

Longitudinal impact of newly acquired closed-circuit  
televisions (CCTV) on quality of life for low vision  
patients

by

Jessica Huber

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## **Author's Declaration**

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

## **Abstract**

Ongoing efforts to quantify changes in quality of life attributable to low vision rehabilitation have focused on the utility of a single test instrument to measure this multidimensional concept. It is hypothesized that quality of life is best assessed using multiple instruments to capture some of its component facets, including functional status and psychosocial impact. Low vision devices have a predictably spontaneous impact on functional vision status, but associated psychosocial impact occurs with different magnitudes and over more protracted time intervals.

The National Eye Institute Visual Function Questionnaire (NEI VFQ-25) measures the functional status of individuals in key vision areas that are associated with quality of life. The Psychosocial Impact of Assistive Devices Scale (PIADS) is an instrument that measures the psychosocial impact of assistive device intervention in three quality of life domains: competence, adaptability, and self-esteem.

68 participants were obtained from an ongoing parent study. These participants were recruited through the Low Vision Clinic at the University of Waterloo. They had a primary diagnosis of age-related macular degeneration (ARMD) and were obtaining a CCTV system for the first time. Assessments from the parent study used in this thesis included follow-up from 2 weeks, 1 month, 3 months, and 6 months post-adoption of the CCTV. The two tests administered were to measure functional vision status (NEI VFQ-25) and

perceived psychosocial impact (PIADS), according the framework outlined by the Consortium for Assistive Technology Outcomes Research (CATOR).

Multivariate repeated-measures ANVOA results confirmed that CCTV systems have an immediate and robust effect on the daily visual functioning of their users, and that this effect is stable over long periods of device use. The psychosocial impact of CCTV device use peaks in the shorter term and then seems to wane in the longer term for reasons that are not yet understood.

The NEI VFQ-25 and the PIADS appear to have differential sensitivity to important influences on low vision rehabilitation outcomes. This project has demonstrated the value of longitudinal outcomes research in low vision rehabilitation. After obtaining a CCTV, visual function status remains static while psychosocial impact is dynamic during 6-months of follow-up.

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## **Dedication**

I dedicate this thesis to everyone who helped and supported me through this time of my life. I am forever grateful.

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# Chapter 1: Introduction

## 1.1 Overview of the problem

As population ages, there has been a concurrent increase in the prevalence of vision loss due to age-related eye conditions. One of these conditions is age-related macular degeneration (ARMD). Elderly people with ARMD face functional and psychosocial difficulties in addition to the physical concerns of ARMD. Reading difficulty is one of the most prominent concerns as it affects independence and quality of life. The closed-circuit television device (CCTV) is one important device to assist people with ARMD-related vision loss. Data on the longitudinal impact of newly acquired CCTV devices on the quality of life for ARMD-related low vision patients is scarce. Understanding the entirety of the impact of CCTV devices is important for the future direction of rehabilitative services.

The rapidly aging population has contributed to an increased pressure on medical care and other social services. A significant factor in this aging population is the large number of baby boomers (those born between 1946 and 1962) who are approaching retirement age. The 2006 Census indicates that the 65-and-over population made a record of 13.7 % of the total population of Canada.<sup>2</sup> Also, a new record of 3.7 million Canadians age 55 to 64 were recorded (many of whom are workers approaching retirement).<sup>2</sup> The demand for health care is increasing faster than the resources available to provide services due to the aging of the population, the development of new

knowledge and technology, and the heightened awareness and expectations of patients and professionals.<sup>3</sup> A better understanding of the impact of assistive devices on people with ARMD and how it changes over time will allow us to develop a better plan for dealing with these people as their numbers increase in the future.

The increased number of elderly people is associated with an increased prevalence of ARMD within the population. ARMD is the most common cause of irremediable vision in elderly population; consequently, there will be increased numbers of people with ARMD-related low vision seeking rehabilitation services and assistive devices. The elderly are disproportionately affected by vision loss. Individuals over the age of 65 years experience more vision loss than any other age group.<sup>4</sup> Next to arthritis, vision impairment is the most common cause of disability in the elderly.<sup>4</sup> When decrements in vision occur, they compromise an older person's ability to carry out routine activities, diminish overall function, and decrease quality of life.<sup>4,5</sup> Many of the negative consequences of vision loss (such as those of ARMD) can be mitigated by rehabilitation, and needless suffering can be diminished. Given the association between age and vision loss, the demand for low vision rehabilitative services will increase significantly.<sup>3</sup> In order to provide better rehabilitative care, it is important to address the issues related to the impact of assistive devices on people with ARMD-related low vision. With the increasing number of elderly persons with ARMD and with the increasing pressure this creates on rehabilitation resources, finding measurement tools

which reflect the visual function status and the psychosocial impact experienced by those who have received a CCTV (through the rehabilitative process) is critical in order to improve rehabilitative services. *Psychosocial impact* refers factors within the individual person and to factors related to the environment that affects the psychological adjustment of an individual with a disability.<sup>6</sup> Understanding of the functional and psychosocial factors will contribute to improved outcomes for device adoption and retention.<sup>6</sup>

The impact of ARMD-related low vision has been investigated through a variety of studies; however no study has specifically looked at the *longitudinal* impact of assistive devices for people with age-related macular degeneration. Studies pertaining to ARMD are: quality of life studies,<sup>7-10</sup> low vision rehabilitation studies,<sup>4, 11, 12</sup> and studies assessing visual function.<sup>13-16</sup> In a clinical setting, measurements such as visual acuity and contrast sensitivity are used to assess the severity of ARMD, but these measures may be poor indicators of the overall impact of the disease on a person's life. This has led to an increased interest in measuring quality of life for people with ARMD. In clinical vision rehabilitation settings, patients are provided the opportunity to be assessed functionally with assistive devices such as CCTV devices. Due to the lack of longitudinal research for the impact of assistive devices, there is limited information about how the CCTV affects a person's life after leaving the clinic. Longitudinal research can show the changes which occur over time while the patient uses her/his CCTV.

Assessing the longitudinal impact of newly acquired CCTV devices on quality of life for low vision patients with ARMD will allow us to better understand the impact of assistive devices (CCTV) and to identify missing gaps in current research. We need to understand the impact of such devices on people with ARMD. Important concepts, terminology, and background information will be covered including: age-related macular degeneration low vision, low vision rehabilitation, assistive devices, quality of life, outcomes research, models in outcomes research and measurement tools in outcomes research.

## **1.2 Age-Related Macular Degeneration Low Vision**

Age-related macular degeneration (ARMD) is the leading cause of vision loss in the industrial world.<sup>17</sup> A full understanding of the impact of ARMD low vision includes the understanding of the two main classifications of ARMD (wet and dry), treatment options, and the population affected. Finally, it is important to comprehend how functional vision and quality of life is affected by ARMD.

Dry ARMD occurs as a result of accumulation of deposits (drusen) on the central retina followed by the gradual loss of photoreceptors, which is accompanied by a gradual reduction in visual acuity.<sup>18</sup> Dry ARMD may lead to profound loss of photoreceptors in the central retina (geographic atrophy).<sup>18</sup> Wet ARMD or exudative ARMD occurs when blood vessels invade the retina from below in the macular region.<sup>18</sup> The progression of wet ARMD is much faster compared to dry ARMD. As the condition progresses, a non-seeing area

(scotoma), distortion, or relative loss of sensitivity may develop in the central field of vision. People with central scotoma must use eccentric retinal areas to perform visual tasks that the non-functioning (or impaired) fovea used to perform.<sup>19</sup> According the National Eye Institute (US), 1.5% of Americans have advanced ARMD, and 6.1% of Americans have intermediate ARMD.<sup>20</sup> The prevalence increases directly with age; the largest proportion of ARMD is in people over the age of 80 years old.<sup>20</sup> The population prevalence and incidence of ARMD are likely to increase dramatically with the aging population – some estimates state by 50%.<sup>21</sup> The ratio of patients diagnosed with dry versus wet ARMD has been typically reported as about 90% versus 10% respectively.<sup>19</sup> Although more people have dry ARMD, indications are that the prevalence of people referred to vision rehabilitation services by dry versus wet ARMD is nearly 50-50.<sup>19</sup>

Treatments available for ARMD are relevant for a select group of patients, for whom the treatments primarily slow or arrest the progression of vision loss.<sup>7</sup> Recent advances have improved the efficacy of treatments, but vision still cannot be restored to a “normal” level of functioning. Recent treatments have been somewhat more effective at restoring some vision, but not to the previous level. For wet ARMD, treatment options include laser surgery, photodynamic therapy, and intravitreal injections. The results of treatments for dry ARMD indicates that high-dose formulations of antioxidants and zinc may significantly reduce the risk of advanced ARMD and its associated vision loss.<sup>22</sup> Nevertheless, people with both types of

ARMD have the option of seeking rehabilitative care in order to maximize their remaining visual function.

Many definitions of low vision pose a challenge because they are based on how treatable a disorder may be.<sup>21</sup> The term “vision loss” may include modest low vision to total blindness, whereas “low vision” indicates that the person is not functionally blind and that the vision is less than normal.<sup>21</sup> *Low vision* is defined as any condition of diminished vision not correctable by standard glasses, contact lenses, medication or surgery that disrupts a person’s ability to perform common age-appropriate visual tasks.<sup>21</sup> With ARMD-related low vision, central vision may be lost but the person always retains a significant amount of peripheral vision, and treatments are most effective in slowing the progression of vision loss.

The impact of ARMD-related low vision is detrimental to the well-being of a person. Blindness is one of the three leading fears of Americans, after cancer and AIDS/HIV.<sup>23</sup> Vision loss interferes with instrumental activities of daily living and social function, leisure activities, and mobility. ARMD can make daily activities such as reading, driving, recognizing people, and cooking extremely difficult or impossible. Vision loss has been linked to an increase in hip fractures, falls, and depression.<sup>24</sup> There is an increase in physician visits, hospitalizations, mortality, and family stress.<sup>5</sup> Patients with ARMD are more likely than their normally sighted peers to need help with daily activities.<sup>25</sup> Severity of ARMD is associated with poorer scores for near vision activities and driving.<sup>25</sup> The limitations and frustrations experienced by

people with low vision can result in depression and, in many cases, a deterioration in general health.<sup>26</sup> Research has shown that visual impairment is significantly associated with decreased functional status, diminished self-reported quality of life, and increased emotional distress.<sup>25</sup> Fortunately, there is a possibility of people returning to active, productive, and independent life styles with the assistance of low vision aids and rehabilitative training.<sup>26</sup> It is estimated that ninety percent of individuals with significant vision loss may benefit from vision rehabilitation that includes enhancement of adaptive skills and training in the use of optical and non-optical low vision devices.<sup>4</sup>

When a person experiences increased difficulty in performing daily living tasks, her or his physical, functional, and psychosocial life is affected. In order to improve the rehabilitative process for persons with ARMD-related low vision, it is important to understand the impact of rehabilitation on the functional and psychosocial aspects of their lives.

### **1.3 Low Vision Rehabilitation**

Low vision rehabilitation provides opportunities for people affected by ARMD-related low vision by offering a wide range of devices and training. Rehabilitation was defined by the World Health Organization (WHO) as a process aimed at enabling persons with disabilities to reach and maintain their optimal functional levels.<sup>27</sup> With the development of the International Classification of Functioning, Disability and Health (ICF), the definition of rehabilitation was broadened to recognize the personal and environmental factors directly influencing the experience of people with disabilities.

Currently, *rehabilitation* is considered to be a coordinated process that enhances activity and participation.<sup>1</sup>

The primary objectives of low vision rehabilitation are to maximize functional independence, to maintain quality of life, and to help people adapt to the psychosocial aspects of vision loss. The requisite interventions may include assistive devices, training, and counselling services.<sup>25</sup> At the outset, it is important to ensure that the causal medical eye condition is evaluated and treated in order to maintain and maximize the patient's visual potential. People are then trained to use their residual vision more effectively. Services also may include practical environmental adaptations to facilitate activities of daily living, to ensure safety, and to maintain independence. Rehabilitation uses assistive technology, adaptive skills, and environmental modifications.<sup>28</sup> All of these techniques increase independence, reduce stress and depression, improve mobility, and increase quality of life.<sup>29</sup>

Another goal for rehabilitation is to provide the individual with some functional reserve capability. *Functional reserve* is the difference between the patient's-total visual ability and the actual visual ability that is required to perform an activity.<sup>30,31</sup> For example, a person may be able newspaper text using a 4x magnifier, but an 8x magnifier often provides enhanced reading proficiency, which may mean that the person can read more comfortably and for a longer period. To be functionally independent, individuals must be able to perform activities that allow them to maintain themselves in their habitual environment.<sup>30</sup> Inability to perform desired activities may have negative

impact on some or all of the following: daily living, social interaction, recreational, vocational, and educational.<sup>30</sup> Functional reserve for a given activity can be increased by increasing the visual ability of the patient or by decreasing the visual ability needed to perform the activity.

Successful low vision rehabilitation alters the relationship between visual impairments and their consequent visual disabilities. The level of visual impairment may remain stable (visual acuity, contrast sensitivity, and visual field defect), but the person's ability to perform vision related tasks is improved due to vision rehabilitation (which may or may not include training and assistive device use).<sup>32</sup> Vision rehabilitation is a multidimensional learning process in which a patient must acquire new skills, change behavior patterns, grieve the loss of normal vision, and make the emotional shift from a normal sighted to a visually impaired person.<sup>4</sup> These changes go well beyond evaluation and prescription of devices.

With the definition of low vision rehabilitation (a coordinated process that enhances activity and participation) we are able to specify the goals of rehabilitation and assistive use. Those goals are: to maximize functional independence, to maintain quality of life, to help a patient adapt to the psychosocial aspects of vision loss, and to improve functional reserve.

## **1.4 Assistive Devices**

An important component in vision rehabilitation is the assessment and provision of assistive devices. Most people use some form of assistive technology on a daily basis. Whether it is a computer, glasses, or even our can

opener, we are using devices to help us in every day tasks. *Assistive technology* includes structural alterations, special equipment, assistive devices, material adjustment, or environmentally-based behavioral modifications.<sup>33</sup> Assistive technology is recognized as one environmental factor which can have a major impact on activities and participation.<sup>12</sup> It provides a means for circumventing barriers (such as inability to read), which subsequently increases activity participation.<sup>34</sup> Persons use assistive technology in order to gain access to, operate within, move through, and/or have an effect on their physical and social environments.<sup>34</sup> Older adults use assistive technology to diminish the disabling effects of illness and the physiological and cognitive changes due to ageing.<sup>34</sup>

*Assistive devices* are applied to, or directly manipulated by, a person; e.g. wheelchairs, reaching devices, voice-output communication aids, and hearing or vision aids.<sup>33</sup> They are considered essential to the health and well-being of all people, but especially people with sensory or physical disabilities.<sup>35</sup> Studies have shown that persons with visual impairment are more dependent in daily activities than persons with normal vision at the same age.<sup>12</sup> For example, approximately 25% of persons aged 65 years and older own an assistive device and about one-third of these people own multiple devices.<sup>34</sup>

*Low vision assistive devices* are assistive devices that are specifically designed for people who have low vision. Examples of low vision assistive devices are magnifiers, telescopes/binoculars, glare control devices, closed-

circuit television (CCTV) devices, or adapted computer systems. Ninety percent of seniors over 75 years of age who reported vision limitations also reported using vision aids.<sup>36</sup>

As described earlier, people with ARMD often experience some amount of central vision loss which interferes with high visual acuity tasks such as reading. A major rehabilitation objective for someone with ARMD-related low vision is to be able to read normal sized print/text. In order to do this, many people require some form of magnification device, such as an optical magnifier or a CCTV system. Other commonly prescribed devices help people with ARMD cope with glare. For example lenses with selective transmission properties in them and proper illumination control are strategies for lessening glare and increasing contrast. CCTV devices were chosen for research in this study because they are versatile and effective devices with demonstrated potential utility for a broad range of impairment presentations and task activities.<sup>32</sup>

CCTV assessments are conducted in accordance with a competitive enablement approach. *Competitive enablement* is “a conceptual approach wherein the functional impact of competing device interventions is evaluated by individual patients while performing a series of self-identified problematic tasks having high functional relevance to the individuals themselves”.<sup>32</sup> Using a competitive enablement approach to selecting devices allows the patient to have side-by-side comparisons of the devices to decide which device is most appropriate for the activities she/he feels are important.

Technology assisted rehabilitation using CCTV devices is intended to promote a healthy outcome by adoption of the CCTV, acceptance of the CCTV and adherence to its prescription, and satisfaction with the CCTV.<sup>37</sup> The decision-making process for older adults who are contemplating the use of assistive technology is influenced by various personal factors. These include whether the assistive technology will serve as an effective strategy for coping with their limitations, the preservation of preferred self-image, and/or the degree of importance attributed to independence, control and cost savings. The competitive enablement approach allows the person to evaluate various CCTV models in order to determine whether the CCTV will meet their personal needs. CCTV use may promote increased participation, which provides a basis for coping with and adapting to barriers, improves function, and may enhance quality of life.<sup>34, 38</sup>

Contemporary research is investigating the success of rehabilitation using assistive devices. Dahlin-Ivanoff *et al.* (2004) found a high proportion of assistive device users among the visually impaired population and these users reported assistive devices to be important tools in their attempts to remain independent in daily living.<sup>12</sup> Mann (2002) found that device effectiveness (for maximizing independence) plays an important role in determining whether people with severe visual impairments view assistive technology as an effective or ineffective strategy for coping with limitations.<sup>34</sup> Mann (2002) suggests that employing healthy or unhealthy coping strategies is a personal choice and will influence assistive technology use or non-use.<sup>34</sup>

Specific to CCTV devices, it has been shown that CCTV devices provide substantial psychosocial benefit to patients with low vision.<sup>32</sup> Reading speed and endurance are improved significantly with CCTV systems in comparison with prescribed optical devices for participants whose primary diagnosis was ARMD.<sup>39</sup> The CCTV has been shown to be a successful device in assisting people with ARMD and improving their quality of life.

## **1.5 Quality of Life**

As mentioned previously, the goal of technology assisted rehabilitation is to improve quality of life. The definition of quality of life has evolved over time. Quality of life has been measured in the form of assets and environmental conditions and it has been viewed as the impact of assets on one's emotions and mood (i.e. happiness and well-being).<sup>25,37</sup> The limitation of these perspectives is that they are more descriptive of a standard of living.<sup>37</sup> In the health care field, quality of life is measured as health-related quality of life. Health-related quality of life is more focused on assessing health status or change in health status and not the impact of rehabilitation.<sup>6</sup> The limitation with this perspective is that it is too medically orientated.<sup>6</sup> CCTV devices are not intended to promote health or healing, but rather to improve functional capabilities. In order to obtain a definition of quality of life which would be suitable to someone affected with low vision, the assumption has been made that quality of life is complex, a multidimensional construct, dynamic, changing over time, and changing over a person's life.<sup>6</sup> Quality of life arises from a person's interaction with their environment and it is experienced

differently from person to person, but it has the same components for everyone.<sup>40</sup> For the purposes of this research, *quality of life* is defined the degree to which a person enjoys the important possibilities of their life.<sup>37</sup>

Vision-related quality of life is often measured by means such as cognitive functioning, depression, activities of daily living, or social functioning.<sup>25</sup> The value of these criteria lies in the ability to assess selected parameters in depth.<sup>25</sup> These vision specific quality of life measures provide an overview of the effect of the condition related to the visual impairment.<sup>41</sup> To understand low vision rehabilitation and to measure the effects of intervention, we must be able to measure visual impairment. Obviously, such measurements must be based on measurements of visual ability.<sup>41</sup> Therefore vision-specific quality of life is the subjective interpretation of the patient's visual ability since her/his vision has been affected by a condition such as ARMD.

Vision-related quality of life is not the same as functional vision. Two people with the same degree of functional vision do not necessarily have the same quality of life. Similarly, two people with the same functional vision receiving the same assistive device may report different impacts because the device affects different aspects of their quality of life. Another important feature to understand about quality of life is that it changes throughout a person's life. Therefore, it is imperative to evaluate quality of life over time in order to track any changes that are occurring. If a test is administered only at

one point in time, any changes experienced by the person (such as someone with ARMD who has received a CCTV) over time will not be recognized.

Assistive devices such as the CCTV are shown to have a positive impact on quality of life in areas of functional status and psychosocial impact.<sup>32</sup> An assistive device should promote good quality of life for the user to the extent to which it makes the user feel competent, confident, and inclined (or motivated) to exploit life's possibilities.<sup>37</sup> Subjective measurements of quality of life are imperative because changes in the patient's own perception of his or her quality of life is one of the most meaningful intervention outcomes.<sup>31</sup>

A longitudinal study on quality of life is necessary to monitor and understand changes after a person receives an assistive device such as a CCTV. Quality of life in this study is seen as the effect of the devices on the degree to which a person enjoys the important possibilities of their life. The loss of reading is typically a major complaint for people with ARMD-related low vision. By using measurement tools to assess the longitudinal psychosocial impact and functional status of a person with ARMD-related low vision, we can comprehend the changes in quality of life which occurs after obtaining a CCTV device to restore lost reading capability.

## **1.6 Outcomes Research**

Outcomes research serves several functions in evaluating the interventions recommended by providers whose intention is to assist individuals in improving their quality of life. Outcomes research is concerned

with verifying that the interventions are causally responsible for observed changes in the targeted individuals or populations and with developing an improved understanding of these causal relationships.<sup>42</sup> Outcome research helps answer questions such as what services work, under what particular conditions, for what service recipients.<sup>43</sup> Patient-based outcomes, that measure constructs such as health-related quality of life, subjective health status, and functional status, are used increasingly as primary or secondary end-points in clinical trials.<sup>44</sup>

Outcomes research – specifically assistive technology outcomes research – uses systematic investigations to identify changes that are produced by assistive technology in the lives of users and their environments.<sup>33</sup> An ideal model for rehabilitation treatment would explain why particular interventions achieve the outcomes they do.<sup>33</sup> Low vision outcomes must be studied with the same rigor as other medical treatments to develop an evidentiary basis to guide policy and funding decisions.<sup>3</sup> Although it is incontrovertible that many patients can improve their performance with low-vision devices, not all patients are successful device users. In the evaluation of outcomes, some studies have recognized this difference between efficacy (the ability to perform tasks in the clinic) and effectiveness (the use of device and skills in everyday life, once the patient returns home).<sup>45</sup> Outcomes research provides an avenue for studying the link between rehabilitation, assistive devices, and a person's perspective on quality of life.

Outcomes research is essential for understanding participants with ARMD-related low vision who use CCTV devices to improve their quality of life.

## **1.7 International Classification of Functioning, Disability, and Health (ICF)**

The International Classification of Functioning, Disability and Health (ICF) is one conceptual framework which can be used in order to understand the impact of assistive device use in patients with low vision. It is important to understand what the ICF is describing and how it differs from past models.

The International Classification of Functioning, Disability and Health (ICF) was developed in response to the shortcomings of the predecessor model of the International Classification of Impairments, Disabilities, and Handicaps.<sup>46</sup> The overall aim of the ICF classification is to provide a unified standard language and framework for the description of health and health-related status.<sup>1</sup> It defines components of health and some health-related components of well-being.<sup>1</sup> The ICF differs from the original 1980 model in that it has two essential factors, each with two subcomponents: (1) Functioning and disability – body functions and structure; activities and participation; (2) Contextual factors - environmental factors, and personal factors.<sup>1</sup> These domains interact with each other and are influenced by both environmental and personal factors.<sup>46</sup> Functioning is an umbrella term encompassing all body functions, activities and participation. Disabilities

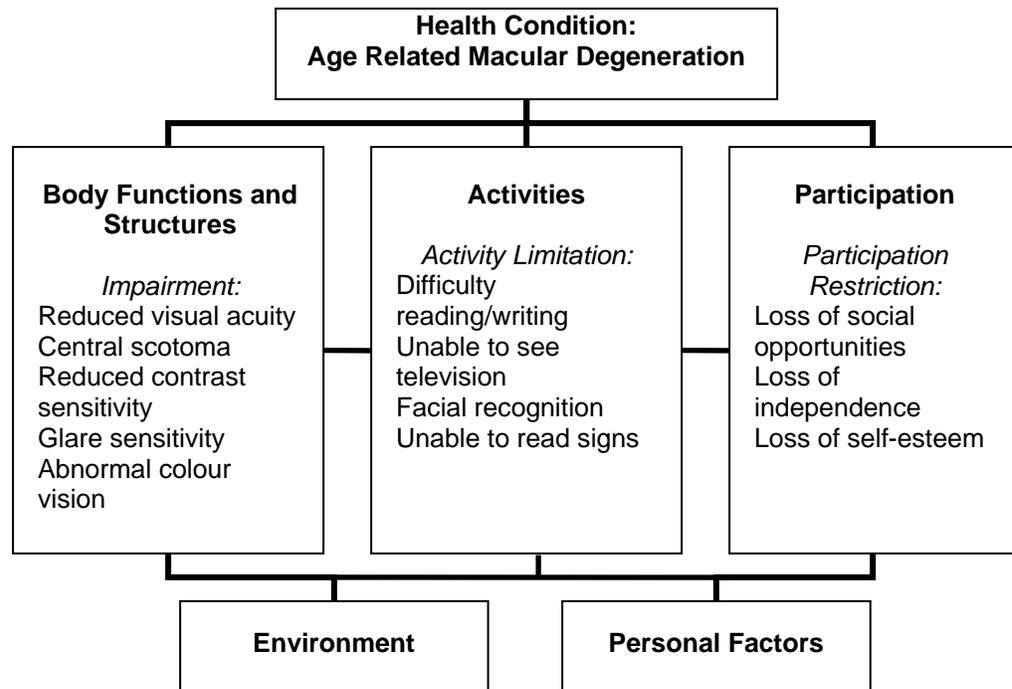
serves as an umbrella term for impairments, activity limitations or participation restrictions.<sup>1</sup> The concept of the ICF is listed in Table 1.

**Table 1: An overview of ICF**<sup>1</sup>

|                 | Part: Functioning and Disability  |  | Part 2: Contextual Factors  |   |
|-----------------|---|--|---|---|
| Components      | Body Functions and Structures   | Activities and Participation   | Environmental Factors   | Personal Factors                                  |
| Domains         | Body Functions<br><br>Body Structures   | Life areas (tasks, actions)  | External influences on functioning and disability   | Internal influences on functioning and disability |
| Constructs      | Change in body functions (physiological)<br><br>Changes in body structures (anatomical) | Capacity<br>Executing tasks in a standard environment<br><br>Performance<br>Executing tasks in the current environment | Facilitating or hindering impact of feature of the physical, social, an attitudinal world | Impact of attributes of the person                |
| Positive aspect | Functional and structural integrity   | Activities<br><br>Participation  | Facilitators  | Not applicable                                    |
|                 | Functioning   |  |   |   |
| Negative aspect | Impairment  | Activity limitation  | Barriers/<br>hindrances   | Not applicable                                    |
|                 |   | Participation restriction  |   |   |
| Disability      |   |  |   |   |

The concepts of the ICF are useful in portraying the multidimensional experience of older people who report vision loss.<sup>46</sup> The ICF provides a broader model for health. Research has started to focus on how the ICF might explain health outcomes across a spectrum of health conditions.<sup>47</sup> The ICF takes a neutral stand with regard to etiology, so researchers can draw casual inferences using appropriate scientific methods.<sup>1</sup> The ICF framework has the potential to provide a universal, standardized, disablement language and a

framework that looks beyond mortality and disease to focus on how people live with their conditions.<sup>48</sup> Figure 1 provides an illustration of the ICF model applied to age-related macular degeneration.



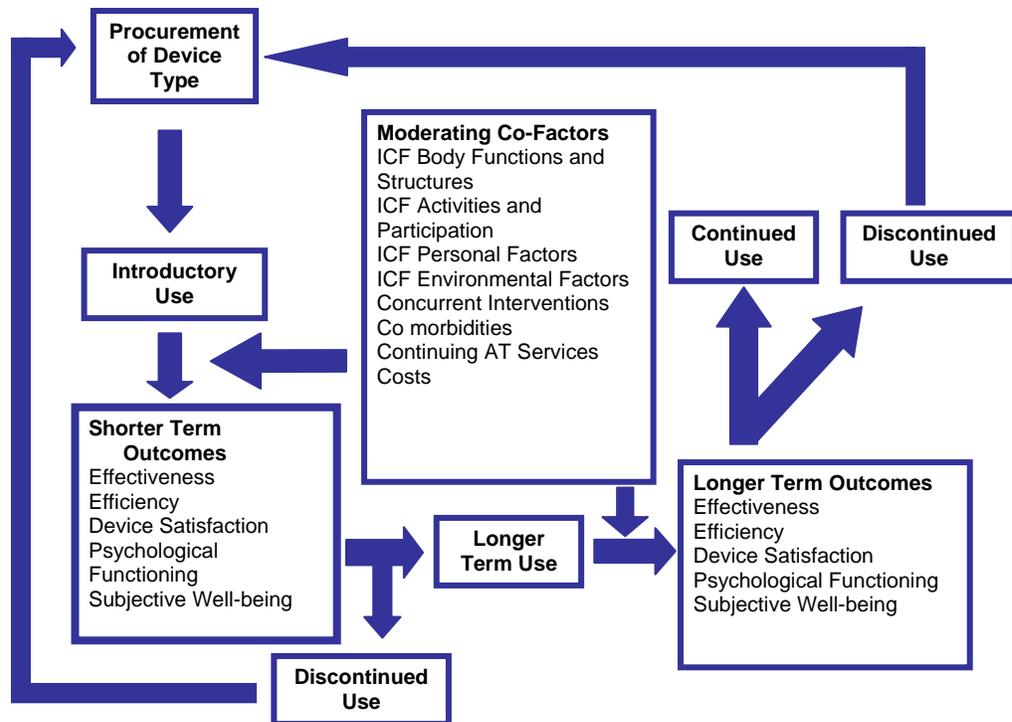
**Figure 1: International Classification of Functioning (ICF) model applied to age-related macular degeneration<sup>1</sup>**

By applying the concepts of the ICF, one is able to explore the various components associated with ARMD-related low vision.

## **1.8 The Consortium for Assistive Technology Outcomes Research**

The ICF does not model the ‘process’ of functioning and disability, but it does provide the building blocks for users who wish to create models and study different aspects of this process.<sup>1</sup> One such framework, which uses the ICF as its building block, is the Consortium for Assistive Technology

Outcomes Research (CATOR) framework. The CATOR framework and the CATOR taxonomy for modeling the outcomes of assistive technology intervention embraces the ICF framework and describes the sequence of possible outcomes experienced by an individual after procuring an assistive device, such as a CCTV system (see Figure 2).<sup>33, 42</sup>



**Figure 2: The CATOR framework for modeling the outcomes of assistive technology**

The CATOR taxonomy is used to map the outcome areas defined by the CATOR framework and the ICF components into a single, hierarchical classification scheme.<sup>42</sup> The procurement of a device-type is as a result of a progressed health condition – for example ARMD, followed by impairment, activity limitation, and participation restriction. Low vision rehabilitation uses assistive devices which are appropriate for the tasks affected by a person’s disability such as the CCTV system. A key component to this framework is

recognizing it is a time-dependent framework. There are two stages involved - an initial stage associated with dispensing of the device and a longer term stage associated with events after dispensing.<sup>33</sup> The outcome measures are identical at the shorter term and longer term outcomes (see Figure 2). The CATOR framework implies that those dimensions measured in the shorter and longer term outcomes can change. For example, at introductory use the participant may continue to use their device, but when measured at the longer term, the reported outcomes may have changed. Therefore we see different results in the longer term outcomes compared the to shorter term outcomes. The CATOR framework can be used as a predictor of device use as well it demonstrates the importance of measuring at various times in order to understand the changes occurring post-adoption. The CATOR framework proposes that every form of assistive technology outcome can be slotted uniquely into one of the three subordinate vantages: effectiveness (how assistive devices might affect users' functioning or change in health condition), social significance (the meaning that society attaches to effectiveness outcomes), and subjective well-being (subjective quality of life, how the assistive devices affects their lives).<sup>33</sup>

In accordance with the CATOR framework, the subjective quality of life outcomes for participants with ARMD who obtained a CCTV can be tracked and analyzed to model the impact of these devices. The NEI VFQ-25 and the PIADS are examples of relevant measurement tools which will be discussed in subsequent sections. By administering these measurement tools

in a longitudinal study, the shorter term and longer term outcomes will be reported.

## **1.9 The National Eye Institute 25 Item Visual Function Questionnaire**

The National Eye Institute 25 Item Visual Function Questionnaire (NEI VFQ-25) is a vision-targeted survey that assesses the influence of visual impairment on health-related quality of life.<sup>49</sup> In this section, the creation, purpose, validity, and reliability of the NEI VFQ-25 will be explained. Also, how the NEI VFQ-25 relates to the CATOR framework will be explained. Finally, the advantages and disadvantages of vision specific questionnaires will be explained.

The NEI VFQ-25 originally was a fifty one question survey, the NEI VFQ-51. The contents were derived empirically from a multi-condition focus group process.<sup>50</sup> The majority of the items from the longer version were dropped based on linear regression models to the 25 question version.<sup>49</sup> The 25 question version was developed to preserve the multidimensional content, reliability, and the validity of the full length version, but it was changed in order for it to be performed in about 5 minutes.<sup>49</sup> In general, it was intended to measure “functioning and well-being in physical, mental, and social health realms of life and reflects the influence of a broad range of health conditions simultaneously”.<sup>49</sup> Specifically, the NEI VFQ-25 survey is designed to measure the influence of visual symptoms and visual disability on generic health domains such as emotional well-being and social functioning, in

addition to task-oriented domains related to daily visual functioning.<sup>49</sup> This scale attempts to address the limitations of traditional by health related questionnaires, because it is designed specifically for individuals with vision disabilities.

This is a 25-item survey that covers areas of general health, general vision, ocular pain, and vision specific tasks.<sup>49</sup> These subscales are transformed to 0 - 100 scales, where 100 represents the best possible score, and 0 represents the worst.<sup>49</sup> The subscale scores are generated as independent, function-specific measures of visual functioning. After completing all computations, there are 12 subscale items - general health, general vision, ocular pain, near activities, distance activities, social functioning, mental health, role difficulties, dependency, driving, colour vision, and peripheral vision.

The NEI VFQ-25 has been shown to be valid and reliable. It has been used to show that those with ocular disease and accompanying visual impairment have lower scores compared to a reference group without ocular disease or visual impairment.<sup>23, 49, 51-54</sup> This scale has been used to assess quality of life of those with uncorrected refractive error.<sup>55</sup> The NEI VFQ-25 has been used to assess self-reported visual impairment in patients with multiple sclerosis.<sup>56</sup> NEI VFQ-25 has been validated in populations of patients with diverse sets of eye diseases.<sup>23</sup> Most importantly, the NEI VFQ-25 has been found to be suitable in measuring the health-related quality of life issues in patients with ARMD.<sup>7</sup>

The importance of the NEI VFQ-25 for this research is that it is designed to capture functional status of individuals in key areas that are associated with quality of life, that is, it is able to capture some of the outcomes outlined by the CATOR framework. The NEI VFQ-25 is able to specifically assess the shorter term outcomes described in the CATOR framework. For the purposes of this research study, the NEI VFQ-25 was used as a status measure to monitor for any the functional vision changes over six-months.

The advantages of condition-specific surveys, such as the NEI VFQ-25, is that they are intended to have relevant content when used in trials for a specific disease, they are more likely to detect important changes that occur over time in the particular disease studied, and they are more acceptable to patients because they are clearly relevant to the patients' presenting problem.<sup>44</sup> A major disadvantage of condition-specific questionnaires is that they preclude any obvious or easy comparison with outcomes of different treatments for patients with different health problems.<sup>44</sup> Also, they may overlook any health problems or treatment issues that were not anticipated when the instrument was designed. An instrument with a broader range of items may be more likely to detect such unexpected effects.<sup>44</sup> The questions on the NEI VFQ-25 that require difficulty ratings for specific activities are likely to be selectively sensitive to the effects of interventions targeted to easing the performance of those activities. In other words, a question about reading difficulty will be sensitive to device interventions to help with

reading. In contrast, the more general questions are likely to be sensitive only to changes in the patient's visual ability or to targeted reduction in difficulty in a broad range of activities (based on functional reserve).<sup>31</sup>

## **1.10 Psychosocial Impact of Assistive Devices Scale (PIADS)**

The other measurement tool which can be used to assess the outcomes described by the CATOR is the Psychosocial Impact of Assistive Devices Scale (PIADS). There are advantages and disadvantages to using a generic application such as the PIADS. It is for this reason that the PIADS and the NEI VFQ-25 was used together to compile their strengths and counteract their disadvantages.

PIADS items were created from three principal sources: empirical explorations with the Pleasure-Arousal-Dominance scale; qualitative research (focus groups) wherein assistive technology users were asked to describe how they expected devices to impact their quality of life; and the literature on personality research.<sup>6</sup> The goal of the PIADS is to measure the impact of an assistive device (such as the CCTV) on functional independence, well-being, and quality of life.<sup>6, 35</sup> The PIADS is a 26-item questionnaire which measures the psychosocial impact of assistive device intervention in three quality of life domains – competence, adaptability, and self-esteem. *Competence* measures feelings of efficacy where it is sensitive to the perceived impacts of assistive technology on performance and productivity.<sup>6</sup> *Adaptability* indicates a willingness to try out new things and to take risks. This measure is sensitive to

the enabling and liberating aspects of assistive technology that might be expected if assistive devices enhanced participation.<sup>6</sup> Finally, *self-esteem* indicates feelings of emotional health and happiness, and is sensitive to the perceived impact of assistive technology on self-confidence and emotional well-being.<sup>6</sup> Scores can range from -3 (max. negative impact) to zero (no perceived impact) up to +3 (max. positive impact).<sup>35</sup> *Psychosocial impact* refers to both factors within the person and factors attributable to the environment that affect the psychological adjustment of individual who have a disability.<sup>35</sup>

This scale has been shown to be a reliable, valid and responsive measure.<sup>35, 38, 57</sup> This scale has been successfully translated into Canadian-French.<sup>59</sup> This scale has been shown to be valid and reliable in assessing quality of life and functional status in participants who have undergone a stapedotomy.<sup>58</sup> The PIADS has successfully been used in other device areas such as hearing aid, mobility aids, visual aids, and electronic aids.<sup>57, 60-62</sup>

The PIADS was chosen to measure the psychosocial impact of CCTV users because it is able to capture the longer term outcomes outlined by the CATOR framework. As explained previously, the CATOR framework is a time dependent framework. Therefore, not all of the outcomes may be experienced at an initial assessment. The NEI VFQ-25 is able to capture the early outcomes such as effectiveness of the device, efficiency, and device satisfaction. The PIADS designed so that it is able to capture the elements of the psychological functioning and subjective well-being.

The advantage of a generic questionnaire, such as the PIADS, is that it can be used for a broad range of health problems, it enables comparison across treatments for groups of patients with different conditions, and has the capacity to detect and measure unexpected positive or negative effects of an intervention (such as the impact of assistive devices).<sup>23, 44</sup> Another advantage is they reduce patient burden produced by completing a number of questionnaires. A more general body of experience and comparative evidence could emerge to enhance the value and interpretability of patient based outcome measures.<sup>44</sup> However generic questionnaires have a disadvantage in that they must sacrifice some level of detail in terms of relevance to any one illness, they would have fewer relevant items to the particular disease and intervention and therefore be less sensitive to change that might occur as a result of an intervention.<sup>44</sup>

It has been recommended that researchers include a generic measure together with disease-specific measure in order to overcome the disadvantages of using generic applications and a vision specific applications in isolation (therefore making the results stronger by having both present).<sup>44</sup> The main argument for such an approach is that the two kinds of measures are likely to produce complementary evidence and may also detect unexpected positive or negative effects of a novel intervention.<sup>44</sup> By combining both the NEI VFQ-25 and the PIADS, it is possible to measure the changes in functional vision status and the psychosocial impact of technology-assisted rehabilitation for those affected by ARMD. Self-reported visual function and quality of life

measures have become useful adjuncts for evaluating the impact of a patient's visual functioning or disease state on that particular individual and the effects of rehabilitation on the individual's level of function.<sup>23</sup> Combining both the NEI VFQ-25 and the PIADS allows us to evaluate the short and long term outcomes experienced by CCTV users can be measured in accordance with the CATOR framework.

This research is needed to advance our understanding of the process by which ARMD-related low vision patients successfully adopt and use low vision assistive devices like CCTV devices. In doing so, we may discover new opportunities for more effective clinical interventions at various points within the rehabilitation process.

## Chapter 2: Research Hypotheses

A CCTV system can be used to assist those with ARMD-related low vision, specifically by improving their reading ability. In accordance with the ICF model, one expects the CCTV will have a direct impact on the user's functional abilities, and thus this improved ability will have a consequential impact on the user's psychosocial status. This research project hypothesized that assistive devices will have immediate and robust impact on functional vision status, but that psychosocial impact will be delayed over the period following device adoption. The functional status change is expected to occur first because the assessment and prescribing protocols (competitive enablement) ensure that the device will redress the functional deficit reported by the presenting patient. The full psychosocial impact of the CCTV will be delayed as the patient has an opportunity to experience the benefits of the device and how it impacts on daily living.

Accordingly we expect:

- 1) The NEI VFQ-25 scores will indicate impact on functional status following CCTV adoption indicating successful rehabilitation.
- 2) The NEI VFQ-25 scores will remain stable over the study period of six months.
- 3) The PIADS scores will indicate positive psychosocial impact following CCTV adoption.
- 4) The PIADS scores will increase over the ensuring period.

## Chapter 3: Methods

### 3.1 Participants

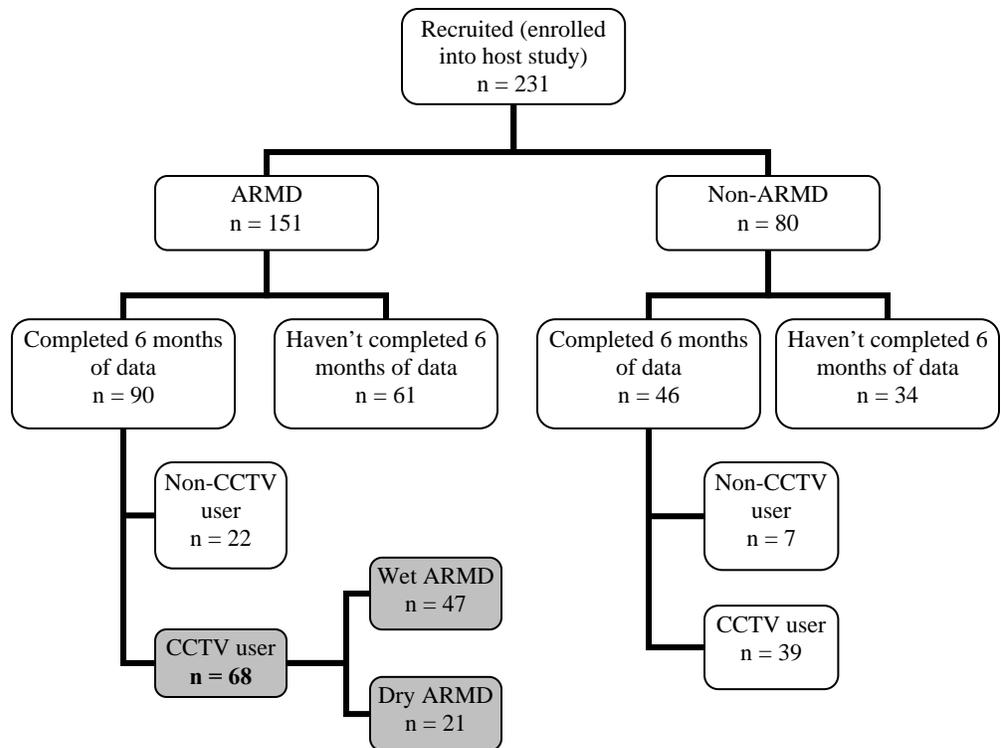
Data for this research were obtained from a host cohort study of low vision device outcomes entitled “Dynamic program approach to modeling assistive technology device outcomes in low vision rehabilitation”, funded by the CIHR (grant # MOP-74522). Participants were first time patients over the age of 18 years who attended the University of Waterloo Low Vision Clinic. They were recruited sequentially from consecutive appointments at the Low Vision Clinic. The reason for selection of first time participants was to include persons who would have little to no experience with assistive devices. Due to linguistic complexities of the measurement tools, the youngest age allowed into the host study was 18 years.

Potential participants were approached by a trained recruiter on the day of their Low Vision Clinic assessment. Details of the study were explained to participants and each participant was given a large print information letter that described the study being conducted. They were able to ask any questions about the study. If they agreed to participate, they were asked to sign a consent form confirming their agreement. For those patients who refused to take part, their reasons were noted and recorded in a database.

After a person completed his or her low vision clinical assessment, the clinic file was reviewed and data was collected from the low vision patient record. This included information such as gender, age, living circumstance, and support.

Participants were contacted two weeks after their clinic visit to confirm that they had received and were using their prescribed devices. The host study allowed for anyone new to the clinic and over 18 years to enter the study as long as they have received a low vision device. If they had not yet received their low vision device, a subsequent contact time was arranged to ensure they were using their device before taking part in the first assessment. Data collection was administered by telephone interview for both the PIADS and the NEI VFQ-25. Participants were contacted for follow-up assessment biweekly for six months and then monthly for six months to assure the capture of significant changes throughout the one year of assessments. At the end of one year of assessments, participants would have completed 18 assessments.

For the purposes of this thesis, the data from the host study were filtered to identify only participants with ARMD, who were new CCTV users, and who had completed at least six-months of assessments. Participants had little to no experience using a CCTV system prior to the study. The data collected were the initial (2-weeks), 1 month, 3 months, and six months assessments. Figure 3 shows a flow chart on how participants were filtered from the host study to be included into this research. Of the 231 participants of the host study, only 68 participants were eligible for this study. Of these, 47 had wet ARMD and 21 had dry ARMD.



**Figure 3: Flow chart of how data from host study was filtered for the purposes of this research**  
(Shaded indicates the 68 participants used in this study)

### 3.2 Intervention Protocols

Patients are referred to the University Of Waterloo School Of Optometry Low Vision Clinic by a variety of methods including self-referral, optometrists, ophthalmologists, organizations (such as the CNIB), physicians, service organizations, rehabilitation facility schools, and word of mouth. The clinic's goal is to maintain or improve functional status as well as to enhance psychosocial well-being through interventions involving several trained professionals of the rehabilitation team (optometrist, high technology assessment specialist, rehabilitation worker, and social worker).<sup>63</sup> Patients are

required to complete intake paperwork prior to their appointment to better understand their goals and objectives.

During appointments, patients have the possibility of seeing a variety of people. See Table 2 for services available at the Low Vision Clinic.

**Table 2: Description of the variety of services available at the Low Vision Clinic**

| Service Provider                      | Services Provided   |
|---------------------------------------|---|
| Optometry Low Vision Clinician        | <ul style="list-style-type: none"> <li>- Functional history</li> <li>- Education and emotional support</li> <li>- Assessment of visual abilities: visual acuity, contrast sensitivity, visual field, colour vision, glare sensitivity, refraction</li> <li>- Determination of assistive optical and non-optical systems</li> <li>- Recommendations for rehabilitation and communication with the rehabilitation team</li> <li>- Registration with ADP funding program</li> <li>- Prescription of devices</li> </ul>   |
| Rehabilitation Worker                 | Evaluation and Training in: <ul style="list-style-type: none"> <li>- Prescribed optical devices</li> <li>- Non-optical adaptive devices</li> <li>- Provides daily living skills</li> <li>- Demonstrating techniques and teaching concepts to assist in educational, occupational, recreational, daily living, social and leisure activities</li> <li>- Environmental modifications (i.e.) marking items, lighting, colour contrast and organization</li> <li>- Basic sighted guide techniques</li> <li>- Systemic tracking, scanning, localizing</li> <li>- Assistance with maintaining independence</li> <li>- Maintain loans program</li> </ul> |
| High Technology Assessment Specialist | <ul style="list-style-type: none"> <li>- Client assessment with video, CCTV, and computer based devices</li> <li>- Outcome recommendations</li> <li>- Authorize government funding for eligible clients</li> <li>- Coordinate with low vision assessment and low vision clinician</li> </ul>  |
| Low Vision Rehabilitation Counsellor  | <ul style="list-style-type: none"> <li>- Provide individual and family counselling to help clients and their families cope with progressive vision loss</li> <li>- Referral to community resources</li> <li>- Advocacy</li> <li>- Provide additional or follow-up counselling to those interested (either at the clinic or telephone counselling)</li> </ul>  |

The Assistive Devices Program (ADP) is a highly successful Ontario government initiative that provides significant levels of funding support toward the purchase of any assistive devices that have been duly prescribed and authorized for Ontario residents with disabilities.<sup>64</sup> These include both high and low technology rehabilitation devices in the categories of augmented communication, respiration, mobility, ostomy, hearing, seating, prosthetic, orthotics, and vision. Program consultants were asked to develop a series of sound and defensible protocols for the assessment and training of all clients being seen, regardless of the presentation or service/device needs.<sup>32</sup> The ADP program is used at the Low Vision Clinic in the prescription of CCTV devices.

CCTV systems are demonstrated to interested and suitable low vision patients with vast range of acuity impairments. There are many generic features of CCTV devices, however many patients are also sensitive to other more particularized and subtle features that may improve their comfort, speed, facility, and endurance while using a CCTV.<sup>32</sup> The overall goal is to provide patients with an opportunity to use each system in the way that they expect to use it after they purchase it.<sup>32</sup>

### **3.3 Measurements and Data Collection**

All data collection was performed over the telephone and all clinical information was obtained from clinic files. The instruments used were the National Eye Institute Visual Function Questionnaire (NEI VFQ-25) and the Psychosocial Impact of Assistive Devices Scale (PIADS) (see Appendix).

Four (4) time periods were analyzed for this thesis. Both the PIADS and the NEI VFQ-25 were conducted at 2 weeks, 1 month, 3 months, and 6 months post-adoption of the CCTV. From the clinic files the age, sex, support level, living circumstance and distribution of eye conditions were collected. Participant's level of education was asked during the first assessment.

### **3.4 Data Analysis**

The recommended NEI VFQ-25 scoring algorithms, which consist of linear transformations of raw scores for each of 12 domains, were calculated as per the instructions provided with the NEI VFQ-25. The 12 subscales were general health, general vision, ocular pain, near activities, distance activities, social functioning, mental health, role difficulties, dependency, driving, colour vision, and peripheral vision. The PIADS subscale score for competence, adaptability, and self-esteem were calculated as per instructions in the manual. All data analysis was done through SPSS version 15.0. Multivariate repeated-measures ANOVA was performed on the subscales for each measurement tool separately to see if there is a significant change in the NEI VFQ-25 results post adoption of CCTV system and then to see if there is a change in PIADS over the four time periods. Multivariate repeated-measures ANOVA is an appropriate test since there are more than one dependent variables (multiple variable in each of the subscales) and these multiple dependent variables are being tested over a period of time (four time intervals).<sup>65</sup>

To see if the NEI VFQ-25 scores were stable over time, we tested the null hypothesis that the mean differences within pairs of NEI VFQ-25

subscales scores were zero. If the results were not zero, we would assume a change had occurred and post-hoc tests would be applied to see where the change had occurred. Multivariate repeated-measures ANOVA tests were then done with the PIADS subscales items to see if the mean difference within pairs were zero. If the results of the PIADS' mean differences were not zero, post-hoc tests were performed to see where the change had occurred. Significance was set at a p-value of less than 0.05.

# Chapter 4: Results

## 4.1 Study Participants

All of the 68 participants were obtained from the ongoing cohort CIHR funded study entitled “Dynamic program approach to modeling assistive technology device outcomes in low vision rehabilitation” (PIs: Dr. J. Jutai, Dr. G. Strong, Dr. H. Ariizumi, and Dr. A. Plotkin). They were first time users of the CCTV system, and were diagnosed with either wet or dry ARMD. The distribution of age and gender, education, support, living circumstance, and eye condition can be seen in Figure 4, Figure 5, Figure 6, Figure 7, and Figure 8 (respectively).

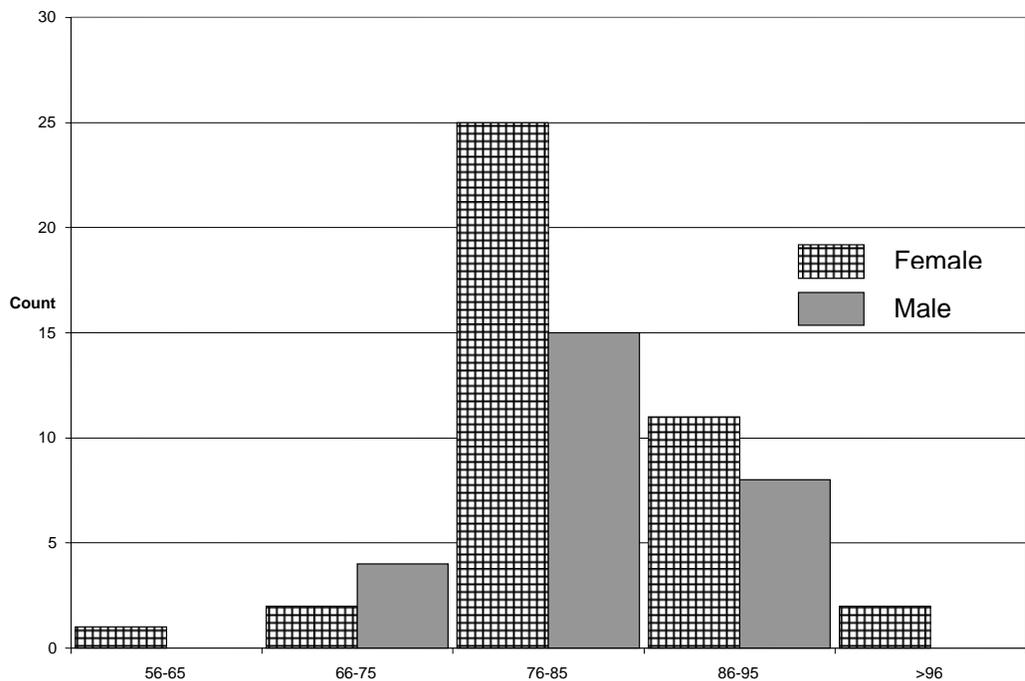
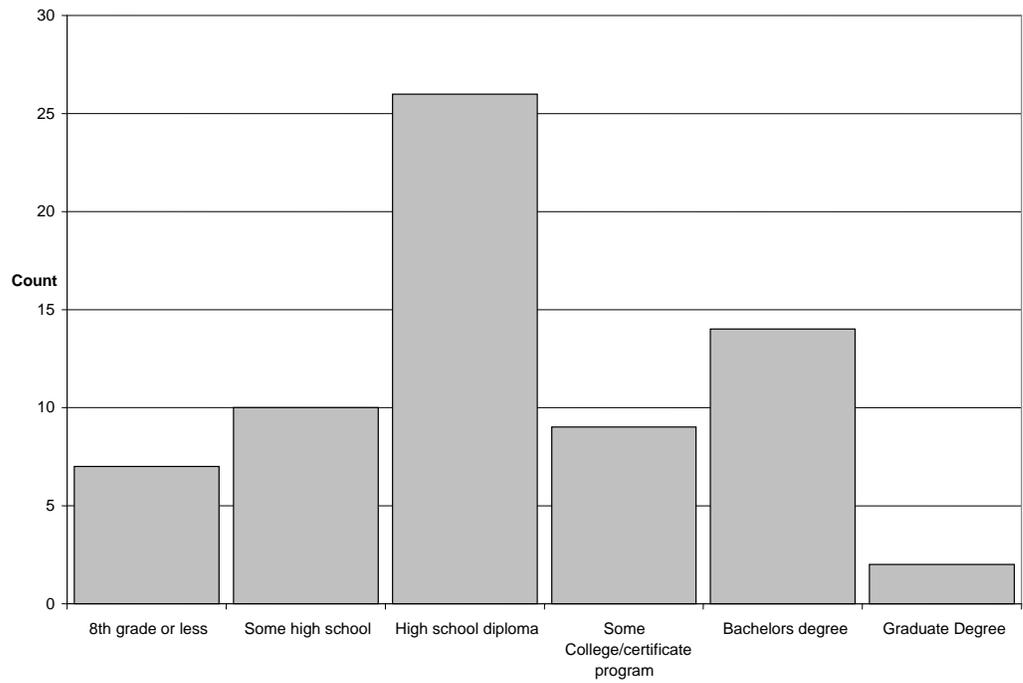
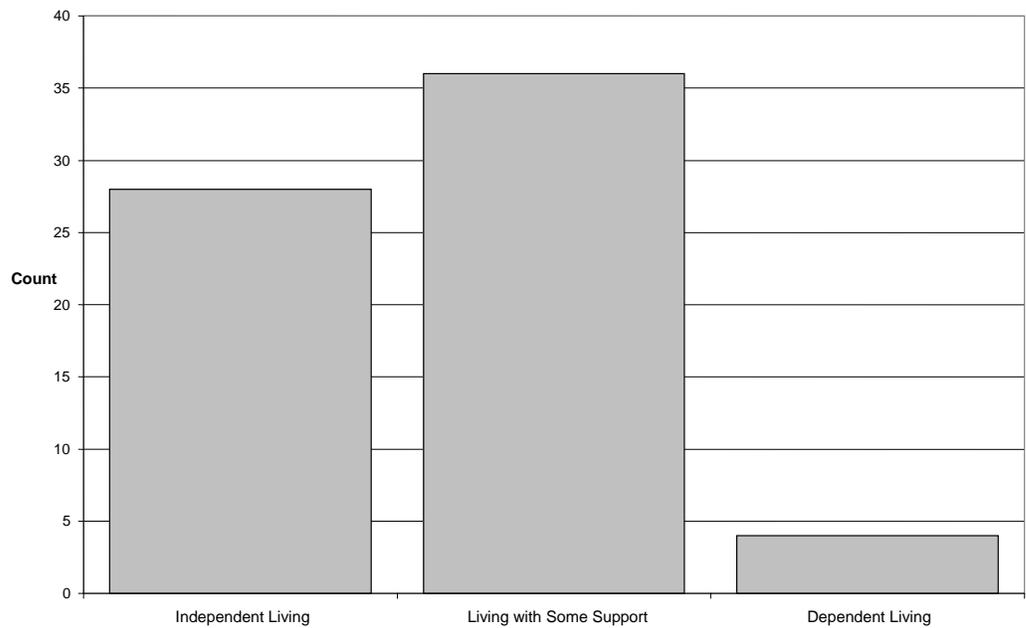


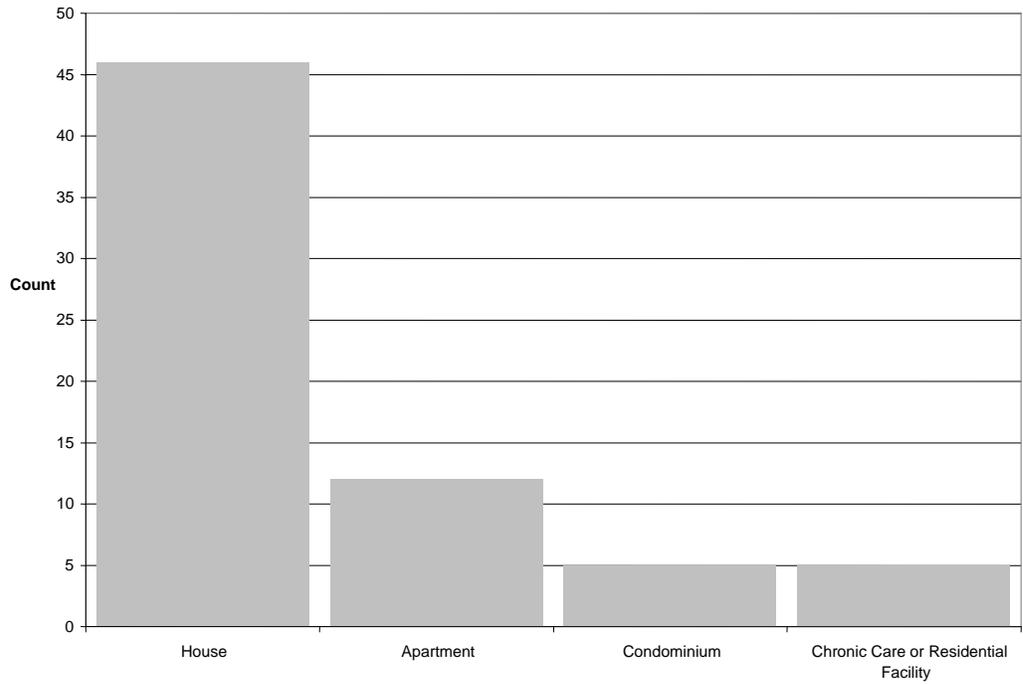
Figure 4: Profile of age and gender for the 68 participants



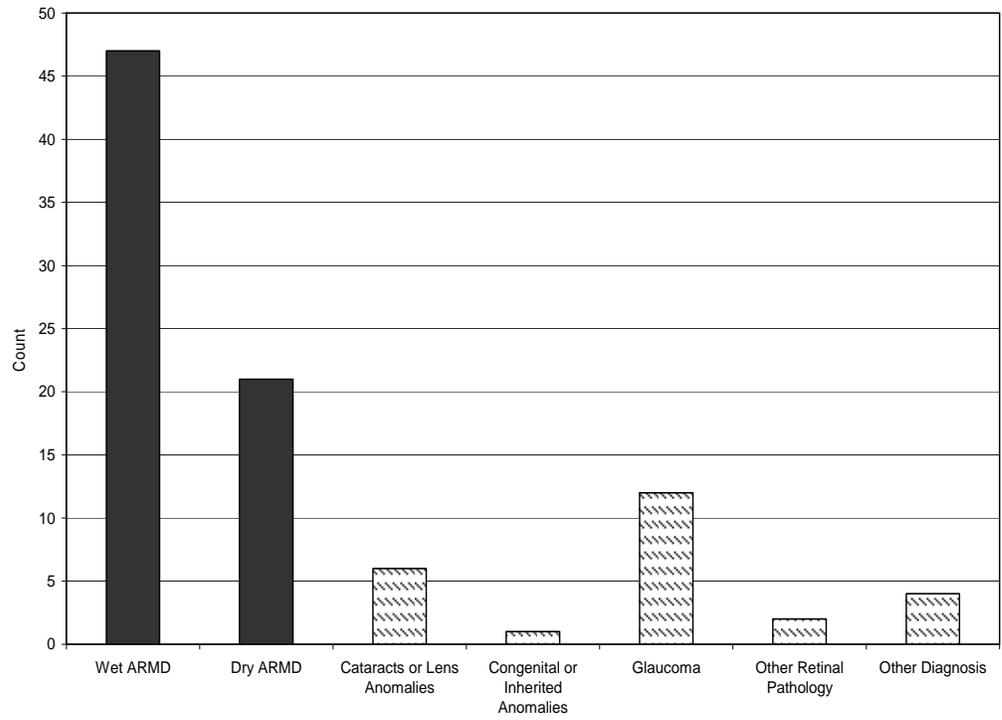
**Figure 5: Profile of educational levels of the 68 participants**



**Figure 6: Profile of support provided to the 68 participants**



**Figure 7: Profile of living circumstance of the 68 participants**



**Figure 8: Profile of eye conditions**  
(Black indicates types of ARMD, pattern indicates other diagnoses)

## 4.2 NEI VFQ-25 Results

Descriptive statistics from the NEI VFQ-25 are provided in Table 3. These results are for all 68 participants post adoption of their CCTV device and were normally distributed. There were several questions which resulted in no answer from some of the participants. This is seen especially in the driving category where a large majority of the participants were no longer legally allowed to drive, therefore could not answer those questions. The NEI VFQ-25 results indicate that, functional status is stable following adoption of a CCTV device.

**Table 3: Descriptive statistics of NEI VFQ-25 for the four time periods.** (Where 1 = 2 weeks, 2 = 1 month, 3 = 3 months, 4 = 6 months post-adoption of CCTV)

|                                    | N  | Mean  | Std. Deviation |
|------------------------------------|----|-------|----------------|
| VFQ Subscore General Health 1      | 68 | 53.31 | 28.94          |
| VFQ Subscore General Vision 1      | 68 | 47.06 | 18.21          |
| VFQ Subscore Ocular Pain 1         | 68 | 88.24 | 20.59          |
| VFQ Subscore Near Activities 1     | 68 | 54.60 | 22.41          |
| VFQ Subscore Distance Activities 1 | 68 | 49.75 | 22.64          |
| VFQ Subscore Social Functioning 1  | 68 | 53.31 | 25.34          |
| VFQ Subscore Mental Health 1       | 68 | 50.83 | 27.63          |
| VFQ Subscore Role Difficulties 1   | 68 | 40.07 | 28.45          |
| VFQ Subscore Dependency 1          | 68 | 56.37 | 30.00          |
| VFQ Subscore Driving 1             | 49 | 1.96  | 10.03          |
| VFQ Subscore Colour Vision 1       | 68 | 72.43 | 31.19          |
| VFQ Subscore Peripheral Vision 1   | 67 | 83.21 | 28.33          |
| VFQ Subscore General Health 2      | 68 | 54.78 | 26.01          |
| VFQ Subscore General Vision 2      | 68 | 46.76 | 13.21          |
| VFQ Subscore Ocular Pain 2         | 68 | 89.15 | 16.85          |
| VFQ Subscore Near Activities 2     | 68 | 56.07 | 22.22          |
| VFQ Subscore Distance Activities 2 | 68 | 47.98 | 21.55          |
| VFQ Subscore Social Functioning 2  | 68 | 52.76 | 23.14          |
| VFQ Subscore Mental Health 2       | 68 | 55.70 | 24.62          |
| VFQ Subscore Role Difficulties 2   | 68 | 36.21 | 28.34          |
| VFQ Subscore Dependency 2          | 68 | 56.62 | 29.98          |
| VFQ Subscore Driving 2             | 50 | 2.00  | 10.45          |

|                                    |    |       |       |
|------------------------------------|----|-------|-------|
| VFQ Subscore Colour Vision 2       | 68 | 74.63 | 30.99 |
| VFQ Subscore Peripheral Vision 2   | 68 | 81.62 | 26.49 |
| VFQ Subscore General Health 3      | 68 | 53.31 | 27.96 |
| VFQ Subscore General Vision 3      | 68 | 46.76 | 15.30 |
| VFQ Subscore Ocular Pain 3         | 68 | 89.34 | 18.36 |
| VFQ Subscore Near Activities 3     | 68 | 52.57 | 22.27 |
| VFQ Subscore Distance Activities 3 | 67 | 47.39 | 23.32 |
| VFQ Subscore Social Functioning 3  | 68 | 51.29 | 21.61 |
| VFQ Subscore Mental Health 3       | 68 | 53.58 | 23.79 |
| VFQ Subscore Role Difficulties 3   | 67 | 28.36 | 25.15 |
| VFQ Subscore Dependency 3          | 68 | 49.51 | 28.90 |
| VFQ Subscore Driving 3             | 52 | 2.88  | 15.38 |
| VFQ Subscore Colour Vision 3       | 68 | 66.54 | 33.07 |
| VFQ Subscore Peripheral Vision 3   | 68 | 83.46 | 26.84 |
| VFQ Subscore General Health 4      | 68 | 48.16 | 28.43 |
| VFQ Subscore General Vision 4      | 68 | 44.41 | 15.39 |
| VFQ Subscore Ocular Pain 4         | 68 | 88.42 | 18.11 |
| VFQ Subscore Near Activities 4     | 68 | 52.21 | 20.39 |
| VFQ Subscore Distance Activities 4 | 68 | 46.45 | 23.17 |
| VFQ Subscore Social Functioning 4  | 68 | 51.29 | 20.28 |
| VFQ Subscore Mental Health 4       | 68 | 53.86 | 26.10 |
| VFQ Subscore Role Difficulties 4   | 68 | 31.43 | 30.66 |
| VFQ Subscore Dependency 4          | 68 | 51.47 | 29.54 |
| VFQ Subscore Driving 4             | 52 | 4.01  | 17.66 |
| VFQ Subscore Colour Vision 4       | 68 | 65.81 | 32.01 |
| VFQ Subscore Peripheral Vision 4   | 68 | 81.99 | 22.38 |
| Valid N (listwise)                 | 47 |       |       |

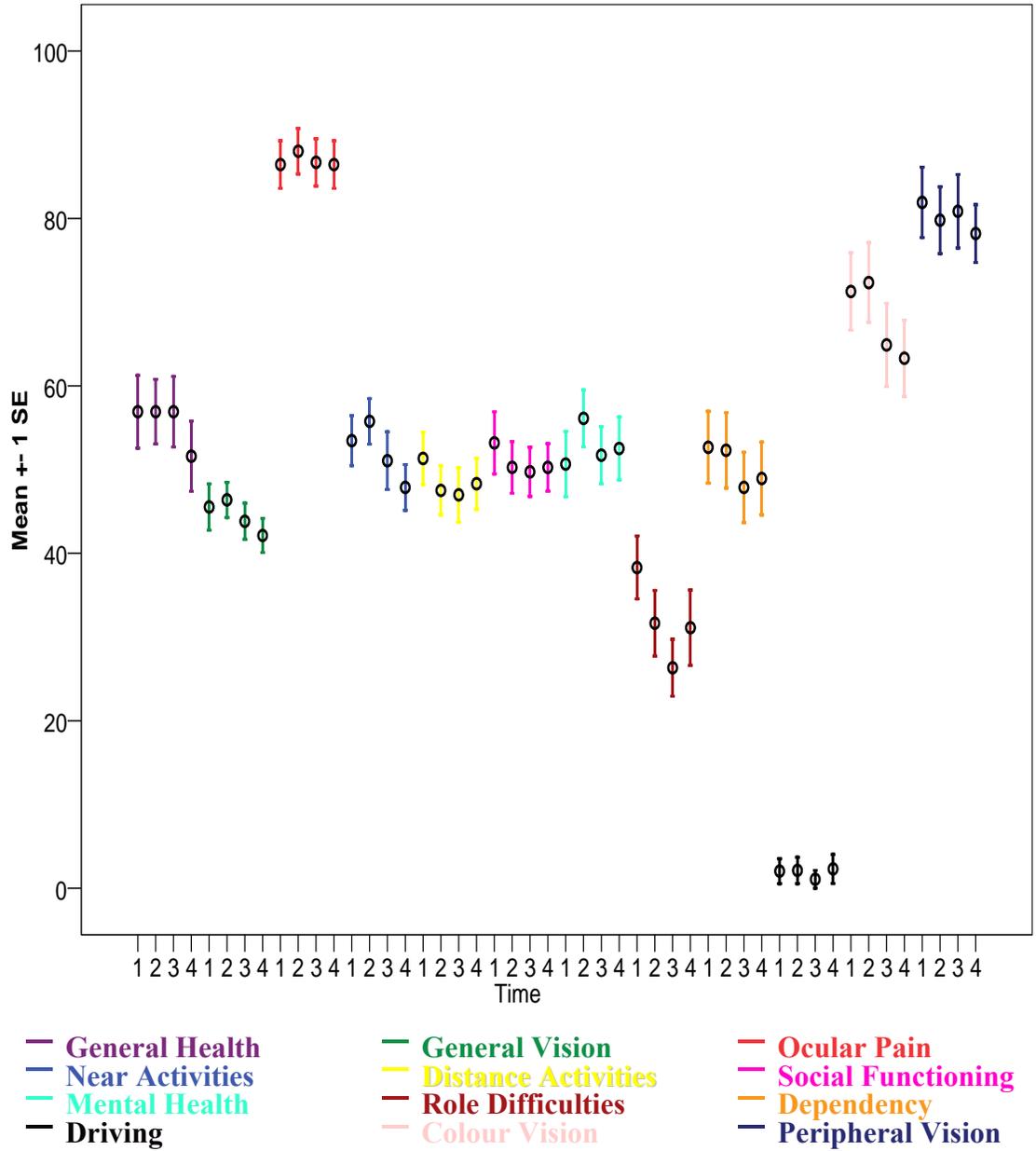
Paired T-tests were performed on the NEI VFQ-25 subscales between 2 weeks and 1 month, between 1 month and 3 months, between 3 months and 6 months, and between 2 weeks and 6 months (see Table 4). Bonferroni correction concerns the question if the alpha level should be adjusted downward to consider chance capitalization (in the case of doing more than one test in a particular study).<sup>66</sup> The alpha level (0.05) was adjusted to a level of 0.00416. The NEI VFQ-25 subscales did not reveal any significant change over the six months of follow-up post adoption of CCTV.

**Table 4: Results from the paired T-test for the 12 NEI VFQ-25 subscale items**

|                            | T     | Df | P     |
|----------------------------|-------|----|-------|
| <b>General Health</b>      |       |    |       |
| Initial – 1 month          | -0.59 | 67 | .559  |
| 1 month- 3 months          | 0.48  | 67 | .631  |
| 3 months - 6 months        | 1.94  | 67 | .056  |
| Initial – 6 months         | 1.65  | 67 | .104  |
| <b>General Vision</b>      |       |    |       |
| Initial – 1 month          | 0.16  | 67 | .874  |
| 1 month- 3 months          | 0.00  | 67 | 1.000 |
| 3 months - 6 months        | 1.43  | 67 | .159  |
| Initial – 6 months         | 1.04  | 67 | .302  |
| <b>Ocular Pain</b>         |       |    |       |
| Initial – 1 month          | -0.46 | 67 | .647  |
| 1 month- 3 months          | -0.10 | 67 | .923  |
| 3 months - 6 months        | 0.42  | 67 | .677  |
| Initial – 6 months         | -0.08 | 67 | .939  |
| <b>Near Activities</b>     |       |    |       |
| Initial – 1 month          | -0.68 | 67 | .497  |
| 1 month- 3 months          | 1.26  | 67 | .212  |
| 3 months - 6 months        | 0.17  | 67 | .864  |
| Initial – 6 months         | 0.75  | 67 | .459  |
| <b>Distance Activities</b> |       |    |       |
| Initial – 1 month          | 0.96  | 67 | .339  |
| 1 month- 3 months          | 0.44  | 66 | .664  |
| 3 months - 6 months        | 0.12  | 66 | .909  |
| Initial – 6 months         | 1.20  | 67 | .236  |
| <b>Social Functioning</b>  |       |    |       |
| Initial – 1 month          | 0.30  | 67 | .765  |
| 1 month- 3 months          | 0.59  | 67 | .555  |
| 3 months - 6 months        | 0.00  | 67 | 1.000 |
| Initial – 6 months         | 0.69  | 67 | .493  |
| <b>Mental Health</b>       |       |    |       |
| Initial – 1 month          | -2.17 | 67 | .034  |
| 1 month- 3 months          | 0.90  | 67 | .372  |
| 3 months - 6 months        | -0.12 | 67 | .904  |
| Initial – 6 months         | -1.13 | 67 | .264  |
| <b>Role Difficulties</b>   |       |    |       |
| Initial – 1 month          | 1.34  | 67 | .185  |
| 1 month- 3 months          | 2.18  | 66 | .033  |
| 3 months - 6 months        | -1.10 | 66 | .275  |
| Initial – 6 months         | 1.81  | 67 | .075  |
| <b>Dependency</b>          |       |    |       |
| Initial – 1 month          | -0.09 | 67 | .931  |

|                          |       |    |      |
|--------------------------|-------|----|------|
| 1 month- 3 months        | 2.23  | 67 | .029 |
| 3 months - 6 months      | -0.74 | 67 | .464 |
| Initial – 6 months       | 1.53  | 67 | .130 |
| <b>Driving</b>           |       |    |      |
| Initial – 1 month        | -0.09 | 47 | .926 |
| 1 month- 3 months        | -0.47 | 49 | .644 |
| 3 months - 6 months      | -1.41 | 51 | .164 |
| Initial – 6 months       | -0.15 | 48 | .881 |
| <b>Colour Vision</b>     |       |    |      |
| Initial – 1 month        | -0.93 | 67 | .358 |
| 1 month- 3 months        | 2.22  | 67 | .030 |
| 3 months - 6 months      | 0.21  | 67 | .837 |
| Initial – 6 months       | 1.79  | 67 | .077 |
| <b>Peripheral Vision</b> |       |    |      |
| Initial – 1 month        | 0.61  | 66 | .545 |
| 1 month- 3 months        | -0.70 | 67 | .488 |
| 3 months - 6 months      | 0.57  | 67 | .568 |
| Initial – 6 months       | 0.41  | 66 | .686 |

The results of the NEI VFQ-25 over the six-month period can be seen graphically in Figure 9. While some mean subscale scores were higher than others, mean scores did not change significantly over time for any single subscale.



Where 1 = 2 weeks, 2 = 1 month, 3 = 3 months, and 4 = 6 months post-adoption of CCTV

**Figure 9: Error Bar Plot of NEI VFQ-25 Subscale items during the 6 months**

### 4.3 PIADS Results

The descriptive statistics from the PIADS subscales are presented in Table 7. These are results for all 68 participants post adoption of their CCTV device. They are normally distributed. For the PIADS questionnaire, all (100%) of the questions were answered. These data indicate a positive psychosocial impact upon receiving a CCTV device.

**Table 5: Descriptive statistics for the PIADS subscales for the 6 months period.**

(Where 1 = 2 weeks, 2 = 1 month, 3 = 3 months, and 4 = 6 months post-adoption of the CCTV)

|                               | N  | Mean | Std. Deviation |
|-------------------------------|----|------|----------------|
| PIADS Subscale Competence 1   | 68 | 1.39 | 0.69           |
| PIADS Subscale Adaptability 1 | 68 | 1.05 | 0.66           |
| PIADS Subscale Self-Esteem 1  | 68 | 1.05 | 0.62           |
| PIADS Subscale Competence 2   | 68 | 1.41 | 0.68           |
| PIADS Subscale Adaptability 2 | 68 | 1.15 | 0.62           |
| PIADS Subscale Self-Esteem 2  | 68 | 1.10 | 0.60           |
| PIADS Subscale Competence 3   | 68 | 1.33 | 0.73           |
| PIADS Subscale Adaptability 3 | 68 | 1.02 | 0.68           |
| PIADS Subscale Self-Esteem 3  | 68 | 1.06 | 0.59           |
| PIADS Subscale Competence 4   | 68 | 1.21 | 0.83           |
| PIADS Subscale Adaptability 4 | 68 | 0.76 | 0.68           |
| PIADS Subscale Self-Esteem 4  | 68 | 0.99 | 0.76           |
| Valid N (listwise)            | 68 |      |                |

Multivariate repeated-measures ANOVA performed on the PIADS subscales reveal that no significant difference throughout the six-month time frame in the self-esteem or competence subscales. However, there was a significant difference in the adaptability subscale (see Table 6).

**Table 6: Repeated-measures ANOVA for the three subscales of the PIADS.**

*Competence*

|             | Sum of Square | Df  | Mean Square | F    | P    |
|-------------|---------------|-----|-------------|------|------|
| Participant | 1.64          | 3   | 0.55        | 2.36 | .073 |
| Error       | 46.53         | 201 | 0.23        |      |      |

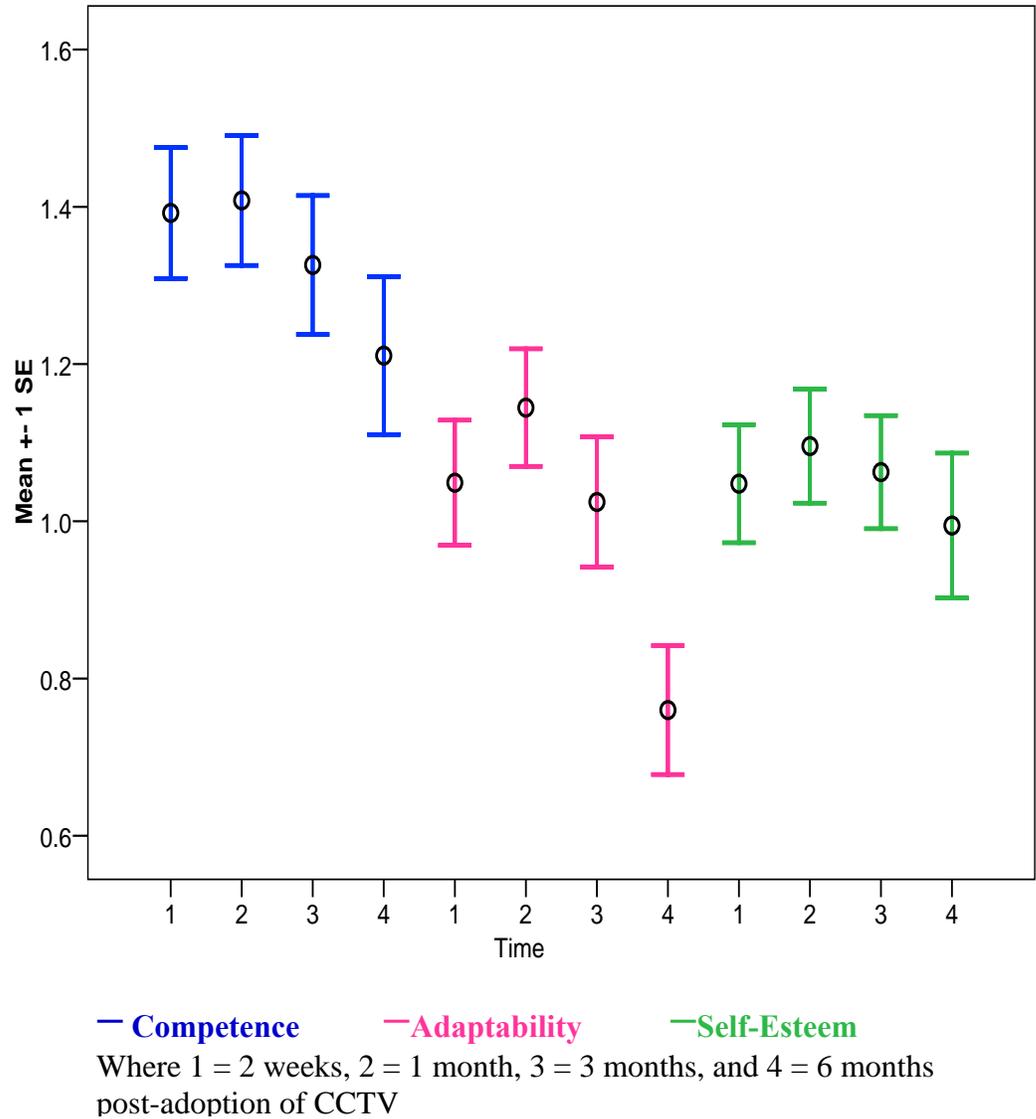
*Adaptability*

|             | Sum of Square | Df  | Mean Square | F    | P                      |
|-------------|---------------|-----|-------------|------|------------------------|
| Participant | 5.54          | 3   | 1.85        | 7.31 | 1.119x10 <sup>-4</sup> |
| Error       | 50.77         | 201 | 0.25        |      |                        |

*Self-Esteem*

|             | Sum of Square | Df  | Mean Square | F    | P    |
|-------------|---------------|-----|-------------|------|------|
| Participant | 0.36          | 3   | 0.12        | 0.67 | .569 |
| Error       | 35.99         | 201 | 0.18        |      |      |

These results can be seen graphically in Figure 10 where we see a peak in the psychosocial impact of the devices at the one month interval for all three subscales. This is followed by attenuation for all subscales. However, the only significant attenuation is in the adaptability subscale.



**Figure 10: Estimated marginal means for the three subscale items of the PIADS**

Paired T-tests were performed on the PIADS subscales between 2 weeks and 1 month, between 1 month and 3 months, between 3 months and 6 months, and between 2 weeks and 6 months (see Table 7). Bonferroni adjustment was applied to the alpha level (0.05) to a level of 0.0167. The

results reveal that there was a significant difference in the adaptability subscale around the 3 and 6 month time period post adoption of the CCTV.

**Table 7: Paired T-test results of the PIADS subscale items**

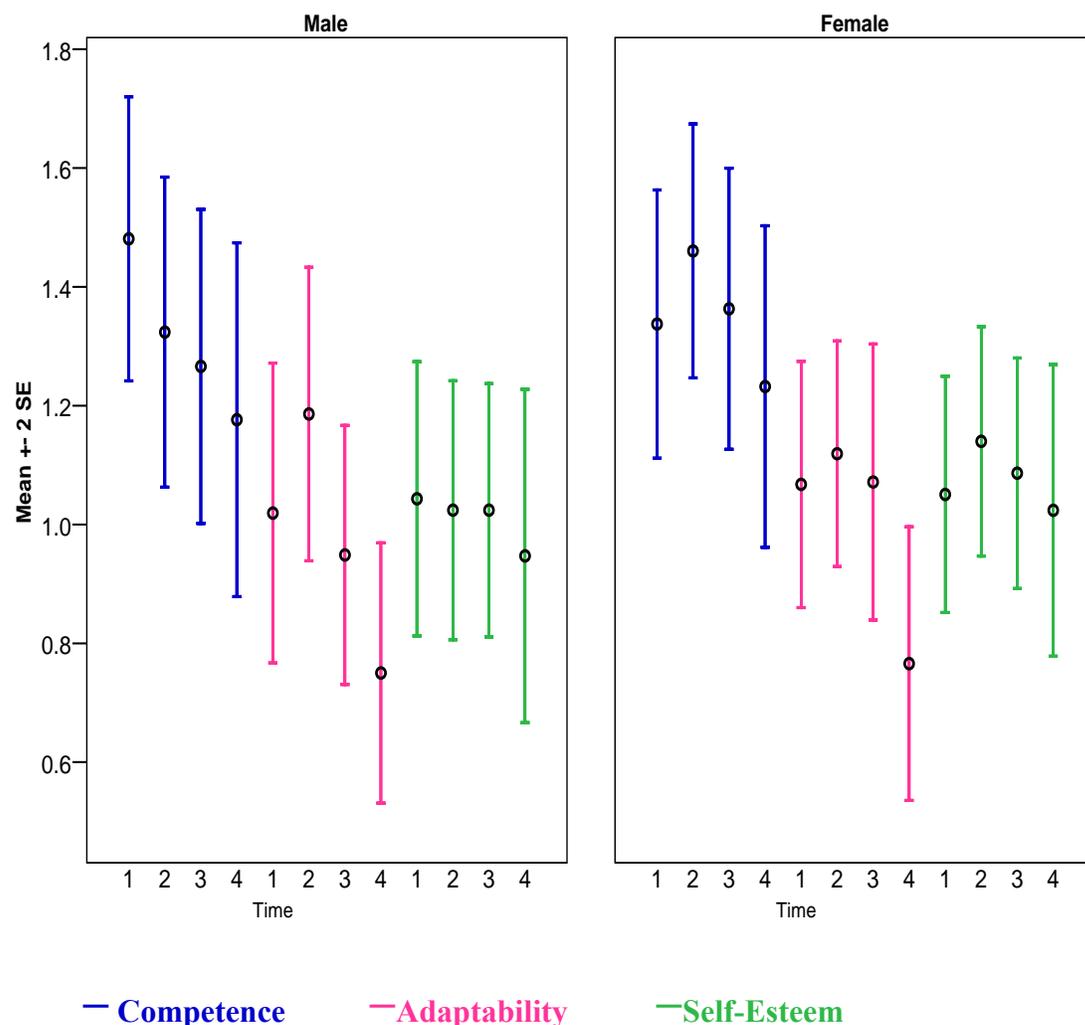
| Df = 67             | T     | P       |
|---------------------|-------|---------|
| <b>Competence</b>   |       |         |
| Initial – 1 month   | -0.26 | .794    |
| 1 month – 3 months  | 1.02  | .313    |
| 3 months – 6 months | 1.47  | .147    |
| Initial – 6 months  | 1.92  | .060    |
| <b>Adaptability</b> |       |         |
| Initial – 1 month   | -1.18 | .244    |
| 1 month – 3 months  | 1.46  | .148    |
| 3 months – 6 months | 3.60  | .001*** |
| Initial – 6 months  | 2.99  | .004*** |
| <b>Self-Esteem</b>  |       |         |
| Initial – 1 month   | -0.88 | .383    |
| 1 month – 3 months  | 0.49  | .625    |
| 3 months – 6 months | 1.00  | .321    |
| Initial – 6 months  | 0.66  | .514    |

#### 4.4 Gender

When the results were separated for males and females, there was no significant difference between the PIADS results for the two genders (See Table 8 and Figure 11)

**Table 8: Results of the test of between-participants effects for gender**

| Source | Type III Sum of Squares | df | Mean Square | F     | Sig. |
|--------|-------------------------|----|-------------|-------|------|
| Gender | 0.37                    | 1  | 0.37        | 0.120 | 0.73 |
| Error  | 205.45                  | 66 | 3.11        |       |      |



— Competence      — Adaptability      — Self-Esteem  
 Where 1 = 2 weeks, 2 = 1 month, 3 = 3 months, and 4 = 6 months post-adoption of CCTV

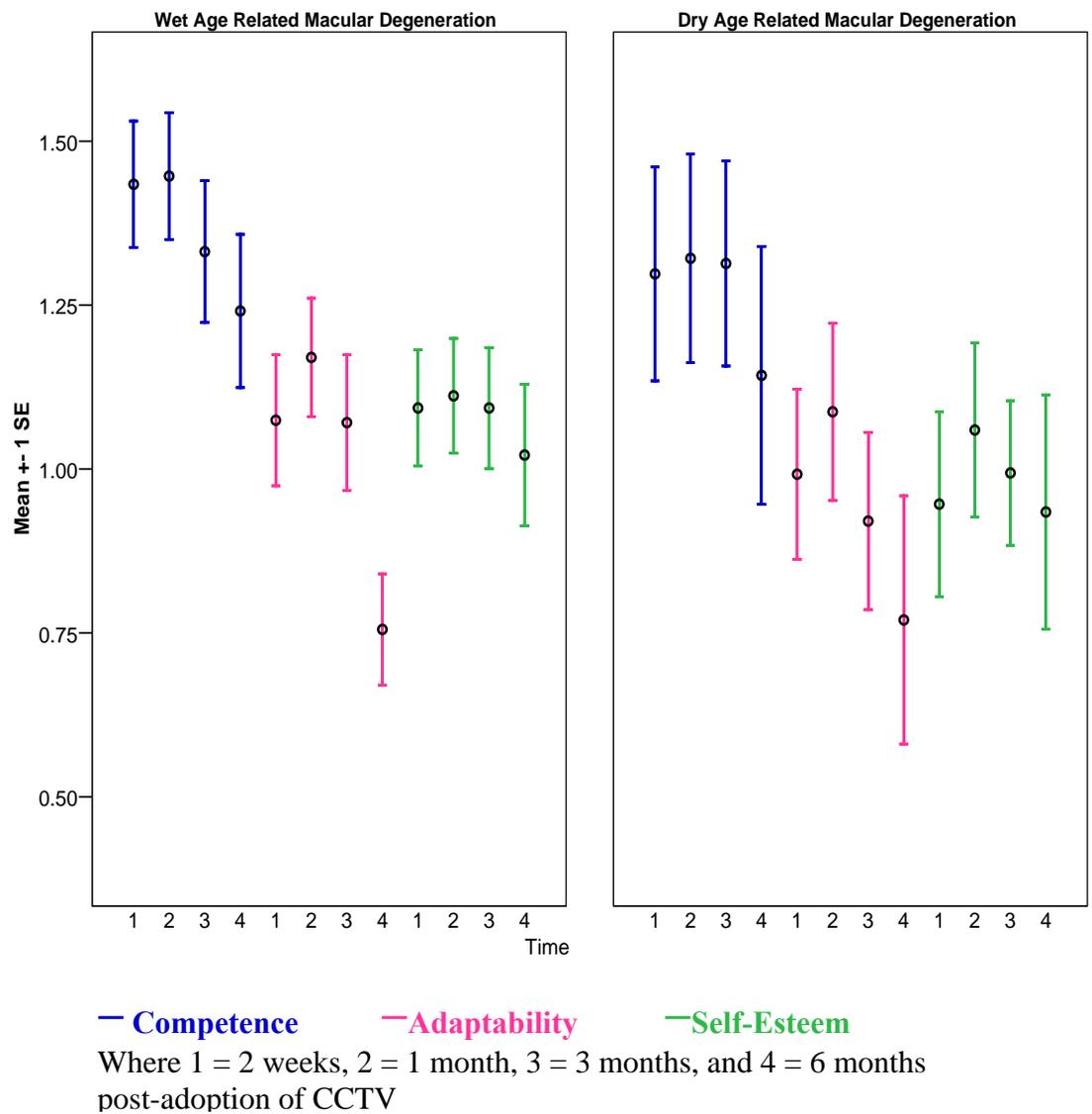
**Figure 11: PIADS subscales results for either male or female**

### 4.5 Wet versus Dry age-related macular degeneration

When the results were separated for type of ARMD, it was shown that there was no significant difference between Wet ARMD and Dry ARMD. Although wet ARMD has slightly higher results than dry, these differences are not statistically significant. This can be seen in the between participant effects test of Table 9 and graphically in Figure 12.

**Table 9: Test of between-participant effects for type of ARMD**

| Source    | Type III Sum of Squares | df | Mean Square | F    | Sig. |
|-----------|-------------------------|----|-------------|------|------|
| Diagnosis | 1.37                    | 1  | 1.37        | 0.44 | .051 |
| Error     | 204.46                  | 66 | 3.10        |      |      |



**Figure 12: PIADS subscales results for participants with either wet or dry ARMD**

## Chapter 5: Discussion

### 5.1 CCTV Adoption and Impact on Visual Function

The results from the NEI VFQ-25 survey indicate subjective visual functioning stabilizes post CCTV adoption. Although some mean subscale scores were higher than others, the mean scores did not change significantly following six-months of post CCTV adoption (see Table 4 and Figure 9).

The results from this research complement and extend current research on CCTV adoption and impact on visual function. The study by Brody *et al.* (2005) focused on a six-month follow up of patients with advanced ARMD after they had undergone treatments based on a 12-hour self management program.<sup>67</sup> This study was with 8 to 10 participants and the components of the 12-hour self management program focused on cognitive elements (including information about ARMD, services, reevaluation of barriers, and positive challenges) and behavioral elements (communication about ARMD, problem solving using vignettes, modeling of adaptive behaviors, and a simple exercise program).<sup>67</sup> Using the NEI VFQ-25, Brody *et al.* (2005) found increased visual functioning in patients from baseline to the six-month follow up.<sup>67</sup> It is important to note, however, that the study by Brody *et al.* (2005) specifically identified patients with advanced ARMD, their results were not based on device outcome, and only one follow-up was conducted at the 6 month follow up time. The study by Brody *et al.* (2005) differs from this study in that they focused on a rehabilitation program and not on device adoption. In addition their results were comparing baseline results and follow-up at six-months;

they were not looking at the changes that occur over the six-month time. It is interesting to speculate whether the results Brody *et al.*'s (2005) would change if assessments were measured at intervals.

Results from this study also are consistent with findings reported by Stelmack *et al.* (2002) who used the NEI VFQ-25. Stelmack *et al.* (2002) used NEI VFQ-25 to compare two low vision programs and their rehabilitation procedures. Their results demonstrated that the NEI VFQ-25 was effective at measuring the effects of rehabilitation, but they reported that a subset of the NEI VFQ-25 items were sensitive to change after rehabilitation for a low vision population.<sup>31</sup> Their measurements were taken at the conclusion of the rehabilitation program, just prior to patients discharge. Again, these results are based on a single assessment and the participants were still in the program (or just about to leave) when the measurements were taken. It seems possible that there may be changes in response to the questions after the participants returned to their daily tasks in their own homes. Nonetheless, the NEI VFQ-25 results of this study of ARMD participants are similar to those reported by Stelmack *et al.* (2002) for their low vision population.

Another similar study, conducted by Scilley *et al.* (2004), used telephone interviews with ARMD participants approximately two weeks after they received low vision rehabilitation and low vision assistive devices.<sup>7</sup> Participants were diagnosed with wet or dry ARMD as in my research. The NEI VFQ-25 scores in my study are consistent with those reported by Scilley *et al.* (2004) who found that ARMD patients who seek out low vision services

have significantly diminished vision specific quality of life as measured by the NEI VFQ-25.<sup>7</sup> Although their study was not specific to CCTV devices, Scilley *et al.* (2004) reported results that are similar to those of my study.

Therefore, the results of the NEI VFQ-25 in this thesis are consistent with the results of previous studies pertaining to low vision participants. We believe that these results indicate stabilized visual function following adoption of the CCTV device.<sup>7, 31, 67</sup>

## **5.2 Psychosocial Impact Following CCTV Adoption**

The results from PIADS reveal a positive psychosocial impact that is attributable to the adoption of a CCTV. As indicated in Table 7 and Figure 10, positive psychosocial impact peaks at a maximum value at approximately one month following adoption and subsequently attenuates after one month.

These PIADS results are consistent with the results in other research studies. Jutai *et al.* (2000) found the use of electronic aids had a positive psychosocial impact on daily living for participants with degenerative neuromuscular disorders.<sup>57</sup> However, Jutai *et al.* (2000) found that the positive impact remained stable over time. A consideration for the stability in the PIADS results is that the participants had longer experience time with their devices and therefore were accommodated to any potential changes (participants had an average of four years experience with their electric aids).

Another study investigating the psychosocial impact of devices was done by Day *et al.* (2001). Day *et al.* (2001) study examined the PIADS results for participants with newly acquired prescription glasses. Participants

were asked to complete the surveys at two months and then one year post adoption of their prescription glasses.<sup>38</sup> The study by Day *et al.* (2001) were similar to my study because their results indicated positive psychosocial impact upon adoption of prescription glasses; however their results did not diminish over time as it did in my study.<sup>38</sup> One possibility for these results (as similar to the Jutai *et al.* 2000) is that these participants may have had been exposed to the use of prescription glasses prior to this study and may have anticipated the impact of the glasses, therefore no change would be apparent. As well, there were only two time measurements taken and small changes in the psychosocial impact may not have been reflected.

Strong *et al.* (2004) assessed the psychosocial impact of CCTV devices on low vision participants over three years using a similar design to this study.<sup>32</sup> My study results are similar to the results of psychosocial impact reported in the study by Strong *et al.* (2004). Strong *et al.* (2004) also experienced an attenuation of scores, the most significant being in the third year.<sup>32</sup> The results presented in this thesis further validate and extend the research reported by Strong *et al.* (2004). Due to the more specific design of the current study we were able to detect a more precise map of the changes in psychosocial impact upon receiving CCTV devices compared to the yearly assessments of the Strong *et al.* (2004) study.

The results of this current research add to evidence of the validity of previous work. Therefore we believe that psychosocial impact upon adoption

of a CCTV is positive and these results are dynamic post adoption and they attenuate as time goes on.<sup>32, 38, 57</sup>

### **5.3 Confounding Factors (Gender and Type of ARMD)**

The differences in gender did not influence the results of the measurement tools (see Figure 11). This was expected based on previous studies.<sup>32</sup>

The results from the separation of wet and dry ARMD indicate no significant changes; however it does appear that wet ARMD participants reported a slightly higher psychosocial impact from CCTV use (see Figure 12). This difference could be attributable to the severity of their condition. Wet ARMD produces a sudden, dramatic loss of central vision compared to dry ARMD (which is more gradual and slow in progression).<sup>19</sup> People with dry ARMD have a longer time to adapt to smaller and gradual changes. Since wet ARMD is more severe compared to dry ARMD we may expect to see a slightly higher psychosocial impact of CCTV devices; however, this requires further investigation.

### **5.4 Limitations**

The validity of the NEI VFQ-25 for an elderly population with low vision has been debated.<sup>7, 31</sup> It is believed that lower scores are recorded compared with other NEI VFQ-25 results due to the fact that the questions may not adequately represent the rehabilitation needs of patients with low vision over the range of vision loss in this population.<sup>31</sup> For example, three items are relevant to mobility (going down steps/curbs, peripheral vision, and

taking part in active sports) and these mobility-related activities are not expected to change in response to adoption of a CCTV.<sup>31</sup>

As well, the participant instructions for the NEI VFQ-25 questionnaire state “the next questions are about how much difficulty, if any, you have doing certain activities wearing your glasses or contact lenses if you use them for that activity”. These directions were modified for the assessment interviews to add consideration of use of CCTV devices.

The PIADS posed several problems based on patient interpretation of concepts. Some subjects reported difficulty with the PIADS when administered over the telephone and they felt many of the questions were repetitive or inapplicable to their lifestyle (i.e. self-esteem versus self-confidence, willingness to make changes versus ability to take advantage of opportunities, sense of control, and productivity).

## **5.5 Clinical Significance**

This study provides insight into the content and timing of follow-up services and outcomes following device assisted rehabilitation. One possibility for clinical changes is that the NEI VFQ-25 could be administered prior to patients’ appointments to assess and quantify functional vision deficits. By administering the NEI VFQ-25 and the PIADS after their appointment, clinicians could then verify if they have addressed and improved the patients concerns. By comparing the NEI VFQ-25 pre- and post-assessment, the results could be used to see if the services and/or devices

altered perceived functional vision status. The PIADS can be used to measure the psychosocial impact the device had on the patient.

By understanding that attenuation occurs following one month of CCTV usage, the clinic might consider a follow-up appointment around the one month period to ensure that the patient is still satisfied with their device. It may be that patients are satisfied with their device and it is the impact of the CCTV that has diminished (not device satisfaction). Providing a follow-up will clearly distinguish if there is dissatisfaction with the device or if there is a change in the impact of the device that is affecting the attenuation.

Also, traditional methods to test how well a patient can see have been the norm for a very long time (such as visual acuity, contrast sensitivity test, and visual field tests), but we are encountering a more ‘patient-centered’ view in clinical practice in order to understand the impact of rehabilitation on a patients’ entire life. With the above results, patients are not expressing a change in their visual function (as shown with NEI VFQ-25), but the PIADS reveals that there are changes occurring as reported by patients’ psychosocial impact. Clinicians need to be aware of these changes in order to better comprehend the impact of ARMD and rehabilitation on patients’ lives.

## **5.6 Future Direction**

The results of this study leave several questions unanswered. The reasons for the eventual attenuation of PIADS scores are not clear, but the stable NEI VFQ-25 results suggest that it is not caused by any perceived changes in visual function. Future research should investigate why attenuation

occurs and whether it presents an important opportunity for intervention. One possibility is that attenuation represents a *response shift*, wherein patients undergo a change in health state that changes their internal standards, their values, or the conceptualization of quality of life.<sup>45</sup> As their ‘new normal’ baseline for estimating device impact becomes elevated over time, the amount of perceived impact measured by the PIADS is diminished. This same prediction has been made by Strong *et al.* (2004).<sup>32</sup> There are several theories as to response shift (related to stress and coping, related to suppression of the relation between physical health and quality of life, and/or related to personal goals) and investigation into these theories may provide insight as the reasoning for the attenuation.<sup>45</sup>

Another possibility is that the ‘competitive enablement’ approach to low vision assessment and the selection process for CCTV systems, allows the patients to develop realistic expectations about the impact of the CCTV. This phenomenon has also been seen in patients with amyotrophic lateral sclerosis (ALS) using writing aids.<sup>68</sup> Jutai (2001) found there was little difference between PIADS responses over time due to the fact that users were able to accurately anticipate the benefit of their device use.<sup>68</sup>

This research provides further agreement in the argument that the NEI VFQ-25 may not be very sensitive to changes in low vision participants, in that the NEI VFQ-25 did not detect any changes over six-months. Further research into providing a sufficient measurement tool to measure visual function for low vision participants could be investigated.

## Chapter 6: Conclusions

This study provides insight into the importance of investigating longitudinal outcomes experienced by people with ARMD-related low vision who have obtained a CCTV through a competitive enablement assessment. These outcomes may lead to knowledge for the development of rehabilitation interventions which may diminish the limitations created by vision loss. This may be accomplished by understanding how a person's psychosocial status changes over six months after receiving a CCTV device. The results are consistent with the CATOR framework, which implies that changes in activity (such as those related to assistive device intervention as revealed by the NEI-VFQ-25) may precede changes in participation (as revealed by PIADS).

In response to the proposed hypotheses: CCTV systems appear to have an immediate and positive impact on the functional status of their users that remains stable following six-months of follow-up (as shown through the NEI VFQ-25). The psychosocial impact of CCTV devices was shown to be positive with a peak impact around the one-month follow-up which was followed by decreased scores into the six-months of follow-up (as shown through the PIADS).

This project shows that CCTV devices are effective in improving the psychosocial status of patients with age-related macular degeneration. It is clear that CCTV devices “provide a means to circumvent barriers and subsequently increasing active participation. Increased participation provides the basis to cope and adapt to barriers, and can enhance the quality of life”.<sup>34</sup>

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# Appendix

PB/IA

## National Eye Institute Visual Functioning Questionnaire - 25 (VFQ-25)

version 2000

(INTERVIEWER ADMINISTERED FORMAT)

January 2000

RAND hereby grants permission to use the "National Eye Institute Visual Functioning Questionnaire 25 (VFQ-25) July 1996, in accordance with the following conditions which shall be assumed by all to have been agreed to as a consequence of accepting and using this document:

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7/29/96

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**Instructions:**

I'm going to read you some statements about problems which involve your vision or feelings that you have about your vision condition. After each question I will read you a list of possible answers. Please choose the response that best describes your situation.

Please answer all the questions as if you were wearing your glasses or contact lenses (if any).

Please take as much time as you need to answer each question. All your answers are confidential. In order for this survey to improve our knowledge about vision problems and how they affect your quality of life, your answers must be as accurate as possible. Remember, if you wear glasses or contact lenses for a particular activity, please answer all of the following questions as though you were wearing them.

# Visual Functioning Questionnaire - 25

## PART 1 - GENERAL HEALTH AND VISION

1. In general, would you say your overall health is\*:

*(Circle One)*

- READ CATEGORIES:
- Excellent..... 1
  - Very Good ..... 2
  - Good ..... 3
  - Fair ..... 4
  - Poor..... 5

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

*(Circle One)*

- READ CATEGORIES:
- Excellent..... 1
  - Good ..... 2
  - Fair ..... 3
  - Poor..... 4
  - Very Poor..... 5
  - Completely Blind..... 6

\* Skip Question 1 when the VFQ-25 is administered at the same time as the SF-36 or RAND 36-Item Health Survey 1.0

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

(Circle One)

- READ CATEGORIES:
- None of the time ..... 1
  - A little of the time ..... 2
  - Some of the time ..... 3
  - Most of the time ..... 4
  - All of the time?..... 5

4. How much pain or discomfort have you had in and around your eyes (for example, burning, itching, or aching)? Would you say it is:

(Circle One)

- READ CATEGORIES:
- None..... 1
  - Mild..... 2
  - Moderate..... 3
  - Severe, or ..... 4
  - Very severe?..... 5

PART 2 - DIFFICULTY WITH ACTIVITIES

The next questions are about how much difficulty, if any, you have doing certain activities wearing your glasses or contact lenses if you use them for that activity.

5. How much difficulty do you have reading ordinary print in newspapers? Would you say you have:

(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all ..... 1
- A little difficulty..... 2
- Moderate difficulty ..... 3
- Extreme difficulty ..... 4
- Stopped doing this because of your eyesight ..... 5
- Stopped doing this for other reasons or not interested in doing this ..... 6

6. How much difficulty do you have doing work or hobbies that require you to see well up close, such as cooking, sewing, fixing things around the house, or using hand tools? Would you say:  
(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all ..... 1
- A little difficulty..... 2
- Moderate difficulty ..... 3
- Extreme difficulty ..... 4
- Stopped doing this because of your eyesight ..... 5
- Stopped doing this for other reasons or not interested in doing this ..... 6

7. Because of your eyesight, how much difficulty do you have finding something on a crowded shelf?  
(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all ..... 1
- A little difficulty..... 2
- Moderate difficulty ..... 3
- Extreme difficulty ..... 4
- Stopped doing this because of your eyesight ..... 5
- Stopped doing this for other reasons or not interested in doing this ..... 6

8. How much difficulty do you have reading street signs or the names of stores?  
(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all ..... 1
- A little difficulty..... 2
- Moderate difficulty ..... 3
- Extreme difficulty ..... 4
- Stopped doing this because of your eyesight ..... 5
- Stopped doing this for other reasons or not interested in doing this ..... 6

9. Because of your eyesight, how much difficulty do you have going down steps, stairs, or curbs in dim light or at night?

(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all ..... 1
- A little difficulty..... 2
- Moderate difficulty ..... 3
- Extreme difficulty ..... 4
- Stopped doing this because of your eyesight ..... 5
- Stopped doing this for other reasons or not interested in doing this ..... 6

10. Because of your eyesight, how much difficulty do you have noticing objects off to the side while you are walking along?

(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all ..... 1
- A little difficulty..... 2
- Moderate difficulty ..... 3
- Extreme difficulty ..... 4
- Stopped doing this because of your eyesight ..... 5
- Stopped doing this for other reasons or not interested in doing this ..... 6

11. Because of your eyesight, how much difficulty do you have seeing how people react to things you say?

(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all ..... 1
- A little difficulty..... 2
- Moderate difficulty ..... 3
- Extreme difficulty ..... 4
- Stopped doing this because of your eyesight ..... 5
- Stopped doing this for other reasons or not interested in doing this ..... 6

12. Because of your eyesight, how much difficulty do you have picking out and matching your own clothes?

(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all ..... 1
- A little difficulty..... 2
- Moderate difficulty ..... 3
- Extreme difficulty ..... 4
- Stopped doing this because of your eyesight ..... 5
- Stopped doing this for other reasons or not interested in doing this ..... 6

13. Because of your eyesight, how much difficulty do you have visiting with people in their homes, at parties, or in restaurants ?

(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all ..... 1
- A little difficulty..... 2
- Moderate difficulty ..... 3
- Extreme difficulty ..... 4
- Stopped doing this because of your eyesight ..... 5
- Stopped doing this for other reasons or not interested in doing this ..... 6

14. Because of your eyesight, how much difficulty do you have going out to see movies, plays, or sports events?

(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all ..... 1
- A little difficulty..... 2
- Moderate difficulty ..... 3
- Extreme difficulty ..... 4
- Stopped doing this because of your eyesight ..... 5
- Stopped doing this for other reasons or not interested in doing this ..... 6

Now, I'd like to ask about driving a car. Are you currently driving, at least once in a while?

(Circle One)

Yes..... 1 Skip To Q 15c

No ..... 2

15a. IF NO, ASK: Have you never driven a car or have you given up driving?

(Circle One)

Never drove..... 1 Skip To Part 3, Q 17

Gave up..... 2

15b. IF GAVE UP DRIVING: Was that mainly because of your eyesight, mainly for some other reason, or because of both your eyesight and other reasons?

(Circle One)

Mainly eyesight..... 1 Skip To Part 3, Q 17

Mainly other reasons..... 2 Skip To Part 3, Q 17

Both eyesight and other reasons .... 3 Skip To Part 3, Q 17

15c. IF CURRENTLY DRIVING: How much difficulty do you have driving during the daytime in familiar places? Would you say you have:

(Circle One)

No difficulty at all ..... 1

A little difficulty..... 2

Moderate difficulty ..... 3

Extreme difficulty ..... 4

16. How much difficulty do you have driving at night? Would you say you have: (READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all ..... 1
- A little difficulty..... 2
- Moderate difficulty ..... 3
- Extreme difficulty ..... 4
- Have you stopped doing this because of your eyesight ..... 5
- Have you stopped doing this for other reasons or are you not interested in doing this ..... 6

16a. How much difficulty do you have driving in difficult conditions, such as in bad weather, during rush hour, on the freeway, or in city traffic? Would you say you have:

(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all ..... 1
- A little difficulty..... 2
- Moderate difficulty ..... 3
- Extreme difficulty ..... 4
- Have you stopped doing this because of your eyesight ..... 5
- Have you stopped doing this for other reasons or are you not interested in doing this ..... 6

PART 3: RESPONSES TO VISION PROBLEMS

The next questions are about how things you do may be affected by your vision. For each one, I'd like you to tell me if this is true for you all, most, some, a little, or none of the time.

*(Circle One On Each Line)*

| READ CATEGORIES:  | All of<br>the<br>time | Most of<br>the<br>time | Some<br>of the<br>time | A little<br>of the<br>time | None of<br>the<br>time |
|---|-----------------------|------------------------|------------------------|----------------------------|------------------------|
| 17. <u>Do you accomplish less than you would like because of your vision?</u>   | 1                     | 2                      | 3                      | 4                          | 5                      |
| 18. <u>Are you limited in how long you can work or do other activities because of your vision?.....</u>   | 1                     | 2                      | 3                      | 4                          | 5                      |
| 19. <u>How much does pain or discomfort in or around your eyes, for example, burning, itching, or aching, keep you from doing what you'd like to be doing? Would you say:</u> | 1                     | 2                      | 3                      | 4                          | 5                      |

For each of the following statements, please tell me if it is definitely true, mostly true, mostly false, or definitely false for you or you are not sure.

(Circle One On Each Line)

|   | Definitely True | Mostly True | Not Sure | Mostly False | Definitely False |
|---|-----------------|-------------|----------|--------------|------------------|
| 20. I <u>stay home most of the time</u> because of my eyesight. ....                                      | 1               | 2           | 3        | 4            | 5                |
| 21. I feel <u>frustrated</u> a lot of the time because of my eyesight. ....                               | 1               | 2           | 3        | 4            | 5                |
| 22. I have <u>much less control</u> over what I do, because of my eyesight. ....                          | 1               | 2           | 3        | 4            | 5                |
| 23. Because of my eyesight, I have to <u>rely too much on what other people tell me...</u>                | 1               | 2           | 3        | 4            | 5                |
| 24. I <u>need a lot of help</u> from others because of my eyesight. ....                                  | 1               | 2           | 3        | 4            | 5                |
| 25. I worry about <u>doing things that will embarrass myself or others</u> , because of my eyesight. .... | 1               | 2           | 3        | 4            | 5                |

*That's the end of the interview. Thank you very much for your time and your help.*

## PIADS Questionnaire

Client Name: \_\_\_\_\_  
(Last name, then first name)

male  female

Diagnosis: \_\_\_\_\_

Date of Birth: \_\_\_\_\_  
Month/day/year

**The form is being filled out at (choose one)** 1.  home 2.  a clinic 3.  other (describe): \_\_\_\_\_

**The form is being filled out by (choose one)** 1.  the client, without any help 2.  the client, with help from the caregiver (e.g., client showed or told caregiver what answers to give) 3.  the caregiver on behalf of the client, without any direction from the client 4.  other (describe): \_\_\_\_\_

Each word or phrase below describes how using an assistive device may affect a user. Some might seem unusual but it is important that you answer every one of the 26 items. So, for each word or phrase, put an "X" in the appropriate box to show how you are affected by using the \_\_\_\_\_ (device name).

|   | Decreases | -3                       | -2                       | -1                       | 0                        | 1                        | 2                        | 3                        | Increases                |
|---|-----------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 1) competence   |           | <input type="checkbox"/> |
| 2) happiness  |           | <input type="checkbox"/> |
| 3) independence   |           | <input type="checkbox"/> |
| 4) adequacy   |           | <input type="checkbox"/> |
| 5) confusion  |           | <input type="checkbox"/> |
| 6) efficiency   |           | <input type="checkbox"/> |
| 7) self-esteem  |           | <input type="checkbox"/> |
| 8) productivity   |           | <input type="checkbox"/> |
| 9) security   |           | <input type="checkbox"/> |
| 10) frustration   |           | <input type="checkbox"/> |
| 11) usefulness  |           | <input type="checkbox"/> |
| 12) self-confidence                                       |           | <input type="checkbox"/> |
| 13) expertise   |           | <input type="checkbox"/> |
| 14) skillfulness  |           | <input type="checkbox"/> |
| 15) well-being  |           | <input type="checkbox"/> |
| 16) capability  |           | <input type="checkbox"/> |
| 17) quality of life                                       |           | <input type="checkbox"/> |
| 18) performance   |           | <input type="checkbox"/> |
| 19) sense of power  |           | <input type="checkbox"/> |
| 20) sense of control                                      |           | <input type="checkbox"/> |
| 21) embarrassment   |           | <input type="checkbox"/> |
| 22) willingness to take chances                           |           | <input type="checkbox"/> |
| 23) ability to participate                                |           | <input type="checkbox"/> |
| 24) eagerness to try new things                           |           | <input type="checkbox"/> |
| 25) ability to adapt to the<br>activities of daily living |           | <input type="checkbox"/> |
| 26) ability to take advantage<br>of opportunities         |           | <input type="checkbox"/> |