compelled to see an ophthalmologist due to a disturbing visual anomaly that required immediate ophthalmic evaluation. Other participants noticed that they could not read well, while some did not experience any indication that they had the disease.

[I] covered my left eye and see a big patch like blood in front of my face. [I] covered my left eye, I see everything well.

I was in a bus trip (…) when it suddenly felt like an explosion in my left eye and I saw big black spots, irregular (…) I don’t know how to explain it. To me the closest was like an explosion. So when I came [back] to the hotel I called my doctor.

I was playing golf with my very close friend and (…) she said why don’t you hit the ball up to the flag? I said you know I can’t see the flag or the green (…) it hit me like a bomb.

I have bottle of vitamins, I used to be able to see the name and everyday it got weaker and weaker and weaker.

It was such a gradual process that I can’t even tell you when.

I was not aware that I was losing any sight at all. I [just] came back to Bascom Palmer (…) to get my last check up, after I had my cataract removed.

The urgency of the condition and need for a referral to an ophthalmologist who specializes in AMD was apparent in the responses of the participants.

[The doctor said] the first thing I will do, if I were you, is to take a plane right now to Miami.

So when I came to the hotel I called my doctor (…) I was going to come back home two to three days later, [but] the doctor instead said “come immediately”.

And he [physician] looked at me and then he said, oh no, no, this is not cataract. I have to send you to my friend Dr___ right away. This is scary. Oh no, this is not cataract. This is much worse (…) This is scary.

(…) Immediately, I started moving to get my money and come to [the] USA.
I spoke to my husband and my son [who is a physician]... My son [said] no, no, no, no, no (…) Go back to [the] United States and ah, go to the Bascom Palmer.

Reactions. The participants’ initial reactions to the diagnosis of AMD were varied. Some who did not know anything about the disease were not as devastated as the others who did. They started to recognize that some members of their family have it.

I didn’t know anything about it. I said it is just like cataract, everybody my age has cataract.

I was very taken aback. Because I understood that it was hereditary. To the best of my knowledge no one in my family had it.

From my talks with my brother I learned a few things. So I was, how shall I say, I was not shocked.

I felt dejected, terrible.

Well I wasn’t at all happy but I was happy that I was not gonna go completely blind.

Some of the participants had never heard of the disease, a few had some past knowledge, and others knew about it from those who had the disease from family members prior to their diagnosis. One participant talked about her lack of knowledge by talking about others who may not know about the disease.

No. I didn’t know. The first thing I ever heard of it. I never knew anybody that has it.

Didn’t know exactly what it was all about.

My mother had it.

I was suspicious because my brother has it. And I was so suspicious that one day I will be diagnosed with that too.

It’s genetic, unfortunately in the part of the family from my father’s side (…) We have another cousin affected with it, and another sister, for we are still a few around.

No. I didn’t know. The first thing I ever heard of it. I never knew anybody that has it. Didn’t know exactly what it was all about.
I didn’t know very much. But it knew it was disaster (…) Many people may have the disease they don’t know what it is, or where to go, what to do.

**Seeking information.** The information-seeking behavior of the participants was diverse. Some readily asked their physicians about the disease and their prognosis and thereafter started to embark on finding everything about the disease from various sources including their family. Others stated that they were not given enough information by their physicians.

**Initial questions and information from the ophthalmologist.** The initial questions asked by the participants to their ophthalmologists were the following:

- Will it go away?
- What is the prognosis, how bad was it, ah, and what do we do about it.
- Will I get better?
- What is it? Explain it to me. I don’t know what it is.
- I don’t know how you get it. Is it because you are very weak, or you are very old, or you do too much reading, or [there is] pus in your eyes?
- What was it? and if I could correct it in anyway.
- Am I going blind?
- I think I just asked if it was wet or dry, because I read about it.

Some of the participants expressed their satisfaction at being given the realistic outcomes of the disease on losing vision and were given adequate information while others have strong opinions that they were never told of having AMD, or that they did not receive enough information or adequate care. The kind of understanding they have of the disease is reflected in their narratives.
The doctor said “No you are not going to get blind. Your central vision is going to be impaired”.

The doctors gave me books to read… I don’t even know whether it’s the wet or the dry but I have to look it up.

I went to a doctor who told me that I have ah, macular degeneration beginning very mild, nothing could be done at that time he said, and I waited. He gave me glasses and all (…) it turned out (…) that I had begun to lose rapidly, you know, the clear sight. So I went to [another] doctor.

(…) [The doctor] told me that there was no cure for macular degeneration. I have the dry. [They] have injections for the wet which is worse but nothing for the dry.

I was treated by two different ophthalmologists for glaucoma. So what happened I said let me go to Bascom Palmer (…) And then when I went there, I saw a lady ophthalmologist [who said], why are you going to see me for glaucoma when what you really have is macular degeneration? And I say didn’t even know. What was macular degeneration?

Nobody told me [about macular degeneration]. Only they told me that your eyes [are] not so good (…) The doctor explained to me that it [injections] is good for the liquid I have in my eyes.

He [Doctor] never did tell me anything about it, until I started seeing wavy lines…And he took his pictures …sent me home and gave me an appointment for I think ,it was two weeks later. And so I went back after two weeks, he took more pictures, and he said, Oh more fluid is built up in your eyes. I didn’t know what they were talking about. In fact till this day (…) he never told me I had macular degeneration. I don’t go to him anymore.

**Searching for answers and getting the best care.** After learning of their diagnosis some of the participants started their information search from the internet and publications about AMD. Others obtained information from their relatives and friends and started to inform others.

I was in the internet finding out everything (…) learn all you can about it, so you can avoid getting it.

When I found that what I had and I wanted to learn all about it. I read everything there is to read. I went to Google, I read the Cleveland Clinic, I went to Mayo Clinic (…) Every report there is about macular degeneration, I read.

I have a daughter who is an ophthalmologist. We talked a lot.
By knowing from some friends I sort of figured that it was macular degeneration. My sister in law who (...) passed away she had it very badly.

I read, [and got information from)] the television, and the internet. And my cousin was a source, ‘cause he was a doctor so he knew everything.

My husband explained [macular degeneration] to me because I can’t read English (...) he explained to me many things you know. He is reading a lot (...) Sometimes, I talk to people and I tell [them]. Many people don’t know what it is. I had a neighbor who had macular degeneration.

I started to [read] some more literature and learned more about it. Oh from all kind[s] of (...) publications of help (...) all kind[s] of magazines (...)

Participants readily conveyed recommending their current ophthalmologists and where they practice. Some participants who went through a circuitous route to get to their current retina specialists for treatment felt that they should have come on their own sooner, and not waited for a referral. The vetting process of getting the best health care was succinctly explained by one participant. Another pointed out the importance of being given adequate information so individuals can make decisions about their care.

Have a qualified board certified ophthalmologist and get an examination and follow what he tells you. And if it is something that you have to think about, go for a second opinion.

Get a good doctor who can tell you if you are beginning to get it, so you can stop it. Had he told me I could have stopped it way back before it caused any damage.

Go to Bascom Palmer.

**Category 3: Living with AMD.** Living with AMD (see Figure 4.4) is a depiction of the experiences of the participants with AMD over time. This sub-category illustrates the vision changes that characterize the disease as described by the participants.

Receiving treatment for wet AMD depicted periodic temporary stabilizations and modest temporary gains in vision made possible by the serially scheduled anti-VEGF injections
that change the nature of the disease. For those with dry AMD, periods of clinical trials may offer the promise of regaining vision. The treatment regimen and clinical trials require strict monitoring by the ophthalmologist. The devastating consequences of AMD on the individuals’ QOL as depicted in implications to participation in DLA are illustrated.

**Figure 4.4.** Category 3 Living with AMD

*Progressing disease and loss of sight.* This sub-category of *Living with AMD* identifies the changes in vision as described by the participants and how it has affected
them. Their experiences with the progressing disease involved receiving a difficult
treatment regimen and/or participation in clinical trials.

*Changing vision.* The presentations of the changes in vision vary as articulated by
the participants on how they “see”, how much vision they have lost, and the current status
of their eye disease. Some participants have difficulty in distinguishing colors and in dark
adaptation.

I don’t see my fingernails. I don’t know the color they put on. I said what color did you
put on my nails? (laughs).

I didn’t lose my sight completely, because with this disease you don’t lose your complete
sight. In other words, you lose just the center of your vision not the sides.

Now it’s a blur (…) There’s nothing they can do for me. There is nothing they can do for
that disease.

It's very fuzzy. In wet you don’t see the line’s straight, very wavy, it moves like it’s all
like curled up, not straight. The dry you see straight.

I would have to say the area between seven and ten (o’clock) and halfway may be down
to the middle like a triangle, that’s the maximum loss that I got. The rest is okay… [but] I
cannot read with my right eye [and] I’m a prodigious reader (…) The biggest change in
my life is I can’t see very well out of my right eye. I can’t see say eighty seventy five
percent.

One participant had severe difficulties with color discrimination and dark adaptation:

I have problems with colors and I have to trust someone who has to tell me what color it
is. I see primary colors but what is in between is very difficult. So to make sure I have to
have someone I trust (…) When there is not enough light, but even then between navy
blue and black is difficult to know which is which. And green is the same. (…) at night if
the lights go off I am totally lost. I don’t see anything, there is nothing.

*Receiving treatment.* Considering the urgency of the threat to vision loss, after the
diagnosis is confirmed the participants were placed on a regimen of intra-ocular
injections for wet AMD. Table 4.4 (p. 66) indicates that 15 participants (83.3%) have the
wet and dry forms of AMD. These participants received a series of intravitreal *Anti-*
VEGF injections are the currently established treatment. The participants’ experiences of receiving intraocular injections and participation in clinical trials are captured in this item.

The participants described a difficult regimen of Anti-VEGF injection treatments that they received involving repeated injections over time. No matter how difficult or uncomfortable the procedure might have been, the participants opted to receive the injections. Some participants have learned to adopt ways that help them adjust to the procedure while others have become resigned to the difficult treatment. The participants’ experiences and knowledge of the treatment regimen are reflected in their narratives.

The first time they [took] pictures and everything, then they gave me the needle [(injection)] because you have the, the “llueve” [Spanish - rain - wet] like a water…

I feel that if it’s necessary I want to do it (...) Oh I just try to be calm. That’s all.

You have to have discipline. Don’t move, do what they say and I have mastered it because I need it. I don’t have any problem. It’s something difficult to adjust to even then today. I wouldn’t say it’s painful like any other injection is. They put anesthesia (...) to numb the eye. I don’t know how painful it is or it isn’t (...) when they put it on [my eye] I don’t have sensitivity there. The only thing is that I can’t move. Not one iota. So you have to make a point in your brain not to move and you keep looking straight not to move, not to move until when he [doctor] takes the needle out. It is an effort and you have to have discipline. You cannot let nerves dominate you because it is gonna be a mess. It’s not fair to yourself and it’s not fair to the doctor and the nurse. So it’s an effort between three people to do it right and it will come out alright. You want it and you are in it to make sure it’s fine.

The injection was supposed to make it from getting any further. That there is moisture in your eye and that is what caused the problems.

It is very painful, very painful (...) And I hope that they find another kind of remedy to that disease (...) with the new technology right?

Some of the participants recounted the number of injections they received through the years, the conversion of the dry AMD to wet or vice versa and back again to the dry or wet form, and results.
The first time the needle and three months later, the needle, three months later, the needle, and may be for more than three years they put a needle (... every 3 months. I think I see, I did [see] a little better.

I came every 2 months every, 3 months (...) then I came once a year (...) Then I came in July, September, the first week of December, and came here again [March]. The macula was wet and before it was dry, but this time they didn’t have to put an injection in my eye because the macula was getting dry again. And then I have to come [back] on August.

They gave me ten injections in the left eye, and it didn’t get better. It got worse (...) The left eye already I wrote off. It’s no good. The right eye was good, but now the right eye is going bad, and very fast. Everyday it’s getting worse. I had wet in the left eye and I had dry in the right eye (...) There’s nothing they can do for me. Mine is not stable. Mine is advancing rapidly.

Most of the participants have participated in one or more Clinical trials for both wet and dry AMD. Twelve participants (66.6%) have had AMD for more than 5 years and most have had experienced being part of one or more clinical trials. The participants articulated their experience with new promising drugs and its outcomes.

(...) some people have a very slow speed (... ) they got an injection and they’re probably good enough for maybe two or three months but the other people [are]not. It all depends. I think each one is an individual case (...) it’s no good. It’s no good at all.

Then around six years ago, or seven, I don’t remember too well, he [doctor] [had] a try out for three different vitamins for the eye and asked me if I want to be in the program which was going once a year and they will take a photos of my eye and then I would take the taking pills for five years. And he [doctor] was telling me that I was fine but I tell you what, I knew I was not getting any better from the vitamins because I watch a lot of tv and I watch a lot of sports and when I could not recognize very well,(..) I end[ed] up buying a plasma 55 inches.

And then they ah, anesthetized my eye and dilated my pupils and did what they had to do to inject (...) they didn’t have Lucentis™ before, they used (...) another drug before Lucentis™, the one they use for women’s breast for cancer.

Changing participation in DLA. This sub-category is a description of the consequences of vision loss in the participants DLA. As AMD advances, its concomitant effects on the participants’ managing their daily life are evident in Changing Participation
in DLA. Reading and face recognition difficulties were disabilities that affected their ways of performing DLA and maintaining social connectedness. Participants adopted ways of being independent but at the same time, they had to depend on others. They are curtailed by mobility limitations, yet they kept their social lives active. Safety issues due to central vision loss were identified that included incidence of falls, driving pitfalls, and the risk of taking wrong medication. The participants’ experiences of worsening central vision due to changes in the disease patterns made them fear blindness, but they kept their hope alive by their optimism on the advances of clinical research. Acceptance of AMD was apparent however, denial of visual impairment was voiced strongly in the narratives.

Reading and recognizing faces have been regarded as most debilitating. In reading, the inability to read small print progressed to a disability that affected difficulties in performing daily tasks due to their limited central visual field that blurs or obliterate letters and numbers. The central vision loss also resulted to facial recognition disability that affected the participants’ enjoyment of being with people. The excerpts from their narratives conveyed the difficulties encountered with these disabilities.

Reading. For participants who enjoy reading or depend on reading in continuing to perform their occupation and hobbies, this period was a severe blow to their daily life and income. One participant who did not wish to retire was confronted with the dilemma, but had no other choice. One participant expressed her inability to read jewelry carats in her shopping jaunts and realized that she had a reading disability. How letters and numbers appear and become misread is articulated by some of the participants.

The biggest change was (...) also, conducting a religious service (...) I go to the country and preach. I can’t read. I learned a long time ago to preach. Maybe I’ll take a piece of
paper and have four or five words on that paper but I learned a long time ago not to read a sermon (...) But conducting, to pick up prayer book and conduct a service, I realized that I could no longer that just pick up a book willy nilly. Now, [if] it was Sunday service I memorized a lot of stuff but other than just a Sunday Service.

I feel trapped. Because of what I have done in my life is read. I love to read from the age of three (...) It takes so long for me to read [now]... It’s very difficult. I cannot even write during the day or at night. I can only now read say, without a magnifier I can read headlines because they are big, and the next explanation, they have in a little ah, larger size than the little print. But the [small] print is difficult to read there is no question about that.

I can’t read (...) something below, [or] one row complete[ly], or something like that (...) sometimes I can’t find the place that I already read.

What became difficult for me for example, is to read a very, very small (...) you know, letters [and] marks (...) For example on jewelry [number of carats] (...) But in the last I would say may be a year, or so I notice that I developed the disability to read.

I can’t really read with the distortion.

Sometimes when there’s an I and an L next to each other it’s very difficult.

[(It)] depends on the letters, 8 may be confused with 3 or 0.

Recognizing faces. The implications of vision changes during face-to-face encounters are depicted by some of the narratives by participants whose central vision were severely affected. One participant missed seeing his wife’s face and others expressed that people may think that they were not sociable. The impact of the inability to recognize faces for his profession by a pastor is narrated. This item has social implications.

A lot of changes. I think ah, not being able to see people I am talking with. I can’t even see my wife’s face (...) To look at my wife, I can’t even see the details of her face. I see her ears but not her face.

Most people think I don’t want to talk to them, what happens is, I don’t see, or I almost don’t see.

From a distance, especially in the golf course, I have no idea who they are (...) I feel like, like it's snubbing people.
The major thing besides the reading of the Prayer book is socially. And I [mean when] somebody [I know] across the room I don’t recognize. I may recognize them by their body language or their body size but I do not recognize their face. And so socially on my kind of situation, I have to get up close to somebody unless I know their voice or you know, their body language.

The same participant who missed seeing the details of his wife’s face recalled his experience with his mother who had AMD:

My mother she walked down the side walk, she wouldn’t know me until I spoke and she will say “this is my son and she give[s] me a hug. But she couldn’t see me either walking straight ahead. She can only see from the side of her eye. She couldn’t see me. She couldn’t see me walking straight at me.

*Maintaining independence while depending on others.* In this item participants assert their ability to do things for themselves in spite of the limitations imposed by their visual impairment. However, these same limitations have also made them dependent on others.

The participants demonstrated their *independence* by adopting alternative ways in getting around and continue their usual daily routines. Some participants who currently have minor limitations in their mobility have already made plans on how to go about their daily life, if they are no longer able to perform activities such as driving. One participant articulates that nothing has changed in her role in the household. Another refused to have the disease change her daily life and said that she will continue the do the best she can.

I don’t think I will be that stuck (...) I can walk and next to (...) shops and stuff like that, and there is a very good bus service all over the place (...) play in a croquet tournament (...) You know where I live there’s a lot of (...) first of all, friends and family around

[I] I would hire a driver

I take the bus.
I hardly take the subway. But I have the buses and everything

In my gardening, I have to fix the fence, [or] get the tree up.

[I] work in the house, take care of the house, and wash, and iron, and [do] cleaning, and you know, that’s my life.

My attitude is fantastic. I’ll try to make the best of it as long as I can. I’m very, very happy (...) I refuse to let it change my life. And I’m going to do the best I can until God takes me.

While trying to be independent, the participants have started to depend on others due to their limitations on participation in DLA that is imposed by the vision impairment from the advancing AMD. The responses of the participants denote a role reversal between spouses and the increasing role of children in their care. One participant employed a nursing assistant full time.

I have to make my wife to do all the driving.

So I’m dependent on my wife [to] mainly to drive. We also have a daughter living with us who can do nurse’s training and she can drive me to the airport and pick me up from the airport when I come back.

My daughter takes me places back and forth (...) In the supermarket [I] cannot see products so [I] have to be asking people. Now I have to take the bus, or someone in my family or a friend has to take me places.

Right now I’m living with my daughter, and that’s much easier. If not, I don’t think it will be very easy for me to live by myself anymore.

At night I cannot go shopping (...) Or, go to any place at night by myself. I have to depend on my son, my husband (...) or somebody because I cannot do it by myself.

Now I have to depend on other people (...) [I am] always with someone in my house and every place I go.

I’m very fortunate I’m always with somebody. I need steady help. I needed somebody to move it with me. That was the biggest change in my life. I have a nurse’s aide twenty four seven.
Mobility limitations and keeping social life. Poor vision limits physical and social mobility. This item describes the experiences of participants of their diminishing ability to maintain activities that they enjoy, activities that they are about to lose, or have already given up. However, in spite of these limitations they kept their social lives active by engaging in activities outside their homes.

Giving up driving. Table 4.3 (p. 65) is a depiction of sub-item Giving up driving. Of the 11 participants who still drive (61.1%) four were afraid they will not be able to drive in the next six months and five no longer drive at night restricting their participation in events that transpire during the evening. Two of the seven participants who no longer drive still have their driver’s licenses but opted to give them up because of poor vision. Table 4.2 (p. 64) indicates that of the five participants (27.7%) who live alone, four do not have source of help. Living alone has a wider range of impact on social mobility when the participants are no longer able to drive as indicated by their narratives.

The experiences of participants who are still driving and those who fear that they will have to give up driving were captured in the responses to the probe question, How would things change in your daily life if you are no longer able to drive? The experiences of participants who gave up driving are captured in their responses to the question how did you feel when you were told that you could no longer drive? The responses signify the impact of losing the ability to drive on family life, independence, and social mobility.

Oh God, upside down. Upside down because I live alone, I am, I am very independent and (...) it would extremely difficult for me to, to get used to that.

Horrible. I’ll lose my independence

Very much [so], because I have to go places. I want to go places. And depending upon people is very difficult.
I would be confined.

I would hire a driver.

Terrible because I go to the gymnasium three or four times a week, and I am [a] very independent person. I like to do my shopping for grocery and [drive] around the neighborhood.

I cannot attend the [Board] meeting evening sessions (...) I cannot be confident enough to drive at night time.

I could not drive anymore (...) have to get rid of my car. [I] cannot go to places I want to go. [The] biggest change was I could not drive anymore (...) I cannot transport my wife to places because she doesn’t drive.

Three years ago I gave up driving. I don’t want to hurt anyone, or myself. I am not gonna jeopardize myself or other people’s lives (...) it’s hard to give up driving.

**Giving up activities.** The activities given up consisted of varied activities that the participants used to enjoy. Most participants talked about the difficulty of giving up driving and reading. For some it was aspects of home life, sports, going to the movies, attending stage performances, or visiting the farm. The impact of vision disability on everyday life was evident in their narratives.

Before, I [used to] sew with the machine. I [would] make for my daughter many things, and now, I can’t do it.

I don’t read the newspaper anymore. I used to read the newspaper every day. Now I don’t even subscribe to the newspaper. And I haven’t read a book for more than three years. And I’m a very avid reader (...) I used to twice a week (...) play tennis, I could not play tennis anymore because I cannot see the ball until it gets too close to me. So I cannot react to it.

I can’t see the television set and go to the movies (...) I can’t read my leases, I can’t read the newspaper, I can’t read the computer, I can’t read birthday cards, I can’t read anything.

My grandson is in the drama club and ballet and everything, and I hate to go. Because I have to ask which one is him, which one is him? So I don’t go to the theatre anymore.

Oh playing golf. I used to (laughs). I use profanity because I used to be able to be a pretty good golfer. And now it takes me four shots what I used to do in two shots. Oh yeah, I see the ball but I can’t make it go where I want it to go.
I drove my wife around this country, over a million miles.

I found it very difficult to go to the movie theatre because I have to sit down in the first three or four rows (...) I had sixty years of driving (...) I miss my sports. [I] cannot read good news.

We have a ranch, a plantation, a big one and we have a big farm (...) I love to be there (...) I used to go horing [horseback riding]. I used to drive and the doctor told me not to drive anymore because I can’t see.

I love the stock market. It’s harder for me now to read. I loved to dance (...) Writing is the most important thing [that I miss].

*Keeping social life* conveys the participants maintaining various social activities and connections. Table 4.2 (p. 64) indicates that more than 94% of the participants visited family and friends at least twice the past month and they engaged in activities outside their homes. Some participants were still very active members of the community.

I am in real estate business.

I am one of the directors of the ______ Bank.

I am in a club right now. You got to be about 75 years or older. All men’s club. And there’s a lot of old people around. I do invite my two sons (...) They met my sons (...) They love my sons, so I bring them ah, as much as I can.

I don’t dance all night, I have one or two dances, Oh, I go to the theatre, I go to the opera, and I go to the ballet. I go wherever my friends will take me. And I go to every charity luncheon. I am a pillar of the community. I’m very well respected.

Two of my friends have it...Yeah, and ah, we play croquet together so I saw [(them)] yesterday as a matter of fact. We played in a croquet tournament.

I am ninety-two years old, I am a founding member of our medical school, and I am a founding member of ________ Hospital.

When I have to go to the theatre, I still can go. Movies, it’s complicated.

*Safety issues*. This item is an indication of the safety hazards experienced by the participants that included falls, driving pitfalls, and the possible risk of taking the wrong
medication. The participants’ experiences depict ways of trying to maintain safety however, giving up driving was strongly seen as giving up independence.

*Falls*. Table 4.3 (p. 65) indicates sub-item Falls. Ten participants (55.5%) had fallen the previous year and six had been injured from the fall. Of the eight participants that had not experienced a fall the previous year, one had fallen several times previously and one tripped a few times without falling to the ground. As these data were emerging from constant comparison, two probe questions on falls were added to the Guide questions (see Appendix I). The narratives on falls capture the participants’ experience of depth perception as gathered from responses to the probe questions “When you are walking, how afraid are you that you might fall? How about when taking the stairs? Falls assessment was not found during the review of the participants’ medical records. The description of not seeing the “bottom” or “last step” or sensing a “hole” on the ground, or seeing everything as “flat” has not been found in the literature.

I don’t see well enough in climbing the steps. I don’t see steps because I lost the dimension and when going down I saw this step from far away and there is no, no lower step (...) I broke my left arm (...) I try to touch (...) my desk or the wall or something that is stable.. that keeps me from falling. I could fall very easily.

I tripped (...) I don’t see a step of the bottom (...) I did tumble a couple of times over steps I don’t see the end of the staircase or something. That, I am very cautious about so that I don’t fall. I’m trying to be very, very careful because I have that accident. I looked up at the sign and I stepped into an excavation that should have had a rope around it (...) I broke my hip.

All the steps are fine except the last one going down. That one you don’t see at all. And you can fall right on your face and hurt yourself very badly. The other steps you can see. I’m very fortunate I’m always with somebody. I tell them please help me when we get to the last step. So when they tell me I know to, you know, walk down. Otherwise, I would go straight and I would fall on the floor.
I have to have my husband or someone I [can] hold on to, to walk because I don’t want to fall (...) because I have fallen twice oh once, because I didn’t see where I was going into (...) Oh goodness, the stairs is another, I hold on to the rails or somebody. I don’t like stairs very well (...) You see, everything is like flat. I have to be very careful. Oh that is a problem [last step] because you don’t know if it is the last or not. I have to be very careful about that. I feel like I cannot go down.

One participant did not want to use her spectacles when taking the stairs:

I am very careful. I have fallen. I usually take those glasses off and look. Or else, I would sort of just be very careful, when I step..

Driving pitfalls. Table 4.3 (p. 65) indicates that there are 11 participants who still drive (61.1%). In sub-item Driving pitfalls, the driving practices and how participants’ “see” traffic signs are captured from the narratives of some of the participants who still drive.

Another thing that is a problem is when I go in the car I put the car in a covered garage. The covered garage do not have enough lighting. You turn off the lights of the car and still it’s dark. I park the car but it’s very difficult because it’s dark. You don’t see [the] lights. In day light you see where the next car to fill in the slot. So that I have decided lately I cannot do that unless I am with someone who can park the car for me. Because, I cannot dare to hit someone just because I don’t see.

No I don’t drive at night. I could if the street is lit. But I will do it only in an emergency. You understand? And most streets residential streets are not lit at night. So I would have to from my house go to the main street and there, there are lights and then I can drive stretches. It’s no problem with that. I never was a fast driver in any case.

Reading the signs I have problems. But, the light I don’t have any problems. I don’t go too far anymore. I don’t take the express way. I stopped taking the express way about two years ago something like that.

I am not frightened, no, but I am apprehensive (...) I don’t see the street signs as well. In other words I must be able to see a block or two away, now I have to be up close.

I cannot be confident enough to drive at night time.

I use glasses to drive. And I leave them (...) I hate glasses, I leave them on the dashboard of my car.

I’m able to drive because it doesn’t bother my eye I can see far enough that I can avoid any accident and also the only thing that I don’t see are the street signs so I don’t go to anywhere that I haven’t gone before.
Risk of taking wrong medication. All participants took medications anywhere from 1 to 12 different medications daily in tablet, eye drop, or inhaler form for their comorbidities and general health (see Table 4.4, p. 66). Participants have alluded to the risk of taking the wrong medication due to impaired vision. The fear of making a mistake has implications for the risk of taking the wrong medication. One participant was aware of being more careful in reading.

I have bottle of vitamins, I used to be able to see the name and everyday it got weaker and weaker and weaker.

Now, to read prescription and everything, not even the magnifier works. Thanks God that I live with my daughter and my grandchildren.

I certainly have to use it [magnifier] for the medicines.

I may make a mistake…

You have to slow down and be more careful when you read.

Having fears while keeping hope alive. The fear of blindness is a reality for the participants, especially for those with dry AMD where clinical trials have failed to establish a treatment with significant positive outcomes in stabilizing the disease or regaining vision. For those with wet AMD and receiving treatment, their temporary positive outcomes gave them encouragement to continue the difficult regimen. As indicated by their narratives, their hopes are kept alive by the thought that one day a permanent cure will be found through the advances in clinical research.

The fear of losing sight becomes a part of living with AMD as individuals experience its devastating impact. For those who still have good functional vision, the uncertainty of their future when they may eventually lose their sight is a source of fear
and pre-occupation. One participant whose mother had AMD expressed his fears for his children.

It’s fearful. I don’t want to lose sight.

The biggest change, you know to be honest, [(is)] not the physical change but a slight fear of what the future might bring. You know it’s kind of, not fear, may be slight anxiety how this could this develop, how soon and, and it’s terrible, what can I do? (..) This awful deteriorating (..) Things like this are on my mind.

(…) The people around me in my family, I have to worry that they [(scientific community)] won’t make some advancement in research in macular degeneration.

The advances in research in the treatment of AMD kept the participants’ hopes alive as depicted by their narratives.

Hopefully (…) now they are studying stem cell (…) That would be fabulous.

Something every now and then keeps my hope alive. I think one day they’re gonna find the root of the problem and find the cure for it (…) help all the old folks that suffer, that suffer so much.

I hope they invent something to help, you see it’s only one type that can be helped for the moment with the macular degeneration. So I hope like in my case I have one eye that can be helped a little bit and the other is going fast by the minute.

Accepting AMD. Some participants have optimistic outlook for the future and alluded to other ways of enjoying life while others considered AMD as part of getting old, or reasoned that although the eye is impaired it has other uses. One participant pointed out that others have cancer and she has AMD. The complexity of accepting visual impairment was captured in the participants’ expressed feelings of acceptance, denial, resignation, acceptance, regrets, and loss.

My attitude is fantastic. I just accept it […] I know what my condition is. And I know eventually, if I live long enough, I will be go blind. People are lucky if it’s stabilized. I’m not lucky. I just accept it. I know what it is, and I, I can’t do anything about it. That’s my curse somebody else has cancer. I don’t have cancer I have macular degeneration.
(…) because I got too old (…) Live your life as best as you can, do each day as it comes.

(…) I said well may be because of the age that I accepted that you know. . Like many other things you have to accept when you are old, accept that it can get really bad, like arthritis, that you have to be patient. Live with the disease. [One] should not go crazy or desperate. Accept that it is a disease you cannot control.

Well I’m trying to think positive (…) I’ll be able to use my eyes up to the end, as long as [I am] alive (…) I cannot really read with the eye, but I can still use it. It is not dead.

My life is the same.

I don’t think there has been any change to my life.

Well I haven’t given up anything yet that I didn’t do [before].

Whatever God has in store for you is what’s gonna happen.

It’s unfortunate that you get it but it’s not up to us, it’s up to God and you have to live with it.

What else can I do with no sight (…) and any way that’s about life.

I meant to see the doctor, the eye doctor maybe once a year to every two years, you know (…) I think that ruined my eyes.

So it was too late because [I lost my] sight. If we came immediately (…) they [could have] saved the eye.

Had he told me I could have stopped it way back before it caused any damage whatsoever (…) it could have been stabilized with less damage.

(…) [Follow] religiously as [the doctor] tells you. And get the, injections. Don’t fail to do that. Don’t wait.

It is important to take good care of your eyes in the meantime [you] are in good health.

It is not fun to lose your eyes (…). If I were blind that will be very, very sad. It’s like losing seventy five per cent of your life.

It’s very sad that I lose my, my vision. It’s very bad but I don’t like to think about that.

Practically from one day to another you know that it’s gonna be a little less, and little less, and then less.

**Category 4: Using magnifiers.** Using magnifiers (Figure 4.5) captures the participants’ experiences on continuing the use of LVODs. The impact of Living with AMD (Category 3) has consequences on LVOD use as discerned by two sub-categories.
Using magnifiers in DLA reflects the kinds of activities or tasks for which the participants found LVODs helpful or not helpful and identifies the physical and visual limitations of LVOD use. Agreeable and disagreeable perceptions of using the optical device are reflected in the narratives. The frequency of LVOD use determines the Types of users. Table 4.7 (p. and 4.8 are the characteristics of each type of user. This category was captured from the probe question “Please tell me about your experience with using your magnifier” and what advice would you give someone who is just starting to use a magnifier?”

**Using in DLA.** The participants used their LVODs for near and intermediate distance viewing such as in reading and other household tasks including shopping in a grocery store, viewing the computer or television. The participants suggested keeping small-sized magnifiers for easy accessibility in pockets or handbags and a bigger type kept at home. Others had several types of magnifiers at different areas of their homes for easier access. Users, Semi-users, and Abandoners have indicated how they used the magnifiers in their daily tasks.

The only way to reading is with the magnifier. I like reading the Bible (…) in the supermarket, or I need it on the piano. [It’s] very easy [to] see price[s], [if] the clothes have a tag [for] wash care, I [can] see the letters bigger.

When I go and I want to see the price of something I have to use the magnifier. Well when I want to see how my nails look or something like that, I use my magnifier too.

I use it when I have to look some various small, small things. Very small and to fix something small like [a] broken glass (…) When I have too small things that I need to fix.
Figure 4.5. Category 4: Using Magnifiers

[I] like to read (...) Sometimes you have a telephone [with] too small letters. [When] it is not possible for me to see, I have to look for a magnifier.

I have been reading Scripture, reading newspaper, reading the mail. I certainly have to use it for the medicines. I have the little square magnifying glass when I go shopping and you know you could use it to tell if it’s Campbell soup (both laugh). That much I can tell you. What kind of Campbell soup.
[I] use the magnifier to see where the screw goes and how to work on it. [I] have [it] in my pocket. [If] I have to see something I open it. When you are out of the house you can take it with you. It has the power to increase to different levels.

I got a round one, I have another that is plain, page size, and I have another that is a quarter-page for small reading.

I have a big one in my desk. I have one in my purse (...) a small one that I use to look at the maps, the miniature things in the maps.

**Limitations.** The LVOD limitations identified by the participants include the physical handling of the device, the small magnified reading area covered in the printed material, the slow speed in reading, the inability to use in tasks that require both hands, the inability to write with the device, and for lighted LVODs, the frequency of changing batteries. The apprehension of making a mistake in reading that can have consequences is apparent in the first narrative. The limitations identified are barriers to optical device use as articulated by Users, Semi-users, and Abandoners. One User offered a more thoughtful response by saying that it did not meet his needs because it was not a replacement of what he lost, indicating high expectations of LVOD’s functions.

I get tired holding that thing (...) [It] gives [me] frustration. [I] may make a mistake (...) [I] cannot write with this. [I] have to change the batteries every fifteen days.

You can’t even use them, because you have to hold it in one hand and you have to keep moving it with the other hand. [It is] very uncomfortable. It only covers a certain amount, like three inches and you gotta keep moving it, moving it, moving it.

Unfortunately, you have to use [it] very slow, because most of the time you cannot move and act [read]at the same speed (...) Not helpful reading newspaper, books, that type of print.

It’s difficult (...) It’s not helpful enough because they are limited to an area and [I have] to be moving [it]. It’s bothersome. It’s cumbersome.

I have a lot of difficulty [in] keeping my nail, filing and putting something on my nail, because I cannot see very well. And not even with the magnifier yeah, I can see it with
the magnifier but then when I am going to file I cannot use the magnifier. I need two hands.

You lose your patience after a while. [It is] so small.

They help but not adequate. Adequate [means it] replace[s] what you need. I don’t think they replace what I need. It’s a help, but it’s not really, really a good help. Just a so, so, to keep [you] going. Period (...) [I] think that this is one of the last remedies that we have.

Some participants suggested different types of magnifiers that could help them read better:

I wish that there was a, like a one page. Some magnification thing that I could put over the paper and I could read the page. But they haven’t invented such a thing. I don’t know if there was. I don’t know I haven’t found any.

Buy the square one, not the round, the one that you can put on a letter. You know when a letter is down or a page in a book. It’s the size of a page of a book and you put it on that. And it’s much easier than a magnifier. It is a magnifier but it’s square. And it’s not the one you have to hold. You can put it down.

Another limitation is the lack of prescription for the participant’s LVODs, lack of low vision assessment, and referral for rehabilitation as cited in Table 4.5 (p. 68) and Table 4.6 (p. 69) respectively. Optical devices were not tailored to the participants’ specific needs as to magnification power, focal distance, and contrast. The participants acquired their devices from different sources without any prior assessment or training for appropriateness to their reading needs.

**Types of users.** The frequency of LVOD use in daily tasks or activities determined the type of users. All participants experienced using LVODs through Discovering magnifiers (Category1) which is a continuous throughout the process of *Doing the Best You Can*. Based on this experience and the impact of AMD on their quality of vision, the participants have assessed the efficacy of LVODs based on their own personal situations and pre-dispositions. Some have continued valuing the help they obtain from their
LVODs by using them as often as they can in managing their participation with DLA (Users). Some have determined that they are encumbered by its use so do not use it as often (Semi-users). Others have discerned that their optical devices are not or no longer helpful enough as assistive reading instruments so they let time pass by without using them and put them at the side, where they may or may not pick them up again for a task. Throughout the dynamic process of Doing the Best You Can that evolves with time, the experiences of Users, Semi-Users, and Abandoners were captured from the narratives of the participants that were color coded to signify user type.

For this study, Users were defined as participants who used their LVODs more than once a day ($n=9, 50\%$), Semi-users used their optical devices once a day or less and sporadically the past three months, ($n=5, 27.7\%$), and Abandoners ($n=4, 22.2\%$) have not used their LVODs for three months or longer. The characteristics of each user type (Table 4.7 and Table 4.8) were placed at the end of this Chapter to give the reader the prior experience of immersion in reading their narratives throughout Doing the Best You Can to better understand their journey of losing sight.

*Users.* Table 4.7 (p. 68) indicates that the age Range for Users was 79 to 94 years and the Mean age was 86.2 years. There were five males and four females. Of the nine participants, five are married, three are widows and one is divorced. All participants live with their spouses, family, or partner making them the group with the most help. Five Users still drive but three of them preferred not to drive at night. Out of the four Users that do not drive, one preferred to give up driving for fear of having an accident. Five
### Table 4.7 Demographic Characteristics of Users, Semi-users and Abandoners

<table>
<thead>
<tr>
<th>Variable</th>
<th>Characteristic</th>
<th>User</th>
<th>Semi-user</th>
<th>Abandoner</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of participants</td>
<td>n</td>
<td>9</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Age</td>
<td>Range</td>
<td>79-94</td>
<td>75-89</td>
<td>85-96</td>
</tr>
<tr>
<td></td>
<td>Mean age</td>
<td>86.2</td>
<td>83.2</td>
<td>89.2</td>
</tr>
<tr>
<td>Sex</td>
<td>Male</td>
<td>5</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>4</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Marital status</td>
<td>Married</td>
<td>5</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Widow</td>
<td>3</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Divorced</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Home situation</td>
<td>Lives alone</td>
<td>0</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Has help</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Does not live alone</td>
<td>9</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Driving</td>
<td>Still drives</td>
<td>5</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Does not drive at night</td>
<td>3</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Does not drive</td>
<td>4</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Gave up driving</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Fallen the past 12 months</td>
<td>Has fallen</td>
<td>5</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Injured</td>
<td>3</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Has not fallen</td>
<td>4</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Fallen prior</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>“Tripped” a few times</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Users have fallen the past 12 months and 3 sustained injuries. Of the four Users that have not experienced a fall, one has “tripped” a few times but has braced herself and avoided the fall.

Basing on Table 4.8 (p. 69), Users have a wide VA Range in the better seeing-eye is 20/50 to 20/200. Two Users have 20/50 VA and 3 Users have 20/60, the best VAs in the range. One User has a VA of 20/80, one with 20/100, one User with 20/125, and one legally blind User (20/200), the worst VA in the Range. For the other eye, Users have a
wider VA impairment range, from 20/50 to Hand motion. Three Users have a VA of 20/200, and the others had 20/50 ($n=1$), 20/80 ($n=1$), 20/100 ($n=1$), 20/250 ($n=1$), 8/200E (reads letter E at 8 feet, $n=1$) and Hand Motion. The VA wide ranges indicate that among the three groups, Users have worse vision as compared to Semi-Users and Abandoners. A User with 20/200 OD and 20/250 OS VA reacted to his magnifier use in this excerpt of his narrative:

That thing is my eyes (...) I don’t find it useless in any way.

Five of the Users have had AMD for more than 10 years, and two Users have had the disease for 6 to 10 years and 1 to five years, respectively. Users have had the longest duration of AMD as compared to Semi-Users and Abandoners. This finding supports their having the worst vision. The Range for how long Users have acquired their LVODs was 8 months to 20 years with a Mean of 5.87 years, making them the group with the shorter experience of using LVODs as compared to Semi-Users and Abandoners. The range for number of medications taken was 1 to 11 kinds with a Mean of 6.1 medications taken daily.

*Semi-users.* The age Range of the Semi-Users was 75-89 years with a mean age of 83.2 and this group is the younger group as compared to Users and Abandoners. Semi-Users were all females with two married participants and three widows. Three Semi-Users live alone, and has no source of help, but asserted their independence by indicating that they did not need any help. Two Semi-users do not live alone. Similar to Users and Abandoners there are drivers among the Semi-users. Three still drive with one participant opting not to drive at night due to poor night vision. Of the two non-drivers, one still have
her driver’s license but preferred to no longer drive. Semi-users also have experienced falling like Users and Abandoners. Out of the five Semi-users three have fallen the past 12 months and all were injured. Two participants have not fallen but one admitted to falling several times the previous years.

The VA range of Semi-Users for the better seeing-eye was 20/50 to 20/80, a narrower and better VA range as compared to Users and Abandoners. The narrow range means Semi-users have better vision in the better seeing-eye than Users or Abandoners, but this did not prevent them from falling (see Table 4.8). Of the five Semi-users, two participants have 20/50 in the better-seeing eye, two participants with 20/60, and one participant with 20/70. The VA in the other eye was distributed as follows: 20/50 (n=1), 20/60 (n=1), 20/80 (n=1), 20/400 (n=1), and 20/500 (n=1).

There was one Semi-user who had AMD longer than 10 years, two participants have had the disease for 6 to 10 years, and two have had AMD for 1 to 5 years. The range for how long their LVODs were acquired was 1-20 years and the Mean was 10 years. Semi-users take 7 to 2 medications daily (Range) with a Mean of 9.2 medications, making them the group that take the most number of medications per day.

An excerpt from an 88 year-old Semi-user’s narrative (20/500 OD and 20/60 OS VA) indicates why the participant sparingly uses LVODs:

Never liked it. [I] bend like this very close to the book, I can’t do that. Makes me very ah, very tired, you know my back. No, no. no. To me it’s too much. That thing is very tiring. No, I don’t really use it too much.
Table 4.8. Ophthalmic Profile, Duration of LVOD Acquisition, and Number of Medications Taken Daily by Users, Semi-Users, and Abandoners

<table>
<thead>
<tr>
<th>Variable</th>
<th>Characteristic</th>
<th>User</th>
<th>Semi-User</th>
<th>Abandoner</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visual Acuity</td>
<td>20/50</td>
<td>2</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Better-seeing-eye</td>
<td>20/60</td>
<td>3</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>20/70</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>20/80</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>20/90</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>20/100</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>20/125</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>20/200</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Visual acuity</td>
<td>20/50</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Other eye</td>
<td>20/60</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>20/80</td>
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<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>20/100</td>
<td>1</td>
<td>0</td>
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</tr>
<tr>
<td></td>
<td>20/200</td>
<td>3</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>20/250</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>20/400</td>
<td>0</td>
<td>1</td>
<td>1</td>
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<tr>
<td></td>
<td>20/500</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>8/200E</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>2/200E</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Hand motion</td>
<td></td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Duration of AMD</td>
<td>1-5 years</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>6-10 years</td>
<td>2</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>&gt;10 years</td>
<td>5</td>
<td>1</td>
<td>1</td>
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<tr>
<td>How long LVOD acquired</td>
<td>&gt; 6 months &lt;1 year</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>1-5 years</td>
<td>6</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>6-10 years</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>&gt;10 years</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Range</td>
<td>8 months to 20 years</td>
<td>5.87</td>
<td>1-20 years</td>
<td>10</td>
</tr>
<tr>
<td>Mean</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of medications taken daily</td>
<td>Range</td>
<td>1-11 kinds</td>
<td>7-12 kinds</td>
<td>3-7 kinds</td>
</tr>
<tr>
<td></td>
<td>Mean</td>
<td>6.10</td>
<td>9.2</td>
<td>4.75</td>
</tr>
</tbody>
</table>

*Abandoners.* The age range for Abandoners was 85-96 years with a Mean of 89.2 years, which make them the older group as compared to Users and Semi-Users. There were three females and one male. There was one married Abandoner, two widows, and one was divorced. Two participants live alone with one having available help from a
Nursing Assistant. Two participants do not live alone. Similar to Users and Semi-Users, Abandoners were also still driving. There were three drivers in the group and one non-driver. Two Abandoners have fallen the past 12 months without sustaining any injury and two participants have no incidences of a fall. There was a narrow VA Range for the better-seeing eye among Abandoners which was 20/50 to 20/90, better than the Users. Three participants have 20/50 VA in the better-seeing-eye, and one had a VA of 20/90. For the other eye the VA range was wider, 20/80 to 2/200E, but not as wide as the Users: 20/90 (n=1), 20/200 (n=1), 20/400 (n=1), 2/200E (n=1). There were two Abandoners who have had AMD for 1 to 5 years, one has had the disease for 6 to 10 years, and one has had AMD for more than 10 years. Abandoners have acquired their LVODs the longest, from 2 to 30 years (Range) with a Mean of 11 years giving them the group with the longest experience with using the optical device. They also have the least number of medications taken daily ($R=3-7$, $M=4.75$).

A 96 year-old Abandoner with a 20/90 OD and 2/200E OS VA explained why she doesn’t use her LVOD and pointed out that she has been to the Lighthouse for the Blind but believed she could not be helped.

They [magnifiers] are a pain in the neck (...) I don’t find the magnifier useful at all. Other people may find it very handy. But it is difficult for me to manage. You can’t even use them, because you have to hold it in one hand and you have to keep moving it with the other hand (...) Very uncomfortable, it was never easy. I’ve tried everything.

I’ve been there. I’ve been to the Lighthouse in___ [City] I’ve been to the ___ [Group] Guild in ___ [City] I’ve been to the Lighthouse here, I’ve been to the Lighthouse in ___ [City] (...) They are very, very nice but there is very little anybody can do.
Summary

This Chapter is a presentation of the sample characteristics and findings revealed by the substantive theory that emerged from the data analysis. The theory of Doing the Best You Can is a dynamic process that includes categories of Discovering magnifiers where individuals start acquiring LVODs for their changing vision, Losing sight from AMD where they first experience the disease, Living with AMD that includes the experiences of treatment and the devastating effects of AMD on their daily life patterns, and Using LVODs where different factors affect decisions on using, semi-using, or abandoning the optical device. The common thread that weaves through the process is discovering magnifiers where individuals keep looking for devices that will optimize their residual vision.

New findings on signs of AMD and depth and space perception were revealed that have not been cited in the literature. More than 50% of the participants had incidence of falls. Three user types were identified: Users, Semi-Users, and Abandoners. Users used their LVODs more than once a day, had worse visual acuities, experienced AMD longer, acquired their LVODs for a shorter period of time, and had the most sources of help. Semi-Users used their LVODs once or less daily and sporadically the past three months, had better visual acuities, were younger, were all females, and took more medications daily. Abandoners have not used their LVOD the past three months, were older, acquired their LVODs for a longer period of time, and took the least number of medications. None of the participants were referred for low vision assessment or training and none of the LVODs were prescribed.
Reading disability, facial recognition disability, giving up driving, and dependence on others were found to severely impact daily lives. The treatment of wet AMD with intra-ocular injections of anti-vascular endothelial growth factor is a difficult repetitive regimental procedure that has varying outcomes. The study also found that accepting AMD and vision impairment is complex however the participants were socially mobile and engaged in activities outside the home. Barriers to LVOD use included factors that involve physicians, the individual with low vision, the device, and service delivery.
Chapter 5

Discussion

The constant comparative method and theoretical sampling of Grounded theory methodology were used to collect and analyze data that addressed the research question “What are the experiences of older adults with AMD on losing vision and using LVODs?” A theory of Doing the Best You Can emerged from a triangulation of data sources that included 18 recorded interviews, 18 demographic surveys, 18 ophthalmic and medical profile reviews of participant’s medical records, and a literature review that revealed a paucity in nursing research on LVOD use and vision impairment.

The purpose of this study was to explore the experiences of older adults with vision impairment from AMD in managing participation in daily living activities with the use of assistive optical devices and arrive at a substantive theory that captured the essence of these phenomena. Barriers to optical device use that may result in abandonment and differences between individuals who find the devices useful and those who have abandoned using them were also explored.

The findings revealed the theory Doing the Best You Can, a process that include categories of discovering optical devices where individuals start acquiring LVODs for their changing vision, losing sight from AMD where they first experience the disease, living with AMD that includes the experiences of treatment and the devastating effects of AMD on their daily life patterns, and using LVODs where different factors affect decisions on using, semi-using, or abandoning the optical device. The common thread
that weaves through the process is discovering magnifiers where individuals keep looking for devices that will optimize their residual vision.

**The Experience with AMD**

The participant’s experiences with AMD are captured in the categories of *Losing sight* and *Living with AMD*.

1. **AMD has different presentations.** This finding was new. Three participants had dramatic signs and described the visual distortion as an “explosion” or a “bomb”, or patch of “blood” and others experienced the distortions in central vision while others did not show any signs and symptom so the disease was undetected for some time. These varying signs and symptoms are not included among the information disseminated about the disease which only include blurred vision, inability to recognize faces, wavy lines, and blind spot (National Eye Institute, 2013).

2. **AMD can be misdiagnosed.** This finding underscores the importance of the vetting process for obtaining the best health care. Some of the participants were treated for a different eye condition, or were diagnosed correctly but did not receive any form of treatment, and others had to go through circuitous routes to find their current ophthalmologists.

3. **There is low awareness of AMD.** Most participants lacked information or did not know anything about AMD until their diagnosis. Some patients were not well informed of their condition by their ophthalmologists, nor were they directed to sources of information including information in Spanish. This lack of information can result in disparities in health communication and decision
making on the part of patients who may not fully understand the importance
of keeping appointments for their treatment. ‘Am I going to get blind?’ “What
is my prognosis?” or “What is it?” are important questions that are critical to
address. The public awareness campaigns of agencies such as those
sponsored by AMD Alliance International since 2005, Prevent Blindness
America since 2010, and observing February every year as National AMD
Awareness month address this problem.

4. The treatment for wet AMD is a difficult repetitive procedure. Not all older
adults can follow the strict regimen of treatment, especially if they have other
comorbidities. Those who do, adopt ways of making the experience as
comfortable as possible. One female participant explained the procedure as a
joint effort between the patient, physician and nurse and did not find it to be
painful.

The experience of not having pain during the procedure is consistent with
the findings of Rifkin & Schaal (2012) who reported that among 60 patients
receiving Intraocular VEGF inhibitor, Females ($p<.010$), those $>65$ years
($p<.050$), and those receiving Tetracaine™ topical anesthesia ($p<.010$),
reported less pain than Males, younger than 65 years of age, or those who
received other kind of anesthesia. In the study one male participant
commented on having pain during the treatment procedure.

5. The treatment of wet AMD is long-term and vision outcomes vary. The long
term treatment and differences in vision outcomes are consistent with the
literature. The current literature on anti-VEGF treatment suggests a 90%
chance of stabilization or increasing vision that has become a substantial achievement in treating the disease (Mitchell, et al., 2010). After a two year follow-up, the gain in reading letters in the eye chart that range from 1.4 to 3.8 letters depending on the type of VEGF used and frequency of every three months or monthly injections respectively, has important implications in improved QOL, but may require a lifetime of treatment as there is no certainty of non-recurrence (Velez-Montoya et al., 2010). Disappointments in treatment outcomes may lead to depression and screening for depression was suggested by Casten & Rovner (2010) as a standard of care. Two participants in the study with wet AMD had depression as comorbidity and were taking medications, however depression screening was not a part of ophthalmic evaluations.

6. Reading disability, giving up driving, depending on others, and face recognition disability severely impact daily lives. The loss of reading ability included a myriad of losses in participation in DLAs. This finding is consistent with the results reported by Ryan et al. (2003) where 26 individuals (AMD n=23) with moderate to severe visual impairment identified meal preparation, telephone use, finances, travelling, shopping, medications, and laundry as types of DLA affected by reading disability. Coping strategies included memorization, using assistive and adaptive reading instruments such as LVODs and audio devices, and asking for help from others. Participants also continued to read for leisure which was corollary to the findings of this
study where avid readers continued their interest in reading by using different kinds of lighting and types of LVODs, in spite of their reading difficulties. The possible risk of taking wrong medication was alluded to by some participants. The need for help among visually impaired individuals who manage their medications was pointed out by McCann et al., (2012). The researchers found that among 156 visually impaired individuals only 3% could read medication information clearly and 24% had difficulty in identifying various tablets, in spite of using LVODs, and needed more help from other people [(29% vs. 13%), OR=2.8; 98% CI, 1.6-5.0)] than the control group. A statistically significant relationship was also found by Schmier et al. (2006) between visual impairment and taking the wrong medication (p<.05) indicating the heightened health risk of older adults with AMD due to reading disability. From the descriptive variables, number and type of medications taken, home situation of living alone, and no access to source of help are factors that can compound self-management of medications.

Giving up driving was considered by several participants as the most disabling consequence that affected independence and social mobility. The difficulties encountered in reading traffic signs and night vision, or the practice of not using spectacles by those who still drive raise red flags on their safety and that of the public.

In a simulated study, drivers with central field loss were found to have more failures in detecting pedestrians (6.4% vs. 0.2%, p<.001), reacted more
slowly (4.28 vs. 2.43 seconds, *p*<.001), and overall had more late and missed responses (29% vs. 3%, *p*<.001) on the driving simulator than control subjects (Bronstad, Bowers, Albu, Goldstein, & Peli, 2013). Results of a previous study (*n*=10) comparing older adults with and without AMD, also indicated that individuals with AMD exhibited poorer performance in driving by their delayed breaking response times to stop signs, slower speeds, number of lane crossings, and accidents on the driving simulator (Szlyk, et al., 1995). The authors found that drivers with AMD compensate by not driving in unfamiliar areas, traveling in slower speeds, self-restricting night time driving, and taking fewer risks like changing lanes, that were also revealed by the drivers in this study.

Studies on QOL of older adults in different stages of AMD indicate that independence and dependence are major domains impacted by vision loss (Clemons, et al., 2003; Brody et al., 2001; Girdler et al., 2008; Mitchell et al., 2005; Moore & Miller, 2003; Stanford et al., 2009). In this study, the drivers expressed their strong sentiments to giving up driving as “horrible”, or they will be “confined”, “lose their independence”, or will turn their lives “upside down”. Those who no longer drive recounted their days of driving and stated that they have to accept role reversal by being dependent on their wives or children. Role difficulties were also found to be domains of QOL impacted by vision loss as reported by Clemons, et al. (2003) and Scilley et al. (2004), (*p*<.001, *p*<.005) respectively.
Facial recognition disability as a result of AMD was expressed by several participants as severely impacting their personal lives. Examples of the devastating implications of facial recognition disability to personal and social relationships were identified in the study. The QOL vision specific questionnaires such as NEIVFQ25 that is mainly used by QOL studies (Clemons et al., 2003; Mitchell, 2005; Sahel et al., 2007; Scilley, et al., 2004) lists facial recognition as item number 11 under subscale social functioning; a question on how much difficulty is it for the individual to see someone react. Social functioning was found to be significantly associated with decreased QOL (p<.001, Clemons, et al., 2003; Scilley et al., 2005).

7. Older adults with AMD are at high risk for falls. The high incidence of falls among the participants is disturbing but consistent with the literature. Older individuals with AMD are at high risk for multiple falls (Ivers et al., 1998; Lord & Dayhew, 2001; Wang et al., 2012, Wood, et al., 2012) and women were found to be at higher risk (Szabo et al., 2008). Ivers et al. (1998) based their sample from Black Mountain Population Study (n=3,654) and identified VA (worse than 20/30, p<.010), contrast sensitivity (p<.010) and depth perception (p<.010) as statistically significant predictors of falls. This was confirmed by a more recent study by Wood et al., (2011) who also found that VA and contrast sensitivity were statistically significant predictor of falls [(n=76); VA (p<.001), contrast sensitivity (p=.008)]. Contrast sensitivity was not measured in the ophthalmic examinations of the participants in this study.
Some of the participants were not happy with their spectacles and removed them when taking the stairs, driving, or reading. Wood et al., (2011) found that 21% of the participants who fell were not wearing the spectacles. Most participants described their being extra cautious in navigating the stairs as they could not see the “bottom” or “last step” or they sensed a “hole” or everything was “flat” when they were walking. These vivid descriptions are indicative of depth and space perception abnormalities that limit mobility and have not been detailed in the literature.

Activity limitations have been reported among individuals with AMD due to fear of falling (Wang, et al., 2012). A Life Space Assessment was given to 345 participants with visual impairment (AMD $n=93$, 27%), to take into account life space levels traveled inside the home, outside the home, or out of town and whether they required help to reach the various levels. Results indicated that individuals with AMD were most likely to report activity limitations due to fear of falling as compared to the control group (OR=2.42; 95% CI, 1.09-5.35). Older age and number of comorbidities were also found as statistically significant variables ($p<.050$).

In this study, the participants expressed their activity limitations and were captured under *Giving up driving and activities* as being more related to the advancing AMD effects on near and distance visualization, and not due to fear of falling (e.g. reading and playing tennis or golf). Rudman and Durdle (2009) in a qualitative study of visually impaired older community dwellers ($n=18$, Mean age=82.95) and urban dwellers ($n=16$, Mean age=80.75) described
community mobility as risky and the core theme developed was that older adults with low vision are “living with a pervasive sense of fear”, which was not captured in *Doing the Best You Can*.

In *Living with AMD* (Category 3), although participants expressed their sense of danger in taking staircases and more than 50% had fallen, they cited ways of taking safety precautions and seeking assistance as preventive measures and were highly mobile in getting around as evidenced by 94% visiting friends or family the previous month and being involved in activities outside the home. Most participants also were well educated and have income sources other than Social Security, so affordability of paying a driver, or a companion nursing assistant may not have been a constraint. This finding was not consistent with the older adult profile identified by the Administration on Aging (2011).

8. Acceptance of visual impairment among older individuals with AMD is complex. The complexity of acceptance of visual impairment was captured in accepting AMD. Although acceptance and resignation were apparent in the narratives over all, denial was a strongly voiced sentiment. This finding was not surprising because in a qualitative study of 12 older individuals, Mogk (2008) found that legally blind individuals with AMD do not consider themselves as blind persons because doing so would be “claiming a hardship that they are not actually experiencing” (p.12). They continue to see themselves as sighted in spite of the visual disabilities that they experience because being blind is seen as being older and in need of help in the society’s
cultural context (Mogk, 2008; Orticio, 1994). Furthermore, they consider themselves as sighted because their peripheral vision remains intact. This finding was also compatible with the findings of McLahlan et al., (2007) who suggested that strong determination of retaining normalcy and independence result in staying away from or delaying access to low vision training as much as possible, in spite of acknowledging the undesired impact of low vision.

In the case of older adults with AMD in this study, their disease may affect one eye with wet and the other eye with dry AMD, both eyes may have wet AMD, or both eyes may have dry AMD, or the dry may convert wet or vice-versa. There is no established treatment for dry AMD; however some respondents are currently participants in an on-going clinical trial. The anti-VEGF treatment has given most participants gains in vision as per their narratives (a “little better”), however, these were transient outcomes that diminished with time and they had to come back again for treatment. Hence, the cycle begins again. These episodic highs and lows distinguish them from other older individuals who are visually impaired from other age-related eye diseases that Casten et al. (2010) alluded to as indicative for depression screening. Furthermore, their gains in vision although transient support the notion that they are sighted and is consistent with the findings articulated by Mogk (2008). Their experience of accepting or not accepting their visual impairment may be different, although their fear of being blind is real as expressed by one participant with 20/200 OD and 20/250 VA that being blind is comparable to losing 75 % of his life.
9. Not all older individuals with visual impairment are socially isolated and desolate. This finding is corollary with “keeping with life while managing risk” (MacLahlan, et al.,) a theme that was generated from a phenomenological study of four older women (Mean age = 74.36) with low vision. In Living with AMD (Category 3) participants acknowledged their mobility restrictions but continued their social activities out of their homes, as depicted in the item mobility limitations and keeping social life. The optimistic outlook of the participants in spite of their fears (having fears and keeping hope alive) was also found in the captured themes “confrontation of uncertainties and fears” and “persistence of hope and optimism” from a phenomenological study of eight older men with AMD (Age Range = 68-87) by Moore & Miller (2003).

In a recent study, Bookwala & Lawson (2011) found that social isolation ($\beta=.43, z=17.90, p<.001$) and limitations on physical activities ($\beta=.26, z=10.22, p < .001$) contribute significantly to depressive symptoms. Social isolation did not emerge from the data analysis of this study and the mobility limitations imposed by AMD did not curtail the social mobility of the participants.

**The Experience with LVOD Use**

The experience with LVOD use was captured from the categories *Discovering magnifiers* and *Using magnifiers*.

1. LVODs are used for close and intermediate distance. The participants used their LVODs in different DLA that involved close reading tasks or
visualization and intermediate distance viewing. Studies suggest that a VA of worse than 20/30 is already disabling (Ivers, et al., 1998; Schmeir, et al., 2006). Stelmack et al. (2003) classified the uses LVODs in DLA as using in (a) travel activities, (b) food and shopping, (c) household tasks, (d) self-care, (e) recreation and socialization, (f) communications, and (g) use in contrast. The authors also found that participants with 20/25 to 20/150 VA \( (n=149, \text{ Age Range}=51-96, \text{ Mean age}=76, \text{ AMD } n=56.3 \%) \) self-reported that they could see well without using the LVODs to perform some activities while individuals with less than 20/125 VA could not do so. All the activities cited were captured in the narratives of the participants in this study.

Watson et al. (1997) found that among 273 individuals using handheld optical devices in the Veterans Affairs rehabilitation centers, 82% use them for reading, 20% for repairing, 20% for cooking, 18% for writing, and 6% for lawn and garden. These findings were consistent with the LVOD use of the participants in this study except for writing. An exploratory analysis on Watson et al.,’s (1997) findings on reading was conducted and the authors found that participants used the handheld and stand magnifiers for short term-reading several times a day which corresponded to the LVOD use of Users in the category of Using magnifiers.

2. Individuals with vision impairment use compensatory mechanisms in addition to or instead of using LVODs. Some of the participants used talking books and clocks or asked others for help in lieu of using their LVODs. Horowitz et al. (2006) explained that perhaps individuals who have the worst degree of
visual impairment have the fewest alternatives in continuing to manage their DLA and place greater reliance on compensatory mechanisms instead of using LVODs that optimize their residual vision.

Conversely, Watson et al., found that having a helper was the only statistically significant demographic variable associated with continued use of LVODs ($\chi^2=7.53$, $p=.006$) among the veterans who were all men. In this study Users had the most sources of help in their homes and was consistent with this finding. However, using compensatory mechanisms suggests the complexity of adapting to visual impairment where older adults with AMD strive to maintain continuity in managing their daily living patterns.

3. Individuals with more severe vision impairment are LVOD users, but continued LVOD use depends on the individual’s perception of need. The direct causal relationship of VA and LVOD use was consistent with the findings of previous studies cited (Casten et al., 2005; Schmeir, et al., 2006; Stelmack, et al., 2003). However, Dougherty et al., (2011) found that VA was not statistically significant in the sustained use of LVOD ($\beta=0.935$, SE=1,117, Wald statistic=0.70, $df=1$, $p=0.403$). The authors also found that there was a statistically significant relationship between with non-central vision loss and abandonment ($\beta=1.603$, SE=0.815, Wald statistic=3.87, $df=1$, $p<.050$) suggesting individuals with central vision loss do not abandon their LVODs. In this study there were four identified Abandoners.

Watson et al. (1997) also reported VA as non-significant in the continued use of LVODs in a variety of tasks except for reading ($\chi^2=9.74$, $p<.050$). This
finding suggests that as vision changes as a consequence of AMD, individuals may change their decisions on using LVOD in a variety of tasks. Horowitz et al. (2006) explains that the ability of individuals to continue using assistive devices in their everyday tasks varies and is based on the extent to which they optimize their existing sensory resources against the threat of functional loss. Therefore, the continued use of LVODs depends on individualized perceptions of its efficacy in everyday management of their daily life patterns as individuals experience the progressive consequences of AMD on their vision. Hence, in this study Using Magnifiers yielded Users, Semi-users, and Abandoners.

4. Barriers to LVOD Use

The barriers to optical device use identified by the study include physician, LVOD, personal, and service factors. These are key factors in the continued use of LVODs in optimizing residual vision among individuals with low vision.

a) Physician factors. A comprehensive low vision assessment is important in determining maximum reading potential and prescription of LVODs tailored for the specific needs of an individual with low vision. However, none of the participants were referred for low vision assessment and none of the LVODs were prescribed including those that were purchased from optical shops and the Lighthouse for the Blind. Contrast sensitivity, a basic parameter in assessing the reading ability of individuals with low vision (Glacomelli et al., 2013) was
also not found as a part of the ophthalmic evaluations of the participants. As magnifiers were acquired from various sources and not by prescription, the participant’s LVODs were not designed for their specific individual needs on magnification to maximize the use of their residual vision.

None of the participants was referred for low vision rehabilitation training. With training, eccentric reading and enhancing peripheral vision have been shown to improve the reading ability of individuals with central vision impairment (Palmer, et al., 2010; Yu, Cheung, Legge, & Chung, 2010). The importance of training and use of prescribed LVODs was demonstrated in a study where individuals with low vision improved their ability to read prescribed medication labels from a baseline of 58%-94% among 57 visually impaired adults (Median age=80) 78% of whom have AMD (Markowitz et al., 2008). Although Medicare does not pay for LVODs, central scotoma and moderate to severe vision in the better eye are among the allowable criteria for home visits from low vision professionals (DHHS, Centers for Medicare & Medicaid Services, 2002).

The lack of referral for low vision assessment, training, and prescribed LVODs are not unusual findings. Casten et al., (2005) found that among 80 visually impaired individuals only 24% were aware of low vision services and 83% expressed the desire to enroll, and only 6% of the participants’ LVODs were prescribed. The failure
of the ophthalmologist to discuss the need for low vision training was cited by participants in an ethnographic study \((n=15, \text{Age Range}= 56-90, \text{Mean age} = 75.7)\) by Copolilo & Teitelman (2005). The participants believed that their ophthalmologists did not think of low vision training as a treatment intervention.

The non-referral by ophthalmologists has also been reported by these researchers as serving as barriers to rehabilitation care (Casten et al., 2005; Copolilo & Teitelman, 2005). Furthermore, low vision care has been referred to as “maze care” (Zekert & Gingerich, 2007) due to the circuitous routes that visually impaired individuals have to go through to eventually find their way to a comprehensive low vision assessment and training.

The American Academy of Ophthalmology’s Preferred Practice Patterns (2013) has recommendations on low vision that include statements where ophthalmologists are “encouraged” to give patients information on the available resources for low vision rehabilitation and they “can encourage” individuals with central vision loss by advising them on the effective use of peripheral intact retina. The first citation is labeled as Strong recommendation, Moderate evidence, and the second citation as Strong recommendation, Strong evidence. The language used in this policy reflects weak implementation.

b) LVOD factors. The identified limitations in Using LVODs in DLA (Category 4) are consistent with the findings of other studies about
difficulties in the ergonomic use of the device i.e. how the device was cumbersome and awkward to use (Copolilo & Teitelman, 2005), or they were ineffective for the required task (Dougherty, et al., 2011). Watson et al. (1997) reported the reasons for handheld and stand magnifiers abandonment that included shifting to other types of devices, awkwardness, poor design, little magnification, poor illumination, and changes in vision that were also found in the study, except for shifting to other devices as only handheld devices were included in the study.

Some of the participants suggested better ergonomic LVOD types that would free their hands while reading. Watson et al. (1997) presented the participants’ suggestions for improving handheld and stand LVODs. The suggestions included a wider field view and range of magnification, seeing more detail, automatic focusing, bright contrast, seeing better in close and far distance, and ease of use, cleaning, and maintenance. Currently, handheld optical devices have a wide variety of features that address most of these suggested improvements.

Cost was identified as a barrier. With the wide array of handheld optical devices, notebooks, and the like that feature magnification options, the cost for optical devices is a factor to consider, especially for those who rely on Social Security income only. The participants have pointed out that magnifiers of good quality are expensive. These
magnifiers are not covered by Medicare or insurance third party providers.

c) Personal factors. None of the participants who purchased their LVODs from the Lighthouse for the Blind accessed low vision training. Some of the participants mentioned that they supported the agency through donations, so were aware of the services they offer. According to Freely, Vetere, & Myers, (2007) individuals must be motivated to participate in low vision training and must accept that they are visually impaired. Maclahlan et al. (2007) captured the complexity of the acceptance of vision impairment as related to accessing low vision services. The authors found that avoiding low vision rehabilitation services was a characteristic of individuals with low vision because they don’t consider themselves as “blind” or going “blind”. The authors suggested that strong determination of retaining normalcy and independence result in staying away from or delaying access to low vision training as much as possible. This finding was supported by the strongly voiced “my life is the same” or “I don’t think anything has changed” by the participants in this study that was also consistent with the findings of Southall and Wittich (2012) who identified subjective perception of visual impairment as an inhibitor in accessing low vision care among six focus groups.

d) Service factors. In Discovering magnifiers (Category 1), participants continued to look for new devices that would suit their needs (e.g.
through the internet), but did not have guidance on which type was best suited for their particular needs. The market offers a wide array of devices with the advancement in technology and impulse buying without trying to use the devices first can lead to problems (Copolilo & Teitelman, 2005). The transference of learning from training to optical device use must first transpire for better outcomes (D’Allura, McInerney, & Horowitz, 1995). The literature for non-acceptance of visual impairment is robust, yet the rehabilitation sector has not identified how to bridge the gap of bringing service to this population as the lucrative market of selling magnifiers continues to expand.

**Doing the Best You Can as a Middle-Range Theory**

*Doing the Best You Can* is a theoretical framework of facing adversity through the use of an assistive device, where the adversity is an impending disability and has the rudiments of a middle range theory. The categories represent the core attributes of *Discovering, Losing, Living with, and Using* that are dynamic processes in meeting adversity. The meta-paradigms of people, environment, health, and nursing are well represented in the theory. However, the theory is in its very early stage of development.

The decisions that people have to make in continuing to manage and maintain normalcy while undergoing a devastating change that can eventually lead to catastrophic consequences in daily life patterns are seen in *maintaining independence while depending on others, mobility limitations and keeping social life, having fears and keeping hope alive, and accepting AMD*. These elements are processes where individuals do their best
over time subject to their daily situations as they experience a progressing disease that has physical, social, emotional, and financial consequences.

The theory has similarities with Orem’s self-care deficit theory (1971), where self-care agency is the individual’s ability to meet therapeutic self-care demands of the disease and when there is a deficit, the nurse or care giver assists with nursing agency. Self-care agency is influenced by basic conditioning factors comparable to the descriptive variables of the study. However, losing sight has strong emotional ramifications that characterize Doing the Best You Can and Orem’s theory depicts a more clinical approach that focuses on meeting the individual’s physical needs.

The theory of Doing the Best You Can also shares similarities with resilience (Haase, 2007) where the individual develops strengths to fight stressors and gain positive outcomes and a sense of confidence; and with self-efficacy where individuals execute performance based on their assessments of their capabilities (Bandura, 1997; Resnick, 2007). However, where mastery is the goal of resilience, self-efficacy, and self-care theories, Doing the Best You Can depicts a subjective evaluation of an individual’s “best” that is affected by different forces influencing an individual’s circumstance at a given time so decisions as to what actions to take vary with time. Therefore, an individual’s “best” at a given time may differ to the next moment as different forces influence subjective perceptions of performance as the disease progresses.

The loss paradigm (Kubler-Ross, 1997) may have similar attributes to Doing the Best You Can, where the grief process goes through stages of loss, denial, bargaining, and ends in acceptance. The repeated treatments of the wet form and the advancing disease however, do not equate to a total loss because only the central vision is impaired and the
gains in vision from the treatment keep the hopes of individuals with AMD alive. The nature and process of acceptance in Doing the Best You Can is more complex. The theory requires refinement that can be a subject of future research.

**Implications for Nursing Practice**

The following are potential areas of intervention in nursing practice on the care of the older adult with vision impairment from AMD:

1. Patient’s healthcare assessment
   a. Complaint of seeing “explosion” or a “bomb” or “blood” in front of the eye should warn the healthcare practitioner of potential AMD
   b. Falls assessment, prevention, and education are of extreme importance among individuals with AMD and their families and should be incorporated in documentation. Complaint of not seeing the “bottom”, “last step” or a sense of a “hole” on the ground “everything seems flat” are implications of abnormalities in depth and space perception and are indicative of an imminent fall or history of falls.
   c. Pain assessment and promoting comfort during anti-VEGF treatments. The treatment procedure is uncomfortable and requires strict observance of keeping the eye, head, and body still. The nurse should ensure that patients are comfortable and given adequate instructions ahead of time as to what to expect. Patients should be given practice sessions as to the correct positioning and where to fix gaze prior to the treatment.
   d. Assessment of patient’s understanding of instructions on reporting signs and symptoms of possible adverse reactions from anti-VEGF treatment
indicative of high intra-ocular pressure or infection such as persistent unrelieved eye pain, redness, or swelling.

e. Observe for signs of depression. Individuals with dry AMD have progressing loss of sight without treatment and those with wet AMD who are receiving repetitive anti-VEGF injections have varying outcomes in stabilizing the disease and disappointments may trigger depression.

f. Observe ability to identify multiple medications especially among those who manage their medications and live alone. Ask for recent experiences of adverse reactions.

g. Inquire if the individual’s prescribed spectacles are current. They may be wearing spectacles that are no longer appropriate for their visualization needs.

h. Inquire if still driving and ask probe questions on driving safety (e.g. Are you afraid that you won’t be able to drive the next six months?)

2. Low vision education

Older individuals with vision impairment in any healthcare setting should be educated and given literature on services available for low vision training and transportation services to address access.

3. AMD awareness

AMD is the leading cause of visual impairment and blindness among older adults. Healthcare practitioners should be knowledgeable of the risks and signs and symptoms of the disease. Smoking is a risk so smoking cessation should be
strongly advocated among all age groups. Education literature should include internet sources for access to the National Eye Institute, Prevent Blindness America, and other agencies that focus on educating the public about AMD and should be translated to different languages that comprise the ethnic patient population of the area. The literature should also include detailed information about anti-VEGF injections, procedure of treatment, and signs and symptoms of adverse side-effects.

4. Include the family, significant other, or source of help as an integral part of care as they are the care providers at home. They are valuable in encouraging patients to access low vision care.

5. Involve social services to address needs for transportation access and referral to low vision care, home situation if living alone and need help, and safety assessment.

**Implications for Nursing Research**

There is a paucity of nursing literature on visual impairment and the findings of this study include multiple potential subjects for nursing research in the care of patients with age-related macular disease. Quantitative and qualitative research addressing fall prevention, self-management of medications, avoiding driving pitfalls, improved reading skills, increased use of LVODs, gap in low vision care delivery, pain management and promoting comfort during treatment, continued use of assistive devices, depression, or lifestyle behavioral modifications that lessen risk of AMD are among the many areas of patient care that the study identified. The construction of measurement tools that measure the efficacy of interventions and of theories that capture the experience of losing sight
within the context of the physical, social, emotional, and financial ramifications of AMD is a wide area of exploration.

The theory of Doing the Best You Can needs to be further refined and applied to similar conditions that involve a progressive disease with devastating consequences where the core attributes of Discovering, Losing, Living with, and Using can be tested. Hearing loss, rheumatoid arthritis, or neurologic diseases such as muscular dystrophy and myasthenia gravis come to mind.

Implications for Other Disciplines

The identified gap in service delivery to individuals with AMD is not a new finding. However, the gap has continued to widen and the rehabilitation sector has not caught up with the advances in the expanding business of low vision technology that has proliferated in the internet or have established inventory among optical shops. Currently, visually impaired individuals can access buying optical devices readily at any time however they lack the training that is necessary for the optimized use of their residual vision. Impulse buying without training results to problematic situations. They may find that they cannot follow the instructions considering they have limited vision and there is no one to guide them on how to use the devices.

The old model of low vision training offered in the locations of agencies where visually impaired individuals have to undergo training may no longer work because current and upcoming retirees are active and socially mobile individuals who do not consider themselves as blind or near blind, especially those with AMD. As more baby boomers retire, their demographic characteristics will be different from previous older
adults that rehabilitation specialists previously served, as shown by the characteristics of the participants of the study. Therefore, the paradigm of access to training has to change.

Since a robust literature exists indicating that visually impaired individuals stay away or try to delay low vision rehabilitation, the change should come from the rehabilitation sector. Their services need to be front and center at places where individuals they serve go or frequent and the packaging of the service needs to be presentable to these prospective clients. The rehabilitation sector need to study marketing models on how to introduce their line of service to compete with those whose business is purely vending. Furthermore, a system must be in place where individuals can first receive interactive lessons before their LVOD purchases on line and after the purchase, a live helper over the telephone is available to assist individuals operate their devices. Provisions for trial basis and returns should be guaranteed as long as the device is in good condition.

Ophthalmologists and optometrists who do not specialize in low vision need to refer their patients to low vision specialists for low vision assessment at least once a year so their prescriptions for LVODs that are tailored to their individual current needs can be assessed. Individuals with AMD should also be referred for eccentric or peripheral reading training so they can maximize their reading potential in conjunction with on-going treatments. For their safety, their mobility skills need to be assessed, especially depth and space perception. A conflict of interest exists when the low vision specialist who assesses the individual also owns the optical shop that sells a wide array of LVODs. This practice needs to be regulated.
Ophthalmologists need to refer patients with low vision to social services for assessment of their needs at home and their safety, and for low vision rehabilitation visits at home that is covered by Medicare. Healthcare practitioners must also be keenly aware of their patients’ driving practices and those who continue to drive in spite of the VA restrictions imposed by the state’s Drivers Licenses bureau. Understandably, giving up a driver’s license is equated with curtailed social mobility and independence and should not be taken lightly; however, the safety of the patient and that of the public should be of utmost concern. Screening tests should be improved and renewal of licenses should not be based merely on reading ability. Test driving should be a standard on renewing licenses to test the driver’s reflexes in avoiding obstacles and reading signs.

The American Academy of Ophthalmology would benefit by reviewing its Preferred Practice Policies to reflect a stronger mandate for compliance to low vision assessment and training referrals. Physicians are gate keepers of care and low vision training is a form of treatment and should serve as adjuvant therapy.

**Limitations of the Study**

The study may have been limited by the sample. There were more females than males and Users than Semi-Users or Abandoners. Nevertheless, theoretical saturation was already reached at 12 participant interviews and extended to enrolling six more participants which increased the number of Males and Abandoners. There were three participants who had dry AMD in both eyes and 15 participants who have a combination of both dry and wet AMD. The three patients have a different experience with AMD because they did not receive anti-VGEF treatment.
Recommendations for Future Research

Future studies should be conducted with a more equal distribution of participants as to sex, type of AMD, and LVOD user type to determine consistency of user type characteristics. Visual acuity grouping of moderate and severe visual impairment and grouping of dry and wet forms of AMDS would also yield a more comprehensive comparative analysis of using LVODs among individuals with AMD. A longitudinal study would give more data on continued use of LVODs. A separate study on Hispanic individuals may yield important data on cultural factors that contribute to optical device use and experience with AMD.

Interviewing older adults requires a special skill and review of the literature on conducting active and responsive interviews of older adults would be a good initial approach at reaching an understanding of the interview process. Demographic questions on income level and income sources if not critical to the study should be avoided as these inquiries can be perceived as being intrusive and result in participant withdrawal. Support of the physicians and staff and establishing rapport with the participant during the initial face-to-face contact prior to the interview are critical in recruitment and eliciting responsive interviews. Likewise, interviews need to be conducted as early as possible after obtaining the informed consent to ensure commitment to participation.

The theory of Doing the Best You Can needs further refinement to establish its scope, attributes, elements, and meaning as a quality of life middle range theory. The author hopes that nursing researchers will find this theory helpful in their quest of searching the meaning of nursing.
Summary

This chapter was a discussion of the findings of the study as captured by the theory of *Doing the Best You Can* from the experiences of the participants with living with an age-related macular disease and using optical devices. Although optical devices serve as assistive reading instruments in optimizing residual vision, factors emanating from physicians, the optical device, the individual with AMD, and service delivery serve as barriers for its efficacious use. New findings on signs of AMD and depth and space perception abnormalities as experienced by individuals with AMD and the severe impact of reading disability, facial recognition disability, giving up driving, and depending on others on everyday life were presented.

The author discussed the implications of the findings for nursing practice and research and for other disciplines that serve the needs of the visually impaired and summarized her recommendations. The limitations of the study were identified and recommendations for future research were offered.
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Appendices

Appendix A

The principles of magnification explain how power of lenses, distance, and lighting function in LVOD use.
Principles of Magnification (Brown, 2007)

Low vision optical devices increase the magnification of the retinal image by enlarging the size of the object as it is projected on the retina. The distance of the device to the eye is directly proportional to the size of the object being projected. When the object is brought closer to the eye the retinal image is enlarged. As the object is held farther, the retinal image gets smaller. An enlarged object occupies a bigger area in the retinal surface so it is easier for the functional cells surrounding a scotoma to capture its image.

The power of lenses used for magnification is measured in diopters (D), the optical power needed to focus at 1 meter. As the distance is shortened a higher diopter is required making power and distance inversely proportional. So at one meter, 1D lens is required and at 12.5 cm (1/8 meter) an 8D lens is needed. The focal length is the distance at which an image will appear in focus. So an 8D lens for example has a focal length of 12.5 cm. This is the distance that the reader must hold the magnifying lens from the reading material. In magnification, the number of times the image on the retinal image is enlarged is measured in terms of “X”. Hence 1X means there is no change in size and 2X is double the normal size.

The convex hand held magnifiers add another optical principle, the magnifier–to-eye distance. Modifying the eye-to-magnifying lens distance for a closer view will increase the viewing field and allow more words to be seen without moving the magnifying lens. When moving the lens close to the eye the reading material must also be brought closer to the lens magnifier to maintain the required focal length and obtain optimum magnification results.
Maintaining the required focal distance to the reading material is a disadvantage of handheld magnifiers especially for older adults who may have comorbidities such as arthritis. However, they are inexpensive, portable and best used in activities such as looking at prices, labels, menus, or dialing a telephone. Stand magnifiers are the same as hand magnifiers except for the “stand” that it is mounted on. The height of the stand allows for a constant focal length making it more convenient to simply slide the device across the span of the reading material. Stand magnifiers require the use of bifocals for maximum magnification and have higher diopters than handheld magnifiers. They are mainly used for reading. The disadvantages are less portability and the shadow that it casts directly on the print due to the height of the stand. Hand held and stand magnifiers may or may not be supplied with internal light source that can be switched on and off depending on the need or preference of the user.
Appendix B

The letter sent to Retina specialists and coordinators informing them of the study eliciting support and recruitment of potential participants.
Date

Dear Doctor/Coordinator:

I am a PhD student at the UM school of Nursing & Health Studies and my dissertation research is on “Optical device use: Exploring its impact on the participation in daily living of visually impaired older adults with age related macular degeneration”. The purpose of this study is to explore the experiences of older adults with visual impairment from AMD in managing participation in daily living with the use of assistive optical devices. Barriers to optical device use that result to abandonment and differences between individuals who find LVODs useful and those who have abandoned using them will also be explored.

In-depth interviews following responsive interviewing will be conducted to participants who will be asked “What it is like to lose sight and use optical devices in your everyday activities?” Data analysis will utilize the comparison and theoretical sampling techniques of grounded theory. The inclusion criteria are 65 year old or older individuals, English speaking, primary diagnosis of dry AMD in better seeing eye, BCVA 20/50-20/200 visual acuity in the better seeing-eye, and has been using prescribe low vision devices for more than 6 months. Exclusion criteria include non-English speaking, no telephone access, uncorrected hearing impairment, cognitive impairment, hand restrictions, and nursing home resident. I am hoping that the results of the study will provide a better understanding of our roles as care providers to our visually impaired patients.

I would like to solicit your support through encouragement of your patients or family members to participate should they mention the study during their clinic appointments with you. This research has been approved by the UM IRB. Attached are a post-card summary of the study and the UM IRB approval letter.

Thank you.

Lily P. Orticio RN MSN MBA
Doctoral candidate
University of Miami School of Nursing & Health Studies
Appendix C

Postcard summary of study given to Retina coordinators and placed in clinic rooms that include title, purpose, PI’s contact telephone number, inclusion criteria and exclusion criteria.
Study: Optical device use: Exploring its impact on participation in daily living older adults with age-related macular degeneration

Principal Investigator: Lily P. Orticio RN MSN MBA
Cell: 305-331-3742

Purpose: To explore the experiences of older adults with visual impairment from AMD in managing participation in daily living with the use of assistive optical devices. Barriers to optical device use that result to abandonment and differences between individuals who find LVODs useful and those who have abandoned using them will also be explored.

Inclusion criteria:
1. 65 year old or older
2. Primary diagnosis of dry AMD in best seeing eye
3. BCVA 20/50-20/200 in better seeing eye
4. English speaking
5. Purchased handheld, stand, and/or portable video magnifiers prior to July 1, 2012

Exclusion criteria:
1. No telephone access
2. Non-English speaking
3. Uncorrected hearing impairment
4. Restrictions in hand use
5. Cognitive impairment
6. Nursing home resident
Appendix D

The University of Miami Informed Consent Form for Human Research which the participants signed upon signifying interest to join the study. The form used 20 font size and bold-faced subtitles to accommodate the visual acuity and contrast sensitivity deficits of the participants.
Optical device use: Exploring its impact on participation in daily living activities of older adults with age-related macular degeneration

PURPOSE:
Low vision optical devices help people with severe vision problems improve their ability to perform everyday tasks such as reading, using the telephone, or watching the television. Doing these tasks make them more involved in the activities in daily life.

The purpose of this study is to learn from individuals with age-related macular degeneration like yourself what it is like to lose sight and use optical devices in everyday life such as the ones prescribed for you. Another purpose is to learn what made you decide to continue or stop using the devices.

PROCEDURE:
If you decide to participate in this study I will schedule a telephone interview with you. During the telephone interview I will first ask questions about yourself to learn more about you. I will then, listen
to your story on what it is like to lose sight and what it is like to use the optical devices in your everyday activities. I also want to learn the reasons that made you continue using the device or stop using them.

The interview session may last up to one hour and will be done according to your own pace. You will not be hurried to answer the questions and you may re-schedule if the time is inconvenient. Our conversation will be audiotape recorded. After the interview is completed, I will listen to the interview word for word and compare it to the written version to make sure that everything was recorded. Should I find that I need to clarify a few things that I was not able to address during the interview, I may have to call you again to do so.

**BENEFITS:**

No benefits can be promised for your participation. However, the results of the study may help nurses, physicians, and others in addressing the needs of individuals with low vision like you.

**RISKS:**

The follow-up telephone calls may interrupt your daily routines at home so I will ask you what time is best to call. You may experience emotional discomfort when talking about your loss of sight or
feel that the interview is tedious. Should this happen you have the option to stop the interview momentarily or to resume the interview at a later scheduled time.

**COST:**
There will be no cost to you in participating in this study.

**COMPENSATION:**
You will not be compensated for participating in this study.

**CONFIDENTIALITY:**
The study allows me to read your medical records and obtain information that will be used in this study. I will also ask you questions about yourself. However your records in this study will not be identified as belonging to you. So your name will not be written on any part of your study records. After you have signed your consent, it will be removed and stored separately.

You will be assigned a number that will serve as your identification. A blank sheet will be the top cover of your records to maintain confidentiality. All records will be stored securely and locked in a safe place at my office. All your records will be
considered confidential to the extent permitted by law. I will destroy the audiotape after the study is completed.

The information that you have provided will be combined with the information from other participants of this study. I plan to present the results of this study to professional publication journals and conferences. The results will not identify you.

The Department of Health & Human Services (DHHS) may request to review and obtain copies of your records. The University of Miami or other agents authorized by the University may also review your records for audit purposes. Any individual or entity who reviews your records will be bound by the same provisions of confidentiality.

**RIGHT TO DECLINE OR WITHDRAW:**

You will receive answers to all questions that you may have. You are free to withdraw your consent at any time during the study and discontinue participation without any change to your further care in the University of Miami.
CONTACT INFORMATION:
You may call anytime if you have any questions or concerns. My mobile phone number is (305)-331-3742.

If you have any question or concern about your rights as a research participants you may contact the Human Subjects Research Office at the University of Miami, at (305)- 243-3195.

PARTICIPANT AGREEMENT:

I understand the information in this consent form and agree to participate in this study. I have the chance to ask questions about this study and they have been answered to my satisfaction. I am entitled to a copy of this form after it has been read and signed.

Date: __________________________________________

Signature of participant: ________________________

Date: __________________________________________

Signature of person obtaining consent: ____________
Lily P. Orticio RN
Appendix E

The University of Miami HIPAA Research Authorization utilized to obtain consent from the participants to use and disclose health information from their medical records.
HIPAA Authorization Form

IRB Protocol Number: 20091024
Principal Investigator: Doris Ugartena/Lead-Lilly Ortiz
Departmental Study Code:

HIPAA Research Authorization Template – Form B

AUTHORIZED TO USE AND DISCLOSE HEALTH INFORMATION

I agree to permit the [x] University of Miami [ ] Jackson Health System [ ] both, and any of my doctors or other health care providers (together “Providers”), Principal Investigator and [his/her/their/its] collaborators and staff (together “Researchers”), to obtain, use and disclose health information about me as described below. Authorized staff not involved in the study may be aware that I am participating in a research study and may have access to my information. If the study is related to my medical care, any study-related information may be placed in my permanent hospital, clinic or physician’s office records.

1. The health information that may be used and disclosed may include:

- All information collected during the research and procedures described in the Informed consent Form for the Research as described in the accompanying study specific Informed Consent Form (“the Research”); and

- Health information in my medical records that is relevant to the Research, includes my past medical history including medical information from my primary care physician and other medical information relating to my participation in the study; and

[The following checked boxes must be separately initialed by you in order to permit access to these records]

- [ ] HIV / AIDS status.
- HIV-related information, which includes any information indicating that I have had an HIV-related test, or have HIV infection, HIV-related illness or AIDS, or any information which could indicate that I have been potentially exposed to HIV.
- [ ] Sexually transmitted diseases (STD’s).
- Mental health treatment records governed under state law (including mental health records relating to involuntary or voluntary mental health treatment).
- Mental health records may include substance abuse information.
- [ ] Substance abuse (drug and alcohol) treatment records.
- Substance abuse information may be part of the mental health records.
- [ ] Sexual assault information.

2. The Providers may disclose health information in my medical records to:

- the Researchers;
- representatives of government agencies, any applicable Cooperative Groups, review boards, and other persons who watch over the safety, effectiveness, and conduct of research; and
- the sponsor of the Research, [Enter Sponsor Name],

and its agents, monitors and contractors (together “Sponsor”).

3. The Researchers may use and share my health information:

- among themselves, with the Sponsor, with any applicable Cooperative Groups, health care facilities, research sites, independent data and safety monitoring boards, study monitors and with other participating Researchers (internal and/or external) to conduct the Research;
- Federal and State agencies that have oversight of the study or whom access is required under the law. These may include FDA, OHRP, NIH and Florida DOH; and
- as permitted by the Informed Consent Form.

University of Miami - Office of HIPAA Privacy and Security
PO BOX 010132 (W079)
Miami, FL 33101
(305) 243-5000

HIPAAprivacy@med.miami.edu

AUTHORIZATION TO USE AND DISCLOSE HEALTH INFORMATION

Form 03901001E
Revised 1210/10

Required Information: Please Complete.

NAME:__________

MRN:__________ □ IDX □ SMS

ID#:__________ □ SS # □ DL # □ PASSPORT # □ OTHER

AGE: ______/_____/______

DOB: ______/_____/______

DATE OF SERVICE: ______/_____/______

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Page 1 of 2
4. The Sponsor and any applicable Cooperative Groups may use and share my health information for purposes of the Research, data safety and monitoring and as permitted by the consent form.

Contract Research organization(s): [insert name of CRO or SMO if applicable or delete]

5. Once my health information has been disclosed to a third party, federal privacy laws may no longer protect it from further disclosure.

6. I hereby authorize the Sponsor to observe any medical procedures I undergo as part of the Research.

7. Please note that:
   You do not have to sign this Authorization, but if you do not, you may not participate in the Research. If you do not sign this authorization, your right to other medical treatment will not be affected.

   You may change your mind and revoke (take back) this Authorization at any time and for any reason.

   To revoke this Authorization, you must write to either of the following:

   Research Study Personnel Name: Lily P. Ortizio
   Address: 3551 Magellan Cirle #422 Aventura, FL 33180
   Tel. No.: 305-231-3742
   Human Subjects Research Office
   Address: 1500 NW 12th AVE, Suite 1002 Miami, FL 33136
   Tel. No.: (305) 243-3195

   However, if you revoke this Authorization, you will not be allowed to continue taking part in the Research. Also, even if you revoke this Authorization, the Providers, Researchers, any applicable Cooperative Groups and the Sponsor may continue to use and disclose the information they have already collected to protect the integrity of the research or as permitted by the Informed Consent Form.

   While the Research is in progress, you may not be allowed to see your health information that is created or collected by the University of Miami, Jackson Health System, both, in the course of the Research. After the Research is finished, however, you may see this information as described in the University of Miami, Jackson Health System, both, Notice of Privacy Practices.

   *Study personnel must send copies of participant revocations to: Office of HIPAA Privacy and Security AND the Human Subjects Research Office.

8. This Authorization does not have an expiration (ending) date. There is no set date at which your information will be destroyed or no longer used. This is because the information used and created for the study may be analyzed for many years, and it is not possible to know when this will be complete.

9. You will be given a copy of this Authorization after you have signed it.

   Signature of participant or participant’s legal representative

   Date

   Printed name of participant

   Printed name of legal representative (if applicable)

   Representative’s relationship to participant

   Study personnel must send copy with signature to the Office of HIPAA Privacy and Security

   For questions, contact the Human Subjects Research Office at 305-243-3195.

   University of Miami - Office of HIPAA Privacy and Security
   PO BOX 019132 (M878)
   hppa.privacy@med.miami.edu
   Miami, FL 33101
   (305) 243-5000

   AUTHORIZATION TO USE AND DISCLOSE HEALTH INFORMATION

   Form
   03901001E
   Revised
   12/10/10

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Appendix F

The demographic survey questionnaire used to collect data on age, gender, marital status, ethnicity, income and source of income, educational attainment, primary language spoken, whether they have insurance and type of insurance, whether living alone, source of help, activities of interest and hobbies, type/s of LOVDs being used, how long ago LVOD was purchased, how it was obtained, frequency of use, and if they have used the LVOD the past three months, whether the participants are still driving, source of transportation help if not driving, and incidences of falling the past year.
Demographic Survey

Study: Optical device use: Exploring its impact on participation in daily living activities of older adults with AMD

Principal Investigator: Lily P. Orticio RN MSN MBA

Participant ID number_____________ Date________________

1. Type of LOVD prescribed: _____ handheld _____ stand _____ portable video Had for _______ Months/years How obtained ______ prescribed ______ purchased from store ______ given by someone __________ Other ______________________________________________________________________

   How frequently used per day? _____ Have used in the past 3 months? ____ YES _____ NO


5. Ethnicity: □ White Caucasian □ Hispanic □ African descent □ Asian/Pacific Islander □ Other ______________

6. Gross Income: □ Below $25,000/yr. □ $26,000 -50,000/yr □ $51,000 -75,000/yr □ $76,000 -100,000/yr □ 101,000 -125,000/yr □ $125,000 -150,000/yr □ above 150,000/yr

7. Source of income: □ Social Security □ Retirement □ SSI □ Investment □ Salary, still employed □ Other ______________

8. Insurance: □ Medicare □ Medicaid □ Private Insurance □ Self-pay □ PHT □ DBS □ Other ______________


   ____ NO Who do you live with? □ Spouse □ Family □ Friend □ Other ______________

10. Primary language spoken □ English □ Spanish □ Creole □ Other ______________

11. Educational level: □ Primary □ High School □ College □ Masters □ PhD □ Other ______________

12. Are you retired? □ YES □ NO Number of years retired □ less than 1 yr □ 2-5 yrs □ 6-10 yrs □ > 10 yrs □ more than 10 years

13. What kind of work do you do? ______________

14. Hobbies: □ Reading □ Watching television □ Crafts/Sewing □ Shopping □ Gardening □ Going to the movies or theatre □ Going to sports events □ Going to political events □ Other ______________

15. How many times have you gone out to visit friends or family the past month? □ once □ 2 times □ 3 times or more □ does not go out of the house

16. Do you still drive? ____ YES □ NO How far do you drive? □ < 5 miles □ 5-10 miles □ 11-20 miles □ >20 miles

   □ NO Is there someone who drives or takes you to where you want to go? ____ YES ____ NO

   □ If YES Who takes you? □ Family □ Friend □ Neighbor □ Other

   □ If NO How do you get around? □ Public transportation □ Taxi □ Pays somebody □ Medicaid transportation □ Does not get around anymore □ Other ______________

17. If you are still driving, are you afraid that you won’t be able to drive in the next 6 months? _____ YES _____ NO

18. Have you fallen the past 12 months? _____ NO _____ YES How many times? _____ 1 _____ 2 _____ 3 _____ > 3 times

   Were you injured during at any time? _____ YES _____ NO
Appendix G

The ophthalmic and medical data tool used to collect data on near BCVA, distance BCVA, contrast sensitivity, duration of AMD, ophthalmic and medical comorbidity/ies, and current medications taken.
Ophthalmic and Medical Profile

Study: Optical device use: Exploring its impact on participation in daily living activities of older adults with AMD

Principal Investigator: Lily P. Orticio RN MSN MBA

Participant ID number_________ Date file reviewed ______________

Type of LOVD prescribed: _______ handheld _______ stand _______ portable video

1. BCVA Near VA: OD _______ OS _______ BCVA Distance VA: OD _______ OS _______

2. Contrast sensitivity: Near OD _______ OS _______ Distance: OD _______ OS _______

3. Duration of AMD: □ less than a year □ 1-5 years □ 6-10 years □ more than 10 years

5. Low vision rehabilitation home visits: □ YES Number of visits _______ □ NO

6. Other eye conditions: □ Cataract □ Glaucoma □ Diabetic Retinopathy □ Other ____________________________

7. Other Co-morbidities: □ HTN □ Diabetes □ Cardiovascular disease □ Other ____________________________

8. Medications currently taken: ________________________________________________________________
   _______________________________________________________________________________________
   _______________________________________________________________________________________
   _______________________________________________________________________________________
   _______________________________________________________________________________________
Appendix H

The set of interview questions used as guide during the in-depth responsive interviewing.
Interview Guide Questions

1. Tell me when did losing good vision begin for you?

2. Tell me how you felt when you were told you have AMD?

3. How was it to use __________(type/s of LOVD/s) the first time? The succeeding times? Now?

4. What activities do you find __________(types of LOVD/s) useful? Less useful?

5. What made it easier for you to use your __________(type/s of LOVD/s) ?

6. What hindered you from using __________(type/s of LOVDs) ?
Appendix I

Additional probe questions utilized as data collection and analysis progressed from the in-depth interviews.
Probe question added to the Interview Guide Questions:

1. Please tell me about your losing good vision.
   a) How and when did you notice that you were losing sight?
   b) Please describe what is wrong with your sight (Added 4/4/2013)
   c) How do you see letters? (Added 5/6/2013)
   d) How do you see colors? (Added 5/27/2013)

2. Please tell me how you felt when you were told you have AMD?
   a) What questions did you ask? (Added 3/6/2013)
   b) How did you find out about AMD (Added 3/6/2013)

3. Please tell me about your using your experience with using your magnifier.
   a) How was it to use your magnifier the 1st time? The succeeding times? Now?
   b) What activities do you find your magnifier useful? Less useful?
   c) What made it easier for you to use your magnifier?
   d) What stops you from using your magnifier?
   e) How did you obtain your magnifier? How easy was it to get?
   f) What advice would you give someone who is just starting to use a magnifier? (Added 3/6/2013)

4. Living with AMD, what was the biggest change in your everyday life?
   (Added 3/6/2013)
   a) What activities do you miss because of poor vision? (Added 3/6/2013)
   b) How did you feel when you were told that you could no longer drive Or, how would things change in your daily life if you are no longer able to drive? (Added 3/28/2013)

5. What advice would you give to someone who is recently diagnosed with AMD (Added 3/28/2013)

6. When you are walking, how afraid are you that you might fall? How about taking the stairs? (Added 3/10/2013)
Lily Perete Orticio was born in Sagpon, Daraga, Albay Philippines to Elizabeth Perete, an elementary grades teacher and Adolfo Orticio, a businessman (both deceased) and spent a happy childhood with four siblings. She graduated from kindergarten, elementary and high school from Bicol University, Legazpi City, Philippines. She was admitted to the College of Nursing of the same university in June 1973 and graduated with a Bachelors’ degree in April 1978.

In 1981, while working as a Head Nurse in Tondo General Hospital in Manila, Philippines, she was recruited by Hospital Corporation International to work at the University of Miami Bascom Palmer Eye Institute considered as the best institution for ophthalmology in the U.S. She arrived in Miami in March 1982, learned the rudiments of ophthalmic nursing, and easily adjusted to the multi-ethnic city and its tropical climate. She decided to advance her scholarly pursuits while she was working as an R.N. She was accepted at the University of Miami, where she graduated with a Master’s degree in Nursing in August 1989, a Master’s degree in Business Administration in December 1994, and a Ph.D. in Nursing in August 2013. Her area of business specialization is Healthcare administration and her Master’s thesis and Ph.D. dissertation research area is the care of individuals with vision impairment.

Lily worked with leading ophthalmologists and scientists in the world renowned Bascom Palmer Eye Institute for 30 years and rose in rank to Director of Nursing until May 2012. She is a national and international lecturer in ophthalmic nursing and nursing management and an author of several peer-reviewed publications. She continues to enjoy tropical Florida and lives in the city of Aventura with her furry friend Georgia.