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Adjustment to Vision Loss after a Functional and Psychosocial Intervention  
in Individuals with Low Vision and their Spouses

par

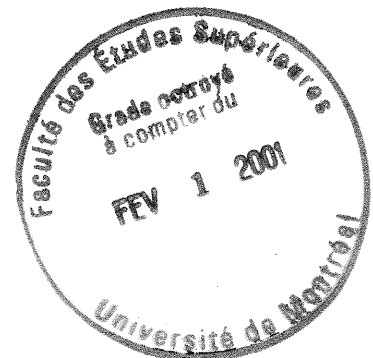
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Ce mémoire intitulé

Adjustment to Vision Loss after a Functional and Psychosocial Intervention  
in Individuals with Low Vision and their Spouse

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## **Abstract**

### **Adjustment to Vision Loss following a Functional and Psychosocial Intervention in Individuals with Low Vision and their Spouses**

Involving the visually impaired person in low vision rehabilitation is not sufficient for achieving a high level of psychosocial functioning. Vision impairment does not occur in isolation. The people intimately tied to the visually impaired person must be considered. The family, specifically the spouse, is a necessary ingredient to the adaptation success of the affected individual and the couple. Increasing awareness of what it is like to contend with vision impairment on a daily basis and opening the lines of communication are necessary for successful adaptation to the present situation and future coping success for the couple. The spouse, although not functionally affected by vision loss, experiences the psychosocial upheaval and subsequent need for readjustment in the joint experience of vision loss. Accordingly, it was hypothesized that the involvement of the spouse in a couple format and in a peer group setup in a psychosocial and functional intervention would promote higher overall adjustment scores in both the visually impaired person and the spouse. Adjustment was measured by the Nottingham Adjustment Scale (N.A.S.). There were 5 groups. Group composition was as follows: group 1- persons with low vision ; group 2- spouses; group 3- persons with low vision and spouses;



group 4- peer group and group 5- control. Each group received the N.A.S. as a pretest and posttest measure. The pretest was administered before the first intervention. Four weeks later, posttest 1 was administered, followed by the second intervention. Four weeks later, posttest 2 was administered to all participants by telephone. The control group answered the pretest and posttests by telephone. The hypotheses were not supported. Group composition had no effect on adjustment to vision loss as measured by the Nottingham Adjustment Scale. The findings are discussed in the context of current theoretical formulations and implications for further research are addressed.

## Summary

The study conducted was designed to determine whether the involvement of the family, specifically the spouse in a low vision rehabilitation intervention would improve the adjustment success obtained by both the visually impaired person and his / her spouse. The premise was that a comprehensive rehabilitation program, one that addresses functional as well as psychosocial concerns, would be effective in engendering overall adaptive change in both participants. Additionally, it was also hypothesized that individuals with vision loss, who participated with their spouse or in a peer-group setup would achieve a higher level of adjustment than individuals who participated alone or the control group.

There were 58 participants, 29 visually impaired individuals accompanied by their spouses. Participants were recruited from the Montreal Association for the Blind. Those who were selected for the study had to have one or a combination of macular degeneration, diabetic retinopathy, glaucoma and cataracts (see Table 1). Additionally, participants were married to a spouse with good functional vision.

Participants were read a consent form that provided them with the objective of the study. There was a separate consent form for the visually impaired individuals and spouses. Participants were randomly assigned to one of five groups. Group 1 was

composed of visually impaired participants only. Each visually impaired person was seen on a one-to-one basis. Group 2 consisted of spouses only. Each spouse received the intervention on an individual basis. Group 3 was comprised of couples who took part in the study together. Group 4 was a peer group that consisted of several visually impaired participants and their spouses who took part in the interventions in a group format. Group 5 was comprised of a visually impaired person and his/her spouse.

The interventions were a psychosocial and a functional segment. The psychosocial segment required that participants discuss any concerns or issues that they may have regarding life with vision loss. This was conducted using the help of the McGill Low Vision Manual to help incite discussion. The functional segment was comprised of 10 activities of daily living, such as finding a telephone number in the yellow pages, signing a cheque and reading a medicine label. These tasks were rated in a previous study as by persons with vision loss, as being difficult things to contend with on a daily basis. The interventions were administered in a random manner. Each intervention lasted approximately 90 minutes. The control group did not participate in the interventions.

On visit one, participants answered a consent form, then a questionnaire followed by the first intervention. Approximately 4 weeks later, they were asked to return to answer the same questionnaire, followed by the second intervention. Another 4 weeks

later, participants were contacted by telephone for the last questionnaire and for a 5 minute debriefing session.

The questionnaire used as the pretest, posttest 1 and posttest 2 measure was the Nottingham Adjustment Scale. This is a 55-item questionnaire assessing the psychosocial adjustment to vision loss. There are 7 subscales, each one assessing a different psychosocial variable. The 7 subscales are said to comprise a global definition of adjustment. The questionnaire is in a Likert-scale format.

Results indicate that there are no overall, significant observable changes in adjustment to vision loss as a function of group composition. Improvements were observed with respect to time on self-esteem. A difference between pretest and posttest 1 was observed,  $t(57) = -4.84$ ,  $p < 0.001$ , as well as a significant difference between posttest 1 and posttest 2,  $t(57) = 2.74$ ,  $p < 0.01$ . Posttest 1 scores were higher than posttest 2 scores, indicating that scores reverted back to baseline. There was a significant interaction between time and the spouse group on the acceptance subscale. The difference was observed between pretest and posttest 1,  $t(11) = 2.83$ ,  $p < 0.05$ . Posttest 1 scores were higher than pretest scores but posttest 2 scores were lower than posttest 1 scores, again indicating that scores reverted back to baseline. Another time by group interaction was observed for the attributional style subscale, with differences

found at pretest,  $F(8, 94) = 2.428, p < 0.05$ . The couple group performed better than the visually impaired group with a mean difference of 4.25. The couple group also scored higher than the spouse group, with a mean difference of 3.33. The couple group performed better than the peer group, with a mean difference of 4.6. An effect of time was observed for the locus of control subscale. Scores improved from posttest 1 to posttest 2,  $t(57) = 3.23, p < 0.01$ .

In conclusion, it may be beneficial to consider the same intervention strategy on a more comprehensive and lengthy basis. Personality variables, such as self-esteem, and attributional style are developed over one's lifetime and are difficult to change in a short time period. The scores reverting back to baseline may be a good indication of this.

## Résumé

La participation des individus présentant un handicap visuel à un programme de réadaptation en déficience visuelle n'est pas suffisant en soi pour acquérir un niveau élevé de fonctionnement psychosocial. La détérioration de la condition visuelle n'est pas un phénomène isolé. Les proches des personnes atteintes de déficiences visuelles doivent également être considérés. La famille, surtout le conjoint, sont des éléments nécessaires pour que l'adaptation des individus ayant un handicap visuel et leur couple puisse réussir. La conscience des problèmes quotidiens rencontrés par les individus atteints de déficience visuelle ainsi que l'ouverture à la communication sont également nécessaires pour une meilleure adaptation à la situation présente et future. Bien que le conjoint ne soit pas fonctionnellement affecté par une perte de vision, il connaît des bouleversements psychosociaux et le besoin d'ajustement à l'expérience de la perte de vision de leur conjoint. En conséquence, la participation du conjoint à des interventions psychosociales et fonctionnelles devrait favoriser les ajustements psychosociaux chez les personnes atteintes de basse vision ainsi que chez leurs conjoints. L'adaptation psychosociale a été mesurée à l'aide du *Nottingham Adjustment Scale (NAS)*. Les participants ont été regroupés en cinq groupes : groupe 1 - individus avec perte de vision, groupe 2 - conjoints, groupe 3 - individus avec perte de vision et leurs conjoints, groupe 4 - groupe de pairs, groupe 5 - groupe contrôle. Chacun des groupes a reçu le NAS en mesure prétest et posttest. Le prétest a été administré juste avant la première

intervention. Le posttest 1 a été administré quatre semaines plus tard, suivi de la deuxième intervention. Enfin, le posttest 2 a été administré par téléphone à tous les participants quatre semaines après la dernière intervention. Le groupe contrôle a répondu aux prétests and posttests par téléphone. L'hypothèse n'a pas été confirmée. L'ajustement à la perte de vision tel que mesuré par le *Nottingham Adjustment Scale* n'a pas varié de manière significative en fonction des groupes. Les résultats obtenus sont discutés en les replaçant dans le contexte théorique actuel. L'implication de ces résultats sur d'éventuelles recherches est également formulée.

## Sommaire

L'étude a été conçue de façon à déterminer si l'implication de la famille, spécifiquement du conjoint, lors de l'intervention en réadaptation en déficience visuelle pouvait améliorer l'ajustement psychosocial de la personne ayant des incapacités visuelles ainsi que celui de son conjoint ou de sa conjointe. La prémisse était qu'un programme complet de réadaptation qui s'adresserait aussi bien aux aspects fonctionnels qu'aux aspects psychosociaux, serait plus efficace pour engendrer des changements adaptatifs chez les deux participants. De plus, l'étude a été conduite de manière à vérifier qu'un individu handicapé de la vue, participant avec son conjoint ou faisant parti d'un groupe de support pourrait acquérir un niveau d'ajustement psychosocial plus élevé qu'un individu qui participait seul ou dans le groupe contrôle.

Cinquante-huit participants ont été recrutés par l'Association pour les aveugles de Montréal. Pour être retenu dans l'étude les participants devaient présenter soit: une dégénérescence maculaire liée à l'âge, une rétinopathie diabétique, un glaucome ou des cataractes. De plus, les participants devaient avoir un conjoint ayant une bonne vision. Les formulaires de consentement stipulant les objectifs de l'étude et les conditions de participation ont été lus aux participants. Le formulaire destiné aux personnes présentant des déficiences visuelles était différent de celui s'adressant au conjoint.

Les participants ont été assignés au hasard à l'un des cinq groupes décrits ci-dessous : Le premier groupe composé uniquement d'individus handicapés de la vue qui ont reçu les intervention de manière individuelle. Dans le deuxième groupe composé



uniquement des conjoints les participants ont reçu l'intervention de manière individuelle. Le troisième groupe était composé de couples. Les membres de ce groupe ont reçu les interventions par couple. Le quatrième groupe regroupait des individus handicapés de la vue et leurs conjoints qui ont pris part à l'intervention tous ensemble. Le cinquième groupe était composé d'individus handicapés de la vue et de leur conjoint qui n'ont reçu aucune intervention.

Les interventions ont composées de deux segments: le psychosocial et le fonctionnel. La partie psychosociale a exigé que les participants discutent de leurs inquiétudes et questions pour faire face aux conditions de vie avec une basse vision. Celles-ci ont été conduites avec l'aide du *McGill Low Vision Manual* pour initier les discussions sur le sujet. La partie fonctionnelle comportait dix activités journalières, tel que trouver un numéro de téléphone dans les pages jaunes, signer un chèque ou lire la posologie sur une bouteille de médicament. Ces tâches ont été évaluées lors d'une étude précédente par des individus atteints de basse vision comme étant des tâches journalières difficiles. L'ordre des interventions a été déterminé au hasard. Chaque intervention a duré approximativement une heure et demie. Le groupe contrôle n'a pas participé à ces interventions.

Lors de la première visite, les participants ont répondu au formulaire de consentement, puis à un questionnaire suivi de la première intervention. Approximativement quatre semaines plus tard, ils ont dus revenir pour répondre au même questionnaire, suivi d'une deuxième intervention. Après quatre semaines, ils ont été contactés par téléphone pour répondre à un dernier questionnaire et recevoir un

compte rendu oral des buts et objectifs de l'étude d'une durée de cinq minutes environ.

Le questionnaire *Nottingham Adjustment Scale* a été l'instrument de mesure du niveau d'adaptation psychosocial au cours des prétest, posttest 1 et posttest 2. Ce questionnaire contenant 46 items, mesure l'ajustement psychosocial des individus présentant un handicap visuel. Il comprend sept sous-échelles évaluant chacune une variable psychosociale différente. Les sept sous-échelles sont sensées répondre à une définition globale de l'adaptation psychosociale. Le questionnaire utilise l'échelle de Likert.

Les résultats indiquent que globalement, il n'y a pas de changements significatifs de l'ajustement à la déficience visuelle parmi les membres des différents groupes. Certaines améliorations ont été observées en fonction du temps vis-à-vis de « l'estime de soi ». Une différence significative est observée entre le prétest et le posttest 1,  $t(57) = 4.84$ ,  $p < 0.001$ , ainsi qu'entre le posttest 1 et le posttest 2,  $t(57) = 2.74$ ,  $p < 0.01$ . Les résultats du posttest 1 sont supérieurs à ceux du posttest 2, indiquant que les résultats tendent à revenir à la ligne de base. Il existe une importante interaction entre le temps et le groupe conjoint sur la sous-échelle « acceptation ». Une différence significative est observable entre le prétest et le posttest 1,  $t(11) = 2.83$ ,  $p < 0.05$ . Cependant si les résultats du posttest 1 sont plus élevés que les résultats du prétest, ils sont également plus élevés que ceux du posttest 2, indiquant ici aussi, que les résultats tendent à revenir à la ligne de base. Une autre interaction du temps et du groupe est observée pour la sous-échelle « style d'attribution », les résultats étant différents au prétest,  $F(8,94) = 2.428$ ,  $p < 0.05$ . Le groupe composé de couples présente un meilleur rendement que le

groupe composé d'individus handicapés de la vue, avec une différence moyenne de 4.25. Le groupe composé de couples a également un meilleur rendement que le groupe des conjoints, la différence moyenne est de 3.33. Le groupe de couples a aussi une meilleure performance que le groupe de pairs, avec une différence moyenne de 4.6. Un effet du temps est observé pour la sous-échelle « locus de contrôle ». Les résultats montrent une amélioration entre le posttest 1 et le posttest 2,  $t(57) = 3.23$   $p < 0.01$ .

En conclusion, il serait bénéfique de reproduire la même stratégie d'intervention mais sur une base plus longue et plus complète. Les déterminants de la personnalité, tels que l'estime de soi et le style d'attribution sont développées tout au long de la vie de l'individu et il est difficile de faire changer ces éléments par une intervention de courte durée. Comme le confirme les retours aux valeurs initiales observées quatre semaines après la dernière intervention.

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### List of Abbreviations

ANOVA	: Analysis of Variance
AVL	: Adaptation to Age-Related Vision Loss Scale
df	: Degrees of Freedom
<i>F</i>	: Fischer's Test for ANOVA
M	: Mean
MS	: Mean Squared
N.A.S.	: Nottingham Adjustment Scale
<i>p</i>	: Probability Value
P.A.I.S.	: Psychosocial Adjustment to Illness Scale
Sd	: Standard Deviation
SS	: Sums of Squares
<i>t</i>	: Student's t test
V.I.P.	: Visually Impaired Person

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## Introduction

Most studies, intervention strategies, and rehabilitation programs have addressed the visual needs of children, young adults and middle-aged adults with the objective of establishing educational skills or re-establishing vocational skills (Dodds, Bailey, Pearson, & Yates, 1991; Dodds, et al., 1994; Dodds, Flannigan & Ng, 1993). There is a dearth of research addressing the specific needs of the elderly visually impaired individual. Specifically, there has been little research examining the adjustment indicators to a wide range of visual disorders in persons over the age of 65 (Davis, Lovie-Kitchin & Thompson, 1995). Traditional models of rehabilitation have focused on the individual living with vision loss, with little, if any family and spousal involvement (Chlasta & Perski, 1988; Slay, et al., 1998). Specifically, the role of the spouse in the adjustment success of an elderly couple living with vision loss has been underestimated and overlooked in the past. Boter (1999) has demonstrated the usefulness of cognitive-behavioral strategies in helping the marital dyad learn to adjust and adapt to life with vision loss. Horowitz, Bird, Reinhardt, and Goodman (1997) have acknowledged the importance of the family and social supports of the person with a vision impairment in influencing the maintenance of functional and psychosocial rehabilitation outcomes.

Although great strides have been made in dealing with the medical aspects of disability, the social aspects have only recently been given necessary attention. Most people who begin experiencing the effects of low vision are over the age of 60. Elderly low vision individuals generally do not require services aimed at re-establishing vocational skills. Their needs are different from a younger visually impaired subgroup. Vision loss has different meanings and implications to the elderly than it does to young or middle-aged persons.

The onset of a vision impairment can be insidious and may not be noticed until damage has been done. Low vision compromises an elderly person's ability to perform routine tasks such as reading, recognizing faces and driving (Crews, 1994). Although each individual experiencing sight loss shares commonalities, it is imperative to remember that vision loss is a heterogeneous experience, affecting every person differently.

Sixty percent of the cerebral cortex is involved in visual processes (DeYoe & Van Essen, 1988; Felleman & Van Essen, 1991; Maunsell, & Newsome, 1987, as cited in Goldstein, 1996). Vision provides us 80 % of all the information we process daily (Phillips, 1990). Vision is one of our most important senses, vital to our independence

mobility and social interaction. Reduced vision can affect functional independence, self-sufficiency and psychosocial well being.

The age distribution of the visually impaired population is heavily skewed toward the elderly (Bruce, McKennel & Walker, 1991, as cited in Kelly, 1993). More than two-thirds of persons with low vision are aged 60 and over (Lovie-Kitchin & Bowman, 1985; Naeyaert & Grace, 1990). Canada has witnessed an unprecedented growth rate in the 65-and-older age group. From 1971 to 1981, the number increased by 35%, whereas the total population grew by only 13%. By 2001, the elderly, in Canada alone, will increase by 11% to 13% (Statistics Canada, 1976).

Concomitant with the growth of an aging population is an increase in the number of people experiencing multiple, chronic age-related health concerns. With an increase in longevity comes the heightened probability of chronic health problems, such as vision loss (Havlik, 1986). Vision loss is ranked third, after arthritis and heart disease among the most common chronic disabling conditions of later life causing a need for assistance in activities of daily living (Fletcher, 1994). Vision loss is greatly under-reported in older populations (Warren, 1985), with only half of the elderly with a vision impairment being appropriately diagnosed (Cullinan, 1978; Faye, 1970, as cited in Jose, 1983). As a

result, there is an ever-increasing imperative to address the specific needs of the elderly experiencing low vision.

### **The Double-Edged Sword: Being Elderly and Visually Impaired**

Growing old has never been portrayed as a glamorous process. Media bombard us with potions and regimens that claim to maintain a youthful appearance. Classic children's literature, such as Cinderella, Snow White, and Hansel and Gretel all portray the wicked and the evil as old. Additionally, common expressions in daily conversation illustrate the attitudes society harbors toward aging, for example, "you are only as old as you feel," "young at heart" and "you don't look your age." Additionally, aging has been made synonymous with illness and disease (Conway & Hockey, 1998). Aging is also associated with a decrease in economic productivity. Modern industrialized societies emphasize competition for economic wealth, which is valued over social productivity (Restrepo & Rozental, 1994). The golden years are a time when less valued social productivity replaces the more valued economic productivity. This undervaluation only further denigrates the view of the elderly (Restrepo & Rozental, 1994).

Moreover, aging has been referred to as a second childhood (Arluke & Levin, 1984). The phenomenon of infantilizing speech is an evident feature in the interaction

between younger and older generations. This treatment of the elderly illustrates the belief that, with advancing age, there is a regression into a childlike state. Infantilization is manifested through language or behavior that implies that the elderly have a childlike status (Kastenbaum & Hendricks, 1995; Whitmer & Whitbourne, 1997). Consequently, younger people begin to view and interact with the elderly as an adult would interact with a child. Whitmer and Whitbourne (1997) have observed that this treatment of the elderly contributes to a diminished sense of competence and control and a decline in self-esteem. It is difficult to harbor positive attitudes toward growing old and toward the elderly, given the negative reputation that aging has developed. Old age has been referred to as a time to disengage from the rest of the world. It has been called the last chapter of life (Palmore, 1979). As children, we rush to become teen-agers and rush once again to become adults, viewing life as a destination rather than a journey. Once we reach middle age, we are no longer in a hurry to get to the next phase; life suddenly becomes a journey. This is an ominous sign of how the final stage of life is perceived.

Positive attitudes toward aging are one of the best predictors of self-esteem over time (Coleman, Ivani-Chalian, & Robinson, 1993). A person going through life believing that old age is a time for dependence, loss of autonomy and diminished self-worth will struggle with esteem issues, which may only be compounded by chronic



health concerns, such as age-related vision loss. Adaptability is key to successful aging. With advanced age, the tendency to lose certain things, such as youth, functional spontaneity, sense of sharpness, perhaps a spouse, an extensive social circle, careers and children who are leaving the nest is a normal occurrence. Lubinski and Welland (1997) stated that, from birth, additions are made and, at middle age, the process of subtracting begins, until the ultimate zero is reached. Expectations of aging are adjusted according to what is already known about it (Dittmann-Kohli, 1990) and if what is already known is negative, arriving there will not be an anticipated process, thereby affecting self-esteem.

Old age is often accompanied by vision loss. This is a double-edged sword. Vision loss is not thought about until it occurs. The attitude, "better you than me" is often secretly expressed upon seeing someone who is visually impaired or blind. The common expression, "I have to see it to believe it" illustrates the notion that a person who cannot see is not a credible source. Expressions such as, "I'd rather be dead than blind" clearly depict the feelings that people harbor toward this physical affliction. Additionally, reflexive responses such as, "look who's there" demonstrate the significance placed on the sense of sight for information.

Studies have shown that non-verbal communication, such as body language, facial expressions, eye contact and gestures are more informative than verbal

communication. If non-verbal communication contradicts verbal communication, the observer will place more weight on the non-verbal in making a judgement about the person or situation (Mehrabian & Weiner, 1967). A visually impaired person is missing this non-verbal source of information. Visually impaired individuals must rely on auditory cues and input from others.

The above mentioned attitudes and consequent behaviors stem from the internalization of negative stereotypes about blindness that have been a ubiquitous part of daily life (Jacobs, 1984). Blindness is one of the most feared physical afflictions (Wagner-Lampl & Oliver, 1994). Monbeck (1973) stated that the most difficult part of being blind is dealing with the attitudes of people in the environment. Bauman (1972) observed that blindness is so pervasive and all-encompassing that it dominates a person's role system. Unlike others who have multiple roles in society, the blind individual tends to be assigned a unitary role- that of a blind person- regardless of other capabilities or roles fulfilled. Blindness has always been one of the most feared physical afflictions (Wagner-Lampl & Oliver, 1994). The Bible gives the example of the unitary role phenomenon, since the blind are typically portrayed as beggars because of the belief that they are incapable of doing anything else (Wagner-Lampl & Oliver, 1994). Blindness being a punishment from God for some misdeed is a centuries-old tenet

(Wagner-Lampl & Oliver, 1994). The idea that the blind are dependent and helpless, pathetic, evil, contagious, and deserving of their fate has been documented in folklore and biblical tales (Blank, 1957, as cited in Wagner-Lampl & Oliver, 1994). Blindness is believed to be the consequence of having been deceptive, evil, immoral, or sexually deviant. The association between blindness, death and castration has been documented in Sophocles' play, "Oedipus Rex", in which Oedipus gouges out his eyes upon discovering that his wife is also his mother (Sophocles, trans., 1956).

On the more positive side, blindness has been equated with the possession of magical abilities and special powers of perception. In ancient Greece, it was believed that blind people made good judges because they could not be deceived by appearances (Wagner-Lampl & Oliver, 1994). It is also believed that blind people have the ability of second sight, such as mind reading or clairvoyance (Monbeck, 1973).

Although the aforementioned beliefs are no longer as widely believed as they once were, blindness is still perceived to be a tragedy and those who are inflicted with it are pitied and, far too often, denied a role as normal, functioning members of society (Hevey, 1991).

Being elderly and visually impaired are two stigmatizing life situations and, as a result of their often concurrent existence, the stigma becomes twice as salient. You

cannot hide the fact that you are elderly and, at some point in time, you cannot hide your vision impairment. The more salient the stigma, the more negatively it is viewed by society (Sim, 1990). Stigmas are bodily signs designed to expose something unusual or bad about the bearer (Goffman, 1963; Susman, 1994). A white cane that a visually impaired elderly person carries becomes the salient feature distinguishing this person as being deviant, deficient, and perhaps a defective member of society. A person who is elderly is stigmatized based on appearance, which clearly divulges age. People who are elderly and visually impaired are also stigmatized based on their social identity. The social identity of a person with sight loss becomes "the visually impaired person or the blind person." Although the person with the vision impairment may be a father, grandfather, former professor and active member of the community, his social identity is reduced to that of a blind person. The spouse of the person with vision loss is also stigmatized and consequent stereotypes are formed of the spouse as well. Goffman (1963) referred to this as the transference of a stigma, where the mere association with a stigmatized person makes the associated person stigmatized as well. Stigmatized persons or groups become the target of stereotypes. The elderly, visually impaired person becomes the possessor and object of these negative and destructive attitudes (Goffman, 1963; Monbeck, 1973). If vision loss was not viewed as a normal part of

aging or as a tragedy, and if growing old was perceived as an accomplishment, perhaps a more positive view of vision loss and the elderly would prevail.

### **Psychosocial Adjustment**

Psychosocial factors have their greatest influence on responses to chronic, non-fatal diseases (Verbrugge, 1985). There are strong pressures for people with vision loss to think of themselves and to act as blind people. These pressures come from family, friends, society, folklore, health care professionals, and often begin with the ophthalmologist or optometrist (Verbrugge, 1985). Terms such as blind, visually impaired, disabled, and handicapped, all have potential negative influences in the ways in which persons with vision loss are treated by the sighted world and in how individuals with sight loss perceive themselves. Moreover, terminology often appears to confuse the matter, since the same word can mean very different things to two people experiencing the same loss at an identical point in time. Type and severity of a vision impairment is also not an accurate predictor of the psychosocial problems that a person may experience (Robbins & McMurray, 1988).

The degree of difficulty that a person has adjusting to vision loss is in large part a consequence of that person's interaction with the environment. The relationship with

one's environment determines one's perception of a situation. This relationship is what contributes to the creation of a handicap. A quadriplegic may not view himself / herself as handicapped, but a person with glaucoma may. Each of these situations is meaningless in isolation. The impairment or disability must be considered along with the individual living with the impairment and the environment in which he/she exists (WHO, 1980). A blind person who encounters a deaf person is in a handicapping situation, since the potential for communication diminishes. Neither the blind person nor the deaf person is handicapped; however, both are in a handicapping situation because of their relationship with a particular environmental situation. The psychosocial dysfunction related to vision impairment occurs long before sight loss (Wulsin, Jacobson, & Rand, 1991). Attitudes toward aging and impairment that develop over a lifetime are greatly indicative of how impairment and potential for adjustment are perceived.

Associated with the progression of vision impairment is the decline in self-esteem, self-worth, confidence, independence, environmental security, ability to participate in formerly enjoyed recreational activities, meaningful interpersonal relationships and social support networks (Cherry, Keller, & Dudley, 1991). The person experiencing vision loss, his or her family, social entourage and society at large have a tremendous effect on the psychosocial functioning of the person living with sight loss.

A person who perceives him/herself positively has a stronger sense of self-esteem than someone who has a less favorable perception of self. Perception of self is created in part by the way in which individuals perceive themselves and by the way in which individuals believe others perceive them. Bishop and Epstein (1980) remarked on the importance of positive perception of self, self-acceptance, self-expression and frequent positive contacts with people who offer the person with low vision security and acceptance in the successful adjustment to vision loss.

Education about the effect that a sensory impairment has on the individual and on the family is an essential part of adaptation and coping. The psychological and emotional upheaval associated with aging and the onset of vision loss, and perhaps other health concerns, affects the family and the marital pair particularly on a variety of psychosocial dimensions. Vision loss may threaten a person's sense of self by destroying the basis on which life has been constructed (Blascovitch & Tomaka, 1991). A man who has worked as an architectural draftsman all his life may need to redefine himself and discover other parts of his self-identity to help maintain his self-esteem. People who define themselves by unitary roles are subject to greater psychosocial turmoil than individuals who ascribe several roles to their personal and social identities. Worsening or unstable vision requires frequent readjustments and changes in social roles (Stern,

1983). A woman who learns to use eccentric viewing to read may experience vacillating emotions if her efforts at adapting are continually undermined by worsening vision. Potential indicators of how stable one's self-esteem may be when faced with vision loss are the perceptions and attitudes this person harbored about others who are visually impaired before becoming visually impaired himself/herself. The narrower and more negative attitudes and perceptions are about vision impairment, the more difficult it will be for the person experiencing sight loss to have a positive view of him/ herself.

Moreover, minimizing the potential isolation experienced by many elderly individuals with low vision can be accomplished through effective communication of wants and needs. A woman who has lost a considerable amount of vision no longer receives the weekly phone-call for movie night. Her friend believes that asking her to go to the movies will only remind her of her visually impaired status. However, it is necessary to advise sighted persons with whom visually impaired persons frequently interact, that being blind or visually impaired does not negate the enjoyment of many activities, even going to the movies.

Self-esteem is an important concept in understanding the experience of vision loss and old age (Coleman, et al., 1993). It is a psychological resource that mediates the negative effects of stress in the coping process (Pearlin, Lieberman, Menaghan, &



Mullen, 1981). Self-esteem is closely related to self-concept. The ideas and perceptions we have of ourselves and the internalization of ideas and perceptions we believe others have of us become part of who we are (Horney, 1950; Rogers, 1951 as cited in Welsh, 1980). Additionally, the perception one has about the groups to which one belongs contributes to a collective sense of self-esteem (Crocker & Luhtanen, 1990). If attitudes toward vision loss and visually impaired persons are negative, then a visually impaired person may have poor self-esteem, since he/she identifies with a group not viewed positively. A change in self-concept may arise from vision loss and the different treatment received from those around the visually impaired person. If a person's view of vision loss is negative and his /her perception of how others perceive vision loss is also negative, he/ she will likely struggle in maintaining a positive view of him/herself and in maintaining self-esteem.

Stotland and Canon (1972) stated that it is the person's sense of self-esteem that affects the perception of the effectiveness of his/her actions, the perceived freedom to select from a number of possible actions, the sense of similarity with others and the communication received from others about his/her competence. Self-esteem is closely intertwined with the way in which one perceives him/herself, how competent one feels and a personal sense of control over one's environment. A person with a resilient sense

of self-esteem will, for example, be less likely to abandon mobility training when efforts initially seem to be unavailing.

Self-esteem is related to the ability to cope with stressors such as loss of a loved one or loss of some physical function (Essex & Klein, 1989; Lund, 1989). Throughout life, we experience a variety of losses and the manner in which we deal with prior losses has implications for how we will deal with subsequent losses. A person who loses a loved one or a job and copes well, managing to maintain a relatively solid sense of self-esteem may use the same personal resources to cope with and adjust to vision loss. Self-esteem is related to competence and psychological well-being (Blascovitch & Tomaka, 1991). A person who is able to maintain self-esteem through trying times will feel more capable and competent to face subsequent challenges and stresses brought on by life. Reality negotiation is likely to occur when a person's self-esteem and sense of self-efficacy have been threatened. Reality negotiation is a strategy that serves to maintain positive beliefs about the self under conditions that threaten the self (Fiske & Taylor, 1984), such as in the case of sight loss.

According to Bandura (1982), people regulate their behavior based on their perceptions of their competence, skills and efficiency. Moreover, people who feel that vision loss detracts from who they are will suffer greater loss of self-esteem, self-

efficacy and competence, to the extent that perceived self-characteristics do not match the self-concept that has been developed over a lifetime. Self-efficacy is the mechanism by which we negotiate paths to achieving our goals. Self-efficacy influences performance (Bandura, 1977). When self-efficacy is low, a consequence may be a decrease in positive mood. The lower the self-efficacy, the greater the feelings of depression and helplessness and the lower the self-esteem (Bandura, 1982). This is a vicious circle, where each personality disposition affects the other in a downward spiral. A visually impaired person who has managed to maintain a sense of self-esteem throughout the experience of sight loss will accept challenges, believing that they can be met. Self-efficacy involves judgements of capabilities to organize and execute courses of action required to attain goals. These judgements influence decisions to engage in specific tasks, to persist in pursuing goals and, eventually, lead to success. Efficacy expectations are a major determinant of how much effort people expend in the pursuit of various tasks, as well as the motivation with which they approach them (Bandura & Cervone, 1983).

Individuals with diminished feelings of personal control tend to believe that they are at the mercy of the social environment and that it is futile to attempt to overcome stressful experiences. A negative emotional state, brought on by a stressful life event,

such as vision loss, may set the stage for a sense of little or no control over that area of life. This lack of control may generalize to other areas of life (Thompson, et al., 1998). These individuals are less likely to efficiently utilize the resources that are available to them during difficult times and, as a consequence, stressful situations tend to get worse (Pruchno, Burant, & Peters, 1997). The maintenance of personal control by remaining an active member of the community, along with the opportunity to give as well as receive, contributes to an elderly person's sense of personal control and psychological well-being (Pruchno, Burant, et al., 1997). Additionally, creating situations where goals are manageable and highly attainable may promote a pattern of behavior that allows the person to build a sense of competence and control in increments, thereby leading him/her to believe in his/her ability when more difficult situations arise. A strong relationship exists between self-esteem and personal competence (Blascovitch, & Tomaka, 1991).

### **Depression/Anxiety**

Illness tends to occur more often in an older population and the combination of illness and depression is common (Bentz, 1987; Gomez & Gomez, 1993). Mood level and social relationships are particularly affected by visual impairment. Visual loss is

associated with a higher risk of chronic and severe depression, including feelings of hopelessness, sadness, loneliness and suicidal ideation (Carabellese, et al., 1993). Higher levels of social support and a high degree of assertiveness are associated with low levels of depression in visually impaired elderly people (Hersen, et al., 1995). Dodds, et al., (1991) observed that depression in response to vision loss may be thought of as learned helplessness. A person who becomes depressed as a consequence of a vision impairment may develop a helpless disposition from not feeling in control of life or from unsuccessful attempts at resuming life. Hoplessness-depression has been recognized as a subtype of depression, whereby the occurrence of a major, negative life event perceived to be global, permanent and beyond the control of the individual permeates the person's life (Abramson, Metalsky & Alloy, as cited in Dodds, et al., 1993). A person with advanced macular degeneration may feel this way if the onset is sudden and if this person defines himself/herself according to a unitary role with vision as the central feature of his/her identity.

A high level of anxiety is associated with depression and a sense of worthlessness or low self-esteem (Dodds, et al., 1993). Sensory loss is associated with greater depression, anxiety, low morale, reduced feelings of worth, social isolation, and low levels of emotional security but only in cases where social supports are unavailable

(Hersen, et al., 1995; Oppegard, et al., 1984). The family and spouse of the visually impaired person serve as depression inhibitors, provided that the person experiencing the vision loss uses his/her social resources for support. A visually impaired person who is hiding his/her sight loss is also reducing his/her potential for social support. As long as the social entourage is oblivious to what is going on, it cannot serve as positive support. By strategically avoiding social situations that may reveal one's identity, one can also diminish social supports, thereby increasing the risk for isolation, loneliness and subsequent depression. When vision loss occurs, depression may be a normal experience but, as an ongoing psychological reaction, it may be indicative of poor acceptance of the reality of the loss and may indicate that the person has not learned to integrate vision loss into his/her life (Fagerstrom, 1994). Depression tends to increase with diminished visual acuity and decrease with improved visual acuity (Fagerstrom, 1994). Depression can be a reaction to the gradual deterioration of vision as a continuous process (Bentz, 1987). Depression and anxiety are commonly observed in people with recent sight loss, since they perceive themselves as no longer being able to carry out even the simplest tasks without difficulty or assistance. This leads to a negative evaluation of the self and promotes a deterioration of one's expectations of self in regard to rehabilitation (Dodds, et al., 1993).

Moreover, a person who attributes successes to internal and stable personality characteristics may have a more resilient sense of self-esteem and control when threatened by a chronic condition such as sight loss. An individual who attributes successes to external, environmental causes, beyond his/her control has a greater chance of experiencing a decrease in self-esteem and control in the situation of vision loss. Such an individual is more likely to develop a helpless attitude and a hopeless disposition. The latter style has been referred to as the depressogenic attributional style in that individuals who adopt this style are likely to fall into depression (Dodds, 1993).

### **Coping Mechanisms**

People often devote much more time to adjusting to a spoiled social identity and social exclusion than to trying to restore their abilities (Hétu, 1996). Disclosing the fact that one has an impairment threatens the social identity that one has developed over a lifetime. This reluctance to disclose the impaired status comes from knowing the negative consequences associated with it being acknowledged (Hétu, 1996). People tend to make comparisons with others whom they perceive to be in a similar situation to themselves. People generally have several selves, making it easier to come to terms with the collapse of a particular image (Hétu, 1996). This is evident in situations where

one of two people in the same predicament feels satisfied and content and the other feels a great loss in purpose and meaning. Someone experiencing late-onset vision loss may have a difficult time relinquishing his/her primary social identity and, as such, may try to maintain the image he/she has upheld during all the years prior to sight loss. Most people are capable of a variety of tasks. Oftentimes, we persevere with a specific hobby or job because it is familiar. In the case of the visually impaired person, a familiarity with other activities and tasks needs to be established in order to help relinquish a primary role that has become less suitable for another more suitable role. The number of hobbies, activities and interests that a person maintains, the variety of excursions outside the home and the perception of oneself as an active person are significantly related to maintained self-esteem over time (Coleman, et al., 1993).

Individuals who have a difficult time accepting their new-found status spend little time adjusting and coping and tend to spend inordinate amounts of time trying to deceive others that there is absolutely nothing about them that is different. Some people have more shame-prone personalities (Kaufman, 1989, as cited in Hetu, 1996). These individuals refuse to use any optical or travel aids, since this only advertises the fact that they are visually impaired. However, with sight that consistently worsens, as is often the case with age-related vision impairments such as macular degeneration, glaucoma and



one of two people in the same predicament feels satisfied and content and the other feels a great loss in purpose and meaning. Someone experiencing late-onset vision loss may have a difficult time relinquishing his/her primary social identity and, as such, may try to maintain the image he/she has upheld during all the years prior to sight loss. Most people are capable of a variety of tasks. Oftentimes, we persevere with a specific hobby or job because it is familiar. In the case of the visually impaired person, a familiarity with other activities and tasks needs to be established in order to help relinquish a primary role that has become less suitable for another more suitable role. The number of hobbies, activities and interests that a person maintains, the variety of excursions outside the home and the perception of oneself as an active person are significantly related to maintained self-esteem over time (Coleman, et al., 1993).

Individuals who have a difficult time accepting their new-found status spend inordinate amounts of time trying to deceive others that there is absolutely nothing about them that is different. Therefore, whether coping seems adaptive or maladaptive, it serves the purpose of managing stressful situational demands. Some people have more shame-prone personalities (Kaufman, 1989, as cited in Hetu, 1996). These individuals refuse to use any optical or travel aids, since this only advertises the fact that they are visually impaired. However, with sight that consistently worsens, as is often the case

with age-related vision impairments such as macular degeneration, glaucoma and diabetic retinopathy, there will come a time when these individuals are no longer able to hide their vision impairment. Consequently, they begin restricting their social appearances to only those which do not reveal their visually impaired identity. If their vision worsens, the people who are trying to pass as sighted may sabotage this façade and give themselves away. This behavior is not adaptive and does not promote adjustment or acceptance of vision loss. These individuals spend time and energy hiding their problem from others rather than allocating the energy to promoting their personal well-being by learning how to maximize functioning. The consequence in the long-run is a life of isolation and loneliness. This behavior is indicative of poor adjustment and of the inability to accept themselves as people with a vision impairment.

Glass (1970 as cited in Jose, 1983) stated that, oftentimes, people cope with vision loss by modifying their expectations. Since many activities may seem unrealistic to a visually impaired individual, personal expectations of what can be accomplished may be low in contrast to what is actually possible. He further explains that there are three personality types in the low vision population. There are those who use their condition to gain advantage. Individuals who perceive their lives as unsuccessful socially may find a safe haven in blindness, where they are freed from expectations that

they were not able to meet as sighted persons. Others will identify themselves as sighted, even though they have very poor residual vision. These individuals will often try deceiving others into believing that they are fully sighted. Contrarily, the converse of this personality is evident when the attempt to mislead others into believing that vision is worse than it really is, becomes the primary focus. The purpose may be to create an interpersonal dynamic whereby the individual is fussed over and taken care of in much the same way as a parent takes care of a child. The third personality type is that of the person who makes great effort at maximizing residual vision.

Both personality variables and situational events affect well-being and potential for adjustment. When lives become disrupted by some uncontrollable event, such as sight loss, people experiencing the stress associated with this uncontrollable event tend to become more external in orientation (Baubion-Broy, Megemont, & Sellinger, 1989). People who are external tend to concern themselves with the evaluations of others more than internals do (Baumgardner, Kaufman, & Levy, 1989). Externals care about what the people in the social environment think about them (DeBono & Snyder, 1989). This may lead to ineffective coping. People who concern themselves with what the general public thinks, will conform their behaviors to meet those expectations to a greater extent

than internals would. If these individuals believe that they are not viewed favorably, they may mask what they perceive to be the cause of the unfavorable judgments.

### **Low Vision Rehabilitation**

Traditional visual rehabilitation services have been targeted at children and working age adults (Horowitz & Reinhardt, 1998) and, currently, a philosophy of vocational rehabilitation prevails. However, with the growing number of elderly living with vision loss, service providers will have to adapt to the different needs of this population. Rehabilitation is considered costly and tends to be concentrated on the young since they are most likely to repay the cost to society through salvaged, gainful employment (Hensley, 1987). At present, however, workers in the field of vision rehabilitation are experiencing an ever-increasing need to address the needs of an older age group and, with the elderly subgroup of the population steadily growing, their specific needs will exert an influence on service provision (Horowitz & Reinhardt, 1998).

A universal rehabilitation program cannot be created and applied to everyone experiencing similar problems. Rehabilitation programs must be created for a target population, to meet the specific needs of that population, using a multidimensional approach. Interdisciplinary efforts are essential in providing comprehensive care.

Rehabilitation curricula should be designed to meet the specific needs and goals of each visually impaired individual. At the onset of a rehabilitation encounter, individuals should be questioned as to what their lifestyle was like before their vision loss, what interests they had, what kind of work they performed and what they would like to resume doing or have greater facility doing. Allowing the visually impaired person to designate the areas that he/she would like to address has been shown to increase rehabilitation effectiveness (Dillon, et al., 1991). This will enable rehabilitation personnel to devise a program best suited to that individual's needs. It would not be cost-effective, productive, or useful to teach someone with macular degeneration how to use residual or peripheral vision to optimize reading ability if this person never enjoyed reading. Initially, assessing each person's individual problems and interests seems time consuming, however, in the long-run, it is beneficial to both the rehabilitation specialist and the visually impaired person.

Successes at different stages of rehabilitation serve as motivational forces to proceed to subsequent stages or merely to persevere. Family members are important because they can encourage efforts and help the person with vision loss to attain goals. Moore (1984) observed that a person can go through rehabilitation, achieving a high level of progress, only to return home where an overprotective or unsupportive

environment eradicates all progress. In the case of an elderly person, the spouse becomes central to the success of the rehabilitation effort. Stephens (1980) stated that it is necessary to determine a person's level of psychosocial functioning and the difficulties that arise as a result of vision loss in establishing an effective and useful rehabilitation program. The variability in the success of low vision rehabilitation has been related to the amount of residual acuity (Wulsin, et al.,1991) and to psychological factors including depression, life satisfaction, social support, self-esteem, stress and motivation (Ringering & Amaral, 1988). Other studies of adjustment to sight loss have failed to link adjustment success to visual factors and etiology of the loss, abruptness of the loss, or visual acuity within the range of legal blindness (Fitzgerald, Ebert, & Chambers, 1987).

Effective rehabilitation programs geared toward an elderly population strive to maximize rehabilitation success by teaching visually impaired individuals how to maintain interdependence and sustain a satisfying quality of life. Rehabilitation should help the person with vision loss cultivate the necessary tools with which to continue coping and adjusting, with the option of returning for subsequent help if necessary (Ringering & Amaral, 1988). Factual and understandable patient and family education can do much to reduce inaccurate, negative cognitions (Lovett, 1988). Additionally,

there is a need to refocus one's feelings, energies and satisfactions previously related to visual stimulation and visual input to new sources of input and satisfaction (Klebaner, 1989). A person who loses his/her vision to macular degeneration, may need to discover other satisfying and personally meaningful past-times and activities that do not rely exclusively on vision.

Initially, rehabilitation can be costly. However, it is probably the most efficient and cost-effective way of reducing the potentially disabling and handicapping effects that an impairment such as vision loss can engender. The goals of low vision rehabilitation become increasingly clear when the psychosocial dimensions most affected by sight loss are contemplated. Moore (1984) stated that accommodating to vision loss involves adjusting one's self-concept and goals to include realistic limits that are imposed, while developing new capabilities that are compatible with one's personal resources. While many people experiencing vision loss cope well with the demands and the challenges brought on by sight loss, others have tremendous difficulty managing their situation. Psychosocial dysfunction related to vision impairment occurs long before blindness (Wulsin, et al., 1991). Engaging the visually impaired person in a rehabilitation program at the onset of his/her sight loss may help to buffer the effects of helplessness, dependency and consequent depression (Dodds, et al., 1991). A positive

introduction to rehabilitation services for both the person with vision loss and the spouse is a key factor to whether the visually impaired person will continue using the services (Lueck, 1997). Rehabilitation needs to be ongoing and flexible (Davis, et al., 1995) and not merely recommended at the onset of a vision impairment, since worsening or unstable vision requires frequent readjustments and changes in social roles (Stern, 1983). Jacus (1981) stated that family attitudes and behaviors are largely responsible for the success or failure of rehabilitation efforts. Cutsforth (1950, as cited in Dodds, 1993) observed that the self-regarding attitudes that a visually impaired person maintains are more incapacitating than the functional restrictions imposed by sight loss. Therefore, self-regarding attitudes need to be explored before any rehabilitation intervention begins. One of the primary goals of rehabilitation is to understand the origins of attitudes and beliefs that the visually impaired person possesses about him/herself. Likewise, family attitudes must be examined. This may facilitate the subsequent functional skills training, openness to use assistive devices and greater psychological freedom to reintegrate oneself with society. Most people with vision loss can resume a lifestyle of high functioning, allowing them to lead autonomous, satisfying lives (Verbrugge, 1985).

The goal of rehabilitation is to help individuals with vision loss to recover lost skills and to address psychological difficulties through some form of counseling (Dodds,



et al., 1991; Jaureguy & Evans, 1983). Functional skills training, mobility training, teaching individuals with vision loss and family the benefits of visual aids and counseling sessions one-to-one with a therapist and in a peer group setting may be useful in helping the visually impaired person and spouse adjust and learn to cope effectively. Moreover, it is important initially to allow the visually impaired individual some private time with the rehabilitation team. Similarly, the family members and spouse may need to address issues and concerns away from the visually impaired other as well. There may be issues that are not addressed when the family or couple is together. In order to achieve a greater understanding of how the family and couple functions, it may be useful to interview those involved as individuals and as a group.

Rehabilitation should emphasize the teaching of visual and non-visual functioning. Visual memory, perceptual awareness of stimuli and reasoning ability may help a person with vision loss to establish more control over how residual vision is used (Dodds, 1993). Conrod and Overbury (1998) demonstrated the success that perceptual training and psychological counseling has on the use of residual vision and in how well individuals adapt to their visually impaired status. Goals of rehabilitation include maximizing specific skills, self-esteem and quality of life for individuals living with sight loss (Lueck, 1997). Prosthetic devices are playing an increasingly important role

in improving the functional performance of visually impaired persons and therefore, should be integrated into the rehabilitation setup (Greig, West & Overbury, 1986; Mann, Hurren, Karuza, & Bentley, 1993). Education and training in the use of appropriate visual aids and assistive devices is necessary to help promote optimal functioning. Comprehensive low vision care involves treatment and assistance to individuals with low vision to ensure that their visual impairment does not become a disability or a handicap (Lueck, 1997).

Medical interventions are not sufficient in themselves to equip the visually impaired person with essential coping skills to resume life at a level of functioning that is personally satisfying. Information, social support, the opportunity to express concerns and feelings about sight loss, and training in the use of assistive devices and alternative techniques are necessary. A person who is diagnosed with macular degeneration is often told that there is nothing more that can be done to improve his/her vision. Where does the individual go from here? These people need to be referred for rehabilitation services. The attitude conveyed by the ophthalmologist and optometrist to the visually impaired patient is a strong determinant of whether the patient will proceed with rehabilitation. If the ophthalmologist or optometrist tells the patient that there is nothing further that can be done and that it's normal for this to happen at such an age, the patient

will not think in terms of alternative ways to enhance functioning from this point on. At a time where guidance and support may be most needed, the patient is often left alone to deal with the problem.

The field of rehabilitation has been criticized for not having produced valid and reliable outcome measures in the past. It is difficult to quantify success on a consistent measure, when one of the most meaningful outcome measures of any clinical intervention is the person's perception of change in his /her functioning (U.S. Department of Health and Human Services 1988, as cited in Elliott & Kuyk, 1994; Head, Babcock, Goodrich, & Boyless, 2000). It is important to quantify and qualify the success of any intervention. Comprehensive outcome measurements may be more meaningful than those that rely on figures or verbal reports alone. A subjective measure can show the researcher that the overall well-being of the individual has increased as a result of having participated in the program. However, quantitative outcome measures can indicate how much improvement there was, where the improvement was greatest, and whether there is any residual disability. Subjective outcome measures should also include the family's perception of how the visually impaired person is doing. The use of both qualitative and quantitative measures may allow for a more comprehensive

understanding of the problem and formulation of intervention strategies that are most conducive to engender overall adaptive functioning.

### **Role of the Family**

Vision loss is a shared experience. People are not islands living in isolation from one another. On a daily basis, most people interact with their family, friends, work environment, and society at large. Addressing the concerns of the individual experiencing vision loss is not sufficient to engender long-term adaptive change. One must consider the people intimately tied to the person experiencing sight loss. It is increasingly acknowledged that the family should be an integral part of the adjustment to vision loss (Greig, et al., 1986; Horowitz & Reinhardt, 1998). Moore (1984) stated that the family serves as a major source of interpersonal influence that affects what visual impairment comes to mean to the affected person, what he or she does with it, and the outcome of plans made with the person. Additionally, the overall psychosocial adjustment of the visually impaired person is shaped, in part, by reciprocal exchanges in the family relationship. Stresses among family members when vision loss occurs is representative of earlier unresolved emotional reactions (Lowenfeld 1980, as cited in Jose, 1983).

It is important to consider the way that other people in the life of a visually impaired person view him/her and the impairment itself (Stotland & Canon, 1972). Family attitudes about impairment may serve as an impeding or motivating force behind the entire family's adjustment success (Welsh, 1980). Family has the capacity to turn an impairment into a handicap or to encourage the person with the impairment to strive for to meet personal satisfaction and autonomous functioning. Those involved in the life of the visually impaired person experience their own emotional and psychosocial upheaval and they, too, must make adjustments and learn to accept this new status. Vision loss affects the family unit as much as or more than it does the person experiencing the physical loss (Moore, 1984). It is necessary for individuals with sight loss to cope on a personal level, and on a joint level, with others who play key roles in their lives. Due to limited knowledge or total lack of information, family members may sabotage any attempts that the visually impaired individual makes at resuming life as a functional person. This is evident in the tendency to be overprotective and to take on the responsibility of doing everything for the visually impaired person. The flipside may be a situation where family members express indifference toward the person experiencing the vision loss. This may manifest itself through ignoring any successful or failed attempts toward resuming independence and not being receptive to the visually impaired

person's needs. If family members do not believe in the necessity of regaining competencies, yet the visually impaired person wants to re-establish a sense of control over life, additional strain will be added to the familial relationship. The way in which a family reacts to an impairment may be the result of fear, not knowing what else to do. These are ineffective ways of coping with the problem. Family fears may contribute to the perpetuation of self-defeating behaviors or may induce a handicapped mentality in the person experiencing vision loss. This fear and anxiety can develop through interaction with others who express their disbelief or apprehension about a visually impaired person engaging in independent travel or activities. The implications are profound, in that the visually impaired person may internalize these fears and accept the dependent role imposed by family members. Wilson (1967) observed that parents often transfer their fears to their visually impaired child. Family members can also transfer their fears to an adult member of the family who is visually impaired.

Family members may not be knowledgeable or competent in helping immediately from the onset of sight loss. Helping the family to understand the diagnosis, prognosis, as well as medical and non-medical interventions may help to maximize independent functioning. Ponchillia (1984) stated that it is the lack of information that promotes over-protection or over-reaction by the family members. The

family may not believe in the visually impaired person's potential for independent functioning. When a visually impaired person manages to maneuver around his/her environment successfully, a family's tendency to attribute the success to luck and to discourage further attempts is detrimental to subsequent efforts at re-establishing independence.

Additionally, family members need to know what role they play in a visually impaired family member's life. Relationships have to be redefined so that the family may actively participate in the adaptation process, while learning new and positive roles that can facilitate the visually impaired person's independent functioning (Freeman, 1954). The social aspects of family and, specifically, conjugal coping and social support has been neglected in the literature (Nixon, 1994). Dumas and Sadowsky (1984) demonstrated the positive outcome of teaching family members to cope with the needs of visually impaired veterans. The aim of their study was to increase knowledge about vision loss so that family members would be better equipped to determine when and how to help and when to allow greater autonomy. Results revealed positive benefits over three and a half years after the training had taken place. Family members remarked that their active participation decreased feelings of burden, helped them to understand the nature of their family member's impairment and taught them how to be more

responsive to his/her needs. The reality of an impairment can have different meanings to different family members (Nixon, 1994). It is important to consider family dynamics in the adjustment process. Family relations, the meaning that is attributed to impairment, and social support from outside are important factors in the ability to cope successfully with vision impairment (Nixon, 1994).

### **Role of the Spouse**

Two-thirds of the visually impaired population is over the age of 50 (Crews, 1991) and this implies that the family unit has become smaller. Children are grown up and have families of their own. The family unit is now a dyad comprised of husband and wife. Additionally, a decline in health, which often accompanies aging, tends to increase dependence on and need for conjugal support. This situation occurs at a time when satisfying and positive intimate relationships are particularly important for well-being (Lowenthal & Haven, 1968). The key person in the life of the visually impaired individual is the partner or spouse. Most people have one relationship which dominates their social system. This relationship is usually with a permanent partner and impairments and disabilities become a shared problem where both parties search for joint solutions (Boter, 1999). In the case of the elderly, it is the spouse who becomes



paramount to the successful adaptation to vision loss. However, virtually no attention has been paid to the marital pair who, as a family unit, are facing the challenges associated with chronic illness (Dewis & Chekryn, 1987). A couple who has been together for decades has developed coping strategies for various life stressors that require significant life changes in the ongoing pattern of the couple (Boter, 1999). It is important to understand the meaning that the couple attributes to vision loss as it is being experienced in the present and the implications that this loss has for their future.

Understanding the meaning that the person with a vision impairment attributes to sight loss is invaluable in helping to re-establish harmonious balance within the dyadic relationship. Disruptions to the couple's equilibrium are brought on by the struggle to accept and adapt to this life change (Boter, 1999). Both the spouse and the visually impaired person experience the psychosocial upheaval of sight loss. The onset of vision impairment creates constraints with which each partner must cope. Plans made for retirement throughout one's married life may have to be dramatically modified after vision loss occurs. There may also be role changes. If a wife becomes visually impaired, she may require assistance in maintaining the home and in meal preparation, if these were tasks for which she took sole responsibility in the past. The husband will have to assume some of these responsibilities in order to maintain equilibrium. The

couple must confront managing the disorder, managing the business of everyday living, and managing changes in their mutual aid and individual life biographies (Dewis & Chekryn, 1987). The couple functions as a unit and dysfunctions as a unit. Moreover, a sighted spouse may encourage a handicapped mentality in their visually impaired other. A woman who is retired and whose children have left the nest may induce a handicapped mentality in her spouse if his impairment fills a void in her life. Handicapping the visually impaired spouse may serve a psychological function. It is important to consider the couple's dynamics in understanding what the impairment entails to those involved and the way in which the impairment is dealt with by both partners.

Older couples whose interaction brought little satisfaction in previous marital years are not likely to experience a sudden upsurge in happiness, particularly given the changes in income, physical competencies, employment and health status (Spanier, Lewis & Cole, 1975). Cavan (1973) stated that elderly people who share ideas and feelings with someone who helps them to deal with day-to-day problems are happier than those who do not. The spouse is the person with whom this communication and interaction is likely to occur, since the spouse is the primary companion. Couples who cope with the problem of vision loss separately, each in his/her own way, fare less well than couples and families who cope together. Since the experience is a joint one, the

troubles and the triumphs should also be shared. When a difficult situation arises, the visually impaired person has the support of the spouse to motivate continued efforts. The couple will struggle with vision loss and with the disagreements on how to manage the vision loss. Additionally, couples whose partnership is based on an egalitarian balance of power fare better than couples with a unilateral balance of power and conflictual couples (Grand, Grand-Filaire, & Pous, 1993).

The nature of the relationship between the partners at the time of the vision loss is an essential determining factor in how well the couple copes with the experience of vision loss (Grand, et al., 1993). A marital relationship must be based, among other things, on a solid foundation of trust, openness, support and a willingness to face life's situations as a team. Conjugal support and coping behaviors contribute to the psychological well-being of the elderly couple (Ducharme, 1994). Conjugal support is acknowledged as the most important form of social support for the elderly (Depner & Ingersoll-Dayton, 1985). According to theories of self-concept formation, it is the spouse who has the greatest impact on the self-concept of the visually impaired other (Scott, 1969). A spouse who discourages his/her visually impaired partner from regaining capabilities and expresses no enthusiasm regarding accomplishments is contributing to the already weakened sense of competence and self-esteem begun by the

visually impaired person's own uncertainties about the acceptance and adjustment to vision loss. A couple's interaction before the onset of a vision impairment often predicts how the couple is likely to cope with their newfound status. However, little has been established about the family support needs and relationships of older persons who are visually impaired (Crews, 1991).

### **Rationale for the Present Study**

Vision loss requires continuous adjustment and adaptation by both the person experiencing the vision loss and by those intimately connected to the experience. Research in the field of low vision rehabilitation has addressed important concerns regarding mobility, functional skills training, counseling for depressed individuals, and the caregiver burden. Qualitative research has been successful in defining the differences in individuals' psychosocial responses to vision loss as a mediator to successful adjustment (Kleinschmidt, 1999). There has been little research specifically addressing the functional and psychosocial needs of the elderly dyad living with vision loss. Specifically, a neglected area is the continuous and comprehensive rehabilitation needs of the visually impaired person and his/her spouse. Some important psychosocial,

cognitive and functional aspects of the dyad in achieving adaptation to vision loss have been addressed (Boter, 1999; Dumas & Sadowsky, 1984; Horowitz et al., 1997).

Accordingly, the aim of the present study was to determine whether a functional skills awareness intervention in addition to a psychosocial discussion would improve the couple's psychosocial adjustment as measured by the Nottingham Adjustment Scale (N.A.S.). The assumption was that subjects who participated as a couple and those who participated as a peer group would experience an improvement in their overall adjustment to sight loss. The belief was that promoting functional skills awareness in the sighted spouse through simulation and addressing the psychosocial concerns of couple would enable a better understanding of the implications of life with vision loss on a psychological and practical level. This is believed to facilitate the way in which the couple communicates and deals with daily disturbances brought on by a chronic impairment such as sight loss. Moreover, involving a peer group of spouses and visually impaired persons in this intervention design was also expected to promote greater psychosocial adaptation to vision loss. This assumption was based on the literature review discussing the success of peer groups and mutual aid groups in promoting adjustment to life crises through the sharing of mutual experiences (Harshbarger, 1980; Lewis, 1998; McCulloh, Crawford & Resnick, 1994).

## **Hypotheses**

One objective of the present study was to determine whether a psychosocial and/or functional intervention would be useful in aiding individuals with vision loss and their spouses in the adaptation and adjustment process. The psychosocial intervention required that participants discuss any concerns related to their experience of vision loss. The functional intervention required that participants perform tasks of daily living that had been rated in a previous study as being difficult to contend with on a daily basis. Spouses wore visual simulators for this segment.

A second objective involved determining which group would obtain better scores after having received both interventions. There were five groups in this study. Group 1 consisted of the person with the vision impairment undergoing the interventions alone. Group 2 consisted of the spouse undergoing the interventions alone. Group 3 consisted of the person with the vision impairment and the spouse undergoing the interventions together. Group 4 was a peer group of several couples undergoing the interventions together. Group 5 was the control group who did not experience either intervention.

A third objective of the present study was to determine whether any of the five groups would perform better on either or both posttests. The independent variables were

the two interventions and the group structure. The dependent measure was the Nottingham Adjustment Scale (N.A.S.). The N.A.S. was administered as a pre-intervention measure, between-intervention measure, and as a post-intervention measure.

It was hypothesized that group 3 – visually impaired individuals who participated with their spouse and group 4 – the peer group, would demonstrate an overall improvement in scores from pretest to both posttests compared to the other groups, indicating better overall adjustment to vision loss as a function of a psychosocial and functional intervention.

## **Methods**

### **Subjects**

The participants were 29 visually impaired people and 29 sighted spouses. Visually impaired participants and their spouses were recruited from the Montreal Association for the Blind. Visually impaired participants ranged in age from 31 to 82. The median age was 67 years. For purposes of the present study, people with diagnoses leading either to peripheral and central field loss were selected. Table 1 presents a complete list of all visual diagnoses. Table 2 presents comorbid health problems. Visually impaired participants were accompanied by their spouses and demonstrated a working knowledge of the English language. There were 5 groups. Groups 1, 2, 3, and 5 contained 12 subjects each. Group 4 contained 10 subjects. Two subjects in group 4 were lost to follow-up. Group 1 consisted of visually impaired persons who participated alone. Group 2 was composed of spouses only. Group 3 involved the visually impaired person and spouse together. Group 4 was a peer group made up of several visually impaired participants and spouses who participated at the same time. Group 5 was the control group which consisted of visually impaired participants and spouses. No face-to-face contact occurred with the control group. The control group received neither of the interventions and was asked to answer the pretest and both post-tests by telephone. The control group answered the pretest, posttest 1 and posttest 2 at approximately the same time intervals as Groups 1 through 4. A total of six participants were lost to follow-up.

### **Materials**

Materials consisted of a separate consent form for the visually impaired person (Appendix A) and the spouse (Appendix B), which was read to all participants. The



**Table 1: Participant Demographics**

Median age	67 years	
Participant age range	31 years - 82 years	
No. of visually impaired female participants	12	
No. of visually impaired male participants	16	
<b>Diagnoses:</b>	<b>Frequency</b>	<b>%</b>
Macular Degeneration	7	24
Glaucoma	2	7
Cataracts	7	24
Diabetic Retinopathy	4	14
Retinal Blastoma	1	3.4
Best's Disease	1	3.4
Stargardt's Disease	1	3.4
Rod-Cone Dystrophy	1	3.4
Histoplasmosis	1	3.4
Retinitis Pigmentosa	1	3.4

**Table 2: Comorbid Health Problems**

	<b>Frequency</b>	<b>Percentage %</b>
Stroke	4	14
Depression	3	10.7
Emphezema	1	3.6
Trigeminal Neuralgia	1	3.6
Scleroderma	1	3.6
Hearing Impaired	3	10.7
Diabetes	4	14
Concussion	1	3.6
Parkinson's	2	7
Arthritis	12	20

Nottingham Adjustment Scale (Appendix C) was the questionnaire used for the pretest, posttest 1 and posttest 2. It (N.A.S.) was read to all participants. There were two interventions, a psychosocial (Appendix D) and a functional intervention. The McGill Low Vision Examination Form was used to begin the psychosocial segment of the study. The questions on this form were used to incite discussion regarding vision loss. The purpose of the psychosocial segment was to allow for the opportunity to express any thoughts and feelings that either party may have regarding vision loss in a conducive environment. Activities of daily living were used for the functional segment of the study, such as filling out a cheque, and finding a number in a telephone book ( Appendix E). These activities were selected in a previous study by individuals with low vision as being some of the everyday tasks that are difficult to contend with as a result of vision loss. The purpose of the functional segment was not to teach any new skills but, rather, to raise functional-skills awareness in the person with low vision and his/her spouse. Visual simulators made from welder's goggles, altered with styrofoam and cellophane wrap to mimic decreased visual acuity and loss of peripheral field, were used by the spouses in the functional segment.

### ***Nottingham Adjustment Scale***

The Nottingham Adjustment Scale (N.A.S.) is a 55-item questionnaire assessing psychosocial adjustment to vision loss. The N.A.S. consists of seven subscales. These include, anxiety and depression, self-esteem, attitudes toward vision loss, locus of control, acceptance, self-efficacy, and attributional style. The questionnaire is in a Likert-scale format, where a low score designates low adjustment and a high score is an indication of better adjustment with the exception of the anxiety/depression section, where a low score is indicative of low anxiety and depression and a high score is indicative of high levels of

depression and anxiety. The scores on the anxiety/depression subscale were reversed. This was done in order to keep the designation of scores consistent, where a high score indicates good adjustment and a low score indicates poor adjustment (see column 5 in Appendix F for reversed scores). The highest possible scores for each subsection on the N.A.S. can be seen in Table 3. For the purposes of this study, four questions were omitted. These questions deal with depression and suicidal ideation, which were beyond the scope of this study. The omitted questions are in section A, anxiety/ depression, number 8, 9, 11 and 12 (see Appendix C). Original Cronbach alpha coefficients for each of the seven subscales revealed high correlations, ranging from 0.72 and 0.92. The seven N.A.S. subscales are sensitive enough to evaluate psychosocial change and adaptation. However, the attributional style subsection has been criticized for producing response biases, yielding valid scores where there may be none (Eysenck, 1962; Oppenheim, 1992, as cited in Dodds, Flannigan, Ng, 1993). The aforementioned seven subscales constitute a global definition of the term adjustment (Dodds, et al. , 1993). The N.A.S. is presently being validated in French ( Appendix F).

### **Procedure**

Participants were read a consent form explaining the details of the study and were asked to sign it. A pretest was administered first, followed by the first intervention. Participants were randomly assigned to the sequence of interventions. Intervention A represents the psychosocial segment and intervention B represents the functional segment. Intervention order can be seen in Column 3 of the raw data sheet (Appendix F). Random assignment ensured that carryover effects from one of the interventions having been consistently administered first were not responsible for a possible observed effect. The functional segment consisted of performing activities of daily living. Spouses wore visual

**Table 3: Nottingham Adjustment Scale Scores**

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<b>Subscales</b>	<b>Highest Possible Scores</b>
Section – 1 – Anxiety / Depression	48
Section – 2 – Self-Esteem	45
Section – 3 – Attitudes	35
Section – 4 – Locus of Control	20
Section – 5 – Acceptance	45
Section - 6 – Self-Efficacy	40
Section – 7 – Attributional Style	30

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simulators while engaging in the activities of daily living, listed in Appendix E. The psychosocial portion of the study consisted of a semi-structured discussion that encouraged participants to express any concerns about vision loss. Subjects returned approximately four weeks later for the second intervention. Participants were required to answer posttest 1 before the second intervention was administered. Following the second intervention, subjects were told that they would be contacted in four weeks to answer some questions and for a five-minute debriefing session, where comments about their participation in the study could be expressed. Posttest 2 was administered at this time. The control group did not receive the interventions and was not asked to come to the M.A.B. to answer the questionnaire. The participants in the control group answered the pretest and both posttests by telephone. The purpose of including five groups was to determine whether benefits of a two-part functional and psychosocial intervention were enhanced in a group of individuals with low vision, in a group of spouses, in a group where husband and wife participated together, or in a peer group of several individuals sharing similar experiences.

## Results

Raw data consisted of pretest, posttest 1 and posttest 2 scores (Appendix F). Individual scores were tallied for each of the seven subscales in the Nottingham Adjustment Scale (N.A.S.). Means and standard deviations were calculated for each group (Table, 4, 5, 6, 7, 8, 9, 10). A preliminary analysis of variance (ANOVA) was conducted on the functional and psychosocial interventions to determine whether one was more effective than the other. No such differences were found, therefore an analysis of variance (ANOVA) was conducted on the order of intervention presentation.

A 3 (time) X 2 (intervention) X 5 (group) mixed factorial analysis of variance (ANOVA) was conducted on the raw data for the dependent measure (Table, 11, 12, 13, 14, 15, 16, 17). The data were screened for outliers and skewedness. All the variables were normally distributed. Significant within-subjects effects were followed by *post hoc t*-tests with a Bonferroni correction. Between-subjects effects were analyzed using the Scheffé *post hoc* test. Only significant differences are discussed.

A significant main effect of time was observed on the self-esteem subscale of the N.A.S. ,  $F(2, 94) = 4.102, p < 0.05$  (see Figure 1, Table 5 and Table 12). *Post hoc* analyses revealed a significant difference between pretest and posttest 1 for all groups,

**Table 4: Means and Standard Deviations for Anxiety / Depression on the N.A.S**

<b>Measure</b>	<b>Pretest</b>		<b>Posttest 1</b>		<b>Posttest 2</b>	
	<b><u>M</u></b>	<b><u>Sd</u></b>	<b><u>M</u></b>	<b><u>Sd</u></b>	<b><u>M</u></b>	<b><u>Sd</u></b>
<b>V.I.P.</b>	25.58	(6.72)	28.78	(4.14)	29.59	(5.91)
<b>Spouse</b>	26.66	(5.69)	27.36	(3.70)	26.59	(4.28)
<b>Couple</b>	24.16	(4.82)	25.61	(1.55)	26.59	(3.10)
<b>Peer</b>	25.50	(4.35)	27.48	(2.48)	25.94	(2.63)
<b>Control</b>	27.33	(1.61)	28.94	(1.87)	26.92	(3.62)



**Table 6: Means and Standard Deviations for Attitudes on the N.A.S.**

<b>Measure</b>	<b>Pretest</b>		<b>Posttest 1</b>		<b>Posttest 2</b>	
	<b><u>M</u></b>	<b><u>Sd</u></b>	<b><u>M</u></b>	<b><u>Sd</u></b>	<b><u>M</u></b>	<b><u>Sd</u></b>
<b>V.I.P.</b>	21.83	(4.68)	22.50	(4.60)	23.66	(3.91)
<b>Spouse</b>	22.91	(4.33)	22.75	(4.04)	23.41	(6.27)
<b>Couple</b>	23.91	(5.14)	22.50	(3.08)	21.60	(3.34)
<b>Peer</b>	21.60	(3.34)	24.20	(3.35)	25.30	(3.16)
<b>Control</b>	23.50	(3.60)	22.50	(4.03)	25.41	(3.91)

**Table 7: Means and Standard Deviations for Locus of Control on the N.A.S.**

Measure	Pre-test		Post-test 1		Post-test 2	
	<u>M</u>	<u>Sd</u>	<u>M</u>	<u>Sd</u>	<u>M</u>	<u>Sd</u>
<b>V.I.P.</b>	16.33	(2.60)	15.16	(2.62)	17.00	(2.13)
<b>Spouse</b>	16.33	(2.05)	15.25	(2.17)	16.33	(1.55)
<b>Couple</b>	16.00	(3.04)	15.41	(1.67)	16.41	(3.23)
<b>Peer</b>	14.90	(.99)	14.80	(1.87)	15.60	(1.64)
<b>Control</b>	17.33	(2.57)	18.00	(2.21)	18.41	(2.23)

**Table 8: Means and Standard Deviations for Acceptance on the N.A.S.**

<b>Measure</b>	<b>Pretest</b>		<b>Posttest 1</b>		<b>Posttest 2</b>	
	<b><u>M</u></b>	<b><u>Sd</u></b>	<b><u>M</u></b>	<b><u>Sd</u></b>	<b><u>M</u></b>	<b><u>Sd</u></b>
<b>V.I.P.</b>	32.58	(5.69)	33.33	(7.43)	32.66	(8.06)
<b>Spouse</b>	30.50	(7.79)	35.08	(6.34)	30.25	(5.86)
<b>Couple</b>	31.91	(8.24)	33.66	(6.06)	35.25	(7.33)
<b>Peer</b>	32.70	(1.82)	34.60	(3.20)	36.10	(3.10)
<b>Control</b>	32.00	(8.09)	33.00	(5.59)	1.47	(5.11)

**Table 9 : Means and Standard Deviations for Self-Efficacy on the N.A.S.**

Measure	Pretest		Posttest 1		Posttest 2	
	<u>M</u>	<u>Sd</u>	<u>M</u>	<u>Sd</u>	<u>M</u>	<u>Sd</u>
<b>V.I.P.</b>	29.66	(5.46)	32.00	(4.78)	31.50	(3.96)
<b>Spouse</b>	30.08	(3.89)	32.50	(4.50)	29.66	(6.59)
<b>Couple</b>	31.41	(4.90)	31.91	(2.50)	31.33	(6.80)
<b>Peer</b>	30.00	(3.23)	29.60	(3.16)	31.10	(3.17)
<b>Control</b>	27.25	(4.11)	30.58	(5.05)	30.41	(3.14)

**Table 10 : Means and Standard Deviations for Attributional Style on the N.A.S.**

Measure	Pretest		Posttest 1		Posttest 2	
	<u>M</u>	<u>Sd</u>	<u>M</u>	<u>Sd</u>	<u>M</u>	<u>Sd</u>
<b>V.I.P.</b>	18.75	( 2.22)	20.83	(3.85)	19.25	3.84)
<b>Spouse</b>	19.66	(2.49)	21.25	(4.26)	19.25	(4.65)
<b>Couple</b>	23.00	(2.98)	22.16	(2.82)	21.16	(4.58)
<b>Peer</b>	18.4	(1.64)	19.00	(3.01)	19.50	(2.32)
<b>Control</b>	20.58	(1.08 )	19.00	(2.55)	20.58	(1.08)

**Table 11: Analysis of Variance for Anxiety / Depression Subscale on the N.A.S**

<b>Source</b>	<b><u>SS</u></b>	<b><u>df</u></b>	<b><u>MS</u></b>	<b><u>F</u></b>
Group	101.221	4	25.305	1.052
Intervention	53.185	2	26.592	1.106
Group x Intervention	122.159	4	30.540	1.270
Error	1130.038	47	24.043	
Time	5.921	2	2.960	.226
Time x Group	116.658	8	14.582	1.114
Time x Intervention	57.790	4	14.447	1.104
Time x Group x Intervention	78.437	8	9.805	.749
Error	1230.471	94	13.090	

**Group (1-5)****Intervention (psychosocial/functional)****Time (pretest, posttest 1, posttest 2)**

**Table 12: Analysis of Variance for Self-Esteem Subscale on the N.A.S.**

<b>Source</b>	<b><u>SS</u></b>	<b><u>df</u></b>	<b><u>MS</u></b>	<b><u>F</u></b>
Group	319.550	4	79.887	1.093
Intervention	126.504	2	63.252	.865
Group x Intervention	443.528	4	110.882	1.516
Error	3436.758	47	73.123	
Time	134.192	2	67.096	4.102*
Time x Group	192.716	8	24.089	1.473
Time x Intervention	69.907	4	17.477	1.068
Time x Group x Intervention	19.963	8	2.495	.153
Error	1537.723	94	16.359	

\*  $p < .05$

**Group (1-5)**

**Intervention (psychosocial/functional)**

**Time (pretest, posttest 1, posttest 2)**

**Table 16: Analysis of Variance for Self-Efficacy Subscale on the N.A.S**

<b>Source</b>	<b>SS</b>	<b>df</b>	<b>MS</b>	<b>F</b>
Group	81.091	4	20.273	.519
Intervention	143.038	2	71.519	1.832
Group x Intervention	56.806	4	14.202	.364
Error	1834.623	47	39.035	
Time	21.124	2	10.562	.882
Time x Group	94.539	8	11.817	.987
Time x Intervention	35.853	4	8.963	.748
Time x Group x Intervention	114.124	8	14.265	1.191
Error	1125.707	94	11.976	

**Group (1-5)****Intervention (psychosocial / functional )****Time (pretest, posttest 1, posttest 2)**



**Table 17: Analysis of Variance for Attributional Style Subscale on the N.A.S.**

<b>Source</b>	<b>SS</b>	<b>df</b>	<b>MS</b>	<b>F</b>
Group	196.630	4	49.158	2.718*
Intervention	73.044	2	36.522	2.019
Group x Intervention	37.596	4	9.399	.520
Error	850.007	47	18.085	
Time	24.309	2	12.155	2.248
Time x Group	104.991	8	13.124	2.428*
Time x Intervention	69.150	4	17.288	3.198*
Time x Group x Intervention	59.416	8	7.427	1.374
Error	508.162	94	5.406	

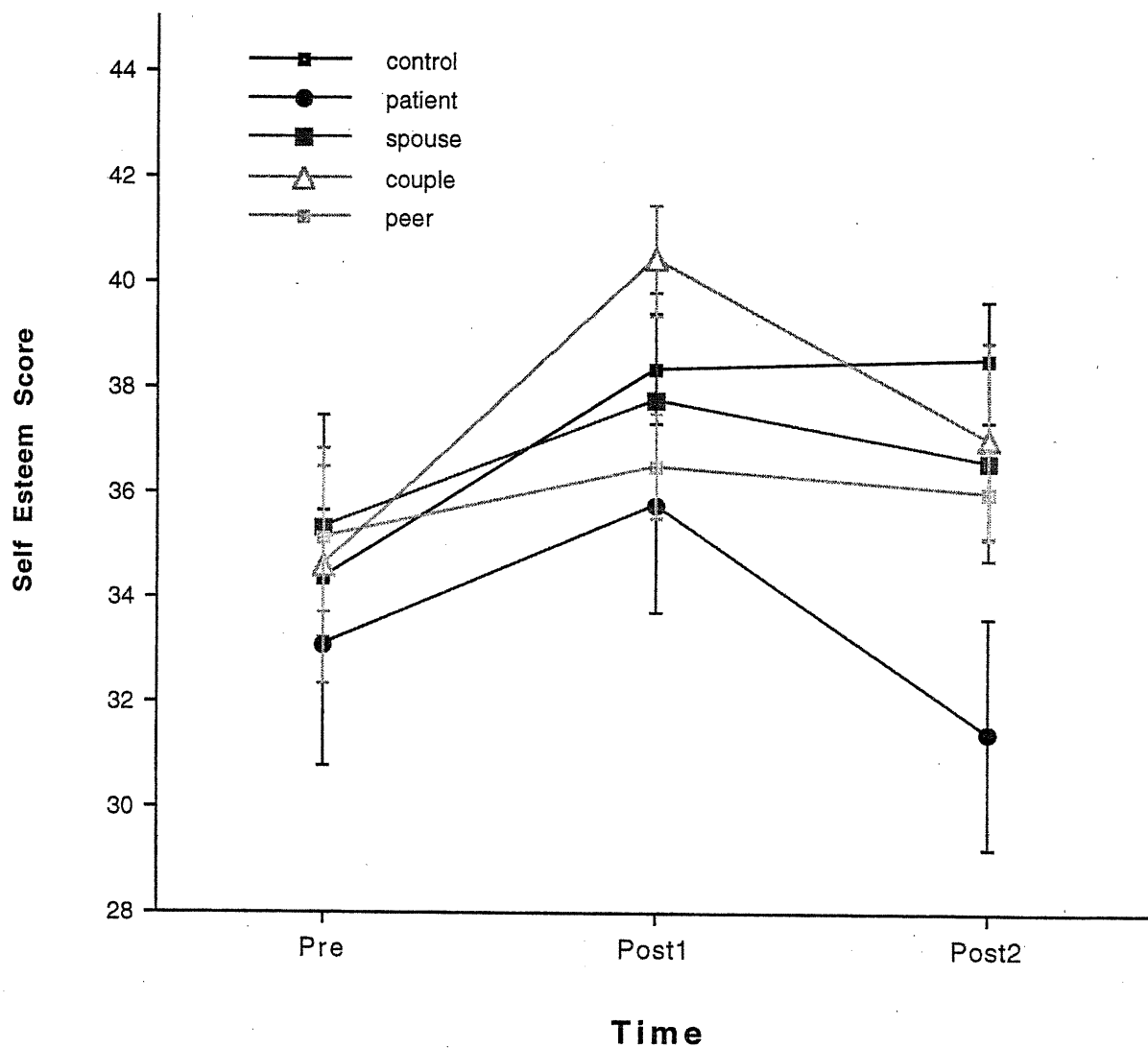
**p < .05**

**Group (1-5)**

**Intervention (psychosocial/functional)**

**Time (pretest, posttest 1, posttest 2)**

### Self Esteem by Group as a Function of Time



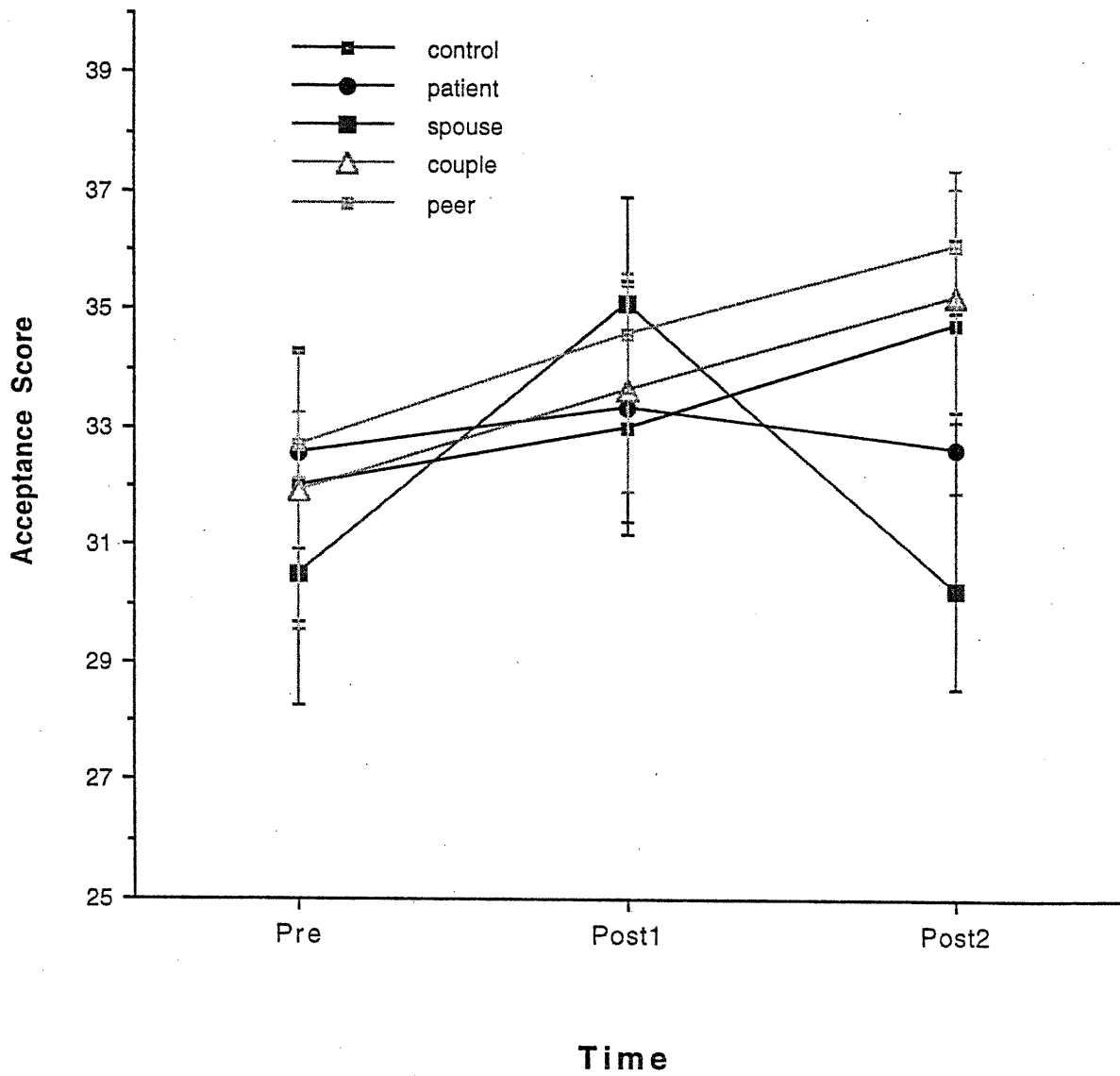
**Patient = Visually Impaired Person**

Figure 1. Performance by group as a function of time on the self-esteem subscale of the Nottingham Adjustment Scale (N.A.S)

$t(57) = -4.84, p < 0.001$ , as well as a significant difference between posttest 1 and posttest 2 for all groups,  $t(57) = 2.74, p < 0.01$ . Pretest scores were lower than posttest 1 scores and posttest 1 scores were higher than posttest 2 scores.

A significant interaction between time and group was observed in the acceptance subscale,  $F(8, 94) = 2.33, p < 0.05$  (see Figure 2, Table 8 and Table 15). *Post hoc* analyses revealed that there was a difference between pretest and posttest 1,  $t(10) = -3.34, p < 0.01$ , and between posttest 1 and posttest 2,  $t(10) = 2.83, p < 0.05$  in the spouse group. Posttest 1 scores were higher than both pretest scores and posttest 2 scores. Pretest scores and posttest 2 scores are almost identical, indicating that participant performance in the spouse group reverted back to baseline. A significant interaction was found between group and intervention,  $F(4, 47) = 3.292, p < 0.05$ . *Post hoc* analyses revealed that there was a difference between intervention order in the visually impaired group,  $t(10) = 2.75, p < 0.05$ , where intervention A (psychosocial) yielded higher scores from pretest to posttest 1 and posttest 2 ( $M = 35.83, 38.67, 36$ ) than did intervention B (functional), ( $M = 29.33, 28, 29.33$ ) when administered first. Upon examining the raw data, it can be seen that the scores for all participants in the functional intervention were lower at pretest time than were the scores for the psychosocial intervention at pretest time. This lag in scores was maintained through posttest 1 and

### Acceptance by Group as a Function of Time



**Patient = Visually Impaired Person**

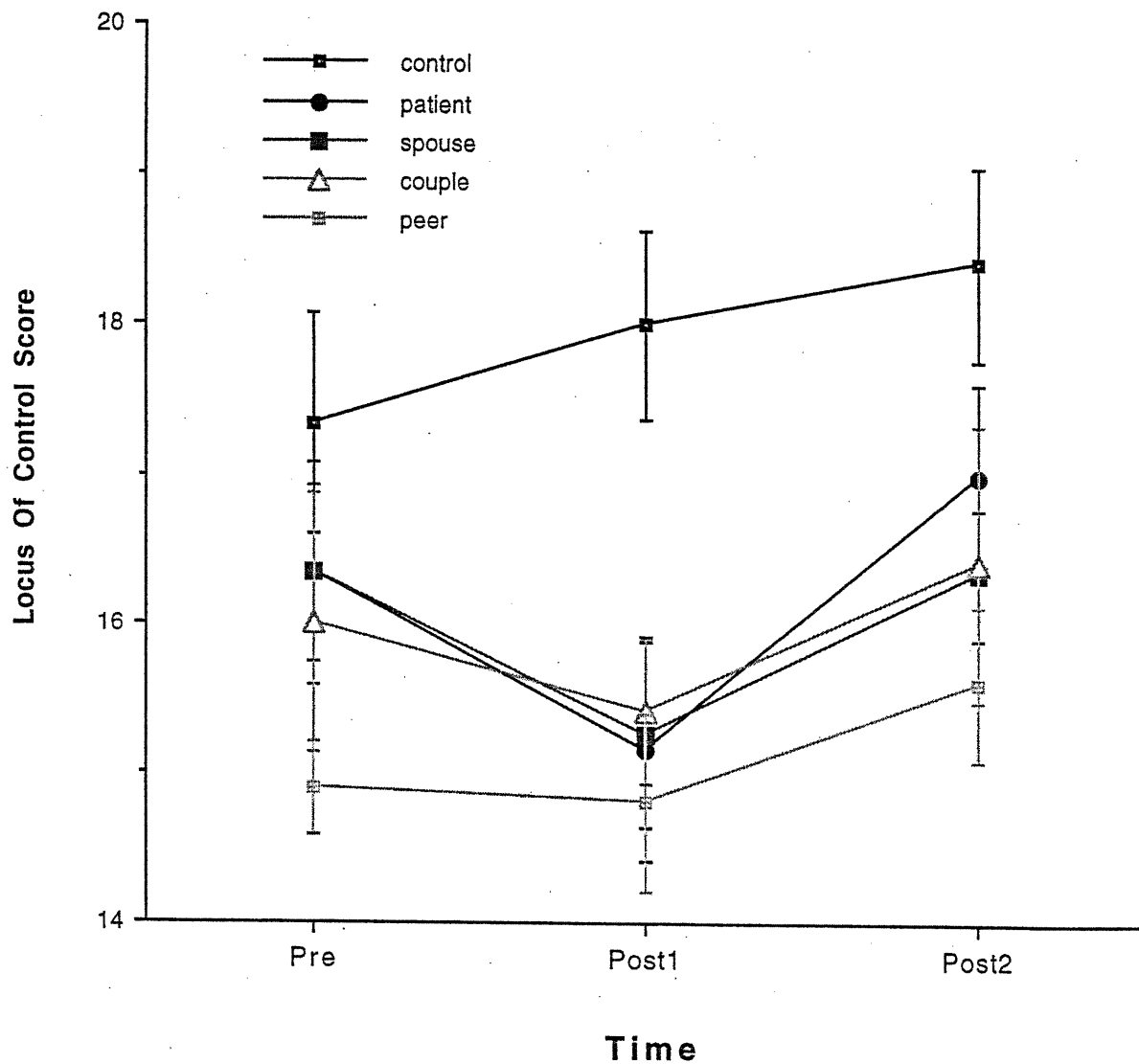
Figure 2. Performance by group as a function of time on the acceptance subscale of the Nottingham Adjustment Scale (N.A.S)

posttest 2 testing times. Although this difference is apparent upon examining the raw data, it is not statistically significant.

A significant effect of time was found for the locus of control subscale,  $F(2, 94) = 3.564$ ,  $p < 0.05$  (see Figure 3, Table 7 and Table 14). *Post hoc* analyses revealed a difference between posttest 1 and posttest 2, with posttest 2 scores being greater than posttest 1 scores,  $t(57) = -3.23$ ,  $p < 0.01$ . A significant group effect was found,  $F(4, 47) = 3.916$ ,  $p < 0.01$ . The peer group differed from the control group with the control group having higher scores than the peer group.

A significant time x group interaction was observed in the attributional style subscale, with group differences found at pretest,  $F(8, 94) = 2.428$ ,  $p < 0.05$  (see Figure 4 Table 10 and Table 17). *Post hoc* analyses revealed a significant difference between the visually impaired group and the couple group. The visually impaired group scored lower than the couple group with a mean difference of 4.25. The mean difference between the visually impaired group and control group was 3.58. The couple group had higher scores than the spouse group, with a mean difference of 3.33. The couple group also scored higher than the peer group, with a mean difference of 4.6. The peer group scored lower than the control group, with a mean difference of 3.93. A time x intervention order interaction was found,  $F(4,94) = 3.198$ ,  $p < 0.05$  (see Figure 5). *Post*

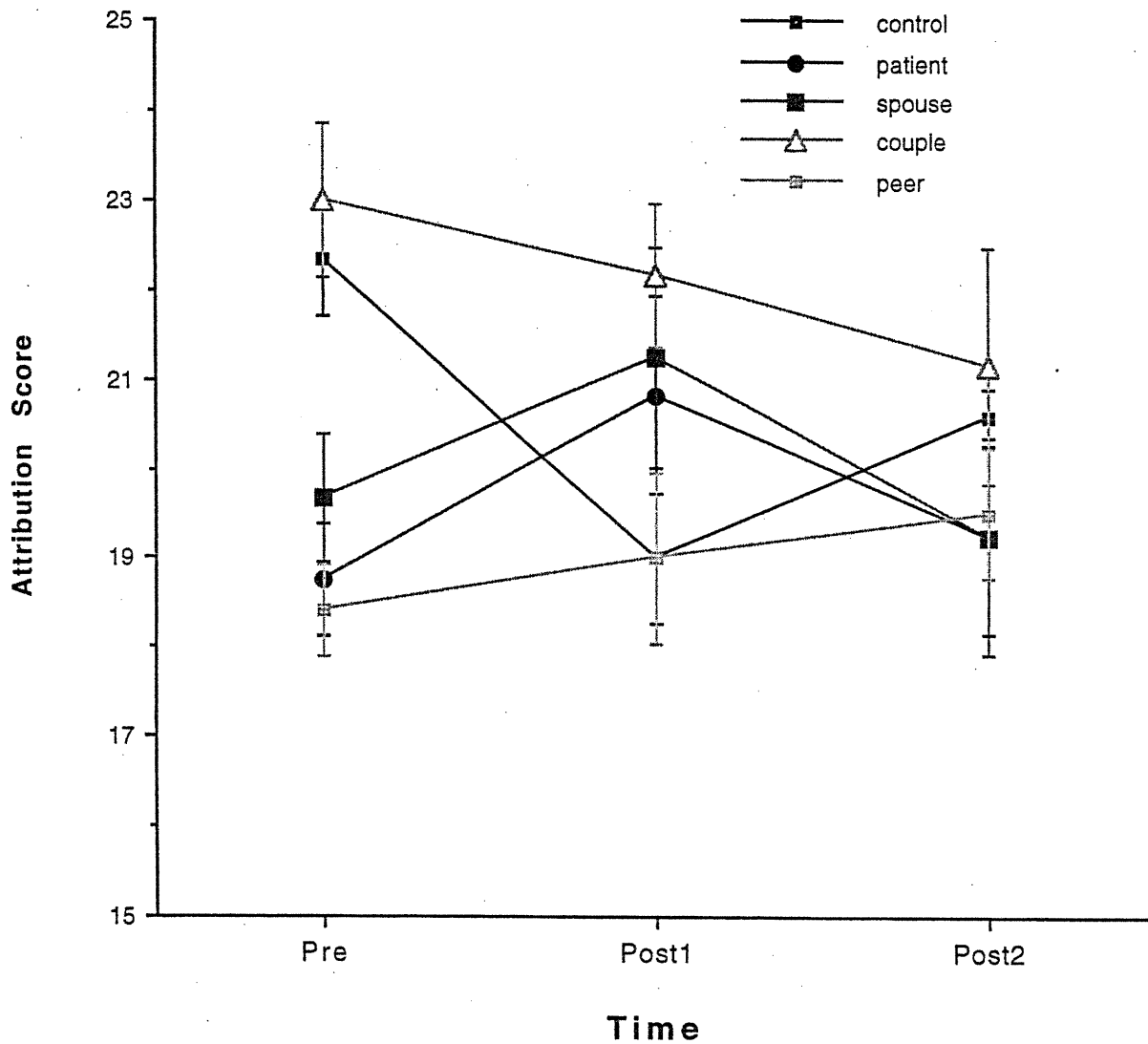
### Locus of Control by Group as a Function of Time



**Patient = Visually Impaired Person**

Figure 3. Performance by group as a function of time on the locus of control subscale of the Nottingham Adjustment Scale (N.A.S)

### Attribution by Group as a Function of Time



**Patient = Visually Impaired Person**

Figure 4. Performance by group as a function of time on the attributional style subscale of the Nottingham Adjustment Scale (N.A.S)

*hocs* revealed that the scores decreased from posttest 1 to posttest 2,  $t(27) = 3.12$ ,  $p < 0.01$ , for intervention B (functional) only. A statistically significant difference was found with intervention type, where the functional intervention yielded higher scores than did the psychosocial intervention  $M = 20.79$  and  $M = 19.67$ ,  $t(57) = 2.322$ ,  $p < 0.01$ .

No statistically significant differences were found for the anxiety/depression subscale, attitudes subscale and self-efficacy subscale for any of the groups or times (see Table 4,6,9,11,13,16 and Appendix G).



## Discussion

Participants had higher scores from pretest to posttest 1 on the self-esteem subscale. The spouse group showed an improvement from pretest to posttest 1 on the acceptance subscale. A decrease in scores from posttest 1 to posttest 2 was observed in both conditions. Scores reverted back to baseline from posttest 1 to posttest 2. A possible explanation for this occurrence may be the short duration of the interventions. The time allotted for each intervention may not have been sufficient to engender any long-term change. In the present study, a pretest was administered first, followed by an intervention. Approximately four weeks after the first intervention, participants answered a posttest followed by the second intervention. Again, four weeks later, the final posttest was administered by telephone. Perhaps the delay in posttest administration did not allow for any changes to be detected, since scores reverted back to baseline over the four-week waiting period.

Moreover, personality variables such as self-esteem and acceptance are byproducts of one's attitudes. Fazio and Williams (1986) stated that attitudes are developed over the course of a lifetime, from social learning, instrumental conditioning, modeling and personal experiences. Additionally, it is difficult to exert an effect on overall psychosocial functioning in a restricted time frame. Psychosocial variables such

as self-esteem, locus of control, depression and attitudes are difficult to change, since they are based on a lifetime of coping and personality characteristics.

There was an improvement in scores from posttest 1 to posttest 2 on the locus of control subscale. Perhaps participants felt more in control of their present situation, given the thought-provoking nature of the interventions. According to Rotter (1966), behavior occurs as a function of the expectancy that a given act will result in reinforcement or punishment and the value assigned to that particular reinforcement or punishment. Beliefs about who or what controls these meaningful reinforcements in life are developed. Individuals who believe that their own actions determine the outcome of a situation have a stronger sense of control than individuals who attribute what happens as a consequence of the external, uncontrollable environment. These individuals have a less solid sense of control over their personal life events. On the locus of control subsection of the N.A.S., participants may have had a chance to review the deeper implications of statements such as, "It's what I do to help myself that is going to make all the difference." From a functional perspective, a visually impaired participant may, at first, respond negatively. The same statement may later be interpreted on a more instrumental level, implying that the person can make accommodations that reduce his/her reliance on vision as a primary means toward independence. The respondent may realize that the statement does not necessarily apply to medical intervention alone.

Therefore, the manner in which the respondent interprets this type of statement may affect the overall locus of control scores.

For attributional style, a significant difference was found at pretest, with the couple group having better scores than the visually impaired group. The couple group also had higher scores than the spouse group and the peer group at pretest. Perhaps having the support and companionship of a spouse is helpful in maintaining a solid and stable attributional style with respect to life events, such as vision loss.

A significant obstacle in obtaining overall significance in the present study was the small sample size of 58 participants. The 58 participants had to be assigned to one of five groups, reducing power. It was difficult to recruit participants in this age group, especially since they had to travel some distance twice during the winter months. Future studies may consider using a much larger sample size to correct this problem.

A power analysis was conducted to determine the sample size needed to obtain significance at the 80% level (Appendix H). The power analysis was a 5 x 3 fixed effects ANOVA. The study would have to include 14 participants per cell, in a balanced design, for a total of 210 cases. The analysis is non-directional, indicating that an effect size in either direction will be interpreted. Factor A would require 5 levels, with 42 cases per level, with an effect size is 0.25, yielding power of 0.81. Factor B would

require 3 levels, with 70 cases per level. The effect size is 0.25, yielding power of 0.89.

An interaction (AB) would require an effect size of 0.25, yielding power of 0.70.

Approximately 200 people were contacted by telephone to participate in the present study. Of the 200 people contacted, only 58 agreed to participate. In order to obtain a power level of 80%, several thousand people would have to be contacted in order to obtain a sample size of approximately 200 participants. Psychosocial research is one of the greatest challenges, given the difficulties in recruitment, content validity, and interpreting results. The qualitative component of psychosocial research can enhance the understanding of the results, provided that the information is interpreted within the context of the statistically significant results. Additionally, if the findings are not as hypothesized, it is difficult to isolate the exact reason for which significance in the direction predicted was not obtained.

Other problems in obtaining significance may be the danger of a volunteer effect and informed consent. Individuals had to be given a summary of the purpose of the research. Those who agreed to participate may not have had any significant adjustment problems, whereas those who refused may have been in need of intervention. For example, when people are asked to participate in a study of depression, individuals who are genuinely depressed may be much more reluctant to participate than individuals who

are not depressed. Informed consent often leads to the loss of the low end of the population distribution.

People tend to self-select, which leads to sampling bias. Assuming that individuals who agreed to participate were at midrange with respect to their adjustment to vision loss, it becomes increasingly difficult to detect change. Any experimentally sound intervention has the potential of exerting an effect on the sample tested. An intervention designed to teach mobility skills to newly visually impaired persons may yield greater measurable success than the same mobility instruction for individuals who have been visually impaired for some time.

Additionally, participants may have improved, but perhaps not enough to be detected by an alpha level of 0.05. Statistical analyses can mask important findings. Several subjects did show an improvement in scores from pretest to posttest 1 and again from posttest 1 to posttest 2. Perhaps the participants who demonstrated this consistent upward change in scores were too few to be detected statistically. Moreover, scores may have consistently improved from pretest to posttest 2, however, minimally.

The content of some of the questions on the Nottingham Adjustment Scale may have led some participants to respond in a favorable direction. Some of the questions probed the core of a person's self-esteem issues. It is not easy to admit to anyone, even for the purposes of research, that you wish you had more respect for yourself or that you

feel you were not worth much. A possible explanation for this occurrence may be that individuals who are very aware of their social environment may monitor their response closely, and respond in a socially desirable manner. High self-monitors are more likely to respond in accordance with what they believe to be more socially acceptable. Snyder (1974) observed that high self-monitors regulate their behavior according to the present situation. Perhaps participants in the peer group were affected by this phenomenon, since they had to respond to the questions of the N.A.S. in a group situation, where other participants were an audience to their responses.

Several participants reported that their vision worsened significantly from the time they agreed to participate to the second posttest time. This may have influenced their scores. If vision deteriorates and then remains stable for a certain period of time, it allows the person to make necessary changes and to come to terms with the visual loss. An individual who loses vision in increments is always a step behind, never quite managing to adapt to a particular stage of vision loss. Depression and anxiety are often the consequence of unstable and worsening vision. Two participants in the present study stated that their vision was on a continuous downslide.

Self-esteem is a critical aspect of human functioning. It is determined by the way we perceive ourselves and by how we believe others perceive us (Moretti & Higgins, 1990). Felson (1989) demonstrated that children tend to evaluate themselves,

in part, on the basis of how they believe their parents evaluate them. Perhaps the low self-esteem and self-efficacy scores of some of the visually impaired participants are due, in part, to the perceptions they have about how their spouses view them. Perhaps future work may consider examining the perceptions that visually impaired persons have of themselves, how they believe their spouses perceive them and also the actual perception of the sighted spouses toward their visually impaired others.

Individuals with low self-esteem and low self-efficacy tend to attribute successes to outside factors which are not in their control and to attribute failure to personal, internal factors (Baumgardner, et al., 1989). Attributing successes to outside factors and failures to personal factors does not promote a person's sense of competence or control over their life events. Individuals who had low scores on the locus of control subscale, and on the attributional style subscale may be victim to this type of cognitive strategy of explaining behavior. These cognitive strategies are not conducive to proper acceptance and adjustment. Perhaps further rehabilitation efforts could incorporate activities which clearly demonstrate to the visually impaired person that successes are indeed a consequence of personal effort and will.

Questions pertaining to suicidal ideation were omitted, since they were beyond the scope of this study. This makes it impossible to determine whether there were participants who were clinically depressed and in need of professional intervention.

Furthermore, comorbidity may have confounded subject responses. All participants had a visual impairment along with at least one additional chronic health concern. With an elderly age group, it becomes increasingly difficult to isolate one variable, such as vision impairment. It is not known whether the comorbid health concerns affected the responses that participants gave on the Nottingham Adjustment Scale (N.A.S.).

The N.A.S. was used as the pretest and both posttest measures. A memory effect may have accounted for participants who responded consistently throughout. The concept of selective memory has been used to explain a person's inclination to attend to information that is consistent with already existent attitudes and to ignore information that goes counter to the already developed attitudes (Olson & Zanna, 1993). It is difficult to determine whether the consistent responses were a result of a memory effect or a consequence of the stability of attitudes.

Measurement error may have increased with each administration of the N.A.S., especially given the small sample size. The exclusive use of the N.A.S. may not have been the best option. In future studies, perhaps the Adaptation to Age-Related Vision Loss Scale (AVL) (Horowitz & Reinhardt, 1998) or the Psychosocial Adjustment to Illness Scale (Derogatis, 1983) may be used in addition to the N.A.S. Furthermore, the inclusion of a personality hardiness subscale may be useful as an indicator of successful



adjustment to low vision rehabilitation, as evidenced by other studies (Kobasa & Puccetti, 1983; Robbins & McMurray, 1988). The Likert scale format of the N.A.S. was tedious and difficult for some of the participants to follow.

Since both client and spouse answered the N.A.S., the fully sighted spouse was asked to answer the questions in section E – Acceptance, with respect to how they perceived their spouse's standing on these points. The visually impaired spouse answered the questions with respect to how they perceived themselves. For example, "Because of my eye problems, I feel miserable most of the time?" The fully sighted spouse was asked, "Because of your wife's / husband's visual problem, does she / he feel miserable most of the time?" Since the questionnaire was read to all participants, this did not pose any methodological problems.

The psychosocial and functional intervention of the present study may be useful in identifying participants who need intervention and those who do not. The seven N.A.S. subscales are regarded as constituting a global definition of the term adjustment (Dodds, et al., 1993). The NAS has proven useful in detecting individuals who are suffering from depression and in evaluating the psychological impact of rehabilitation interventions, such as counseling or skill training ( Dodds, et al.,1992; Eysenck, 1962; Oppenheim, 1992, as cited in Dodds, Craig, & Flannigan, 1996).

Moreover, the psychosocial and functional interventions lasted approximately 90 minutes. This may not have been enough time to engender change in adjustment. Perhaps future research could emphasize a lengthier and more comprehensive intervention, allowing the participants more time to assimilate what they have experienced.

Three of the visually impaired participants were under the age of 65 and had young children. The issues concerning a younger visually impaired population cannot be examined in the same context as that of the elderly visually impaired population. The needs and problems specific to this population require separate examination and intervention. Since there were only three younger participants, this did not allow for adequate analysis of the needs and concerns specific to this age group. Moreover, addressing this age group was beyond the scope of the present study.

Low vision rehabilitation is complex and multidimensional. It requires that each individual have a program designed for his or her specific needs. This does not entail that, after each rehabilitation success, the template is thrown out and rehabilitation workers must devise programs from scratch. A modular approach may be useful. A visually impaired person and spouse begin by providing a comprehensive biography of what life was like before vision loss and what they would realistically want life to be after vision loss. The rehabilitation team uses this information to select an appropriate

regimen. The length and goals of rehabilitation should be determined by the visually impaired person and the rehabilitation staff. This will help ensure that the individual's goals and rehabilitation staff objectives are similar. Additionally, the visually impaired person should actively participate in finding solutions in accomplishing difficult tasks. The rehabilitation staff serves as facilitators toward those solutions. Finally, the visually impaired person and rehabilitation instructor may co-design take-home assignments so that problem areas can be addressed. The homework assignment involves the family taking on the role of the rehabilitation coach, encouraging and supporting the efforts and the decisions made by the visually impaired individual. Additionally, once rehabilitation goals have been obtained, the visually impaired person and those intimately involved in his/her life should have the option of returning if there is a need to do so.

Future research could continue to consider the multifaceted nature of low vision rehabilitation and the different implications that vision loss has on various age groups. Moreover, culture cannot be neglected in the adjustment and rehabilitation to vision loss either (Katzko, Steverink, Dittman-Kohli & Herrera, 1998). Some cultures tend to be more collectivistic, while others are more individualistic. This has an impact on how services are received. One must be cautious in designing rehabilitation programs tailored to meet the needs of specific cultures and age groups. There are inherent differences that are part of the culture and, therefore, part of the person living within that culture.

These issues need to be acknowledged and understood in order to offer effective interventions. Furthermore, a significant relationship exists between poverty status and the prevalence of vision impairment among the elderly (Brennan, Horowitz, Reinhardt, Goodman, & Cantor, 1999). This may be an area requiring additional attention, since the elderly are more likely to experience vision loss and a decline in financial independence. By identifying risk factors, one can be better prepared to deal with future vision-related concerns. Lastly, outcome measures that rely on subjective reports and objective measures are important in assessing the success of any rehabilitation regimen.

Furthermore, if each person living with a vision impairment educated those in their immediate environment about the consequences, perhaps there would be more empathy, fewer people trying to pass as sighted, and less reluctance to use assistive devices and travel aids. Explaining vision loss to people who are fully sighted may be beneficial in preventing uncomfortable situations. Part of the problem is that people do not understand the multitude of distinguishing characteristics of the visually impaired population. There is a tendency to think of sight loss in black and white terms. If someone is visually impaired, then he/she can't see. Therefore, he/she must be blind. The media propagate this confusion. It is not easy to think of partially sighted characters on television, but totally blind persons or characters come easily to mind—Stevie Wonder, Roy Orbison, Al Pacino in "Scent of a Woman".

Another area of concern pertains to the various definitions of vision loss. Terms such as impairment, disability and handicap help professionals in the field of vision classify visual problems with respect to severity and eligibility for services. However, these terms are often less helpful and less meaningful to the person who is labeled by them than to the person classified under them. A person with a vision impairment may not appreciate the subtle difference between the terms "disorder" and "impairment" but may be quite surprised to have the term "handicapped" applied to him/her. Since the term "handicap" often implies helplessness, this person may not have thought about himself/herself as handicapped until he/she was so labeled. Using terminology that is clear, unambiguous, helpful and useful to the clinician, as well as to the person with vision loss and his/her family is part of the education and rehabilitation process. Program planning requires that language and terminology be consistent, clear and meaningful to all those involved. In essence, this will facilitate the manner in which interventions are designed and administered and in the overall utility of the rehabilitation process.

### **Conclusions**

In summary, the results of this study indicate that there is a continued need to establish guidelines for effective vision rehabilitation. Additionally, it is necessary to

include the family and spouse in any rehabilitation effort. Workers in the field of vision rehabilitation need to combine their efforts and aptitudes in creating a comprehensive and effective program. An eclectic approach, involving the expertise, skill and knowledge of various professions can enhance client satisfaction and the final rehabilitation outcome. Furthermore, it is necessary to determine the effectiveness of any rehabilitation effort on a qualitative and quantitative level. At present, efforts are being made to establish a global rehabilitation assessment tool (Head, et al., 2000). Ultimately, the objective of rehabilitation is to help the visually impaired person adapt to life with vision loss, aid in communication enhancement between the affected person and his/her social environment, and provide comprehensive and personalized care to promote optimal functioning and life satisfaction.

The area of vision rehabilitation is complex and multidimensional. Unlike acute health concerns, chronic problems are much more complicated to contend with for all those involved. The objective is to provide individuals with vision loss with the necessary tools to help themselves. The end result is a functional and satisfied person who can resume life at a maximal level of functioning that is personally satisfying.

This may seem like an idyllic portrayal of low vision rehabilitation. However, it is a realistically attainable one. Without prior efforts and accomplishments in the field of rehabilitation, present day advances would not be possible. We need to learn from the

strengths and weaknesses of past models. As Saint Francis of Assisi said, " Start by doing what is necessary, then what is possible and suddenly you are doing the impossible."

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**APPENDIX A**  
**CONSENT FORM FOR THE VISUALLY IMPAIRED PARTICIPANT**



**Sir Mortimer B. Davis Jewish General Hospital Department of Ophthalmology  
and the Montreal Association for the Blind**

**Title: Adjustment to Vision Loss after a Functional and Psychosocial  
Intervention in Low Vision Patients and their Spouse**

This is a student project conducted in the department of ophthalmology at the Sir Mortimer B. Davis Jewish General Hospital and at the Montreal Association for the Blind. The purpose of this study is to investigate the effects a task oriented and discussion on the effects of low vision have on the psychological and social adjustment to visual impairment in both the patient and the family member with the help of visual simulators. This may provide important information for low vision patients and family members on how to communicate different needs and emotions.

If you agree to participate in this study, we will provide you with a consent form and a questionnaire to complete. The consent form and questionnaire will require approximately 15 minutes of your time. Your task may end after this questionnaire or you may be asked to participate in some preplanned activities and in a discussion group. This will be determined in a random manner. For example, you may be asked to locate a telephone number in the telephone book. This functional segment will require approximately 90 minutes of your time. You may be performing these activities in the company of other individuals, alone or with your spouse only. On a subsequent visit, you will be asked to complete a brief questionnaire. This questionnaire will require 10 minutes to complete. You will then be asked to take part in a discussion session where your concerns related to your vision may be expressed. You may be performing this segment with other individuals, alone or with your spouse. The time required for this segment is

approximately 90 minutes. Approximately four weeks after having completed this intervention, you will be contacted by telephone to answer another brief questionnaire. This questionnaire will require 20 minutes of your time. The order of the two interventions may vary. A 10 minute debriefing session will be part of the telephone contact, where you are invited to address concerns and make commentary about the study.

Information that you provide will be kept confidential. Your responses on the questionnaires will not be given to your ophthalmologist. Following the completion of the study, you may be informed of the results, if you so wish. Should the results of this study be published, neither your name nor any other information about you will be used. Study data will not be included in your clinical chart but will be kept in a separate file, identifiable by file number only. If you would like to discuss issues that are a result of your participation in this study, a qualified professional will be made available to you.

Your participation is voluntary and you remain free to withdraw from participating at any time. Your decisions will not affect the care you receive from your ophthalmologist. Your signature indicates that you have understood the consent form and that you agree to participate in this study. A copy of this form will be given to you, if you so wish.

If you require more information, please contact Dr. Overbury at [REDACTED] at the Jewish General Hospital and Maria Moschopoulos at the Montreal Association for the Blind at 489-8201 ext. 1022.

Researcher: **Patrizia Ferraresi**

Supervisors: **Dr. Olga Overbury & Dr. Jacques Gresset**

**Name**

**Date**

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**Signature**

**Telephone number**

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**APPENDIX B**  
**CONSENT FORM FOR THE SPOUSE**

**Sir Mortimer B. Davis Jewish General Hospital Department of Ophthalmology  
and the Montreal Association for the Blind**

**Title: Adjustment to Vision Loss after a Functional and Psychosocial  
Intervention in Low Vision Patients and their Spouses**

This is a student project conducted in the department of ophthalmology at the Sir Mortimer B. Davis Jewish General Hospital and at the Montreal Association for the Blind. The purpose of this study is to investigate the effects a task oriented intervention and discussion on the effects of low vision have on the psychological and social adjustment to visual impairment in both the patient and spouse with the help of visual simulators. This may provide important information for low vision patients and family members on how to communicate different needs and emotions.

If you agree to participate in this study, we will provide you with a consent form and a questionnaire to complete. The consent form and questionnaire will require approximately 15 minutes of your time and will be read to you. Your task may end after this questionnaire or you may be asked to participate in some preplanned activities and in a discussion group. This will be determined in a random manner. For example, you may be asked to locate a telephone number in the telephone book. While performing these tasks, you will be given visual simulators that mimic the visual situation of your spouse. This functional segment will require approximately 90 minutes of your time. You may be performing these activities in the company of other individuals, alone or with your spouse. On a subsequent visit, you will be asked to answer a brief questionnaire. This questionnaire will require 10 minutes to complete. You will then be asked to take part in a discussion session where your concerns related to your vision may be expressed. You

may be performing this segment with other individuals, alone or with your spouse. The time required for this segment is approximately 90 minutes. You will be contacted by telephone approximately four weeks after having completed the intervention to answer some general questions and discuss any concerns you may have. This contact will require 20 minutes of your time. The order of the interventions may vary. A 10 minute debriefing session will be part of the telephone contact, where you are invited to address concerns and make commentary about the study.

Information that you provide will be kept confidential. Your responses on the questionnaires will not be given to your spouse's ophthalmologist. Following the completion of the study, you may be informed of the results. Should the results of this study be published, your name nor any other information about you will be used. Study data will not be included in your spouse's clinical chart but will be kept in a separate file. If you would like to discuss issues that are a result of your participation in this study, a qualified professional will be made available to you.

Your participation is voluntary and you remain free to withdraw from participating at any time. Your decisions will not affect the care your spouse receives from his/her ophthalmologist. Your signature indicates that you have understood the consent form and that you agree to participate. A copy of the form will be given to you, if you so wish.

If you require additional information, please contact Dr. Overbury at [REDACTED] at the Jewish General Hospital or Maria Moschopoulos at the Montreal Association for the Blind at 489-8201 ext. 1022.

Researcher: **Patrizia Ferraresi** Supervisors: **Dr. O. Overbury & Dr. J. Gresset**

\_\_\_\_\_  
Name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Telephone number

**APPENDIX C**  
**NOTTINGHAM ADJUSTMENT SCALE**

## Section A ANXIETY/DEPRESSION

N= not at all; n= no more than usual; m= rather more than usual; M= much more than usual.

(Recently = in the last few weeks).

	N	n	m	M
1. Have you recently been feeling run down and out of sorts?	4	3	2	1
2. Have you recently felt that you are ill?	4	3	2	1
3. Have you recently felt constantly under strain?	4	3	2	1
4. Have you recently found everything getting on top of you?	4	3	2	1
5. Have you recently been feeling nervous or strung up all the time?	4	3	2	1
6. Have you recently been thinking of yourself as a worthless person?	4	3	2	1
7. Have you recently felt that life is entirely hopeless?	4	3	2	1
8. Have you recently felt that life is not worth living?	4	3	2	1
9. Have you recently thought of the possibility of doing away with yourself?	4	3	2	1
10. Have you recently found at times you couldn't do anything because your nerves were so bad?	4	3	2	1
11. Have you recently found yourself wishing that you were dead and away from it all?	4	3	2	1
12. Have you recently found that the idea of taking your life kept coming into mind?	4	3	2	1

**Section B SELF-ESTEEM.** Client must agree/disagree with the following statements.

A= strongly agree; a= agree; \*= don't know; d= disagree; D= strongly disagree

	A	a	*	d	D
1. On the whole, I am satisfied with myself.	5	4	3	2	1
2. At times I think I am no good at all.	1	2	3	4	5
3. I am able to do things as well as most other people.	5	4	3	2	1
4. I certainly feel useless at times.	1	2	3	4	5
5. I feel that I do not have much to be proud of.	1	2	3	4	5
6. I feel that I am a person of worth; at least on an equal plane with others.	5	4	3	2	1
7. I wish I could have more respect for myself.	1	2	3	4	5
8. All in all, I'm inclined to feel that I'm a failure.	1	2	3	4	5
9. I take a positive attitude towards myself.	5	4	3	2	1

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**Section C. ATTITUDES.** Client must agree/disagree with the following statements.

	A	a	*	d	D
1. Visually impaired people are used to failing at most things they do.	1	2	3	4	5
2. Most visually impaired people are constantly worried about what might happen to them.	1	2	3	4	5
3. Most visually impaired people keep a lot of things to themselves.	1	2	3	4	5
4. Most visually impaired people feel that they are worthless.	1	2	3	4	5
5. Visually impaired people are generally more easily upset than sighted people.	1	2	3	4	5
6. Most visually impaired people are dissatisfied with themselves.	1	2	3	4	5



7. Most visually impaired people believe that sight loss is the worst thing that could happen to them.

1      2      3      4      5

**SectionD. LOCUSOFCONTROL.** Client must agree/disagree with the following statements.

	A	a	*	d	D
1. It's what I can do to help myself that's really going to make all the difference.	5	4	3	2	1
2. It's up to me to make sure I make the best of my future in these circumstances.	5	4	3	2	1
3. My own contribution to my rehabilitation doesn't amount to much.	1	2	3	4	5
4. I have little or no control over my progress from now on.	1	2	3	4	5

**SectionE. ACCEPTANCE.** Client must agree/disagree with the following statements.

	A	a	*	d	D
1. Because of my eye problems, I feel miserable most of the time.	1	2	3	4	5
2. It makes me feel very bad to see all the things sighted people can do which I cannot.	1	2	3	4	5
3. Because of my eye problem, I have little to offer other people.	1	2	3	4	5
4. Because of my eye problem, other people's lives have more meaning than my own.	1	2	3	4	5
5. I feel satisfied with my abilities, and my eye problem doesn't bother me too much.	5	4	3	2	1
6. Almost every area of life is closed to me because of my eye problem.	1	2	3	4	5
7. My eye problem prevents me from doing just about everything I really want to do and from being the kind of person I really want to be.	1	2	3	4	5
8. In just about everything, my eye problem is so annoying that I can't enjoy anything.	1	2	3	4	5

9. Often there are times when I think about my eye problem, and it upsets me so much that I am unable to think of or do anything else.
- |  |   |   |   |   |   |
|--|---|---|---|---|---|
|  | 1 | 2 | 3 | 4 | 5 |
|--|---|---|---|---|---|

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**Section F SELF-EFFICACY.** Client must agree/disagree with the following statements.

- |   | A | a | * | d | D |
|---|---|---|---|---|---|
| 1. I give up on things before completing them.  | 1 | 2 | 3 | 4 | 5 |
| 2. If something looks too complicated, I will not even bother to try.                   | 1 | 2 | 3 | 4 | 5 |
| 3. When I decide to do something, I go right to work on it.                             | 5 | 4 | 3 | 2 | 1 |
| 4. When trying to learn something new, I soon give up if I am not initially successful. | 1 | 2 | 3 | 4 | 5 |
| 5. I avoid trying to learn new things when they look too difficult for me.              | 1 | 2 | 3 | 4 | 5 |
| 6. Failure just makes me try harder.  | 5 | 4 | 3 | 2 | 1 |
| 7. I give up easily.  | 1 | 2 | 3 | 4 | 5 |
| 8. I do not seem capable of dealing with most problems that come up in life.            | 1 | 2 | 3 | 4 | 5 |

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**Section G. ATTRIBUTIONAL STYLE.** Client must indicate how often the statements refer to him/herself.

A= Always; B= Often; C= Sometimes; D= Rarely; E= Never.

- |   | A | B | C | D | E |
|---|---|---|---|---|---|
| 1. Any successes I have had have been due to good fortune.  | 1 | 2 | 3 | 4 | 5 |
| 2. When things go wrong it's because of circumstances beyond my control.                          | 1 | 2 | 3 | 4 | 5 |
| 3. Any successes I've had have been due to outside influences.                                    | 1 | 2 | 3 | 4 | 5 |
| 4. Any successes I've had have been due to the fact that circumstances have happened to be right. | 1 | 2 | 3 | 4 | 5 |
| 5. If things go well it's just good luck.   | 1 | 2 | 3 | 4 | 5 |

6. If things go well it's because the system helped me.

1 2 3 4 5

Copyright: Dr Allan Dodds, CPsychol, FBPsS, RMIP,  
Rehabilitation Consultant,



**APPENDIX D**  
**PSYCHOSOCIAL COUNSELING SEGMENT**

## PSYCHOSOCIAL COUNSELING SEGMENT

All participants were asked to take part in an open-ended discussion about vision loss and were encouraged to address any issues that concerned them. The following questions were used to engage participants in thought and provoke discussion about how the following activities make them feel.

### Startup Questions

1/ Do you or your spouse have trouble with near tasks ?

- newspaper
- books
- magazines
- mail
- money
- food/medication labels

2/ Do you or your spouse have trouble with written tasks ?

- handwriting
- signing your name
- personal accounting

3/ Do you or your spouse have trouble with

- telling the time
- sewing/knitting
- stamp/coin collecting
- arts and crafts
- gardening

4/ Do you or your spouse have trouble with

recognizing faces

distinguishing food on your plate

dialing the phone

cooking

grooming

stove/washer dials

being spontaneous

entertaining guests

using a computer

**APPENDIX E**  
**FUNCTIONAL INTERVENTION**

## FUNCTIONAL SEGMENT ACTIVITES

Participants were asked to perform the following:

1/ reading small print

2/ finding a magazine subscription

3/ finding a telephone number in the phone book

4/ reading the dosage and instructions on a medicine bottle

5/ identifying faces on a face chart

6/ finding the specified card in a deck of cards

7/ telling the time on a wristwatch

8/ signing a cheque

9/ differentiating different denominations of money

10/ finding an object on a carpeted floor



**APPENDIX F**  
**RAW DATA**

	idno	group	interord	anxdep	trialad	selfeste
1	1.00	1.00	A	17.00	34.00	33.00
2	2.00	1.00	A	31.00	20.00	42.00
3	3.00	1.00	A	31.00	20.00	44.00
4	4.00	1.00	B	35.00	16.00	18.00
5	5.00	1.00	B	25.00	26.00	31.00
6	6.00	1.00	A	29.00	22.00	36.00
7	7.00	1.00	A	12.00	39.00	21.00
8	8.00	1.00	B	28.00	23.00	35.00
9	9.00	1.00	B	20.00	31.00	42.00
10	10.00	1.00	B	23.00	28.00	29.00
11	11.00	1.00	B	23.00	28.00	30.00
12	12.00	1.00	A	31.00	20.00	36.00
13	13.00	2.00	B	23.00	28.00	40.00
14	14.00	2.00	B	31.00	20.00	45.00
15	15.00	2.00	A	32.00	19.00	44.00
16	16.00	2.00	B	17.00	34.00	28.00
17	17.00	2.00	B	26.00	25.00	42.00
18	18.00	2.00	A	30.00	21.00	34.00
19	19.00	2.00	A	23.00	28.00	35.00
20	20.00	2.00	A	26.00	25.00	36.00
21	21.00	2.00	B	28.00	23.00	32.00
22	22.00	2.00	B	13.00	38.00	18.00
23	23.00	2.00	A	22.00	29.00	36.00
24	24.00	2.00	B	31.00	30.00	34.00
25	25.00	3.00	A	24.00	27.00	23.00
26	26.00	3.00	A	20.00	31.00	29.00
27	27.00	3.00	B	17.00	34.00	22.00
28	28.00	3.00	B	32.00	19.00	42.00
29	29.00	3.00	B	32.00	19.00	45.00

	attitude	locus	accept	effic	attribut	p1ad	triap1ad
1	26.00	20.00	36.00	37.00	19.00	24.00	31.28
2	23.00	18.00	35.00	34.00	18.00	31.00	24.28
3	29.00	15.00	40.00	29.00	19.00	30.00	25.28
4	10.00	14.00	27.00	35.00	18.00	21.00	34.28
5	21.00	19.00	23.00	30.00	17.00	25.00	30.28
6	22.00	19.00	36.00	32.00	23.00	24.00	31.28
7	24.00	19.00	34.00	27.00	18.00	24.00	31.28
8	22.00	12.00	34.00	33.00	14.00	28.00	27.28
9	21.00	14.00	40.00	28.00	18.00	32.00	23.28
10	21.00	16.00	25.00	16.00	20.00	20.00	35.28
11	18.00	14.00	27.00	26.00	21.00	27.00	28.28
12	25.00	16.00	34.00	29.00	20.00	32.00	23.28
13	26.00	20.00	38.00	37.00	19.00	27.00	28.28
14	28.00	20.00	41.00	31.00	20.00	31.00	24.28
15	29.00	16.00	36.00	31.00	19.00	32.00	23.28
16	18.00	14.00	28.00	26.00	22.00	21.00	34.28
17	25.00	14.00	25.00	33.00	21.00	32.00	23.28
18	22.00	18.00	37.00	34.00	23.00	24.00	31.28
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22	21.00	16.00	16.00	26.00	18.00	24.00	31.28
23	18.00	16.00	25.00	23.00	23.00	27.00	28.28
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25	17.00	16.00	22.00	30.00	24.00	31.00	24.28
26	18.00	14.00	23.00	26.00	21.00	31.00	24.28
27	17.00	13.00	20.00	30.00	19.00	28.00	27.28
28	22.00	17.00	34.00	26.00	28.00	31.00	24.28
29	35.00	20.00	45.00	40.00	29.00	30.00	25.28

	triap2ad	p2se	p2att	p2loc	p2acc	p2sef	p2atr
1	30.34	40.00	20.00	20.00	41.00	40.00	29.00
2	25.34	36.00	24.00	16.00	33.00	31.00	19.00
3	23.34	32.00	20.00	14.00	30.00	26.00	15.00
4	38.34	20.00	25.00	18.00	30.00	30.00	18.00
5	39.34	24.00	19.00	18.00	18.00	32.00	21.00
6	31.34	42.00	29.00	20.00	42.00	37.00	22.00
7	28.34	30.00	28.00	17.00	30.00	31.00	18.00
8	25.34	37.00	31.00	17.00	43.00	32.00	14.00
9	22.34	33.00	21.00	14.00	32.00	29.00	18.00
10	37.34	17.00	21.00	18.00	20.00	32.00	18.00
11	25.34	32.00	22.00	14.00	33.00	26.00	21.00
12	28.34	34.00	24.00	18.00	40.00	32.00	18.00
13	25.34	42.00	31.00	19.00	39.00	37.00	17.00
14	24.34	40.00	28.00	14.00	37.00	31.00	21.00
15	22.34	44.00	26.00	16.00	27.00	40.00	30.00
16	34.34	25.00	14.00	14.00	26.00	16.00	14.00
17	31.34	28.00	20.00	16.00	24.00	32.00	21.00
18	33.34	32.00	27.00	17.00	33.00	30.00	21.00
19	25.34	45.00	21.00	19.00	26.00	32.00	18.00
20	23.34	38.00	34.00	16.00	38.00	29.00	14.00
21	22.34	37.00	21.00	16.00	29.00	30.00	19.00
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23	27.34	39.00	22.00	17.00	34.00	26.00	24.00
24	22.34	39.00	24.00	16.00	29.00	33.00	14.00
25	31.34	31.00	14.00	19.00	32.00	32.00	26.00
26	27.34	45.00	16.00	19.00	42.00	36.00	18.00
27	25.34	31.00	16.00	11.00	18.00	14.00	15.00
28	23.34	38.00	20.00	16.00	34.00	30.00	22.00
29	22.34	42.00	35.00	20.00	43.00	38.00	25.00

	p1se	p1att	p1loc	p1acc	p1sef	p1atr	p2ad
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2	44.00	29.00	17.00	41.00	34.00	21.00	29.00
3	42.00	26.00	14.00	40.00	35.00	23.00	31.00
4	27.00	16.00	10.00	24.00	24.00	18.00	16.00
5	35.00	16.00	18.00	25.00	37.00	24.00	15.00
6	38.00	26.00	16.00	41.00	39.00	24.00	23.00
7	29.00	19.00	19.00	38.00	32.00	12.00	26.00
8	42.00	27.00	16.00	37.00	34.00	18.00	29.00
9	38.00	24.00	12.00	32.00	30.00	22.00	32.00
10	20.00	20.00	13.00	18.00	25.00	20.00	17.00
11	37.00	22.00	14.00	32.00	26.00	25.00	29.00
12	39.00	27.00	17.00	37.00	34.00	18.00	26.00
13	38.00	18.00	16.00	35.00	34.00	25.00	29.00
14	45.00	27.00	14.00	43.00	33.00	23.00	30.00
15	45.00	26.00	15.00	40.00	31.00	23.00	32.00
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22	29.00	17.00	14.00	21.00	26.00	18.00	27.00
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26	38.00	20.00	14.00	26.00	32.00	26.00	27.00
27	36.00	22.00	14.00	30.00	32.00	22.00	29.00
28	40.00	22.00	14.00	30.00	32.00	22.00	31.00
29	45.00	17.00	18.00	40.00	35.00	23.00	32.00

	idno	group	interord	anxdep	trialad	selfeste
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31	31.00	3.00	A	31.00	20.00	35.00
32	32.00	3.00	A	25.00	26.00	38.00
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43	43.00	4.00	B	30.00	21.00	38.00
44	44.00	4.00	B	24.00	27.00	35.00
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51	51.00	5.00	B	23.00	28.00	32.00
52	52.00	5.00	B	24.00	27.00	35.00
53	53.00	5.00	B	22.00	29.00	28.00
54	54.00	5.00	A	22.00	29.00	32.00
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56	56.00	5.00	A	25.00	26.00	38.00
57	57.00	5.00	A	24.00	27.00	46.00
58	58.00	5.00	A	23.00	28.00	33.00

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31	25.00	12.00	29.00	35.00	24.00	29.00	26.28
32	23.00	12.00	30.00	35.00	20.00	31.00	24.28
33	28.00	14.00	32.00	22.00	23.00	27.00	28.28
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36	24.00	20.00	41.00	33.00	23.00	30.00	25.28
37	24.00	14.00	33.00	27.00	17.00	29.00	26.28
38	25.00	14.00	34.00	32.00	18.00	26.00	29.28
39	26.00	16.00	31.00	32.00	18.00	27.00	28.28
40	22.00	14.00	32.00	22.00	16.00	30.00	25.28
41	20.00	14.00	32.00	31.00	19.00	24.00	31.28
42	22.00	15.00	31.00	32.00	18.00	30.00	25.28
43	22.00	14.00	36.00	32.00	18.00	29.00	26.28
44	20.00	16.00	34.00	30.00	20.00	28.00	27.28
45	21.00	16.00	34.00	30.00	22.00	31.00	24.28
46	14.00	16.00	30.00	32.00	18.00	24.00	31.28
47	20.00	14.00	32.00	30.00	26.00	21.00	34.28
48	20.00	16.00	24.00	26.00	22.00	27.00	28.28
49	24.00	20.00	30.00	31.00	20.00	27.00	28.28
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53	19.00	16.00	23.00	33.00	22.00	28.00	27.28
54	19.00	16.00	21.00	33.00	20.00	27.00	28.28
55	27.00	13.00	42.00	27.00	26.00	27.00	28.28
56	28.00	16.00	45.00	28.00	24.00	26.00	29.28
57	29.00	20.00	45.00	21.00	23.00	25.00	30.28
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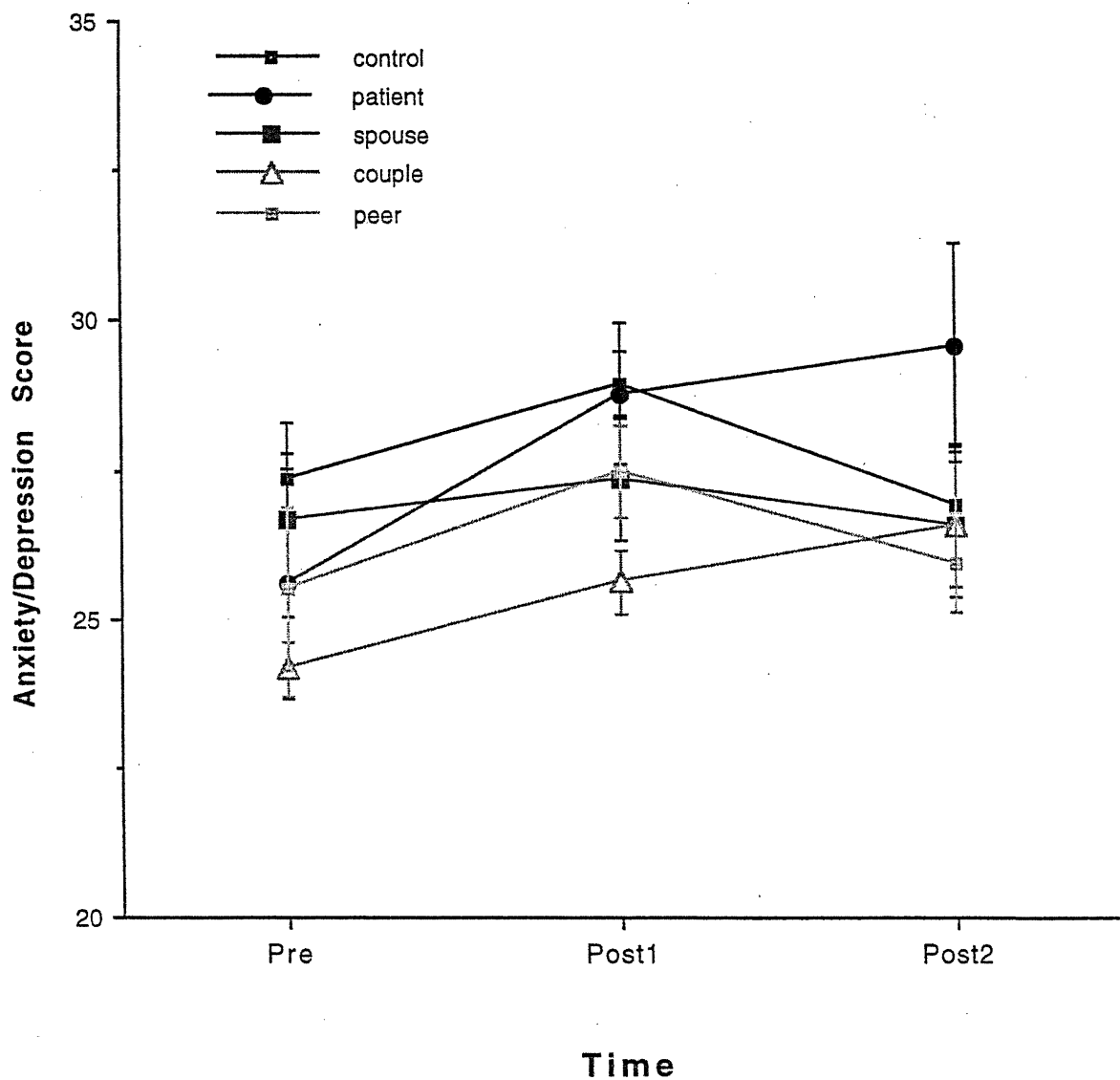
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32	38.00	25.00	15.00	32.00	35.00	21.00	30.00
33	37.00	26.00	14.00	36.00	29.00	17.00	31.00
34	41.00	26.00	16.00	36.00	29.00	20.00	24.00
35	45.00	24.00	16.00	39.00	32.00	22.00	24.00
36	44.00	26.00	16.00	39.00	32.00	22.00	28.00
37	34.00	26.00	14.00	36.00	31.00	18.00	27.00
38	40.00	26.00	13.00	36.00	34.00	16.00	26.00
39	36.00	24.00	16.00	32.00	28.00	23.00	27.00
40	42.00	20.00	14.00	29.00	25.00	18.00	32.00
41	33.00	21.00	12.00	34.00	26.00	16.00	24.00
42	34.00	24.00	16.00	34.00	26.00	19.00	29.00
43	34.00	26.00	13.00	39.00	31.00	20.00	30.00
44	38.00	30.00	18.00	38.00	30.00	21.00	30.00
45	40.00	26.00	16.00	37.00	32.00	24.00	32.00
46	34.00	19.00	16.00	31.00	33.00	15.00	27.00
47	32.00	20.00	14.00	32.00	24.00	22.00	22.00
48	32.00	18.00	16.00	24.00	27.00	22.00	26.00
49	42.00	22.00	16.00	32.00	35.00	17.00	24.00
50	42.00	21.00	17.00	25.00	34.00	17.00	30.00
51	38.00	21.00	16.00	33.00	31.00	18.00	30.00
52	42.00	23.00	17.00	32.00	30.00	20.00	30.00
53	35.00	21.00	20.00	30.00	39.00	16.00	27.00
54	39.00	16.00	20.00	30.00	39.00	14.00	30.00
55	39.00	26.00	20.00	38.00	27.00	21.00	30.00
56	39.00	26.00	20.00	41.00	27.00	20.00	20.00
57	42.00	25.00	20.00	38.00	27.00	21.00	30.00
58	38.00	31.00	20.00	41.00	27.00	20.00	30.00



	trip2ad	p2se	p2att	p2loc	p2acc	p2sef	p2atr
30	25.34	45.00	22.00	17.00	34.00	38.00	21.00
31	29.34	32.00	24.00	10.00	31.00	35.00	29.00
32	24.34	31.00	30.00	16.00	30.00	32.00	13.00
33	23.34	31.00	26.00	16.00	34.00	26.00	18.00
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35	30.34	31.00	24.00	20.00	42.00	26.00	23.00
36	26.34	42.00	31.00	18.00	43.00	36.00	23.00
37	27.34	34.00	26.00	14.00	36.00	31.00	18.00
38	28.34	41.00	28.00	13.00	42.00	37.00	16.00
39	27.34	36.00	26.00	18.00	34.00	28.00	23.00
40	22.34	36.00	23.00	16.00	36.00	31.00	19.00
41	30.34	34.00	23.00	14.00	34.00	28.00	19.00
42	25.34	34.00	24.00	16.00	34.00	26.00	19.00
43	24.34	34.00	28.00	15.00	39.00	34.00	20.00
44	24.34	36.00	30.00	18.00	38.00	32.00	21.00
45	22.34	41.00	26.00	16.00	37.00	32.00	23.00
46	27.34	34.00	19.00	16.00	31.00	32.00	17.00
47	32.34	32.00	21.00	14.00	31.00	24.00	22.00
48	28.34	36.00	24.00	16.00	24.00	28.00	21.00
49	30.34	35.00	24.00	20.00	33.00	31.00	22.00
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53	27.34	31.00	21.00	19.00	32.00	32.00	18.00
54	24.34	42.00	23.00	20.00	34.00	38.00	20.00
55	24.34	40.00	26.00	16.00	37.00	30.00	21.00
56	34.34	41.00	33.00	20.00	43.00	31.00	21.00
57	24.34	40.00	26.00	16.00	37.00	30.00	21.00
58	24.34	41.00	33.00	20.00	43.00	31.00	21.00

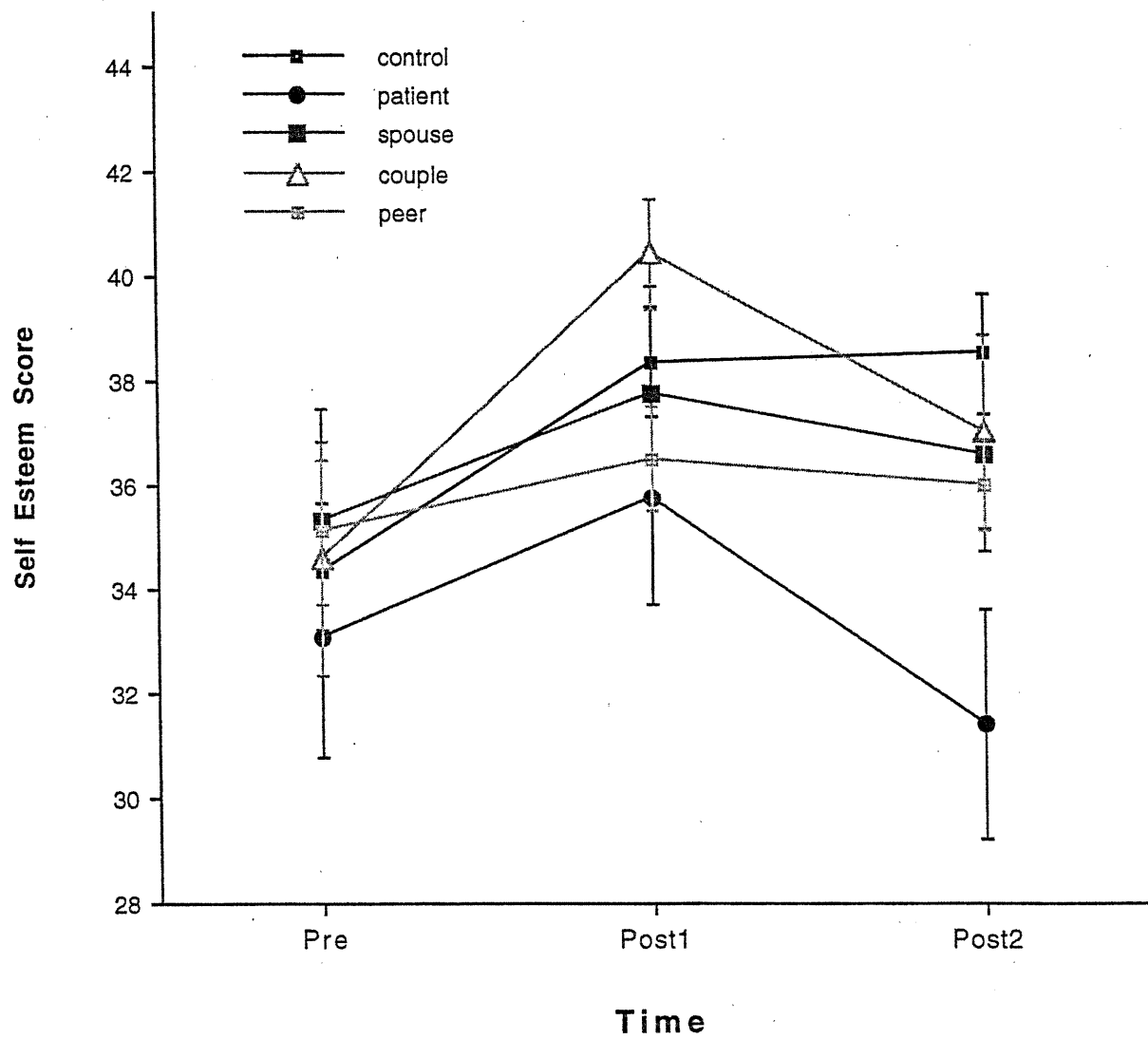
**APPENDIX G**  
**GRAPHS**

Anxiety/Depression by Group as a Function of Time



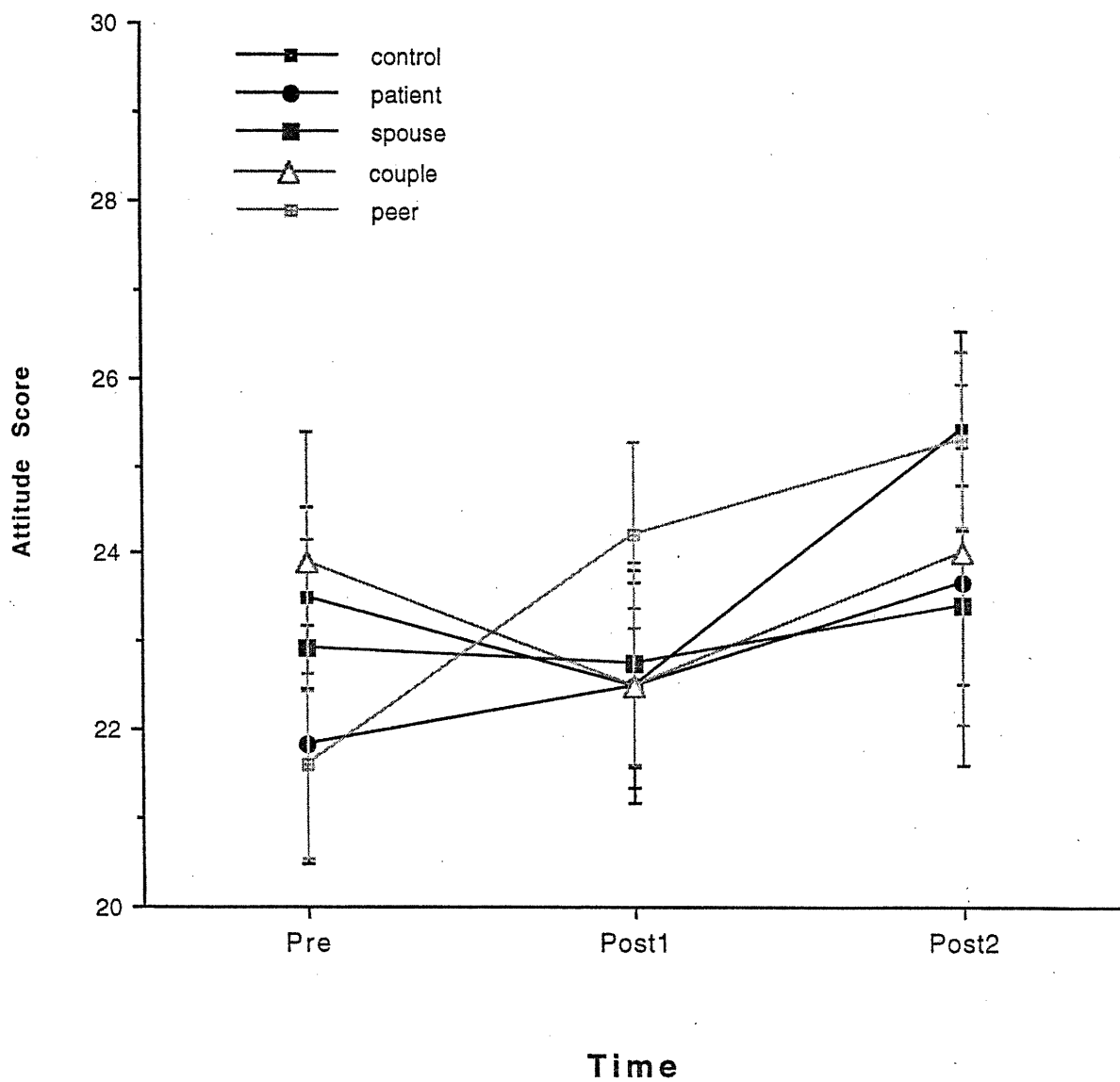
Patient = Visually Impaired Person

### Self Esteem by Group as a Function of Time



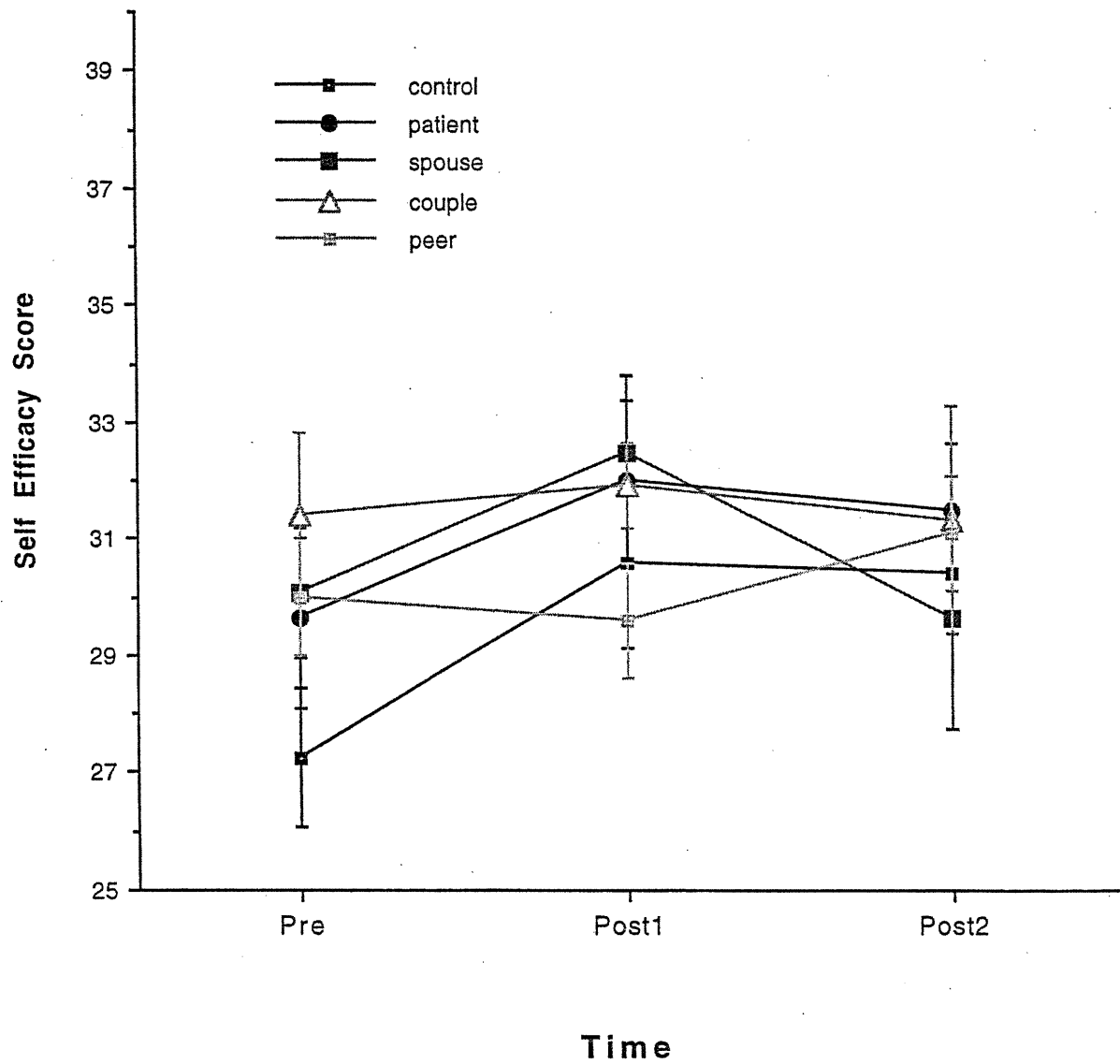
**Patient = Visually Impaired Person**

### Attitude by Group as a Function of Time



**Patient = Visually Impaired Person**

### Self Efficacy by Group as a Function of Time

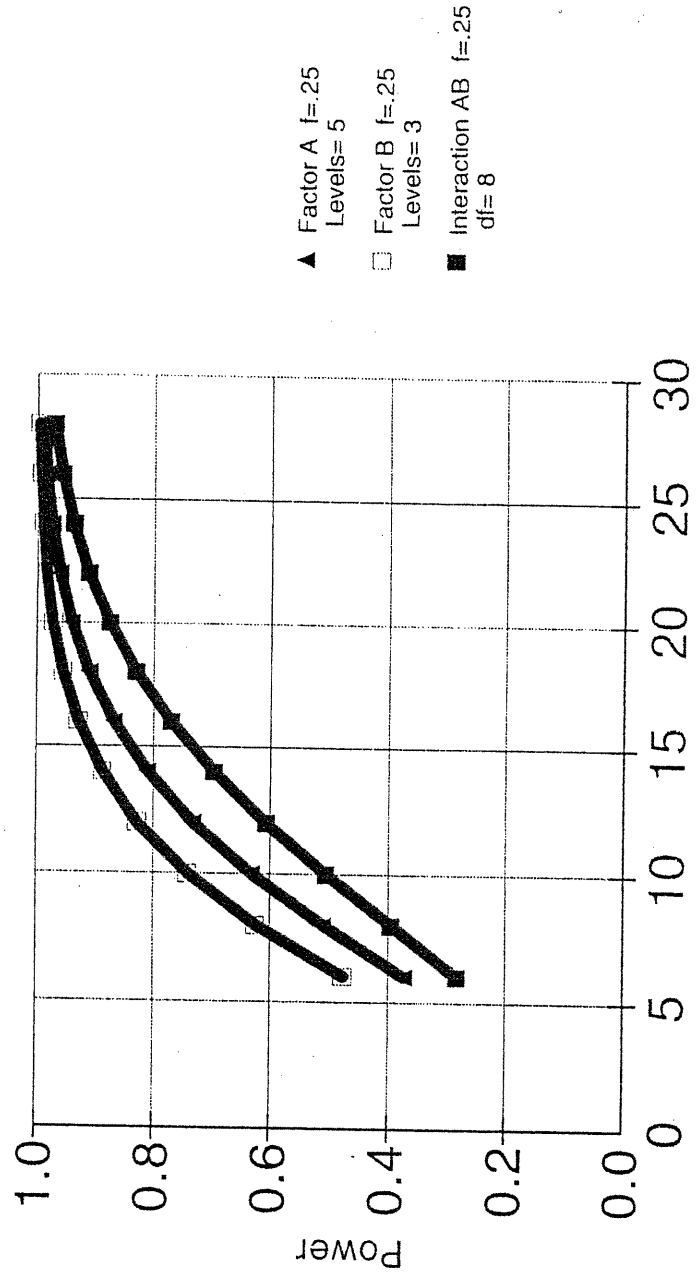


**Patient = Visually Impaired Person**

**APPENDIX H**  
**POWER ANALYSIS**

# Power as a Function of Effect Size and N

## Factorial analysis of variance



Number of cases per cell  
Factors as shown Alpha=.05 Tails=2



**APPENDIX I**  
**FRENCH VALIDATION OF THE NOTTINGHAM ADJUSTMENT SCALE**

**SECTION A ANXIETE / DEPRESSION****N= pas du tout****m= un peu plus que d'habitude****n = pas plus que d'habitude****M= beaucoup plus que d'habitude****Récemment = en rapport aux quelques semaines précédentes**

- 1/ Récemment, vous êtes-vous senti sans énergie et épuisé ?
- 2/ Récemment, vous êtes-vous senti malade ?
- 3/ Récemment, vous êtes-vous senti constamment sous tension ?
- 4/ Avez-vous trouvé récemment que vous vous sentiez dépassé, ou que vous ne saviez plus ou donner de la tête ?
- 5/ Récemment, vous êtes-vous senti nerveux(se) ou très tendu ?
- 6/ Avez-vous pensez récemment que vous ne valiez pas grand chose ?
- 7/ Avez-vous pensez récemment que la vie est absolument sans espoir ?
- 8/ Avez-vous pensez récemment que la vie ne vaut pas la peine d'être vécue ?
- 9/ Avez-vous pensez récemment à la possibilité de mettre fin à vos jours ?
- 10/ Avez-vous trouvé récemment que parfois vous ne pouviez rien faire parce que vous étiez trop nerveux(se) ?
- 11/ Avez vous souhaitez récemment être mort et loin de tout ?
- 12/ Avez vous trouvé récemment que l'idée de mettre fin à vos jours surgissait fréquemment dans votre esprit ?

**SECTION B ESTIME DE SOI**

**A= fortement d'accord**  
**d = pas d'accord**

**a = d'accord**  
**D= fortement en désaccord**

**\* = ne sait pas**

1/ Généralement, je suis satisfait de moi-même.

2/ À l'occasion, je pense que je suis incapable / bon à rien.

3/ Je suis capable de faire les choses aussi bien que la plupart des gens.

4/ Je me sens parfaitement inutile à l'occasion.

5/ J'ai l'impression que je ne peux pas à être fier de grand chose.

6/ Je pense que je vauds quelque chose; du moins autant que les autres.

7/ J'aimerais avoir plus de respect de moi-même.

8/ Généralement parlant, j'ai tendance à penser que je suis un raté.

9/ J'ai une attitude positive vis-à-vis moi-même.

### **Section C ATTITUDES**

- 1/ Les personnes atteintes d'une déficience visuelle sont habituées à ne pas réussir la plupart des choses qu'elles entreprennent.
- 2/ Les plupart des personnes atteintes d'une déficience visuelle s'inquiètent constamment au sujet de ce qui pourrait leur arriver.
- 3/ La plupart des personnes atteintes d'une déficience visuelle gardent beaucoup de choses pour elles-mêmes.
- 4/ La plupart des personnes atteintes d'une déficience visuelle ont l'impression qu'ils ne valent rien.
- 5/ Les personnes atteintes d'une déficience visuel sont plus facilement vexées que les voyants.
- 6/ La plupart des personnes atteintes d'une déficience visuelle ne sont pas satisfaits d'eux-mêmes.
- 7/ La plupart des personnes atteintes d'une déficience visuelle pensent que perdre la vision est la pire chose qui pouvait leur arriver.

### **SECTION D LOCUS DE CONTROLE**

- 1/ C'est ce que je peux faire pour m'aider qui fera réellement toute la différence.
- 2/ C'est à moi de m'assurer que je ferai de mon mieux compte tenu des circonstances
- 3/ Ma contribution personnelle à ma réadaptation ne compte pas pour grand chose.
- 4/ Je n'ai peu ou pas de contrôle sur mes progrès futurs.

## SECTION E ACCEPTATION

- 1/ À cause de mes problèmes visuels, je me sens misérables la plupart du temps.
- 2/ Cela me déprime beaucoup de voir toutes les choses que les voyants peuvent faire et qui me sont impossibles à faire.
- 3/ À cause de mes problèmes visuels, j'ai peu à offrir aux autres.
- 4/ À cause de mes problèmes visuels, la vie des autres personnes est plus significative que la mienne.
- 5/ Je me sens satisfaits de mes capacités et mon problème visuel ne me dérange pas trop.
- 6/ Presque toutes les options futures de la vie me sont fermées à cause de mes problèmes visuels.
- 7/ Mes problèmes visuels m'empêchent de faire à peu près tout ce que je désire et aussi d'être la personne que je veux vraiment être.
- 8/ Mon problème visuel est tellement ennuyant que je ne peux profiter de quoi que ce soit.
- 9/ Souvent lorsque je pense à mon problème visuel, cela me déprime tellement que je suis incapable de penser ou de faire quoi que ce soit.

**SECTION F EFFICACITE PERSONELLE**

- 1/ Je ne complète pas ce que j'entreprends
- 2/ Si quelque chose semble trop compliqué, je n'essaierai même pas.
- 3/ Lorsque je décide de faire quelque chose, je m'y mets tout de suite.
- 4/ Lorsque j'essaie d'apprendre quelque chose de nouveau, j'abandonne rapidement si je n'y arrive pas du premier coup.
- 5/ J'évite d'apprendre des choses nouvelles si elles m'apparaissent trop difficile.
- 6/ L'échec me stimule d'essayer d'avantage
- 7/ J'abandonne facilement.
- 8/ Je me sens pas capable de faire face à la plupart des problèmes qui surgissent dans ma vie.

**SECTION G STYLE D'ATTRIBUTION**

**A= toujours**  
**B= souvent**  
**C= parfois**  
**D= rarement**  
**E= jamais**

- 1/ Tous les succès que j'ai eus sont dus au hasard.
- 2/ Lorsque les choses tournent mal, cela est dû à des circonstances hors de mon contrôle.
- 3/ Tous les succès que j'ai eus étaient dus à des influences extérieures.
- 4/ Tous les succès que j'ai eus étaient dus au fait que les circonstances étaient favorables.
- 5/ Si les choses vont bien, il s'agit juste de chance.
- 6/ Si les choses vont bien, c'est parce que le système m'a aidé.

**APPENDIX J**  
**ETHICS COMMITTEE APPROVAL**





HÔPITAL GÉNÉRAL JUIF  
SIR MORTIMER B. DAVIS  
JEWISH GENERAL HOSPITAL

UNIVERSITÉ  
MCGILL  
UNIVERSITY



BUREAU D'ÉTHIQUE DE LA RECHERCHE  
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June 10, 1999


Dr. Overbury  
Department of Ophthalmology  
SMBD - Jewish General Hospital

Subject: Protocol #99-025 entitled "Psychosocial Adjustment after a Functional and Cognitive Intervention in Low Vision Patients and Significant Others"

Dear Dr. Overbury:

The above protocol and English consent form have been approved for a period of one year from the date of this letter, after which continuing review must be sought. If French speaking patients are to be enrolled a French consent form must be submitted to this office for approval.

Sincerely,

  
J. Mendelson, MD  
Chairman, Research Ethics Committee