Université de Montréal

Socio-demographic, visual and psychological factors associated with adjustment to vision loss in retinitis pigmentosa

par

Nathalie De la Haye Duponsel

Ecole d'optométrie

Mémoire présenté à la Faculté des études supérieures

en vue de l'obtention du grade de Maîtrise en science

en Sciences de la vision

option Sciences fondamentales et Appliquées

Avril, 2012

Université de Montréal

Faculté des études supérieures

Ecole d'optométrie

Ce mémoire intitulé :

Socio-demographic, visual and psychological factors associated with adjustment to vision loss in retinitis pigmentosa

présentée par :

Nathalie De la Haye Duponsel

a été évalué par un jury composé des personnes suivantes :

Marie-Chantal Wanet-Defalque, Ph.D.
présidente rapporteuse

Olga Overbury, Ph.D.
directrice de recherche

Judith Renaud, O.D., Ph.D. (candidate)
membre du jury

SUMMARY

While there is extensive research on retinitis pigmentosa (RP) focusing on biological and hereditary aspects of the disease, little research regarding psychological adjustment has been conducted. These few studies suggest that people with RP adapt differently to vision impairment. This study investigated whether those with RP adapt differently to vision loss/impairment than those with other vision disorders.

Telephone interviews of those with RP, diabetic retinopathy (DR), and albinism were conducted. Demographic information was gathered and psychological wellbeing was assessed using the *Visual Function-14, Centre of Epidemiology Studies Depression-10 symptoms index, Impact of Vision Impairment Profile, Brief COPE, and Adaptation to Vision Loss Scale.*

In Experiment I it was found that individuals with RP did not differ from those with other diagnoses on any of the measures of psychological wellbeing and adaptation. Rather, demographic factors, visual factors such as declining and fluctuating vision, and pattern of vision loss, were better correlates of adaptation to and psychological wellbeing associated with vision loss/impairment.

In Experiment II there was no difference found between those with RP and other diagnoses on any of the measures. Rather, factors such as perceived visual ability, self-identity, fear of social stigma and level of dependence were more closely related to adaptation to and psychological wellbeing associated with vision loss/impairment.

The results of this study suggest that individuals with RP do not differ from those with other vision disorders in their adaptation to and psychological wellbeing associated with vision loss/impairment, but that other demographic, visual and psychological factors are more important.

Key words: Retinitis pigmentosa, vision loss, vision impairment, adaptation, psychological wellbeing

RÉSUMÉ

Malgré des recherches intensives portant sur l'hérédité et les aspects biologiques de la rétinite pigmentaire (RP), peu de recherches fondées ont porté sur les aspects psychologiques. Ces quelques études suggèrent que les personnes atteintes de rétinite pigmentaire s'adaptent différemment à la déficience visuelle. Le but de la présente étude était donc de vérifier si les personnes atteintes de rétinite pigmentaire s'adaptaient différemment d'un point de vue psychologique par rapport à des personnes ayant une déficience visuelle causée par une autre pathologie.

Des entrevues téléphoniques incluant des personnes ayant la rétinite pigmentaire, la rétinopathie diabétique (RD) et l'albinisme ont été menées. Cinq questionnaires ont été utilisés afin d'évaluer le bien-être psychologique et de recueillir les données démographique.

Les résultats de la première étude démontrent qu'il n'existe aucune différence entre les individus atteints de rétinite pigmentaire et ceux ayant d'autres pathologies visuelles d'un point de vue « bien-être psychologique ». En fait, les facteurs démographiques, la baisse de vision, les fluctuations et le type de perte de vision semblent être les seuls facteurs directement corrélés à l'adaptation et au bien-être psychologique.

Dans la deuxième étude, aucune différence n'a pu être établie entre les trois types de pathologies. Ce sont plutôt, des facteurs comme la perception des capacités fonctionnelles, l'identité personnelle, l'appréhension de la perception sociale et le niveau d'indépendance qui étaient davantage reliés au bien-être psychologique associé à la déficience visuelle.

Les résultats de cette étude suggèrent que les personnes atteintes de Rétinite pigmentaire ne présentent pas de différences au niveau du bien-être psychologique et de l'adaptation. Les facteurs démographiques et psychologiques sont plus importants que la pathologie elle-même.

Mots clefs : Rétinite pigmentaire, perte de vision, déficience visuelle, adaptation, bien-être psychologique

TABLE OF CONTENTS

LIST OF TABLES

Chapter II

Chapter III

LIST OF FIGURES

Chapter II

Chapter III

LIST OF ABBREVIATIONS

AVL: Adaptation to Vision Loss Scale

CES-D: Centre for Epidemiological Studies Depression-10 Symptoms Index

DR : diabetic retinopathy

INLB: Institut Nazareth et Louis-Braille

IVI: Impact of Vision Impairment Profile

IVI-Emotional: Emotion related subscale of the Impact of Vision Impairment Profile

MMRC: MAB-Mackay Rehabilitation Centre

RP: retinitis pigmentosa

VF-14: Visual Function 14 Scale

To my parents, my brother, and all my family:

You are the source of all my joy.

ACKNOWLEDGEMENTS

First, I'd like to express my gratitude to the School of Optometry of the University of Montreal and the Reseau vision of the FRSQ for the financial support that funded my studies.

I'd like to thank the MAB-Mackay Rehabilitation Centre and the Institut Nazareth et Louis-Braille for access to their clients for recruitment of participants for this study. Much appreciation to Dr. Walter Wittich and Mme Claire Trempe for making the initial contact with all the participants.

I'd also like to thank Tanja Gninka, the lab manger in the Overbury lab, for all of her help and for keeping me sane during this process. And also, thanks to Carole Deharnais for testing some participants during an absence.

Merci à Marie-Chantal Wanet-Defalque, à Didier Chelin et à Anne Jarry de votre aide pour les traductions. Votre aide est bien appréciée.

I'd like to give a special thanks to my parents for being so supportive as I completed this degree. A special thanks too to my aunts, Elisabeth and Catherine, for their support and encouragement from a distance.

And finally, because I like to save the best for last, I'd like to thank my supervisor Dr. Olga Overbury, without whom this thesis would not have been possible. I thank her for her guidance and direction during this process, and for making it an enjoyable one. Mostly, I thank her for her kindness and patience as extenuating circumstances not related to this degree could have ended it all had it not been for her understanding. I appreciate all that you have done for me.

Chapter 1

INTRODUCTION

Retinitis pigmentosa (RP) is a hereditary vision disorder that involves the breakdown of the retinal pigment regeneration cycle, leading to the dystrophy of the photoreceptors beginning in the peripheral retina and moving to the fovea. Retinitis pigmentosa is characterized by a gradual loss of vision over a relatively extended period of time. The first symptoms of RP typically occur in adolescence or early adulthood with night blindness and mild peripheral field loss. As the disorder progresses, further peripheral loss is experienced and central vision may become affected as well. The final prognosis of RP remains relatively unpredictable with some individuals maintaining fairly good central vision, while others lose all light perception.

As with any cause of vision impairment, the psychological impact of RP can be significant. Depression and anxiety are found to be higher in individuals with acquired vision impairment, including those with RP. The stressors associated with the loss of vision resulting in an individual's inability to continue performing daily activities, including reading, writing, driving, moving around independently, taking care of personal grooming, and earning a living, can lead to significant psychological distress. In the case of RP, due to the nature of the disease, individuals are forced to endure this loss over an extended period of time, without a predictable end. Relatively little research has been conducted in this area but, in the little that has been done, it has been suggested that individuals with RP may, in fact, adapt differently and not fare as well as individuals with other causes of vision loss.

The purpose of the following studies was to investigate whether individuals with RP differ from those with other visual diagnoses in their psychological wellbeing associated with, and adaptation to, vision loss/impairment and, if not, what factors are more closely associated with psychological outcomes. In order to do this, individuals with RP were compared to those with diabetic retinopathy (DR) and oculocutaneous albinism. Diabetic retinopathy shares many similar characteristics to RP, not so much in the symptoms themselves, but in the nature of the loss (unpredictable and extended over time) and in its psychological implications. Oculocutaneous albinism, on the other hand, is almost completely unlike RP and DR as it is a stable condition, with no changes in vision, but still involves a visual impairment with functional implications that can be significant. Factors independent of visual diagnosis that were considered included socio-demographic factors, functional vision, perceived functional vision, coping strategies, and personal identification with disability.

LITERATURE REVIEW

1. VISION IMPAIRMENT

Vision loss represents one of the most difficult and stressful life events an individual may encounter. In Canada, vision is within the top five conditions that cause significant disability among the elderly (Griffith, Raina, Wu, Zhu & Stathokostas, 2010). It is estimated that, in Canada, 6.7% individuals over the age of 65 years and up to 24.9% over the age of 85 years are visually impaired (Jin & Wong, 2008). In the developed world, the three most prevalent causes of permanent vision impairment are age-related macular degeneration (AMD), diabetic retinopathy (DR), and glaucoma (World Health Organization (WHO), 2009a). However, not all vision impairments are age-related. There exist a multitude of vision disorders that affect younger individuals either from birth or in early to mid-life.

Vision impairments can be grossly divided into two major categories: those that are congenital and those that are acquired. Congenital refers to disorders that are present at birth and are based on the physical characteristics of the organism at birth (i.e., lack of pigmentation and foveal underdevelopment in albinism). Congenital disorders can be genetically inherited or may occur spontaneously as a result of pre-natal environmental influences. Therefore, although a disorder may be genetic, it is not classified as congenital unless the physical effects are already present at birth. Some examples of congenital vision impairments due to environmental causes are retinopathy of prematurity, infections such as rubella and toxoplasmosis, or other unknown influences that may lead to hypoplasia of the retina, optic nerve and/or visual cortex. Some examples of hereditary congenital vision

impairments are ocular albinism, retinal blastoma, Leber's congenital amaurosis and aniridia (Crick & Khaw, 2003).

Acquired vision impairment, on the other hand, as the name suggests, is an impairment that develops after birth. This implies that, even if vision is lost when an infant is one month old, the visual system was functionally normal at birth. As previously mentioned, most individuals affected by visual impairment are affected by age-related as opposed to early-onset disorders. These typically include AMD, DR, glaucoma, and cataracts. There are other impairments, however, which are typically genetically inherited that can result in vision impairment as early as infancy (Leber's hereditary optic neuropathy), childhood (Stargardt's disease), or adolescence (retinitis pigmentosa). Many other vision disorders can also occur any time during life either due to trauma or infection (retinal detachment, corneal occlusion, cataracts, etc.) or as a secondary effect of a systemic disease such as diabetes or multiple sclerosis (Crick & Khaw, 2003).

Regardless of the cause, all vision impairments are classified by the functional effect and not based on biological and physiological characteristics. The World Health Organization (WHO) defines vision impairment as a visual acuity in the better eye with best correction of 20/60 (6/18) or worse, or a visual field in the better eye with best correction and 10 degrees or less from the point of fixation (WHO, 2009b). These definitions were established based on when a person's function becomes significantly impaired due to the lack or loss of vision. Although these definitions exist for practical purposes, such as in the case of government assistance and tax exemptions, the visual experience and functional

implications for each individual may vary even if objetively measured vision may be similar.

1.1 Functional Impact of Vision Impairment

The functional impact of vision impairment varies depending on the cause of vision loss, the extent of loss and the individual reaction of each person. Although many vision disorders exist, the functional effects may be somewhat similar depending on how they affect the eye or visual system. In general, the functional effects of vision impairment can be divided into three major categories: peripheral vision impairment and central vision impairment (Faye, 1984), and generalized vision impairment.

1.1.1. Peripheral Vision Impairment

Disorders such as glaucoma and retinitis pigmentosa typically result in visual field loss beginning in the extreme periphery and moving toward the fovea. The major functional impact of these disorders, before the fovea is affected, is difficulty with orientation and mobility as the visual field is restricted to the point of inability to view enough of a visual scene to move freely within it. Reading, driving and other tasks involving tracking may also become difficult as the individual may frequently lose orientation and have difficulty re-establishing it. Although visual acuity may eventually be reduced in these individuals, tasks involving fine resolution vision are not usually affected in these disorders until late stages (Faye, 1984).

1.1.2. Central Vision Impairment

On the other hand, disorders such as macular degeneration, Stargardt's, and albinism, affect the macula and fovea such that fine-detail resolution becomes impossible. In these cases, reading, writing, recognizing faces, driving and any other activity requiring a person to see fine-details becomes difficult. Mobility, apart from driving, is not generally severely affected in these disorders as the visual field remains intact. However, as contrast sensitivity is usually also affected in these situations, seeing the edges of steps or changes in level of terrain may become difficult, which can lead to falls (Faye, 1984).

1.1.3. Generalized Vision Impairment

Disorders such as diabetic retinopathy or retinal detachment can affect the retina in various locations. Therefore, the impact of the disorder will correlate with the location of the affected retina, and thus can have varying effects either on central vision or peripheral vision. Also, disorders such as cataracts, corneal opacities, amblyopia, albinism, aniridia and others can create general interference in vision due to glare, photophobia, and reduced contrast sensitivity, among others.

In all of the above cases, simple day-to-day activities can become severely impaired. Tasks such as cooking, cleaning, reading, watching TV, personal care, and participating in social activities can become difficult, if not impossible when vision impairment is severe. For younger individuals, school, work, and taking care of one's family can also become

difficult. As a result, vision impairment can have indirect consequences on all aspects of an individual's life, including psychological wellbeing.

1.2. Psychological Impact of Vision Loss/Impairment

Research has shown that vision impairment often results in significant psychological distress. Upton and colleagues (1998) reported high levels of anxiety and psychological distress in their participants, while Brody and colleagues (2001) found a depression rate among AMD sufferers at 32.5%, more than double the rate among an age-matched population. Elevated levels of depression rates in the visually impaired have been reported in many studies (Burmedi, Becker, Heyl, Wahl & Himmelsbach, 2002; Wahl, Schilling, Becker, & Burmedi, 2003). Vision-specific quality of life is understandably frequently poor in the visually impaired (Brody, Gamst, Williams, Smith, Lau, Dolnak et al., 2001; Seo, Yu & Lee, 2009; Wu, Nemesure, Hennis & Leske, 2009), but some studies have also found significant reduction in overall quality of life due to vision loss (Gillman, Simmel, & Simon, 1986; Good, 2008). Vision loss can also result in feelings of embarrassment (Nemshick, McCay & Ludman, 1986), loss of personal integrity (Taylor & Upton, 1988), and reduction in self-confidence (Tolman, Hill, Kleinschmidt & Gregg, 2005), often resulting in low self-esteem (Roy & Mackay, 2002). The psychological implications of vision loss have been shown to go so far as to threaten individuals' perception of their identity as they may no longer be able to work in their chosen profession, thus feeling unable to provide for their family, and participate in activities that once contributed to their

personal identity (Estrada-Hernandez & Harper, 2007; Hayeems, Geller, Finkelstein, & Foden, 2005).

2. ADAPTATION TO VISION LOSS/IMPAIRMENT

The Oxford Dictionary of Psychology defines adaptation as "any process whereby behaviour or subjective experience alters to fit in with a changed environment or circumstance" (2009; p.11). The change in environment or circumstance in the case of this thesis refers to vision impairment. Also, adaptation is a neutral term that can result in negative or positive outcomes. Determining good or poor adaptation is usually done through measures of psychological wellbeing. Wellbeing is defined as "the condition of being contented in mind or health" (The Collins English Dictionary, 2004; p.987). In the case of research referred to in this text, wellbeing is limited to that of the mind, hence the use of "psychological wellbeing". Many factors have been shown to contribute to individuals' ability to adapt well, or not, to vision impairment. Some socio-demographic factors, functional ability, perceived functional ability, and coping styles and strategies have all been shown to impact the individual's ability to adapt to vision loss/impairment.

2.1. Socio-Demographic Factors and Adaptation to Vision Loss/Impairment

A person's age, gender, education level, susceptibility to depression, duration of vision impairment, the presence of co-morbidities, and ocular diagnosis have all been associated with adaptation to vision loss/impairment. Younger individuals have been shown to adapt

better to vision loss than their older counterparts (Lindo & Nordholm, 1999; Tolman, et al., 2005). Findings have suggested that men generally tend to adapt better to vision loss than women (Tolman et al., 2005). Those with higher education tend to adapt better, as well as those who have received vision rehabilitation services (Tolman et al., 2005). Depressive symptoms and susceptibility to depression have frequently been associated with poorer adaptation to vision loss (Brody et al, 2001; Burmedi et al., 2002; Hahm, Shin, Shim, Jeon, Seo, Chung et al, 2008; Reinhardt, Boerner & Horowitz, 2009; Tolman et al., 2005; Wahl et al., 2003). While some research suggests that the presence of co-morbidities may be associated with poorer adaptation to vision loss (Horowitz, Reinhardt, Boerner & Travis, 2003; Reinhardt, 1996; 2001), Coyne and colleagues (2004) and Rubin and Peyrot (1999) indicate that this may not be the case.

The type of ocular diagnosis has also been suggested to affect adaptation to vision loss. Some research has suggested that those with some ocular diagnoses, such as diabetic retinopathy and retinitis pigmentosa, may adapt more poorly to vision loss and impairment (Jangra, Ganesh, Thackray, Austin, Ulster, Sutherland, et al., 2007; Mangione, Lee, Pitts, Gutierrez, Berry & Hays, 1998). This research suggests that the nature of the progression of some visual disorders and their functional implications may result in more difficulty in adapting to vision loss (Fourie, 2007; Hahm et al., 2008; Jangra et al., 2007).

2.2. Functional and Perceived Functional Ability and Adaptation to Vision Loss/Impairment

Although some research suggests that adaptation to vision loss and psychological wellbeing is correlated with functional loss (Seo et al., 2009), there is a large body of evidence that suggests that severity of visual functional loss, typically measured as visual acuity, is not necessarily associated with adaptation and psychological wellbeing, but rather, is associated with changes and fluctuations in functional vision (Bittner, Edwards, & George, 2010; Brody et al., 2001; Wulsin, Jacobson & Rand, 1991). Wulsin and colleagues (1991) conducted a study examining visual function and psychological wellbeing and found that, although a lower visual acuity was correlated with poorer wellbeing with time, this was not the case at baseline. Upton and colleagues (1998) found similar results where severity of vision loss was not correlated with psychological wellbeing. They found that it was a recent loss in visual acuity, rather than severity of acuity loss, that was more strongly associated with wellbeing (See also Brody et al., 2001). Furthermore, studies have demonstrated that gradual loss over an extended period of time has particularly negative psychological consequences (Jangra, et al., 2007).

In addition to recent loss, fluctuations in vision have also been shown to be particularly detrimental to the wellbeing of those experiencing them. Bernbaum and colleagues (1988) found that participants with fluctuating vision had poorer scores on several psychosocial measures of wellbeing than those with stable vision or even blindness. Bittner and colleagues (2010) and Coyne and colleagues (2004) reported similar experiences in their

participants where fluctuations of vision from day-to-day were found to be extremely difficult to cope with and very anxiety provoking. Similar to the uncertainty of day-to-day visual fluctuations, the uncertainty of an unknown final prognosis of vision has also been found to result in significant anxiety and distress in individuals with diagnoses that are unpredictable (Jangra, et al., 2007; Nemshick et al., 1986)

2.3. Coping Styles and Strategies in Adaptation to Vision Loss/Impairment

Perhaps one of the most important influences on adaptation to vision loss, or any other life stressor, is one's coping strategy. Coping is any cognitive or behavioural reaction to a given stressor in order to relieve anxiety and negative feelings associated with the stressor. However, coping strategies may or may not be beneficial in dealing with the stressor.

While several models of coping do exist (for example: The Assimilative and Accommodative Coping Model of Brandtstädter and Renner (1990), The Stress and Coping Model of Lazarus and Folkman (1984), The Health Realization/Innate Health Model of Mills (1995), the Perrson Model of Persson (1990), and the Life-Span Theory of Control by Heckhausen and Schulz (1995)), only three models have been investigated in more depth in the context of vision impairment: 1) The Stress and Coping Model, 2) The Assimilative and Accommodative Coping Model, and 3) The Life-Span Theory of Control, as well as one other model, Persson's model of coping, having been investigated in a single study to date. Most research on coping in vision impairment tends to focus on the various coping strategies that individuals may use, and whether these result in positive or negative

outcomes, rather than on the development of coping models. Furthermore, this research typically aims to describe the coping strategies that this population uses, rather than to determine if these coping strategies are beneficial for successful adaptation (Benn, 1997; Bittner et al., 2010; Brennan, Horowitz, Reinhardt, Cimarolli, Benn, & Leonard., 2001; Lee & Brennan, 2006). Finally, even in the limited research that exists on coping with vision impairment, most of the studies focus on age-related vision loss and do not compare the coping strategies used by individuals with vision impairment due to different vision disorders.

The earliest studies investigating coping models in vision loss examined the most well-known coping theories developed by Lazarus and Folkman (1984), who divided coping strategies into two major types: problem-focused coping and emotion-focused coping. Problem-focused coping involves a strategy of coping aimed at proactively alleviating the problem at hand by tackling it directly. Problem-focused strategies may include seeking out information about the problem, seeking assistance from those that are aware of the problem and may be able to offer advice, attempting various possible solutions, etc. Emotion-focused coping, on the other hand, aims at alleviating the emotions associated with the problem, not so much the problem itself. This may involve avoiding the problem in order to reduce feelings of anxiety and depression, distracting oneself from the problem, venting about the problem, or focusing uniquely on the emotions in order to determine steps to be taken and choices to be made. Lazarus and Folkman suggested that problem-focused coping was the more effective of the two in successfully adapting to a stressor with a positive outcome.

Much research has supported this theory, including studies on vision impairment (Ben-Zur & Debi, 2005; Reinhardt et al., 2009; Wulsin et al., 1991). For example, Reinhardt and colleagues (2009) found that participants who utilized problem-focused coping had better outcome scores on measures of adaptation to vision loss and depressive symptoms. Conversely, they also found that emotion-focused coping was negatively associated with these scores. Similarly, Ben-Zur and Debi (2005) found that problem-focused coping was correlated with higher positive affect and better functioning, while emotion-focused coping was associated with negative affect and worse functioning. This may be problematic as research by Wulsin and colleagues (1991) found that use of emotion-focused coping was correlated with poorer visual acuity.

Some investigators have already suggested that coping strategies may not remain consistent throughout the lifespan. Lindo and Nordholm (1999) found that younger individuals with vision loss seem to cope better than their older counterparts. The authors suggest that it is due to a less prevalent feeling of hopelessness among the younger participants. Boerner (2004) also found differences in coping across the lifespan. In this study, accommodative coping became more prevalent in younger participants with an increase of functional disability, but this was not found in older adults where accommodative coping was present regardless of the level of functional disability. Boerner suggests that chronic impairment posed more of a risk for younger participants than for those who were older. She proposes that this may be because older adults expect and are already more accustomed to making changes due to their age and declining physical health. It may also be the case that it is not

expected for younger individuals to acquire chronic impairments and, thus, it is more difficult to accept when generally one is supposed to be healthy.

Research also suggests that coping strategies may change at different stages of disease progression. Boerner and colleagues (2006) found that problem-focused coping decreased with disease progression. They suggested that problem-focused coping may decrease with time and age as there may no longer be any action to be taken to achieve a cure or halt further loss, and individuals may have already consulted all possible services and information that could assist them with their impairment. Conversely, as use of problem-focused coping decreases, emotion-focused coping may increase as an individual no longer has any action that may be taken, or may be older and unable to take any further action.

Finally, some studies also propose that coping may be different as a function of various vision disorders. It has been suggested that individuals with RP follow a different adjustment process compared to individuals dealing with other significant physical disorders. Research conducted by Strougo and colleagues (1997) found that RP patients suffered from significant anxiety and depression, while research by Siple Milles (2004) found that individuals with RP demonstrated a more frequent tendency for avoidance coping than average. Furthermore, regardless of their stage of adjustment, individuals with RP in this study demonstrated a consistent tendency for avoidance coping, which did not necessarily correlate with successful adjustment.

2.4 Self-Identity and Adaptation to Vision Loss/Impairment

It has also been suggested that individuals may adapt better to vision loss, and have more positive psychological wellbeing, if they are able to identify themselves as visually impaired versus sighted (Hayeems et al., 2005; Pollard, Simpson, Lamoureux & Keeffe, 2003). In a study conducted by Hayeems and colleagues (2005), important differences in life-style changes and device use were found between individuals who considered themselves as 'sighted' versus 'visually impaired'. In this study, those who still identified themselves as 'sighted' resisted life-style changes and refused to use devices that could be helpful. Those who already identified themselves as 'visually impaired', on the other hand, were found to have already made life-style changes in accordance with their visual ability and were prepared to use assistive devices. Interestingly, a third group who considered themselves to be as 'in transition' admitted to the benefit of assistive devices but were not prepared to use them immediately. In another study by Pollard and colleagues (2003), participants who did not yet consider themselves as visually impaired were significantly less likely to seek and participate in vision rehabilitation services.

2.5 Stigma and Adaptation to Vision Loss/Impairment

It has also been suggested that one of the major factors for the resistance of beneficial change in lifestyle by visually impaired people is the fear of the stigma associated with visual impairment and blindness (Bittner et al., 2010; Hayeems et al., 2005; Lund & Gaigher, 2002; Roy & Mackay, 2002; Wan, 2003). In fact, in the above mentioned study by

Hayeems and colleagues (2005), participants who still considered themselves as sighted, but recognized the benefit of making life-style changes that more suited their needs, admitted that their fear of stigma was the primary reason for the lack of change. Fear of social stigma has also been reported by participants in other studies (Bittner et al., 2010; Estrada-Hernandez & Harper, 2007; Fourie, 2007; Jangra, et al., 2007; Nemshick & Ludman, 1986). Participants in Hayeems and colleagues' (2005) study actually likened their use of assistive devices in public for the first time to 'coming out', presumably due to the extent to which they believed society stigmatizes the visually impaired and blind persons.

3. RETINITIS PIGMENTOSA

3.1 Description of the Disease

Retinitis Pigmentosa (RP) is a set of hereditary diseases involving the gradual degeneration of the rod and cone photoreceptors over a relatively lengthy period of time (Hartong, Berson & Dryja, 2006). As RP is a set of diseases, progression manifests itself at different rates and in different ways both physiologically and, potentially, psychologically. While there is extensive research in RP focusing on the biological and hereditary aspects of the disease, little research regarding the psychological adjustment has been conducted (Fourie, 2007).

It has been demonstrated in much research that RP progresses relatively slowly compared to other visual disorders. The disease typically begins with the death of the rod photoreceptors in the peripheral visual field, resulting in the initial symptoms of night blindness and peripheral field loss. The disease then progresses to the central visual field, with the eventual death of the cone photoreceptors, which results in blindness. However, this process typically unfolds over many years, even decades, and may, or may not, lead to blindness. Over 58 genes (The National Center for Biotechnology Information (NCBI): Gene Database, 2012) have already been identified as being implicated in RP, and it has already been suggested that disease progression of RP may be dependent on the type of inheritance pattern, or the specific gene associated with the given form of RP. As a result, individuals with RP are faced with a widely varying range of possible progression rates and final outcomes for their disease. Faced with this uncertainty, individuals with RP are forced to adjust to an unpredictable and typically lengthy period of gradual vision loss, a process almost unique among vision disorders (Hartong et al., 2006). Unfortunately, at this time, there is no treatment or cure for RP.

3.2 Functional and Psychological Implications

While the vast majority of individuals who are visually impaired in developed countries are the elderly, RP is generally diagnosed early in life, typically during late childhood or adolescence. Nemshick and Ludman (1986) found that 69% of their 307 participants were diagnosed with RP between the ages of 6 and 19 years. This early diagnosis has consequences not typically encountered by older individuals. For example, their

participants reported difficulties in school and work, as well as problems with social activities and family life. Although older individuals may encounter the social difficulties that those with RP might have, it is not during the formative years when friendships are developed, sometimes for life. Also, older individuals are not usually still supporting their family when their vision is affected, whereas those with RP often have young children to care for and support financially when the majority of their vision loss is taking place (Jangra, et al., 2007).

Another difficulty encountered by those with RP is the extended duration of vision loss. The progression of RP and the corresponding symptoms can take place over an extremely long period of time. Generally, visual symptoms in those with RP begin in adolescence with night blindness (nyctalopia). At this point, dystrophy of the photoreceptors, particularly the rods, is occurring, resulting in the onset of night blindness and visual field loss. However, as the loss in the visual field is to the extreme limits of the normal field, this loss is not typically noticed in this initial stage of RP. The deterioration of the visual field continues to progress toward the fovea over an extended period, sometimes spanning over several decades. Once the visual field is diminished to approximately 30 degrees, central vision also starts to become affected (Madreperla, Palmer, Massof & Finkelstein, 1990).

While visual acuity may not change until the very late stages of the disorder, changes in contrast sensitivity (Alexander, Barnes, Fishman, Pokorny, & Smith, 2004), color vision (Massof, Johnson, & Finkelstein, 1981; Nimsgern, Krastel, Auffarth, Eggers, & Lang, 1998), reading (Sandberg & Gaudio, 2006; Virgili, Pierrottet, Parmeggiani, Pennino,

Giacomelli, Steindler, et al., 2004), and motion (Alexander, Derlacki, & Fishman, 1999) have been reported. Finally, at the end stages of the disorder, the fovea degenerates and even central vision is lost.

However, to complicate matters even further, not everyone experiences the same rate of progression. Massof and Finkelstein (1979) indicate that various forms of RP progress differently. As multiple genes can cause RP, the physiological progression of the disease may occur differently depending on the biological mechanisms associated with each gene. Research concerning the progression rate of visual field loss has produced varying rates ranging from a visual field half-life of 3.8 years (Fishman, Bozbeyoglu, Massof & Kimberling, 2007) to 8.4 years (Madreperla et al., 1990), or an average annual loss of 2.6% (Berson, Rosner, Weigel-DiFranco, Dryja, & Sandberg, 2002) to 4.7% (Sandberg, Rosner, Weigel-DiFranco, Dryja, & Berson, 2007).

To further understand the difficult nature of RP, the pattern of the vision loss also needs to be taken into consideration. The first symptom of RP is typically night blindness. For those who are unaware of their diagnosis, this symptom can be confusing and anxiety provoking as it appears gradually and is situation specific. Often a person experiencing this may begin to avoid situations where scotopic vision is required, most often evening social events (Jangra, et al., 2007). This has been shown to lead to social isolation (Fourie, 2007; Jangra, et al., 2007), which may have particularly negative consequences during these socially formative years.

The progression of vision loss from periphery to central vision is also problematic. As is well known, the visual system favours central vision, as evidenced by cortical magnification of the fovea in the visual cortex, as most tasks in our day-to-day environment require detailed resolution (Bear, Connors & Paradiso, 2001). As a result, individuals losing peripheral vision may not even be aware of this loss in the initial stages. Later, even if this loss may become noticeable, if visual acuity remains good, a person can still function relatively well. At this point, mobility may become more difficult, however, and a person might begin to avoid situations where independent travel is necessary. Similar to night blindness, individuals with RP who have reduced mobility have indicated that they felt isolated as a result (Fourie, 2007; Jangra, et al., 2007).

The uncertainty of the final prognosis of RP is also an element found to be difficult for those with the disorder. While most individuals with RP stabilize within the legal blindness range, some fare quite well never reaching this stage, while others lose all vision. Multiple studies have found that the most frequent fear reported by participants with RP was that of losing their vision completely and the uncertainty of the final outcome (Hahm, et al., 2008; Jangra, et al., 2007; Nemshick & Ludman, 1986). Additionally, it has been reported that individuals with RP may experience fluctuations in vision on a day-to-day basis. This too has been shown to be anxiety provoking, causing psychologically distress (Bittner et al., 2010).

4. STUDY RATIONALE

The combination of the above-mentioned symptoms may explain the reported differences in coping and adjustment found between people with RP and those with chronic disabilities or other vision impairments. However, each individual symptom in itself is not unique to RP and all have been associated with difficulties experienced by individuals with other vision impairments. Why, therefore, should those with RP experience more difficulty coping and adjusting than people with other vision impairments? In order to examine this question, it is necessary to make a comparison to individuals with a vision impairment that has similar consequences if not the same physiological basis. It is also necessary to determine if the challenges experienced by those with RP are due to the loss of vision, and the consequent adjustment it necessitates, or if the difficulty lies in living with a vision impairment itself. In order to determine this, a comparison with a group of a similar age and vision characteristics but with a congenital condition, where no vision loss has occurred but rather poor vision has been present since birth, is also necessary. The two disorders that may allow for these comparisons are diabetic retinopathy and oculocutaneous albinism.

4.1 Diabetic Retinopathy

4.1.1 Description of the Disease

Diabetic retinopathy (DR) is a complication of diabetes mellitus that affects about a third of diabetics (Klein, 2007; Mitchell, Smith, Wang, Attebo, 1998), and accounts for

approximately 80% of legal blindness in individuals between the ages of 20 and 74 years (New Jersey Society of Optometric Physicians, 2004). Blood vessels throughout a diabetic's body are damaged due to glucose fluctuations, particularly hyperglycemia, resulting in damage to blood-vessel walls, which can cause leakage from the vessels, having detrimental effects in the case of the retina. The initial stage of this damage in the retina is known as nonproliferative DR. During this stage, although there is already accumulation of glucose and fructose in the blood vessels, the damage is not usually sufficient to alter vision. Some individuals, however, develop macular oedema as blood vessels in the vicinity leak fluids and lipids into the macula causing swelling that can blur vision and reduce visual acuity.

In advanced stages, the growth of new, small, fragile blood vessels (neovascularization) begins as there is a lack of oxygen in the retina. When this occurs, DR is categorized as proliferative DR. These fragile blood vessels, if left untreated, can haemorrhage into the vitreous humour and the retina damaging the photoreceptors. Furthermore, the neovascularization can also cause retinal detachment due to traction, and neovascular glaucoma if the blood vessels grow into the angle of the anterior chamber.

4.1.2 Functional and Psychological Implications

Although nonproliferative DR is typically asymptomatic, proliferative DR can severely affect vision, often leading to complete blindness. Depending on the location of the haemorrhages, peripheral and/or central vision can be irreversibly affected. Typically,

individuals with DR will have multiple scotomas in both peripheral and central vision. This can have a wide variety of functional implications. If central vision is affected, as in AMD, individuals with DR will experience difficulties with tasks that require fine-detail vision, such as reading and writing, recognizing faces, driving, seeing bus numbers and street signs, etc. If peripheral vision is affected, as in RP, these individuals can experience difficulty with orientation and mobility tasks, such as avoiding obstacles and crossing roads, driving, and even reading.

As in RP, vision in DR tends to fluctuate, is unpredictable, and can decline over a very short period of time or over an extended period. Although the blood in the vitreous humour can clear up with time, haemorrhages can also occur repeatedly. If the photoreceptors in the area of the haemorrhage are not directly affected, vision may return in that given area. However, if the photoreceptors are damaged, vision is permanently affected or lost. Unfortunately, it is difficult to predict haemorrhages and whether vision will return after the blood has cleared up. The uncertainty regarding when and how severely vision will decline, as in RP, results in significant psychological distress and anxiety in individuals with DR (Coyne et al., 2004).

Also similarly to RP, DR can occur earlier in the lifespan. Although most cases of DR occur in late adulthood, it can occur in early or mid-adulthood as well. As previously mentioned, the impact of a visual impairment may have differing consequences at different stages of life.

However, DR is not identical to RP. Unlike RP, which has no current treatment or cure, DR can currently be treated in an attempt to slow progression of vision loss (although this does not cure the disease). The possibility of slowing disease progression may have some psychological effects that make coping with DR different than coping with RP. For example, Jangra and colleagues (2007) reported that their participants with RP expressed more dissatisfaction with the medical field than those with DR. They suggest that this may be the case due to the lack of any treatment for RP as opposed to DR. Also, unlike RP, DR is a result of a systemic disorder that may have other complications, and thus other stressors. Researchers in this area seem, however, to disagree as some studies suggest that the additional problems associated with DR affect the psychological wellbeing of patients (Devenney & O'Neill, 2011; Hirai, 2010) while other studies suggest that it does not (Rubin, & Peyrot, 1999). Furthermore, while RP occurs regardless of the sufferers' actions, DR can be the result of their actions, or lack thereof. As DR is linked to fluctuations of glucose levels in the blood, those with DR may feel partially or fully responsible for their condition if, for example, they did not control their glucose levels sufficiently. Feelings of responsibility for the condition should not normally occur in RP and may have significant effects on overall wellbeing in those with DR, which would not be the case in RP.

Overall, research by Jangra and colleagues (2007) does seem to suggest that comparing those with DR and RP is valid because, although the precise nature of vision loss is not the same, the psychological experience may be similar given that both conditions are unpredictable and can progress over an extended period of time. Furthermore, although there may be some concern that the mere presence of diabetes and its potentially related

health issues may affect adaptation, Jacobson and colleagues (1985) have demonstrated that while the onset of proliferative DR leads to significant negative psychological distress, those with late-stage proliferative DR and those with diabetes but without DR did not demonstrate significant distress. These results suggest that, as long as the affected person experiences no major health conditions due to diabetes, the presence of disease itself does not necessarily lead to significant negative psychological distress.

4.2 Albinism

4.2.1 Description of the Disorder

Albinism is a set of hereditary, autosomal recessive conditions that result in hypopigmentation of the eyes, and in some cases the skin and hair as well. Albinism is divided into two major types: the rarer type that only occurs only in the eyes, known as ocular albinism, and the more common type that occurs in the eyes as well as the skin and hair, known as oculocutaneous albinism. As this condition can be the result of multiple genes, the amount of hypopigmentation can vary, with some individuals having near normal appearance and vision while others have no pigmentation resulting in white-blond hair, pale skin and light blue or grey eyes. The prevalence of albinism is estimated to be about 1 in 18,000 in the United States (Summers, 2009).

The cause of hypopigmentation in albinism is a lack of melanin which normally gives colour to the skin, hair and eyes. However, in the case of albinism, melanin is not present in

the body either due to a metabolic inability to produce melanin, or to a lack of tyrosine, which is a precursor necessary for the production of melanin.

This lack of melanin has consequences reaching much further than just the appearance of a person. During foetal development, melanin triggers the decussation of the optic nerve and foveal development. As a result of the lack of melanin in the case of albinism, the optic nerve is almost completely decussated, with little neural information reaching the ipsilateral visual cortex. This is believed to result in poor depth perception as the visual cortex cannot integrate information from both eyes within each hemisphere. The lack of melanin during development also results in an underdevelopment of the fovea (foveal hypoplasia), which results in a reduction of visual acuity. Visual acuity in albinism can range anywhere from 20/20 (6/6) to 20/400 (6/120), but is usually around 20/80 (6/24) (Summers, 2009).

However, a lack of melanin has even further effects on vision. Due to very little pigment in the iris of those with albinism, even when it constricts in an attempt to reduce incoming light into the eye, the iris is almost translucent, thus still letting most light into the eye. This results in significant light sensitivity (photophobia) and glare. Furthermore, as the retinal pigment epithelium (RPE) of the eye in albinism is also lacking pigmentation, light that is normally absorbed by the RPE bounces around in the eye further creating glare and a reduction in contrast sensitivity (Summers, 2009). Albinism is also associated with an involuntary movement of the eye (nystagmus), typically horizontal in nature, which can significantly reduce visual acuity (Meiusi, Lavoie & Summers, 1993), as well as strabismus and high astigmatism (Summers, 2009).

4.2.2 Functional and Psychological Implications

Due to the foveal hypoplasia, individuals with albinism have similar acuity restrictions as those with AMD. Although there is no scotoma as in AMD, this reduction in acuity results in difficulty with tasks requiring detailed vision such as reading, writing, driving, recognizing faces, and seeing computer displays, cell phone displays, street signs, store signs, etc. Although the visual field in individuals with albinism is normal, the glare and photophobia resulting from the iris transillumination and the lack of pigment in the retinal pigment epithelium results in reduced contrast sensitivity. This can reduce acuity further, particularly when contrast is already poor, such as with a newspaper. It also can make mobility difficult as it is more difficult to detect changes in elevation, such as steps, and more difficult to see signs, particularly with a bright sky or other bright lights in the background. Night travel can also be difficult due to glare as oncoming headlights from cars can temporarily blind an individual with albinism.

Unlike RP and DR, vision in albinism typically remains stable as the causes of vision impairment are present at birth and are not degenerative [However, it is worth noting that slight changes in visual function may occur when individuals with albinism are tired or sick as nystagmus during these times typically increases in amplitude, thus further reducing visual acuity (Summers, 2009).]. Furthermore, unlike with DR and most forms of RP, the person with albinism is visually impaired from birth, which means that there is never a point of vision loss.

These two factors, not having to deal with vision loss and the uncertainty of loss, represent two elements that can have devastating consequences for those with RP and DR, but with which those with albinism do not have to cope. In fact, multiple studies, and a literature review by Estrada-Hernandez and Harper (2007), have demonstrated that those with albinism have a normal range of psychological characteristics, such as intellectual abilities, coping, personality traits, self-concept and self-esteem, compared to the general population (Gold, 2002; Palmer, 2007).

There is, however, one point of difference. Those with oculocutaneous albinism have an innate visible difference that can lead to problems of social stigma, particularly in cultures identifying more with religious and myth-based beliefs than scientific and evidence-based beliefs (Estrada-Hernandez & Harper, 2007). In these contexts, it has been reported that affected individuals feel that myths regarding albinism affect their social interactions and even their parents' approach to them versus their siblings (Lund & Gaigher, 2002). The few studies that have examined albinism in a Western context suggest that these individuals do not have poorer self-esteem due to social stigma (Gold, 2002).

5. STUDY OBJECTIVES

The two principal objectives of this thesis were: (1) to determine if individuals with RP adapt differently to vision loss than those with other ocular disorders and, if not, (2) to identify the factors (functional, socio-demographic and psychological) associated with

adaptation to and psychological wellbeing associated with vision loss/impairment in early and mid-adulthood.

In order to accomplish this, two experiments were conducted. The first investigated functional and socio-demographic factors that may be associated with adaptation to vision loss. Functional factors may include visual acuity, visual field size, recent vision loss, fluctuations of vision, and time since diagnosis. Socio-demographic factors include age, gender, education level, marital status, level of independence, and socio-economic status. The second experiment investigated psychological factors that may be associated with adaptation to vision loss. Such factors may include perceived functional ability, perceived impact of visual impairment, depression, coping strategies, visual identity (sighted vs visually impaired or blind), and concern about social stigma.

Chapter II

EXPERIMENT 1: Socio-Demographic Factors and Physiological Influences on Psychological Wellbeing and Adaptation In Young and Middle-Aged Adults with Vision Impairment

Retinitis Pigmentosa (RP) is a set of hereditary diseases involving the gradual degeneration of the rod and cone photoreceptors over a relatively lengthy period of time (Hartong et al., 2006). As RP is a set of diseases, progression manifests itself at different rates and in different ways physiologically and functionally, thus potentially resulting in varying psychological adjustment. While there is extensive research in RP focusing on the biological and hereditary aspects of the disease little research has been conducted regarding the socio-demographic influences and the effects of functional loss on psychological adjustment to the disease (Fourie, 2007).

Anecdotal evidence and some research studies suggest that those with RP may adjust differently to vision loss than those with other vision disorders (Jangra et al., 2007) or chronic disabilities (Strougo, Badoux & Duchanel, 1997). Guignard (1990) and Hayeems and colleagues (2005) propose that this may be due to the relatively unique pattern of vision loss in RP. Not only does vision loss in RP generally occur over an extended period of time, but the pattern of the loss itself may also be problematic. Vision loss in RP typically involves the gradual loss of peripheral vision moving toward the fovea, often eventually affecting central vision as well. Research has suggested that this is problematic as, perceptually and physiologically, the visual system places more importance on central vision (as evidenced in cortical magnification of the fovea in the visual cortex). Thus, those

with RP may underestimate the extent of their vision loss and may be less inclined to make necessary preparations and seek the assistance they need. In fact, research by Nemshick and Ludman (1986) found that, although half of their participants with RP recognized the eventual need to change occupation, only 1/5 had made any attempt to prepare for this eventuality.

Although it may be true that RP represents a combination of difficult elements in one eye disorder, each element is not necessarily unique in itself. Other eye disorders, such as glaucoma, progress with vision loss from periphery to the fovea, are unpredictable, such as in diabetic retinopathy (DR), and can occur over an extended period of time (both glaucoma and DR). Thus, the question of why RP should be so detrimental comes to mind. Do the individual elements themselves lead to the difficulty in adapting to RP, or is it the combination of these elements that causes this difficulty? Unfortunately, there is little research investigating this question and the research that does look at the functional implications of vision loss generally involves older individuals with disorders other than RP.

The limited research that has been conducted suggests that, although the severity of vision loss may be associated with vision-specific quality of life, severity of vision loss may not be associated with general quality of life and psychological wellbeing. Robbin and Murray (1988) found that the degree of vision loss in their participants did not correlate with adaptation. Similarly, Brody and colleagues (2001) found that visual acuity was not correlated with depressive symptoms. Rather, research suggests that both recent loss and

fluctuations in vision have more detrimental effects on wellbeing and adaptation than the severity of vision impairment. Brody and colleagues (2001) found that acuity loss, rather than the degree of loss was most associated with depression. Upton and colleagues (1998) also reported that recent vision loss (not duration or severity) was correlated with a poorer sense of wellbeing, more depressive symptoms, higher functional difficulties and higher negative affect. Furthermore, fluctuations in vision also seem to result in more anxiety and distress than poor, but stable vision (Bernbaum et al., 1988; Bittner et al., 2010). Bernbaum and colleagues (1988) even found that participants with fluctuating vision faired more poorly on several psychological wellbeing measures than blind participants.

Other factors that seem to be involved in whether a person adapts well or not to vision loss are level of education, participation in vision rehabilitation, gender and age. Tolman and colleagues (2005) found that participants with higher education expressed fewer depressive symptoms. Similarly, findings by Horowitz and colleagues (2003) and Reinhardt (1996; 2001) demonstrated better adaptation in those who had completed higher levels of education. Tolman and colleagues (2005) also found that those who did not participate in, or only received limited services from, a vision rehabilitation agency were also more likely to express depressive symptoms. This same study also suggested that women may be more at risk for depression than men.

Age also seems to play a role in how well an individual adapts to vision loss. Some research suggests that the experience of younger individuals with vision loss is different to those with age-related loss. However, results seem to be somewhat mixed. Tolman and

colleagues (2005) reported a higher frequency of depressive symptoms in older participants than their younger participants. Lindo and Nordholm (1999) also found that their younger participants coped better than their older participants, chiefly due to a more prevalent sense of hopelessness in the older people. Boerner (2004), on the other hand, found that younger participants were more at risk for poor psychological wellbeing due to chronic vision impairment as opposed to older individuals. In this case, Boerner suggests that this may be because older adults expect and are already more accustomed to making changes due to their age and declining physical health, whereas this is not a common expectation among younger individuals.

As previously noted, the majority of research on the impact of vision impairment is centered on the elderly, the findings of which are not informative concerning the issues faced by younger visually impaired individuals. Understanding the impact of demographic factors and the state of the person's vision on psychological wellbeing in younger participants is crucial in order to appropriately assist them at their stage in life. Challenges that a younger individual will face may be considerably different than an older individual experiencing the same degree of vision impairment, and understanding which factors affect them the most will enable those working with younger people to better assist them in adapting successfully.

This experiment investigated whether those with RP adapt differently to vision impairment/loss to those with other visual diagnoses and, if not, to determine which socio-demographic factors (gender, marital status, employment status, etc.) and what elements of

vision loss (visual acuity loss, peripheral loss, duration since loss, etc.) have an impact on psychological wellbeing and adaptation to vision impairment in young to middle-aged adults. In order to identify what elements are unique to RP, a comparison of individuals with RP to those with other disorders sharing similar characteristics was necessary. Furthermore, in order to identify which elements may make adapting to vision loss difficult, it was necessary to isolate the difficulties inherent to vision impairment, and those due to *adapting* to the loss of vision. In order to do this, individuals with RP, DR, and albinism were interviewed and assessed using several questionnaires. Both RP and DR are acquired vision disorders that lead to frequent changes and unstable vision. Albinism, on the other hand, is a congenital vision disorder that remains stable, but can still lead a significant vision impairment.

The two principal hypotheses of this experiment were that (1) individuals with RP would not differ significantly from those with DR or albinism on measures of adaptation to, and psychological wellbeing associated with, vision loss/impairment, but rather that (2) demographic (ex: age, age at diagnosis, marital status, gender, level of education, employment status, etc.) and visual factors (ex: time elapsed since diagnosis, recent vision loss, the pattern of loss, etc.) would be better correlates of psychological wellbeing and adaptation to vision loss/impairment.

METHOD

Participants

Clients of the Institut Nazareth et Louis-Braille (INLB) and the MAB-Mackay Rehabilitation Centre (MMRC) who had been diagnosed with RP, DR or albinism were recruited for this study. Clients were included in the participant pool only if they were between the ages of 18 and 64 years, spoke either English or French fluently, and had no other ocular disorder or impairment other than their vision loss at the time of the study. The 61 participants (21 with RP, 21 with DR and 19 with albinism) ranged in age from 22 to 64 years, with a mean age of 43.89, SD = 12.83. Fifty-one percent of participants were male. The mean logMAR visual acuity across the three diagnoses was comparable, $F(2, 59) = .303$, $p > .05$. See Table 2.1 for other participant characteristics and basic demographic information across the three diagnoses.

Materials

Demographic information was collected by interview with participants and by consulting the client files at both the INLB and MMRC. A demographic questionnaire (See Appendix A) was used to collect information such as age, gender, marital status, living situation, family support, etc., directly from participants, while information regarding current vision (visual acuity, visual field, etc.) was retrieved from the appropriate client files.

Psychological wellbeing was measured using two scales: one measuring the general presence of depressive symptoms and the other the presence and frequency of negative emotions associated with vision impairment. To measure the general presence of significant

Table 2.1

Participant Characteristics and Demographic Information across Diagnoses

Characteristic		Diagnosis		
		RP	DR	Albinism
Age		42.1	50	39.1
Gender	Male	11	9	11
	Female	10	12	8
Family history	Yes	9	0	9
	No	12	21	10
Age at diagnosis		18	35.4	0.1
Time elapsed since diagnosis		24.1	14.6	39.1
Time elapsed since last decline		55.6	42.5	452.8
Level of impairment	Mild/Moderate*	8	14	16
	Legally blind**	13	7	3
Pattern of vision loss	Central	2	7	19
	Peripheral	9	4	0
	Combined	10	10	0
Current vision	Stable	12	9	19
	Declining	9	12	0
Fluctuations in vision	Yes	7	11	1
	No	14	10	18
Self-rated health	Very good	15	3	12
	Fairly good	3	8	6
	Fairly poor	3	10	1
	Very poor	0	0	0
Employment status	Working	6	5	12
	Studying	4	1	5
	Not working	5	3	1
	Not working (due to vision)	6	12	1
Level of education	Primary/Secondary	3	13	2
	Post-secondary	18	8	17
Marital status	Married/partner	12	8	7
	Single	7	10	11
	Divorced	2	2	1
	Widowed	0	1	0

Uses assistive devices	Yes	19	20	19
	No	2	1	0
Uses long cane	Yes	15	15	2
	No	6	6	17
Uses devices in public	Yes	15	17	14
	No	5	2	4
	N/A	1	2	1
Comfort level of device use in public	Comfortable	10	11	8
	Not comfortable	8	8	9
Level of dependence on others for visual tasks	Independent	8	12	14
	Somewhat dependent	13	9	5
	Dependent	0	0	0
Visual self-identity	Sighted	2	3	4
	Visually impaired	15	15	14
	Blind	4	3	1
Disability self-identity	Disabled	14	12	9
	Not disabled	7	9	10

*Mild/moderate: visual acuity of 6/21 to better than 6/60 in the better eye with best correction or a visual field of less than 60° to better than 20° in the better eye.

**Legally blind: visual acuity of 6/60 or worse in the better eye with best correction or a visual field of 20° or less in the better eye.

depressive symptoms the *Centre of Epidemiology Studies Depression* (CES-D) 10 symptoms index (Kohout, Berkman, Evans, & Cornoni-Huntley, 1993), a shortened version of Radloff's (1977) original scale, was used. This scale is comprised of 10 questions regarding various symptoms of depression (e.g. feelings of depression or loneliness, lack of appetite or sleep disturbances). Participants were asked to indicate how frequently they experienced such symptoms during the week prior to the study (For example, 0-1 day a week, 2-3 days a week, 4-5 days a week, 6-7 days a week). Scores can range from 0 to 30 with higher scores indicating a higher presence of depressive symptoms. Scores above 10 indicate a significant number of depressive symptoms, however, this test does not determine whether or not a person is clinically depressed (See Appendix B). Internal consistency of the CES-D 10 has been shown to be good, with Cronbach's alphas ranging from .68 to .82. Reliability has also shown to be good, with correlations ranging from .84 to .91 (Carpenter, Andrykowski, Wilson, Hall, Rayens, Sachs et al., 1998).

To complement the CES-D, a subsection of the *Impact of Vision Impairment* (IVI) Profile (Weih, Hassell, & Keeffe, 2002) was used. For the purpose of this study, this subsection was titled 'IVI-Emotional'. The IVI consists of 32 questions covering five areas of possible impact of vision impairment on an individual, eight of which focus on emotional wellbeing. Examples of such questions are "In the past month have you felt embarrassed because of your eyesight?" or "In the past month have you felt lonely or isolated because of your eyesight?" (See Appendix C for the full list of questions in this subsection). Scores for the IVI-Emotional subsection could range between 0 and 24 where higher scores indicate higher presence of negative emotions associated with vision loss/impairment.

Psychosocial adaptation to vision loss was assessed using the *Adaptation to Vision Loss* (AVL) Scale (Horowitz & Reinhardt, 1998; See Appendix D). This scale consists of 24 items measuring three domains of adaptation to vision loss: 1) acceptance of the vision loss, 2) realistic attitudes regarding functional ability, specifically attitudes toward remaining vision capabilities and vision rehabilitation, and 3) realistic attitudes regarding independence, specifically, attitudes toward being independent when possible while accepting assistance when needed. The AVL is comprised of 19 negative items (e.g. "A visually impaired person can never really be happy.") and five positive items (e.g. "I can still do many of the things that I love, it just takes me longer because of my vision impairment.") to which participants are asked to indicate whether they agree or disagree. Scores on the AVL range between 0 and 24 with higher scores indicating better psychosocial adaptation to vision loss. The AVL has been shown to have good internal consistency (Cronbach's alpha = 0.86) and validity (positively correlated with life satisfaction, r = .49; negatively correlated with depressive symptoms, r = -.55; and positively correlated with a single-item rating of adaptation to vision loss, r = .45) (Horowitz & Reinhardt, 1998). As the name suggests, this scale measures adaptation to the loss of vision. Therefore, in order for this scale to be relevant to those with albinism, the phrasing of some statements was changed (See Table 2.2).

Finally, the *Brief COPE* (Carver, 1997) was used to assess the coping styles and tendencies of participants. As one's coping style may heavily influence how well an individual adapts to a given situation this scale was included. It is comprised of 28 questions covering

Table 2.2

Adapted Questions on the AVL for Participants with Albinism

Item #	Original Statement	Adapted Statement
1.	Because of my vision loss, I feel I can never really do things for myself.	Because of my vision impairment, I feel I can never really do things for myself.
20.	I still do many of the things I enjoy, it just takes me longer because of my vision impairment.	I do many of the things I enjoy, it just takes me longer than others because of my vision impairment.
21.	By learning new ways of doing things (that compensate for vision loss), a visually impaired person has a chance to be more independent.	By learning different ways of doing things (that compensate for a vision impairment), a visually impaired person has a chance to be more independent.
22.	Although the circumstances of my life have changed, I am still the same person I was before my vision impairment.	Although the circumstances of my life are different, I am the same person I would be without a vision impairment.
24.	There are worse things that can happen to a person than losing vision.	There are worse things that can happen to a person than being visually impaired.

Underlined text identifies changed text.

14 styles of coping with stress or stressful events, 10 of which measure adaptive coping tendencies (strategies believed to effectively resolve or remove the stressor, for example, "I've been trying to get advice or help from others about what to do.") and four that measure maladaptive coping tendencies (strategies not believed to resolve or remove the stressor, for example, "I've been using alcohol or other drugs to make myself feel better."). Answers range from "I haven't been doing this at all" to "I've been doing this a lot" on a 4-point Likert scale (See Appendix E). Scores on the Brief COPE range between 28 and 112 where higher scores indicate better coping. This scale has been shown to be internally reliable as all item values meet or exceed a minimum alpha value of .50 (Carver, 1997). As the Brief COPE is used to test coping in individuals encountering a new stressor in life, it was necessary to change the wording for those with albinism. Instead of asking these individuals to think of how they've been coping with their vision loss, they were asked to think about how they cope in situations that they encounter where vision results in a difficulty or a problem. Therefore, each item was preceded by the phrase "When I encounter a problem because of my vision I…" followed by the item sentence. Carver and colleagues (1989) have already suggested the necessity to change verb tense depending on the need of the survey.

All of the above questionnaires were available and validated in both English and French.

Procedure

A cross-sectional study was conducted investigating physiological and socio-demographic characteristics and their effects on psychological wellbeing and adaptation to vision loss.

Potential participants were identified using InfoReadapt, the central database currently used at both the INLB and MMRC. The primary investigator identified the potential participants using the inclusion criteria stated above. Once potential participants were selected, an employee of the INLB or the MMRC contacted the individuals by phone in order to inform them of the existence of the study and to determine whether they were interested in participating. A script had been provided for this task.

A list of the individuals who agreed to receive further information regarding the study was compiled. The primary investigator, or a trained research assistant, then called the potential participants in order to explain the study in more detail as well as the procedure for signing the consent form (See Appendix F and G). For those individuals who agreed to participate, a consent form was sent to them which they were required to read, sign and return in a provided addressed and stamped envelope. Once the consent form had been returned, individuals were called and interviewed using the socio-demographic questionnaire, as well as the measures of psychological wellbeing and adaptation to vision loss as indicated above. The interviews typically lasted between 30 to 45 minutes. Information on participants' current visual status was then collected from the client files at either the INLB or the MMRC.

Statistical Analysis

Correlational analyses, Student *t*-tests, analyses of variance (ANOVAs) and analyses of covariance (ANCOVA) were conducted in order to identify any physiological or socio-

demographic factors that had an effect on psychological wellbeing and adaptation to vision loss. A value of $p < .05$ was used to determine statistical significance.

RESULTS

Participant-Pool Breakdown

A total of 182 individuals with RP, 409 with DR, and 128 with albinism were in the combined databases of the two agencies. Of these individuals, 49 with RP, 71 with DR, and 55 with albinism were contacted (not all clients were contacted due to time limits imposed for the completion of the study). Of those contacted, 24 with RP, 22 with DR, and 20 with albinism agreed to participate in the study. Only one individual who had originally accepted to participate in the study declined when contacted by the researcher herself (due to a death in the family). Three individuals were excluded from the participant pool, due to unreported diagnoses that were discovered during the telephone interview, and two were not reachable after the initial contact for their consent to participate. Thus, 61 individuals participated in this study.

Statistical Comparison of the Three Groups

The three diagnostic groups were comparable on all major demographic factors (e.g. gender, health, marital status, etc.) except age, $F(2, 58) = 4.35$, $p = .017$, level of impairment, $\chi^2(2, N = 59) = 9.29$, $p = .01$, and educational level, $\chi^2(4, N = 59) = 16.56$, $p = .002$.

Although best efforts were made to ensure that the mean age was similar among the three diagnosis groups this was not possible due to the later onset of DR. In this case, the mean age for those with DR (M = 50.0, SD = 9.74) was significantly higher than those with albinism (M = 39.11, SD = 12.57), Sheffé's $F(2, 58) = 10.9$, $p = .024$, but did not differ from those with RP (M = 42.1, SD = 13.87). Nonetheless, age was not found to be a significantly contributing factor to outcomes on any of the measures.

As groups could not be compared based on central or peripheral loss due to the different pattern of each type of vision loss, the participants were classified as either visually impaired but not yet legally blind (visual acuity of 6/21 to better than 6/60 in the better eye with best correction or a visual field of less than 60° to better than 20° in the better eye) or legally blind (visual acuity of 6/60 or worse in the better eye with best correction or a visual field of 20° or less in the better eye) based on Quebec Ministry of Health standards. With these definitions, it was found that the RP group had a significantly higher proportion of participants who were legally blind, $\chi^2(2, N = 59) = 9.26$, $p = .01$. Again, this is not problematic as level of impairment was not found to be a significant factor in the outcome measures.

Finally, the level of education of the participants was found to differ significantly with those with DR having the lowest proportion of individuals having completed post-secondary studies, $\chi^2(4, N = 59) = 16.56$, $p = .002$.

Outcome Measures and Visual Diagnosis

Only the IVI-Emotional scores were found to differ significantly when groups were compared across visual diagnosis, $F(2, 58) = 5.57$, $p = .006$. It was found that those with DR ($M = 14.1$, $SD = 5.38$) expressed having felt the most frequent negative emotions as a consequence of their vision impairment, differing significantly from those with albinism ($M = 7.84$, $SD = 7.01$), Scheffé's $F(2, 58) = 6.25$, $p = .006$. Mean scores for those with RP ($M = 10.52$, $SD = 5.44$) fell between these two groups (See Figure 2.1). However, as individuals with DR were found to have the lowest proportion of higher education level, which was found to be a significant contributing factor to psychological wellbeing and adaptation, an ANCOVA was conducted among diagnoses with level of education as a covariate. The results of this analysis showed that, when level of education was held constant, diagnosis was no longer a significant contributing factor towards psychological wellbeing and adaptation scores (See Figures 2.2).

Outcome Measures and Other Participant Characteristics

Visual acuity at the time of the study was not found to correlate significantly with any of the measures of psychological wellbeing. However, a significant difference was found among the various patterns of vision loss (central, peripheral and combined central and peripheral loss) on the Brief COPE, $F(2, 58) = 3.5$, $p = .037$. Individuals with peripheral loss *only* were found to score significantly poorer on the Brief COPE ($M = 75.62$, $SD = 10.4$) than those with central loss only ($M = 84.21$, $SD = 8.87$), Sheffé's $F(59) = 8.6$, $p = .047$. Those with combined loss ($M = 83.5$, $SD = 11.41$) closely followed those with central loss (See Figure 2.3). It was also found that individuals who were already considered

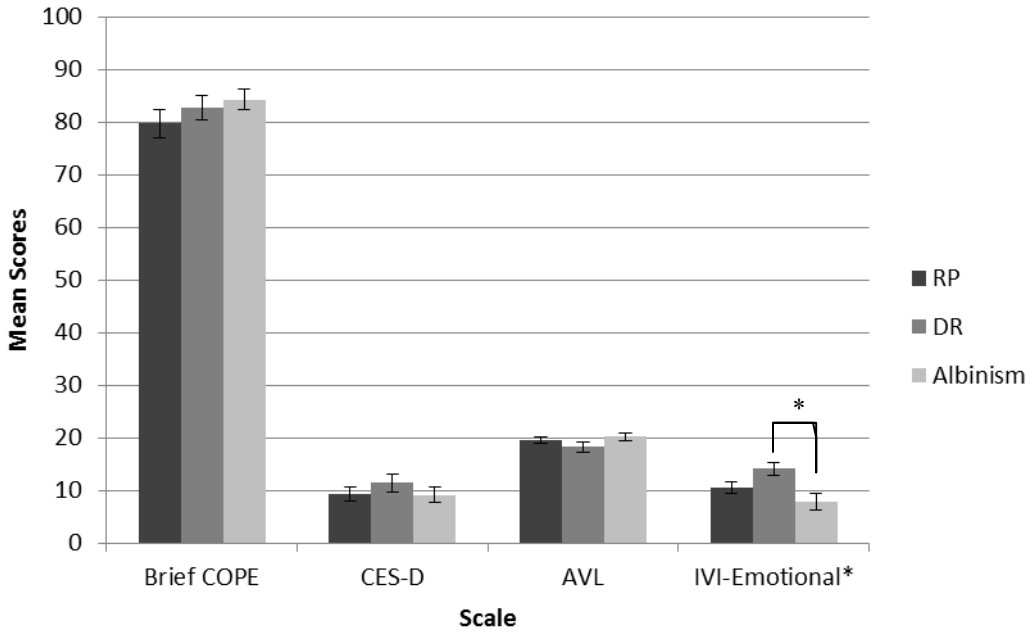

Figure 2.1. Mean scores on all psychological measures as a function of diagnosis. Higher scores on Brief COPE and AVL indicate better outcomes, while higher scores on CES-D and IVI-Emotional indicate poorer outcomes. Only IVI-Emotional scores indicated a significant difference among the three groups. *$p = 0.006$.

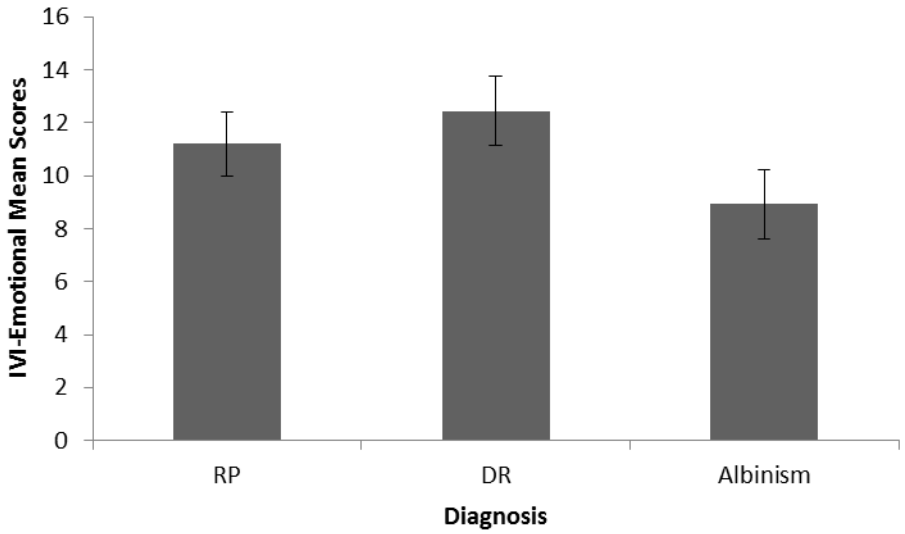

Figure 2.2. IVI-Emotional mean scores as a function of diagnosis with education level held constant. Higher scores indicate a higher presence and frequency of negative emotions associated with vision loss/impairment.

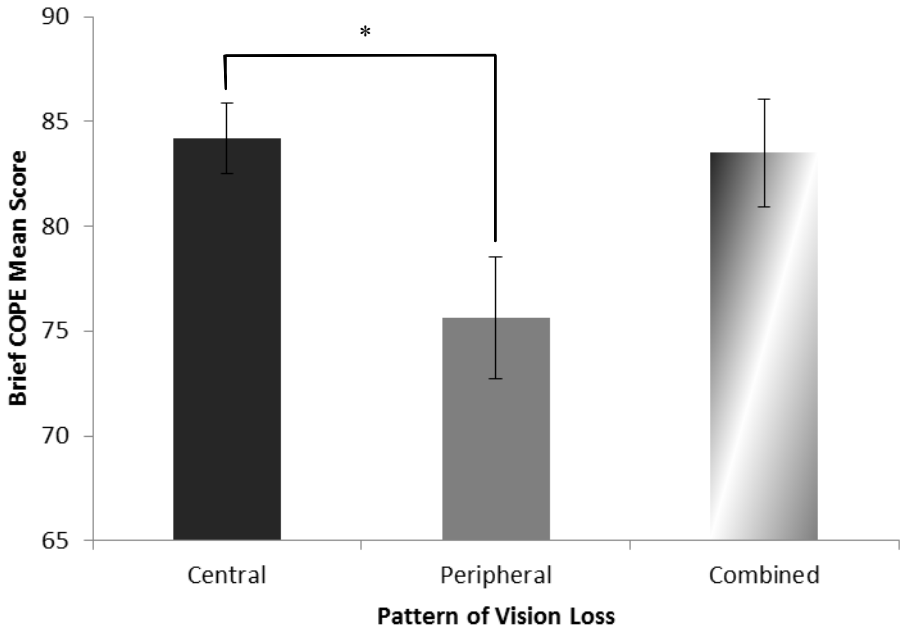

Figure 2.3. Brief COPE scores as a function of pattern of vision loss. Higher scores on the Brief COPE indicate better coping. *p = 0.047.

legally blind had, on average, better scores on the Brief COPE (M = 86.04, SD = 11.01) than those who were visually impaired but not yet legally blind (M = 79.79, SD = 9.56), $t(59) = -2.34$, $p = .023$ (See Figure 2.4). Also, those who were experiencing a decline in their vision at the time of the study (M = 13.71, SD = 6.05) had significantly poorer scores on the IVI-Emotional than those who had stable vision at the time of the study (M = 9.45, SD = 6.14), $t(59) = -2.59$, $p = .012$ (See Figure 2.5). Similarly, those who were experiencing fluctuations in their vision at the time of the study (M = 13.37, SD = 5.54) also had poorer scores on the IVI-Emotional than those whose vision remained stable (M = 9.81, SD = 6.5), $t(59) = -2.07$, $p = .043$ (See Figure 2.6). Regardless of the level of impairment, whether an individual used visual aids and assistive devices or not, was not associated with any of the psychological measures of wellbeing.

Age was not found to correlate significantly with any of the measures of psychological wellbeing. However, both a person's age at the time of diagnosis and the time elapsed since diagnosis were found to be significantly correlated with outcome measures. As the age at diagnosis increased, participants scored more poorly on the AVL, $r(59) = -.331$, $p = .009$, IVI-Emotional, $r(59) = .488$, $p < .001$, and CES-D, $r(59) = .253$, $p = .049$ (See Table 2.3). However, as the time elapsed since diagnosis increased, participants' scores improved on these measures, AVL, $r(59) = .34$, $p = .007$, IVI-Emotional, $r(59) = -.381$, $p = .002$, CES-D, $r(59) = -.281$, $p = .028$ (See Table 2.3). Also, the time elapsed since the last decline in vision was found to correlate with better scores on the AVL, $r(59) = .264$, $p = .04$, and the IVI-Emotional, $r(59) = -.364$, $p = .004$ (See Table 2.3).

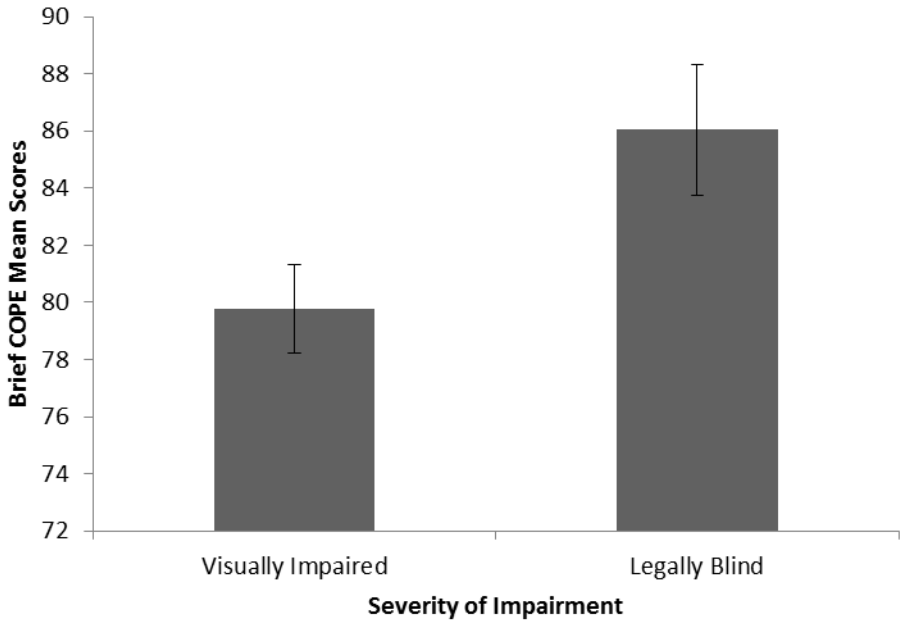

Figure 2.4. Brief COPE mean scores as a function of severity of impairment. Higher scores indicate a better coping. $p = 0.023$.

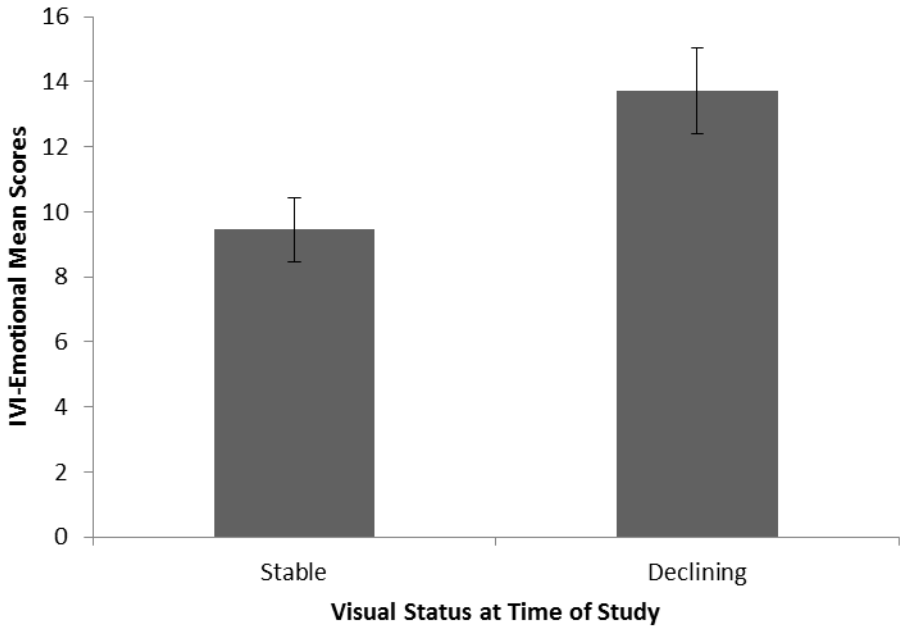

Figure 2.5. IVI-Emotional mean scores as a function of visual status at the time of the study. Higher scores indicate a higher presence and frequency of negative emotions associated with vision loss/impairment. $p = 0.012$.

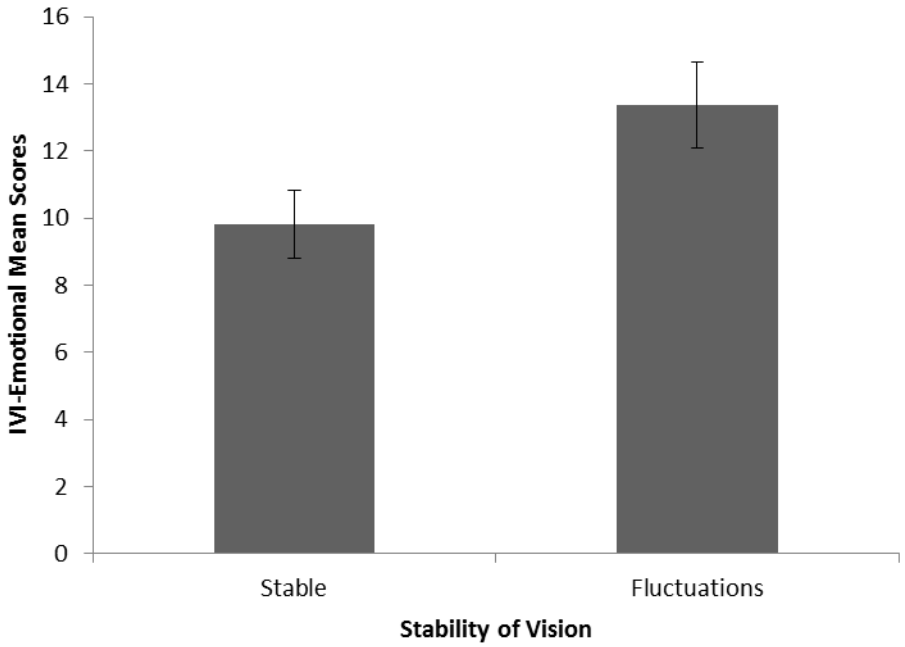

Figure 2.6. IVI-Emotional mean scores as a function of visual stability at the time of the study. Higher scores indicate a higher presence and frequency of negative emotions associated with vision loss/impairment. $p = 0.043$.

Table 2.3

Correlations Between Measures of Psychological Wellbeing and Adaptation and Age at Diagnosis, Time Elapsed Since Diagnosis and Time Elapsed Since Last Decline in Vision.

	Age at Diagnosis	Time Elapsed Since Diagnosis	Time Elapsed Since last Decline in Vision
AVL	-.331*	.34*	.264*
IVI-Emotional	.488*	-.381*	-.364*
CES-D	.253*	-.281*	-.22

* $p < .05$

Higher scores on the AVL indicate better outcome, while higher scores on the IVI-Emotional and CES-D indicate poorer outcome.

On all measures of psychological wellbeing, participants' responses were significantly affected by how they rated their own health, AVL, $F(2, 58) = 7.35$, $p = .001$; IVI-Emotional, $F(2, 58) = 13.71$, $p < .001$; CES-D, $F(2, 58) = 9.3$, $p < .001$; Brief COPE, $F(2, 58) = 3.58$, $p = .01$) (See Figure 2.7). Although individuals who had other health problems and disabilities apart from their visual impairment and, although those with significant complications due to diabetes were excluded from the study, those who rated their health as 'poor' (none of the participants rated their health as 'very poor') were significantly more likely to score worse on the AVL, the IVI-Emotional, the CES-D, and the Brief COPE (Sheffé's $F(2, 58) = 3.99$, $p = .003$, $F(2, 58) = 8.99$, $p < .001$, $F(2, 58) = 6.02$, $p = .03$, $F(2, 58) = 9.65$, $p = .04$, respectively). In order to assure that the previous differences found between diagnoses were not due to health, a 3x3 ANOVA was conducted on all of the outcome measures, with the three diagnoses and the three levels of self-rated health as the factors. There was no interaction of health and diagnosis suggesting that these effects are independent of each other even though both the main effects of diagnosis and self-rated health were found to be significant on all of the above measures.

Whether an individual was able to work, study, or do neither due to their visual impairment had a significant effect on their AVL scores, $t(59) = -3.47$, $p = .001$, and IVI-Emotional scores, $t(59) = 3.75$, $p < .001$. In both cases, those who were *not* able to work or study as a result of their vision impairment had significantly poorer AVL and IVI-Emotional scores.

It was also found that those with a higher level of education (university) had significantly better scores on the AVL, $t(59) = -2.36$, $p = .022$; IVI-Emotional, $t(59) = 3.65$, $p = .001$;

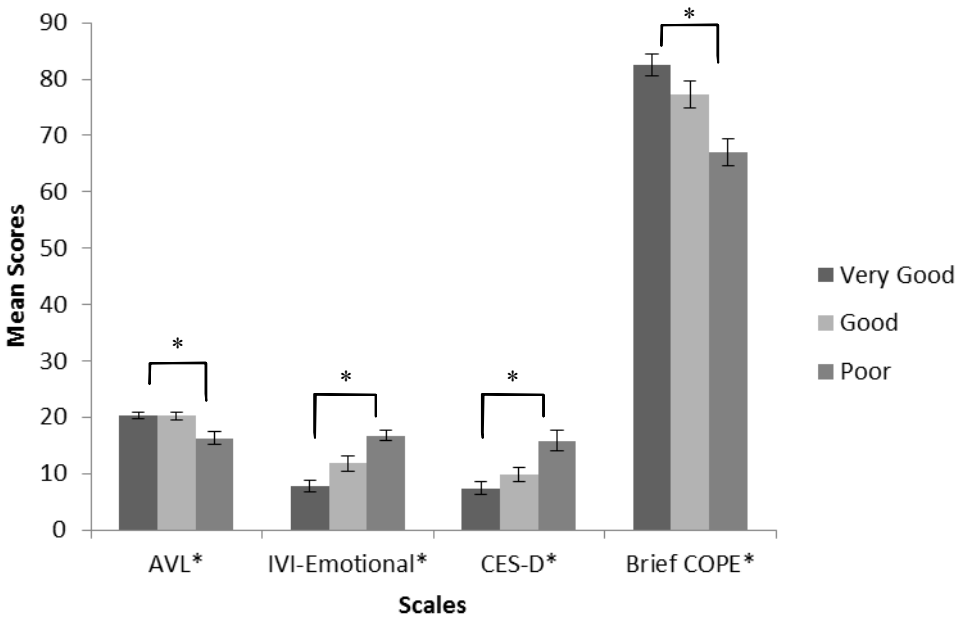

Figure 2.7. Mean scores of all psychological measures as a function of participants' self-rating of health. Higher scores on Brief COPE and AVL indicate better outcomes, while higher scores on CES-D and IVI-Emotional indicate poorer outcomes. * AVL, $p = .001$; IVI-Emotional, $p < .001$; CES-D, $p < .001$; Brief COPE, $p = .01$.

and CES-D, $t(59) = 3.29$, $p = .002$, than those with only high school or elementary school education (See Figure 2.8).

Two other factors that were found to have an impact on psychological wellbeing and adaptation to vision loss/impairment were marital status and family history of the same diagnosis. Individuals who were married had the highest scores on the IVI-Emotional, significantly higher, $F(2, 58) = 4.86$, $p = .011$ (Sheffé's $F(2, 58) = -9.05$, $p = .012$), than those who were divorced (See Figure 2.9). Additionally, participants with family members who also had the same visual diagnosis were significantly more likely to score better on the IVI-Emotional, $t(59) = 2.5$, $p = .02$, and the CES-D, $t(59) = 2.7$, $p = .009$ (See Figure 2.10).

Gender and language spoken (English or French) were the only participant characteristics that were not related to psychological wellbeing on any of the scales.

DISCUSSION

The purpose of this experiment was to determine whether individuals with RP have a different psychological profile compared to people in other diagnostic groups and, if not, which demographic and visual factors may influence psychological wellbeing and adaptation to vision loss/impairment.

Only the presence and frequency of negative emotions associated with vision loss/impairment was found to differ among the three diagnostic groups. Those with DR had

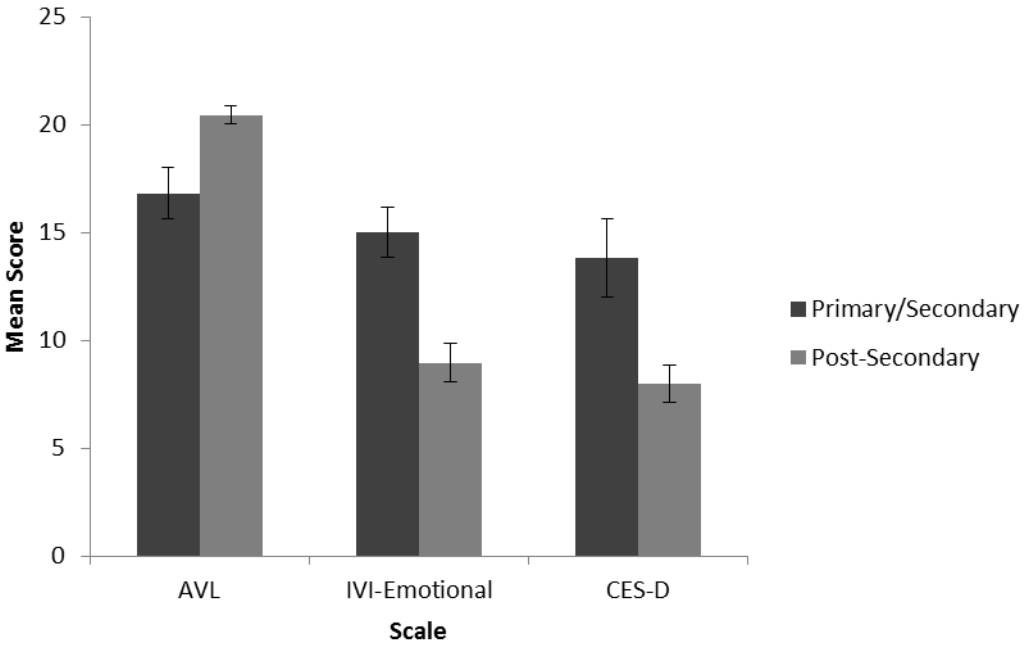

Figure 2.8. Mean scores of psychological measures as a function of education level. Higher scores on AVL indicate better adaptation, while higher scores on IVI-Emotional and CES-D indicate poorer affect. AVL, $p = .022$; IVI-Emotional, $p = .001$; CES-D, $p = .002$.

Figure 2.9. IVI-Emotional mean scores as a function of marital status. Higher scores indicate a higher presence and frequency of negative emotions associated with vision impairment/loss. $p = .012$.

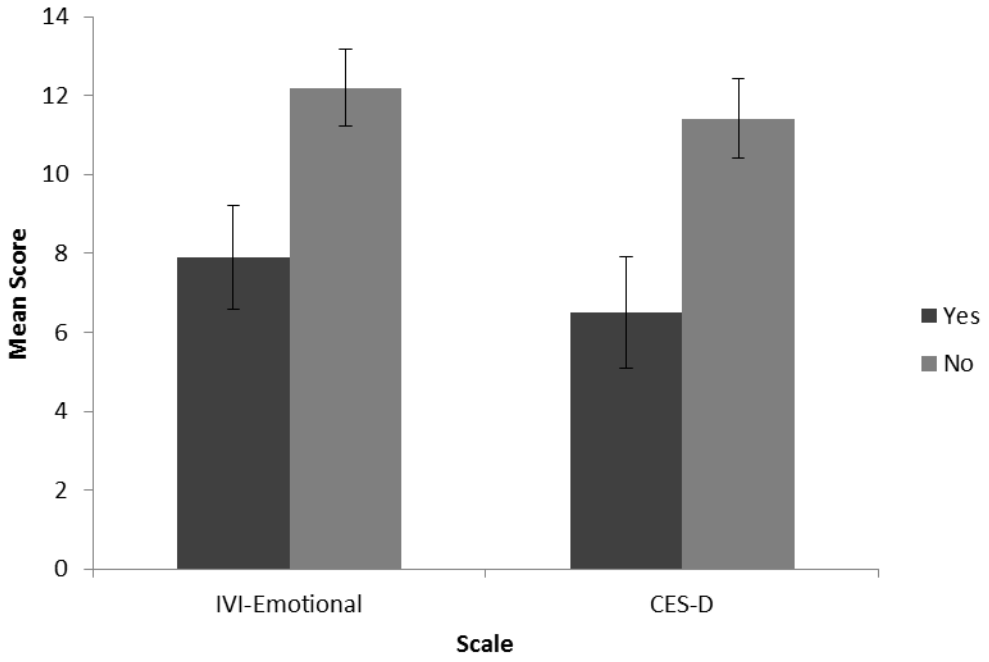

Figure 2.10. Measures of affect as a function of family history of diagnosis. Higher scores on both IVI-Emotional and CES-D indicate the higher presence and frequency of negative emotions. IVI-Emotional, $p = .02$; CES-D, $p = .009$.

the poorest scores on the IVI-Emotional, suggesting that they experienced the highest frequency of negative emotions associated with vision loss/impairment. However, it was noted that education level and self-rated health also differed significantly among the three diagnostic groups. Therefore, when an ANCOVA was conducted in order to eliminate the possibility that these variables were contributing to this finding, there was no longer a difference between those with DR and people with the other two diagnoses. This suggests that those with DR do not necessarily differ in their emotional experience of vision loss/impairment, but that it may be due to other factors.

As found by previous researchers (Bernbaum et al., 1988; Bittner et al., 2010; Brody et al., 2001; Hahm, 2008; Jangra et al., 2007; Upton et al., 1998), none of the measures of psychological wellbeing were found to correlate with visual acuity, but rather they were associated with factors such as recent loss of, and fluctuations in, vision. As Upton and colleagues (1998) had found, this study demonstrates that those who were experiencing a decline in their vision expressed a higher presence and frequency of negative emotions associated with vision loss/impairment. Furthermore, supporting the findings of Bernbaum and colleagues (1988) and Bittner and colleagues (2010), it was found that those who experience regular fluctuations in their vision also experience more frequent negative emotions associated with vision loss/impairment. In fact, as demonstrated by Bernbaum and colleagues (1988), those who were already legally blind, in this study, coped better than those who were visually impaired but not legally blind. All of these results suggest that the level of impairment itself may not be as critical to psychological wellbeing and adaptation as recent loss and fluctuations in vision. As suggested by Bittner and colleagues

(2010), this may be due to anxiety of losing vision, which would be heightened by loss and threat of it through fluctuations. When vision is stable, even if it is very poor, individuals may adapt sufficiently to realise that they can function with the given level of vision impairment, but may not feel that they would be capable of functioning with further decline, resulting in anxiety and depression at any indication of such loss. In fact, it was found that the time elapsed since the last decline in vision correlated with adaptation to, and negative emotions associated with, vision loss/impairment. Specifically, with increased time since the last decline in vision, individuals demonstrated better adaptation (AVL) and fewer negative emotions associated with vision loss/impairment. Although vision does not necessarily improve, a person may begin to feel less anxiety about vision loss when more time has elapsed since the last decline.

The pattern of vision loss was also found to have a significant impact on coping. Individuals with peripheral loss *only* reported significantly poorer coping methods than those with central loss only and those with combined loss. This may be due to the psychological impact of peripheral vision loss for two reasons. Firstly, as suggested by Guinard (1990) and Hayeems and colleagues (2005), peripheral loss is 'easier' to ignore than central vision loss. As most of our daily activities require central vision in order to function, individuals experiencing central vision loss are, in a way, forced to deal with their loss immediately. However, those with peripheral loss can ignore the problem for a time as they can continue to function, albeit, potentially not well. Secondly, from the clients' perspective, those with central visual loss are offered more ways of overcoming their vision impairment than those with peripheral loss. Those with central vision loss can be offered

magnifiers, filters, CCTVs, telescopes, and many other visual aids to assist them in using their remaining vision to improve their functioning ability. Those with peripheral vision loss, however, are handed a long cane, the ultimate symbol of blindness, given training in its use, thus potentially leading them to conclude that this is all that can be done for them. This may represent a huge psychological difference for those experiencing peripheral versus central loss. In fact, research by Rees and colleagues (2007) indicated that one of the leading reasons that individuals resist participating in vision rehabilitation is because they feel it is a sign of weakness and resignation. At least for individuals with central vision loss, there is 'something that can be done' through a number of visual aids, however, for those with peripheral loss the only option is to use a long cane. This may be too much of a sign of resignation for these individuals to accept. In fact, a study by Lamoureux and colleagues (2007a) found that orientation and mobility was the least sought sector of vision rehabilitation services.

Although age at the time of the study was not found to have had an impact on psychological wellbeing and adaptation (AVL), the age of an individual at the time of their diagnosis was found to have a significant impact on adaptation to and negative emotions associated with vision loss/impairment, as well as the presence and frequency of depressive symptoms. In all cases, as the age at diagnosis increased, individuals fared more poorly in their ability to adapt to vision loss, in their negative emotions associated with vision loss/impairment, and in their general affect as demonstrated by the presence and frequency of depressive symptoms. These findings seem to support results reported by Lindo and Nordholm (1999) and Tolman and colleagues (2005), where younger participants were

found to cope better and have fewer depressive symptoms than older participants. Lindo and Nordholm (1999) reported that the reason for this was due to fewer feelings of hopelessness in the younger participants than in the older participants. However, the older participants in that study were much older than the older participants in this study as the current one limited participants to under 65 years of age. Furthermore, psychological wellbeing and adaptation (AVL) were not correlated directly with age, but rather, with the age of the participant at the time of diagnosis. Therefore, feelings of helplessness may not be relevant in this case. Further research would be necessary in order to investigate the reason for these findings.

Self-perceived health was also found to be a significantly associated with psychological wellbeing and adaptation to vision loss/impairment. As previously mentioned, although individuals who had other health problems and disabilities apart from their visual impairment, including those with significant complications due to diabetes, were excluded from the study, and although no participants rated their health as 'very poor', self-rated health was still found to significantly impact adaptation (AVL) to and negative emotions associated with, vision loss/impairment, the presence of depressive symptoms, and successful coping with vision loss/impairment. This effect was found to be independent of diagnosis suggesting that, regardless of the cause of vision loss, individuals who perceive their health to be poor also have poorer psychological wellbeing and adaptation (AVL) to vision loss/impairment in general. Unfortunately, it is not possible, in the context of this study, to determine whether participants reported poorer self-rated health as a result of

overall poorer psychological wellbeing and adaptation to vision loss/impairment, or vice versa.

Another factor that was found to be an important contributor to psychological wellbeing and adaptation was whether an individual was able to work or study, or do either as a result of their vision impairment. Both adaptation (AVL) to and the presence and frequency of negative emotions associated with vision loss/impairment were found to be poorer for those who could neither work nor study as a result of their condition. As working provides a significant amount of independence to an individual and, as it allows for the ability to support one's family in an important way, it is not surprising that the inability to do so due to vision loss would result in negative outcomes. Some studies have shown that those with a vision impairment fear greatly the loss of independence, and find it very difficult when it does occur (Coyne, et al., 2004; Nemshick & Ludman, 1986; Tolman et al., 2005). It has also been reported that one of the leading fears of younger individuals losing vision is not being able to provide for their families (Nemshick & Ludman, 1986).

Level of education was also found to play a significant role in psychological wellbeing and adaptation to vision loss/impairment, in that those who had a higher level of education (college or university) adapted (AVL) better to their vision loss/impairment, had fewer negative emotions associated with it, as well as fewer symptoms of depression. These findings support existing research that has reported similar results (Horowitz et al., 2003; Reinhardt, 1996; 2001; Tolman et al., 2005). This may be due to more resources that are available to more highly educated individuals as a result of their lifestyle. Although all

individuals in this study had been contacted via a vision rehabilitation centre, it is possible that those who were more highly educated had more resources beyond rehabilitation than their counterparts.

Finally, but not least importantly, it was found that those who were married or had a partner had fewer negative emotions associated with vision loss/impairment than those who were single, widowed or divorced. Also, participants who had family members with the same diagnosis experienced fewer negative emotions associated with vision loss/impairment, and fewer depressive symptoms, than those without any family members with the same diagnosis. Both of these results suggest that individuals fare better when they are in contact with other understanding and supportive people. A number of other studies have demonstrated the benefit of social support for those experiencing vision loss (Bittner et al., 2010; Devenney & O'Neill, 2011; Reinhardt, 2001; Reinhardt, et al., 2009). Additionally, in the case of those who have family members with the same visual diagnosis, it might be possible that, because these individuals had already been exposed to such a diagnosis, and were familiar with the resulting life changes, they experience less anxiety and fewer negative emotions associated with the loss as they have a better understanding of the condition than individuals who had no prior knowledge of their condition.

Unlike results reported by Tolman and colleagues (2005), no gender differences were found in this study population [although there does exist a gender difference in the general population for depression prevalence, where women have higher rates of depression, (Delisle, Beck, Dobson, Dozois & Thombs, 2012)].

Implication and Conclusion

Given the results of this experiment, one cannot presume that those with RP adapt and fare differently than those with other visual disorders. In fact, one cannot even predict adaptation to and psychological wellbeing associated with vision loss/impairment by looking at the severity of impairment, nor by considering factors such as a person's age or gender. Factors that are more indicative of adaptation and wellbeing in the case of vision loss include any recent loss of and fluctuations in vision, the person's age at diagnosis, time elapsed since diagnosis, educational level, and the amount of social support that the individual may or may not have. By understanding and being able to identify factors that may put a person at risk for not adapting well, eye-care specialists and vision rehabilitation providers can better help their clients. It has already been demonstrated that adapting to vision loss is very difficult and stressful (Brody, et al., 2001; Fourie, 2007; Heyl & Wahl, 2001; Rees et al., 2007; Wahl et al., 2003), and many individuals 'give up' and do not receive vision rehabilitation services (Rees et al., 2007; Tolman et al., 2005). Therefore, any additional support and assistance that eye-care specialists and rehabilitation providers can offer may increase the chances that an individual will choose to receive beneficial services.

Chapter III

EXPERIMENT 2: Effects of Coping, Depression, Functional Vision and Impact of Vision Impairment on Adaptation to Vision Loss in Young and Mid-Adulthood

Retinitis pigmentosa (RP) is a set of hereditary diseases that involves the degeneration of the rod and cone photoreceptors over a relatively extended period of time, often over decades. RP is typically diagnosed early in life, with initial symptoms of night blindness and the beginning stages of peripheral field loss. With time, peripheral vision continues to diminish and central vision begins to be affected as well. At the end of progression, vision may either be completely lost, or some minimal vision may remain. In the case of RP, individuals are faced with an extended period of vision loss, with no certain end, and distressful fluctuations in vision throughout the process (Hartong et al., 2006).

Vision loss has been noted to be one of the most difficult life stressors an individual can encounter. Vision impairment can result in significant loss of independence as an individual is unable to perform simple day-to-day tasks such a reading, cooking, house cleaning, personal care, shopping and travelling independently (Faye, 1984). Vision impairment has also been shown to have significant effects on psychological wellbeing as it can lead to social isolation, dependence, and feelings of inadequacy, that in turn, can lead to depression (Brody et al., 2001; Burmedi, et al., 2002; Wahl, 2003), poorer self-confidence (Tolman et al., 2005) and lower self-esteem (Roy & Mackay, 2002).

Although numerous eye disorders can lead to vision impairment, the three most frequent causes of vision impairment in developed countries (age-related macular degeneration, glaucoma, and diabetic retinopathy) are all problems associated with aging. For this reason, the vast majority of research investigating the effects of vision impairment on quality of life and psychological wellbeing applies to older populations (Lee & Brennan, 2006; Rees et al., 2007; Reinhardt et al., 2009). RP, however, occurs much earlier in life and may involve an entirely different set of challenges.

Based on the relatively few studies that have examined psychological adjustment specific to RP, it has been suggested that individuals with RP follow a different adjustment process compared to individuals dealing with other significant physical disorders. Strougo and colleagues (1997) found that RP patients suffered from significant anxiety and depression and questioned why these problems are so much more prevalent in the RP population than among individuals with other chronic, disabling diseases. Hayeems and colleagues (2005) found similar results and suggest that this may be due to a slow shift from a self-concept of being a 'sighted person' to that of a 'visually impaired person'. Guignard (1990) also suggests that, in the case of RP, the adjustment period is extended due to the slow progression of the disease resulting in a slow, continuous adjustment, where the individual repeatedly has to give up daily activities that he/she was once capable of doing. Whatever the reasons may be, this research does seem to suggest that individuals with RP adjust differently than those with other disabling disorders.

Research on coping has suggested that, while older individuals demonstrate normal coping patterns when faced with vision loss (Boerner et al., 2006), individuals with RP may not (Siple Milles, 2004). Coping is a general term that refers to the strategy by which an individual attempts to deal with life stressors or the negative emotions associated with a given stressor. Coping strategies can result in positive outcomes, where the stressor is successfully handled or overcome; or they can result in negative outcomes where the stressor is avoided or handled inappropriately so that the problem is not resolved or becomes worse (Nevid, Rathus & Greene, 2000). Research by Siple Milles (2004) found that individuals with RP demonstrated a more frequent tendency for avoidance coping than average. Furthermore, regardless of their stage of adjustment according to the Transtheoretical Model of Change (TMC), individuals with RP demonstrated a consistent tendency for avoidance coping which, in this study, did not necessarily correlate with successful adjustment.

It has also been suggested that individuals may adapt better to vision loss and have more positive psychological wellbeing if they are able to identify themselves as visually impaired versus sighted (Hayeems et al., 2005); Pollard et al., 2003). In a study conducted by Hayeems and colleagues (2005), it was found that those who already considered themselves as visually impaired had made significant life-style changes that benefited them due to their visual circumstance versus those who still considered themselves as sighted and had not made any life-style changes, thus resulting in difficulty due to their vision. The authors also suggest that one of the major factors for the resistance of beneficial change is the fear of the stigma of visual impairment. Those participants who still considered themselves as sighted,

but recognized the benefit of making life-style changes that more suited their needs, admitted that their fear of stigma was the primary reason for the lack of change. No research has been conducted to date comparing self-identity in those with RP to patients in other diagnostic groups.

This study investigated psychological factors such as coping, depression, and self-concept, in individuals with RP in order to determine whether, in fact, they adapt differently compared to individuals with other causes of vision loss and, if not, which psychological factors are most associated with adaptation to vision impairment/loss. As such factors may reduce the likelihood that a person seeks beneficial assistance or handles vision loss in a positive manner, it is important to be able understand their role and identify any risk factors unique to RP.

In order to identify the psychological factors implicated in successful adjustment to RP versus vision loss/impairment in general, a comparison was conducted using individuals of a same age-group with other visual impairments. Individuals with diabetic retinopathy (DR) are relatively similar to those with RP in that the disease progression can occur at the same relatively early period in life. They also experience an unpredictable and lengthy period of vision loss. For further comparison, individuals with albinism were included in order to determine whether difficulty dealing with vision impairment is, in fact, due to loss of vision after having had good vision versus the inherent difficulties of vision impairment itself, which is present since birth in individuals with albinism.

The two principal hypotheses of this experiment were that (1) those with RP would not differ significantly from those with DR or albinism on measures of adaptation to and psychological wellbeing associated with vision loss/impairment, but rather that (2) psychological factors (ex: coping methods, presence of depressive symptoms, impact of vision loss, personal identity, etc.) would be stronger correlates of psychological wellbeing and adaptation to vision loss/impairment.

METHOD

Participants

The description of the participants given in Experiment 1 also applies herein.

Materials

Five questionnaires were used to evaluate perceived visual function, psychological wellbeing and adaptation to vision loss of participants. All five questionnaires are used in their respective domains and have been validated by research.

The *Visual Function 14* (VF-14) Scale (Steinberg, Tielsch, Schein, Javitt, Sharkey, Cassard, et al. 1994) was used to evaluate the participants' perceived ability to perform 14 categories of daily living tasks that involve vision (*ex.,* Do you have difficulty reading fine print? Do you have difficulty seeing the edges of doors or sidewalks?). The VF-14 consists of 14 questions with responses on a 5-point Likert scale. Individuals are required to respond to each question by choosing the most appropriate answer that applies to their situation (not at all, a little, a moderate amount, a lot, I cannot perform this task due to my

vision loss, or This task does not apply to me) (See Appendix H). Calculated scores range from 0 to 100 with higher scores indicating better perceived visual ability. The VF-14 has been shown to have good internal consistency (Cronbach's alpha > 0.83), effect size (0.99) and correlation with other measures of satisfaction with vision (Friedman, Tielsch, Vitale, Bass, Schein & Steinberg, 2002).

The *Impact of Vision Impairment* (IVI) Profile (Weih et al., 2002) was used to assess the impact of visual impairment on participation in daily activities and emotional wellbeing (See Appendix I). This scale consists of 32 questions covering five areas of possible impact (leisure, household tasks, social activities, mobility, and emotional wellbeing). At this time the IVI is unique in that it includes aspects present in various other questionnaires but not all within the same scale. The IVI also includes aspects not necessarily *directly* related to vision loss but may still be affected due to other changes as a result of vision loss (For example, an individual may not have any difficulties participating in a given social activity as their vision is still sufficient, however, he/she still may not participate as vision is no longer sufficient to drive.). Calculated scores on the IVI range from 0 to 100 such that higher scores indicated higher negative impact of visual impairment. As in the VF-14, participants are required to choose an answer from a 4- or a 5-point Likert scale that best reflects their current situation (not at all, a little, a fair amount, a lot, don't do this for other reasons). Internal consistency of the IVI has been shown to be high with total and domain scores (Cronbach's alphas = .80 – .96). Reliability is also good with Guttman split-half reliability coefficients ranging from .73 to .94 (Weih et al., 2002).

As in Experiment 1, a subsection of the IVI, titled IVI Emotional, was used to measure the presence of negative emotions related to vision impairment. For a full description of this subsection, refer to Experiment 1. The subsection not related to negative emotions associated with vision impairment, named "IVI-Visual Ability" for the purposes of this experiment, was also used. This subsection deals with perceived visual ability associated with various daily tasks and activities, much like the VF-14.

Again, as in Experiment 1, the *Brief COPE* (Carver, 1997) was used to assess the coping styles and tendencies of participants, the *CES-D* (Kohout et al., 1993) was used to evaluate the presence of significant depressive symptoms at the time of the study, and the *AVL* (Horowitz & Reinhardt, 1998) was used to measure psychosocial adaptation to vision impairment. For a full description of each of these scales refer to Experiment 1.

In addition to the five questionnaires, participants were asked four supplementary questions regarding their perception of themselves in order to investigate self-identity and stigma as factors that may play a role in psychological wellbeing and adaptation to vision loss/impairment. Participants were asked whether they considered themselves as visually impaired, blind, or sighted, as well as whether they considered themselves as a person with a disability or not. They were also asked whether they feel that they are visually dependant on others, somewhat dependant, or completely independent. Finally, participants were asked if they used visual aids and/or a cane in public and whether they felt comfortable using such devices.

Procedure

The description of the procedure given in Experiment 1 also applies herein.

Statistical Analysis

Correlational analyses, Student t-tests and Analyses of Variance (ANOVAs) were conducted in order to identify any psychological factors that had an effect on adaptation to vision loss. A value of $p < .05$ was used to determine statistical significance.

RESULTS

Participant-Pool Breakdown

The description of the participants-pool given in Experiment 1 also applies herein.

Statistical Comparison of the Three Diagnoses

The description of the statistical comparison of the three diagnoses given in Experiment 1 also applies herein (See Table 2.1).

Outcome Measures and Diagnosis

Participants did not differ significantly by diagnosis on the AVL, CES-D and Brief COPE. They did, however, differ significantly on the VF-14, $F(2, 58) = 7.33$, $p = .001$, the IVI, $F(2, 58) = 11.25$, $p < .001$, and the IVI-Emotional, $F(2, 58) = 5.57$, $p = .006$ (See Figure 3.1). It was found that those with DR had the poorest scores on the VF-14, closely followed by those with RP, with those with albinism having the best scores. Although the DR group's mean scores were not significantly different from those with RP, and the RP mean

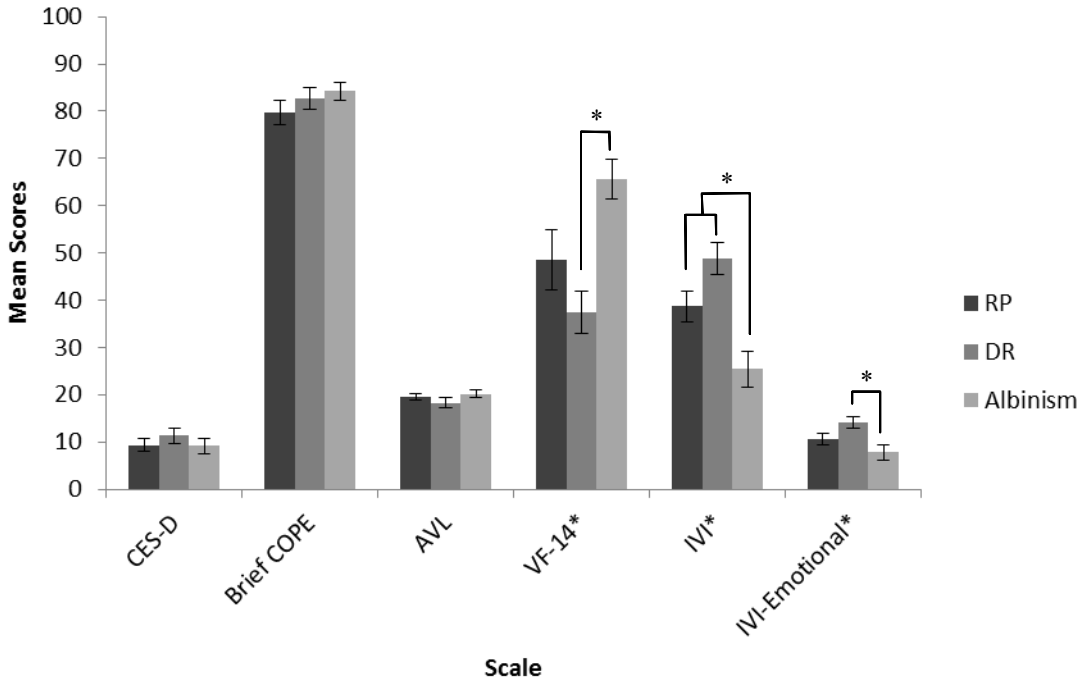

Figure 3.1. Measures of psychological wellbeing and adaptation to vision loss/impairment as a function of diagnoses. Higher scores on CES-D, IVI and IVI-Emotional indicate poorer outcomes. Higher scores on the Brief COPE, VF-14 and AVL indicate better outcomes.

* VF-14, $p = .001$; IVI, $p < .001$; IVI-Emotional, $p = .006$.

scores were not significantly different from those with albinism, the DR mean scores were significantly worse than the mean scores of the albinism group, Sheffé's $F(2, 58) = 28.23$, $p = .002$. Similarly, those with DR had the poorest scores on the IVI, again closely followed by those with RP, with those with albinism having the best scores. In this case, DR and RP scores did not differ from each other but both groups did differ significantly from the scores of those with albinism, Sheffé's $F(2, 58) = 13.2$, $p = .034$; $F(2, 58) = 23.34$, $p < .001$, respectively. In order to eliminate the possibility that these individuals did, in fact, have poorer vision, thus leading to poorer perception of vision, an ANCOVA was run with level of impairment (legally blind or visually impaired but not yet legally blind) as a covariate while analysing the difference among diagnostic groups on VF-14 and IVI scores. Even when severity of impairment was held constant, there was still a significantly different main effect of diagnosis with those with DR scoring most poorly: VF-14, $F(2, 58) = 7.32$, $p = .001$; IVI, $F(2, 58) = 10.93$, $p < .001$ (See Figure 3.2).

As reported in Experiment 1, those with DR had the poorest scores on the IVI-Emotional where those with RP had mid-range scores and those with albinism had the best scores. Only the scores of those with DR and albinism differed significantly, Sheffé's $F(2, 58) = 6.25$, $p = .006$.

When asked whether participants considered themselves sighted, visually impaired or blind, and whether they considered themselves a person as having a disability or not, no differences were found among the three diagnostic groups. The use of visual aids and/or a

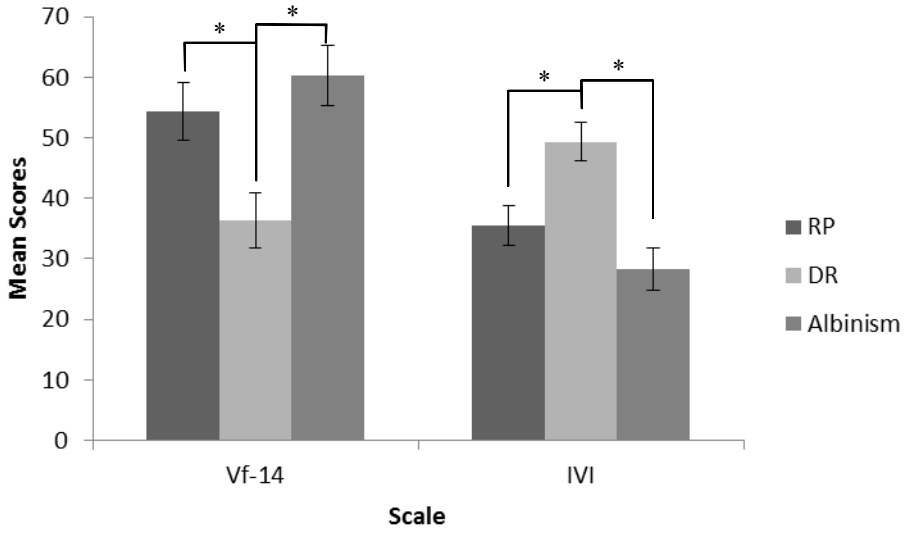

Figure 3.2. Measures of perceived visual ability as a function of diagnosis with severity of impairment held constant. Higher scores on IVI, and lower scores on the VF-14, indicate poorer perceived visual ability. *VF-14, $p = .001$; IVI, $p < .001$.

long cane as well as the comfort-level associated with the use of such devices in public were not found to be significant factors among the three groups.

Outcome Measures and Non-diagnosis Factors

Because the AVL assesses adaptation to vision loss/impairment, it was used as an outcome measure in order to investigate if elements of psychological wellbeing, perception of function and coping have an effect on adaptation to vision loss/impairment. A significant negative correlation was found between the IVI and the AVL, $r(59) = -.41$, $p = .001$, indicating that, as the impact of vision impairment increases, adaptation decreases. The CES-D was also found to correlate significantly with the AVL, $r(59) = -.56$, $p < .001$, again with a negative relationship such that, as the presence of depressive symptoms increase, adaptation decreases. No relationship was found between the VF-14, the Brief COPE and the AVL (See Table 3.1).

When considering the supplementary questions included in the study, it was found that AVL scores did not differ among those who considered themselves sighted, visually impaired, or blind, nor was there a difference between those who considered themselves as a person with a disability or not. There was also no difference found between those who were comfortable using devices in public or not.

As most participants scored well on the AVL, many reaching near perfect scores, it is possible that this scale was not sensitive enough in the context of this study and a ceiling effect occurred. In order to investigate whether this was the case, and whether results would

Table 3.1

Correlations between AVL and Other Measures of Psychological Wellbeing and Adaptation.

	AVL	IVI	CES-D	VF-14	Brief COPE
AVL	--				
IVI	-.414*	--			
CES-D	-.556*	.487*	--		
VF-14	.135	-.732*	-.197	--	
Brief COPE	-.016	.272*	.141	-.222	--

* $p < .05$

Higher scores on AVL and Brief COPE indicate better outcomes. Higher scores on IVI, CES-D and VF-14 indicate poorer outcomes.

differ using only statements for which there was no existing effect, statements where more than 80 percent of participants selected the same answer were eliminated, which left merely 10 of the original 24 statements. When using only these 10 statements to conduct the same analyses, there were still no significant relationships found.

Therefore, as the AVL may not be a sensitive enough scale for the context of this study, the same analyses were conducted using the IVI-Emotional as the outcome measure. Although the IVI-Emotional does not measure adaptation, it was determined that emotional wellbeing was also a valid measure for a person's ability to adjust to vision loss/impairment. In itself, the IVI-Emotional was found to correlate significantly with all of the measures of psychological wellbeing and adaptation except for the Brief COPE (VF-14, $r(59) = -.43$, $p = .001$; IVI-Visual Ability, $r(59) = .6$, $p < .001$; CES-D, $r(59) = .63$, $p < .001$; and AVL, $r(59) = -.53$, $p < .001$)(See Table 3.2). The VF-14 correlated negatively with the IVI-Emotional such that, as VF-14 scores increased (improved), IVI-Emotional scores decreased (improved). Similarly, the questions not pertaining to the emotional impact of vision loss/impairment of the IVI, (i.e. the perceived functional impact of vision loss/impairment which can be called IVI-Non-Emotional) also correlated with the IVI-Emotional such that, as IVI-Non-Emotional scores decreased (improved), so did the scores of the IVI-Emotional (also improving). The CES-D correlated positively with the IVI-Emotional such that, as CES-D scores decreased (improved), IVI-Emotional scores decreased (improved). And finally, the AVL correlated negatively with the IVI-Emotional as an increase in AVL scores (improvement) correlated with a decrease in IVI-Emotional scores (improvement).

Table 3.2

Correlations between IVI-Emotional and Other Measures of Psychological Wellbeing and Adaptation.

	IVI-Emotional	AVL	IVI-Visual Ability	CES-D	VF-14	Brief COPE
IVI-Emotional	--					
AVL	-.527*	--				
IVI-Visual Ability	.601*	-.414*	--			
CES-D	.628*	-.556*	.487*	--		
VF-14	-.432*	.135	-.732*	-.197	--	
Brief COPE	.143	-.016	.272*	.141	-.222	--

* $p < .05$

Higher scores on AVL and Brief COPE indicate better outcomes. Higher scores on IVI-Emotional, IVI, CES-D and VF-14 indicate poorer outcomes.

In addition, the IVI-Emotional was also found to differ significantly among those who considered themselves sighted versus visually impaired or blind, $F(2, 58) = 3.36$, $p = .042$, as those who still considered themselves as sighted had significantly better scores on the IVI-Emotional than those who considered themselves as visually impaired or blind, Sheffé's $F(2, 58) = 7.02$, $p = .047$ (See Figure 3.3).

There was also a significant difference found between those who felt they were somewhat dependent on others versus independent, $t(59) = -2.04$, $p = .046$, as those who felt somewhat dependent on others for visual tasks had significantly poorer scores on the IVI-Emotional than those who did not feel dependent on others. Finally, a trend was found between those who were comfortable using their devices in public and those who were not, $t(59) = 1.98$, $p = .053$, such that those who were not comfortable using visual aids and devices in public had significantly poorer scores on the IVI-Emotional than those who were comfortable using such devices in public.

DISCUSSION

The purpose of this experiment was to determine whether those with RP had a different psychological profile in comparison with other diagnostic groups and, if not, which psychological factors may influence adaptation to vision loss/impairment and mental wellbeing.

It was found that the three diagnostic groups did not differ on their adaptation to vision loss/impairment, presence and frequency of depressive symptoms, and use of

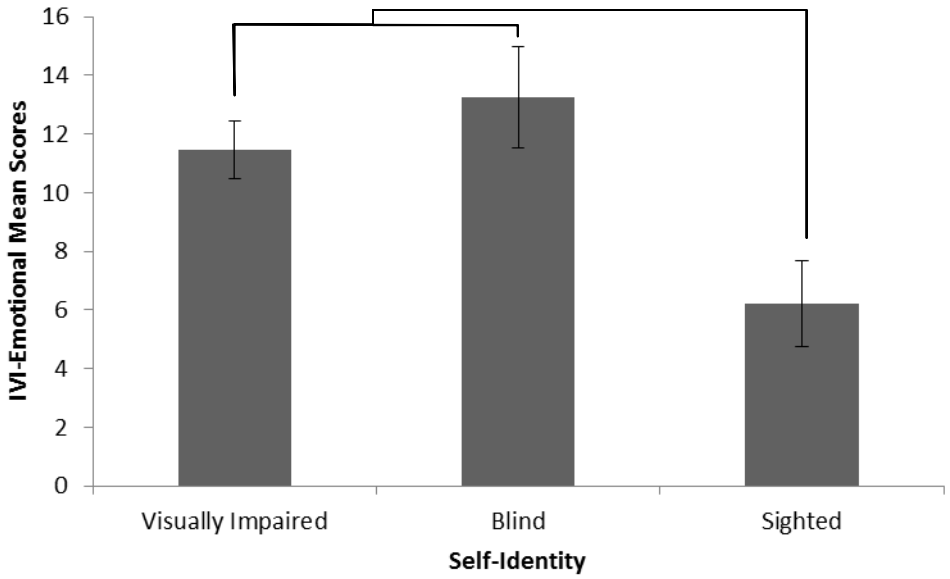

Figure 3.3. IVI-Emotional mean scores as a function of self-identity. Higher scores on IVI-Emotional indicate higher frequency of negative emotions associated with vision loss/impairment. *p = .047.

positive/negative coping styles. However, those with DR were found to have poorer scores on the VF-14 and IVI suggesting that they had* a poorer perception of their visual ability. Even when severity of vision impairment was held constant in an ANCOVA the effect of diagnosis was still present. Therefore, regardless of the level of impairment, those with DR felt that they had poorer visual function than those with RP and albinism. This may be due to the fact that DR can result in sudden, unpredictable, rapid decline and fluctuations in vision that is not found in RP or albinism. As recent decline in and fluctuations of vision were found in Experiment 1 to have a significant negative impact on adaptation and wellbeing, it is not surprising that, in the case of DR, these factors may also affect individuals' perception of their vision.

As reported in Experiment 1, it was found that those with DR had the poorest scores on the IVI-Emotional, suggesting that they experienced the highest frequency of negative emotions associated with vision loss/impairment. However, this possibility was found to be unlikely due to the diagnosis of DR as there was no longer a significant effect after level of self-perceived health and levels of education were accounted for in an ANCOVA.

These results suggest that while those with DR perceive their vision to be worse than the other two diagnostic groups, there are no differences in measures of psychological wellbeing and adaptation to vision loss/impairment among the three diagnostic groups. Therefore, based on the findings in this experiment, unlike the findings of Hayeems and colleagues (2005), Siple Milles (2004), and Strougo and colleagues (1997), one cannot conclude that those with RP cope or adapt more poorly to, experience depressive symptoms

or more negative emotions associated with, vision loss/impairment than other individuals of approximately the same age also experiencing vision loss and vision impairment.

When considering non-diagnosis related factors, it was found that the impact of vision impairment and the presence and frequency of depressive symptoms were associated with adaptation to vision loss/impairment, specifically, as the impact of impairment increases, adaptation decreases. However, because the IVI measures both the self-perceived impact of vision impairment on daily tasks, similar to the VF-14, and the presence of negative emotions associated with vision loss/impairment, it was necessary to verify which of the two elements, if not both, contributes to the correlation. When these two elements were analysed individually, it was found that the visual ability questions, as well as the emotional questions, correlated negatively with adaptation to vision loss/impairment, $r(59) = -.527$, $p < .001$; $r(59) = -.301$, $p = .018$, respectively. This finding suggests that, as both the impact of vision impairment on daily tasks and the impact of impairment on emotional wellbeing increases, adaptation decreases. As the VF-14 did not correlate with the AVL in this study, it is possible that either the VF-14 was not sensitive enough in this case, or that the IVI includes factors not included in the VF-14 which correlated significantly with the adaptation to vision loss/impairment.

The presence and frequency of depressive symptoms was also found to correlate with adaptation to vision loss/impairment such that, as depressive symptoms increase in frequency, adaptation decreases. It is not possible to indicate whether the depressive symptoms affect adaptation or the opposite, however, it is not surprising that depressive

symptoms are associated with adaptation. However, although these results may not be surprising, the implications of the high presence of depressive symptoms in this population must not be overlooked. All three diagnostic groups demonstrated a higher proportion of individuals with depressive symptoms (RP = 43%, DR=48%, and albinism=37%) than the general population which hovers around 10% (Hahm, 2008). These results reflect findings of other studies that have also found a high proportion of depressive symptoms in individuals with vision loss (Brody et al., 2001; Burmedi et al., 2002; Heyl & Wahl, 2001; Wahl et al., 2003; Woods-Fry, Duponsel, Wittich, Wanet-Defalque & Overbury, 2011).

As previously noted, because there may have been a ceiling effect in the AVL results, the analyses were repeated using a subsection of the IVI. Using the IVI-Emotional scores as an outcome measure gave much more interesting results that mirror more closely what has been found in past research, as well as what has been suggested theoretically. Here, negative emotions associated with vision loss/impairment were found to worsen as self-perceived visual function worsened. Although visual function itself was not found to correlate with the IVI-Emotional in Experiment 1, it does seem that the way people perceive their visual function, does correspond with their emotional reaction to vision loss/impairment. Interestingly, as reported in Experiment 1, negative emotions associated with vision loss/impairment were not found to be significantly affected by the degree or type of vision loss but, rather, by whether individuals had experienced a recent decline in vision and whether they experience regular fluctuations. Therefore, it seems that people's perception of their own visual ability, or lack thereof, depends heavily on whether they have experienced recent loss or fluctuations, regardless of how poor their vision actually is.

Similar to the finding with adaptation as the outcome measure, the presence and frequency of depressive symptoms was found to be related to the presence and frequency of negative emotions associated with vision loss/impairment. Again, although these results are not surprising, and although the nature of this relationship could not be determined in this study, the implications of the high proportion of depressive symptoms in this population should not be overlooked.

When considering the supplementary questions regarding personal identification in terms of visual disability, and disability in general, those who still considered themselves as sighted had significantly better scores on the IVI-Emotional suggesting that they experience fewer negative emotions, and less frequently, than those who considered themselves visually impaired or blind. Interestingly, whether participants considered themselves as disabled or not did not seem to be related to their experience of negative emotions associated with vision loss/impairment. These results do not seem to be in line with propositions by Pollard and colleagues (2003) and Hayeems and colleagues (2005) who both suggested that those who already identify themselves as visually impaired or blind would fare *better* than those who still identify themselves as sighted. Their argument was that those who still identify themselves as sighted have not yet accepted their situation and are still resisting change and, therefore, have not come to terms with the situation. Interestingly, even when an ANOVA was conducted with level of impairment as one factor and self-identification as the other, there was no interaction, suggesting that those who considered themselves sighted and were already legally blind were experiencing more negative emotions than those who already considered themselves visually impaired or blind. In the case of this

study, as participants were younger than in previous studies, it may be possible that, as suggested by Boerner (2004), younger individuals may have a more difficult time accepting conditions that may occur as a result of vision impairment and, therefore, experience more negative emotions as a consequence.

The same line of reasoning may be used to explain the finding that those individuals who felt that they were more dependent on others as a consequence of their vision impairment experienced negative emotions associated with vision loss/impairment more frequently than those who did not feel they were dependent others. Although no other study has documented younger individuals' response to such a question, it may be possible that these individuals find it more difficult to ask for and accept help as they are at a point in life when they feel they should still be self-sufficient. As Boerner (2004) points out, individuals at this stage in life do not expect to have to depend on others, while older individuals might do to increasing impairments linked to their age (though this is not to say that the process is any easier for them). However, regardless of age, the loss of independence has been reported to be one of the major fears among individuals losing their vision (Bittner et al., 2010; Coyne, et al., 2004; Nemshick & Ludman, 1986).

Another finding of the study was a trend towards a significant difference of the presence and frequency of negative emotions between those who were comfortable using their assistive devices and visual aids in public and those who were not. Those who were not comfortable reported experiencing negative emotions more frequently than those who were. Although participants were not asked why they felt comfortable or not, many reported that

they were not comfortable because they feared being judged or treated differently. Stigma has already been reported in many studies as one of the key outcomes that those with developing impairments fear (Bittner et al., 2010; Estrada-Hernandez & Harper, 2007; Lund & Gaigher, 2002; Roy & Mackay, 2002; Wan, 2003).

Implications and Conclusion

Given the findings of this experiment, it is not possible to conclude that individuals with RP adapt or fare any more poorly than individuals with other eye disorders. Factors that seem to be more associated with adaptation and psychological wellbeing are the presence of depressive symptoms, the perception of the impact of vision impairment and the associated negative emotions, as well as whether individuals identify themselves as blind, somewhat dependent on others and whether they are comfortable using their devices in public. Through a better understanding of the psychological factors that may be critical for successful adjustment and a positive outcome in individuals with vision loss, eye-care professionals and vision rehabilitation providers may be able to better help those with vision loss who present with possible risk factors. As such risk factors may reduce the likelihood that individuals seek beneficial assistance, or handle their vision loss in a positive manner, it is important to be able understand and identify such risk factors as soon as possible, so that they may receive the necessary assistance they need. This is important as research has already demonstrated that earlier rehabilitative intervention is significantly more likely to benefit clients than intervention after a significant delay (Head, Babcock, Goodrich & Boyless, 2000).

Chapter IV

GENERAL DISCUSSION

The two principal objectives of this thesis were: (1) to determine if individuals with RP adapt differently to vision loss than those with other ocular disorders and, if not,
(2) to isolate which factors (functional, socio-demographic and psychological) are associated with adaptation to and psychological wellbeing associated with vision loss/impairment in early and mid-adulthood.

The results of both experiments indicate that it is not possible to state that those with RP adapt more poorly and have more negative psychological outcomes than those with other vision disorders. Rather, factors involving function, socio-demographics, and psychological wellbeing were found to be more influential.

Existing arguments for a suspected difference in adaptation and psychological profile in individuals with RP rely on the relatively unique nature of RP in that it occurs earlier in life, the loss of vision takes place over an extended period, this loss is unpredictable in its progression and final outcome, and its pattern of loss, from peripheral to central, is problematic (Hahm, 2008). However, as previously mentioned, the above symptoms, while perhaps being unique in their combined presentation in RP, are not unique in themselves and are found in other disorders. In fact, as the above experiments demonstrated, those with DR showed similar adaptation and psychological wellbeing to RP as they too experienced vision loss earlier in life, experienced fluctuations and decline over a long period of time,

and had difficult patterns of vision loss. Furthermore, while those with albinism did generally fare better on most of the scales of adaptation and psychological wellbeing, they did not have significantly better scores than individuals with RP and DR. This suggests that, while the loss of vision may be extremely difficult, the mere presence of a vision impairment represents a difficulty in itself. Therefore, it is important to consider the various other factors not related to visual diagnosis that may have significant implications on adaptation to, and psychological wellbeing associated with, vision impairment.

Visual Function and Adaptation and Psychological Wellbeing

Factors related to visual function that were found to have an effect on adaptation to and psychological wellbeing associated with vision impairment were not the severity of vision loss as much as the stability of vision and pattern of impairment. Those experiencing a decline and/or fluctuations in vision fared more poorly than those who had stable vision that had not declined for some time. Furthermore, those who had central loss fared better than those who had peripheral loss *only*, which was argued to be the case due to the psychological implications of peripheral loss with central vision intact (i.e. central loss is not as 'ignorable' as peripheral loss and there may exist the impression that there is little that can be done for peripheral loss).

When it comes to factors that involve visual function, it seems that time is an important element. While decline in vision and fluctuations had an effect on adaptation and psychological wellbeing, these effects were not as strong as the recency of the last decline

in vision lengthened. Furthermore, the time elapsed since diagnosis also seems to be important as adaptation and psychological wellbeing improved with time.

The fact that individuals improve in their adaptation and psychological wellbeing may have important implications for the timing of vision rehabilitation. At the onset of vision loss, and at the time of diagnosis, adaptation and psychological wellbeing may be very poor, thus necessitating more active encouragement on the part of eye-care specialists and vision rehabilitation providers. This is very important as previous research has already demonstrated that early rehabilitation is significantly more likely to benefit clients than intervention after a delay (Head et al., 2000).

Furthermore, research by Wahl and colleagues (2007) regarding control strategies used by individuals experiencing vision loss has identified two crucial points at which control strategies shift, potentially having significant effects on adjustment and the introduction of rehabilitative services and use of assistive devices. One of these crucial factors is time since diagnosis. Their results point to a time period between diagnosis and a decrease in the use of control strategies that result in seeking external assistance (i.e. vision rehabilitation and assistive devices), which they found to be alarmingly short. They found that almost immediately after the time of diagnosis, participants with AMD increased their use of a control strategy resorting to external assistance but that, typically, this new effort to use external resources declined as early as six months after diagnosis. As of two years after diagnosis, no change in resorting to external resources was found. In other words, it appears that the first year after diagnosis is crucial for the introduction of external resources

such as rehabilitative services and visual aids because the tendency to resort to these resources is strongest during this time and declines significantly within the first year.

Moreover, these results were found with individuals experiencing central loss, not taking into consideration the further complications of individuals experiencing peripheral loss only. Research has shown that individuals with RP and DR are less likely to recognize the implications of their eye disorder and may not take sufficiently early steps to making life adjustments (Nemshick & Ludman, 1986 and Coyne, et al., 2004, respectively). Combine this denial found in individuals with these diagnoses with the short time-span when external assistance is likely to be sought, and it becomes even more imperative that eye-care specialists and vision rehabilitation providers be proactive in encouraging individuals who were recently diagnosed with vision disorders to seek vision rehabilitation as soon as possible.

Socio-Demographic Factors and Adaptation and Psychological Wellbeing

Socio-demographic factors that were found to have a significant impact on adaptation to and psychological wellbeing associated with vision impairment were ability to work or study, level of education, marital status, and family history of the disorder.

Implications of vision impairment on a person's ability to work or study are great during early and mid-adulthood. This stage in life is generally marked by a need for financial independence as individuals start families or expand their life experiences. As previously

reported, one of the leading fears of younger individuals losing vision is not being able to provide for their families (Nemshick & Ludman, 1986). Furthermore, the ability to study may later affect work as many of the more manual or vocational careers are not well suited to visually impaired persons. This may partially explain the finding that those who were more highly educated adapted and coped better than those who were not. Furthermore, the life-style that is most likely associated with a higher education is also more likely to be conducive to a better outcome as there is a higher possibility that beneficial resources will be available to individuals with such lifestyles.

Some studies have already demonstrated the importance of social support in dealing with vision loos/impairment (Bittner et al., 2010; Devenney & O'Neill, 2011; Reinhardt, 2001; Reinhardt et al., 2009). As found in the current study, those who have individuals in their social circle who are understanding, or who experience the disorder as well, function better psychologically. However, almost as many studies have shown that social isolation often occurs in those with vision loss (Lindo & Nordholm, 1999; Tolman et al., 2005). In fact, research investigating social support of those with RP found that one fifth of them felt that they had no one with whom they could speak regarding their condition (Nemshick & Ludman, 1986). The main reported reason for this was that they did not feel that many people understood their condition and its daily and life consequences (Bittner et al., 2010; Nemshick & Ludman, 1986). When participants in the current study were asked if they had any comments or questions, many asked why discussion groups for those with the same diagnosis were not organized by the rehabilitation agencies. In fact, Nemshick and Ludman (1986) reported that 66% of the participants in their study felt that sharing with peers with

the same diagnosis would be helpful. Organizing and creating support groups of individuals with similar diagnoses may be a consideration that agencies should take into account when dealing with people who have been recently diagnosed, especially if they are not married, do not have a partner, or do not have someone in their family with the same diagnosis.

Psychological Factors and Adaptation and Psychological Wellbeing

Although it was found that the impact of vision impairment and the presence of depressive symptoms have a significant effect on adaptation to and the presence of negative emotions associated with vision loss/impairment, it is impossible to indicate which is the cause and which is the effect due to the nature of this study. However, the fact that these symptoms are present to such a high degree is concerning and should be taken into consideration by eye-care specialists and vision rehabilitation providers (especially as the actual prevalence may be higher than found in this study as it is possible that some individuals with depression declined to participate as a result of their negative affect).

Some studies have already indicated the need for and benefit that counselling could provide for those with vision loss/impairment (Nemshick & Ludman, 1986; Rees et al., 2007; Zaborowski, 2007). Rees and colleagues (2007) indicated that most of their low vision participants expressed a desire for help with emotional distress, and Nemshick and Ludman (1986) reported that 72% of their participants felt that counselling would be beneficial.

It also seems that a person's self-identity regarding vision impairment has an effect on adaptation and psychological wellbeing. In the case of the present study, those who already considered themselves as visually impaired or legally blind adapted more poorly and had poorer psychological wellbeing. These findings do not immediately seem to reflect those of other researchers (Hayeems et al., 2005; Pollard et al., 2003). However, as the participants in this study current were all recruited from a vision rehabilitation agency, it is possible that they had already accepted, to a certain extent, the circumstance of their visual condition.

When considering individuals who have not yet sought rehabilitation, it might be more important to examine how they view their self-identity in terms of their vision and the consequences it may have on whether or not they seek vision rehabilitation and whether they make important life changes that will facilitate their daily functioning with their diminishing vision. For example, Pollard and colleagues (2003) found that, although half of their participants already had moderate to severe vision loss, only 25% considered themselves as visually impaired. In their study, those who did not yet do so were much less likely to seek vision rehabilitation. Similarly, Hayeems and colleagues (2005) found that their participants needed to shift their identity from 'sighted' to 'visually impaired' before they would seek rehabilitation and make important life changes in order to successfully adjust to their vision loss. In both studies, one of the major reasons participants reported for not seeking vision rehabilitation was fear of negative judgment from others.

Fear of social stigma is one of the most reported concerns of visually impaired people (Bittner et al., 2010; Hayeems et al., 2005; Lund & Gaigher, 2002; Pollard et al., 2003;

Wan, 2003). Pollard and colleagues (2003) indicated that their participants expressed a fear of mixing with others with low vision as they would become categorized as outsiders or part of a disabled group. As found in Hayeems and colleagues (2005), some participants equated seeking rehabilitation and using assistive devices in public with 'coming out'. For this reason, Roy and Mackay (2002) even suggest that stigma, not the disease or impairment itself, is what leads to low self-esteem.

Stigma, however, does not only stem from other's beliefs about a condition or disorder, but one's own beliefs as well. In fact, Zaborowski (2007) suggested that successful adjustment to blindness or vision impairment requires people to shift their beliefs of blindness or vision impairment from an entirely negative view to one that is more realistic and positive. He suggests that both visually impaired clients, and sometimes the therapist, hold an unrealistic view of blindness based on misguided common belief that focuses on the negatives aspects such as loss, incapability and total dependence, which decreases the value of the individual. In this view, sight itself is what gives an individual value and independence so that people may avoid tasks and relationships which they believe requires good vision. Instead, Zabowoski suggests that therapists and rehabilitation agencies should focus more on a philosophy of blindness that views it as a normal characteristic of a small number of people (Jernigan, 1982). With this view, blindness or visual impairment is no longer the defining element of a person and his/her value, but rather a characteristic that simply requires some changes of certain aspects of life in order to maintain normal day-to-day activities. Therefore, although changes may be difficult to adjust to initially, the adjustment is no longer viewed as a change of one's self-worth, but simply a change in order to participate

in the same activity, just differently. Zabowoski emphasises the need for providing good counselling, peer support groups, and examples of individuals who have successfully adjusted as a regular component of vision rehabilitation.

Limitations and Future Directions

There still exists a great need for further research in this area. Although the results of this study suggest that it is not possible to conclude that individuals with RP adjust any differently to vision loss than people with other diagnoses, further research with larger samples and a more diverse range of ocular diagnoses is necessary. Furthermore, although this study could only touch on various issues concerning vision impairment, such as social support, social stigma, etc., more in-depth research looking specifically at these issues and exactly how they have a positive or negative impact on adapting and dealing psychologically with vision loss/impairment is necessary.

Implications and General Conclusion

The major finding in this study is that one cannot judge a person's likely outcome in rehabilitation, or life in general, based only on diagnosis and the extent of vision loss but, rather, one must take into consideration other visual, socio-demographic and psychological factors that can, and have been shown to have significant implications for adaptation to and psychological wellbeing associated with vision loss/impairment. Eye-care specialists and vision rehabilitation providers need to be aware of such factors so that they may better

identify individuals who may need added support. As has already been pointed out, it is essential that individuals receive assistance as soon as possible as such assistance has been shown to effective in leading to better chances of positive adaptation and psychological wellbeing (Brody et al., 2001; Lamoureux et al., 2007).

REFERENCES

Alexander, K.R., Barnes, C.S., Fishman, G.A., Pokorny, J. & Smith, V.C. (2004). Contrast sensitivity deficits in inferred magnocellular and parvocellular pathways in retinitis pigmentosa. *Investigative Ophthalmology and Vision Science, 45*(12), 4510-4519.

Alexander, K.R., Derlacki, D.J. & Fishman, G.A. (1999). Coherence and the judgment of spatial displacements in retinitis pigmentosa. *Vision Research, 39*(13), 2267-2274.

Bear, M.F., Connors, B.W. & Paradiso, M.A. (2001). Neuroscience: Exploring the Brain. 2nd Edition. Baltimore, U.S.A. Lippincott Williams & Wilkins.

Benn, D.T. (1997). The role of personality traits and coping strategies in late-life adaptation to vision loss. Dissertation Abstracts International: Section B: The Sciences and Engineering, 58(4-B), 2151.

Ben-Zur, H. & Debi, Z. (2005). Optimism, social comparisons, and coping with vision loss in Israel. *Journal of Visual Impairment and Blindness, 99(3)*, 151-164.

Bernbaum, M., Albert, S.G. & Duckro, P.N. (1988). Psychosocial profiles in patients with visual impairment due to diabetic retinopathy. *Diabetes Care, 11*(7), 551-557.

Berson, E.L., Rosner, B., Weigel-DiFranco, C., Dryja, T.P. & Sandberg, M.A. (2002). Disease progression in patients with dominant retinitis pigmentosa and rhodopsin mutations. *Investigative Ophthalmology and Vision Science, 43(9)*, 3027-3036.

Bittner, A.K., Edwards, L., & George, M. (2010). Coping strategies to manage stress related to vision loss and fluctuations in retinitis pigmentosa. *Optometry, 81(9)*, 461-468.

Boerner, K. (2004). Adaptation and disability among middle-aged and older adults: The role of assimilative and accommodative coping. *Journal of Gerontology, 59B(1),* 35-42.

Boerner, K., Reinhardt, J.P. & Horowitz, A. (2006). The effect of rehabilitation service use on coping patterns over time among older adults with age-related vision loss. *Clinical Rehabilitation, 20*(6), 478-487.

Brandtstädter, J. & Renner, G. (1990). Tenacious goal pursuit and flexible goal adjustment: explication and age-related analysis of assimilative and accommodative strategies of coping. *Psychology and Aging, 5(1)*, 58-67.

Brennan, M. (2004). Spirituality and religiousness predict adaptation to vision loss in middle-aged and older adults. *The International Journal for the Psychology of Religion, 14(3),* 193-214.

Brennan, M., Horowitz, A., Reinhardt, J.P., Cimarolli, V., Benn, D.T. & Leonard, R. (2001). In their own words: Strategies developed by visually impaired elderly to cope with vision loss. *Journal of Gerontological Social Work, 35(1),* 107-129.

Brody, B.L., Gamst, A.C., Williams, R.A., Smith, B.A., Lau, M.A., Dolnak, D., Rapaport, M.H., Kaplan, R.M. & Brown, S.I. (2001). Depression, visual acuity, comorbidity, and disability associated with age-related macular degeneration. *Ophthalmology, 108*(10), 1893–1900.

Burmedi, D., Becker, S., Heyl, V., Wahl, H.-W. & Himmelsbach, I. (2002). Behavioral consequences of age-related low vision. *Visual Impairment Research, 4(1)*, 15-45.

Carpenter, J.S., Andrykowski, M.A., Wilson, J., Hall, L.A., Rayens, M.K., Sachs, B. & Cunningham, L.L. (1998). Psychometrics for two short forms of the Center for Epidemiologic Studies—Depression Scale. *Issues in Mental Health Nursing, Vol 19*(5), 481-494.

Carver, C.S. (1997). You want to measure coping but your protocol's too long: consider the brief COPE. *International Journal of Behavioral Medicine, 4*(1), 92-100.

Carver, C.S., Scheier, M.F. & Weintraub, J.K. (1989). Assessing coping strategies: a theoretically based approach. *Journal of Personality and Social Psychology, 56*(2), 267-283.

Colllins English Dictionary (2004). Glasgow, Harper Collins Publishers.

Coyne, K.S., Margolis, M.K., Kennedy-Martin, T., Baker, T.M., Klein, R., Paul, M.D. & Revicki, D.A. (2004). The impact of diabetic retinopathy: perspectives from patient focus groups. *Family Practice, 21(4)*, 447-453.

Crick, R.P. & Khaw, P.T. (2003). Clinical Ophthalmology: A Practical Guide to Disorders of the Eyes and Their Management (3rd Ed.). Singapore: World Scientific Publishing.

Delisle, V.C., Beck, A.T., Dobson, K.S., Dozois, D.J. & Thombs, B.D. (2012). Revisiting gender differences in somatic symptoms of depression: Much ado about nothing? *PLoS One, 7(2)*, e32490.

Devenney, R. & O'Neill, S. (2011). The experience of diabetic retinopathy: A qualitative study. *British Journal of Health Psychology, 16(4)*, 707-721.

Estrada-Hernandez, N. & Harper, D.C. (2007). Research on psychological and personal aspects of Albinism: A critical review. Rehabilitation Psychology, 52(3), 263-271.

Faye, E.E. (Ed.). (1984). Clinical low vision. (2nd Ed.). Boston: Little & Brown.

Fishman, G.D., Bozbeyoglu, S., Massof, R.W. & Kimberling, W. (2007). Natural course of visual field loss in patients with type 2 Usher syndrome. *Retina, 27(5)*, 601-608.

Fourie, R. (2007). A qualitative self-study of retinitis pigmentosa. *British Journal of Visual Impairment, 25*(3), 217-232.

Friedman, D.S., Tielsch, J.M., Vitale, S., Bass, E.B., Schein, O.D., Steinberg, E.P. (2002). VF-14 item specific responses in patients undergoing first eye cataract surgery: can the length of the VF-14 be reduced? *British Journal of Ophthalmology, 86*(8), 885-91.

Gillman, A.E., Simmel, A. & Simon, E.P. (1986). Visual handicap in the aged: Self-reported visual disability and the quality of life of residents of public housing for the elderly. *Journal of Visual Impairment & Blindness, 80(2)*, 588-590.

Gold, M.E. (2002) – The effects of the physical features associated with albinism on the self-esteem of African-American youths. *Journal of Visual Impairment and Blindness, 96(3),* 133-142.

Good, G.A. (2008). Life satisfaction and quality of life of older New Zealanders with and without impaired vision: A descriptive, comparative study. European Journal of Ageing, 5(3), 223-231.

Griffith, L., Raina, P., Wu, H., Zhu, B., & Stathokostas, L. (2010). Population attributable risk for functional disability associated with chronic conditions in Canadian older adults. *Age and Ageing, 39*(6):738-45.

Guignard, E. (1990). Psychosocial management of retinitis pigmentosa patients from the viewpoint of the physician and the patient. *Klinische Monatsblätter für Augenheilkunde, 196*(5):436-437.

Hahm, B-J., Shin, Y-W., Shim, E-J., Jeon, H.J., Seo, J-M., Chung, H. & Yu, H.G. (2008). Depression and the vision-related quality of life in patients with retinitis pigmentosa. *British Journal of Ophthalmology, 92*, 650-654.

Hartong, D.T., Berson, E.L. & Dryja, T.P. (2006). Retinitis Pigmentosa. *The Lancet, 368*, 1795-1809. Hayeems, R.Z., Geller, G., Finkelstein, D. & Faden, R.R. (2005). How patients experience progressive loss of visual function: a model of adjustment using qualitative methods. *British Journal of Ophthalmology, 89*(5), 615-620.

Hayeems, R.Z., Geller, G., Finkelstein, D. & Foden, R.R. (2005). How patients experience progressive loss of visual function: A model of adjustment using qualitative methods. *British Journal of Ophthalmology, 89*, 615-620.

Head, D., Babcock, J., Goodrich, G., & Boyless, J., (2000). A geriatric assessment of functional status in vision rehabilitation. *Journal of Visual Impairment & Blindness*, *94*(6), 357-371.

Heckhausen, J. & Schulz, R. (1995). A life-span theory of control. *Psychology Review, 102(2)*, 284-304.

Heyl, V & Wahl, H.W. (2001). Psychosocial adaptation to age-related vision loss: A six-year perspective. *Journal of Visual Impairment and Blindness, 95(12)*, 739-748.

Hirai, F.E. (2010). Health-related quality of life, visual functioning, and depression in a Type 1 diabetes population: Wisconsin epidemiologic study of diabetic retinopathy. *Dissertation Abstracts International: Section B: The Sciences and Engineering. 71(1-B)*, 257.

Horowitz, A. & Reinhardt, J.P. (1998). Development of the Adaptation to age-related Vision Loss Scale. *Journal of Visual Impairment and Blindness, 92*(1), 30-41.

Horowitz, A., Reinhardt, J.P., Boerner, K. & Travis, L.A. (2003). The influence of health, social support quality and rehabilitation on depression among disabled elders. *Aging and Mental Health, 7*(5), 342-350.

Jacobson, A.M., Rand, L.I. & Hauser, S.T. (1985). Psychologic stress and glycemic control: A comparison of patients with and without proliferative diabetic retinopathy. *Psychosomatic Medicine, 47(4),* 372-380.

Jangra, D., Ganesh, A., Thackray, R., Austin, L., Ulster, A., Sutherland, J. & Levin, A.V. (2007). Psychosocial adjustment to visual loss in patients with retinitis pigmentosa. *Ophthalmic Genet, 28*(1), 25-30.

Jin, Y.P. & Wong, D.T. (2008). Self-reported visual impairment in elderly Canadians and its impact on healthy living. *Canadian Journal of Ophthalmology, 43(4)*: 407-13.

Klein, B.E. (2007). Overview of epidemiologic studies of diabetic retinopathy. *Ophthalmic Epidemiology, 14(4)*, 179-83.

Kohout, F.J., Berkman, L.F., Evans, D.A., & Cornoni-Huntley, J. (1993). Two shorter forms of the CES-D depression symptoms index. Journal of Aging and Health, 5, 179-193.

Lamoureux, E.L., Pallant, J.F., Pesudous, K., Rees, G., Hussell, J.B. & Keeffe, J.E. (2007). The Effectiveness of Low-Vision Rehabilitation on Participation in Daily Living and Quality of Life. *Investigative Ophthalmology and Visual Science, 48(4),* 1476-1482.

Lazarus, R.S. & Folkman, S. (1984). Stress, Appraisal, and Coping. New York: Springer Publishing.

Lee, E. & Brennan, M. (2006). Stress constellations and coping styles of older adults in age-related visual impairment. *Health & Social Work, 31*(4), 289-298.

Lindo, G. & Nordholm, L. (1999). Adaptation strategies, wellbeing, and activities of daily living among people with low vision. *Journal of Visual Impairment and Blindness, 93(7),* 434-446.

Lund, P.M. & Gaigher, R. (2002). A health intervention programme for children with albinism at aspecial school in South Africa. *Health and Education Research: Theory and Practice,17(3)*, 365-372.

Madreperla, S.A., Palmer, R.W., Massof, R.W. & Finkelstein, D. (1990). Visual acuity loss in retinitis pigmentosa. Relationship to visual field loss. *Archives of Ophthalmology, 108(3)*, 358-361.

Mangione, C.M., Lee, P.P., Pitts, J., Gutierrez, P., Berry, S. & Hays, R.D. (1998). Psychometric properties of the National Eye Institute Visual Function Questionnaire (NEI-VFQ). NEI-VFQ Field Test Investigators. *Archives of Ophthalmology, 116*(11), 1496-1504.

Massof, R.W. & Finkelstein, D. (1979). Vision threshold profiles in X-linked retinitis pigmentosa. *Investigative Ophthalmology and Vision Science, 18*(4), 426-429.

Massof, R.W., Johnson, M.A. & Finkelstein, D. (1981). Peripheral absolute threshold spectral sensitivity in retinitis pigmentosa. *British Journal of Ophthalmology, 65*(2), 112-121.

Meiusi, R.S., Lavoie, J.D. & Summers, C.G. (1993). The effect of grating orientation on resolution acuity in patients with nystagmus. *Journal of Pediatric Ophthalmology and Strabismus, 30(4)*, 259-61.

Mitchell, P., Smith, W., Wang, J.J., Attebo, K. (1998). Prevalence of diabetic retinopathy in an older community. The Blue Mountains Eye Study. *Ophthalmology, 105(3)*, 406-411.

The National Center for Biotechnology Information: Gene Database. (2012). Retrieved at http://www.ncbi.nlm.nih.gov/gene

Nemshick, L.A., McCay, V. & Ludman, F. (1986). The impact of retinitis pigmentosa on young adults: Psychological, educational, vocational and social considerations. *Journal of Visual Impairment & Blindness, 80(*7), 859-862.

Nevid, J., Rathus, S. & Greene, B. (2000). Abnormal Psychology in a Changing World. Fourth Edition. Prentice Hall, New Jersey.

New Jersey Society of Optometric Physicians, http://www.eyecare.org/consumer/disease, In Coyne K.S., Margolis, M.K., Kennedy-Martin, T., Baker, T.M., Klein, R., Paul, M.D. & Revicki, D.A. (2004). The impact of diabetic retinopathy: perspectives from patient focus groups. *Family Practice, 21(4)*, 447-453.

Nimsgern, C., Krastel, H., Auffarth, G.U., Eggers, I. & Lang, H. (1998). Standardized evaluation of red, green and blue perception. Comparison between color arrangement and computer-assisted test procedures. Der *Ophthalmologe, 95*(8), 559-563.

Oxford Dictionary of Psychology (2009). Colman, A.M. (Ed), New York, Oxford University Press.

Palmer, C. (2007). Myths, stereotypes and self-perception: The impact of albinism on self-esteem. *The British Journal of Visual Impairment, 25(2),* 144-154.

Perssons, L.O. (1990). Adaptation vid kronisk sjukdom och handikapp: En kritisk analys och sammanfattning [Adaptation to chronic disease and handicap: A critical analysis and summary]. Goteborg, Sweden: Department of Psychology, University of Goteborg.

Pollard, T.L., Simpson, J.A., Lamoureux, E.L. & Keeffe, J.E. (2003). Barriers to accessing low vision services. *Ophthalmic and Physiological Optics, 23*(4), 321-327.

Radloff, L.S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*(3), 385-401.

Rees, G., Saw, C.L., Lamoureux, E.L. & Keeffe, J.E. (2007). Self-management programs for adults with low vision: needs and challenges. *Patient Education and Counselling. 69*(1-3), 39-46.

Reinhardt, J.P. (1996). The importance of friendship and family support in adaptation to chronic vision impairment. *The Journals of Gerontology: Series B: Psychological Sciences and Social Sciences, 51B*(5), 268-278.

Reinhardt, J.P. (2001). Effects of positive and negative support received and provided on adaptation to chronic visual impairment. *Applied Developmental Science, 5*(2), 76-85.

Reinhardt, J.P., Boerner, K. & Horowitz, A. (2009). Personal and social resources and adaptation to chronic vision impairment over time. *Aging and Mental Health, 13*(3), 367-375.

Robbin, H.G. & Murray, N.E. (1988). Psychological and visual factors in rehabilitation of patients with related maculopathy. *Journal of Vision Rehabilitation, 2*, 11-21.

Roy, A.W.N., MacKay, G.F. (2002). Self-perception and locus of control in visually impaired college students with different types of vision loss. *Journal of Visual Impairment and Blindness, 96*(4), 254-266.

Rubin, R.R., & Peyrot, M. (1999). Quality of life and diabetes. *Diabetes/Metabolism Research and Reviews,* 15(3), 205-218.

Sandberg, M.A. & Gaudio, A.R. (2006). Reading speed of patients with advanced retinitis pigmentosa or choroideremia. *Retina, 26*(1), 80-88.

Sandberg, M.A., Rosner, B., Weigel-DiFranco, C., Dryja, T.P. & Berson, E.L. (2007). Disease course of patients with X-linked retinitis pigmentosa due to RPGR gene mutations. *Investigative Ophthalmology and Vision Science, 48(3)*, 1298-1304.

Seo, JH.., Yu, H.G. & Lee, B.J. (2009). Assessment of functional vision score and vision-specific quality of life in individuals with retinitis pigmentosa. *Korean Journal of Ophthalmology, 23(3)*, 164-168.

Siple Milles, B., (2004). Coping responses and adjustment of adults with retinitis pigmentosa. Dissertation Abstracts International: Section B: The Sciences and Engineering, 65(2-B), 1018.

Steinberg, E.P., Tielsch, J.M., Schein, O.D., Javitt, J.C., Sharkey, P., Cassard, S.D., et al. (1994). The VF-14: An Index of Functional Impairment in Patients With Cataract. *Archives of Ophthalmology, 112*(5), 630-638.

Strougo, Z., Badoux, A. & Duchanel, D. (1997). Psycho-affective problems associated with retinitis pigmentosa. *Journal français d'ophtalmologie, 20*(2), 111-116.

Summers, C.G. (2009). Albinism: Classification, Clinical Characteristics, and Recent Findings. *Optometry and Vision Science, 86(6)*. 659-662.

Taylor, R.E. & Upton, L.R. (1988). Stress and coping: Implications for visual impairment. *Journal of Vision Rehabilitation, 2,* 22-28.

Tolman, J., Hill, R.D., Kleinschmidt, J.J. & Gregg, C.H. (2005). Psychosocial adaptation to visual impairment and its relationship to depressive affect in older adults with age-related macular degeneration. *The Gerontologist, 45*(6), 747-753.

Upton, L.R., Bush, B.A. & Taylor, R.E. (1998). Stress, coping, and adjustment of adventitiously blind male veterans with and without diabetes mellitus. *Journal of Visual Impairment and Blindness, 92(9)*, 656-665.

Virgili, G., Pierrottet, C., Parmeggiani, F., Pennino, M., Giacomelli, G., Steindler, P., Menchini, U. & Orzalesi, N. (2004). Reading performance in patients with retinitis pigmentosa: a study using the MNREAD charts. *Investigative Ophthalmology and Vision Science, 45*(10), 3418-3424.

Wahl, H.W., Schilling, O. & Becker, S. (2007). Age-related macular degeneration and change in psychological control: role of time since diagnosis and functional ability. *Journal of Gerontology: Psychological Sciences, 62(2)*, 90-97.

Wahl, H.W., Schilling, O., Becker, S. & Burmedi, D. (2003). A German research program on the psychosocial adaptation to age-related vision impairment. *European Psychologist, 8(3)*, 168-177.

Wan, N. (2003). 'Orange in a world of apples': The voices of albinism. *Disability and Society, 18(3)*, 277-296.

Weih, L.M., Hassell, J.B. & Keeffe, J. (2002). Assessment of the impact of vision impairment. *Investigative Ophthalmology and Vision Science, 43*(4), 927-935.

Woods-Fry, H., Duponsel, N., Wittich, W., Wanet-Defalque, M.-C. & Overbury, O. (2011). Barriers to Vision Rehabilitation: The Story of Depression. Poster presented at ARVO Annual Conference 2011, Fort Lauderdale, U.S.A. Abstract available at http://www.abstractsonline.com/Plan/ViewAbstract.aspx?sKey=157763ee-bcc4-446e-9f75-6cc15c113508&cKey=c2843a24-1202-426b-bb0a-34f21617a86c&mKey=%7b6F224A2D-AF6A-4533-8BBB-6A8D7B26EDB3%7d

World Health Organization (2009a). Visual Impairment and Blindness: Fact Sheet N*282. Retrieved from http://www.who.int/mediacentre/factsheets/fs282/en/index.html.

World Health Organization (2009b). Prevention of Visual Impairment and Blindness: Priority Eye Diseases. Retrieved from http://www.who.int/blindness/causes/priority/en/index5.html

Wu, S.-Y., Nemesure, B., Hennis, A. & Leske, M.C. (2009). Visual acuity impairment and vision-related quality of life: The Barbados Eye Studies. *British Journal of Visual Impairment, 27(1)*, 9-24.

Wulsin, L.R., Jacobson, A.M. & Rand, L.I. (1991). Psychosocial correlates of mild visual loss. *Psychosomatic Medicine, 53(1)*, 109-117.

Zaborowski, B. (2007). Adjustment to vision loss and blindness: A process of reframing and retraining. *Journal of Rational-Emotive and Cognitive-Behavior Therapy, 15*(3), 215-221.

Appendix A: Demographic Questionnaire (English and French)

Demographic Information

Date of birth:_____ **Age**:_____ **Gender**: F M

Ocular diagnosis: _____
Family history: _____
Duration: _____

Vision: Very good Fairly good Fairly poor Very poor

Stable	_____	How long	_____
Declining	_____	Recent change	_____
Fluctuates	_____	Pattern	_____

Agency: MAB INLB

Health Issues: _____

General Health: Very good Fairly good Fairly poor Very poor

Other impairments: _____

Highest level of education: Primary _____
Secondary _____
Post-secondary _____

Marital Status: Single _____
Married/Partner _____
Divorced _____
Widowed _____

Device Usage:

Magnifiers	_____	Other	_____
Telescopes	_____		_____
Computer software	_____		_____
Long cane	_____		_____

Do you use these devices in public? Yes_____ No_____
If yes: Do you feel comfortable using these devices in public? _____
If no: Why not? _____

Dependence: Independent _____
Somewhat dependent _____
Dependent _____

Do you consider yourself as: Visually impaired _____
Blind _____
Sighted _____

Do you consider yourself as a person with a disability? Yes _____ No_____

Informations démographiques

Date de naissance:_____ **Age**:_____ **Sexe**: F M

diagnostic oculaire: _____
Autres membres de la famille:_____
Durée: _____

Vision: Très bonne Assez bonne Assez faible Très faible

Stable	_____	Durée	_____
Diminue	_____	changement récent	_____
Fluctue	_____	Tendances	_____

Agence: MAB INLB

Problème de santé: _____

Santé générale: Très bonne Assez bonne Assez faible Très faible

Autres déficiences: _____

Niveau d'éducation:
Primaire _____
Secondaire _____
Post-secondaire _____

État civil:
Célibataire _____
Marié/e _____
divorcé/e _____
Veuf/ve _____

Aides visuelles:

Loupes	_____	Autres	_____
Télescopes	_____		_____
Logiciels adaptés	_____		_____
Canne blanche	_____		_____

Utilisez-vous ces appareils en public? Oui_____ Non_____
Si oui: Sentez-vous à l'aise en utilisant ces appareils en public?_____
Si non: Pourquoi?_____

Dépendance:
Indépendant/e _____
Un peu dépendent/e _____
Dépendent/e _____

Considérez-vous:
Ayant une déficience visuelle _____
Aveugle _____
Voyant/e _____

Considérez-vous une personne handicapée ou non ? Oui _____ Non_____

Appendix B: Centre of Epidemiology Studies Depression-10 Scale
(English and French)

CENTER FOR EPIDEMIOLOGIC STUDIES DEPRESSION SCALE (CES-D), NIMH

	Rarely or none of the time less than 1 day) 0	Some or little of the time (1-2 days) 1	Occasionally or a moderate amount of the time(3-4 days) 2	Most or all of the time (5-7 days) 3
1	**I was bothered by things that usually don't bother me.**			
2	I had trouble keeping my mind on what I was doing.			
3	**I felt depressed.**			
4	I felt that everything I did was an effort.			
5	**I felt hopeful about the future.**			
6	I felt fearful.			
7	**My sleep was restless.**			
8	I was happy.			
9	**I felt lonely.**			
10	I could not get going.			

CENTER FOR EPIDEMIOLOGIC STUDIES DEPRESSION SCALE (CES-D), NIMH

	jamais ou rarement (moins de 1 jour) 0	quelque fois (1 – 2 jours) 1	occasionnellement (3 – 4 jours) 2	la plupart ou tout le temps (5 -6 jours) 3
1	J'ai été ennuyé(e) par des choses qui, habituellement, ne me dérangent pas.			
2	J'ai eu de la difficulté à me concentrer sur ce que je faisais.			
3	Je me suis sentie déprimé(e).			
4	Je sentais que tout ce que je faisais me demandait un effort.			
5	Je me suis senti(e) optimiste face à l'avenir.			
6	Je me suis senti(e) craintif/craintive.			
7	Mon sommeil était agité.			
8	J'étais heureux(se).			
9	Je me suis senti(e) seul(e).			
10	Je n'arrivais pas à me mettre en train.			

Appendix C: Impact of Vision Impairment Profile – Emotional Subscale
(English and French)

Impact of Vision Impairment Profile (IVI) – Emotional Subscale

	Not at all	A little of the time	A fair amount of the time	A lot of the time	Domains
21. Have you felt embarrassed because of your eyesight?	0	1	2	3	Emotional wellbeing
22. Have you felt frustrated or annoyed because of your eyesight?	0	1	2	3	Emotional wellbeing
23. Have you felt lonely or isolated because of your eyesight?	0	1	2	3	Emotional wellbeing
24. Have you felt sad or low because of your eyesight?	0	1	2	3	Emotional wellbeing
25. In the past month, how often have you worried about your eyesight getting worse?	0	1	2	3	Emotional wellbeing
26. In the past month how often has your eyesight made you concerned or worried about coping with everyday life?	0	1	2	3	Emotional wellbeing
27. Have you felt like a nuisance or a burden because of your eyesight?	0	1	2	3	Emotional wellbeing
28. In the past month, how much has your eyesight interfered with your life in general?	0	1	2	3	Emotional wellbeing

PROFIL DE L'IMPACT DE LA DEFICIENCE VISUELLE

	Pas du tout	Un peu du temps	Une bonne partie du temps	Une grande partie du temps
21. Avez-vous ressenti de l'embarras à cause de votre vue?	0	1	2	3
22. Avez-vous été frustré ou agacé à cause de votre vue?	0	1	2	3
23. Vous êtes-vous senti seul ou isolé à cause de votre vue?	0	1	2	3
24. Avez-vous ressenti de la tristesse ou de l'isolement à cause de votre vue?	0	1	2	3
25. Durant le dernier mois, combien de fois vous êtes-vous préoccupé de la détérioration de votre vue?	0	1	2	3
26. Durant le dernier mois, combien de fois avez-vous été soucieux ou inquiet de ne pouvoir faire face à la vie courante?	0	1	2	3
27. Avez-vous eu l'impression d'être une nuisance ou un fardeau à cause de votre vue?	0	1	2	3
28. Durant le dernier mois, dans quelle mesure votre vue a eu un impact sur votre vie en général?	0	1	2	3

Appendix D: Adaptation to Vision Loss Scale (English and French)

Adaptation to Vision Loss Scale

Item #	Item	Agree	Disagree
1	Because of my vision loss, I feel like I can never really do things for myself.		
2	Most services available to visually impaired persons are useless in really helping them with their problems.		
3	Visual impairment is the cause of all my problems.		
4	Some people in the family act as though the visually impaired person is a burden to them.		
5	A visually impaired person can never really be happy.		
6	Because of my trouble seeing, I am afraid that people will take advantage of me.		
7	Visually impaired persons cannot afford to talk back or argue with family or friends.		
8	People should not expect too much from visually impaired persons.		
9	People who experience vision loss late in life will never be able to learn how to get around without bumping into things.		
10	It is too hard for older people to learn new ways of doing things (that compensate for vision loss) if they become visually impaired.		
11	Visually impaired people might as well accept the fact that vision impairment makes people pretty helpless.		
12	It is degrading for visually impaired persons to depend so much on family and friends.		
13	Sighted people generally dislike being with visually impaired people (because of their vision problems).		
14	Sighted people expect visually impaired people to do things that are impossible.		
15	Visually impaired people have to depend on sighted people to do most of the things they did for themselves.		

16	Losing one's sight means losing one's self.		
17	People with vision problems are uncomfortable making new friends because they cannot always see people's faces clearly.		
18	When a person becomes visually impaired, sighted friends don't understand him or her as they did before.		
19	It is better for persons with vision problems to let other people do things for them.		
20*	I can still do many of the things I love, it just takes me longer because of my vision impairment.		
21*	By learning new ways if doing things (that compensate for vision loss), a visually impaired person has a chance to be more independent.		
22*	Although the circumstances of my life have been changed, I am still the same person I was before my vision impairment.		
23*	I feel comfortable asking my family and friends for help with things I can no longer do because of my vision loss.		
24*	There are worse things that can happen to a person than losing vision.		

Items marked with * have response categories re-coded for analysis (1-agree and 0–disagree) and item Nos. 1-18 have response categories coded 0-agree and 1-disagree.

ÉCHELLE D'ADAPTATION À LA PERTE DE VISION

Item #	Item	En accord	En désaccord
1	À cause de ma perte de vision, je ne me sens pas capable de me débrouiller par moi-même.		
2	La plupart des services s'adressant aux personnes ayant une déficience visuelle sont inutiles et n'aident pas à réellement surmonter les problèmes.		
3	La déficience visuelle est la cause de tous mes problèmes.		
4	Certains membres de la famille agissent comme si une personne ayant une déficience visuelle était une charge pour eux.		
5	Il est impossible pour une personne ayant une déficience visuelle d'être vraiment heureuse.		
6	À cause de mes problèmes de vision, j'ai peur que les gens ne profitent de moi.		
7	Les personnes ayant une déficience visuelle ne peuvent se permettre de répliquer ou de se disputer avec leurs amis ou avec les membres de leur famille.		
8	On ne devrait pas avoir trop d'attente vis-à-vis des personnes ayant une déficience visuelle.		
9	Les personnes qui ont une perte de vision à un âge plus avancé ne seront jamais capables de se déplacer sans se cogner aux obstacles.		
10	C'est trop dur pour des adultes, dans le cas d'une perte de vision, d'apprendre de nouvelles façons de faire afin de compenser celles-ci.		
11	Les personnes ayant une déficience visuelle feraient mieux d'accepter le fait que la déficience visuelle rend les gens très vulnérables.		

12	C'est dégradant pour les personnes ayant une déficience visuelle d'avoir à dépendre autant de leur famille et de leurs amis.		
13	En général, les voyants n'aiment pas se trouver en compagnie des personnes ayant une déficience visuelle (en raison de leurs problèmes de vision).		
14	Les voyants attendent l'impossible de la part des personnes ayant une déficience visuelle.		
15	Les personnes ayant une déficience visuelle doivent dépendre des voyants pour accomplir la plupart des choses qu'elles réussissaient auparavant par elles-mêmes.		
16	Perdre la vue, c'est perdre son identité.		
17	Les personnes ayant des problèmes de vision ont du mal à se faire de nouveaux amis, parce qu'elles ne peuvent pas toujours voir leur visage clairement.		
18	Quand une personne perd sa vision, ses amis voyants la comprennent moins bien qu'auparavant.		
19	Pour les personnes ayant des problèmes de vision, mieux vaut laisser les autres faire des choses pour elles.		
20*	Je peux toujours faire la plupart des choses que j'aime, c'est seulement un peu plus long à cause de ma déficience visuelle.		
21*	Pour une personne avec déficience visuelle, il est possible de devenir plus indépendant en apprenant de nouvelles façons de faire qui compensent la perte visuelle.		
22*	Bien que les circonstances de ma vie aient changé, je suis resté(e) le (la) même personne qu'avant ma déficience visuelle.		
23*	Je me sens à l'aise de demander l'aide de ma famille ou de mes amis pour les tâches et activités que je ne peux plus entreprendre seul à cause de ma perte de vision.		
24*	Une perte de vision n'est pas la pire chose qui peut arriver à une personne.		

*20-24: 1-en accord et 0-en désaccord (1-18: 0-en accord et 1- en désaccord).

Appendix E: Brief COPE (English and French)

Brief COPE

I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
1	2	3	4

1	I've been turning to work or other activities to take my mind off things.
2	I've been concentrating my efforts on doing something about the situation I'm in.
3	I've been saying to myself "this isn't real."
4	I've been using alcohol or other drugs to make myself feel better.
5	I've been getting emotional support from others.
6	I've been giving up trying to deal with it.
7	I've been taking action to try to make the situation better.
8	I've been refusing to believe that it has happened.
9	I've been saying things to let my unpleasant feelings escape.
10	I've been getting help and advice from other people.
11	I've been using alcohol or other drugs to help me get through it.
12	I've been trying to see it in a different light, to make it seem more positive.

13	I've been criticizing myself.
14	I've been trying to come up with a strategy about what to do.
15	I've been getting comfort and understanding from someone.
16	I've been giving up the attempt to cope.
17	I've been looking for something good in what is happening.
18	I've been making jokes about it.
19	I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
20	I've been accepting the reality of the fact that it has happened.
21	I've been expressing my negative feelings.
22	I've been trying to find comfort in my religion or spiritual beliefs.
23	I've been trying to get advice or help from other people about what to do.
24	I've been learning to live with it.
25	I've been thinking hard about what steps to take.
26	I've been blaming myself for things that happened.
27	I've been praying or meditating.
28	I've been making fun of the situation.

Brief COPE (version française)

pas du tout **n petit peu** **beaucoup** **tout à fait**

1 2 3 4

1	Je me tourne vers le travail ou d'autres activités pour me changer les idées.
2	Je détermine une ligne d'action et je la suis.
3	Je me dis que ce n'est pas réel.
4	Je consomme de l'alcool ou d'autres substances pour me sentir mieux.
5	Je cherche un soutien émotionnel de la part des autres.
6	Je renonce à essayer de résoudre la situation.
7	Je concentre mes efforts pour résoudre la situation.
8	Je refuse de croire que ça m'arrive.
9	J'évacue mes sentiments déplaisants en parlant.
10	Je recherche l'aide et le conseil d'autres personnes.
11	Je consomme de l'alcool ou d'autres substances pour m'aider a traverser la situation.
12	J'essaie de voir la situation sous un jour plus positif.
13	Je me critique.
14	J'essaie d'élaborer une stratégie a propos de ce qu'il y a à faire.
15	Je recherche le soutien et la compréhension de quelqu'un.

16	J'abandonne l'espoir de faire face.
17	Je recherche les aspects positifs dans ce qu'il m'arrive.
18	Je prends la situation avec humour.
19	Je fais quelque chose pour moins y penser (comme aller au cinéma, regarder la TV, lire, rêver tout éveillé, dormir ou faire les magasins).
20	J'accepte la réalité de ma nouvelle situation.
21	J'exprime mes sentiments négatifs.
22	J'essaie de trouver du réconfort dans ma religion ou dans des croyances spirituelles.
23	J'essaie d'avoir des conseils ou de l'aide d'autres personnes à propos de ce qu'il faut faire.
24	J'apprends à vivre dans ma nouvelle situation.
25	Je planifie les étapes à suivre.
26	Je me reproche les choses qui m'arrivent.
27	Je prie ou médite.
28	Je m'amuse de la situation.

Appendix F: Consent Forms – MAB-Mackay Rehabilitation Centre
(English and French)

Title: Use of Vision Rehabilitation Services and Psychological Adjustment to Vision Impairment in Early- and Mid-Adulthood
Principal Investigator: Nathalie Duponsel
Study sponsor: Réseau de recherche en santé de la vision (FRSQ)

Consent Form

Introduction

We invite you to take part in this research study because you have visual problems. This study is being conducted under the direction of Nathalie Duponsel, a graduate student under the supervision of Dr. Overbury at the University of Montreal. You have the right to be informed about the procedures, possible risks and benefits of this study in order to decide whether or not you want to participate.

Purpose of this study

The purpose of this study is to find out about the types of rehabilitation services that you may have received in the past, or are receiving presently, and how you are coping with your vision impairment.

Study Procedures

If you choose to participate in this study, and once you have returned this consent form with your signature using the self-addressed, stamped envelope that you have been provided, you will be called by a research assistant at one of the convenient times that you indicate below. You will be asked a series of questions about vision rehabilitation services you have received in the past, or are receiving presently, as well as, five brief questionnaires which will be read to you by the research assistant. These questionnaires relate to how well you can do daily activities that involve vision and how well you feel you are adjusting to your vision loss. For example, you will be asked about any difficulties you may have traveling in unfamiliar places, how comfortable you are with it, and how you cope with such situations. Answering these questionnaires should take approximately 30-45 minutes (if breaks are

required). Even if you choose to participant in this research, you should know that you have the right to refuse to answer any question at any time.

Benefits and Risks

This study poses no risks to you or your vision. However, it is possible that you may find it difficult to talk about your visual problems. You may feel sad or a little upset. If this happens, we ask that you feel free to mention that you are upset and the researcher can assist you in contacting MAB-Mackay where professionals can help you regarding any difficulties you may be experiencing.

There will be no immediate direct benefit to you from this study; but please know, you will be contributing to medical knowledge that could help you, or others like you, in the future.

Withdrawal from the Study

Your participation in this study is completely voluntary. You have the right to withdraw your participation at any time. Your decision to not participate or to withdraw your participation will not affect the services you are currently receiving from MAB-Mackay.

Compensation

Unfortunately we cannot offer you any compensation for your participation in this study.

Participant Rights

While agreeing to participate in this study, you do not give up any of your legal rights nor release the researchers, sponsors or institutions involved of their legal and professional obligations.

Confidentiality

The information collected during this study will remain confidential within the limits of the law. Only Ms. Duponsel and Dr. Overbury will have direct access to this information. Your results will be kept secure (under lock and key) within the Low Vision Lab and will be destroyed after 5 years after

completion of the study. In the case that these results are published, your name and identity will not be revealed.

Questions

If you have any questions regarding the study, you may contact the following individuals:

Investigator: N. Duponsel	(514) 340-8222 ext. .
Co-Investigator: Dr. Overbury	(514) 343-6111 ext. .

If you have any questions about your rights and recourse or your participation in this research study, you can contact Ms. Anik Nolet, Research Ethics Coordinator for the CRIR's Institutions at (514) 527-4527, extension , or by e-mail at .

Researcher's Agreement

I, the undersigned, _____, certify that I have a) explained to the participant the terms of this form, b) answered all the questions he/she has asked in this regard, c) clearly indicated that he/she remains free, at any time, to end his/her participation in the above described research study, d) and that I will give him/her a signed and dated copy of this consent from.

Signature of the principal investigator or representative_____
Signed at _____, the _____, 20_____.

Participant's Agreement

I have read and understand the purpose, risks, possible benefits and alternatives of this project. I have indicated below the most convenient times that I may be called to answer the research questions. I will keep one copy of this consent form and return the second copy, signed, in the self-addressed, stamped envelope that I have been provided.

I understand that I do not waive any of my legal rights by participating in this study.

_____	_____	_____
Print Name	Signature	Date

Please indicate the most convenient time (please specify from which hour to which hour) that we may call you:

Weekday mornings	_____
Weekday afternoons	_____
Weekday evenings	_____
Weekend	_____
Other specific time	_____

Titre: Utilisation des services de réadaptation visuelle et l'adaptation psychologique à la déficience visuelle en début et au milieu de l'âge adulte
Chercheur principale: Nathalie Duponsel
Sponsor de l'étude: Réseau de recherche en santé de la vision (FRSQ)

Formulaire de consentement

Introduction

Vous êtes invité à participer à un projet de recherche qui implique des personnes ayant un problème visuel. Cette étude est menée sous la direction de Nathalie Duponsel, étudiante du Dr. Olga Overbury à l'Université de Montréal. Ce formulaire de consentement vous explique les procédures, les risques potentiels et les avantages de l'étude, afin de vous permettre de décider si vous désirez ou non y participer.

But de l'étude

Le but de cette étude est d'explorer les services de réadaptation en déficience visuelle que vous avez reçus dans le passé ou que vous recevez présentement et comment vous vous adaptez à votre déficience visuelle.

Déroulement de l'étude

Si vous acceptez de participer à l'étude, renvoyez ce formulaire de consentement signé dans l'enveloppe affranchi que nous vous avons fourni. Un assistant de recherche vous contactera au moment que vous aurez indiqué ci-dessous. L'assistant de recherche vous posera une série de questions sur les services de réadaptation en déficience visuelle que vous avez reçus dans le passé ou que vous recevez présentement. Il vous sera également demandé de répondre à 5 brefs questionnaires qui vous seront lus par l'assistant de recherche. Ces questionnaires porteront sur votre fonctionnement lors des activités simples de la vie quotidienne impliquant la vision; Ils porteront aussi sur votre état de santé général. Par exemple, il vous sera demandé une question sur les difficultés que vous pourriez avoir à voyager dans des lieux

inconnus : Vous sentez-vous confortable dans de telles situations? Si non, comment vous adaptez-vous?
Le temps nécessaire pour répondre aux questionnaires devrait prendre approximativement 30 à 45 minutes (selon qu'une pause est requise ou non). Même si vous choisissez de participer à cette recherche, vous devez savoir que vous avez le droit de refuser de répondre à une ou plusieurs questions et cela à tout moment.

Avantages et risques

Cette étude ne comporte aucun risque pour vous et/ou votre vision. Cependant, il est possible que vous trouviez difficile de parler de vos problèmes visuels. Il se peut aussi que vous vous sentiez triste ou contrarié. Si cela se produit, n'hésitez pas à mentionner que vous êtes contrarié et le chercheur peut vous aider à communiquer avec MAB-Mackay ou des professionnels qui sauront vous aider en ce qui concerne les difficultés que vous rencontrez.

Personnellement, vous ne retirerez pas d'avantages directs et/ou immédiats en participant à cette étude; toutefois, vous aurez contribué à l'avancement des connaissances médicales.

Retrait de votre participation à l'étude

Votre participation à cette étude est entièrement volontaire. Vous avez le droit de vous retirer de l'étude en tout temps. Votre décision de ne pas participer ou de vous retirer de l'étude n'affectera en rien les services que vous recevez de MAB-Mackay.

Compensation

Vous ne recevrez aucune compensation pour votre participation à cette étude.

Droits du participant

Tout en acceptant de participer à cette étude, vous n'abandonnez pas vos droits légaux, ni ne libérez les chercheurs, les promoteurs ou les établissements concernés de leurs obligations légales et professionnelles.

Confidentialité

Les informations recueillies durant cette étude resteront confidentielles, dans les limites de la loi. Seul Mme Duponsel et Dr. Overbury auront accès direct à ces informations. Les données recueillies à votre sujet durant l'étude seront conservées sous clé au Laboratoire de Basse Vision et seront détruites 5 ans après l'achèvement de l'étude. Si les résultats sont publiés, votre nom et/ou votre identité seront tenus secrets.

Questions

Si vous avez des questions, vous pouvez contacter les personnes suivantes :

Chercheur:	N. Duponsel	(514) 340-8222, local .
Co-chercheur:	Dr. Overbury	(514) 343-6111, local .

Si vous avez des questions sur vos droits, recours ou votre participation à cette étude, vous pouvez contacter Mme Anik Nolet, coordonnatrice de l'éthique de la recherche pour les institutions de CRIR au (514) 527-4527, poste , ou par courriel à : .

Accord du chercheur

Je soussigné,_____ certifie que j'ai a) expliqué au participant les termes du présent formulaire; b) répondu à toutes les questions qu'il/elle a posées à ce sujet; c) a clairement indiqué qu'il/elle reste libre, à tout moment, de mettre fin à sa participation à l'étude de recherche décrit ci-dessus; d) et que je vais lui donner une copie signée et datée de ce consentement.

Signature du chercheur principal ou son représentant_____
Signé à_____, le _____, 20____.

Signature

Je déclare avoir lu et compris le présent projet, ses risques potentiels et implications. J'ai indiqué ci-dessous les moments qui me conviennent ou l'assistant à la recherche peut m'appeler. Je vais garder une copie de ce formulaire de consentement et je renverrai l'autre copie, signé, dans l'enveloppe fourni.

En participant à cette étude, je comprends que je ne renonce à aucun de mes droits légaux.

_____	_____	_____
Nom du Participant	Signature	Date

S'il vous plaît, indiquez les moments qui vous conviennent pour notre appelle (S.V.P., préciser de quelle heure à quelle heure) :

Matins de la semaine	_____
Après-midi de la semaine	_____
Soirs de la semaine	_____
Fin de la semaine	_____
Autre moment plus spécifique	_____

Appendix G: Consent Forms – Institut Nazareth et Louis-Braille
(English and French)

Title: Use of Vision Rehabilitation Services and Psychological Adjustment to Vision Impairment in Early- and Mid-Adulthood
Principal Investigator: Nathalie Duponsel
Study sponsor: Réseau de recherche en santé de la vision (FRSQ)

Consent Form

Introduction

We invite you to take part in this research study because you have visual problems. This study is being conducted under the direction of Nathalie Duponsel, a graduate student under the supervision of Dr. Overbury at the University of Montreal. You have the right to be informed about the procedures, possible risks and benefits of this study in order to decide whether or not you want to participate.

Purpose of this study

The purpose of this study is to find out about the types of rehabilitation services that you may have received in the past, or are receiving presently, and how you are coping with your vision impairment.

Study Procedures

If you choose to participate in this study, and once you have returned this consent form with your signature using the self-addressed, stamped envelope that you have been provided, you will be called by a research assistant at one of the convenient times that you indicate below. You will be asked a series of questions about vision rehabilitation services you have received in the past, or are receiving presently, as well as, five brief questionnaires which will be read to you by the research assistant. These questionnaires relate to how well you can do daily activities that involve vision and how well you feel you are adjusting to your vision loss. For example, you will be asked about any difficulties you may have traveling in unfamiliar places, how comfortable you are with it, and how you cope with such situations. Answering these questionnaires should take approximately 30-45 minutes (if breaks are

required). Even if you choose to participant in this research, you should know that you have the right to refuse to answer any question at any time.

Benefits and Risks

This study poses no risks to you or your vision. However, it is possible that you may find it difficult to talk about your visual problems. You may feel sad or a little upset. If this happens, we ask that you feel free to mention that you are upset and the researcher can assist you in contacting INLB where professionals can help you regarding any difficulties you may be experiencing.

There will be no immediate direct benefit to you from this study; but please know, you will be contributing to medical knowledge that could help you, or others like you, in the future.

Withdrawal from the Study

Your participation in this study is completely voluntary. You have the right to withdraw your participation at any time. Your decision to not participate or to withdraw your participation will not affect the services you are currently receiving from INLB.

Compensation

Unfortunately we cannot offer you any compensation for your participation in this study.

Participant Rights

While agreeing to participate in this study, you do not give up any of your legal rights nor release the researchers, sponsors or institutions involved of their legal and professional obligations.

Confidentiality

The information collected during this study will remain confidential within the limits of the law. Only Ms. Duponsel and Dr. Overbury will have direct access to this information. Your results will be kept secure (under lock and key) within the Low Vision Lab and will be destroyed after 5 years after

completion of the study. In the case that these results are published, your name and identity will not be revealed.

Questions

If you have any questions regarding the study, you may contact the following individuals:

Investigator: N. Duponsel	(514) 340-8222 ext. .
Co-Investigator: Dr. Overbury	(514) 343-6111 ext. .

If you have any questions about your rights and recourse or your participation in this research study, you can contact Ms. Anik Nolet, Research Ethics Coordinator for the CRIR's Institutions at (514) 527-4527, extension , or by e-mail at .

Researcher's Agreement

I, the undersigned, _____, certify that I have a) explained to the participant the terms of this form, b) answered all the questions he/she has asked in this regard, c) clearly indicated that he/she remains free, at any time, to end his/her participation in the above described research study, d) and that I will give him/her a signed and dated copy of this consent from.

Signature of the principal investigator or representative_____
Signed at _____, the _____, 20_____.

Participant's Agreement

I have read and understand the purpose, risks, possible benefits and alternatives of this project. I have indicated below the most convenient times that I may be called to answer the research questions. I will keep one copy of this consent form and return the second copy, signed, in the self-addressed, stamped envelope that I have been provided.

I understand that I do not waive any of my legal rights by participating in this study.

_____	_____	_____
Print Name	Signature	Date

Please indicate the most convenient time (please specify from which hour to which hour) that we may call you:

Weekday mornings	_____
Weekday afternoons	_____
Weekday evenings	_____
Weekend	_____
Other specific time	_____

Institut Nazareth & Louis-Braille

Titre: Utilisation des services de réadaptation visuelle et l'adaptation psychologique à la déficience visuelle en début et au milieu de l'âge adulte
Chercheur principale: Nathalie Duponsel
Sponsor de l'étude: Réseau de recherche en santé de la vision (FRSQ)

Formulaire de consentement

Introduction

Vous êtes invité à participer à un projet de recherche qui implique des personnes ayant un problème visuel. Cette étude est menée sous la direction de Nathalie Duponsel, étudiante du Dr. Olga Overbury à l'Université de Montréal. Ce formulaire de consentement vous explique les procédures, les risques potentiels et les avantages de l'étude, afin de vous permettre de décider si vous désirez ou non y participer.

But de l'étude

Le but de cette étude est d'explorer les services de réadaptation en déficience visuelle que vous avez reçus dans le passé ou que vous recevez présentement et comment vous vous adaptez à votre déficience visuelle.

Déroulement de l'étude

Si vous acceptez de participer à l'étude, renvoyez ce formulaire de consentement signé dans l'enveloppe affranchi que nous vous avons fourni. Un assistant de recherche vous contactera au moment que vous aurez indiqué ci-dessous. L'assistant de recherche vous posera une série de questions sur les services de réadaptation en déficience visuelle que vous avez reçus dans le passé ou que vous recevez présentement. Il vous sera également demandé de répondre à 5 brefs questionnaires qui vous seront lus par l'assistant de recherche. Ces questionnaires porteront sur votre fonctionnement lors des activités simples de la vie quotidienne impliquant la vision; Ils porteront aussi sur votre état de santé général. Par exemple, il vous sera demandé une question sur les difficultés que vous pourriez avoir à voyager dans des lieux

inconnus : Vous sentez-vous confortable dans de telles situations? Si non, comment vous adaptez-vous?
Le temps nécessaire pour répondre aux questionnaires devrait prendre approximativement 30 à 45 minutes (selon qu'une pause est requise ou non). Même si vous choisissez de participer à cette recherche, vous devez savoir que vous avez le droit de refuser de répondre à une ou plusieurs questions et cela à tout moment.

Avantages et risques

Cette étude ne comporte aucun risque pour vous et/ou votre vision. Cependant, il est possible que vous trouviez difficile de parler de vos problèmes visuels. Il se peut aussi que vous vous sentiez triste ou contrarié. Si cela se produit, n'hésitez pas à mentionner que vous êtes contrarié et le chercheur peut vous aider à communiquer avec l'INLB ou des professionnels qui sauront vous aider en ce qui concerne les difficultés que vous rencontrez.

Personnellement, vous ne retirerez pas d'avantages directs et/ou immédiats en participant à cette étude; toutefois, vous aurez contribué à l'avancement des connaissances médicales.

Retrait de votre participation à l'étude

Votre participation à cette étude est entièrement volontaire. Vous avez le droit de vous retirer de l'étude en tout temps. Votre décision de ne pas participer ou de vous retirer de l'étude n'affectera en rien les services que vous recevez de l'INLB.

Compensation

Vous ne recevrez aucune compensation pour votre participation à cette étude.

Droits du participant

Tout en acceptant de participer à cette étude, vous n'abandonnez pas vos droits légaux, ni ne libérez les chercheurs, les promoteurs ou les établissements concernés de leurs obligations légales et professionnelles.

Confidentialité

Les informations recueillies durant cette étude resteront confidentielles, dans les limites de la loi. Seul Mme Duponsel et Dr. Overbury auront accès direct à ces informations. Les données recueillies à votre sujet durant l'étude seront conservées sous clé au Laboratoire de Basse Vision et seront détruites 5 ans après l'achèvement de l'étude. Si les résultats sont publiés, votre nom et/ou votre identité seront tenus secrets.

Questions

Si vous avez des questions, vous pouvez contacter les personnes suivantes :

Chercheur:	N. Duponsel	(514) 340-8222, local .
Co-chercheur:	Dr. Overbury	(514) 343-6111, local .

Si vous avez des questions sur vos droits, recours ou votre participation à cette étude, vous pouvez contacter Mme Anik Nolet, coordonnatrice de l'éthique de la recherche pour les institutions de CRIR au (514) 527-4527, poste , ou par courriel à : .

Accord du chercheur

Je soussigné,_____ certifie que j'ai a) expliqué au participant les termes du présent formulaire; b) répondu à toutes les questions qu'il/elle a posées à ce sujet; c) a clairement indiqué qu'il/elle reste libre, à tout moment, de mettre fin à sa participation à l'étude de recherche décrit ci-dessus; d) et que je vais lui donner une copie signée et datée de ce consentement.

Signature du chercheur principal ou son représentant_____
Signé à_____, le _____, 20____.

Signature

Je déclare avoir lu et compris le présent projet, ses risques potentiels et implications. J'ai indiqué ci-dessous les moments qui me conviennent ou l'assistant à la recherche peut m'appeler. Je vais garder une copie de ce formulaire de consentement et je renverrai l'autre copie, signé, dans l'enveloppe fourni.

En participant à cette étude, je comprends que je ne renonce à aucun de mes droits légaux.

_____	_____	_____
Nom du Participant	Signature	Date

S'il vous plaît, indiquez les moments qui vous conviennent pour notre appelle (S.V.P., préciser de quelle heure à quelle heure) :

Matins de la semaine	_____
Après-midi de la semaine	_____
Soirs de la semaine	_____
Fin de la semaine	_____
Autre moment plus spécifique	_____

Appendix H: Visual Function-14 (English and French)

The Visual Functioning Index (VF-14-R)

not applicable	no	a little difficulty	moderate difficulty	a great deal of difficulty	unable to do activity
NA	4	3	2	1	0

1	Do you have any difficulty, even with glasses, reading small print, such as labels on medicine bottles, a telephone book, food labels?
2	Do you have any difficulty, even with glasses, reading a newspaper or a book?
3	Do you have any difficulty, even with glasses, reading a large-print book or large-print newspaper or numbers on a telephone?
4	Do you have any difficulty, even with glasses, recognizing people when they are close to you?
5	Do you have any difficulty, even with glasses, seeing steps, stairs or curbs?
6	Do you have any difficulty, even with glasses, reading traffic signs, street signs, or store signs?
7	Do you have any difficulty, even with glasses, doing fine handwork like sewing, knitting, crocheting, carpentry?
8	Do you have any difficulty, even with glasses, writing checks or filling out forms?
9	Do you have any difficulty, even with glasses, playing games such as bingo, dominos, card games, mahjong?
10	Do you have any difficulty, even with glasses, taking part in sports like bowling, handball, tennis, golf?
11	Do you have any difficulty, even with glasses, cooking?
12	Do you have any difficulty, even with glasses, watching television?

Do you still drive a car? Y_____ N_____.
If Yes, Answer the following questions using the following:

none a little a moderate amount a great deal
1 2 3 4

13	How much difficulty do you have driving during the day because of your vision?
14	How much difficulty do you have driving at night because of your vision?

Échelle de vision fonctionnelle (VF-14-R)

ne s'applique pas NA **non 4** **un peu 3** **moyen 2** **beaucoup 1** **incapable parce que ma vision est insuffisante 0**

1	Avez-vous de la difficulté, même avec des lunettes, a lire les petits caractères que l'on trouve, par exemple, sur les étiquettes de flacons a médicaments, dans l'annuaire du téléphone ou sur les emballages de produits alimentaires ?
2	Avez-vous de la difficulté, même avec des lunettes, a lire le journal ou un livre ?
3	Avez-vous de la difficulté, même avec des lunettes, a lire un livre imprimé en gros caractères, un journal imprime en gros caractères ou les numéros sur un téléphone ?
4	Avez-vous de la difficulté, même avec des lunettes, a reconnaître les gens quand ils sont près de vous ?
5	Avez-vous de la difficulté, même avec des lunettes, à voir les seuils de porte, les escaliers ou les bordures de trottoir ?
6	Avez-vous de la difficulté, même, avec des lunettes, a voir les panneaux de signalisation routière, les noms de rue ou les enseignes de magasins ?
7	Avez-vous de la difficulté, même avec des lunettes, à faire des travaux a la main, comme de la couture, du tricot, du crochet ou de la menuiserie ?
8	Avez-vous de la difficulté, même avec des lunettes, à faire un chèque ou à remplir un formulaire ?
9	Avez-vous de la difficulté, même avec des lunettes, à participer à des jeux, tels que le bingo, les dominos ou les jeux de carte ?
10	Avez-vous de la difficulté, même avec des lunettes, à participer à des sports comme les quilles, la pétanque, le tennis ou le golf ?

11	Avez-vous de la difficulté, même avec des lunettes, à faire la cuisine ?
12	Avez-vous de la difficulté, même avec des lunettes, à regarder la télévision ?

Conduisez-vous une voiture ? Oui ____ Non ____

Si oui, répondez aux questions suivantes:

aucune difficulté légère moyenne grande difficulté
1 2 3 4

13	Avez-vous de la difficulté a conduire de jour a cause de votre vision ?
14	Avez-vous du mal à conduire le soir ou la nuit a cause de votre vision ?

Appendix I: Impact of Vision Impairment Profile (English and French)

Impact of Vision Impairment Profile (IVI)

INSTRUCTIONS

Please read each question carefully and circle the answer that BEST applies to you.
Put one circle on each row.
If you use GLASSES, CONTACT LENSES OR MAGNIFIERS for some activities please answer according to how you can see when using them.

Here are two examples:
In the past month how often has your eyesight made you concerned or worried about…

	Not at all	A little	A fair amount	A lot	Don't do this for other reasons
Crossing the street?	**0**	**1**	**2**	**(3)**	**8**
Preparing a meal for yourself?	**0**	**1**	**(2)**	**3**	**8**

Put one circle on each row. Please do not leave any rows blank.
Please answer about YOUR eyesight with GLASSES, CONTACT LENSES, or MAGNIFIERS, if you use them.

In the PAST MONTH, how much has YOUR EYESIGHT INTERFERED with the following activities:

	Not at all	A little	A fair amount	A lot	Don't do this for other reasons	Domains
1. Your ability to see and enjoy T.V?	0	1	2	3	8	Reading and accessing information
2. Taking part in recreational activities such as bowling, walking or golf?	0	1	2	3	8	Mobility and independence
3. Shopping? (finding what you want and paying for it)	0	1	2	3	8	Reading and accessing information
4. Visiting friends or family?	0	1	2	3	8	Mobility and independence
5. Recognising or meeting people?	0	1	2	3	8	Reading and accessing information
6. Generally looking after your appearance? (face, hair, clothing etc.)	0	1	2	3	8	Reading and accessing information
7. Opening packaging? (for example, around food, medicines)	0	1	2	3	8	Reading and accessing information

Please answer about YOUR eyesight with GLASSES, CONTACT LENSES, or MAGNIFIERS, if you use them. **In the PAST MONTH, how much has YOUR EYESIGHT INTERFERED with the following activities:**						
	Not at all	**A little**	**A fair amount**	**A lot**	**Don't do this for other reasons**	**Domains**
8. Reading labels or instructions on medicines?	**0**	**1**	**2**	**3**	**8**	**Reading and accessing information**
9. Operating household appliances and the telephone?	**0**	**1**	**2**	**3**	**8**	**Reading and accessing information**
10. How much has your eyesight interfered with getting about outdoors? (on the pavement or crossing the street)	**0**	**1**	**2**	**3**	**8**	**Mobility and independence**
11. In the past month, how often has your eyesight made you go carefully to avoid falling or tripping?	**0**	**1**	**2**	**3**	**8**	**Mobility and independence**
12. In general, how much has your eyesight interfered with travelling or using transport? (bus & train)	**0**	**1**	**2**	**3**	**8**	**Mobility and independence**
13. Going down steps, stairs, or curbs?	**0**	**1**	**2**	**3**	**8**	**Mobility and independence**

Please answer about YOUR eyesight with GLASSES, CONTACT LENSES, or MAGNIFIERS, if you use them.
In the PAST MONTH, how much has YOUR EYESIGHT INTERFERED with the following activities:

	Not at all	A fair amount	A lot	Don't do this for other reasons	Domains
14. Reading ordinary size print? (for example newspapers)	0	1	2	8	Reading and accessing information
15. Getting information that you need?	0	1	2	8	Reading and accessing information

Please answer about YOUR eyesight with GLASSES, CONTACT LENSES or MAGNIFIERS, if you use them.
In the PAST MONTH, how often has YOUR EYESIGHT MADE YOU CONCERNED OR WORRIED about the following:

	Not at all	A little of the time	A fair amount of the time	A lot of the time	Domains
16. Your general safety at home?	0	1	2	3	Mobility and independence
17. Spilling or breaking things?	0	1	2	3	Mobility and independence
18. Your general safety when out of your home?	0	1	2	3	Mobility and independence
19. In the past month, how often has your eyesight stopped you doing the things you want to do?	0	1	2	3	Mobility and independence
20. In the past month, how often have you needed help from other people because of your eyesight?	0	1	2	3	Mobility and independence

Please answer about YOUR eyesight with GLASSES, CONTACT LENSES or MAGNIFIERS, if you use them. Think about how YOUR eyesight has made you FEEL in the PAST MONTH.

	Not at all	A little of the time	A fair amount of the time	A lot of the time	Domains
21. Have you felt embarrassed because of your eyesight?	0	1	2	3	Emotional wellbeing
22. Have you felt frustrated or annoyed because of your eyesight?	0	1	2	3	Emotional wellbeing
23. Have you felt lonely or isolated because of your eyesight?	0	1	2	3	Emotional wellbeing
24. Have you felt sad or low because of your eyesight?	0	1	2	3	Emotional wellbeing
25. In the past month, how often have you worried about your eyesight getting worse?	0	1	2	3	Emotional wellbeing
26. In the past month how often has your eyesight made you concerned or worried about coping with everyday life?	0	1	2	3	Emotional wellbeing
27. Have you felt like a nuisance or a burden because of your eyesight?	0	1	2	3	Emotional wellbeing
28. In the past month, how much has your eyesight interfered with your life in general?	0	1	2	3	Emotional wellbeing

Please check that you have answered all the questions and Thank you!

PROFIL DE L'IMPACT DE LA DEFICIENCE VISUELLE

Durant le dernier mois, dans quelle mesure votre vision a-t-elle affecté les activités suivantes :

	Pas du tout	Peu	Assez bien	Beaucoup	Ne le fais pas pour d'autres raisons
1. Regarder la télé et y prendre plaisir?	**0**	**1**	**2**	**3**	**8**
2. Participer à des activités de loisir telles que le jeu de quilles, la marche ou le golf?	**0**	**1**	**2**	**3**	**8**
3. Magasiner? (Trouver ce que vous cherchez et le payer)	**0**	**1**	**2**	**3**	**8**
4. Visiter des amis ou de la famille?	**0**	**1**	**2**	**3**	**8**
5. Reconnaître ou rencontrer des gens?	**0**	**1**	**2**	**3**	**8**
6. De façon générale, prendre soin de votre apparence? (Visage, cheveux, vêtements, etc.)	**0**	**1**	**2**	**3**	**8**
7. Ouvrir les emballages? (Par exemple de nourriture, de médicaments)	**0**	**1**	**2**	**3**	**8**

8. Lire les étiquettes et les instructions des médicaments?	**0**	**1**	**2**	**3**	**8**
9. Se servir des appareils ménagers et du téléphone?	**0**	**1**	**2**	**3**	**8**
10. Dans quelle mesure votre vision a-t-elle affecté vos déplacements à l'extérieur? (Sur les trottoirs ou pour traverser la rue)	**0**	**1**	**2**	**3**	**8**
11. Durant le dernier mois, combien de fois avez-vous eu à prendre un soin particulier pour ne pas glisser ou tomber à cause de votre vue?	**0**	**1**	**2**	**3**	**8**
12. En général, dans quelle mesure votre vision a eu un impact sur votre utilisation du train ou de l'autobus?	**0**	**1**	**2**	**3**	**8**
13. Descendre des marches, des escaliers ou des rebords de trottoir?	**0**	**1**	**2**	**3**	**8**

N.B: Response choice is has changed for the following questions:

	Pas du tout	Assez bien	Beaucoup	Ne le fais pas pour d'autres raisons
14. Lire de l'imprimé courant? (Les journaux par exemple)	**0**	**1**	**2**	**8**
15. Obtenir l'information dont vous avez besoin?	**0**	**1**	**2**	**8**

Dans le dernier mois, combien de fois étiez vous préoccupé, à cause de votre vue, de:

	Pas du tout	Un peu du temps	Une bonne partie du temps	Une grande partie du temps
16. Votre sécurité en général à la maison?	**0**	**1**	**2**	**3**
17. Renverser des liquides ou briser des objets?	**0**	**1**	**2**	**3**
18. Votre sécurité en général en dehors de la maison?	**0**	**1**	**2**	**3**
19. Durant le dernier mois, combien de fois votre vue vous a empêché de faire ce que vous vouliez?	**0**	**1**	**2**	**3**
20. Durant le dernier mois, combien de fois avez-vous eu besoin d'aide à cause de votre vue?	**0**	**1**	**2**	**3**

Dans le dernier mois:

	Pas du tout	Un peu du temps	Une bonne partie du temps	Une grande partie du temps
21. Avez-vous ressenti de l'embarras à cause de votre vue?	**0**	**1**	**2**	**3**
22. Avez-vous été frustré ou agacé à cause de votre vue?	**0**	**1**	**2**	**3**
23. Vous êtes-vous senti seul ou isolé à cause de votre vue?	**0**	**1**	**2**	**3**
24. Avez-vous ressenti de la tristesse ou de l'isolement à cause de votre vue?	**0**	**1**	**2**	**3**
25. Durant le dernier mois, combien de fois vous êtes-vous préoccupé de la détérioration de votre vue?	**0**	**1**	**2**	**3**
26. Durant le dernier mois, combien de fois avez-vous été soucieux ou inquiet de ne pouvoir faire face à la vie courante?	**0**	**1**	**2**	**3**
27. Avez-vous eu l'impression d'être une nuisance ou un fardeau à cause de votre vue?	**0**	**1**	**2**	**3**
28. Durant le dernier mois, dans quelle mesure votre vue a eu un impact sur votre vie en général?	**0**	**1**	**2**	**3**

Appendix J: ANOVA Source Tables

EXPERIMENT 1

ANOVA Source Table – Analysis 1

Age as a function of diagnosis

ANOVA

Age

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	1286.598	2	643.299	4.345	.017
Within Groups	8587.599	58	148.062		
Total	9874.197	60			

ANOVA Source Table – Analysis 2

Measures of psychological wellbeing as a function of diagnosis

ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
BriefCOPETotalScore	Between Groups	215.036	2	107.518	.976	.383
	Within Groups	6390.637	58	110.183		
	Total	6605.672	60			
CESDTotalScore	Between Groups	64.526	2	32.263	.687	.507
	Within Groups	2725.409	58	46.990		
	Total	2789.934	60			
AVLTotalScore	Between Groups	36.212	2	18.106	1.300	.280
	Within Groups	808.050	58	13.932		
	Total	844.262	60			
IVIEmotional	Between Groups	395.016	2	197.508	5.573	.006
	Within Groups	2055.574	58	35.441		
	Total	2450.590	60			

ANCOVA Source Table – Analysis 3

Brief COPE mean scores as a function of diagnosis with level of education held constant

Tests of Between-Subjects Effects

Dependent Variable:BriefCOPETotalScore

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	891.996[a]	3	297.332	2.966	.039
Intercept	18889.209	1	18889.209	188.440	.000
LevelofEducation	676.960	1	676.960	6.753	.012
Diagnosis	340.838	2	170.419	1.700	.192
Error	5713.676	57	100.240		
Total	418247.000	61			
Corrected Total	6605.672	60			

a. R Squared = .135 (Adjusted R Squared = .090)

ANCOVA Source Table – Analysis 4

CES-D mean scores as a function of diagnosis with level of education held constant

Tests of Between-Subjects Effects

Dependent Variable:CESDTotalScore

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	711.448[a]	3	237.149	6.504	.001
Intercept	1487.189	1	1487.189	40.784	.000
LevelofEducation	646.922	1	646.922	17.741	.000
Diagnosis	22.080	2	11.040	.303	.740
Error	2078.486	57	36.465		
Total	8850.000	61			
Corrected Total	2789.934	60			

a. R Squared = .255 (Adjusted R Squared = .216)

ANCOVA Source Table – Analysis 5

AVL mean scores as a function of diagnosis with level of education held constant

Tests of Between-Subjects Effects

Dependent Variable:AVLTotalScore

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	148.541[a]	3	49.514	4.057	.011
Intercept	250.341	1	250.341	20.510	.000
LevelofEducation	112.328	1	112.328	9.203	.004
Diagnosis	1.905	2	.953	.078	.925
Error	695.722	57	12.206		
Total	23516.000	61			
Corrected Total	844.262	60			

a. R Squared = .176 (Adjusted R Squared = .133)

ANCOVA Source Table – Analysis 6

IVI-Emotional mean scores as a function of diagnosis with level of education held constant

Tests of Between-Subjects Effects

Dependent Variable:IVIEmotional

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	721.716[a]	3	240.572	7.932	.000
Intercept	1057.196	1	1057.196	34.855	.000
LevelofEducation	326.700	1	326.700	10.771	.002
Diagnosis	105.919	2	52.959	1.746	.184
Error	1728.874	57	30.331		
Total	9722.000	61			
Corrected Total	2450.590	60			

a. R Squared = .295 (Adjusted R Squared = .257)

ANOVA Source Table – Analysis 7

Measures of psychological wellbeing as a function of pattern of vision loss

ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
BriefCOPETotalScore	Between Groups	710.881	2	355.440	3.497	.037
	Within Groups	5894.791	58	101.634		
	Total	6605.672	60			
CESDTotalScore	Between Groups	12.864	2	6.432	.134	.875
	Within Groups	2777.071	58	47.881		
	Total	2789.934	60			
AVLTotalScore	Between Groups	6.726	2	3.363	.233	.793
	Within Groups	837.536	58	14.440		
	Total	844.262	60			
IVIEmotional	Between Groups	174.082	2	87.041	2.218	.118
	Within Groups	2276.508	58	39.250		
	Total	2450.590	60			

ANOVA Source Table – Analysis 8

Measures of psychological wellbeing as a function of self-rated health

ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
BriefCOPETotalScore	Between Groups	726.590	2	363.295	3.584	.034
	Within Groups	5879.082	58	101.363		
	Total	6605.672	60			
CESDTotalScore	Between Groups	677.552	2	338.776	9.302	.000
	Within Groups	2112.383	58	36.420		
	Total	2789.934	60			
AVLTotalScore	Between Groups	170.635	2	85.317	7.346	.001
	Within Groups	673.628	58	11.614		
	Total	844.262	60			
IVIEmotional	Between Groups	786.808	2	393.404	13.714	.000
	Within Groups	1663.783	58	28.686		
	Total	2450.590	60			

ANCOVA Source Table – Analysis 9

Brief COPE mean scores as a function of and diagnosis with self-rated health held constant

Tests of Between-Subjects Effects

Dependent Variable:BriefCOPETotalScore

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	1157.080[a]	8	144.635	1.380	.227
Intercept	220854.335	1	220854.335	2107.779	.000
Diagnosis	162.500	2	81.250	.775	.466
RateHealth	710.025	2	355.012	3.388	.041
Diagnosis * RateHealth	79.754	4	19.939	.190	.942
Error	5448.592	52	104.781		
Total	418247.000	61			
Corrected Total	6605.672	60			

a. R Squared = .175 (Adjusted R Squared = .048)

ANCOVA Source Table – Analysis 10

CES-D mean scores as a function of and diagnosis with self-rated health held constant

Tests of Between-Subjects Effects

Dependent Variable:CESDTotalScore

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	750.401[a]	8	93.800	2.392	.028
Intercept	4110.786	1	4110.786	104.809	.000
Diagnosis	39.829	2	19.914	.508	.605
RateHealth	385.815	2	192.908	4.918	.011
Diagnosis * RateHealth	35.591	4	8.898	.227	.922
Error	2039.533	52	39.222		
Total	8850.000	61			
Corrected Total	2789.934	60			

a. R Squared = .269 (Adjusted R Squared = .157)

ANCOVA Source Table – Analysis 11

AVL mean scores as a function of and diagnosis with self-rated health held constant

Tests of Between-Subjects Effects

Dependent Variable:AVLTotalScore

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	245.696[a]	8	30.712	2.668	.016
Intercept	11782.152	1	11782.152	1023.565	.000
Diagnosis	30.683	2	15.341	1.333	.273
RateHealth	18.589	2	9.295	.807	.451
Diagnosis * RateHealth	73.970	4	18.493	1.607	.187
Error	598.567	52	11.511		
Total	23516.000	61			
Corrected Total	844.262	60			

a. R Squared = .291 (Adjusted R Squared = .182)

ANCOVA Source Table – Analysis 12

IVI-Emotional mean scores as a function of and diagnosis with self-rated health held constant

Tests of Between-Subjects Effects

Dependent Variable:IVIEmotional

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	904.448[a]	8	113.056	3.802	.001
Intercept	4478.601	1	4478.601	150.625	.000
Diagnosis	33.652	2	16.826	.566	.571
RateHealth	304.106	2	152.053	5.114	.009
Diagnosis * RateHealth	37.033	4	9.258	.311	.869
Error	1546.142	52	29.733		
Total	9722.000	61			
Corrected Total	2450.590	60			

a. R Squared = .369 (Adjusted R Squared = .272)

ANOVA Source Table – Analysis 13

Measures of psychological wellbeing as a function of marital status

ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
BriefCOPETotalScore	Between Groups	606.767	3	202.256	1.922	.136
	Within Groups	5998.905	57	105.244		
	Total	6605.672	60			
CESDTotalScore	Between Groups	240.791	3	80.264	1.795	.158
	Within Groups	2549.144	57	44.722		
	Total	2789.934	60			
AVLTotalScore	Between Groups	164.118	3	54.706	4.585	.006
	Within Groups	680.144	57	11.932		
	Total	844.262	60			
IVIEmotional	Between Groups	400.526	3	133.509	3.712	.016
	Within Groups	2050.065	57	35.966		
	Total	2450.590	60			

EXPERIMENT 2

ANOVA Source Table –Analysis 1

Measures of perceived visual ability and psychological wellbeing as a function of and diagnosis

ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
BriefCOPETotalScore	Between Groups	215.036	2	107.518	.976	.383
	Within Groups	6390.637	58	110.183		
	Total	6605.672	60			
CESDTotalScore	Between Groups	64.526	2	32.263	.687	.507
	Within Groups	2725.409	58	46.990		
	Total	2789.934	60			
AVLTotalScore	Between Groups	36.212	2	18.106	1.300	.280
	Within Groups	808.050	58	13.932		
	Total	844.262	60			
IVIEmotional	Between Groups	395.016	2	197.508	5.573	.006
	Within Groups	2055.574	58	35.441		
	Total	2450.590	60			
VF14TotalScore	Between Groups	8020.366	2	4010.183	7.331	.001
	Within Groups	31726.820	58	547.014		
	Total	39747.186	60			
IVITotalScore	Between Groups	5447.698	2	2723.849	11.253	.000
	Within Groups	14039.199	58	242.055		
	Total	19486.897	60			

ANCOVA Source Table – Analysis 2

VF-14 mean scores as a function of diagnosis with level of impairment held constant

Tests of Between-Subjects Effects

Dependent Variable:VF14TotalScore

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	15064.831[a]	3	5021.610	11.597	.000
Intercept	40704.689	1	40704.689	94.001	.000
LevelofImpairRecent	7044.465	1	7044.465	16.268	.000
Diagnosis	6340.234	2	3170.117	7.321	.001
Error	24682.355	57	433.024		
Total	191847.196	61			
Corrected Total	39747.186	60			

a. R Squared = .379 (Adjusted R Squared = .346)

ANCOVA Source Table – Analysis 3

IVI mean scores as a function of diagnosis with level of impairment held constant

Tests of Between-Subjects Effects

Dependent Variable:IVITotalScore

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	7462.365[a]	3	2487.455	11.791	.000
Intercept	2339.065	1	2339.065	11.088	.002
LevelofImpairRecent	2014.667	1	2014.667	9.550	.003
Diagnosis	4613.031	2	2306.516	10.934	.000
Error	12024.533	57	210.957		
Total	107775.295	61			
Corrected Total	19486.897	60			

a. R Squared = .383 (Adjusted R Squared = .350)

ANOVA Source Table – Analysis 4

AVL mean scores as a function of self-identification

ANOVA

AVLTotalScore

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	25.126	2	12.563	.890	.416
Within Groups	819.136	58	14.123		
Total	844.262	60			

ANOVA Source Table – Analysis 5

AVL-10 mean scores as a function of self-identification

ANOVA

AVLLessThan2080Total

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	9.777	2	4.888	.920	.404
Within Groups	308.158	58	5.313		
Total	317.934	60			

ANOVA Source Table – Analysis 6

IVI-Emotional mean scores as a function of self-identification

ANOVA

IVIEmotional

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	254.626	2	127.313	3.363	.042
Within Groups	2195.965	58	37.861		
Total	2450.590	60			