

**AGE-RELATED VISION LOSS: A STUDY OF ADAPTIVE TASKS**

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**TABLE OF CONTENTS**

	<b>Page</b>
<b>LIST OF TABLES</b> .....	
<b>ACKNOWLEDGEMENTS</b> .....	
<b>CHAPTER</b>	
<b>I INTRODUCTION</b>	
Study Rationale .....	1
Overview of Research Problem and Purpose .....	2
The Concept of Adaptation .....	5
Research Objectives .....	7
Research Questions .....	7
Research Hypotheses .....	13
<b>II REVIEW OF RELATED LITERATURE</b>	
Overview .....	16
The Phenomenon of Adaptation .....	17
Theoretical and Empirical Studies of Adaptation .....	18
The Sequence of Adaptation (Time Since Onset) .....	27
Five Adaptive Tasks .....	31
<b>III RESEARCH DESIGN AND METHODOLOGY</b>	
Overview .....	44
Research Design .....	44
Study Site .....	46
Preliminary Activity .....	47
Study Population .....	49
Sampling Plan and Procedures .....	50
Sample Response .....	52
Bias Due to Non-Response .....	52
Demographic Characteristics of the Sample .....	54
Research Instrument .....	58
Data Collection Procedures .....	59
Identification of Study Variables .....	60
Scales and Indexes .....	62
<b>IV FINDINGS I: DESCRIPTIVE DATA</b>	
Overview .....	80
Vision Loss in the Sample Population .....	81
The Context of Age-Related Vision Loss: Health, Social Supports, Life Events .....	105
Beliefs and Feelings about Vision Loss .....	116
Summary/Discussion of Descriptive Data .....	125

V	<b>FINDINGS II: BI-VARIATE CORRELATIONS</b>	
	Overview .....	128
	The Independent Variables .....	128
	The Intervening Variables .....	136
	The Dependent Variables .....	152
	Summary/Discussion of Bi-Variate Correlations	176
VI	<b>FINDINGS III: THE MULTI-VARIATE ANALYSIS</b>	
	Overview .....	182
	Self Esteem .....	184
	Use of Help .....	189
	Social/Recreational Activities .....	194
	Activities of Daily Living .....	201
	Summary/Discussion of Multi-Variate Analysis	206
VII	<b>SUMMARY AND RECOMMENDATIONS</b>	
	Overview .....	210
	Summary of Major Findings .....	210
	Limitations of Study.....	217
	Recommendations	
	Practice .....	217
	Research .....	220
	<b>BIBLIOGRAPHY</b> .....	223
	<b>APPENDIX</b>	
	A. Letter of Introduction to Potential Respondents .....	232
	B. Release Form .....	234
	C. Client Safeguards in the Research Process .....	236
	D. Questionnaire .....	238

## LIST OF TABLES

	Page
<b>CHAPTER III</b>	
Table III-1	Sample Response.....53
Table III-2	Demographic Characteristics.....55
Chart III-1	Identification of Variables.....61
Table III-3	Summary Table of Scales and Indexes.....63
<b>CHAPTER IV</b>	
Table IV-1	Vision Status As Reported by Low Vision Clinic.....82
Table IV-2	Self-Reported Vision Status.....86
Table IV-3	Use of Low Vision Aids and Environmental Changes.....91
Table IV-4	Percent Distribution of ADL Dependence Due to Vision Loss and Other Health Problems.....94
Table IV-5	Percent Distribution of Participation in Social and Recreational Activities as Related to Vision Loss .....98
Table IV-6	Percent Distribution of Decreased Participation in Social and Recreational Activities after Vision Loss.....100
Table IV-7	Percent Distribution of Unchanged or Increased Participation in Social And Recreational Activities after Vision Loss.....104
Table IV-8	Self Reported Hearing.....107
Table IV-9	Percent Distribution of Chronic Health Conditions Before, After, and Concurrent with Vision Loss.....108
Table IV-10	Informal and Formal Supports.....110
Table IV-11	Percent Distribution of Use of Help by Informal and Formal Supports.....112
Table IV-12	Elder Satisfaction with Help.....114
Table IV-13	Co-Existing Life Events of Change And Loss.....115
Table IV-14	Elder Ratings of Overall Health and Comparison of Vision Loss with Other Health Problems.....117
Table IV-15	Elder Attitudes About Vision Loss.....119
<b>CHAPTER V</b>	
Table V-1	Zero-Order Correlations Between Demographic Characteristics.....130
Table V-2	Zero-Order Correlations Between Major Eye Diagnoses and Demographic Characteristics.....131
Table V-3	Zero-Order Correlations Between Major Eye Diagnoses and Vision-Related Data.....132
Table V-4	Zero-Order Correlations Between Vision-Related Data and Demographic Characteristics.....133
Table V-5	Zero-Order Correlations Between Social Supports and Demographic Characteristics.....138

Table V-6	Zero-Order Correlations Between Social Supports, Major Eye Diagnoses and Vision-Related Data.....	139
Table V-7	Zero-Order Correlations Between Health and Demographic Characteristics.....	142
Table V-8	Zero-Order Correlations Between Health, Major Eye Diagnoses and Vision-Related Data.....	143
Table V-9	Zero-Order Correlations Between Social Supports and Health.....	146
Table V-10	Zero-Order Correlations Between Co-Existing Life Events and Demographic Characteristics.....	147
Table V-11	Zero-Order Correlations Between Co-Existing Life Events, Major Eye Diagnoses and Vision-Related Data .....	148
Table V-12	Zero-Order Correlations Between Co-Existing Life Events and Health.....	149
Table V-13	Zero-Order Correlations Between Co-Existing Life Events and Social Supports.....	150
Table V-14	Zero-Order Correlations Between Independent Variables and Self Esteem.....	154
Table V-15	Zero-Order Correlations Between Intervening Variables and Self Esteem.....	157
Table V-16	Zero-Order Correlations Between Independent Variables and Use of Help.....	158
Table V-17	Zero-Order Correlations Between Intervening Variables and Use of Help.....	160
Table V-18	Zero-Order Correlations Between Independent Variables and Social/Recreational Activities....	162
Table V-19	Zero-Order Correlations Between Intervening Variables and Social/Recreational Activities....	163
Table V-20	Zero-Order Correlations Between Independent Variables and Activities of Daily Living.....	166
Table V-21	Zero-Order Correlations Between Intervening Variables and Activities of Daily Living.....	167
Table V-22	Zero-Order Correlations Between Four Adaptive Tasks.....	168
Table V-23	Understanding of Loss.....	170
Table V-24	Zero-Order Correlations Between Independent Variables and Understanding of Loss.....	173
Table V-25	Zero-Order Correlations Between Intervening Variables and Understanding of Loss.....	174
Table V-26	Zero-Order Correlations Between Understanding of Loss and Four Adaptive Tasks.....	175

**CHAPTER VI**

Table VI-1	Zero-Order Correlation Coefficients of Predictor Variables and Self Esteem.....	185
Table VI-2	Correlation Matrix of Predictor Variables: Self Esteem .....	186
Table VI-3	Hierarchical Multiple Regression Analysis for Self Esteem as Criterion.....	187
Table VI-4	Zero-Order Correlation Coefficients of Predictor Variables and Use of Help.....	190

Table VI-5	Correlation Matrix of Predictor Variables: Use of Help.....	191
Table VI-6	Hierachical Multiple Regression Analysis for Use of Help as Criterion.....	192
Table VI-7	Zero-Order Correlation Coefficients of Predictor Variables and Social/Recreational Activities .....	195
Table VI-8	Correlation Matrix of Predictor Variables: Social/Recreational Activities.....	196
Table VI-9	Hierachical Multiple Regression Analysis for Social/Recreational Activities as Criterion I.....	197
Table VI-10	Hierachical Multiple Regression Analysis for Social and Recreational Activities as Criterion II.....	200
Table VI-11	Zero-Order Correlation Coefficients of Predictor Variables and Activities of Daily Living.....	202
Table VI-12	Correlation Matrix of Predictor Variables: Activities of Daily Living.....	203
Table VI-13	Hierachical Multiple Regression Analysis for Activities of Daily Living as Criterion.....	204

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Chapter I  
INTRODUCTION

STUDY RATIONALE

The aged blind are a growing population about whom little is known. In contrast to ophthalmologists who have studied the physiological phenomenon in depth, social scientists have accorded little attention to the psycho-social correlates and consequences of age-related vision loss.

The demographic imperative for knowledge building is compelling. Visual impairment is the third most common disability (following heart disease and arthritis) among the elderly. In fact, 266,000 individuals over the age of 65 account for over one-half of the legally blind in the United States (National Society for the Prevention of Blindness, 1980). A far greater number of the aged suffer from lesser, but still disabling, degrees of vision loss.

It is projected that by the year 2000, 1,760,000 older persons will have a severe visual impairment (Kirchner & Peterson, 1979; Kirchner, 1984). This is a 78% increase over current figures (Donahue & McFarland, 1984). Those over 85, the fastest growing segment of the aged population, are predicted to show the greatest increase; 36% of the visually impaired elderly will fall into this "old old" category as compared to 25% in 1977.

These figures may well be underestimated. Wineburg (1981), among others, notes that elderly people often do not seek

services because they do not consider themselves blind or do not want others to consider them blind. Many others do not even know that services exist. He suggests that denial of blindness is so prevalent among the elderly that a majority of aged Americans with vision impairment are not even counted much less treated.

#### OVERVIEW OF RESEARCH PROBLEM AND PURPOSE

What is known about the psycho-social aspects of age-related vision loss? Although there has been increased interest dating from the late 1960s, it has largely been reflected in epidemiological reports. Case studies on therapeutic strategies and small-scale studies of service utilization of the aged appear with some regularity in the pages of the *Journal of Visual Impairment*, a publication of the American Foundation for the Blind and major interdisciplinary journal of the low vision field. However, there is minimal reference to the aged with vision loss in comparable journals in the aging field, such as *The Journal of Gerontology* and *The Gerontologist*, publications of the Gerontological Society of America.

This disparity has been echoed in the service arena. In social agencies for the blind, the elderly typically comprise over half the clientele, while aging agencies have made minimal effort to accommodate the needs of the visually impaired. Only 6% of the clients of Area Agencies on Aging are recorded as being blind or visually impaired (Biegel et al, 1989).

Overall, the fields of low vision and gerontology have remained separated in the social science literature. While theories and studies abound on psychosocial aspects of the aging process, and of psychosocial aspects of vision loss in early and mid-life, the two have not been linked conceptually or empirically.

Even when social and rehabilitation agencies attempt to serve the visually impaired aged, there are no empirically based guidelines for practice. Moos (1979) defines physical illness as a crisis in which the psycho-social need for equilibrium parallels the physiological need for homeostasis. He argues that the "new balance achieved may represent a healthy adaptation which promotes personal growth and maturation, or a maladaptive response which signifies psychological deterioration and decline". He goes on to note that the receptiveness of the individual to outside influence is great at a time of crisis, offering a unique opportunity for health professionals to have a positive impact.

As the sheer number of older persons requiring help with problems related to vision loss has increased, agencies for the blind have struggled to adapt rehabilitation and counselling strategies developed with other populations. For the most part, the professional service providers in these agencies depend upon classifications and expectations developed by the major funder of services; in New York State, this is the Commission for the Blind

and Visually Handicapped. The Commission (CBVH) is the central registry of the blind and conduit of public monies for their care. It has its parallel in states throughout the U.S.A.

The Commission funds services for the elderly through its Non-VR (Non-Vocational Rehabilitation) program. The program title is telling. Services are defined as what they are not, rather than what they are. If a job is not the goal of rehabilitation with the visually impaired aged, what is? Most funded care plans for the elderly are under the Independent Homemaker category. Thus, older people are taught skills to manage activities of daily living by rehabilitation teachers and orientation and mobility instructors. Social workers are funded on an as-needed basis; in cases where emotional and social problems interfere with participation in the rehabilitation process. The Commission's perspective is widely felt. Even in cases where the older person is not funded by CBVH, providers often define his goals in "independent homemaker" terms.

In all of this, recognition of how age-related vision loss may be different than vision losses at other stages of the life cycle is missing. Many older people are uninterested or reluctant participants in rehabilitation efforts. Are they to be written off as "unmotivated" or may it be that the services offered are not in keeping with their felt needs? And then there are the older people who are willing participants but do not respond as expected to interventions directed toward helping

them "adjust" or meet the rehabilitation goals set for them. Is this always because of some personality or functional problem or may it also be tied to a process of adaptation to age-related vision loss that is not well understood?

In writing on rehabilitation of the aged, Becker & Kaufman (1988) state that the crucial research questions are not how older people can fit into existing programs but how programs can be designed to meet their specific needs. In so doing, it is necessary to understand how the needs and interests of the aged are different from younger adults for whom rehabilitation strategies were originally developed.

#### THE CONCEPT OF ADAPTATION

"Living creatures....will constantly strive for an adaptive compromise that not only preserves them as they are, but also permits them to grow" (White, 1974).

The concept of adaptation is particularly salient to a study of the visually impaired elderly. Because old age is a time of multiple stressors (losses of significant others, and of one's own capacities) survival is dependent upon adaptation in many crucial areas of life. Understanding the correlates of adaptation to loss and the meaning of loss to older persons is critical to practitioners who work with the aged. At the same time, it is important to single out the specific impact of vision loss. The resulting knowledge could be utilized in assessment of

visually impaired elders for rehabilitation and counselling; suggesting unmet needs and areas for exploration. It could also be employed in program planning and the design of interventions that meet the special needs of the population.

In the language of adaptation theorists, a "task" is the challenge posed by a stress. Performance, (or negotiation) of the adaptive task is the extent to which the challenge is met by the individual.

This study of adaptation is based on the concept of task performance. Specifically, it operationalizes and tests the five adaptive tasks most often cited in the literature of adaptation to loss: Maintenance or restoration of Self Esteem, Use of Help, Modification of Daily Schedule, Balance between Continuity and Change in Social and Recreational Activities, and Understanding/Appraisal of Loss.

The tasks mentioned above are a compendium, drawn from the writings of several theorists and researchers who are cited in the literature review in Chapter II.

It should be noted that these five adaptive tasks have never, to my knowledge, been united in a theoretical or empirical model and it is not the intent of this study to do so. The tasks have been selected because, individually, they represent a general consensus of the areas of life most affected by disability.

The performance of each task is examined in relation to independent and intervening variables in order to identify its

correlates and predictors.

There is only one adaptive task for which there can be said to be a "good" or "bad" outcome; self esteem (self esteem being the sine qua non of mental health). No such value judgments can be made about the other adaptive tasks.

#### RESEARCH OBJECTIVES

The following research objectives form the basis of this study.

1. To identify demographic and vision factors that influence the performance of adaptive tasks.
2. To determine under what conditions vision impairment is a significant independent contributor to performance of adaptive tasks in age-related vision loss.
3. To determine whether time since onset of vision loss is a predictor of adaptive task performance.
4. To identify the perceptions of older people as to the impact of vision loss on their daily functioning and quality of life.

#### RESEARCH QUESTIONS



There are two types of research questions in this study: descriptive and explanatory. Descriptive questions are designed to provide a profile of the visually impaired elderly population, their informal and formal supports, health and functional status, other stressful life situations they face, and their attitudes toward vision loss. Explanatory questions cover a range of variables hypothesized as influencing performance of adaptive tasks and the relationship of adaptive task performance to time since onset.

Hypotheses were formulated for each research question. These hypotheses were based on the empirical and theoretical literature on adaptation as well as the extensive clinical experience of the investigator. As this is exploratory research, additional hypotheses were expected to emerge as data analysis progressed. The hypotheses stated in this section are the beginning, rather than the end point, of the investigation into adaptation to age-related vision loss.

### Descriptive

1. What are the dimensions of the problem of visual impairment in elders with age-related vision loss?

What diagnoses, prognoses, and degree of impairment are found in the population?

What are the types and circumstances of onset?

Are visual aids, lighting changes, and physical changes employed to compensate for vision loss?

How many ophthalmological "opinions" do elders gather before accepting a diagnosis? Who do they believe?

What are elders told is wrong with their vision?

What changes do elders expect in their vision?

How is eye condition related to demographic variables?

2. What are the consequences of age-related vision loss in daily life?

In what activities of daily living are elders dependent because of vision impairment?

What occupational, social and recreational activities are given up or changed?

3. What informal and formal supports are available to elders with age-related vision loss?

What is the type and extent of contact with actual and potential caregivers?

How satisfied are elders with the help they receive?

4. What is the health condition of elders with visual impairment?

What conditions are the most prevalent?

What conditions are most likely to precede vision loss?

What conditions are most likely to develop after vision loss?

What is the incidence of hearing loss?

5. What co-existing life events of change and loss are faced by visually impaired elders?

With what frequency do elders themselves move or experience the move of "someone close"?

How common is the serious illness of "someone close"?

How common is the death of "someone close"?

What relationships are defined by elders as being "someone close"?

6. What beliefs and feelings do visually impaired elders hold about their condition?

How do they describe themselves?

What advice would they give to others in a similar

situation?

Do attitude changes take place in the course of the eye disease?

Explanatory

1. To what extent is the elder's sense of self-esteem related to vision impairment?

Do demographic variables such as age, income, marital status, living arrangement affect self esteem in the visually impaired elderly?

Does self esteem increase with the time since onset of visual impairment?

Does a high degree of visual impairment decrease self-esteem?

2. To what extent is the elder's use of help related to vision impairment?

Do the most visually impaired people use the most help?

Does using help negatively affect self esteem?

Does living alone with a spouse increase the likelihood of using help?

Does use of help decrease with time since onset?

3. To what extent is the elder's level of participation in social and recreational activities affected by vision impairment?

Are the older people who stop activities or participate the least the most visually impaired?

Are the older people with high participation in activities younger, healthier or more independent in activities of daily living?

Does activity level increase with time since onset of vision impairment?

4. To what extent is the elder's performance of activities of daily living related to vision impairment?

Is the dependence in activities of daily living positively related to vision impairment?

Does dependence in activities of daily living decrease with time since onset?

5. How is the elder's understanding of vision impairment related to performance of adaptive tasks?

Do clinical prognoses and elders' expectations of change agree?

Are the most visually impaired elders the most despairing about their conditions?

Does understanding of vision impairment increase with time since onset?

6. What are the most salient independent predictors of the elder's performance of adaptive tasks?

Do demographic variables or eye data predict elder performance of adaptive tasks?

7. To what extent is the elder's performance of adaptive tasks influenced by formal service interventions?

How is the use of formal services related to adaptive task performance?

Are elders satisfied with the services they receive?

8. To what extent is the elder's performance of adaptive tasks influenced by informal service interventions?

What kinds of help do elders receive from informal supports?

How is the extent of and contact with informal supports related to performance of adaptive tasks?

9. To what extent is the elder's performance of adaptive tasks related to health?

Is good health associated with independence in activities of daily living?

Is good health associated with high participation in social and recreational activities?

Is good health associated with low use of help?

**RESEARCH HYPOTHESES**

- H1 Self esteem will be positively related to younger age, independence in activities of daily living, and good health.
- H2 There will be a positive relationship between severity of visual impairment and poor self esteem.
- H3 Self esteem will not relate to time since onset of visual impairment.
- H4 Visual impairment will be positively related to use of help.
- H5 Use of help will not be positively related to low self esteem.
- H6 Use of help will be negatively related to time since onset.
- H7 Visually impairment will be positively related to less participation in social and recreational activities.
- H8 Participation in social and recreational activities will increas

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with the time since onset of vision loss.

**H9** There will be a positive relationship between dependence in activities of daily living and degree of visual impairment.

**H10** Dependence in activities of daily living will increase with time since onset.

Chapter II presents a review of the literature on which the preceding research questions and hypotheses are based.



## CHAPTER II

### REVIEW OF RELATED LITERATURE

#### OVERVIEW

The research questions in Chapter I are grounded in a literature review of adaptation that includes readings in three fields of inquiry: aging, blindness, and chronic illness.

This chapter begins with a general discussion of adaptation: definitions, major theories, and selected studies. This information was useful in formulating the broader research questions as well as in identification of intervening variables.

Next, notions about a possible sequence or pattern of adaptation will be addressed. This concept of sequence generated the "time since onset" thrust of the study as well as suggesting individual questions about changes in attitudes over time and "turning points".

Finally, literature about each of the adaptive tasks that form the basis of the study will be discussed separately. These tasks are: maintenance or restoration of self esteem, use of help, balance between consistency and change in social and recreational activities, modification of schedule in activities of daily living, and understanding/appraisal of loss. Each section concludes with a brief discussion of its contribution to the research study.

## THE PHENOMENON OF ADAPTATION

### Definitions

A few terms that are used repeatedly in this section are commonly used, and confused, in the literature and in professional discussion. Definitions follow:

Adaptation, in this study as in general usage, is the broadest term. It refers to the process through which individuals respond to a changing environment or circumstances.

Adaptive Task is a term widely used by theorists and researchers in the field of adaptation. It refers to the challenge posed by the change in environment or circumstances; what must be accomplished if adaptation is to occur. For example, adaptation to retirement might include the adaptive task of living on reduced income.

Coping is sometimes used as a synonym for adaptation. Actually, it should be used only to refer to the strategies or skills the individual employs in the pursuit of accomplishing an adaptive task. For example, a coping strategy for living on reduced income might include preparing a budget. However, preparing a budget might be defined as a successful adaptation or performance of an adaptive task.

Loss is the condition of being deprived of what one has had.

Crisis is the state of disequilibrium in the individual when he is faced with a changed environment or circumstances.

Stress refers to the individual's response to a crisis.

In formulating the conceptual base for this study of adaptive tasks, I have read in all of the above areas and often found that data or ideas located in the literature in one of the other areas is relevant; for example, that what is referred to as coping in one instance, or stress reduction in another could just as well be termed adaptive task performance. When this has been the case, I have gone with the intent rather than the word and included it as appropriate in the literature review.

#### THEORETICAL AND EMPIRICAL STUDIES OF ADAPTATION

Crisis Theory has held a central role in social work thinking and practice since its origin over two decades ago (Rapoport, 1962; Parad, 1965; Lukton, 1974). Crisis Theory identifies two forms of crisis to which individuals are subject; developmental and situational. Developmental, also known as maturational or expected, crises occur at anticipated intervals throughout the life cycle. Erikson (1958) was one of the first to build upon the work of Freud in extending the concept of psychic growth past childhood. Thus, in the language of developmental theorists, Old Age is the last "stage" of human development. Situational, also known as accidental or unexpected, crises may occur at any time of the life cycle. Illness and accidents are prime examples of situational crises.

Whether developmental, situational, or possessing elements of both, a crisis is a disruptive intrusion into the ongoing life

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of the individual. He is thrown off balance, in a state of disequilibrium with concomitant feelings of stress. This state may be exacerbated by the fact that crises tend to reawaken areas of the past that are conflictual or unresolved. The individual's attempt to handle the changed circumstances of his life are observed by many theorists and researchers to follow a sequence. Although steps of the sequence differ in number, duration, and name according to the author, they commonly are believed to follow a progression, manifested by attitudinal and behavioral changes over time.

Thus, age-related vision loss can be viewed as a situational crisis arising in the midst of a developmental crisis. Clinical experience affirms that elders themselves often perceive vision impairment in this way - as particularly troubling when they are simultaneously struggling with a host of other losses endemic to the aging process.

Resolution of either kind of crisis is inevitable. It is the level at which it takes place that is variable. White's "compromise" that preserves the individual and permits him to grow is not always achieved and a diminished level of functioning results. The fact that age-related vision loss is both a situational and developmental crisis suggests a high risk of that possibility.

If, as White suggests, adaptation is the "compromise" with the stresses arising from life crises, we must look at the components of adaptation.

The notion of reciprocal adaptations between persons and their environments over time is at the heart of open-systems theory. It has been translated by social workers into the eco-systems perspective (Meyer, 1976). Many practice models have been developed that incorporate ideas about adaptation. For example, The Life Model cites crises arising from life transitions (developmental crises) as one of three "problems in living" for which practitioners must develop understanding and appropriate interventions (Germain & Gitterman, 1980).

The concept of adaptation has also been a potent one for social researchers and theorists of other disciplines. Studying individuals undergoing a wide range of situational crisis, at different points in the life cycle, they have attempted to delineate situation-specific adaptive tasks, sequences, and coping strategies.

Mechanic (1974) notes, "one of the largest tasks that stress researchers face is the developmental of models that specify in a predictive sense under what conditions one set of adaptations will develop in contrast to some other set. If the study of adaptation is to develop as a theoretical area, then we must do more than describe the array of behaviors characteristic of a person's adaptive attempts; we must begin to specify the relative probabilities that, under given circumstances, one coping attempt will follow rather than another".

This study concentrates on one such "given circumstance": age-related vision loss. There is evidence for the existence of

both general and situation-specific adaptive tasks and sequences. Generally, chronic illnesses are accepted by the elderly as an expected part of old age. It is widely believed that it is the degree to which an impairment influences the ability to function independently that affects the subjective meaning of the illness to the individual.

A number of studies have borne out the idea that functional consequences of a physical loss are paramount to adaptation.

Belgrave & Haug (1986), for example, studied the experience of chronic disease in the everyday lives of non-institutionalized elderly women. They identified three basic typologies: the individual who defined illness as a problem to deal with, to accommodate and endure; the individual who identified herself as ill and doing the best that could be done under the circumstances; and the individual who identified herself as ill and overwhelmed by physical problems. Further, they noted that although each disease was discussed in different terms, it was the functional consequence rather than the disease as an abstract medical condition that the respondents were relating to.

Another study of illness-related stresses in four chronic illnesses (cancer, rheumatoid arthritis, diabetes mellitus, and hypertension) of elderly outpatients found that contending with physical manifestations of illness, emotional distress, potential disruptions in social relations, threats to one's self concept and uncertainty about the future held true in most situations. However, there were also strong differences in the

kind and degree of stress faced by patients with different diagnoses (Revenson, 1985).

Those who have theorized about adaptation to loss of vision throughout the life span suggest that differences in response to different illnesses may be related to role expectations. They hold that blindness is a social role, learned within personal relationships with "normals" and in organizations that exist to serve the blind.

Scott (1969) states, "when those who have been screened into blindness agencies enter them, they may not be able to see at all or they may have serious difficulties with their vision. When they have been rehabilitated they are all blind men". They are "blind men", in his opinion, because they have learned the attitudes toward their disability and behavior that professionals believe they should have; a focus on accommodation to the comfortable environment of the "blind world" rather than restitution or compensation for lost functional capacity.

A different point of view on adaptation to loss, is expressed by The Continuity Theory (Atchley, 1989). The Continuity Theory holds that adaptation to a life event has less to do with the specific type of event or the social role it casts the individual into than it does with the habitual responses to crises that the elder has exhibited throughout his life time.

One of the seminal studies that generated the notion of Continuity Theory was a longitudinal study of 70-79 year old men and women. Neugarten & Tobin (1968) identified four basic

personality types and eight patterns of coping within them. In summarizing their findings, the authors set forth the necessity for a developmental or "personality continuity" theory of aging, asserting that the older person "ages according to a pattern that has a long history and maintains itself, with adaptation, to the end of life".

The view of Neugarten and Tobin was reinforced by one small-scale study of coping with vision loss in old age. It was found that those who had coped successfully with other life changes in the past were more likely to have dealt successfully with blindness, employing coping skills that had worked for them previously (Jacobs, 1981).

There is also evidence to suggest that physical and psychosocial adaptation may be two separate phenomena. In a study of the impact of life events, Palmore found that "medical events had most impact on physical adaptation but surprisingly little impact on psychosocial adaptation".

Whether or not, adaptation to any one stress is viewed as growing out of a life time pattern, most contemporary researchers and theorists cite the importance of considering the subjective meaning of the experience to the individual.

The idea of considering the cumulative effect of individual stresses is shared by several writers. Pearlin et al (1981) call attention to the impact of hardships over time, "eventful experience and chronic strains may converge in the production of stress". They go on to note that the number of events, magnitude



of changes and quality of changes all combine to determine the degree of stress.

Freedman and Inkster (1981) point out that adaptation to visual impairment is more difficult for older people than for young people because in old age there are more likely to be additional forms of disability. And this coexistence causes a cumulative effect of disability. For example, vision loss makes it harder to deal with unsteadiness of gait due to arthritis. They state that "the impact of blindness upon the aging process appears to result in a pervasive apprehension that effectively questions the person's total physical integrity...the question is, "now that I'm blind or losing my vision, what's going to happen next".

The notion of cumulative stress has been tested repeatedly with all populations by a multitude of life event scales, some particularly designed for use with the elderly (Kahana, 1982). However, a systematic study of 23 methods of weighing life events in terms of how well they predict psychiatric symptomatology found that the most predictive and efficient undesirability index consisted of simply adding up undesirable events (Ross & Mirowsky, 1979).

The results of a large-scale Rand corporation study of the negative effects of life events and physical limitations on mental health showed that social supports do not make a significant difference. The study also found that statistical measurements of life events do not yield significant findings

(Williams, Ware & Donald, 1981).

A somewhat different perspective on adaptation is taken by recent researchers who have examined the phenomenon of coping. Coping strategies are overt and covert behaviors taken to reduce or eliminate psychological distress or stressful conditions (Fleishman, 1984). They may be utilized in reference to any adaptive task and in any sequence. Coping strategies commonly encompass a range of responses for any one person, and a wide range is associated with success. Coping strategies are the techniques with which individuals try to meet the challenges of adaptive tasks.

White (1974) employs a military metaphor to account for available coping options: delay, strategic retreat, regrouping of forces, abandoning of untenable positions, seeking fresh intelligence, and deploying new weapons. The military metaphor seems to accurately convey the mobilization of combative forces necessary to cope with stress for Pearlin & Schooler (1978) also call upon it. They note that in successful coping having one particular weapon is less important than having an arsenal of them.

An early study of adaptation to the aging process underscores the importance of flexibly and differentially employing a variety of coping strategies (Neugarten et al, 1968). More recently, in two cross-sectional studies that compared the influence of age on 28 coping mechanisms, it was found that middle aged and old people exhibited the same variety in their

responses to stress as did younger respondents. The one significant difference found was that the older group were less inclined to use hostile reaction and escapist fantasy; this held true regardless of the type of stress (McCrae, 1982).

### Discussion

In summary, the literature on adaptation to loss draws on several, sometimes contradictory notions. Adaptation is variously described as determined by the nature of the specific event, determined by the cumulative effect of losses, determined by the past history and psychological structure of the individual. Adaptation is seen by some as being the same process across the life span and by others as dependent on one's age.

At the same time, there is agreement on the end result of successful adaptation. Many writers speak of the necessity of maintaining a pattern of activity that accommodates both loss-related and non-loss activities; as Kiefer (1974) puts it, maintaining consistency in the face of change. Another point of agreement is that successful adaptation is based on a willingness to face problematic new situations with some degree of confidence that they can be mastered (Heppen & Petersen, 1979). In writing about adaptation to a variety of losses Simos (1979) notes a common theme; the recognition that life can be different but still good.

The readings in this section were helpful in generating identification of intervening variables (health, social supports, and co-existing life events). They also suggested explanations

for some of the study findings.

THE SEQUENCE OF ADAPTATION (TIME SINCE ONSET)

Everyone who has thought about or studied adaptation, regardless of the age of the population or the crisis involved, agrees that there are phases through which individuals pass from first knowledge of the challenge presented to its resolution. There, however, the agreement ends. The number of stages, the period of time they last, the turning points from one to another, the characteristic behaviors that occur within each, and whether or not they are passed in consecutive order for any or all people, are questions for which the answers vary considerably.

Clearly, an understanding of the normative pattern (if any) through which elders move in adapting to the loss of vision would have clinical value in assessing the individual situation and in planning strategic interventions.

The recognition that adaptive tasks and the ways they are met change over the course of the individual's experience with a stressful life situation is implicit, if not explicit, in the writing of all theorists. The widely popular work of Kubler-Ross (1969) on the stages of adaptation to the idea of one's own imminent death is echoed by those who have studied the processes accompanying adaptation to a variety of losses (Simos, 1979). Shock and disbelief, denial, anger, depression, bargaining and acceptance are cited as typical responses in their most frequently occurring sequence; although it is noted that the full

cycle is not accomplished by everyone, that there is frequently a back and forth rather than a straight progression, and that, indeed, what has been claimed as universal actually shows a great deal of variation.

Kastenbaum (1978) warns against a "set" of the worker that blinds her to the individual nature of each situation. He suggests that differentials of illness, mode of treatment, environmental context, ethnicity, and life style will influence reactions and their sequence.

Time is much on the mind of most theorists of adaptation. White (1974) writes, "strategy is not created on the instant. It develops over time and is progressively modified in the course of time". Writing of coping with a physical disability, Adams & Lindemann (1974) agree that the final outcome of rehabilitation is dependent on the patient's capacity to deal successfully with his disability over a relatively long period of time.

Mallick (1979) suggests three overlapping stages of coming to terms with severe illness; onset (the diagnostic stage), adaptation to long-term or disabling aspects of the illness, and illness ending (through remission or death). In common with many who write about adaptation to illness and disability, she cites the importance of the first phase, its resolution providing the potential for later success.

Heppen & Petersen (1979) write about facing possible blindness, and underscore the importance of the first phase which culminates with acceptance of the disability and all that it

entails.

Cholden (1958) and Carroll (1961) were among the first writers on adaptation to vision loss and remain widely quoted in the blindness field. They both dramatically focussed on the "death-rebirth" theme of coming to terms with blindness in this first phase; i.e. one must mourn for the old self before coping with the changed self. Bauman (1972) does not go so far, but notes that with the loss of vision there is almost always a period of seeking to come to terms with the changes.

Riffenburgh (1967) accepts that not all adventitiously blinded persons go through an entire cycle but suggests that certain reactive states are characteristic. Along with other theorists, he identifies shock, denial, anger, and depression as characteristic of the beginning stage.

Those writing from the rehabilitation field, whether to low vision or to other disabilities, tend to agree that rehabilitation cannot proceed until denial is past and the permanency of the disability is accepted (Gull, 1972).

Blaxter (1976) holds that the difficulty of the first phase is worsened by uncertainty about diagnosis, prognosis, and implications for future functioning. If there is disagreement or misunderstanding about what is wrong, the period of seeking second opinions and defining the problem will prolong the denial period and retard the onset of rehabilitation. This observation is also made by Mailick (1979)

Practitioners in the Low Vision clinic of The Lighthouse

report greatest success in utilization of aids among elderly clients who know their diagnosis and have been sent by their ophthalmologists as part of the initial treatment plan.

All theorists characterize the first stage of adaptation as representing both approach and avoidance behavior as the individual struggles to integrate the disability into his ongoing life. This stage ends with acceptance of the permanency of the situation and beginning efforts to deal with it.

The first stage is usually described as one in which emotional responses are prevalent. Shock and disbelief, denial, anxiety, anger, guilt, and depression are commonly accepted to follow in sequence. Falek & Britton (1974) reported that all or most of these reactions were found in a literature review of such disparate conditions as those reacting to radical mastectomy, severe burns, poliomyelitis, national disasters, terminal cancer, and death of a loved one.

Adams & Lindemann (1974) concur, "a significant point is reached after the initial period of denial, when experiences and behavior analogous to mourning are observed. The accustomed life style and its range of functions and rewards are not abandoned without pain, and the attending depression must be accepted before new functions and roles can be found.

The certainty and unanimity with which the first phase is delineated is not seen in descriptions of later phases. In fact, later phases seem subject to so much individual variation that they are scarcely delineated at all.

Goffman (1963) posits that people who share a stigma tend to also share a similar "moral career", a sequence that is both cause and effect of coping with the same challenges. He suggests that life events are often cited as turning points at which the individual passed from one stage to the other in coping with disability. Personal experiences or experiences even heard or read about may thus be cited as occasions for a changed attitude.

### Discussion

The literature on adaptive sequence suggests inquiry into whether or not adaptive task performance is related to "time since onset" in the case of age related vision loss. Further, it raises questions about the possibility of a normative illness career. Are there common turning points and/or time spans for each stage? Or are differences among the aged so great that no commonalities can be found?

This study employs the "time since onset" concept to test whether a sequence of adaptation exists. (if a sequence did exist, there would be significant differences in adaptive task performance related to time since onset of vision loss). Questionnaire items about attitude changes over time and turning points are derived from this section's literature review.

### FIVE ADAPTIVE TASKS

The five adaptive tasks that follow form the core of the study. They are the tasks most frequently appearing in the



literature of adaptation to chronic disability, adaptation to aging, and adaptation to low vision across the life span. As noted in Chapter I, the five adaptive tasks are not united in any theoretical or empirical model. They are, simply, the most frequently cited tasks in the literature of adaptation. The purpose of this study is to determine their applicability to the situation of age related vision loss.

#### Maintenance or Restoration of Self Esteem

The importance of retaining a positive sense of self in the face of adversity is most often cited as the crucial determinant of adaptation (Visotsky, 1961; Kuypers, 1972; Mechanic, 1974). Preservation of a self image that is congruent with the ego ideal is closely correlated with success in physical rehabilitation for a number of disabilities (Adams & Lindemann, 1974).

In the field of aging, where the concept of adaptive task has a developmental interpretation, the Eriksonian (1950) concept of life stages is one approach to understanding the notion of self esteem. The psychological issue that he believes embodies the central crisis for the individual in late life is the resolution of the polarities of ego-integrity and ego-despair. Ego-integrity is "the acceptance of one's one and only life cycle as something that had to be and that, by necessity, permitted of no substitutions."

Peck (1968) building on the work of Erikson posited an amplification that old age presents three separate tasks; each,

paradoxically, preserving the ego by transcending it. Ego differentiation vs Work role preoccupation involves finding a sense of self worth in activities and roles outside the workplace. Body transcendence vs. Body preoccupation involves the capacity to move beyond a focus on the inevitable decline of physical powers to appreciation of mental and social powers which may stay the same. Ego transcendence vs. ego-preoccupation involves a continuing interest and effort in the betterment of life for others even though one's own death may be imminent. The importance of maintaining self esteem in the face of loss is an implicit, if not explicit, theme in the writings of both Erikson and Peck on aging.

Authors in the low vision field generally make no age discriminations in their theories (Chevigny & Braverman, 1950; Cholden, 1958; Carrol, 1972; Monbeck, 1973). They cite societal attitudes toward blindness as crucial in the development of negative self-attitudes and a resultant loss of self-esteem. The underlying assumption of their writing is that neither the age of the individual nor the degree of the impairment are mitigating factors.

For example, it has been stated that blindness is often irrationally seen as a punishment for sin, a view historically reflected in biblical, mythological, and Shakespearean texts (Monbeck, 1975). Or that even when the blind person is not blamed, or does not blame himself, for the affliction, societal myth is that he is rendered helpless in his own behalf and of no

use to others.

Interestingly, inaccurate and inflated perceptions of ability are said to coexist with negative images. For example, extra-sensory perception as well as heightened acuity of other senses is often attributed to the blind (Koestler, 1974; Monbeck, 1975).

Because body image is so closely related to self-image, a change in body function produces a particular threat to the integrity of self. This is particularly the case when the change in body function is to a stigmatized condition. Old age and blindness are both stigmatized conditions in our culture.

Goffman (1963) wrote earliest and most eloquently of the dilemma faced by someone who acquires a devalued characteristic after childhood, "such an individual has thoroughly learned about the normal and the stigmatized long before he must see himself as deficient. Presumably he will have a special problem in reidentifying himself and a special likelihood of developing disapproval of self".

Empirical data supports Goffman's theory. For example, Becker (1985) compared a group of individuals over 60 who had been born deaf with a group of individuals over 50 who had suffered a recent stroke. She found that a devalued status was harder to adapt to if it occurred late in life. Life as it was known was said to "crumble" with ensuing identity problems. Of course, the 50s are not the 80s. It is questionable if status is of such great concern to the aged as to the middle aged; or if it

is built upon the same criteria as in middle age.

### Discussion

The literature on aging, the literature on low vision, and the literature on chronic disability agree that maintenance or restoration of self esteem is a primary adaptive task - whatever the age or the health problem. Thus, a scale on self esteem was incorporated into the questionnaire. It is discussed at length in Chapter III

### Use of Help

Loss of any area of functioning requires use of help with areas of life once handled independently. Help can come from two sources: the informal system (family, neighbors, and friends) and from the formal system (private providers and social agencies).

For those suffering age-related vision loss, help is often needed due to difficulties handling activities of daily living and/or participation in social and recreational activities independently.

"Use of Help" depends upon the ways in which individual requirements and outside supports mesh. Mechanic (1974) accords the social structure basic importance in determining how well an individual will cope in a given circumstance. Pearlin & Schooler (1978) would agree, arguing that coping failures are not always attributable to the shortcomings of the individuals; many reflect

the failure of social systems in making necessary supports available.

White (1974) suggests that to cope requires an ongoing balance between inner and outer resources. The individual must simultaneously do three things: keep securing adequate information about the environment, maintain satisfactory internal conditions for action and for processing information, and maintain autonomy or freedom of movement.

Thus, resources - of the informal and formal system, and how, when, and why they are differentially employed to meet the individual's adaptive needs - are variables to be looked at in relation to his ability to use help.

To speak of help in care for the aged from the informal system is to speak of family caregiving. "The caregiving relationship is differentiated from typical family exchanges and is defined by the existence of some degree of physical, mental, emotional, or economic impairment on the part of the older person which limits independence and necessitates ongoing assistance" (Horowitz, 1985). Research on patterns of family caregiving indicates that the type and level of impairment, the quality of the affective relationship, and attitudes of other family members are primary determinants of variation.

Most research has been on the effect on families of caring for a disabled elder, with minimal emphasis on the impact on the elder of being the recipient of care. Yet two findings are of interest. In one study, 55% of older people who lived with their

relatives reported that the caregiver attempted to do too much for them (Noelker & Poulshock, 1982). In other studies, it was questioned whether receiving services from one's spouse was more or less acceptable than receiving help from adult children. The findings here were equivocal; in one study, services from one's spouse were favored (Johnson, 1980); in another, care from adult children was met with greater satisfaction (Noelker & Poulshock, 1982). Further, a study showed that elders with low vision who perceived that families thought them capable of independent functioning did, indeed, function more independently than those who did not perceive such expectations (Marcus, 1982).

If families are present they are usually the link to the formal system of help, often functioning as case managers for their frail elders. In such cases, the help called for from the formal system is usually limited to what families can't do. If families are not present, the demand on the formal system will, of necessity, be greater.

Mailick (1979) notes that health care workers have a symbolic as well as real importance to the chronically ill, and that learning how to deal with them and assume an active role in one's own care is important.

### Discussion

"Use of Help" emerges as an important adaptive task. The literature review suggests inquiry into elders' perception of and satisfaction with services, the differential employment of

informal and formal supports, and the search for aid. These ideas stimulated specific single items on the questionnaire as well as development of the scale "Help" described in Chapter III.

Balance between continuity and change in social and recreational activities.

Modification of Daily Schedule

These are two separate tasks conceptually close but quite different areas of investigation. Together they refer to the ways in which physical disability affects how older people spend their days.

Social and recreational activities include a range of passive and active pastimes that are a source of affirmation and gratification to individuals. Modification of Daily Schedule includes what are commonly described as activities of daily living: self care, household and money management, etc.

Some of the aging research on recreational participation focusses on constraints in general (McGuire, 1982). Some focusses on activity-specific restraints. None, has come to this investigator's attention that starts with the constraint of vision impairment and then goes on to look at what activities are affected in what way. In a nationwide study of limitors and prohibitors of participation in outdoor activities by the elderly, personal health was listed as one of 11 reasons. Personal health was responsible for 33.1% of prohibitors and 8.3%

of limitors. Further, age was a salient factor. While individuals from 61 - 75 years of age frequently mentioned lack of time as a constraint, "time became a decreasingly salient factor across the life span whereas health became increasingly common as a constraint. Income and transportation were not found to be major limitations" (McGuire et al, 1986).

Another study also found age to be extremely significant as predictor for giving up of activities with no differences for men or women. However, gender differences were pronounced in the types of activities, running against the commonly held belief that there is increasing similarity between male and female activities in late life (Herzog, 1989).

Recreational and social activities have long been identified by theorists as providing new roles for older people, new arenas to exercise their skills and receive affirmation of their worth after the challenges of the workplace and raising a family are ended (Atchley, 1980). Thus, the decrease in participation in social and recreational activities due to physical limitations has potentially serious ramifications for adaptation.

Glaser & Strauss (1971) define normalization in the management of disease as the steps individuals take to rearrange their lives so that impairments remain hidden from others; for example, making up a reason for total withdrawal from a previously meaningful activity rather than continuing at a lower performance level that would arouse pity or concern from others. Goffman (1963) too, speaks to the strategies whereby disabled



individuals "cover" for themselves in social situations.

Activities of Daily Living are rarely studied by themselves but most usually in relation to other factors such as service utilization or health. The aspect of activities of daily living relevant to this study is the extent to which older people are affected by vision impairment.

### Discussion

The literature review pointed to the importance of expanding upon Activity of Daily Living and Recreational scales currently in use with the elderly to meet the purposes of this study. Specifically, items were added to determine the reason for low participation or dependence in each activity on the list (whether for vision loss or another problem).

### Understanding of Loss

Understanding and appraisal are related but different phenomenon. Understanding refers to the elder's recognition of the loss sustained; his knowledge of the diagnosis and prognosis.

Appraisal refers to the elder's judgment of the meaning of the loss

Theorists differ on the importance of understanding a diagnosis. Blaxter (1986) holds that patient, family, and physician must all know, understand, and accept the cause for the clinical label. This is perceived as a process during which the patient strives to find a "rational" reason for what is

happening. She reflects that accepting the random occurrence of illness is difficult and most individuals seek to relate it to a pattern. In other words, that understanding accords a measure of perceived control.

On the other side are those who believe that knowledge is either not essential for adaptation or may take place quite late in the process. "Sometimes adaptation to a severely frustrating reality is possible only if recognition of the bitter truth is for a long time postponed" (White, 1974).

Others suggest that understanding of the parts might be as important or more important than understanding the whole. Writing from the field of low vision, Overbury (1982) believes that positive attitudes toward the use of residual vision and a lack of depressive symptoms are essential, regardless of understanding of diagnosis.

Appraisal is repeatedly cited in the literature as crucial to the employment of coping strategies. Mechanic (1974) exhorts students of adaptation to question how individuals perceive the challenges they must master and their own ability to meet them, noting that subjective data is as important as objective data in predicting adaptive responses.

In one theoretical analysis of defense mechanisms and their use by the visually impaired, it is attempted that the degree of blindness is not correlated with the degree of its psychological importance but rather its particular meaning to the individual (Gull, 1972). This idea was underscored in the study of Jacobs

(1981) who found that among those who coped well with loss of vision in old age most felt that they had experienced the same amount or fewer losses than those of others their age and had a high level of life satisfaction. Goffman (1963) found that an unconventional interpretation, such as that the disability was "a blessing in disguise" contributed to being able to deal with it.

Lazarus & Folkman (1984) in a cogent book-length presentation that reviews all recent literature in the field as well as their own research, maintain that perception is crucial in mediating between stressors and adaptation.

At least one study has linked the acceptance of formal help to expectations of the elder as to whether it will promote recovery or rehabilitation (Kaufman, 1985). Stroke victims who expected that participating in a care plan would return their functioning were initially more motivated, but became disillusioned and made fewer efforts on their own behalf when it became evident that they would not return to their prior level of functioning.

Lowenthal's theory of intentionality (1971) posits that the individual's effort to maintain congruence between conscious goals and behavior patterns is a key factor in adaptation to stresses of adulthood.

Black, Dornan & Allegrante (1986) in reviewing the literature on chronic illness also claim that "self appraisal is central to the development of successful coping strategies and the maintenance of self esteem".

While appraisal may be viewed as an intervening variable between the challenge of physical illness and the adaptive tasks (Moos, 1979), most theorists identify it as an adaptive task in itself.

### Discussion

The literature on "Understanding of Loss" suggested the matching of clinical prognosis with elders' expectations of vision changes. The literature on appraisal served as the genesis of many open-ended items; such as, advice to others with the same eye problem, and the description of oneself in relation to vision loss.

(A scale consisting of open-ended appraisal items did not meet reliability criteria precluding it from use in the bi-variate and multi-variate analyses. However, appraisal items are discussed individually in the descriptive analyses.)

In conclusion, Chapter II has identified the theoretical underpinnings of the research study; the ideas that stimulated the research questions and hypotheses in Chapter I. The conversion of these notions into questionnaire items was discussed at the end of each section. Chapter III will expand upon this theme with discussion of the research design and methodology of the study.

**CHAPTER III**  
**RESEARCH DESIGN AND METHODOLOGY**

**OVERVIEW**

This chapter presents the research design and methodology of the study. It is divided into four parts. The first section begins with a brief description of the research purpose and design and continues with a discussion of sampling procedures including: study site, preliminary activity, the study population, sampling plan, and sample response. The second section presents and discusses the demographic characteristics of the sample. The third section presents the research instrument, data collection procedures, and identification of variables. The fourth and final section describes and discusses the scales and indexes used in the study, concluding with an overview of the data analysis used to arrive at the findings in Chapters IV, V, and VI.

**RESEARCH DESIGN**

The aim of this study is to both describe and explain the phenomenon of adaptation to age-related vision loss.

Since the psycho-social consequences of age-related vision loss have received scant research attention, descriptive aspects of the study are primarily exploratory. They may be useful in suggesting future research topics; but are expected to carry most relevance for the design of clinical strategies to meet the specific needs of the visually impaired elderly.

At the same time, there is extensive theoretical and empirical literature about the process of adaptation to aging, adaptation to chronic illness, and adaptation to loss of vision across the life span. Five of the adaptive tasks most frequently cited in this literature form the basis of the explanatory aspect of the study. These tasks are: Maintenance/Restoration of Self Esteem, Use of Help, Modification of Daily Schedule, Balance between Continuity and Change in Social and Recreational Activities, and Understanding of Loss. These tasks form the basis of the explanatory aspect of the study, the main purpose of which is to identify bivariate correlations and explain the statistical variance in adaptive task performance.

At this juncture it is important to state that nowhere in the literature do these five tasks appear together united in an empirical model; thus there is no reason to believe that they do or do not impinge upon one another to result in adaptation as an outcome. Rather, each task was selected because of the frequency and fervor with which it was identified as a measure of adaptation. Moreover, the study looks at adaptation as a continuum rather than an absolute. In other words, the research interest is in the extent to which visually impaired elders perform or negotiate each task.

The research questions of this study required that the question of adaptation to age-related vision loss be approached from the point of view of the visually impaired elderly themselves (with the addition of some verifying eye data

from professionals involved in their care). Given the type of data required and the frailty of the respondents, the in-person home interview was deemed the most appropriate data collection method.

### Study Site

The study site from which the sampling population was chosen is the Low Vision Clinic of The Lighthouse.

The Lighthouse, incorporated in 1906 as the New York Association for the Blind, is the largest multi-service private agency in the United States serving visually impaired persons. The Lighthouse Low Vision Clinic, established in 1952, is available to consumers only upon referral by a physician. Evaluation of the consumer and his needs is followed by prescription of appropriate low vision aids. The Low Vision Clinic functions independently from the social service programs administered by the agency.

### Implications and Rationale for Using the Low Vision Clinic as a Sampling Site

A study of adaptation to age-related vision loss would be most effective if the sample had not received any services prior to the investigation. However, the identification of such a population was beyond the resources of a dissertation study. The Low Vision Clinic of The Lighthouse was chosen as the best

alternative because of particular characteristics of its program and population.

Most of the consumers served by the Low Vision Clinic are over 60 years of age. The majority of these suffer age-related vision loss: all have retained some measure of sight. Because the Low Vision Clinic functions somewhat as a "store" for visual devices it is acceptable to many consumers who would not otherwise avail themselves of the services of a social agency. The majority receive no other services at The Lighthouse. There is a fee for service as well as medicare, medicaid, and private insurance reimbursement for some services. The payment scheme further emphasizes the perception of the Clinic as a health rather than a social service. Parenthetically, clinicians who conducted the interviews spotted respondents who could have benefitted from social services but were unaware of their availability.

#### Preliminary Activity

The researcher has an on-going consultative role to various departments within The Lighthouse and so entered the research process with some familiarity with agency practices and staff. Prior to construction of the research protocol, a series of individual meetings were held with social workers and clinicians involved in the Low Vision Clinic as well as with the Director of Research and Evaluation. These were followed by a group "brain-storming" meeting at which all the involved staff shared



ideas about the process of adaptation to age-related vision loss. The purpose of this activity, which took place during the summer and fall of 1986, was twofold: to foster staff interest and support in the study and to draw upon their practice expertise and clinical observations in formulation of questionnaire items.

The study abstract, design, questionnaire, and procedures were reviewed by a Research Committee at The Lighthouse whose responsibility it is to approve all research done under its auspices. The Committee includes key administrative personnel. The Lighthouse is protective of its consumers and generally would not make names available to an outside researcher. Because my credibility was established as a consultant I had easier access. Even so, concerns were raised about the possibility that respondents would be "upset" if asked to reflect upon their visual impairment. Presentation of the idea that it can be therapeutic and empowering for older people to speak about their adaptation to loss, and assurance that interviewers were trained in handling emotional reactions overcame this objection. Further, a procedure was devised whereby psycho-social problems identified by interviewers could be directed to the social service department. The committee also reviewed the introductory letter to potential respondents from the Director of Research and Evaluation (Appendix A), the Consent Form to be signed at the time of the interview (Appendix B), and Client Safeguards in the Research Process (Appendix C).

### Study Population

The research strategy was designed to include the universe of individuals over the age of 60 who resided in the five boroughs of New York, reported an age of onset of less than six years ago, and were first seen at the Low Vision Clinic of The Lighthouse between March 1987 and November 1988.

Because the study is predicated on the belief that cohort and time since onset differences affect adaptation it was essential to have comparable representation from two age groups (60-74 and 75+) and three times since onset (0-1, 2-3, and 4+ years).

The sampling goal was to interview 15 respondents in each category with a total of 90 in the study. The outcome of the sampling was 86 respondents. There were 15 or more respondents in all three time slots since onset in the 75+ category and 15 respondents in the 4+years since onset in the 60 -74 category.

It was extremely difficult to get respondents in the 0-1 and 2-3 time since onset in the of the 60-74 group. This is attributable to the fact that the incidence of vision impairment increases with age and that a smaller number of "young old" use the services of the Low Vision clinic. It is also recognized by the clinical staff that the "search for aid" for vision loss often continues for more than a year before the Low Vision clinic is approached. (During this time, many of the visually impaired aged are believed to be "shopping" for second opinions, etc. - a belief borne out in the findings of this study). By the time the

sampling ended, there were 14 respondents in the 60-74 group who reported 2 - 3 years in the time since onset; but only 8 in that age group who reported times of onset as a year or less.

#### Sampling Plan and Procedures

Since the majority of individuals in the universe were 75+ with a time since onset of 3 or more years, a random sample was used to determine participants in these groups. Individuals aged 74 or less and individuals of any age with less than a year's time since onset were rare and each one of those who turned up were entered on the potential respondent list.

Approximately 20% of the individuals were listed as having a "case manager" at the agency. In over half of these cases, the case manager was an ophthalmologist in the clinic; in the rest, the case manager was a member of the Department of Individual and Family Services of The Lighthouse. If a case manager had been assigned to someone on the list, he/she was offered the right to veto before contact was made.

Initially, respondents were contacted on the basis of information on the Low Vision Clinic printout; specifically birthdate and difference between current age and age of onset. An average of 10 introductory letters went out at a time, staggered so that the interviewer could make phone contact and an appointment time within one week of their receipt. The letter (Appendix A) over the signature of the Director of Research and Evaluation legitimated the study, promised confidentiality, and

offered the assurance that future service was in no way connected with participation. The interviewer's follow up phone call answered further questions and obtained either appointments or reasons why these were not possible.

Before interviewing began it was assumed that time since onset could simply be calculated by the difference between current age and age of onset; both items of information given to the admission clerk at the time of the Low Vision Clinic appointment. However, the time of onset figure provided by the clinic proved to be inconsistent with recollections of respondents in the interview situation.

Since the time since onset given at the interview was asked directly (How long ago did vision loss become a problem for you?) in the context of a discussion that focussed the respondent's attention on the circumstances of vision loss, and was underscored by a follow up question on who was first talked to about the problem and how long ago, it seemed the more accurate measure and was subsequently used as the measure.

At first the discrepancy between printout information and interviewee responses posed no problem. There were blanks in every category and respondents were simply switched into the appropriate category on the basis of their interview responses. However, by the time 70 people had been interviewed, a full 59% reported a time of onset different than that on the Low Vision chart. 42% of these recalled the onset as occurring earlier in time and only 17% recalled it as occurring later.

Therefore, as the categories became filled it became necessary to pre-screen potential respondents on the phone to make sure they met the criteria of less than 3 years since onset.

### Sample Response

The results of the sampling process are presented in Table III - 1. Out of an N of 194, 128 respondents were eligible. This relatively low number was based on several factors peculiar to the study. 2% were pre-screened by a case manager who vetoed contacting them (the reason generally given being that they were emotionally too unstable to participate). 19.6% were post-screened by the interviewer if the preliminary phone call found them to belong to completed categories. (The 4+ years since onset was the first filled; vacancies in the 0 - 1 year since onset remained until the interviewing ended). The attrition rate of 9.3% included those who had died, were in hospital or nursing home, or who had moved out-of-state.

Of the 128 eligible respondents, 67.2% participated in the study and 21.9% refused, 8.6% could not be reached by phone on repeated tries, and 2.3% could not be interviewed because they only spoke Spanish and we did not have a bi-lingual interviewer.

### Bias Due to Non Response

Most individuals gave no reason for refusal. For those who did, reasons fell into four major categories, here

TABLE III - 1

## SAMPLE RESPONSE

	Frequency (n)	Percent %
<b>A. <u>Sample Population</u></b>		
Pre-Screened (1)	4	2.1
Post-Screened (2)	38	19.5
Attrition (3)	18	9.3
Letter return/Phone Disconnect	6	3.1
Eligible	<u>128</u>	<u>66.0</u>
Total	<u>194</u>	<u>100.0</u>
<b>B. <u>Eligible Population</u></b>		
Completed Interviews	86	67.2
Refused Interviews	28	21.9
Not Reached (4)	11	8.6
Not English Speaking	<u>3</u>	<u>2.3</u>
Total	<u>128</u>	<u>100.0</u>

(1) Included those who the Lighthouse case manager vetoed before letter contact.

(2) Included those who were found to belong to completed categories after telephone contact.

(3) Included those who were found to have died, been institutionalized or moved out of state after telephone contact.

(4) Included those whose phones were unanswered on repeated tries.

discussed in order of the frequency in which they were cited. The first was no time: "too busy", "house being painted", "children coming to visit". The second was illness: "wife sick", "just had surgery", "not feeling well". The third was vision loss: "I use a magnifying glass, I do fine", "It would be far too difficult to talk about it. I haven't got used to it yet". The fourth was feelings about The Lighthouse: "they didn't help me, why should I help them".

In order to identify any bias due to non-response, the information supplied by the Low Vision Clinic on all of the sample was reviewed for those individuals who either refused or were not reached. This information included: gender, address and phone, date of birth, age, onset age (according to clinic records, diagnosis, best corrected vision, exam date, and disposition (case closed or case manager name). On these criteria, there was no discernable difference between those individuals who did not participate and those who did.

#### DEMOGRAPHIC CHARACTERISTICS OF THE SAMPLE

The demographic characteristics of the population are presented in Table III - 2.

The age distribution of the sample ranged from 60 - 99 with a mean of 76.2. As noted earlier, this mean age is not representative either of the visually impaired aged population or of the population of the Low Vision clinic but was sampled selectively to determine if there were differences between the

TABLE III - 2  
DEMOGRAPHIC CHARACTERISTICS

	Frequency (n)	Percent (%)
<u>Gender</u>		
Male	25	29.0
Female	61	71.0
Total	86	100.0
<u>Age</u>		
60 - 69	22	25.6
70 - 79	30	34.9
80 - 89	27	31.4
90 - 99	4	4.6
Missing	3	3.5
Total	86	100.0
Mean = 76.2		
<u>Marital Status</u>		
Married	30	34.9
Widowed	28	32.5
Divorced	5	5.8
Separated	9	10.5
Single/Never Married	12	13.9
Missing	2	2.3
Total	86	100.0
<u>Ethnicity</u>		
White	72	83.7
Black	10	11.6
Hispanic	3	3.5
Other	1	1.2
Total	86	100.0
<u>Religion</u>		
Jewish	38	44.2
Catholic	27	31.4
Protestant	13	15.1
Other	6	6.9
No response	1	1.2
Missing	1	1.2
Total	86	100.0
<u>Education</u>		
Less than 12 years	29	33.7
High School Graduate	21	24.4
Some College	11	12.8
College Graduate	10	11.6
Post College	14	16.3
Missing	1	1.2
Total	86	100.0



	Frequency (n)	Percent (%)
<u>Income Source</u>		
Income Only	3	3.5
Social Security or Pension Only	56	65.1
Social Security or Pension, Plus Income	23	26.7
Missing	4	4.7
Total	86	100.0
<u>Living Arrangement</u>		
Live Alone	38	44.2
Live With Spouse	29	33.7
Live With Spouse and Children	1	1.2
Live With Children	9	10.5
Live With Other Relatives	3	3.5
Live With Non Relatives	5	5.8
Other	1	1.2
Total	86	100.0

"young old" and "old old".

Not surprisingly in a study of elderly respondents, women comprised close to three-quarters of the sample (71 %). Over one-third of the respondents (34.9%) were married and an almost equal number (32.5%) were widowed. Those who had never married comprised the third largest group (13.9%) with those who were separated not far behind (10.5%). Divorced respondents made up 5.8% of the sample.

Eighty-three percent of the sample were White, 11.6% Black, 3.5% Hispanic, and other 1.2%. In 1980 (last census) New York City figures were White 75.8%, Black 14.2%, Hispanic 7.8% (NYC Department for the Aging, 1988).

The numbers of this study do not represent the ethnic diversity of the aged of New York City, perhaps attributable to the fact that access to the Low Vision Clinic requires information and referral opportunities less frequently available to minority groups.

The religious affiliation of the sample was: Jewish 44.2%, Catholic 31.4%, Protestant 15.1% , Other 6.9%, No Response 1.2%, and Missing 1.2%.

One-third of the sample (33.7%) have less than a high school education. One quarter (24.4%) are high school graduates and an equal number attended or graduated from college. Those with post college education account for 16.3% of the sample.

An unusually large number of the respondents (44.2%) live alone. According to 1980 census figures for New York City, 32.2%

of individuals over the age of 65 live alone (NYC Department for the Aging, 1988).

One possible implication could be that such individuals feel the most vulnerable because of vision loss and are most prone to seek out the assistance of Low vision Aids. A third of the respondents live with a spouse (33.7%). While only 1.2% live with spouse and children, a full 10.5% live with children.

The amount of income of the elderly respondents was not deemed an appropriate question or important consideration of the study. However, income source was used as an indicator of financial status. Well over half (65.1%) subsisted only on social security or pension. An additional 26.7% had an additional income to add to their retirement annuities, and 3.5% lived on income only.

#### RESEARCH INSTRUMENT

The research instrument (Appendix D) was a questionnaire consisting of 215 closed and open-ended items constructed for the purpose of eliciting factual and attitudinal data about age-related vision loss. The primary data source was the respondent from whom 210 items of information was gathered in in-person interviews that averaged about an hour in duration. The secondary data source was the Low Vision Clinic that provided information 5 items including birthdate, time since onset, clinical diagnosis, clinical prognosis, and degree of impairment.

A pretest of the questionnaire was conducted with visually

impaired Lighthouse staff over the age of 60 as well as with respondents who fit the study protocol. The input of staff who brought the combined perspective of consumer and provider of vision services was valuable in suggesting subtleties to the areas of inquiry. The experience with respondents from the sample population further refined the instrument.

The final questionnaire included a combination of closed and open-ended items and scales. Open-ended items were designed to elicit attitudinal and behavioral adaptive responses to age-related vision loss on the part of the individual interviewees. Closed items covered demographic and other factual information. Scales were employed to measure health problems, use of services, self-esteem, activities of daily living, and recreational activities. Many of these originated in other instruments and were adapted to meet the specific interests of the study by addition of a component related to vision-loss.

#### Data Collection Procedures

Data collection began in December 1987 and ended in December 1988.

The interviewer called all respondents within ten days after the letter of introduction was mailed by the Director of Research. The purpose of this call was to answer any questions or concerns aroused by the letter and, if possible, to set up an appointment for the interview. Repeated calls were made at different times of day over a two-week period to those

respondents who had a connected phone but did not answer.

Respondents were given the choice of site for the interview. As anticipated, all but two requested that the interviewer come to their homes. The two who requested an office visit (both males) were seen in the Research Department at The Lighthouse.

### Identification of Study Variables

Chart III - 1 summarizes the variables of the study.

The independent variables are primarily demographic data: age, income, ethnicity, education, gender, marital status, living arrangement, degree of impairment, diagnosis, and prognosis. Time since onset is also examined as an independent variable.

The dependent variables are the adaptive tasks themselves as gathered from the literature review on adaptation: maintenance/restoration of self esteem, use of help, modification of daily schedule, balance between continuity and change in social and recreational activities, understanding of loss.

Intervening variables are those factors identified in the literature as impinging on the adaptation of older people: stressful life events, informal supports, formal supports, and health status.

Scales and indexes were developed to operationalize many of the constructs that comprise the dependent and intervening variables of this study.

Most of the scales used were pre-existing instruments whose

## Chart III - 1

## IDENTIFICATION OF VARIABLES

Independent Variables

## A. Demographic

1. Age
2. Gender
3. Income source
4. Education
5. Marital status
6. Living arrangement

## B. Vision Related

1. Degree of impairment
2. Clinical diagnosis
3. Clinical prognosis
4. Time since onset

Intervening Variables

## A. Co-existing Life Events of Change and Loss

1. Moves of self
2. Moves of "someone close"
3. Serious illness of "someone close"
4. Death of "someone close"

## B. Informal Supports

1. Spouse
2. Adult children
3. Other family
4. Friends and neighbors

## C. Formal Supports

1. Social agencies
2. Private pay

## D. Health Status

1. Hearing
2. Medical problems
3. Subjective appraisal

Dependent Variables

## A. Maintenance or Restoration of Self Esteem

## B. Use of Help

## C. Modification of Daily Schedule (Activities of Daily Living)

## D. Balance Between Continuity and Change in Social and Recreational Activities

## E. Understanding of Loss

reliability had been established on other studies. The origin of these instruments is noted in the discussion of reliability. In cases where it was considered of interest to know how the items in question were affected by vision loss, such questions were appended to the scales.

The reliability estimates (coefficient alpha) for the scales used in this study ranged from to .60 to .91 . Table III-4 presents a listing of scales and indexes with accompanying alpha values as appropriate.

The following section defines, describes, and discusses each of the major variables and the scales and indexes developed to measure them.

### SCALES AND INDEXES

#### DEPENDENT VARIABLES

The dependent variables are the five adaptive tasks hypothesized to be negotiated by individuals suffering from age-related vision loss: Maintenance or Restoration of Self Esteem, Use of Help, Modification of Daily Schedule, Balance between Consistency and Change in Social and Recreational Activities, and Understanding/Appraisal of Loss.

I Maintenance or Restoration of Self Esteem refers to the older person's feelings about himself and his capacities. This scale was developed by Rosenberg (1965) and used most notably by Atchley (1969,1976) in large scale surveys of older adults.

TABLE III - 3

## SUMMARY TABLE OF SCALES AND INDEXES

	NO. OF ITEMS	COEFFICIENT ALPHA
<b>SCALES</b>		
Self Esteem	10	.91
ADL	7	.70
IADL	9	.87
Help	17	.70
Activities	17	.73
Health I	3	.60
Health II	19	.65*
Health III	5	.80
<b>INDEXES</b>		
Stressful Life Events	10	**
Informal Supports	11	**
Formal Supports	6	**
Low Vision Aids	11	**
House Changes	7	**
ADL difficult/vision loss	7	**
IADL difficult/vision loss	9	**
Formal Help	17	**
Informal Help	17	**
Activities stop/vision loss	17	**
Activities stop/other health	17	**
Activities/less frequent	17	**
Activities/more frequent	17	**
Activities change in type	17	**
Health before vision loss	16	**
Health after vision loss	16	**

\* Standardized Item Alpha

\*\* Alphas were not computed because the measures of these constructs are not inherently internally consistent.



The scale (SELFESTM) consists of 10 items. Typical positive items are "I feel I am a person of worth", "I feel that I have a number of good qualities". Typical negative items are "I feel I don't have much to be proud of", "I certainly feel useless at times". There were four choices: strongly agree, agree, disagree, strongly disagree. Items were scored in a deviant direction (4 indicated strong agreement with a negative item or strong disagreement with a positive item, 1 indicated the reverse). Corrected item correlations ranged from .48 to .80. The item mean is 1.84 with a minimum of 1.56 and a maximum of 2.19. The alpha of .91 indicates that the scale is highly reliable by internal consistency criteria.

II Use of Help refers to the kinds of help that are used, frequency with which help is received and whether it is provided by the informal system or the formal system. This adaptive task is a dependent variable and the scale used for its measurement is separate and apart from the scales on the intervening variables on social support that measure the availability of help.

A scale was developed to reflect overall frequency. Two indexes were also developed, one to reflect frequency of help provided by the informal system, and one to reflect frequency of help provided by the formal system.

#### Scale

Items on the Help scale were taken from the "Exchanges of Support and Assistance Index" (National Council on Aging,

1975,1976). Follow up questions were added to determine frequency and provider of help.

HELP Sixteen kinds of help (and an "other" category) are suggested. Kinds of help include such diverse items as receiving assistance when sick, accepting advice, and assistance with transportation. Frequencies range from almost every day to less than once a year. The 17 items were scaled in a deviant direction; with the highest score of 7 for an activity requiring daily help. The item mean is 1.37 with a minimum of .08 and a maximum of 4.24. Corrected item correlations ranged from .04 to .61. Internal consistency is as one would expect; older people who are used to receiving help tend to use it in various situations. However, the situations themselves are dissimilar. Thus, the alpha of .70 (.72 with omission of the "other" category) indicates an acceptable level of reliability.

#### Indexes

Formal Help Index (FORMAL) and Informal Help Index (INFORMAL) are scored in a deviant direction such that the more help received, the higher the score. Because the index scores are "add ons" they do not distinguish between individuals who used 4 kinds of help once a month or 4 of the same kind of help once a week.

Formal Help Index (FORMAL) includes help from private pay and social agencies. Values ranged from .00 to 47.00 with a mean of 6.94 and standard deviation of 10.38. Thirty five of the respondents (40.7%) used no formal supports at all.

Nevertheless, the fact that the remaining 59.4% of the sample was scattered over a wide range suggests variety in the frequency and type of use of formal services by the visually impaired.

Informal Help Index (INFORMAL) includes help from spouse, children or other relatives, neighbors and friends. Values ranged from .00 to 51.00 with a mean of 16.35 and a standard deviation of 12.72. Most respondents (88.4%) used informal supports for help. This is in keeping with the widely cited statistic that family members provide 80% of the help received by elders in the community.

III. Modification of Schedule refers to changes made by the older person in performance of activities of daily living. In the gerontological literature these are often divided into two components: personal activities of daily living (ADL) and instrumental activities of daily living (IADL).

Categories and items for the scales were taken from S. Katz et al (1963). However, since the particular interest of the study was the reason for dependence, questions were added to determine whether vision loss or another health problem was responsible for need for help in activities of daily living.

Three scales were constructed to examine these changes separately and together. In addition, three indexes were constructed to determine whether these changes were attributed to vision loss.

### Scales

Activities of Daily Living (ADL) includes items related to physical functioning and self-care. The scale consists of 7 items. Typical items are dressing, taking a bath or shower, going for short walks outside. Choices are: never did, does with no help, does with help, does no more. Items were scored in a deviant direction (does no more = 2, does with help = 1, never did and does with no help = 0). Corrected item correlations ranged from .20 to .59. The item mean is .20 with a minimum of .01 and a maximum of .56. The alpha of .70 indicates that the scale is internally consistent and meets reliability criteria.

Instrumental Activities of Daily Living (IADL) includes 9 items related to household management. Typical items are making one's own bed, preparing a simple meal, managing money. Response choices were the same as in the ADL scale. And, as in the ADL scale, items were scored in a deviant direction. Corrected item correlations ranged from .46 to .74. The scale mean is .42 with a minimum of .10 and a maximum of .69. The alpha of .87 reflects a high degree of internal consistency.

Total Activities of Daily Living (TADL) is a summary scale of 16 items, incorporating the items from ADL and IADL. Added together, the two scales have a mean of .32 with a minimum of .01 and a maximum of .69. Corrected item correlations range from .26

to .73. The alpha is .90. This high level of consistency is as expected. Elders who are functionally impaired generally experience difficulty in several activities of daily living.

Indexes Activities Difficult Due to Vision Loss (ADLVISL) consists of personal activities mentioned by respondents as being changed because of vision loss. Items were scored in a deviant direction such that 1 point was given for an activity changed because of vision loss, and 0 for an activity changed for another reason. Points were added on for each activity mentioned. Values ranged from .00 to 4.00 with a mean of .48 and a standard deviation of .92. 62 respondents (72.1%) did not attribute any ADL difficulties to vision loss. However, a considerable minority of 21 (24.4%) identified performance of 1 or 2 activities as being changed because of vision loss.

IADL Difficult Due to Vision Loss (IADLVISL) consists of household management activities mentioned by respondents as being changed because of vision loss. Items were scored in a deviant direction such that 1 point was given for an activity changed because of vision loss and 0 for an activity changed for another reason. Points were added on for each activity mentioned. Values ranged from .00 to 9.00 with a mean of 1.66 and a standard deviation of 2.18. While 40 respondents (46.5%) did not attribute any IADL difficulties to vision loss, 34 (39.5%) were affected in 2 or more activities.

Total ADL/IADL Difficult Due to Vision Loss (ADLTVISL) is a summary scale of items from ADLVISL and IADLVISL. Values ranged from .00 to 13.00 with a mean of 2.15 and a standard deviation of 2.88.

IV Balance Between Consistency and Change refers to participation in social and recreational activities and how this is affected by vision loss.

Several scales exist on leisure activities in old age. (Leisure Participation: NCOA 1975; "Leisure Activity Score", S. Sherman, 1973; "Free Time Activities", Peterson et al 1976). Basically, these consist of a list of activities, each linked with a variable the researcher finds of interest; (for example, how important the activity is, how much time is spent). For the purposes of this study, questions were added to determine how participation was related to vision loss.

The construct is measured by a 17 item scale that includes such varied items as reading, eating out in a restaurant, gardening and visiting out of town. For each activity, respondents were given four choices. They were asked if they ever did, did before vision loss only, did before and now, or did now only. Follow up questions were asked, as indicated, to determine changes in frequency and type of participation. One scale was developed that incorporated participation and changes through the coding of all responses. Six indexes were developed, with the intent of individually examining the prevalence of each change. Index

scores are "add ons" with a point given for each activity in question.

### Scale

Activities This 17 item scale (ACTIVE) was scaled in a deviant direction. Activities that were stopped because of vision loss or another health problem, were performed less frequently now than before, or had changed in type of participation were scored as 1. All other choices were scored as 0. The scale mean is .30 with a minimum of .08 and a maximum of .94. Corrected item total correlations range from .10 to .57. Although the activities cover a wide gamut of unrelated pursuits, the underlying attribute of participation is related. Thus, the alpha of .73 reflects an expected level of consistency.

### Indexes

Activities Stopped Due to Vision Loss (STOPVISL) Values ranged from .00 to 9.00 with a mean of 2.48 and a standard deviation of 2.30. Only 20 of the respondents (23.3%) did not give up an activity due to vision loss. While an almost equal percent (22.1%) gave up only one activity, the remaining 42% gave up 2 - 5 activities.

Activities Stopped Due to Another Health Problem (STOPHLTHP) Values ranged from .00 to 9.00 with a mean of .49 and a standard deviation of 1.32. 77.7% did not give up any activity due to another health problem. With the addition of those who gave up

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only one activity, 91.9% of the sample is accounted for.

Thus, two indexes on Activities Stopped indicate that vision loss is responsible for a considerable cessation of social and recreational activities.

Activities Less Frequent (LESSFREQ) Values ranged from .00 to 6.00 with a mean of 1.11 and a standard deviation of 1.42. Thirty seven respondents (43.0%) reported no change in frequency of participation in activities continued since vision loss while an almost equal number (41.8%) performed one or two activities less frequently.

Activities More Frequent (MOREFREQ) Values ranged from .00 to 2.0 with a mean of .24 and a standard deviation of .53. 80.2% of the respondents did not increase frequency of participation.

Thus, the two indexes in Frequency of Activities indicate that participation in activities is much more often decreased than increased in the presence of vision loss.

Activities Change In Type (CHANGE) Values ranged from .00 to 6.00 with a mean of 1.30 and a standard deviation of 1.25. 62.9% of respondents changed how they participated in 1 to 3 activities.

Activities No Change in Type (NOCHANGE) Values ranged from .00 to 9.00 with a mean of 2.04 and a standard deviation of 2.20. 42.0% of respondents did not change how they participated in 1 to 3 activities.

Change in type of activities were coded as "add ons"; that



is, one point was given for each activity changed in the change index and one point was given for each activity not changed in the nochange index. Thus, the two indexes in Change In Type of Activities indicate that more respondents changed their type of participation in activities since vision loss than did not.

V. Understanding of Loss is a single measure titled "the match". It refers to the match between the clinical prognosis and the respondent's expectation of change. There were four possible categories, no match, better/good, same/same, and bad/bad. "The match" is scored in a positive direction. No match = 0; Match = 1. However since only 2 of the 25 matches were not in the "bad/bad" category, it means that most of those who matched expected the worst.

It was anticipated that that an attitude scale could be constructed from the open-ended questions but the alpha was extremely low. Consequently these items were only used as descriptive data, in Chapter IV.

#### INTERVENING VARIABLES

The intervening variables of the study include health status, stressful life situations, and the existence of informal and formal supports. Items related to all of these variables have been incorporated into scales. An index was constructed as an additional measure of health conditions.

### Health Status

The overall health condition of the older person bears an obvious relationship to how he will adapt to vision loss. This study has developed three separate scales related to health status. Health I, Health II, and Health III. An index was constructed as an additional measure of Health II.

### Scales

#### Health I (Hearing)

Researchers in the area of sensory loss in the elderly are currently very interested in the combined effects of vision and hearing loss on overall functioning. Since 40% of the respondents in the sample rated themselves as having fair or poor hearing, a scale was developed of the 3 items specifically related to hearing. Choices were: how is your hearing (excellent, good, fair, poor: poor =2, fair = 1, else =0), have you ever worn a hearing aid (yes = 1, no= 0), do you wear a hearing aid now (yes = 1, no=0). The scale mean is .26 with a minimum of .12 and a maximum of .51. Corrected item total correlations range from .34 to .57. The alpha is .60.

Health II (Medical Problems) is a 19 item scale that incorporates two types of information. First, is data related to 8 illnesses that are commonly found in the elderly; such as heart disease, CVA, arthritis, and cancer. (with an "other" category). and whether or not they had been hospitalized for that particular medical problem. The illnesses chosen were based on "Index of

Illness" (Shanas, 1962). Questions were added to determine hospitalizations if any, and the time relationship of the illness to the vision loss. Items were scored in a deviant direction (yes = 1, hospitalized =1, else =0). Second, is data related to incapacitating "sick days" and visits to a doctor in the past six months as well as hospitalization for any reasons other than the forementioned illnesses since the onset of vision loss. These items, too, were scored in a deviant direction. The scale mean is .57 with a minimum of .01 and a maximum of 6.44. The corrected item total correlation ranged from -.02 to .37.

While old age is associated with an increasing number of illnesses, the presence of one does not necessarily mean the presence of others. Moreover, a few of the conditions were relatively rare (emphysema). The standardized item alpha of .65 is commonly found in scales of medical conditions of the elderly.

Health III. (Self Appraisal) is a 5 item scale consisting of responses to questions asked at different points in the interview. Items were scaled in a deviant direction. Respondents were asked to compare their health with others their age (worse=1, else=0) and rate their overall health at the present time (poor=2, fair=1, else=0). They were also asked if their health was the better, same, or worse than at onset of vision loss (worse=1, better, same =0), if health problems other than vision loss stand in the way of doing things they want to do (yes=1, no=0) and how much these problems get in the way (a great deal=2, a little = 1, else = 0). The mean of this scale is .45

with a minimum of .20 and a maximum of .67. Corrected item total correlations range from .45 to .81. The alpha of .80 indicating a high rate of reliability that is expected given that the underlying attribute of the scale, self appraisal of health, is an inherently consistent construct. The concept of self appraisal was based on "Self Perceived Health" (Shanas et al, 1968).

#### Indexes

Two indexes were constructed to determine whether health problems began before or after vision loss.

Health Problems Before Vision Loss (HLTHBEF) Values ranged from .00 to 7.00 with a mean of 1.41 and a standard deviation of 1.39. 29% of the respondents had no health problems before vision loss, but 53.5% had 1 or 2 preexisting conditions.

Health Problems After Vision Loss (HLTHAFT) Values ranged from .00 to 3.00 with a mean of .51 and a standard deviation of .75. While 61.6% of the respondents did not develop any new health problems after vision loss, 38.3% developed 1 to 3 new problems. Stressful Life Events (STRESS) is a scale consisting of 10 items. It was adapted from the "Geriatric Scale of Recent Life Events" (Kyak, Liang, & Kahana, 1976).

Four situations were posited as causing stress to the older person when occurring after the onset of vision loss: moving oneself, the moving away of someone close, the serious illness of someone close, the death of someone close. Since each of these

life events could conceivably happen more than once, there was opportunity to indicate the frequency of the occurrence. Items were scaled in a deviant direction, such that the highest score was achieved by the person undergoing the greatest number of stressful life events. Corrected item total correlations ranged from .08 to .34. The reliability of this scale is an extremely low with an alpha of .28. This is as expected since there is no inherent consistency in the underlying attribute being studied; with the exception of moving oneself, the events are outside the control of the individual and tend to happen independently from one another.

#### Informal Supports (INFORMTOT)

This measure was adapted from several scales; "Kinship Involvement" (H.K. Swarzweller & J.F. Seggar, 1967), "Familial Interaction Index" (Bultena, 1969) and "Frequency of Interaction with Relatives Scale (Cummings & Henry, 1961). There was no attempt to identify primary caregivers as that was not the intent of the study. I added neighbors and friends. The scale consists of 11 items. Respondents were asked about the existence and number of family members, neighbors and friends, as well as the frequency of in-person and phone contact with them. Items were scored in a positive direction, such that the highest score was achieved by those with the most informal supports. Corrected item total correlations ranged from .01 to .70. The overall

reliability of this scale is .72 which is consonant with what has been found in other studies of the elderly; those with family members (especially adult children) tend to be in frequent contact with them, while those with a paucity of personal relationships tend to be socially isolated.

Formal Supports (FRMSUPP) The scale consists of 6 items. Each item refers to a type of social agency serving seniors. Rather surprisingly, the standardized item alpha of the respondents was an extremely low .09. With the exception of elders who used services of The Lighthouse (a mean of .87) , few availed themselves of formal supports. This finding underscores the fact that the sample population are not typical elderly "clients" but rather "customers" of the low vision aids available that are available for purchase only at The Lighthouse.

#### Additional Scales

Two scales were constructed that are not direct measures of dependent or intervening variables but could be useful in explaining variance.

The Lighthouse requested information on the use of low vision aids and environmental adjustments in response to vision loss.

Low Vision Aids (VISAIDS) The scale is an 11 item list of such frequently prescribed aids as special glasses and magnifiers, talking books, cane, watch or timer. Corrected item correlations ranged from -.05 to .51. The alpha is .53.

Environmental Adjustments (HOUSECHG) The scale is a 7 item list of changes in lighting, color, appliances, or furniture. Corrected item correlations range from .04 to .58. The alpha is .53.

#### DATA ANALYSIS

The process of data analysis began with coding of the 86 questionnaires according to a previously developed code book. Open-ended questions were coded according to a scheme developed after review of 40% of the schedules. The next step was data keypunching and processing using the computer program SPSS. Then the data was printed out and frequencies and percentages were studied on each of the variables. These statistics were reviewed for differences on measures of central tendency and on measures of variability. Particular attention was directed to frequency and percent distributions on items that tapped the specific relevance of vision loss to the variable in question (i.e. were activities of vision loss difficult due to vision loss or another health problem; was participation in social activities stopped because of vision loss). Tables on frequencies and percents developed at this early phase of the data analysis are presented and discussed in Chapter IV.

The next major task was the construction of scales and indexes described in the preceding section of this chapter. Scales and indexes were developed to measure key variables wherever possible and appropriate. Cronbach's alpha was used to

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establish the reliability of the scales. Along with several key single items, these scales and indexes were used for the bi-variate and multiple regression analyses.

Bi-variate analysis (Pearson's  $r$ ) was then used to obtain correlations and measures of significance on the independent, intervening, and dependent variables of the study. Tables that reflect these correlations are presented and discussed in Chapter V.

The final step of data analysis was multivariate analysis. Hierarchical multiple regressions were run for four of the five adaptive tasks. The order in which items were entered in the equation was influenced both by theory and by significant correlations at the bivariate level of analysis. The outcome of the multivariate analysis is presented and discussed in Chapter VI.



## CHAPTER IV

### FINDINGS I: DESCRIPTIVE DATA

#### OVERVIEW

The descriptive component of the study covers three basic areas: the extent and impact of age-related vision loss, the life situation in which it occurs, and the meanings that older people ascribe to it. Findings in this chapter yield new information, much of it surprising, and some of it with clear relevance for service planning and delivery.

Because little is known about psycho-social aspects of age-related vision loss, this section is largely exploratory. Many questions were open-ended, guided by the general literature on adaptation and by clinical "hunches" based on my experience as consultant to direct practice staff at The Lighthouse.

The first section of this chapter describes vision loss as found in the study population. It starts with clinical diagnosis, prognosis, and degree of impairment: all drawn from the patient chart at the Low Vision Clinic. It continues with a discussion of time since onset, type of onset, expected changes, and experience with the eye care system, and use of low vision aids and environmental changes: all drawn from respondents' responses. It concludes with a discussion of the affect of vision loss on performance of activities of daily living and participation in social and recreational activities.

The second section discusses three elements of the elder's life that the literature suggests might affect adaptation to

vision loss: health status, the presence and use of informal and formal supports, and co-existing life events of change and loss. These are the intervening variables of the study.

The third section concludes the chapter. It examines elders' beliefs and feelings about their vision loss. In contrast to data in the first two sections of the chapter that is largely responsive to closed questions, this section draws heavily on open-ended responses, descriptions, "advice" to others with the same problem, "turning points" and reports of attitude changes.

The chapter concludes with a summary/discussion of findings on the descriptive data.

#### VISION LOSS IN THE SAMPLE POPULATION

"What is the nature of visual impairment in elders with age-related vision loss?"

##### Diagnosis, Degree of Impairment, Prognosis

Three types of information were obtained from the Low Vision Clinic. These were diagnosis, degree of impairment, and prognosis. Table IV - I summarizes this information.

Diagnoses were taken directly from the Low Vision printout of basic identifying information. The diagnosis of macular degeneration accounted for over half (53.5%) of the population.

TABLE IV - 1

## VISION STATUS AS REPORTED BY LOW VISION CLINIC

	Frequency (n)	Percent %
<u>Diagnosis</u>		
Macular Degeneration	46	53.4
Diabetic Retinopathy	10	11.6
Glaucoma	9	10.5
Cataract/Aphakia	8	9.3
Optic Nerve Disease	5	5.8
Multiple Diagnoses	4	4.7
Retinal	3	3.5
Uveal Tract Infection	1	1.2
Total	86	100.0
<u>Impairment</u>		
Normal/Near Normal	21	24.4
Moderate	28	32.6
Severe	34	39.5
Profound	3	3.5
Total	86	100.0
<u>Prognosis</u>		
Progressive	67	77.9
Progressive (Slowly)	4	4.7
Progressive (Visual Field Reduced)	6	7.0
Surgery could improve	4	4.7
Stable	2	2.3
Remission	1	1.2
Missing/Don't Know	2	2.2
Total	86	100.0

This is not surprising in that macular degeneration is the leading cause of vision loss among the elderly. Diabetic retinopathy (11.6%) and glaucoma (10.5%) account for another 20% of the population. Thus over three quarters the group suffer from one of the three major vision diagnoses of the aged.

Degree of Impairment was based on "best corrected vision", a number that reflects visual acuity in the better eye. I translated "best corrected vision" from the patient chart into four categories based on guidelines used by the clinic (and generally, in the field of low vision). These categories are: normal/near normal, moderate, severe, and profound.

Almost one-quarter (24.4%) of the sample population had normal/near normal vision which may come as a surprise until one remembers that this figure is drawn from best corrected vision in the better eye; that is to say that there may be no vision at all or limited vision in the other eye. Such a condition can seriously compromise depth perception and engender other visual difficulties that affect functional capacity of the individual.

Those with profound vision loss represent only 3.5% of the sample population. Again, this figure is understandable when one remembers the function of the clinic; low vision aids are only helpful to those with usable vision and physician referrals are generally made of those who are deemed able to benefit. (Total vision loss is rare in the general population of the aged and usually represents a congenital condition or onset early in life, while profound vision loss may be age-related, generally the end

stage of a progressive disease).

Almost three-quarters (72.1%) of the sample population had moderate or severe visual impairment. Almost 40% (39.5%) suffer severe impairment. This degree of impairment is what is often termed "legal blindness" (a term favored by funding agencies and the lay public but eschewed by low vision professionals as a crude measure without clinical usefulness). Those with moderate impairment are often very close to severe, and account for 32.6% of the sample population.

Prognosis is not entered on the charts of the Low Vision Clinic. For the purposes of this study, prognosis was determined by Clare Hood, R.N., M.S., Director of the clinic, upon review of the individual eye and medical charts. Prognosis was based on the typical course of the diagnosis and co-existing health problems that might reasonably be expected to influence it in the individual in question.

Of the six prognoses, three are types of progressive: progressive, progressive (slowly), and progressive (visual field reduced). These distinctions were made by Ms. Hood and although they held no obvious import for me were kept to see if they had any bearing on adaptation. Close to 90% (89.6%) of the respondents were deemed to have a progressive prognosis. Since the leading diagnoses of age-related vision loss are progressive diseases, this figure is what would be expected.

Time Since Onset, Circumstances of Onset, Expectations of

### Change, The Search for Aid

Self reports on vision status was based on responses to questionnaire items seeking information on time since onset, circumstances of onset, expectations of change and what the individual was first told about what was wrong with his vision. Table IV - 2 summarizes this information.

Twenty-nine percent of the sample recalled a time since onset of a year or less, 38.4% recalled a time since onset of two to three years, and 30.2% recalled a time since onset of four or more years. As noted in Chapter III, this normal distribution (as in the case of age) is not accidental but the result of pre-screening to ensure adequate representation in each of the categories deemed essential to the study hypotheses.

An unexpected finding was the range of times since onset reported by those in the four or more years category. Although 16.2% reported four or five years since onset, the range extended to twenty years with 11.8% reporting ten or more years since onset. It is possible that individuals may seek causes or reasons for current life events in their past experiences. Thus, visually impaired elders may selectively remember earlier problems "my eyes were always bad" to explain their current problem. At the same time, Macular Degeneration (a leading cause of age-related vision loss) is more likely to occur in individuals who experienced difficulty with vision in early life, so implications of this finding is not clear.

Over half of the sample (58%) recalled a sudden onset of

TABLE IV - 2

## SELF-REPORTED VISION STATUS

	Frequency (n)	Percent %
<u>Time Since Onset</u>		
0 - 1 Year	25	29.1
2 - 3 Years	33	38.4
4 or more Years	26	30.2
Missing/Don't Know	2	2.3
Total	86	100.0
Mean = 3.6		
<u>Circumstances of Onset</u>		
Sudden Onset	48	55.8
Gradual Onset	6	7.0
Unclear Onset	21	24.4
Doctor Told or on Examination	7	8.1
Missing /Don't Know	4	4.7
Total	86	100.0
<u>Expectations of Change</u>		
No Change Expected	37	43.0
Condition Will Get Better	17	19.8
Condition Will Get Worse	24	27.9
Don't Know	8	9.3
Total	86	100.0
<u>What Told About Vision Loss</u>		
Clinical Diagnosis	46	53.5
Descriptive	27	31.4
"Old Age"	4	4.7
Not Told	6	7.0
Missing	3	3.4
Total	86	100.0

vision loss. This was frequently dramatic and linked to a specific event.

"I was crossing the street and the world went black. Someone saw me and took me home."

"I got up one day and picked up the paper and couldn't read it".

"As I went to pick up the car about 1:10p.m, thats when I discovered that the sight was gone. That was the 13th of May, 1982. I drove that morning."

"I had a terrible pain, my eyes went black, I had to be rushed to the hospital".

"When I came back from Florida, I looked outside my window and the buildings were crooked".

The high percentage of individuals recalling a sudden onset of vision loss was surprising given the progressive nature of the prevalent eye diseases and difficulties in recollecting time of onset (giving one time at the Low Vision Clinic and another to the interviewer for the study). One explanation may be found in the work of Goffman (1963). He identifies "turning points" in the "career" of disabled or otherwised stigmatized people that are recalled as pivotal in passing from one stage or status to another. This notion is closely allied to the previously referred to ideas of Atchley (1989) and Kaufman (1980) that individuals seek to construct a pattern to their lives, to find reasons.

Of course, it must be remembered that a respondent's



perception of type of onset may differ from that of the clinician. Thus, vision impairment may exist before the individual has cause to recognize it.

Only 7% of the sample population indicated a gradual loss.

"It began to show up on my job. Its a sneaky thing. The body makes adjustments. I started asking other people for help".

"Every day I saw less. Every six months I had to adjust to seeing less. I need lots of patience.".

Almost one quarter (24.4%) of the respondents did not specifically identify whether onset was sudden or gradual; these types were classified as unclear.

"I was concerned about reading because it became fuzzy after reading for ten minutes".

"I began to bump into things. I couldn't see from the side. I would walk into walls and stumble into things".

Eight per cent did not recognize vision impairment but were told by their doctors that something was wrong.

"When I went to see Dr. F., he told me I had cataracts in the early stages and I'd better see a specialist".

Respondents' expectations of change in their eye condition are particularly interesting as they can be directly related to the clinical prognoses. Although a "matching" of these will be discussed in detail in the summary of bi-variate findings, it can be noted here that a surprisingly high percent (43.0%) of respondents did not expect any change to occur while almost a fifth (19.8%) believed that their condition would get better.

Thus, respondents were considerably more optimistic - or denying- about their eye conditions than the professionals who care for them.

As a general rule, gerontologists believe that elders and their families fare better with a specific medical diagnosis than with a global attribution of health problems to "old age". The former promotes compliance with a medical and rehabilitative regime while the latter often results in neglect and hopelessness. At the same time, ophthalmologists and other professionals working with the visually impaired elderly often note that specific descriptions can be misunderstood, arousing needless fears and anxieties.

When asked what they were first told what was the matter with their vision, just over half of the respondents (53.5%) recalled a clinical diagnosis.

Almost one third (31.4%) were given descriptions of the disease process.

"Hardening of the arteries"

"Lack of circulation"

"The blood was coming out over the pupil"

"A hemorrhage behind the eye"

Seven per-cent claim not to have been told at all, while a small number (4.7%) were told that their vision loss was because of "old age" or "aging eyes".

The literature on adaptation to vision loss and other

disabilities puts great emphasis on the period immediately following the loss. This has been observed in blindness, (Cholden (1958), in chronic disability, Mailick (1979), and in death and dying, Kubler-Ross (1969).

It is believed that this is the period of greatest emotional turmoil and lowest functioning. Often denial is thought to be manifested through a frantic search for doctors who will give a more promising diagnosis/prognosis. Clinicians term this "shopping" and rehabilitative practice wisdom has it that adaptation cannot begin to take place until the period is resolved with the patient's acceptance of her diagnosis.

The respondents in this study were aggressive in their search for aid with the problem of vision loss. At the same time, they were skeptical of the responses they received. Almost one-third (30.2%) got a second opinion from an eye doctor while 33.7% received a third opinion (or more). Of the elders who sought additional opinions, over half (53.8%) believed doctors other than the first, 23.1% believed the first doctor, and 23.1% believed no one!

#### Use of Low Vision Aids and Environmental Changes

Table IV - 3 summarizes the use of low vision aids used by the population as well as changes in the physical arrangements of their apartments or homes, color changes, and lighting changes.

Eighty-seven per-cent of respondents used low vision aids in daily activities, not surprising given the sample universe chosen

TABLE IV - 3

## USE OF LOW VISION AIDS AND ENVIRONMENTAL CHANGES\*

	Frequency (n)	Percent (%)
<u>Low Vision Aids</u>		
Watch/Timer	3	3.5
Cane	18	20.9
Special Glasses/Magnifiers	62	72.1
Kitchen Aids	4	4.7
Playing Cards/Puzzles	3	3.5
Talking Books	23	26.7
Large Print Books/Paper	18	20.9
Writing Guides	7	8.1
Medical Devices	--	--
<u>Changes in Physical Arrangement in Home</u>		
Stairway/ramp	--	--
Furniture	2	2.3
Kitchen Appliances	1	1.2
Bathroom Appliances	2	2.3
<u>Color Changes</u>	1	1.2
<u>Lighting Changes</u>	34	39.5

\*More than one low vision aid or environmental change may be used. Multiple choices are allowed.

from individuals who visited the Low Vision Clinic of The Lighthouse within the past 18 months.

However, the range of vision aids was quite narrow. While special glasses and magnifiers accounted for nearly three-quarters (72.1%), approximately a quarter availed themselves of talking books (26.7%) large print books and paper (20.9%) and cane (20.9%). Other aids accounted individually for less than 8%. Two individuals used aids that were not on the list: one used enlarged sheet music and the other used a telephone with large numbers.

Minimal changes were made in color or physical arrangements in the home (2.3% in furniture and bathroom appliances). This is unfortunate but not surprising. Although the technology for creating physical environments that compensate for the disabilities of the elderly is increasingly used in congregate living facilities, they have not been widely known or used in the community.

Lighting changes fared better. As ophthalmologists who work with the aged frequently expound, "the aging eye like the dying Goethe cries out 'more light'". Thirty-nine percent of the respondents made lighting changes, all in the direction of increasing the number or intensity of light. Hallogen lights were found especially useful. Here again, a few individuals came up with creative solutions. One reported, "every spot in the house has a table lamp on it". Another keeps flashlights all around the house and carries one with her to restaurants and the

library.

"What is the effect of age-related vision loss on daily life?"

If loss of vision is, as the literature suggests, a major disability of the aged, we would expect to see consequences for overall functioning. This study measured overall functioning in three areas: performance of activities of daily living, participation in social and recreational activities, and use of help.

Activities of Daily Living

Activities of Daily Living is a 16 item scale (described in Chapter III) that includes self care, household management, and instrumental activities. Although the scale was constructed and coded using the categories "never did" and "does with no help" for each task, Table IV - 4 reflects only those categories that indicate dependence, "does with help" and "does no more". The table also indicates the reason for dependence, vision loss, other health problems, or a combination of vision loss and other health problems.

The assessment of client areas of dependence in activities of daily living is the first and paramount step in the rehabilitation process at all blindness agencies and is necessary for funding of services from CBVH (The Commission on the Blind and Visually Handicapped). While extensive documentation exists on each individual client, agencies do not typically amass or

TABLE IV - 4

PERCENT DISTRIBUTION OF ADL DEPENDENCE DUE TO VISION LOSS (VL) AND  
OTHER HEALTH (OH) PROBLEMS

Task	DEPENDENCE (a)		REASON GIVEN FOR DEPENDENCE (b)		
	Does With help	Does No More	VL	OH	VL & OH
Dress/Shoes	8.1	1.2	--	62.5	25.0
Take Bath/Shower	11.6	1.2	18.2	54.5	18.2
Prepare Meals	3.5	17.4	80.8	11.1	5.5
Manage Eating	4.7	--	75.0	25.0	--
Short Walk Outside	22.1	11.6	62.1	13.8	6.0
Ride in Bus	22.1	22.1	55.3	18.4	21.0
Grocery Shopping	12.8	27.9	45.7	22.8	22.8
Make Bed	3.5	11.6	46.1	38.5	15.4
Take Your Medicine	12.8	1.2	75.0	--	16.7
Do The Laundry	3.5	24.4	45.9	33.3	12.5
Manage Your Money	15.1	15.1	69.2	15.4	7.7
Get Around Apt/House	3.5	--	66.7	33.3	--
Personal Grooming	5.8	2.3	71.4	28.5	--
Get In/Out Bed	3.5	--	--	33.3	--
Climb Stairs	9.3	23.3	35.7	50.0	10.8
Clean Apt/House	7.0	23.3	53.9	27.0	11.5

(a) Percent of all respondents (N=86) who are dependent in ADL.

(b) Percent of dependent respondents who cite vision loss and other health problems as reasons.

Note: Since other reasons are not included percentages do not total 100%

analyze this data for the entire client population. Most importantly for the aged, agency assessment does not differentiate between dependence caused by vision loss and that caused by other health problems except for rare occasions in which the other disability is obvious. As a typical example, an orientation and mobility instructor may be assigned to teach a visually impaired older person how to cane travel independently in the neighborhood only to discover that this goal cannot be accomplished because of arthritis. Such an occurrence is frequent and an ongoing source of frustration for instructors who were trained to work with younger, healthier people. Thus, an analysis of the reason for dependence in activities of daily living has potential for service planning and delivery.

Approximately one quarter of respondents have ceased riding in a bus, doing the laundry, shopping for groceries, climbing stairs and cleaning their apartment or home. Over 10% have stopped preparing meals, making their bed, and managing money.

Approximately one quarter of respondents require help to walk outside or ride in a bus. Taking a bath or shower, taking medicine, grocery shopping, and managing money are all activities that are done with help over 10% of the time.

Dependence due primarily to vision loss is most frequently found in preparing of meals, taking medicine, managing money, and cleaning house.

Dependence due primarily to other health problems or a combination of vision loss and other health problems is most



frequently found in dressing, taking a bath or shower, and climbing stairs.

These findings are not unexpected if one thinks of the degree of visual acuity, physical agility, and strength needed for each task. However, they raise interesting questions when looked at within the context of current delivery of rehabilitation services.

Those activities that require only rehabilitation teaching (i.e. managing money and preparing meals) are more likely to be caused primarily by vision loss and so be most amenable to current strategies. Those activities that require only orientation and mobility teaching (i.e. climbing stairs and walks outside) are more likely to be caused by other health problems or a combination of vision loss and other health problems. This finding supports clinical observation of difficulties in orientation and mobility teaching with the elderly and suggests that this staff may require additional training or consultation with physical therapists in order to best serve an elderly population with multiple needs.

Three indexes (described in Chapter III) were constructed to look at activities of daily living as related to vision loss. On self-care activities (bathing, personal grooming) almost one quarter of the respondents (24.4%) identified performance of 1 or 2 activities as being changed because of vision loss. On instrumental activities (managing money, shopping for groceries) 39.5% of respondents were affected in 2 or more activities.

Thus we see that visual impairment impedes independence in activities of daily living for well over half of afflicted elders in the study.

### Social and Recreational Activities

The social and recreational activities of elders are not as frequently researched as activities of daily living; perhaps because they are not deemed as essential in determining the needs for care that are a continuing concern for gerontologists. Nevertheless, participation in social and recreational activities is an important indicator of emotional well being in the aged. In the literature on adaptation to disability, emphasis is often given to the necessity for the individual achieving balance between continuance of still possible activities and development of new activities to substitute for those that must be relinquished.

Data pertaining to social and recreational activities as related to vision loss is reflected in three tables. Table IV - 5 presents an overview of participation, divided into four categories: never, before vision loss only, before and now, now only. The purpose of this table is to provide an opportunity to compare participation at three points in time.

It should be noted at the outset that a great many of the activities on the list were never participated in by a majority of the respondents. Approximately three-quarters of the sample

TABLE IV - 5

PERCENT DISTRIBUTIONS OF PARTICIPATION IN SOCIAL AND RECREATIONAL  
ACTIVITIES AS RELATED TO VISION LOSS (VL)

<u>Activity</u>	<u>Never</u>	<u>Before VL</u> <u>Only</u>	<u>Before &amp;</u> <u>Now</u>	<u>Now</u> <u>Only</u>	<u>N</u>
Worked for Pay	44.2	48.9	7.0	—	(85)
Volunteer Work	65.1	20.9	11.6	2.4	(86)
Senior Citizens/ Center Group	77.9	10.4	9.3	2.3	(84)
Church/Synagogue Service	32.6	13.9	52.4	1.2	(86)
Meetings Groups/ Clubs	64.0	13.9	21.0	1.2	(86)
Attendance Movies/Theater	30.2	30.2	39.5	—	(86)
Attendance Sporting Event	73.3	19.9	7.0	—	(86)
Participation in Sport	48.8	30.2	19.8	1.2	(86)
Care of Plants/ Gardening	57.0	12.9	29.2	1.2	(86)
Worked on a Hobby/Handcraft	54.7	35.0	9.3	—	(85)
Painted Pictures/ Played Instrument	79.1	11.6	8.3	1.2	(86)
Dined Out At Restaurant	10.5	11.6	77.9	—	(86)
Babysat for Grand- Child/Other	74.4	7.0	16.3	—	(84)
Visited a Friend/ Out of Town	36.0	19.8	44.1	—	(86)
Vacation/Out of Town	25.6	38.4	36.0	—	(86)
Had a Overnight Visit	43.0	9.3	46.6	—	(85)
Taken Adult Ed. Courses	77.9	12.9	5.8	3.5	(86)
Reading	2.3	48.8	48.8	—	(86)
Television	4.7	4.7	89.5	—	(85)
Other	2.3	16.3	17.6	—	(31)

population never participated in a senior citizens or center group, attended a sporting event, painted pictures or played an instrument, babysat for grandchildren or other children, or took adult education courses. Approximately one-half of the sample population never worked for pay (this finding is not unusual for a predominantly female aging cohort), did volunteer work, went to meetings of groups or clubs, participated in a sport, cared for plants or gardening, or worked on a hobby. While the large percent of "nevers" limits the importance of the findings, they are still generative of ideas about the nature of adaptation to age-related vision loss. Reading and television were activities once participated in by nearly all participants.

Activities that were most dramatically stopped after vision loss were were: work for pay, volunteer work, attendance at a sporting event or participation in a sport, and working on a hobby. Activities that were most likely to be continued after vision loss included dining out at a restaurant, attendance at a church or synagogue service, visiting a friend out of town or receiving an overnight visit, care of plants, and watching television. Activities initiated after the onset of vision loss were very few and affected between one and three respondents.

A few activities had an almost equal likelihood of being stopped or continued. These were vacationing out of town and reading.

Table IV - 6 examines the phenomenon of ceased, decreased and changed participation. The purpose of this table is to

TABLE IV-6

PERCENT DISTRIBUTION OF DECREASED PARTICIPATION IN SOCIAL AND  
RECREATIONAL ACTIVITIES AFTER VISION LOSS

<u>Activity</u>	<u>Stopped Vision Loss</u>	<u>Stopped Other Health</u>	<u>Less Frequent</u>	<u>Ever Did Other</u>
Worked for Pay	17.0	12.8	—	(47)
Volunteer Work	26.7	37.5	37.5	(30)
Senior Citizens/ Center Group	29.4	11.8	--	(17)
Meetings/Groups Clubs	32.2	6.4	16.1	(31)
Church/Synagogue Service	12.1	3.4	13.8	(58)
Attendance Movies/Theater	35.0	5.0	15.0	(60)
Attendance Sporting Event	52.2	4.3	--	(23)
Participation Sport	36.4	13.6	2.3	(44)
Care of Plants/ Gardening	10.8	8.1	10.8	(37)
Worked on Hobby/ Handcraft	63.1	10.5	5.3	(38)
Painted Pictures/ Played Instrum.	27.8	11.1	5.5	(18)
Dined out at Restaurant	5.2	2.6	15.6	(77)
Babysat for Grandchild/other	10.0	20.0	10.0	(20)
Visited a Friend/ Out of Town	21.8	1.8	12.7	(55)
Vacation/Out of Town	36.0	3.1	3.1	(64)
Had an Overnight Visit	4.2	4.2	12.5	(48)
Taken Adult Ed Courses	31.6	15.8	--	(19)
Reading	50.0		27.4	(84)
Television	2.5	1.2	12.3	(81)
Other (Driving)	42.4	--	3.0	(33)

identify whether activities are stopped because of vision loss or other health problems as well as to identify which activities may be performed less frequently or changed in type of participation. Table IV - 6 examines the phenomenon of unchanged or increased participation. Percentages in tables IV - 6 and IV-7 are based on the number of respondents who ever did the activity.

Not surprisingly, reading was the leading activity to be stopped because of vision loss. One-half of the sample population (48.8%) ceased reading completely. Amplifying comments include: "headaches", "eyes tire easily", "I can't see the print", "everything has to be read to me, even mail".

An almost equal number changed the type of way they read. Over one quarter (27.4%) read less frequently. Explanations include: "can't read for long periods". "my reading is cut down 10%", "only newspapers now", "now its laborious", "takes longer to do". Eighteen per-cent mention having changed their type of reading in other ways (although the consequence could also be less frequent). They mention: "now with a magnifying glass", "not as thoroughly now", "only large print", "only when necessary".

Of all the activities on the list reading was responded to with the most emotion and spontaneous comments. Respondents said how much they missed it, or contrasted past patterns with the present.

Working on a hobby was stopped by over half of the respondents (63.1%) who ever did. This was primarily

attributed to vision loss. Hobbies cited were: needlepoint, knitting, sewing, weaving, collecting biographies of sports figures, sculpting. Far lesser percentages performed their hobbies less frequently or made adaptations or changes.

Attendance at movies or theater was stopped by over one quarter (35.0%) of the respondents and participated in less frequently by 15.0%. Comments included: "last time went walked out because I couldn't see", "must sit way down front, too expensive for the theater", "I'm more comfortable watching TV", "films strain my eyes".

Out of town visits, whether to vacation or to visit a friend, were greatly curtailed. Over one third of the respondents (36.0%) stopped vacationing entirely. Twenty-one per-cent of the elders interviewed stopped visiting a friend out of town, while 12.7% changed their type of visiting. Participation in both of these activities was attributed to vision loss. Comments related to out of town visits centered on the need to give up driving and difficulty finding one's way around airports or other unfamiliar places.

Other activities and reasons for curtailment yielded insight into the extent and impact of vision loss on elders in the study. Participation in church or synagogue services may be stopped or less frequent because the older person "can't see the priest" or "feels stupid using a magnifying glass to read the music and prayers, doesn't want people to see her like that".

Playing cards is out when you can't see the cards. The same

is true for the piano when you can't see the notes. Swimming in the sea washes the medication out of your eyes. Balancing a check book "which I used to be good at" and taking care of the mail "you have no privacy" are small acts that together add to the fabric of a life.

The indexes on activities stopped due to vision loss and activities stopped due to another health problem indicate that less than one-quarter (23.3%) of respondents did not give up an activity due to vision loss. But close to half (42.5%) gave up between 2 to 5 activities for vision loss. In contrast, over three-quarters of the sample (77.7%) did not give up any activity due to another health problem. This indicates that vision loss is responsible for a considerable amount of the cessation of social and recreational activities of visually impaired elders. At the same time, the indexes on change in type and no change in type indicate that 62.9% of respondents changed how they participated in 1 to 3 activities while 42% did not change.

One positive note is that 23.3% of the respondents reported a "new interest" since vision loss. In most cases these were talking books and audio cassettes as substitutes for reading. (however, one woman reported she had begun smoking).

While Table IV - 7 illustrates activities in which participation for about one-quarter of the sample remains relatively unchanged (having an overnight visitor, dining out at a restaurant, visiting a friend out of town), it is clear from a



TABLE IV - 7

PERCENT DISTRIBUTION OF UNCHANGED OR INCREASED PARTICIPATION IN  
SOCIAL AND RECREATIONAL ACTIVITIES AFTER VISION LOSS

<u>Activity</u>	<u>Unchanged</u>	<u>More Frequent</u>	<u>New</u>	<u>Ever Did</u> <u>N</u>
Worked for Pay	4.2	2.1	--	(47)
Volunteer Work	6.7	--	6.7	(30)
Senior Citizens/ Center Group	23.5	--	11.8	(17)
Church/Synagogue Service	29.3	5.2	1.7	(58)
Meetings/Groups Clubs	9.7	3.2	3.2	(31)
Attendance Movies/Theater	25.0	--	--	(60)
Attendance Sporting Event	13.0	--	--	(23)
Participation in Sport	11.4	2.3	2.3	(44)
Care of Plants/ Gardening	32.4			(37)
Worked on a Hobby/Handcraft	5.3	2.6	--	(38)
Painted Pictures/ Played Instrument	5.5	5.5	5.5	(18)
Dined out at Restaurant	27.3	—	—	(77)
Babysat for Grand- Child/Other	25.0	--	--	(20)
Visited a Friend/ Out of Town	27.3	--	--	(55)
Vacation/Out of Town	29.7	3.1	—	(64)
Had an Overnight Visit	45.9	--	--	(48)
Taken Adult Ed. Courses	15.8	--	15.8	(19)
Reading	3.6			(84)
Television	26.0	13.6	—	(81)
Other (talking books, audio cassettes)	36.4	3.0	--	(33)

comparison of Tables IV - 6 and 7 that both the quantity and quality of the elder's life are compromised as a result of vision loss. From a reading of open-ended elaborations on social and recreational activities is also clear that very few adaptive strategies are employed to counteract their effects. The woman who simply asks the waiter "whats good today" and so avoids the difficulty of reading the menu, or the man who calls in advance to reserve a table with direct light are clearly exceptional.

According to the index on activities more frequent 80.2% of respondents did not increase frequency of participation. The index of activities with no change in type indicates that 42.0 % did not change how they participated in 1 to 3 activities.

Taken together, the quantitative and qualitative data on participation in social and recreational activities makes a strong case for the negative affect of vision impairment on quality of life for elders.

THE CONTEXT OF AGE-RELATED VISION LOSS: HEALTH, SOCIAL SUPPORTS, CO-EXISTING LIFE EVENTS

"What is the health condition of elders with visual impairment?"

The impact of age-related vision loss on elder functioning cannot be examined by itself, but must be viewed in the context of the total health condition of the older person. Thus, health

is a crucial intervening variable of this study.

Together, the senses of sight and hearing are vital for communication and functioning. Often the use of one sense can compensate for the loss of the other. By the same token, deficit in both areas can be expected to seriously compromise overall functioning.

Individuals were asked to rate their hearing. Table IV - 8 summarizes the results of this rating.

It is interesting, and somewhat disquieting to note, that almost 40% of the respondents rated themselves as fair or poor in hearing. Interviewers who independently rated hearing loss at the end of the interview judged 32.6% of the respondents as "having difficulty" hearing. Thus, it seems safe to assume that at least one-third of visually impaired elders in this study were also suffering from a considerable amount of hearing loss.

Table IV - 9 summarizes chronic health conditions that existed in the sample population before, after, and concurrent with vision loss. Arthritis is, as might be expected, the most frequently occurring health problem affecting over half (52.3%) of the respondents. Hypertension accounted for the next most common health problem, occurring in over one-third (37.2) of the group. heart disease was present in approximately one-quarter of the respondents (25.6%) as was diabetes (26.7%).

With the exception of the high percentage of diabetes, these figures are what would be expected in a sample population of this age group. The unusual prevalence of diabetes in the study

TABLE IV - 8

## SELF REPORTED HEARING

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	Frequency (n)	Percent (%)
Excellent	10	11.6
Good	41	47.7
Fair	24	27.9
Poor	10	11.6
Missing	<u>1</u>	<u>1.2</u>
Total	86	100.0

TABLE IV - 9

PERCENT DISTRIBUTION OF COMMON CHRONIC HEALTH CONDITIONS BEFORE,  
AFTER, AND CONCURRENT WITH VISION LOSS\*

<u>Health Conditions</u>	<u>%</u>	<u>Before</u>	<u>After</u>	<u>Concurrent</u>	<u>Ever Had</u> <u>N</u>
Heart Disease	25.6	63.6	36.4	--	(22)
Hypertension	37.2	58.1	19.4	22.6	(32)
Diabetes	26.7	69.6	21.7	8.7	(23)
CVA	10.5	77.8	22.2	--	(9)
Cancer	16.3	78.6	21.4	--	(14)
Arthritis	52.3	77.8	22.2	--	(45)
Parkinsons	1.2	100.0	--	--	(1)
Emphysema	2.3	66.7	33.3	--	(3)

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population is understandable because diabetic retinopathy, an eye disease that afflicts diabetics, is positively correlated with age and visual impairment.

The majority of health problems pre-dated vision loss. The indexes revealed that 53.5% of the elders studied had one or two health conditions that preceded vision loss and 38.8% developed one to three problems later.

"What informal and formal supports are available to elders with age-related vision loss?"

No study of elder functioning is complete without a consideration of the external supports that are drawn upon for assistance. Tables IV - 10 and IV - 11 summarize the presence of the informal and formal system.

Table IV - 10 illustrates that formal support is far less prevalent than informal support, a situation that is well documented in the literature. As noted on the table, more than one type of support is customarily available.

The figures are as would be expected. The greatest contact of elders is with children (69.8%), grandchildren (60.5%), and friends and neighbors (76.7%). Spouses are, of course, involved when respondents are married (34.9%). However, the prevalence of contact with siblings (43.0%) is interesting, and reinforces clinical impressions that siblings play a generally unrecognized role in the support network of older people.

The Lighthouse accounts for 87.2% of the formal supports

TABLE IV - 10  
 INFORMAL AND FORMAL SUPPORTS\*

	Frequency (n)	Percent (%)
<u>Informal Supports</u>		
Spouse	30	34.9
Children	60	69.8
Grandchildren	52	60.5
Siblings	38	43.0
Niece or Nephew	27	31.4
Cousin	9	10.5
In-Law	12	14.0
Friend/Neighbor	66	76.7
<u>Formal Supports</u>		
The Lighthouse	75	87.2
Other Agency for Blind	9	10.5
Senior Center Meals/Activities/Transport.	3	3.5
Medicare/Medicaid Home Care/Transport.	5	5.8
Private Pay Home Care/Transport.	4	4.7
Other	5	5.8

\*More than one type of support is usually available. Multiple responses are allowed.

mentioned and "another blind agency" accounts for 10.5%. Generic social agencies and private pay services account for only 20% of the formal supports used. Thus, it appears that when the social agency system is tapped by visually impaired elders they are more likely to contact a service that is designed to meet their special needs.

Table IV - 11 describes the use of help by informal and formal supports. Several tasks were mentioned and it is interesting to note the differential use of support within both the informal and formal systems.

For example, private pay (24.4%) or spouses (23.3%) were most likely to help with housework, while advice was far more likely to be sought from children or other relatives (36.0%) than from other informal supports or any formal supports.

When formal supports were used for help they were more likely to be private pay than social agencies. They were also apt to be services that are also used by young unimpaired individuals; such as taxis for transportation, building "supers" for repairs, and "cleaning ladies" for housework.

The figure of 80% of help being provided by families of the aged is often quoted. The index on informal help indicates that within the study population this figure was exceeded with 88.4% of respondents using the informal system. The index on informal help is a stark contrast. Forty percent of the respondents used no formal supports at all. The 59.4% who used formal services tended to do so for a variety of tasks.



TABLE IV - 11

## PERCENT DISTRIBUTION OF USE OF HELP BY INFORMAL AND FORMAL SUPPORTS\*

<u>Task</u>	<u>Informal Supports</u>			<u>Formal Supports</u>	
	<u>Spouse</u>	<u>Child/Rel</u>	<u>Neigh/Frd</u>	<u>Private Pay</u>	<u>Soc. Agcy</u>
Help when Sick	31.4	30.2	22.1	9.3	5.9
Help with Shopping	30.2	23.3	18.6	15.1	5.8
Help with Housework	23.3	5.8	5.8	24.4	7.0
Cook for you	30.2	7.0	4.7	14.0	4.7
Fix in Apt House	8.1	18.6	17.4	24.4	3.5
Advice	18.6	36.0	16.8	3.5	3.5
Transport.	22.1	20.9	10.5	25.6	7.1

\* More than one type of help is often used in a given task. Multiple responses are allowed.

Respondents were asked three questions to assess their satisfaction with help received. The results are summarized on Table IV - 12. In general, respondents were satisfied. Well over half (66.3%) thought the quantity was just about right, and 77.9% found the quality good or better. Somewhat surprisingly, there were minimal disagreements within families as to the type or amount of help needed, with only 7% citing a conflict.

"What co-existing life events of change and loss are faced by visually impaired elders?"

Co-existing life events are an intervening variable of this study. Respondents were queried on five life events posited to be most common and significant to the elderly. Table IV - 12 summarizes the results.

Clearly, the most common occurrence was the death of someone close - a not unexpected finding. Death of someone close was experienced by 50% of the sample population. One woman when asked if "anyone close" had died since she lost her vision summed it up in one word, "everyone"!

Respondents were most likely to lose a sibling, friend, or other relative - presumably because there are apt to be many of these individuals about the same age as the elder. Moves of others were apt to be of grandchildren. Overall, the findings on co-existing life events were unremarkable. Very few respondents appeared distressed by the questions or their answers (and these were widowed spouses). The rest appeared to accept changes and

TABLE IV -12  
ELDER SATISFACTION WITH HELP

	Frequency (n)	Percent (%)
<u>What Do You Think About the Quantity of Help You Receive?</u>		
Just about right	57	66.3
Too little	24	27.9
Don't Know	5	5.8
Total	86	100.0
<u>What Do You Think About the Quality of Help You Receive?</u>		
Excellent	17	19.8
Very Good	21	24.4
Good	29	33.7
Fair	4	4.7
Poor	2	2.3
It Varies	8	9.3
Don't Know	5	5.8
Total	86	100.0
<u>Are There Disagreements in Your Family about The Help You Need?</u>		
Yes	6	7.0
No	79	91.8
Don't Know	1	1.2
Total	86	100.0

Table IV - 13

**CO-EXISTING LIFE EVENTS OF CHANGE AND LOSS\***

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<u>Life Event</u>	Frequency (n)	Percent (%)
Moved	13	15.2
Job Change	3	3.5
Stopped Work	31	36.0
Anyone Close Moved	15	17.4
Anyone Close Seriously Ill	16	18.6
Anyone close Died	43	50.0

\*More than one life event may occur. Multiple responses are allowed.

loss as expected events at this time in their lives.

### BELIEFS AND FEELINGS ABOUT VISION LOSS

#### "What beliefs and feelings do visually impaired elders hold about their condition?"

Theorists on coping and adaptation agree that understanding a life crisis objectively is less important than understanding the meanings that individuals ascribe to it. It is these perceptions of visual impairment that were tapped by many of the open-ended questions of the study.

Table IV - 14 summarizes elder ratings of overall health and comparison of vision loss and other health problems.

When asked to rate their overall health at the present time, the breakdown was 50 - 50. Half of the respondents rated themselves as in excellent or good health while the other half rated themselves as being in fair or poor health.

When asked to compare vision loss with other health problems, three quarters of the sample population (74.4%) said that vision loss was the most troubling. An additional 19.8% found vision loss neither the most nor the least troubling. Only 4.7% found vision loss the least troubling.

Although it could be argued that the respondents were drawn from individuals who had visited a Low Vision Clinic and that this action itself is a symptom of distress, the high percentage can also be understood as a reflection of the impact of vision

TABLE IV - 14

ELDER RATINGS OF OVERALL HEALTH AND COMPARISON OF VISION LOSS  
WITH OTHER HEALTH PROBLEMS

	Frequency (n)	Percent (%)
<u>Self-Rated Health</u>		
Excellent	10	11.6
Good	33	38.4
Fair	28	32.6
Poor	15	17.4
Total	86	100.0
<u>Comparison of Vision Loss with Other Health Problems</u>		
Most troubling	64	74.4
Least troubling	4	4.7
Neither most nor least troubling	17	19.7
Missing	1	1.2
Total	86	100.0

loss on activities of daily living and participation in social and recreational activities discussed previously in Chapter IV.

Table IV - 15 summarizes respondent attitudes about vision loss.

One open ended question read: how would you describe yourself in relation to your vision loss? Based on clinical experience, I originally expected that answers could be coded by whether elders described themselves in terms of their capacity or incapacity. However, the question turned out to be emotionally loaded and the answers filled with meanings and feelings that respondents related to vision loss.

I originally coded the responses in four categories: unambivalent acceptance, ambivalent acceptance, difficulty, and despair. However in analyzing the data, I felt it more appropriate to collapse into three categories; merging ambivalent acceptance and difficulty, categories about which different raters could disagree. The three remaining categories are acceptance, acceptance with difficulty, and despair. These are clearly delineated as evidenced in the following excerpts. (As a rule, the more despairing the respondent the more sentences he used to describe his condition).

Only 7% of the respondents were accepting; that is, mentioned no problems associated with vision impairment.

"I take it a little better than most people. I don't take a 'why me' attitude. I accept it. Its easier to accept it than

TABLE IV - 15

## ELDER ATTITUDES ABOUT VISION LOSS

	Frequency (n)	Percent (%)
<u>Describe Self in Relation to Vision Loss</u>		
Acceptance	6	7.0
Acceptance with Difficulty	49	56.9
Despair	23	26.8
Missing/Don't Know	8	9.3
Total	86	100.0
<u>Advice to Others with Same Problems</u>		
Medical	37	43.0
Psycho-social	18	20.9
Sympathy	2	2.3
Doesn't Give Advice	10	11.7
Combination types of Advice	13	15.1
Other	3	3.5
Missing	3	3.5
Total	86	100.0
<u>Attitude Change since Vision Loss</u>		
No Attitude Change	32	37.2
Attitude Got Better	20	23.2
Attitude Got Worse	22	25.6
Attitude Changes as Eyes Change	10	11.6
Attitude Changes Unrelated to Eyes	1	1.2
Other	1	1.2
Total	86	100.0
<u>Turning Points in Attitude Change</u>		
No Attitude Change	32	37.2
Yes - Specific	30	34.9
Yes - Non-Specific	9	10.5
No Recall of Turning Point	10	11.6
Missing	5	5.8
Total	86	100.0



fight it".

"It doesn't bother me at all as a matter of fact. I had good vision and a good life and good kids. I have a lot to be thankful for. I'm supposed to be legally blind but I can see".

"I would describe myself as good".

"I would consider myself extremely capable considering my condition".

Over half the respondents (56.9%) accepted with difficulty. These responses typically mentioned problems and negative feelings but did not carry the extreme emotional weight of the despairing responses.

"I would say its a great loss when you lose your vision. You lose your independence. I can't read my newspaper. I have to listen to the radio."

"I describe myself as frustrated and depressed at times".

Many of the acceptance with difficulty responses carry a balance of what can and cannot be done.

"I feel frustrated. I was a voracious reader. Now just large print. I'm retired. I could be spending time reading, but I can't. I also feel insecure about crossing the street. But I travel freely, still use the bus".

"I feel bad about not being able to read my letters. I'm thankful that I can still see, and thank God every day that my vision isn't getting worse."

"Its frustrating. I do everything I have to do with

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frustration. Colors, I can see better".

The single most distressing finding of the entire study was the despair over vision loss expressed by over one-quarter of the sample (26.7%).

"I'm depressed. To me this is the worst thing that could happen to me. I'm helpless - I can't make deposits or read things. I need help with everything. Everything is like a film over my eyes. People are shadows. I can't even see my own face."

"Oh, its horrible. You lose your independence. I'm a hermit. Its awful. You have no personal life. Everything has to be read to me. I'm completely beside myself. I can't get adjusted. I can't even cook anymore. I'm completely lost".

"Very upset. It makes me very upset. I have lost 90% of vision. I don't see you at all. I loved nature, the flowers, life, everything that man has created. Now I can't see anything. Its terrible. It cannot be a worse thing to lose your sight. I cannot express myself. I can't write. My life was reading".

"I know its failing. Until recently I've been able to see clearly. I have a slight haze over everything. My life is gone. Its not worthwhile. I can't read. I depended on my eyes. I loved studying, but what can I do now? I can read a couple of words at a time. Its worse than the pain of arthritis".

One open-ended question asked: if someone who just learned that he or she had the same vision problem that you do asked for

advice, what would you say?

It was expected that elders would give advice as to how to cope with the illness; however, an amazing 43 % interpreted the question medically (using the terms doctor, operation, surgery).

"Go to the doctor"

"Not to fear, go through the operation".

"Don't get a second operation until you're certain you need it".

"Be careful. Sometimes the doctor wants business".

"Don't get operated on - leave it. Don't bother".

"To go to an ophthalmologist. Vision is precious".

"See a specialist immediately. Not just a horse doctor".

Of the fifth (20.9%) who gave the question a psycho-social interpretation, most tended to be geared toward passive acceptance rather than active mastery.

"Learn to live with it no matter how much it bothers you".

"Nothing. Absolutely nothing you can do. Learn to live with it".

"Not to worry. That's all".

"Learn to accept it. Its not easy".

"Try to manage".

Some respondents went a step further to share the lessons they had learned.

"You have to have a lot of patience and take it little by little".

"In spite of what the doctor told me, I tried to help myself

with visual aids. I read the newspapers and I read the magazines. I shouldn't stop trying and I tell that to anyone".

I would send them to the Low Vision Center. I've sent lots of people there".

"I was a basket case, so try to be very calm. Teach yourself to get around and remember where you leave things. Join an agency where people have your problems. It will give you a lift".

Over one-tenth of the respondents (11.6%) don't give advice.

" Couldn't give advice. Everyone is different".

Fifteen percent of the sample population gave combination advice; that is, a bit of medical and a bit of psychosocial.

"Don't be 75! Go to the best doctor. Make sure for any fine work to have adequate light".

"Go to the doctor. Don't let it stop you. Still go out".

Overall, responses to the "advice" question indicate that a majority of the visually impaired elders do not feel that they have much control over their eye condition. One respondent summed up this point of view: "if the doctors can't do anything, how can I?" While this medicalization of the problem is understandable for an aging cohort (and reenforced by the health care system) it may well stand in the way of developing creative coping techniques and so impede adaptation.

One open-ended question asked respondents if their attitude had changed since the vision loss and, if so, to specify the ways

in which this occurred.

Over one third (37.2%) reported no change in attitude. A little over a fifth of the elders sampled reported that their attitudes got better and one quarter (25.6) reported that their attitudes got worse.

Examples of better attitudes:

"Its less scary because I'm getting used to it, and there's always hope".

"I'm getting a little more used to it. Before it was always on my mind. Now I'm trying to forget it".

"I've gotten stronger and more patient".

Examples of worse attitudes:

"Its become more aggravating"

"Its become worse because I'm so angry and hurt and frustrated".

"More pessimistic. I feel very helpless. It brought me down physically also. It hit me hard, especially at this late age, when you're alone"

A substantial number of respondents (11.6%) said that their attitude changed along with changes in their eye conditions.

"More agitated due to second operation which made it worse".

If the findings on attitude changes were inconclusive, the same may be said of answers about "turning points" that signalled such changes. Although the answers were sufficiently differentiated to be able to categorize them, responses were too

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idiosyncratic to discern any pattern.

As noted above, 37.2% of the respondents reported no change in attitude.

Of the 57% of elders who reported that their attitude had changed, 45.4% recalled a turning point. Of those who recalled a turning point, 34.9% of the respondents cited a specific time, reason, or incident, and 10.5% reported non specific or gradual change. Eleven percent of those who had an attitude change could not recall a turning point at all.

Examples of specific turning points:

"Can use an eye lens now which helps to see much better".

"The second operation".

"I met new friends who were nice".

"When the doctors said nothing could be done".

Examples of non-specific or gradual turning points:

"Its an ongoing thing"

"Just the worsening of it"

### Summary/Discussion of Descriptive Data

#### Vision Loss in the Sample Population

The elderly respondents of the study resemble the general population of the visually impaired aged in terms of major eye diagnoses, degree of impairment, and prognosis. Over half of them report a time since onset earlier than that recorded by the Low Vision Clinic: possibly a function of selective memory or an

attempt to find a rationale for their current vision problem in earlier life.

There are other real differences between the respondents' perception of the vision loss and that of clinicians in the Low Vision Clinic: more elders expect change for the better than do their professional caregivers; more elders recall a sudden onset of vision loss (often a dramatic event) than warranted given the progressive nature of most of their eye problems. Taken together, these findings suggest that elders struggle to "make sense" of their vision loss and to maintain hope.

This impression is furthered by evidence that the respondents sought out second, third, and even more, medical opinions on their vision as well as using low vision aids.

Nevertheless, the impact of vision loss on the elderly respondents had devastating consequences in terms of activities of daily living and in social and recreational activities. In these important areas of life, vision loss emerged as the factor most responsible for dependence or lack of participation.

#### The Context of Age Related Vision Loss: Health, Social Supports, Co-Existing Life Events

Almost 40% of the sample population had difficulty hearing; contributing to a dual sensory deficit. The number and type of chronic health conditions resembled those of the general aged population; most of these originating before the onset of vision loss.

In common with the general population of aging, respondents had far greater contact with informal supports than with formal agencies and received most of their help from their informal network. Most of them were very satisfied with the help they received and had no disagreements with their families about help.

Co-existing life events of change and loss did not play an important role in the life of the elderly respondents, with the exception of death of someone close which occurred to over half of the respondents and discussed as an expected life event.

#### Beliefs and Feelings about Vision Loss

Three-quarters of the elderly respondents described vision loss as the most troubling of their health problems. And a quarter of the respondents presented despairing attitudes when describing themselves in reference to their eye condition. The respondent group were prone to "medicalize" their problem; looking to physicians and operations for help rather than at psycho-social solutions. Reported changes in attitude since the onset of vision loss were inconclusive.



## CHAPTER V

### FINDINGS II: BI-VARIATE CORRELATIONS

#### OVERVIEW

Chapter IV presented the descriptive data related to this study on age-related vision loss: the objective and subjective meaning of the condition and its consequences for daily life. While major themes were identified, it was evident that there was considerable diversity in the way elders perceived and responded to vision impairment.

In this chapter bi-variate analysis is used to to examine and explain this diversity. The chapter is organized into three sections to examine independent, intervening, and dependent variables. Each section begins with an overview of the variables that will be examined. Then, utilizing individual items and measurement scales, the results of the bivariate analyses are presented. Correlation (Pearson's  $r$ ) is utilized to identify those variables that have a significant relationship with adaptation to vision loss or to each other. Where applicable, research questions and hypotheses are addressed. At the conclusion of each section, the findings relative to that class of variables are summarized and discussed.

#### THE INDEPENDENT VARIABLES

The independent variables consist of demographic data, major eye diagnoses, and vision-related data. There were no research

questions or hypotheses related to these correlations. The purpose of presenting these findings is twofold: to amplify understanding of the composition of the sample population and to identify interesting and/or statistically significant correlations that may have bearing on adaptive task performance.

Tables VI -4 present bi-variate correlations between the independent variables.

As indicated in Table V-1, white ethnicity was correlated positively with advanced age ( $r=.39; p < .001$ ) and greater income ( $r=.27; p < .01$ ) in the sample population. Jewish respondents were found to have higher income ( $r=.18; p .01$ ) while Protestant respondents were found to have lower income ( $r= -.27; p < .01$ ). The sample reflects the general aging population in that being white is correlated with longer life ( $r=.39; p .001$ ) and higher income ( $r=.27; p < .01$ ).

The correlations on education reflect that Catholics have less education ( $r= -.30; p < .01$ ) and Protestants have more education ( $r=.18; p < .05$ ). A likely explanation of the first finding is that the Catholic respondents of the study were predominantly Irish and Italian first generation americans who did not have the same educational opportunities as those who were native born. By the same token, it is likely that both White and Black Protestant consumers are more likely to be native born with more educational opportunities.

Other findings on Table V-1 indicate that respondents reflect the general aging population demographically: men are

Table V - 1

ZERO-ORDER CORRELATIONS (PEARSON'S r)  
BETWEEN DEMOGRAPHIC CHARACTERISTICS

	Pearson's r			
	Age (a)	Gender (b)	Education (c)	Income (d)
<u>Ethnicity</u> (e)	.39***	.13	.04	.27**
<u>Religion</u>				
Catholic	-.16	.01	-.30**	-.08
Protestant	-.04	.02	.18*	-.27**
Jewish	.18	-.05	.04	.29**
<u>Marital Status</u>				
Married	.05	.55***	-.04	-.07
Widowed	.28	-.44***	-.07	.03
Sep./Divorced	-.31**	-.00	-.06	-.13
Never Married	-.09	-.18*	.23*	.21*
<u>Lives Alone</u>	.04	-.41***	-.06	.20*

\*p &lt; .05

\*\*p &lt; .01

\*\*\*p &lt; .001

(a) High scores reflect greater age

(b) 2 = male; 1 = female

(c) High scores reflect greater education

(d) High scores reflect greater income

(e) 1 = white; 0 = non-white

TABLE V - 2

ZERO-ORDER CORRELATIONS (PEARSON'S  $r$ ) BETWEEN  
MAJOR EYE DIAGNOSES AND DEMOGRAPHIC CHARACTERISTICS

	Pearson's $r$			
	Macular Degeneration	Diabetic Retinopathy	Glaucoma	Cataract
<u>Age</u> (a)	.23*	-.17	-.28**	.08
<u>Gender</u> (b)	.03	-.15	.03	-.03
<u>Marital Status</u>				
Married	.09	-.11	-.17	.02
Widowed	.10	.14	-.08	-.22*
Sep//Divorced	-.28*	.04	.36***	.08
Never Married	.11	-.04	-.14	.10
<u>Ethnicity</u> (c)	.35***	.06	-.67***	.14
<u>Religion</u>				
Catholic	.03	.15	-.07	.04
Protestant	.00	-.15	.17	-.02
Jewish	.08	.04	-.23*	-.04
<u>Income</u> (d)	-.08	.07	-.07	-.06
<u>Education</u> (e)	-.04	.03	-.10	.00

\*p &lt; .05

\*\*p &lt; .01

\*\*\*p &lt; .001

(a) High scores reflect greater age

(b) 2 = male; 1 = female

(c) 1 = white; 0 = non-white

(d) High scores reflect greater income

(e) High scores reflect greater education

Table V - 3

**ZERO-ORDER CORRELATIONS (Pearson's r) BETWEEN  
MAJOR EYE DIAGNOSES AND VISION-RELATED DATA**

	Pearson's r			
	Macular Degeneration	Diabetic Retinopathy	Glaucoma	Cataract
<u>Time Since Onset</u> (a)	-.23*	.09	.19*	.05
<u>Type Of Onset</u>				
Sudden	-.13	.03	.15	.12
Unclear	.15	-.12	-.11	.00
<u>Degree Of Impairment</u> (b)	.05	.20*	-.08	-.18*
<u>Prognosis</u> (c)				
Progressive VFR	-.23*	.02	.32*	.10
Slow Progressive	.21*	-.08	-.08	-.07
Progressive	.35***	.08	-.13	-.27**

\*p &lt; .05

\*\*p &lt; .01

\*\*\*p &lt; .001

(a) High scores reflect self-reported longer time since onset

(b) High scores reflect clinically reported greater degree of impairment

(c) 1 = progressive; 0 = other

Table V - 4

**ZERO-ORDER CORRELATIONS (Pearson's r) BETWEEN  
VISION-RELATED DATA AND DEMOGRAPHIC CHARACTERISTICS**

	Time since Onset (a)	Type of Onset (b)		Pearson's r Degree of Impair. (c)	Prognosis		
		S	U		VFR	Slow	Prog
<u>Age</u> (d)	-.31**	-.20*	.12	.18*	-.06	-.07	.09
<u>Gender</u> (e)	-.24**	-.05	-.07	.01	.00	.10	.09
<u>Marital Status</u>							
Married	-.08	-.09	.04	-.08	.05	.07	-.09
Widowed	-.14	-.13	.18*	.05	-.12	-.04	.18*
Sep./Div.	.28**	.01	-.10	.07	.10	.05	-.16
Nvr Marr.	-.05	.22*	-.15	-.10	.00	-.09	.11
<u>Lives Alone</u>	.04	.13	-.12	.04	-.09	-.09	.10
<u>Ethnicity</u> (f)	-.32***	-.14	.18*	.04	-.10	.10	.03
<u>Religion</u>							
Catholic	.09	.10	.02	.21*	-.11	-.03	.17*
Protestant	.21*	.05	-.16	-.07	.11	-.09	.04
Jewish	-.20*	-.20*	.10	.07	.08	.14	-.15
<u>Income</u> (g)	-.00	.04	-.11	.03	-.06	-.04	-.07
<u>Education</u> (h)	.05	-.05	.07	-.11	-.04	-.05	-.16

\*p &lt; .05

\*\*p &lt; .01

\*\*\*p &lt; .001

- (a) High scores reflect self-reported longer time since onset  
 (b) S = self-reported sudden onset. U = self-reported uncertain onset  
 (c) High scores reflect clinically reported greater degree of impairment  
 (d) High scores reflect greater age  
 (e) 2 = male; 1 = female  
 (f) 1 = white; 0 = non-white  
 (g) High scores reflect greater income  
 (h) High scores reflect greater education

more likely to be married ( $r=.55; p < .001$ ), women are more likely to be widowed ( $r=-.44; p < .001$ ), separated and divorced individuals are younger ( $r=.31; p < .01$ ), those who never married ( $r= -.18; p < .05$ ) and those who live alone ( $r=-.41; p < .001$ ) are females.

Living alone is positively correlated with higher income ( $r=.20; p < .01$ ) These findings may reflect widows who are living on their late husband's resources and single women who are or were employed.

Table V-2 presents the correlation of four major eye diagnoses with demographic characteristics. Most of the findings here are consistent with general knowledge in the field of Low Vision. Macular degeneration is positively correlated with advanced age ( $r=.23; p < .05$ ) and white ethnicity ( $r=.35; p < .001$ ).. Diabetic retinopathy occurs earlier in the aging process ( $r=-.17$ ) as does Glaucoma ( $r=-.28; p < .01$ ). Glaucoma is especially likely to occur to younger ( $r=-.28; p < .01$ ), non-white ( $r=-.67; p < .001$ ), non-Jewish ( $r=-.23; p < .05$ ) respondents.

The strong positive and statistically significant correlation between glaucoma and a separated or divorced marital status ( $r=.36; p < .001$ ) may be primarily due to age or ethnicity. There is no ready explanation for why widowed individuals are less likely to have cataracts ( $r=-.22; p < .05$ ).

Table V-3 presents correlations between the four major eye diagnoses and other vision-related data. The diagnosis of macular degeneration is associated with a shorter time since onset ( $r= -.23; p < .05$ ) and a progressive ( $r=.35; p < .001$ ). or

slowly progressive ( $r = .21; p < .05$ ) Individuals with diabetic retinopathy tend to be the most visually impaired ( $r=.20$ ) and those with cataracts the least impaired ( $r=-.18;p < .05$ ). Glaucoma is positively correlated with a progressive reduced visual field prognosis ( $r=.32;p < .05$ ) and a longer time since onset ( $r=.19;p < .05$ ).

Table V-4 presents relationships between vision-related data and demographic characteristics. Many of these correlations -that separated and divorced individuals have a longer time since onset ( $r=.28;p < .01$ ), that widows report an unclear type of onset ( $r=.18;p < .05$ ), that widows ( $r=.18;p < .05$ ) and Catholics ( $r=.17;p < .05$ ) have a progressive prognosis-are no doubt related to intervening variables that are not reflected here.

However, we do note that older respondents are more visually impaired ( $r=.18;p < .05$ ), report shorter time since onset ( $r=-.31;p < .01$ ), do not have a sudden onset ( $r=-.10;p < .05$ ) of vision impairment. This information is important in that cohort differences are one of the research objectives of this study.

#### Summary/Discussion of bi-Variate Correlations of Independent Variables

Correlations of demographic variables confirm the findings of Chapter III that the sample population resembles the general aging population in several ways: gender, marital status, living relationships, education, and income.



At the same time, Non-white individuals are under represented in the sample. As presented on Table III-2, White respondents comprised 83.7% of the sample, Black respondents comprised 11.6% of the sample, and Hispanic represented 3.5%. This is in contrast to the 1980 New York Census statistics that found Whites comprising 75.8% of the population over 60 years of age while Blacks comprised 14.2% and Hispanics comprised 7.8% of this population. (NYC Department for the Aging, 1988).

The findings on major eye diagnoses and vision-related data reflect professional knowledge on these clinical populations.

As might be expected older respondents are more visually impaired. Age is also found to be an important predictor of the type of eye problem and its sequela. The differences between older respondents with a diagnosis of macular degeneration and younger respondents with a diagnosis of diabetic retinopathy is confounded by ethnicity; with macular degeneration being more prevalent in white, and diabetic retinopathy and glaucoma being more associated with non-white ethnicity. The effects of age, ethnicity, and time since onset associated with macular degeneration on intervening and dependent variables are discussed in the following sections.

#### THE INTERVENING VARIABLES

Tables V-5 through V-13 present the intervening variables (social supports, health, and co-existing life events of change

and loss) in relation to the independent variables.

Social supports encompass informal extent, informal frequency, and formal extent. "Extent" indicates the number of supports in the respondent's network while "frequency" refers to the number of contacts with these supports.

Before discussion of the social support tables, it should be noted that informal and formal supports are not inherently comparable constructs. The existence of relatives or friends does not necessarily mean that they are in contact with the older person while the existence of a social agency or private pay support in the older person's life is synonymous with contact. For this reason, it is most useful to compare the last two columns - informal frequency and formal extent. Informal extent has a value, however, in that it indicates potential resources. (As noted in Chapter III, informal extent and informal frequency are united in a total informal scale that is used elsewhere in the study.)

Table V-5 and V-6 present the correlations between social supports, demographic characteristics, major eye diagnoses and vision related data. Although there are no research questions or hypotheses about these relationships, they add further to an understanding of the respondent population.

Not surprisingly, married respondents have the largest extent of informal supports ( $r=.31; p < .01$ ), a moderate frequency of informal contacts ( $r=.06$ ) and a very small extent of formal supports ( $r=-.26; p < .01$ ). It can be assumed that the supports of

Table V - 5

**ZERO-ORDER CORRELATIONS (Pearson's r) BETWEEN  
SOCIAL SUPPORTS AND DEMOGRAPHIC CHARACTERISTICS**

	Informal Extent (a)	Pearson's r Informal Frequency (b)	Formal Extent (c)
<u>Age</u> (d)	-.09	.01	.04
<u>Gender</u> (e)	.02	-.05	-.17
<u>Education</u> (f)	-.21*	-.23*	.06
<u>Income</u> (g)	.15	.35***	.05
<u>Marital Status</u>			
Married	.31**	.06	-.27**
Widowed	.10	.01	.12
Sep./Divorced	.02	.30**	-.02
Never Married	-.49***	.36***	.20*
<u>Lives Alone</u>	-.40***	-.15	.05
<u>Religion</u>			
Catholic	.08	.13	.05
Protestant	-.16	.00	.04
Jewish	.04	.08	-.06
<u>Ethnicity</u> (h)	-.05	-.09	-.08
<u>Formal Extent</u>	-.26**	-.14	_____

\*p &lt; .05

\*\*p &lt; .01

\*\*\*p &lt; .001

- (a) High scores reflect greater extent of informal supports  
 (b) High scores reflect greater frequency of informal contacts  
 (c) High scores reflect greater extent of formal supports  
 (d) High scores reflect greater age  
 (e) 2 = male; 1 = female  
 (f) High scores reflect greater education  
 (g) High scores reflect greater income  
 (h) 1 = white; 0 = non-white

Table V - 6

ZERO-ORDER CORRELATIONS (Pearson's r) BETWEEN  
SOCIAL SUPPORTS, MAJOR EYE DIAGNOSES, AND VISION-RELATED DATA

	Pearson's r		
	Informal Extent (a)	Informal Frequency (b)	Formal Extent (c)
<b>Major Eye Diagnoses</b>			
Macular Degeneration	-.02	-.04	-.14
Diabetic Retinopathy	-.11	.16	-.04
Glaucoma	.01	-.06	.08
Cataract	-.23*	-.20*	.04
<b>Time Since Onset (d)</b>	-.07	.05	.02
<b>Type of Onset (e)</b>			
Sudden	-.22*	-.30**	-.02
Uncertain	.13	.03	-.07
<b>Degree of Impairment (f)</b>	.08	.20*	-.03
<b>Prognosis (g)</b>			
Visual Field Reduced	-.06	-.08	-.15
Slow Progressive	.15	.06	-.14
Progressive	.10	.14	.06

\*p &lt; .05

\*\*p &lt; .01

- (a) High scores reflect greater extent of informal supports  
 (b) High scores reflect greater frequency of informal contacts  
 (c) High scores reflect greater extent of formal supports  
 (d) High scores reflect self-reported longer time since onset  
 (e) High scores reflect self-reported type of onset  
 (f) High scores reflect self-reported greater degree of impairment  
 (g) 1 = progressive; 0 = other

children and grandchildren are there but need not be called upon as the couple have each other for affective and concrete support.

The picture is quite different when we look at respondents who are not currently married. Never married respondents have far fewer informal supports ( $r=-.49;p < .001$ ) but much more frequent contact with them ( $r=.36;p < .001$ ) as well as greater extent of formal agency involvement ( $r=.20;p < .05$ ) than those of other marital statuses. This may well be because the lack of children is compensated for by a few close associations with friends (often age cohorts) who offer affective rather than concrete support. Concrete support is then needed by formal providers.

Separated or divorced respondents have a larger extent of informal supports than never marrieds ( $r=.02$ ) but fewer than those widowed ( $r=.10$ ), yet they have more frequent contacts with these informal supports ( $r=.36;p < .001$ ) than do the widowed ( $r=.01$ ). Again, this might be a function of friendships replacing familial relationships in those who have been unmarried for a long time. Living alone is correlated with the smallest extent of informal supports ( $r=-.40;p < .001$ ) of any demographic status.

More highly educated respondents are less likely to have informal supports ( $r=-.21;p < .05$ ) and contact with them. ( $r=-.23;p < .05$ ). There is no obvious reason for this.

Individuals with higher income are more likely to have informal supports ( $r=.15$ ) and contact with them ( $r=.35;p < .001$ ).

This could be because travel and long-distance phoning cost money.

The extent of formal services is negatively correlated with the extent of informal supports ( $r=-.26;p<.01$ ). This affirms what has been found generally in studies of aging populations; that formal supports are often used because there are no informal supports available.

As to vision related data, a low frequency of contact with informal supports is found in individuals with cataracts ( $r=-.20;p<.05$ ) and individuals with sudden onset ( $r=-.30;p<.01$ ). Both of these findings appear to be related to a lower extent of informal supports rather than anything related to the specific eye conditions. At the same time, a greater frequency of contact is found with those suffering from a high degree of impairment ( $r=.20;p<.05$ ). And this is quite high given the extent of informal supports ( $r=.08$ ). Thus, it would seem that degree of impairment does generate greater frequency of contact with informal supports.

Tables V-7 and V-8 present the correlations between health, demographic characteristics, major eye diagnoses and vision-related data. There are no research questions or hypotheses associated with these tables.

On Table V-7 we have the surprising, and important, finding that in the sample population, age is negatively correlated with medical problems ( $r=-.21;p<.05$ ). While this is the opposite of what would be found in the general population of aged, it is

Table V - 7

**ZERO-ORDER CORRELATIONS (Pearson's r) BETWEEN  
HEALTH AND DEMOGRAPHIC CHARACTERISTICS**

	Pearson's r		
	Hearing Loss (a)	Medical Problems (b)	Self-Appraisal (c)
<u>Age</u> (d)	-.02	-.21*	.07
<u>Gender</u> (e)	-.13	-.16	-.31**
<u>Marital Status</u>			
Married	-.16	-.22*	-.22*
Widowed	.11	.14	.10
Sep./Divorced	-.13	-.04	-.04
Never Married	.13	.14	.18*
<u>Lives Alone</u>	.20*	.19*	.18*
<u>Ethnicity</u> (f)	.12	-.01	.12
<u>Religion</u>			
Catholic	-.19*	-.11	-.13
Protestant	.03	.07	-.12
Jewish	.14	.10	.16
<u>Income</u> (g)	-.06	-.13	-.16
<u>Education</u> (h)	-.09	.00	.03

\*p &lt; .05

\*\*p &lt; .01

- (a) High scores reflect greater hearing loss  
(b) High scores reflect more medical problems  
(c) High scores reflect poorer self appraisal  
(d) High scores reflect greater age  
(e) 2 = male; 1 = female  
(f) 1 = white; 0 = non-white  
(d) High scores reflect greater income  
(h) High scores reflect greater education

Table V - 8

**ZERO-ORDER CORRELATIONS (Pearson's r) BETWEEN  
HEALTH, MAJOR EYE DIAGNOSES AND VISION-RELATED DATA**

	Hearing Loss (a)	Pearson's r Medical Problems (b)	Self-Appraisal (c)
<b>Major Eye Diagnoses</b>			
Macular Degeneration	-.05	-.24*	-.06
Diabetic Retinopathy	.14	.32***	.19*
Glaucoma	-.07	.10	.02
Cataract	.05	-.01	.03
<b>Time Since Onset (d)</b>	-.00	.04	.11
<b>Type of Onset (e)</b>			
Sudden	-.04	.10	-.04
Uncertain	-.02	-.03	-.07
<b>Degree of Impairment (f)</b>	-.07	-.09	-.05
<b>Prognosis (g)</b>			
Progressive VFR	.09	-.02	-.07
Slow Progressive	.01	.03	-.02
Progressive	.04	.06	.15

\*p &lt; .05

\*\*\*p &lt; .001

- (a) High scores reflect greater hearing loss  
 (b) High scores reflect more medical problems  
 (c) High scores reflect poorer self-appraisal  
 (d) High scores reflect self-reported longer time since onset  
 (e) Self-reported type of onset  
 (f) High scores reflect self-reported greater degree of impairment  
 (g) 1 = progressive; 0 = other



explicable when one turns to Tables V-2, V-3, and V-8 to note related correlations. On Table V-2 we see that two major eye diagnoses are negatively correlated with age: diabetic retinopathy ( $r=-.17$ ) and glaucoma ( $r=-.28;p < .01$ ). Table V-8 indicates that diabetic retinopathy is highly correlated with health problems ( $r=.32;p < .001$ ). This is because diabetes is a systemic disease and patients typically have associated health problems and hospitalizations. Thus, it is understandable that diabetics have a much lower self appraisal of health ( $r=.19;p < .05$ ) than those with other eye diagnoses. As noted earlier in the discussion of Table V-3, those with diabetic retinopathy are the most visually impaired as well ( $r=.20;p < .05$ ).

Thus, we see that diabetics are in double jeopardy for poor general health and a high degree of vision impairment. Those with glaucoma do not have the same set of physical problems but are significantly younger. In contrast, macular degeneration occurs later in the life span and independent of other medical problems ( $r=-.24;p < .05$ ). And while there is a positive correlation with degree of vision impairment ( $r=.05$ ) it is neither high nor significant. Thus, although conventional (and lay) gerontological wisdom has it that the older the individual the greater the likelihood of poor health, it may be that in looking at a visually impaired population the eye diagnosis may change the expectation in that those who live long enough to develop macular degeneration may be a sturdier group.

As noted in the earlier discussion, living alone is

correlated with a low extent of social supports. On Table V-7, we see that it is also positively correlated with poor hearing ( $r=.20;p < .05$ ), more medical problems ( $r=.19;p < .05$ ), and poorer self appraisal of health ( $r=.18;p < .05$ ).

On the other hand, the most positive self appraisal of health come from married respondents ( $r=-.22;p < .05$ ) and men ( $r=-.31;p < .01$ ) who appear to do better in other respects as well.

Table V-9 presents the correlations between social supports and health. An interesting finding is that respondents who are hard of hearing have fewer contacts with informal supports ( $r=-.25; p < .05$ ) as well as greater extent of formal services ( $r=.26; p < .01$ ). A possible explanation of the informal support finding is that in-person and phone communication with hearing impaired individuals is difficult and may occasion a dropping off of contact.

Table V-9 also presents the finding that contact with formal agencies is positively correlated with all three health measures (respectively,  $r=.26, r=.26, r=.26;p < .01$ ). This is not surprising since contact with a formal support is specifically for the purpose of receiving assistance while contact with an informal support may be for other reasons.

Tables V-10 and V-11 present the correlations between co-existing life events of change and loss, demographic characteristics, and vision-related data. Table V-12 presents the correlations between co-existing life events and health.

Table V - 9  
 ZERO-ORDER CORRELATIONS (Pearson's r) BETWEEN  
 SOCIAL SUPPORTS AND HEALTH

---

	Pearson's r		
	Informal Extent (a)	Informal Frequency (b)	Formal Extent (c)
Hearing (d)	-.13	-.25*	.26**
Medical Problems (e)	-.18*	-.10	.26**
Self-Appraisal (f)	.02	-.04	.31**

---

\*p &lt; .05

\*\*p &lt; .01

- (a) High scores reflect greater extent of informal supports
- (b) High scores reflect greater frequency of informal contacts
- (c) High scores reflect greater extent of formal supports
- (d) High scores reflect poorer hearing
- (e) High scores reflect more medical problems
- (f) High scores reflect poorer self-appraisal

Table V - 10

**ZERO-ORDER CORRELATIONS (Pearson's r) BETWEEN CO-EXISTING  
LIFE EVENTS AND DEMOGRAPHIC CHARACTERISTICS**

	Pearson's r
	Life Events (a)
<u>Age</u> (b)	-.15
<u>Gender</u> (c)	-.11
<u>Married</u>	
Married	-.05
Widowed	.10
Separated/Divorced	-.02
Never Married	-.10
<u>Lives Alone</u>	-.05
<u>Ethnicity</u> (d)	-.15
<u>Religion</u>	
Catholic	.02
Protestant	-.16
Jewish	.09
<u>Income</u> (e)	-.18
<u>Education</u> (f)	-.00

- (a) High scores reflect greater frequency of stressful life events  
 (b) High scores reflect greater age  
 (c) 2 = male; 1 = female  
 (d) 1 = white; 0 = non-white  
 (e) High scores reflect greater income  
 (f) High scores reflect greater education

Table V - 11

**ZERO-ORDER CORRELATIONS BETWEEN CO-EXISTING LIFE EVENTS,  
MAJOR EYE DIAGNOSES AND VISION-RELATED DATA**

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	Pearson's r Life Events (a)
<hr/>	
<u>Major Eye Diagnoses</u>	
Macular Degeneration	-.26***
Diabetic Retinopathy	.14
Glaucoma	.14
Cataract	.09
 <u>Time Since Onset</u> (b)	 -.07
 <u>Type of Onset</u> (c)	
Sudden	.21*
Uncertain	-.10
 <u>Degree of Impairment</u> (d)	 .03
 <u>Prognosis</u> (e)	
Progressive VFR	-.06
Slow Progressive	-.04
Progressive	-.10

---

\*p &lt; .05

\*\*\*p &lt; .001

- (a) High scores reflect greater frequency of stressful life events  
 (b) High scores reflect self-reported longer time since onset  
 (c) Self-reported type of onset  
 (d) High scores reflect greater degree of impairment  
 (e) 1 = progressive; 0 = other

Table V - 12

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**ZERO-ORDER CORRELATIONS BETWEEN CO-EXISTING LIFE EVENTS  
AND HEALTH**

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	Pearson's r
	Life Events (a)
<u>Hearing Loss</u> (b)	.01
<u>Medical Problems</u> (c)	.12
<u>Self-Appraisal</u> (d)	.07

---

- (a) High scores reflect greater frequency of stressful life events  
(b) High scores reflect poorer hearing  
(c) High scores reflect more medical problems  
(d) High scores reflect poorer self-appraisal

Table V - 13

ZERO-ORDER CORRELATIONS BETWEEN CO-EXISTING LIFE EVENTS  
AND SOCIAL SUPPORTS

	Pearson's r
	Co-Existing Life Events (a)
<u>Informal Extent</u> (b)	.20*
<u>Informal Frequency</u> (c)	.09
<u>Formal Extent</u> (d)	.19*

\*p < .05

- (a) High scores reflect greater number of stressful life events
- (b) High scores reflect greater number of informal supports
- (c) High scores reflect greater frequency of informal contacts
- (d) High scores reflect greater extent of formal supports

Table V-13 presents the correlations between co-existing life events and social supports. There were no research questions or hypotheses about these relationships, and indeed there is not much of interest to report with the exception of the negative correlation between Macular Degeneration and life events ( $r = -.26; p < .001$ ) on Table V-11. A possible explanation for this is that the respondents, being older, have fewer relationships left to change or lose. However, it does add to the growing evidence in the bi-variate correlations that the older respondents with a diagnosis of Macular Degeneration may be in a slightly more advantageous position in performance of adaptive tasks.

Summary/Discussion of bi-Variate Correlations of Intervening Variables

In summary, bi-variate correlations of intervening variables indicate that there are significant differences in the areas of health, social supports, and stressful life events between respondents with different eye diagnoses and demographic characteristics.

Overall, older respondents of the study are doing better than might have been expected. While their vision is slightly more impaired the problem has existed for a shorter period of time, and is accompanied by fewer medical problems. They also have fewer stressful life events. As noted earlier, this is in large measure due to their differential eye diagnosis and related



vision factors.

Although time since onset is mentioned in the literature on adaptation as being an important indicator of adaptation, it does not appear to be the case with the sample population producing no significant correlations.

A difference between sensory impairments is noted in that elders with poorer hearing have less contact with informal supports while those with poorer vision have more. Formal services are more likely to be brought into the scene because of other health problems than because of vision loss.

#### THE DEPENDENT VARIABLES

Tables V-14 to V-21 present the bi-variate correlations between the independent variables, intervening variables, and dependent variables.

A word about the dependent variables. As noted throughout the study, five adaptive tasks were drawn from the literature on adaptation to loss and tested with the sample population. They are: maintenance or restoration of self esteem (Self Esteem) , use of help, modification of daily schedule (Activities of Daily Living) balance Between continuity and change in social and recreational Activities (Activities Social/Recreational) and understanding of loss. The first four of these five tasks were measurable by scales. The last item was handled by matching the clinical prognoses and respondent's expectation of change. Since

this match is quantitatively of a different order than the other four tasks, it is handled separately in the discussion of bi-variate correlations. Tables V-22 to V-25 present the fifth dependent variable.

#### SELF ESTEEM

There are a set of research questions related to Self Esteem.

To what extent is the elder's sense of self-esteem related to vision impairment?

1. Do demographic variables such as age, income, and education increase self esteem in the visually impaired elderly?

Table V-14 presents the finding that older respondents have lower self esteem ( $r=.19; p < .05$ ). Correlations between self esteem and education, and between self esteem and income, are not significant.

2. Does self esteem increase with the time since onset of visual impairment?

Correlations between self esteem and time since onset of vision loss are not significant.

3. Does a high degree of visual impairment decrease self-esteem?

Correlations between degree of visual impairment and self esteem are not significant.

Table V - 14

ZERO-ORDER CORRELATIONS (Pearson's r) BETWEEN  
INDEPENDENT VARIABLES AND SELF ESTEEM

	Pearson's r
	Self Esteem (a)
<u>Demographic Characteristics</u>	
Age (b)	.19*
Gender (c)	-.13
Marital Status	
Married	-.18*
Widowed	.31**
Sep./Div.	-.11
Never Married	-.11
Lives Alone	.10
Education (d)	-.02
Income (e)	-.15
Ethnicity (f)	.08
Religion	
Catholic	.03
Protestant	.02
Jewish	-.02
<u>Major Eye Diagnoses</u>	
Macular Degeneration	-.01
Diabetic Retinopathy	-.02
Glaucoma	.05
Cataract	-.04
<u>Vision Related Data</u>	
Time since onset (g)	-.12
Sudden onset	-.11
Uncertain onset	.06
Degree of Impairment (h)	.10
<u>Prognosis (i)</u>	
Progressive VFR	-.12
Slow Progressive	-.03
Progressive	.13

\*p &lt; .05

\*\*p &lt; .01

- (a) High scores reflect lower self esteem  
 (b) High scores reflect greater age  
 (c) 2 = male; 1 = female  
 (d) High scores reflect greater education  
 (e) High scores reflect greater income  
 (f) 1 = white; 0 = non-white  
 (g) High scores reflect longer time since onset  
 (h) High scores reflect greater degree of impairment  
 (i) 1 = progressive; 0 = other

There are three study hypotheses on self esteem.

H1 High self esteem will be positively related to younger age, independence in activities of daily living and good health.

Table V-14 indicates that younger people have higher self esteem ( $r=.19$ ;  $p < .05$ ).

Table V-22 indicates that elders who are more independent in activities of daily living have higher self esteem ( $r=.26$ ;  $p < .01$ ).

Table V-15 indicates that elders who have better hearing, fewer medical problems, and better self appraisal score higher in self esteem ( $r = .12, .21$  and  $.11$  respectively); however, only the finding on medical problems is significant ( $r=.21$ ;  $p < .05$ ).

H2 There will be a positive relationship between severity of visual impairment and poor self esteem.

This hypothesis was not confirmed as the findings were not significant.

H3 Self esteem will not relate to time of onset since vision loss.

Table V-14 indicates a negative correlation ( $r= -.12$ ) between poor self esteem and longer time since onset.

There are a few unhypothesized correlations between self esteem and other variables that are of interest.

Table V-14 presents that married individuals have higher

self esteem ( $r = -.18; p < .05$ ) while widows have lower self esteem ( $r = .31 ; p < .01$ ).

Table V-15 indicates that individuals with low self esteem use more formal supports ( $r = .36; p < .001$ ).

In addition to presenting a positive correlation between low self esteem and dependence in activities of daily living, Table V-22 indicates that individuals with low self esteem participate less in social and recreational activities ( $r = .24; p < .01$  level) and use more help ( $r = .22; p < .05$ ).

#### USE OF HELP

There are a set of research questions related to use of help.

#### To what extent is the elder's use of help related to vision impairment?

1. Do the most visually impaired people use the most help?  
Correlation was of no statistical significance.

2. Does using help negatively affect self-esteem?

Table V-22 indicates that elders who use the more help have lower self esteem ( $r = .22; p < .05$ ).

3. Does being married increase the likelihood of use of help?

Table V-16 indicates that married people use more help ( $r = .31; p < .01$ ).

4. Does use of help decrease with time since onset?

TABLE V - 15

**ZERO-ORDER CORRELATIONS (Pearson's r) BETWEEN INTERVENING  
VARIABLES AND SELF ESTEEM**

	Pearson's r Self Esteem (a)
<b><u>Social Supports</u></b>	
Informal Extent (b)	-.10
Informal Frequency (c)	-.21*
Formal Extent (d)	.36***
<b><u>Health</u></b>	
Hearing Loss (e)	.12
Medical Problems (f)	.21*
Self-Appraisal (g)	.11
<b><u>Life Events</u> (h)</b>	<b>.02</b>

\*p &lt; .05

\*\*\*p &lt; .001

- (a) High scores reflect lower self esteem  
 (b) High scores reflect greater extent of informal supports  
 (c) High scores reflect greater extent of informal contacts  
 (d) High scores reflect greater extent of formal supports  
 (e) High scores reflect poorer hearing  
 (f) High scores reflect more medical problems  
 (g) High scores reflect poorer self-appraisal  
 (h) High scores reflect greater number of stressful life events

TABLE V - 16

## ZERO-ORDER CORRELATIONS (Pearson's r) BETWEEN INDEPENDENT VARIABLES AND USE OF HELP

	Pearson's r
	Use of Help (a)
<u>Demographic Characteristics</u>	
Age (b)	.00
Gender (c)	.24**
Marital Status	
Married	.31**
Widowed	-.05
Sep./Div.	-.26**
Never Married	-.12
Lives Alone	-.54***
Education (d)	-.02
Income (e)	.01
Ethnicity (f)	-.08
Religion	
Catholic	.07
Protestant	.07
Jewish	-.11
<u>Major Eye Diagnoses</u>	
Macular Degeneration	-.09
Diabetic Retinopathy	.05
Glaucoma	.06
Cataract	-.05
<u>Vision Related Data</u>	
Time since onset (g)	-.07
Sudden onset	-.05
Uncertain onset	.04
Degree of impairment (h)	.02
<u>Prognosis (i)</u>	
Progressive VFR	.02
Slow Progressive	.15
Progressive	.01

\*\*p &lt; .01

\*\*\*p &lt; .001

- (a) High scores reflect greater use of help  
 (b) High scores reflect greater age  
 (c) 2 = male; 1 = female  
 (d) High scores reflect greater education  
 (e) High scores reflect greater income  
 (f) 1 = white; 0 = non-white  
 (g) High scores reflect longer time since onset  
 (h) High scores reflect greater degree of impairment  
 (i) 1 = progressive; 0 = other

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The corresponding correlation was not significant.

There are three hypotheses related to use of help.

H4 Visual impairment will be positively correlated with use of help.

Hypothesis was not confirmed because of no significant findings.

H5 Use of help will be positively related to lower self esteem.

Hypothesis was confirmed. Table V-22 indicates that elders who use more help have lower self esteem.

H6 Use of help will be negatively related to time since onset.

Hypothesis was not confirmed because of no significant findings.

Additionally, there are some unhypothesized correlations between use of help and other variables that are of interest.

Table V-16 indicates that elders who use the most help are male ( $r=.24$ ;  $p < .01$ ) and/or married ( $r=.31$ ;  $p < .01$ ). Elders who use the least help live alone ( $r=-.54$ ;  $p < .001$ ).

Table V-22 indicates that elders who use help are more dependent in activities of daily living ( $r=.34$ ;  $p < .001$ ).



TABLE V-17

ZERO-ORDER CORRELATIONS BETWEEN INTERVENING VARIABLES  
AND USE OF HELP

	Pearson's r
	Use of Help (a)
<u>Social Supports</u>	
Informal Extent (b)	.15
Informal Frequency (c)	.05
Formal Extent (d)	.27**
<u>Health</u>	
Hearing Loss (e)	.02
Medical Problems (f)	.13
Self-Appraisal (g)	.16
<u>Life Events</u> (h)	.02

\*\*p < .01

- (a) High scores reflect greater use of help
- (b) High scores reflect greater extent of informal supports
- (c) High scores reflect greater extent of informal contacts
- (d) High scores reflect greater extent of formal supports
- (e) High scores reflect poorer hearing
- (f) High scores reflect more medical problems
- (g) High scores reflect poorer self-appraisal
- (h) High scores reflect greater number of stressful life events

### SOCIAL AND RECREATIONAL ACTIVITIES

There are a set of research questions and related hypotheses about participation in social and recreational activities.

To what extent is the elder's level of participation in social and recreational activities affected by vision impairment?

1. Are the older people with low participation in activities the most visually impaired?

H7 Visual impairment will be positively related to less participation in social and recreational activities.

Hypothesis confirmed. Table V-18 indicates that elders who are more visually impaired participate less ( $r=.18$ ;  $p<.05$ ).

2. Are the older people with high participation in activities younger, healthier, or more independent in activities of daily living?

Table V-18 indicate a trend toward older individuals participating less ( $r=-.16$ ) but it is not significant.

Table V-19 indicates that elders who participate less are in poorer health. It is correlated with poor hearing ( $r=.16$ ), many medical problems ( $r =.28$ ;  $p <.01$ ) and subjective appraisal ( $r=.29$ ;  $p <.01$ ).

TABLE V - 18

ZERO-ORDER CORRELATIONS (Pearson's r) BETWEEN INDEPENDENT  
VARIABLES AND SOCIAL AND RECREATIONAL ACTIVITIES

	Pearson's r
	Social and Recreational Activities (a)
<u>Demographic Characteristics</u>	
Age (b)	-.16
Gender (c)	-.16
Marital Status	
Married	-.22*
Widowed	.19*
Sep./Div.	.04
Never Married	-.03
Lives Alone	.27**
Education (d)	-.04
Income (e)	-.09
Ethnicity (f)	-.07
Religion	
Catholic	-.08
Protestant	-.20*
Jewish	.19*
<u>Major Eye Diagnoses</u>	
Macular Degeneration	-.21*
Diabetic Retinopathy	.19*
Glaucoma	-.08
Cataract	-.01
<u>Vision Related Data</u>	
Time since onset (g)	.12
Sudden onset	.22*
Uncertain onset	-.20*
Degree of Impairment	.20*
<u>Prognosis (i)</u>	
Progressive VFR	.00
Slow Progressive	.05
Progressive	.02

\*p &lt; .05

\*\*p &lt; .01

- (a) High scores reflect less participation in social and recreational activities  
 (b) High scores reflect greater age  
 (c) 2 = male; 1 = female  
 (d) High scores reflect greater education  
 (e) High scores reflect greater income  
 (f) 1 = white; 0 = non-white  
 (g) High scores reflect longer time since onset  
 (h) High scores reflect greater degree of impairment  
 (i) 1 = progressive; 0 = other

TABLE V - 19

ZERO-ORDER CORRELATIONS (Pearson's r) BETWEEN INTERVENING  
 VARIABLES AND SOCIAL AND RECREATIONAL ACTIVITIES

	Pearson's r Social and Recreational Activities (a)
<u>Social Supports</u>	
Informal Extent (b)	-.09
Informal Frequency (c)	-.14
Formal Extent (d)	.30**
<u>Health</u>	
Hearing Loss (e)	.16
Medical Problems (f)	.28**
Self-Appraisal	.29**
<u>Life Events</u> (h)	.05

\*\*p < .01

- (a) High scores reflect less participation in social and recreational activities  
 (b) High scores reflect greater extent of informal supports  
 (c) High scores reflect greater extent of informal contacts  
 (d) High scores reflect greater extent of formal supports  
 (e) High scores reflect poorer hearing  
 (f) High scores reflect more medical problems  
 (g) High scores reflect poorer self-appraisal  
 (h) High scores reflect greater number of stressful life events

3. Does activity level increase with time since onset of vision impairment?

H8 Participation in social and recreational activities will increase with time since onset.

Hypothesis not confirmed because of no significant findings.

In addition, there were several interesting relationships between social and recreational activities and other variables that were not hypothesized.

In terms of demographics, we observe on Table V-18 that married individuals participate most ( $r=-.22;p<.05$ ) Those who participate least are widowed ( $r=.19<.05$ ) and/or live alone ( $r=.27;p<.01$ ).

In regard to eye diagnoses and vision-related data, Table V-18 indicates that those with Macular Degeneration participate the most ( $r=-.21;p<.05$ ) and those who participate least have Diabetic Retinopathy ( $r=.19;p<.05$ ). Low participation is also correlated with a high degree of impairment ( $r=.20;p<.05$ ).

On Table V-22, are positive correlations between low participation in social and recreational activities and dependence in daily living ( $r=.22;p<.05$ ) and low self esteem ( $r=.24;p<.01$ ).

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### ACTIVITIES OF DAILY LIVING

There are a set of research questions and related hypotheses on activities of daily living.

To what extent is the elder's performance of activities of daily living related to vision impairment?

Is dependence in activities of daily living positively related to visual impairment?

H9 There will be a positive relationship between dependence in activities of daily living and degree of vision impairment.

Table V-20 indicates that the most dependent elders are the most visually impaired ( $r=.18;p<.05$ ).

Does dependence in activities of daily living decrease with time since onset?

H10 Dependence in activities of daily living will increase with time since onset.

Hypothesis not confirmed because of no significant findings.

There were several significant unhypothesized correlations related to dependence in activities of daily living and other variables.

TABLE V - 20

ZERO-ORDER CORRELATIONS (Pearson's r) BETWEEN INDEPENDENT  
VARIABLES AND ACTIVITIES OF DAILY LIVING

	Pearson's r
	Activities of Daily Living (a)
<u>Demographic Characteristics</u>	
Age (b)	.09
Gender (c)	-.30**
Marital Status	
Married	-.24**
Widowed	.18*
Sep.Div.	-.05
Never Married	.10
Lives Alone	.02
Education (d)	.08
Income (e)	-.15
Ethnicity (f)	-.00
Religion	
Catholic	-.04
Protestant	-.03
Jewish	.02
<u>Major Eye Diagnoses</u>	
Macular Degeneration	-.18
Diabetic Retinopathy	.16
Glaucoma	.03
Cataract	.01
<u>Vision Related Data</u>	
Time since onset (g)	.07
Sudden onset	-.11
Uncertain onset	.03
Degree of Impairment (h)	.18*
<u>Prognosis (i)</u>	
Progressive VFR	.07
Slow Progressive	-.16
Progressive	.13

\*p &lt; .05

\*\*p &lt; .01

- (a) High scores reflect greater dependence in activities of daily living
- (b) High scores reflect greater age
- (c) 2 = male; 1 = female
- (d) High scores reflect greater education
- (e) High scores reflect greater income
- (f) 1 = white; 0 = non-white
- (g) High scores reflect longer time since onset
- (h) High scores reflect greater degree of impairment
- (i) 1 = progressive; other = 0

TABLE V - 21

ZERO-ORDER CORRELATIONS (Pearson's r) BETWEEN INTERVENING  
VARIABLES AND ACTIVITIES OF DAILY LIVING

	Pearson's r
Activities of Daily Living (a)	
<u>Social Supports</u>	
Informal Extent (b)	-.02
Informal Frequency (c)	.09
Formal Extent (d)	.43***
<u>Health</u>	
Hearing Loss (e)	.30**
Medical Problems (f)	.35***
Self-Appraisal (g)	.51***
<u>Life Events</u> (h)	.05

\*\* p &lt; .01

\*\*\*p &lt; .001

- (a) High scores reflect greater dependence in activities of daily living  
 (b) High scores reflect greater extent of informal supports  
 (c) High scores reflect greater extent of informal contacts  
 (d) High scores reflect greater extent of formal supports  
 (e) High scores reflect poorer hearing  
 (f) High scores reflect more medical problems  
 (g) High scores reflect poorer self-appraisal  
 (h) High scores reflect greater number of stressful life events



Table V - 22

**ZERO-ORDER CORRELATIONS (PEARSON'S r)  
BETWEEN FOUR ADAPTIVE TASKS**

	Self Esteem (a)	Activities Daily Living (b)	Pearson's r Activities Social/Rec. (c)	Use of Help (d)
Self Esteem	_____			
Activities of Daily Living	.26**	_____		
Activities Soc/Rec.	.24**	.22*	_____	
Use of Help	.22*	.34***	.10	_____

\*p < .05                      \*\*p < .01                      \*\*\*p < .001

(a) High scores reflect lower self esteem

(b) High scores reflect greater dependence in activities of daily living

(c) High scores reflect less participation in social and recreational activities

(d) High scores reflect greater use of help.

Table V-20 indicates that the most independent elders are married ( $r=-.24;p <.01$ ) and/or male ( $r=.30;p<.01$ ). The most dependent elders are widows ( $r=.18;p<.05$ ).

Table V-20 indicates that individuals with Macular Degeneration are less dependent ( $r=-.18;p<.05$ ).

Table V-21 indicates that elders who are dependent use more formal supports ( $r=.43;<.001$ ).

Table V-21 indicates that individuals who are dependent are in poorer health have poorer hearing ( $r=.30;p<.01$ ), with more medical problems ( $r=.35;p<.001$ ) and poorer self appraisal ( $r=.51;p<.001$ ).

Table V-22 indicates that dependent individuals have poorer self esteem ( $r=.26;p<.01$ ), less participation in social and recreational activities ( $r=.22;p<.05$ ) and use more help ( $r=.34;p<.001$ ).

#### UNDERSTANDING OF LOSS

Understanding of Loss, the fifth adaptive task, proved difficult to analyze on the basis of the data collected. The difficulties were both conceptual and methodological. In designing the questions to test this variable, I had been guided by two assumptions; neither of which proved to be the case.

First, I had assumed that the prognoses given could be categorized in three ways (Improvement, Stability, Deterioration)

TABLE V-23

## UNDERSTANDING OF LOSS

	Frequency (n)	Percent (%)
Not matched (a)	61	70.9
Better/Could improve (b)	1	1.2
No change/Stable (c)	1	1.2
Worse/Progressive (d)	23	26.7
	<u>86</u>	<u>100.0</u>

- (a) No agreement between self-reported expectation of change and clinical prognosis
- (b,c,d) Agreement between self-reported expectation of change and clinical prognosis

which could then be matched with the respondent's expectation of change (Do you expect changes to occur in your vision? If yes, do you expect that it will get better or get worse?) My misapprehension about the nature of clinical prognoses in the Low Vision Clinic was based on the fact that prognoses are not routinely made (much less recorded in the chart). At the outset of the study, I had asked the Director of the clinic how I could get this information. At first, she said it was impossible; then conceded that she could look at the chart of each respondent in the study and come up with a prognosis based on the eye disease, its course to date, and coexisting eye conditions. What she did not volunteer (and I did not think to ask) was that a vast majority of the older patients of the Low Vision Clinic have a progressive disorder. As Table IV-1 indicates, 88.6% of the sample had a prognosis of deterioration (Progressive = 77.9, Slowly Progressive = 4.7, Progressive Visual Field Reduced = 7.0). Thus, there was very little variation on clinical prognoses to work with.

My second erroneous assumption was that there would be internal consistency among the answers to open-ended "attitude" questions and that a scale of these could then be correlated with clinical prognoses and respondents' expectation of change respectively. However, the alpha on the proposed scale was so low as to be unusable. Therefore, while individual "attitude" items summarized on Table IV-5 are interesting in a descriptive and exploratory sense they were of no value in the bi-variate

analysis.

My effort to salvage what I could of the dependent variable Understanding of Loss in the bi-variate analysis is presented on Tables V-23 through V-26.

On Table V-23, entitled Understanding of Loss, respondent expectations of change and clinical prognoses are compared. The 61 respondents in the not matched category had expectations that differed from their prognoses. The remaining 25 respondents had expectations that agreed with their prognoses. This, then, became my definition of the dependent variable Understanding of loss. While the definition is based on only one indicator, and caution must be taken not to assign it too much power, some interesting findings did ensue.

The demographic and eye characteristics of the 25 respondents whose expectations of change match their prognoses are presented on Table V-24. While there are no strong correlations with eye data, some demographic relationships do emerge. Not surprisingly, higher education is positively correlated with understanding ( $r=.18; p < .05$ ). Understanding is also positively correlated with living alone ( $r=.26; p < .01$ ) and white ethnicity ( $r=.22$ ). It is negatively correlated with being male ( $r=-.24; p < .01$ ) and being married ( $r=-.20; p < .05$ ). Thus, better educated white women who live alone emerge as a group most likely to understand their eye prognoses.

Table V-25 presents bi-variate correlations between Understanding of Loss and the three intervening variables: social

Table V - 24

ZERO-ORDER CORRELATIONS (Pearson's r) BETWEEN UNDERSTANDING OF  
LOSS AND INDEPENDENT VARIABLES

	Pearson's r Understanding of Loss (a)
<u>Demographic Characteristics</u>	
Age (b)	-.06
Gender (c)	-.24**
Ethnicity (d)	.22*
Catholic	-.04
Protestant	.09
Jewish	-.00
Lives Alone	.26**
Income (e)	-.12
Education (f)	.18*
Married	-.20*
<u>Major Eye Diagnoses</u>	
Macular Degeneration	.08
Diabetic Retinopathy	.08
Glaucoma	-.14
Cataract	.06
<u>Vision Related Data</u>	
Time since Onset (g)	.00
Type of Onset (h)	
Sudden	.05
Unclear	.05
Degree of Impairment (i)	-.11
<u>Prognosis (j)</u>	
Progressive VFR	-.10
Slow Progressive	.10
Progressive	.04

\*p &lt; .05

\*\*p &lt; .01

- (a) Agreement between self-reported expectation of change and clinical prognosis  
 (b) High scores reflect greater age  
 (c) 2 = male; 1 = female  
 (d) 1 = white; 0 = non-white  
 (e) High scores reflect greater income  
 (f) High scores reflect greater education  
 (g) High scores reflect self-reported longer time since onset  
 (h) Self-reported type of onset  
 (i) High scores reflect self-reported greater degree of impairment  
 (j) 1 = progressive; 0 = other

Table V - 25

ZERO-ORDER CORRELATIONS (Pearson's r) BETWEEN UNDERSTANDING OF LOSS AND SOCIAL SUPPORTS, HEALTH, AND CO-EXISTING LIFE EVENTS

	Pearson's r Understanding Of Loss (a)
<u>Social Supports</u>	
Informal Extent (b)	-.20*
Informal Frequency (c)	-.20*
Formal Extent (d)	-.04
<u>Health</u>	
Hearing Loss (e)	.04
Medical Problems (f)	.25**
Self-Appraisal (g)	.06
Life Events (h)	-.16

\*p &lt; .05

\*\*p &lt; .01

- (a) Agreement between self-reported expectation of change and clinical prognosis
- (b) High scores reflect greater extent of informal supports
- (c) High scores reflect greater frequency of informal contacts
- (d) High scores reflect greater extent of formal supports
- (e) High scores reflect poorer hearing
- (f) High scores reflect more problems
- (g) Health III involves subjective appraisal. High scores reflect poorer appraisal
- (h) High scores reflect greater number of stressful life events

Table V - 26

ZERO-ORDER CORRELATIONS--(PEARSON'S r)--BETWEEN UNDERSTANDING OF  
LOSS AND FOUR ADAPTIVE TASKS

	Pearson's r Understanding of Loss (a)
Self Esteem (b)	.33***
Activities of Daily Living (c)	-.10
Social/Recreational Activities (d)	-.01
Use of Help (e)	-.10

\*\*\*p < .001

- (a) Agreement between self-reported expectation of change and clinical prognosis
- (b) High scores reflect lower self esteem
- (c) High scores reflect greater dependence in activities of daily living
- (d) High scores reflect less participation in social and recreational activities
- (e) High scores reflect greater use of help



supports, health, and co-existing life events. The one positive correlation is with medical problems ( $r=.25$ ;  $p < .01$ ). That is to say, individuals who have many medical problems are more likely to understand that their eye condition will worsen. It may be hypothesized that those who are currently ill are more likely to have a pessimistic view of the future and that this attitude may not have much to do with understanding vision loss at all! This view is upheld by the negative correlations of matching with informal social supports (informal extent  $r=-.20$ ;  $p < .05$ ) (informal frequency  $r = -.20$ ;  $p < .05$ ) and co-existing life events ( $r=-.16$ ). Having fewer informal supports and more stressful life events could also contribute to pessimism about the future.

Table V-26 presents the bi-variate correlations between understanding of loss and four additional adaptive tasks. Here we see that understanding of prognosis is positively and significantly correlated with self-esteem ( $r=.33$ ;  $p < .001$ ).

### Summary/Discussion of bi-Variate Correlations of Dependent Variables

#### Self Esteem

In a society that prizes good health, independence and activity, it is not surprising that low self esteem is most importantly correlated with dependence and non activity. In

other words, those who are unwell, dependent in activities of daily living, who use a lot of help, who rely on formal supports and who have a low level of participation in social and recreational activities have the lowest self esteem.

Advanced age, widowhood, infrequent contact with informal supports, a high degree of vision impairment, and a shorter time since onset also contribute to low self esteem.

Thus, although theorists of adaptation posit that maintenance or restoration of self-esteem is an essential component of adaptation, we see that in the case of the visually impaired elderly there are many deterrents. At the same time, being married, having contact with family and friends, and not understanding one's vision loss may contribute to good self esteem.

#### Use of Help

It is not surprising that married people use a great deal of help and those who live alone use the least. The use of help is just as often related to its availability as to the need for it. Men are more likely to use help because they are married and/or of a cohort that relies on women to "do" for them irregardless of whether they can do for themselves.

As easy to understand is the fact that those who use the most help also rely most on the formal system. Spouses and other members of the informal system are limited in the amount and kind of help they can provide.

More surprisingly, health, eye diagnoses and vision related factors appear to have little to do with use of help. At the same time, use of help is positively and significantly correlated with dependence in activities of daily living while showing only a small positive correlation with less participation in social and recreational activities. This adds to the conclusion that use of help has more to do with functional or social reasons than with illness or vision impairment per se. This would appear to uphold the theorists on adaptation who maintain that "appropriateness" is the criterion for an adaptive use of help.

#### Social and Recreational Activities

As might be expected, a low participation in social and recreational activity is associated with many medical problems, dependence in activities of daily living, and impairments of sight and hearing.

Low participators are also more likely to live alone and rely heavily on formal supports.

Contrary to what might be expected, advanced age was not positively correlated with low participation. Thus, it would appear that elders' social and recreational participation is continued as long as health and functional capacity allow.

As to eye data, sudden onset was related to low participation while a longer time since onset was related to low participation. It is understandable that a sudden onset might precipitate a withdrawal from social and recreational activities

sooner than an uncertain or gradual onset, and also that the longer time the individual lives with the visual impairment the less likely he is to participate.

Again, theorists who posit a balance between continuity and change in social and recreational activities as an essential task of adaptation are upheld. Viewed in conjunction with Table IV-6 and IV-7, the bi-variate correlations suggest that visually impaired elders do maintain a balance in keeping with their waning abilities and remaining resources.

#### Activities of Daily Living

The bi-variate correlations on activities of daily living yield no surprises. Poor health, a greater degree of vision impairment, a longer time since onset and more use of the formal system are noted for more dependent respondents. Again, we see that age is not, in itself, a predictor of dependence but rather the conditions accompanying it. There is repeated confirmation that married elders and men are in an advantageous status as to adaptation, in that they comprise the most independent respondents (because of and as well as having fewer medical problems) even though their vision is not necessarily better.

The reasons for a positive relationship between dependence in activities of daily living and lower self esteem, lower participation in social and recreational activities and greater use of help are self evident.

Viewed in conjunction with Tables IV-4, the theorists on modification of daily schedule as being an adaptive task are essentially upheld; those who are dependent have good cause for being so in that their physical abilities are limited. In other words, we do not see cases of "excess disability" in the respondent population.

#### Understanding of Loss

Understanding of loss, as measured by the matching of expectations of change with clinical prognosis, is more likely to occur in higher educated, white, female, respondents and those who live alone. Poor health and stressful life events are also positive correlates with understanding of loss. (Since most respondents believe their condition will worsen, agreement could have as much to do with pessimism as with true understanding).

Respondents who are less likely to understand their loss are those who are married and those who have low informal supports; a contradictory and not easily explicable finding. One conjecture is that married individuals may be involved in a mutual denial. Another is that if given, the prognosis (which in the match is scored deviantly) may have been told to the spouse rather than to the patient himself. Low informal supports may mean a lack of opportunity for reality testing and also enhance denial.

The theory on whether understanding of loss is a necessary adaptive task is mixed - and the bi-variate correlations of this study uphold the sense of complexity in this measure. Since

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understanding of loss is positively and significantly correlated with low self esteem, has little to do with the accomplishment of other adaptive tasks, and occurs in those respondents who have poorer health, fewer supports, and greater stress, it may well be that ignorance, if not bliss, may yet fill an adaptive function.

CHAPTER VI  
FINDINGS III: THE MULTIVARIATE ANALYSIS

OVERVIEW

Chapter V reviewed and analyzed the bi-variate correlations of this study on age-related vision loss; the relationships between independent and intervening variables and the five adaptive tasks that comprise the dependent variables. While many research questions were responded to, and hypotheses tested, it remained to be seen what predictors could be identified for adaptive task accomplishment.

In this chapter, the results of the multiple regression analyses are presented and discussed. A hierarchical, rather than a stepwise, model was employed in this analysis. The hierarchical model was used in light of the considerable theory and data that already exists about the tasks in question and the belief that, in such an instance, the use of a stepwise analysis would not be justified.

Two criteria were used for selecting the variables to be entered in the regression equation. The first criterion was theoretical; thus, variables were primarily chosen because of their conceptual relationship to the adaptive task in question. The second criterion was statistical; variables showing a significant bivariate relationship with the adaptive task were selected.

Variables were entered in the order of their conceptual

relevance. Redundancies were removed and care was taken that input variables were not highly inter-correlated thus leading to an incorrect analysis.

Since one of the purposes of the study is to determine whether age or time since onset make a difference in adaptive task accomplishment, these variables appear in each regression; the location based on the degree of importance they appear to have for task in question. It should be noted at this time that age and time since onset are moderately related ( $r=-.31$ ) with older respondents having the shorter time since onset.

Four of the five adaptive tasks were chosen for multiple regression analysis: self esteem, use of help, social and recreational activities and activities of daily living. As noted in Chapter V, understanding of loss (the fifth adaptive task) was based on a single measure. While there was some heuristic value in using it for the bi-variate analysis, it did not appear of sufficient consequence to submit to multiple regression analysis.

This chapter is divided into four sections; one for each adaptive task. Each section contains three tables: zero-order coefficients of predictor variables, a correlation matrix of the predictor variables, and a hierarchical multiple regression analysis.

While there is redundancy between the first two tables of each section, both appear in order to present statistical significance with the criterion variable as well as correlations



among the predictor variables. Since most of the information on these tables summarizes relationships already discussed in Chapter V, discussion is limited to variables not already addressed.

The chapter concludes with a summary/discussion of the findings on all four dependent variables.

### SELF ESTEEM

Tables VI-1 to VI-3 present findings on Self Esteem.

Two predictor variables were not discussed in Chapter V but included here because of their conceptual link with self esteem. They are: "employed last 10 years" and "lives with spouse".

It was posited that individuals who have not been employed for over 10 years might feel less productive and thus have lower self esteem and a statistically significant correlation was found ( $r=.20$ ;  $p < .05$ ).

"Lives with spouse" was chosen rather than marital status for three reasons. A few respondents who said they were married did not have a spouse in the household (sometimes because of nursing home placement, or perhaps because they prefer not to report themselves as separated). Other respondents who are married and have a spouse in the household also share their living arrangement with other individuals (most often adult children). Most importantly, "lives with spouse" is a living arrangement rather than a marital status and as such it eliminates all those who do not live alone with spouses, whatever

TABLE VI-1

~~ZERO-ORDER CORRELATION COEFFICIENTS OF PREDICTOR VARIABLES  
AND SELF ESTEEM~~

---

<u>Predictor Variables</u>	<u>Self Esteem (a)</u>
Activities of Daily Living (b)	.26**
Medical Problems (c)	.21*
Income (d)	-.15
Degree of Vision Impairment (e)	.10
Age (f)	.19*
Time since Onset (g)	-.12
Social/Recreational Activities (h)	.24**
Employed last 10 years	.20*
Education (i)	.02
Lives with Spouse (j)	-.19*
Total Informal Support (k)	-.17*
Use of Help (l)	.22*

---

\*p &lt; .05

\*\*p &lt; .01

- (a) High scores reflect lower self esteem
- (b) High scores reflect greater dependence in activities of daily living
- (c) High scores reflect more medical problems
- (d) High scores reflect greater income
- (e) High scores reflect greater degree of impairment
- (f) High scores reflect greater age
- (g) High scores reflect longer time since onset
- (h) High scores reflect less participation in social and recreational activities
- (i) High scores reflect greater education
- (j) Lives alone with spouse.
- (k) High scores reflect greater extent and frequency of contact with informal supports.
- (l) High scores reflect greater use of help

TABLE VI - 2  
 CORRELATION MATRIX OF PREDICTOR VARIABLES: SELF ESTEEM

	TADL	Med probs	Income	Deg of Impair	Age	Time Since Onset	Soc/Rec Activities	Empl 10 yrs	Educ	Lives w Spouse	T Inf.	Help
TADL	--											
Medical probs	.35	--										
Income	-.15	-.13	--									
Deg of Impair	.18	-.09	.03	--								
Age	.09	-.21	.40	.18	--							
Time Since Onset	.07	-.04	-.00	.10	-.31	--						
Soc/Rec Activities	.22	-.28	-.09	.20	-.16	.12	--					
Employed last 10 yrs	.24	-.10	.39	.32	-.41	-.01	-.04	--				
Education	.08	.00	-.11	-.11	-.08	-.05	-.04	-.04	--			
Lives w Spouse	-.22	-.20	.13	-.07	.06	-.04	-.21	-.04	-.02	--		
T Informal	.05	-.17	.22	.15	-.02	-.02	-.14	.10	-.24	.23	--	
Help	.34	.13	.01	.02	.00	-.07	.10	.15	-.02	.30	.11	--

TABLE VI-3

## HIERARCHICAL MULTIPLE REGRESSION ANALYSIS FOR SELF ESTEEM AS CRITERION

Step	Variable	Multiple R	RSq.	RSq. Chg.	FChg.	Beta
1	Activities of Daily Living	.26	.07	.07	5.94*	.26
2	Medical Problems	.29	.08	.02	1.52	.14
3	Income	.31	.09	.01	.97	-.11
4	Deg. of Impairment	.32	.10	.01	.66	.09
5	Age	.35	.12	.02	1.94	.15
6	Time since Onset	.37	.13	.01	1.06	-.11
7	Social/Rec. Activities	.41	.17	.03	3.08	.20
8	Employed last 10 years	.43	.18	.02	1.52	.15
9	Education	.43	.18	.00	.02	-.01
10	Lives with Spouse	.44	.19	.00	.80	-.10
11	Total Informal Support	.45	.21	.01	1.30	-.14
12	Use of Help	.49	.24	.03	3.08	.22

\*p &lt; .05

the reason.

It was posited that living alone with one's spouse is the the more socially valued living arrangement in late life and that these respondents might have significantly higher self esteem. In this study, low self esteem is negatively and significantly correlated with "living with spouse" ( $r=-.19$ ;  $p < .05$ ).

Table VI-2 presents the correlation matrix of predictor variables for self esteem. All of the correlations of lives with spouse are of valued social attributes with the exception of a small positive correlation with greater age ( $r=.06$ ) and a small negative correlation with greater education ( $-.02$ ). Also, as expected, those who have not been employed during the last 10 years are the oldest ( $r=.41$ ), and those with the highest income ( $r=.39$ ). The most interesting finding about those who have not been employed is that they have a higher degree of vision impairment ( $r=.32$ ) but not of medical problems ( $r=-.10$ ).

The variables on Table VI-1 and TVI-2 were entered into a regression equation with self esteem as the criterion. Table VI-3 presents the results of this analysis. As can be seen, dependence in activities of daily living emerged as the only significant predictor of low self esteem, accounting for 7 percent of the variance. More medical problems, lower income, and greater degree of impairment each account for only 1 percent of the variance. An additional 3% of the variance is accounted for by the combination of age and time since onset. The largest incremental increase in variance is of 4% with the addition of

low participation in social and recreational activities. Lack of employment in the past 10 years adds only 1%, education adds nothing at all, and living with spouse another 1%. The second largest incremental increases in variance are of 3% with the addition of total informal support and use of help.

This model yields a multiple R of .49 accounting for 24% of the variance in self esteem.

These findings suggest that there are a wide range of variables that affect self esteem in the visually impaired elderly and that, with the exception of dependence in activities of daily living, no one of these emerges as a clear predictor. This is understandable according to many theories of development (i.e. Erikson, 1963) which hold that one's self image and self esteem is formed early in life and generally remains consistent across the life span. Moreover, although society at large holds the position of some attributes (such as good income and greater education) to be desirable, there are individual, class, and cultural differences in the importance ascribed to these. At the same time, dependence on someone else to perform tasks once performed independently is a developmental regression that can be expected to lower self esteem for almost all individuals.

#### USE OF HELP

Tables VI-4 to VI-6 present findings on "Use of Help".

Table VI-4 presents the zero-order correlations. With the exception of "Activities of Daily Living difficult due to Vision

TABLE VI-4

ZERO-ORDER CORRELATION COEFFICIENTS OF PREDICTOR VARIABLES AND  
USE OF HELP

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<u>Predictor Variables</u>	<u>Use of Help (a)</u>
Activities of Daily Living Difficult Vision Loss (b)	.29**
Medical Problems (c)	.13
Lives with Spouse (d)	.30**
Formal Extent (e)	.27**
Age (f)	.00
Time since Onset (g)	-.07
Degree of Impairment (h)	.02

---

\*p &lt; .05

\*\*p &lt; .01

- (a) High score reflects greater use of help  
 (b) High score reflects more activities of daily living  
 difficult because of vision loss  
 (c) High score reflects more medical problems  
 (d) Lives alone with spouse  
 (e) High score reflects greater extent of formal supports  
 (f) High score reflects greater age  
 (g) High score reflects longer time since onset  
 (h) High score reflects greater degree of impairment

TABLE VI - 5  
CORRELATION MATRIX OF PREDICTOR VARIABLES: USE OF HELP

	TADL Diff VL 2	Medl Probs	W spouse	Formal Supp	Age	Time Since Onset	Deg of Impair
TADL diff VL	--						
Medl Probs	.26	--					
Lives w Spouse Supp 2	-.11	-.20	--				
Formal Extent	.34	.26	-.27	--			
Age	.08	-.21	.06	.04	--		
Time Since Onset	.21	.04	-.04	.02	-.31	--	
Deg of Impair	.29	-.09	-.07	-.03	.04	.02	--



TABLE VI-6

## HIERARCHICAL MULTIPLE REGRESSION ANALYSIS FOR USE OF HELP AS CRITERION

Step	Variable	Multiple R	RSq.	RSq.Chg	FChg	Beta
1	Activities of Daily Living Difficult/VL	.29	.08	.08	7.51***	.29
2	Medical Problems	.29	.09	.00	.32	.06
3	Lives with Spouse	.45	.21	.12	12.52***	.36
4	Formal Extent	.53	.28	.07	7.76**	.29
5	Age	.53	.28	.00	.42	-.06
6	Time since Onset	.55	.30	.02	1.93	-.14
7	Deg. of Impairment	.55	.30	.00	.03	.02

\*\*p &lt; .01

\*\*\*p &lt; .001

Loss" and "Lives with Spouse", all of the predictor variables and their correlations were discussed in Chapter V.

"Activities of Daily Living Difficult/VL" was entered as the first variable for two reasons. First, because it has conceptual relevance to a central research question of the study; that is, to what extent is vision loss an independent contributor to adaptive task performance. Second, because of its positive and significant correlation with use of help ( $r=.29$ ;  $p < .01$ ).

Lives with spouse emerges as highly and significantly correlated with use of help ( $r=.30$ ;  $p < .01$ ). As noted in Chapter V, married people and men have a greater use of help and it can be posited that this has less to do with physical need than with marital roles and expectations.

Table VI-5 presents the correlation matrix of all variables. Activities of Daily Living/Difficult VL is positively correlated with more health problems ( $r=.26$ ), extent of formal supports ( $r=.34$ ), longer time since onset ( $r=.21$ , and greater degree of impairment ( $r=.29$ ). The only other relationship not noted in Chapter V is the negative correlation between lives with spouse and extent of formal supports ( $r=-.27$ )

The variables on Tables VI-4 and VI-5 were entered into the regression equation with use of help as the criterion. Table VI-6 presents the results of this analysis. As can be seen, Activities of Daily Living Difficult/VL is a strong significant predictor of use of help accounting for 8% of the variance. While medical problems adds only 1% to the variance, an

additional 11% of the variance is accounted for because of living with spouse, the second significant predictor. The third and last significant predictor of use of help is the extent of formal supports contributing 7% to the variance. Age, time since onset, and degree of impairment together explain only 2% more of the variance. The model yields a multiple R of .55 accounting for 30% of the variance in use of help.

These findings suggest that the consequence of vision loss are better predictors of use of help than the degree of impairment per se. They also suggests that the availability of help (living with spouse) may be as important a predictor of the use of help as the actual need for assistance. Finally, age and time since onset appear to have little to do with the performance of the adaptive task, use of help.

#### SOCIAL/RECREATIONAL ACTIVITIES

Tables VI-7 to VI-10 present findings on Social/Recreational Activities.

All of the predictor variables presented on Table VI-7 are discussed in Chapter V; with one difference. In Chapter V, Activities of Daily Living consists of the total scale; that is, instrumental and personal activities of daily living are combined. This makes obvious sense when we are looking at activities of daily living as an adaptive task. However, conceptually it seemed that when we are looking at activities of daily living as a predictor of participation in social and

TABLE VI-7

ZERO-ORDER CORRELATION COEFFICIENTS OF PREDICTOR VARIABLES  
AND SOCIAL/RECREATIONAL ACTIVITIES

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<u>Predictor Variables</u>	<u>Social/Recreational Activities (a)</u>
Instrumental Activities of Daily Living (b)	.22*
Personal Activities of Daily Living (c)	.20*
Medical Problems (d)	.28**
Sudden Onset	.22*
Degree of Impairment (e)	.20*
Self Esteem (f)	.24*
Age (g)	-.16
Time since Onset (h)	.12

---

\*p &lt; .05

\*\*p &lt; .01

- (a) High score reflects low participation in social/recreational activities
- (b) High score reflects greater dependence in instrumental activities of daily living
- (c) High score reflects greater dependence in personal activities of daily living
- (d) High score reflects more medical problems
- (e) High score reflects greater degree of impairment
- (f) High score reflects lower self esteem
- (g) High score reflects greater age
- (h) High score reflects longer time since onset

TABLE VI - 8  
CORRELATION MATRIX OF PREDICTORS VARIABLES:  
SOCIAL & RECREATIONAL ACTIVITIES

	INST. ADL	PERS ADL	MEDL -PROBS	Sudd Onset	Deg of Impairment	Self Esteem	Age	Time Since Onset
Inst ADL	--							
Pers. ADL	.84	--						
Medl probs	.35	.34	--					
Sudd Onset	-.09	-.14	-.10	--				
Deg of Impairment	-.19	.15	-.09	-.07	--			
Self Esteem	.26	.26	.21	.11	.10	--		
Age	.08	.08	-.21	-.20	.18	.19	--	
Time Since Onset	.03	.15	.04	-.14	.10	-.12	-.31	--

TABLE VI-9

HIERACHICAL MULTIPLE REGRESSION ANALYSIS  
FOR SOCIAL/RECREATIONAL ACTIVITIES AS CRITERION I

Step	Variable	Multiple R	RSq.	RSq.Chg	FChg	Beta
1	Instrumental ADL	.22	.05	.05	4.36*	.22
2	Personal ADL	.22	.05	.00	.03	.03
3	Medical Problems	.31	.10	.05	4.19*	.23
4	Sudden Onset	.38	.14	.05	4.42*	.22
5	Deg. of Impairment	.42	.18	.03	3.20	.19
6	Self Esteem	.44	.19	.01	1.45	.13
7	Age	.48	.23	.04	3.68	-.21
8	Time since Onset	.48	.23	.00	.57	.08

\*p < .05

recreational activities, it would be useful to see if one type of dependence (instrumental or personal activities) emerged as a more significant predictor.

As reflected on Table VI-8, the extremely high correlation of both ADL measures ( $r = .84$ ) renders the distinction of limited value. On the other hand, there are real differences in some vision-related data. For example, dependence in instrumental activities of daily living is less positively correlated ( $r = .03$ ) with a long time since onset than is dependence in personal activities ( $r = .15$ ).

There are smaller but still interesting differences between the two measures, type of onset and degree of impairment. That is to say, dependence in instrumental activities of daily living is negatively correlated with sudden onset ( $r = -.09$ ) and positively correlated with degree of impairment ( $r = .19$ ). While the direction of the correlation is the same for dependence in personal activities of daily living it is greater for sudden onset ( $r = -.14$ ) and smaller for degree of impairment ( $r = .15$ ).

In short, although the two measures are highly correlated they were entered separately in the multi-variate analysis.

All variables on Tables VI-7 and VI-8 were entered into the regression equation with participation in social and recreational activities as the criterion. Table VI-9 presents the results of this analysis. As can be seen, dependence in instrumental activities of daily living and in personal activities of daily living each contribute half, or 5%, of the 10% variance

attributed to activities of daily living. Combined with medical problems, that account for an additional 10%, 20% of the overall 23% of the variance is explained. Again, we see that age and time since onset do not add significantly to the variance. The model yields a Multiple R of .48, accounting for 23% of the variance in social and recreational participation.

These findings reflect that there are three statistically significant predictors of low participation: dependence in activities of daily living, more medical problems, and a sudden onset of vision loss.

After considering the multiple regression findings on Table VI-9, I decided to run a second analysis substituting "activities of daily living difficult because of vision loss" for "dependence in instrumental and personal activities of daily living". The purpose of this was to discover whether the cause of dependence in activities of daily living (vision loss) could explain as much of the variance as its result (the dependence itself).

Table VI-10 presents the results of this analysis. As can be seen, Activities of Daily Living Difficult because of Vision Loss, is a highly significant predictor of lack of participation in social and recreational activities, accounting for 9% of the variance. Together with medical problems, it accounts for 21% of the overall variance of 26%. Sudden onset is a more significant predictor in this analysis, independently contributing an additional 7% of the variance (as opposed to 4% on Table VI-9). This model yields a Multiple R of .51 accounting for 26%



TABLE VI-10

HIERACHICAL MULTIPLE REGRESSION ANALYSIS FOR SOCIAL/RECREATIONAL  
ACTIVITIES AS CRITERION II

Step Variable	Multiple R	RSq.	RSq.Chg	FChg	Beta
1 Activities of Daily Living Difficult/VL	.29	.09	.09	7.95***	.29
2 Medical Problems	.36	.13	.04	4.25*	.22
3 Sudden Onset	.44	.20	.06	6.56**	.26
4 Deg. of Impairment	.46	.21	.01	1.56	.13
5 Self Esteem	.47	.22	.01	.97	.10
6 Age	.50	.25	.03	3.68	-.20
7 Time since Onset	.51	.26	.00	.22	.05

\*p &lt; .05

\*\*p &lt; .01

\*\*\*p &lt; .001

of the variance in social and recreational participation.

The findings on Tables VI-9 and VI-10 suggest that the cause of dependence in activities of daily living (vision loss) is as important an indicator of level of participation in social and recreational activities as the dependence itself. Thus, in predicting social and recreational participation it may be as important to find out the cause of elder dependence as the result. Further, a sudden onset of vision loss may result in less participation as the elder must cope with a crisis rather than gradually accommodating over time.

As noted in the previous multiple regressions, age and time since onset do not contribute much incrementally to variance and this contribution is not significant.

#### ACTIVITIES OF DAILY LIVING

Tables VI-11 to VI-13 present findings on Activities of Daily Living.

Only one predictor variable, "lives with spouse", was not discussed in Chapter V but included here because of its conceptual link with activities of daily living.

I anticipated that elders who lived alone with spouses were more independent in activities of daily living. Table VI-11 illustrates that this is indeed the case ( $r = -.22$ ;  $p < .05$ ). The correlation matrix on Table VI-12 reflects a moderate negative correlation with being widowed ( $r = -.50$ ). This is a self evident

TABLE VI-11

ZERO-ORDER CORRELATION COEFFICIENTS OF PREDICTOR VARIABLES  
AND ACTIVITIES OF DAILY LIVING

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<u>Predictor Variables</u>	<u>Activities of Daily Living (a)</u>
Medical Problems (b)	.35**
Hearing (c)	.30**
Lives w Spouse (d)	-.22*
Widowed	.18*
Age (e)	.09*
Time since Onset (f)	.07
Deg. of Impairment (g)	.18*

---

\*p &lt; .05

\*\*p &lt; .01

- (a) High score reflects greater dependence in activities of daily living  
 (b) High score reflects more health problems  
 (c) High score reflects poorer hearing  
 (d) Lives alone with spouse  
 (e) High score reflects greater age  
 (f) High score reflects longer time since onset  
 (g) High score reflects greater degree of impairment

TABLE VI - 12  
CORRELATION MATRIX OF PREDICTOR VARIABLES:  
ACTIVITIES OF DAILY LIVING

	Medl probs	Hearing	Lives w Spouse	Wid	Age	Time Onset	Deg Impair
Medl probs	--						
Hearing	.47	--					
Lives w Spouse	-.20	-.14	--				
Widowed	.14	.11	-.50	--			
Age	-.21	-.02	.06	.28	--		
Time s Onset	.04	-.00	-.04	-.14	-.31	--	
Deg of Impair	-.09	-.07	-.07	.05	.18	.10	--

TABLE VI-13

HIERACHICAL MULTIPLE REGRESSION ANALYSIS  
FOR ACTIVITIES OF DAILY LIVING AS CRITERION

Step	Variable Name	Multiple R	Rsq	Rsq Chg	F Chg	Beta
1	Medical Problems	.35	.13	.13	12.06**	.35
2	Hearing	.38	.15	.02	2.11	.17
3	Lives w/Spouse	.41	.17	.02	2.03	-.15
4	Widowed	.41	.17	.00	.41	.08
5	Age	.46	.21	.04	3.55	.20
6	Time since Onset	.47	.22	.01	1.23	.12
7	Deg. of Impairment.	.49	.24	.02	2.51	.16

\*\*p < .01

relationship; widowed individuals have no spouses with whom to live. And, as noted on Table III-2, widowed individuals comprise 32.5% of the respondent population.

Another noteworthy relationship on Table VI-12 is the positive correlation between poor hearing and more health problems ( $r=.47$ ).

The variables on Tables VI-11 and VI-12 were entered into the regression equation with activities of daily living as the criterion. Table VI-13 presents the results of this analysis. As can be seen, medical problems are the only significant predictor of dependence in activities of daily living, accounting for 13% (over half of the overall variance). Additional variables add no more than 2% incrementally, with the exception of a combination of age and time that together contribute 5% to the variance. The model yields a Multiple R of .49, accounting for 24% of the variance in activities of daily living.

The surprising aspect of these findings is not that medical and vision problems add as much to the variance as they do, but that they do not add more. The most likely explanation is that a lower energy level and diminished functional ability may not necessarily be related to a specific health problem in old age. Looking back at the bi-variate correlations discussed in Chapter VI, there are two significant correlations that were purposefully not included in the multiple regression were self-appraisal ( $r=.51$ ;  $p < .001$ ) and formal extent ( $r=.30$ ;  $p < .01$ ). These were excluded because they appeared to be a result of dependence in

activities of daily living rather than a predictor of it.

#### Summary/Discussion of Multivariate Analysis

The purpose of this chapter was to present the results of the multiple regression analyses and to identify the most salient predictors of adaptive task performance. The regression models were "successful" in that 24% to 30% of the variance was explained for each adaptive task. However, they were unsuccessful in the sense that they could not generate a profile of those visually impaired elders most likely to perform well, or poorly, on adaptive tasks. That is to say, no more than three - and often only one - significant predictor emerged per task.

However a few conclusions can be drawn.

First, it is clear that age and time since onset are not significant predictors of adaptive task performance in age-related vision loss.

Second, it is clear that medical problems and dependence in activities of daily living (especially due to vision loss) have significant consequences for the performance of all adaptive tasks.

Third, the adaptive tasks themselves are not of equal complexity nor are they truly comparable. For example, use of help, participation in social and recreational activities, and activities of daily living measure physical performance while self esteem is a personality trait.

Fourth, while the scales developed to measure the four adaptive tasks lead to a beginning understanding, they did not prove to be

sufficient to handle the complexity of the task of operationalizing the theoretical constructs of adaptation.

The findings of each multiple regression analysis will be briefly summarized here along with ideas of what could be improved upon.

### Self Esteem

Twenty-four percent of the variance was explained using 12 variables in the equation. The only significant predictor of low self esteem was dependence in activities of daily living.

As suggested earlier in the chapter, self esteem is dependent to a large measure on those values of society with which one identifies. (Lack of education may occasion low self esteem in one elder and matter little to another). It is also a trait with roots early in the life span. While dependence in activities of daily living is a developmental regression that could be a blow to almost everyone's self esteem, the heterogeneity of the respondents suggests that questions about values and beliefs should accompany a self-esteem scale for the most productive inquiry.

### Use of Help

Thirty per-cent of the variance was explained using 7 variables in the equation. Significant predictors of high use of help included "activities of daily living difficult because of vision loss", "lives with spouse", and extent of formal supports.



These findings are most interesting, pointing to both need and availability as being predictors of use of help. (This confirms the findings of the bi-variate analysis).

Additional questions that probed respondent's ideas of why they used one form of help rather than another would have yielded useful information.

### Social/Recreational Activities

Two multiple regression analyses were done for this task. The first used 8 variables in the equation and explained 23% of the variance. Significant predictors of low participation in social and recreational activities included dependence in instrumental activities of daily living, more medical problems and sudden onset. The second used 7 variables in the equation and explained 26% of the variance. Significant predictors were "activities of daily living difficult, because of vision loss", more medical problems, and sudden onset.

These findings build on the evidence presented in Chapters IV and V; elders lack of participation in activities is a result of physical inability rather than a function of social disengagement. The implications of this finding for service provision is discussed in Chapter VII.

### Activities of Daily Living

Seven variables explained 24% of the variance. Medical problems was the only significant predictor and alone accounted

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for over half (13%) of the variance. As noted earlier, the surprise was not that this was the case but that it did not account for more of the variance. A distinct possibility is that the generalized weakness and lower energy level of late life may not be directly tied to a specific medical problem but nonetheless occasion greater dependence in activities of daily living. Obviously identifying such factors is beyond the scope of social research. However, instead of asking elders to say if they were dependent because of vision loss, another health problem, or both; it might have been useful to add "getting older" (which is how elders often refer to it themselves).

CHAPTER VII  
SUMMARY AND RECOMMENDATIONS

OVERVIEW

The research in this study was conducted with visually impaired individuals between the ages of 60 and 99 living in New York City in 1988. Interviews with 86 older adults suffering from age-related vision loss produced a rich data base on the performance of adaptive tasks in the face of this disability.

Literature on adaptation, drawn from the fields of aging, low vision, and chronic illness, suggested the scope and direction of the inquiry. This study is an attempt to better understand the psycho-social aspects of age-related vision loss, an increasingly common occurrence in old age. The purpose has been to contribute to the knowledge base of practitioners and program planners who work with with visually impaired elders, whether in vision agencies serving the aged or in aging agencies serving the visually impaired.

This chapter will summarize the major study findings and draw from them implications for practice.

SUMMARY OF MAJOR FINDINGS

1. Visually impaired elders struggle to "make sense" of their vision loss and to maintain hope.

Often they look for precursors of their current eye condition earlier in life. They remember the time and place when

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they first noticed, or heard from a physician, that they were losing their sight. They seek out at least a second opinion (sometimes three or more) on their vision. They are more apt to expect changes for the better than are the low vision clinicians treat them. When they use low vision aids, these are likely to be magnifying lenses, talking books, audio cassettes, and canes. Very few elders make environmental changes to compensate for vision loss but many make lighting adjustments.

2. When visually impaired elders give up, or are dependent in, activities of daily living, it is much more likely to be as a result of vision loss than of another health problem. However, cessation of or dependence in some activities is a combination of both factors.

3. Participation in social and recreational activities is often stopped or greatly curtailed because of vision loss. While other health problems also contribute, they are less important.

The loss of social and recreational activities are deeply regretted and seldom compensated for by the addition of new activities. While reading is (as expected) the most severe deprivation, the impact of low vision can be felt in such less obvious activities as dining out at a restaurant or attending groups or clubs. Elders are far more likely to avoid or give up an activity than to find new ways of performing it.

4. Visually impaired elders have the same type and combination of chronic health conditions as do the general population of aged (with the exception of an over representation of diabetes) and they appraise their overall health much the same way. Many suffer hearing as well as vision loss.

5. Social supports are most likely to come from the informal system (family, friends, and neighbors) than from the formal system. When the formal system is used it is more likely to be private pay than social agencies. Visually impaired elders are satisfied with the quantity and quality of help they receive.

6. Co-existing life events of change and loss are not perceived as stressors by the visually impaired elderly. While half of them have experienced the death of someone close (usually an age cohort) since their loss of vision it is generally accepted as an expected event at their time of life.

7. When asked to compare vision loss with their other health problems, a great majority of elders find vision loss the most troubling. Most of them accept it with difficulty while a substantial number express despair.

8. Visually impaired elders are prone to "medicalize" their vision problem. ("If the doctor can't do anything, how can I?") When they give advice it is more likely to be passive than active

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mastery. ("Learn to live with it.") There is no clear pattern as to attitude changes across the course of the illness career.

9. Specific eye diagnoses are associated with specific populations. An eye diagnosis of macular degeneration is generally associated with advanced age, white ethnicity, and a better general level of health. On the other hand those suffering from diabetic retinopathy are likely to be younger, non-white, and generally ill. Glaucoma is also more likely to be a disease of minority elders.

10. If one is visually impaired, it is best to be a married man who lives alone with his spouse. These demographic characteristics are associated with better health, independence in activities of daily living, participation in social and recreational activities, high use of help and high self esteem. By the same token, it is worst to be a single woman who lives alone. These demographic characteristics are associated with poorer health, greater dependence in activities of daily living, lower participation in social and recreational activities, and lower self esteem.

19. Age makes little difference in performance of adaptive tasks. In fact the oldest respondents do somewhat better than the younger ones; possibly because they are "survivors" and generally hardier (particularly in relationship to younger

diabetics who suffer from a severe systemic illness).

20. Time since onset makes little difference in performance of adaptive tasks. The sequence or illness career cited by theorists on adaptation did not hold true for the elders in this study.

21. Vision impairment has far greater subjective importance to the elderly than is evidenced in their objective performance of adaptive tasks, with the sole exception of participation in social and recreational activities. This finding suggests that leisure time activities are not a "frill" but rather an arena in which elders affirm their identities.

22. Maintenance or restoration of self esteem is most likely in elders who are male and/or married, relatively healthy, independent in activities of daily living, participate in social and recreational activities, use a lot of help, and do not understand their vision loss.

22. A high use of help is most likely in elders who are male and/or married, living alone with spouse, use the formal system, and are dependent in activities of daily living. Health, eye diagnosis, and vision-related factors have little to do with use of help.

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23. A high level of participation in social and recreational activities is associated with good health, independence in activities of daily living, good hearing, a low degree of vision impairment, and a longer time since onset.

24. Independence in activities of daily living is associated with good health, a low degree of vision impairment, a shorter time since onset, and little use of the informal system.

25. Understanding of loss is associated with being a higher educated, white, female who lives alone, has poor health, stressful coexisting life events and low self esteem.

26. There were ten hypotheses in this study; four of these were confirmed and six were rejected. The following is a summary of hypotheses findings.

The following hypotheses were confirmed.

H1 Self esteem will be positively related to younger age, independence in activities of daily living, and good health.

H5 Use of help will be positively related to lower self esteem.

H7 Visual impairment will be positively related to less participation in social and recreational activities.

H9 There will be a positive relationship between dependence in activities of daily living and degree of vision impairment.



The following hypotheses were rejected.

H2 There will be a positive relationship between severity of visual impairment and poor self esteem.

H3 Self esteem will not relate to time of onset since vision loss.

H4 Visual impairment will be positively related to use of help.

H6 Use of help will be negatively related to time since onset.

H8 Participation in social and recreational activities will increase with time since onset.

H10 Dependence in activities of daily living will increase with time since onset.

In summary, the hypotheses findings underscore the fact that vision impairment is responsible for diminished participation in social and recreational activities and greater dependence in activities of daily living. At the same time, vision impairment does not significantly affect self esteem or use of help.

In this study, time since onset does not affect performance of four adaptive tasks: self esteem, use of help, activities of daily living, and social and recreational activities. Thus, the theories that posit a "career" of adaptation were not confirmed.

In a society that values youth, vigor, and independence it is not surprising that higher self esteem is associated with being young, in good health, and independent in activities of daily living while use of help is positively related to lower self

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esteem.

### LIMITATIONS OF STUDY

Care must be taken in translating the findings of this study to other populations of visually impaired elderly because of four factors. First, the respondents had all followed through on ophthalmologist's referrals to a Low Vision Clinic. The idea of low vision aids supplementing traditional medical interventions is not widely known or accepted. Elders who avail themselves of the opportunity may be more sophisticated and/or more troubled by vision loss than elders who do not. Second, the respondent population reside in a metropolitan urban area and may not be representative of elders who reside elsewhere; particularly in terms of social and recreational activities. Third, findings on "Understanding of Loss" are based on only one measure. Finally, there is an underrepresentation of minority elderly.

### RECOMMENDATIONS

#### Practice

There are some implications for practice in the findings of this study; most specifically for rehabilitation staff (social workers, rehabilitation teachers, and orientation and mobility instructors) who work with visually impaired elderly in the community.

Historically, a rehabilitation assessment focusses on functional abilities in activities of daily living; what elders can and cannot do for themselves. Since elders generally do not receive vocational rehabilitation, there is little effort directed toward exploring their wants or needs outside of caring for themselves and their households. When social and recreational interests are explored, it is generally with the goal of fitting the elder in with already existing services (such as senior centers) or providing aids for reading.

The respondents in this study had given up a wide range of pursuits (many quite personal or idiosyncratic) as a result of vision loss. Many of the activities that had formerly given them pleasure, and which they now mourned, could have been continued with the creative application of current technology, low vision aids and strategies; for example, special goggles could have enabled one man to continue swimming. The few techniques devised by enterprising elders to continue with meaningful activities could be suggested to others; for example, keeping flashlights all around the house and slipping one into a purse when going to a restaurant. In short, psycho-social and functional assessments should move beyond the necessities of life to what gives life meaning. Interventions must be individualized because the visually impaired elderly are a heterogenous group - brailled bingo is not for everyone.

The tendency of elders to medicalize their vision loss is not helpful in that it acts against development of coping

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strategies. Uncurable is not untreatable. Even elderly who had visited the low vision clinic (a self selected group of some sophistication) used only a small fraction of the assistive devices now on the market. There are three practice suggestions to address this problem. The first is education of ophthalmologists as to the many non-medical options open to their patients. The second is community education of elders and their families as to what is available and how to locate it. The third is improving access to these devices at low cost.

The trend in low vision rehabilitation assessment is to identify and address all functional problems as if they were solely attributable to vision loss. This is based, in large part, on the training of most professionals in work with younger people. In old age, many difficulties are caused by a combination of vision and other health problems; requiring a different teaching technique and perhaps a rehabilitation professional from another discipline. For example, orientation and mobility instructors are frequently stymied because they try to teach an elder to cross the street and his gait (slowed by arthritis) is not fast enough to make it on one light. Perhaps, as the elderly population increasingly forms the majority of clients of social agencies serving the blind, there will be a benefit to employment of physical and occupational therapists to participate on the rehabilitation team.

Clinically, knowledge of the profile of individuals most at risk for low self esteem, dependence in activities of daily

living, and low participation may help practitioners better assign their priorities at a time of limited resources. (Interestingly, there appear to be more male rehabilitation clients than their percentage in the aging population would suggest). It is possible that men are more likely to seek out services for themselves. At the same time, the research shows that women (particularly those living alone) may be in greater need. Some outreach efforts to at risk populations may be useful.

The study findings on understanding of loss suggest that it is not necessary or even desirable, for a clinician to insist upon the need for an elder to understand his eye prognosis; especially when, as is usually the case, it is progressive. Whether one terms it "denial" or "hopefulness", elders who do not know what is going to happen do better on all adaptive tasks.

### Research

The study findings suggest a few further areas for inquiry.

The first area of inquiry is the way in which these study findings are applicable to elders who seek compensatory help for other age-related physical disabilities; i.e. mobility training for arthritis, rigorous dietary changes for heart disease.

The second area of inquiry is the effect of dual sensory impairments on performance of adaptive tasks. Over one-third of the sample suffered from hearing as well as vision loss. It would be interesting to look at this sub-group in terms of all

the study variables. It would also be useful to compare this subgroup to elders who suffer only vision loss or only hearing loss.

The third interesting area of future inquiry is the effect of gender. Are ophthalmologists more prone to refer men for low vision aids? Are men more apt to follow through on obtaining them and/or pursuing rehabilitation training? Does marital status alone explain why men perform better on most adaptive tasks (most men are married)? What are the gender differences in adaptation to other disabilities of late life? What is the effect of cohort group on gender differences in adaptation across the life span?

Finally, research is necessary on the relationship between understanding of loss and successful adaptation to disability. Both the literature and the study findings are equivocal. Clearly, much more has to be known about the subjective state of elders who do better with understanding and elders who do worse. We also need to know how information about prognosis is imparted, to whom, and what processes elders and families go through in coming to terms with what they are told. Practice wisdom has it that the health provider should tailor the explanation to the individual patient, how much he appears to understand or wish to know. But how accurate are the health provider's perceptions, how colored by his own wish to deny or to provide hope? A field study and/or one employing many open-ended questions for providers and patients would be necessary in getting at this type

of data. Findings on understanding of loss would have implications for a variety of illnesses across the life span and would make a significant contribution to clinical practice.

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~~LETTER OF INTRODUCTION TO POTENTIAL RESPONDENTS~~

Dear

The Lighthouse is cooperating in a research study on the ways in which older people adapt to visual impairment. The research is being conducted by Ms. Ann Burack-Weiss, educational consultant to The Lighthouse and a faculty member of Columbia University. She will be assisted by Ms. Elizabeth Tuccello.

The research will involve an in-person interview of approximately one hour that can take place at The Lighthouse or in your home; whichever you prefer. It will include questions about your background and current activities and opinions.

Ms. Burack-Weiss or Ms. Tuccello will be phoning you within the next few weeks to answer any questions you might have and, if you wish to be interviewed, to make an appointment.

Please be assured that your participation is completely voluntary and will not affect the services you receive from The Lighthouse or any other agency. If you decide to participate, your responses will be completely anonymous and you will not be identified by name in any report connected with this study.

Thank you for your careful consideration of this request. The Lighthouse maintains a policy of encouraging and cooperating in research that will contribute to better service for blind and visually impaired persons. If you have any questions before you are called, please feel free to contact me directly.

Sincerely,

Amy Horowitz, DSW  
Director, Department of Research &  
Evaluation

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I agree to be interviewed for the research study on Adaptation To Vision Loss as described to me in the mailed letter of introduction from Dr. Amy Horowitz, Director of Research and Evaluation, at The Lighthouse. I understand that the diagnosis from my records at the Low Vision Clinic will also be used in the study.

I understand that my name and all other identifying information will be immediately removed from the data so that all material received will be kept completely confidential.

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Signature

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Date

**APPENDIX C**

## CLIENT SAFEGUARDS IN THE RESEARCH PROCESS

### BENEFITS AND RISKS

Participation in a research study sponsored by The Lighthouse offers significant benefits to visually impaired elders. It affords an opportunity to give as well as to receive; an important source of empowerment for those who often become passive recipients of care due to the combined effects of age and disability. It also conveys the messages that the agency cares about them and that their individual experiences adapting to vision loss can be useful in making the road easier for those who come after. Finally, the telling of one's personal story to an interested, skilled interviewer helps in the assumption of mastery and control over it.

There are no foreseeable risks. The interviews will be conducted by an experienced social work practitioner and Educational Consultant to The Lighthouse, Ms. Ann Burack-Weiss. One research assistant, Ms. Elizabeth Tuccello, will be trained and supervised directly by Ms. Burack-Weiss. Case managers will have an opportunity to veto the initial contact of any potential respondent under their care. The introductory process provides opportunity for questions and withdrawal at any point. The study will be explained briefly in the introductory letter (attached), and at greater length on the follow-up phone call. The in-person interview will be preceded by further discussion and the signing of an informed consent. Respondents who express issues or concerns unrelated to the questionnaire will be asked if they would like these to be conveyed to The Lighthouse and an appropriate referral made.

### CONFIDENTIALITY

Respondents will be identified by number on the questionnaire itself. Names and addresses will be used for scheduling purposes only, kept in a locked file, and destroyed when they are no longer needed. Interviews will be held either in the respondent's home/apartment or in a private office in the Research Department. No one other than the respondent and interviewer will know the time, place, or content of the interviews.

**APPENDIX D**

LOW VISION CLINIC INFORMATION

I.D. Number: -----

Gender: \_\_\_female \_\_\_male

Current Age: \_\_\_\_

Time since Onset

\_\_\_ 0 - 1 years

\_\_\_ 2 - 3 years

\_\_\_ 4+ years

Clinical Diagnosis

\_\_\_ Multiple Diagnoses

\_\_\_ Macular Degeneration

\_\_\_ Diabetic Retinopathy

\_\_\_ Cataract

\_\_\_ Glaucoma

\_\_\_ Other

Degree of Impairment

\_\_\_ Normal/Near Normal

\_\_\_ Moderate

\_\_\_ Severe

\_\_\_ Profound

Prognosis

\_\_\_ Slowly Progressive

\_\_\_ Progressive

\_\_\_ Progressive/Visual Field Reduced

\_\_\_ Surgery could improve

\_\_\_ Stable

\_\_\_ Remission

INTERVIEW QUESTIONNAIRE

240

I'm going to begin by asking you some general questions about yourself, your family, and friends.

1. What is your living arrangement? Do you live with someone?
- 01 Live alone
  - 02 Live with spouse (w/ or w/out other relatives)
  - 03 Live with spouse and children
  - 04 Live with children (w/ or w/out other relatives)
  - 05 Live with other relative(s) only
  - 06 Live with non-relative(s) only
  - 07 Other (Specify relationship \_\_\_\_\_)
  - 08 Congregate or Nursing Home
  - 88 Not Applicable
  - 99 Missing/Don't Know

(a) How many people, overall, do you live with ? \_\_\_\_\_

2. How long have you lived at your present address?
- \_\_\_\_\_ Number of Years
  - 9 Missing/Don't Know

If moved within past seven years, ask:

(a) How many times have you moved? \_\_\_\_\_

(b) What was your primary reason for moving?

First move \_\_\_\_\_

Second move \_\_\_\_\_

Additional moves (Specify each one) \_\_\_\_\_

3. Are you currently employed?

1 Yes

2 No

If yes,

(a) What is your position? \_\_\_\_\_

(b) Have there been any changes in your job responsibilities in the past five years?

Yes

No

If yes

(c) What was the reason for the change? \_\_\_\_\_

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4. Were you employed at any time during the past ten years ?

241

1 Yes

2 No

If yes,

(a) What was the primary reason for stopping work?

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5. May I ask, what is your marital status?

1 Married

3 Divorced

~~2~~ 2 WIDOWED

4 Separated

5 Single, never married

8 Not Applicable

9 Missing/Don't Know

(a) If 1,3,4, How Long? \_\_\_\_\_

6. Do you have any living children?

1 Yes

2 No

If yes

(a) How many daughters?

\_\_\_\_\_ Daughters

(b) How many sons?

\_\_\_\_\_ Sons

If no, skip to question 7.

7. Did you have any other children?

1 Yes

2 No

If yes,

(a) How many \_\_\_\_\_

If yes, skip to question 8.

8. Do you have any grandchildren?

1 Yes

2 No

If yes,

(a) how many? \_\_\_\_\_

9. How often do you see at least one of your children?

1 Almost every day (6+)

2 Several times a week (2-5)

3 At least once a week (1)

4 Every other week (2-3 times a month)

5 At least once a month

6 Less than once a month

7 Once a year or less

8 Not Applicable

9 Missing/Don't Know



10. How often do you talk on the phone to at least one of your children?

- 1 Almost every day (6+)
- 2 Several times a week (2-5)
- 3 At least once a week (1)
- 4 Every other week (2-3 times a month)
- 5 At least once a month
- 6 Less than once a month
- 7 Once a year or less
- 8 Not Applicable
- 9 Missing/Don't Know

11. How often do you see or talk on the phone to at least one of your grandchildren?

- 1 Almost every day (6+)
- 2 Several times a week (2-5)
- 3 At least once a week (1)
- 4 Every other week (2-3 times a month)
- 5 At least once a month
- 6 Less than once a month
- 7 Once a year or less
- 8 Not Applicable
- 9 Missing/Don't Know

12. Do you have any other relatives (besides your children/grandchildren) who you see or talk on the phone to at least twice a month?

- 1 Yes
- 2 No

If yes,

(a) What is their relationship to you? (Check all that apply)

- 1 Sibling
- 2 Niece or Nephew
- 3 Cousin
- 4 In-Law
- 5 Separated Spouse
- 6 Other (Specify) \_\_\_\_\_
- 8 Not Applicable
- 9 Missing/Don't Know

(b) How often do you see or speak on the phone to one of the above?

- 1 Almost every day (6+)
- 2 Several times a week (2-5)
- 3 At least once a week (1)
- 4 At least twice a month
- 8 Not Applicable
- 9 Missing/Don't Know

13. Do you have any friends or neighbors who you see or talk on the phone to at least twice a month?

- 1 Yes
- 2 No
- 8 Not Applicable

\_\_\_ 9 Missing/Don't Know

If yes,

(a) How often do you see or speak on the phone to a friend or neighbor?

- \_\_\_ 1 Almost every day (6+)  
 \_\_\_ 2 Several times a week (2-5)  
 \_\_\_ 3 At least once a week (1)  
 \_\_\_ 4 At least twice a month  
 \_\_\_ 8 Not Applicable  
 \_\_\_ 9 Missing/Don't Know

Now, I'd like to ask you some questions about your health.

14. Compared to others your age, how would you rate your health? Would you say it is:

- \_\_\_ 1 Better  
 \_\_\_ 2 Worse  
 \_\_\_ 3 Same  
 \_\_\_ 8 Not Applicable  
 \_\_\_ 9 Missing/Don't Know

15. How is your hearing?

- \_\_\_ 1 Excellent  
 \_\_\_ 2 Good  
 \_\_\_ 3 Fair  
 \_\_\_ 4 Poor  
 \_\_\_ 8 Not Applicable  
 \_\_\_ 9 Missing/Don't Know

(a) Have you ever had a hearing aid?

- \_\_\_ 1 Yes  
 \_\_\_ 2 No  
 \_\_\_ 8 Not Applicable  
 \_\_\_ 9 Missing/Don't Know

If yes,

(b) Do you wear a hearing aid now?

- \_\_\_ 1 Yes  
 \_\_\_ 2 No  
 \_\_\_ 8 Not Applicable  
 \_\_\_ 9 Missing/Don't Know

16. About how many times have you seen a doctor during the past six months other than as an inpatient in a hospital?

Number of times \_\_\_\_\_  
 \_\_\_ 9 Missing/Don't Know

17. During the past six months how many days were you so sick that you were unable to carry on your usual activities.

- \_\_\_ 1 None  
 \_\_\_ 2 A week or less  
 \_\_\_ 3 More than a week but less than one month  
 \_\_\_ 4 1/3 months

- 5 4/6 months
- 8 Not Applicable
- 9 Missing/Don't Know

18. How would you rate your overall health at the present time?
- 1 Excellent
  - 2 Good
  - 3 Fair
  - 4 Poor
  - 8 Not Applicable
  - 9 Missing/Don't Know

Now, I'm going to ask you some questions about your vision loss.

19. How would you describe yourself in relation to your vision loss?

20. Do you expect any changes in your vision to occur in the future?

- 1 Yes
- 2 No

If yes,

- (a) What changes do you expect?

- 1 It will get better
- 2 It will get worse
- 8 Not Applicable
- 9 Missing/Don't Know

21. How long ago did vision loss first become a problem for you?

- Number of Years
- 88 Not Applicable
- 99 Missing/Don't Know

- (a) Could you please describe the circumstances when you first began to feel that your vision loss was a problem?

22. Do you remember who first talked to you, or who you talked to about about your vision loss? When did this occur?

(Interviewer probe and circle appropriate person and insert date)

- 1 General Practitioner/Internist \_\_\_\_\_
- 2 Eye doctor \_\_\_\_\_
- 3 Family member \_\_\_\_\_

- 4 Friend or neighbor (Specify relationship) \_\_\_\_\_  
 5 Other (Specify relationship) \_\_\_\_\_  
 8 Not Applicable  
 9 Missing/Don't Know

23. Do you remember what you were first told was the matter with your vision? (Write in)

24. After the first time, did you talk to other people about your vision loss?

- 1 Yes  
 2 No  
 8 Not Applicable  
 9 Missing/Don't Know

If yes,

(a) Who were they? (Check all that apply)

- 1 Another eye specialist  
 2 More than one other eye doctor  
 3 A family member (Specify relationship) \_\_\_\_\_  
 4 A friend or neighbor  
 5 Other (Specify relationship) \_\_\_\_\_  
 8 Not Applicable  
 9 Missing/Don't Know

25. Were there contradictions in what you were told; for example, did different people tell you different things?

- 1 Yes  
 2 No

If yes,

(a) What did you believe and why? (Write in)

26. If someone who just learned that he or she has the same vision problem that you do asked you for advice what would you say? (Write in)

27. Has your attitude about vision loss changed since you first began to have problems?

- 1 Yes  
 2 No  
 8 Not Applicable  
 9 Missing/Don't know

If yes,

(a) Please describe how it has changed?

(b) Can you recall a specific situation or turning point as an example of the change?

28. Do you have any of the following illnesses? (if yes, ask if it began before, concurrent with, or after vision loss, hospitalized or not hospitalized since vision loss)

	Yes	No	B	C	A	H	NH
A Heart Disease	—	—	—	—	—	—	—
B Hypertension	—	—	—	—	—	—	—
C Diabetes	—	—	—	—	—	—	—
D CVA (Stroke)	—	—	—	—	—	—	—
E Cancer	—	—	—	—	—	—	—
F Arthritis	—	—	—	—	—	—	—
G Parkinsons	—	—	—	—	—	—	—
H Emphysema	—	—	—	—	—	—	—
I Other (Specify)	—	—	—	—	—	—	—

29. Have you been hospitalized for any other reason since your vision loss?

- 1 Yes

- 2 No  
 8 Not Applicable  
 9 Missing/Don't Know

If yes,

(a) For what reason? (Write In).

30. Compared to the effects of other illnesses, how would you rate the loss of vision. Would you say ?

- 1 Vision loss is the most troubling  
 2 Vision loss is the least troubling  
 3 Vision loss is neither the greatest or least troubling  
 4 Other (Specify) \_\_\_\_\_  
 9 Missing/Don't Know

31. Is your health now better, about the same, or worse than it was at the onset of your vision loss?

- 1 Better  
 2 Same  
 3 Worse  
 8 Not Applicable  
 9 Missing/Don't Know

32. Do you have any health problems, other than vision loss, that stand in the way of your doing the things you want to do?

- 1 Yes  
 2 No  
 8 Not Applicable  
 9 Missing/Don't Know

(a). If yes, ask how much do these health problems get in the way?

- 1 Not at all  
 2 A little  
 3 A great deal  
 8 Not Applicable  
 9 Missing/Don't Know

33. Now, I'm going to read you a list of activities that older people sometimes participate in. For each activity, could you tell me if you never participated in the activity, if you participated before your vision loss only, if you continue to participate, or if you no longer participate?

(Read and check choices for each activity. Then probe reasons for choices 2, 3, and 4. If before only, why stopped? If now only, why began? If before and now, are there differences in how you participate since your vision loss?)

- A Worked for pay  
 1 Never

- 2 Before only
- 3 Now only
- 4 Before and now
- 9 Missing/Don't Know

Reason:

B Volunteer work

- 1 Never
- 2 Before only
- 3 Now only
- 4 Before and now
- 9 Missing/Don't Know

(1) Reason:

C. Gone to a senior center, or attended a senior citizen's group?

- 1 Never
- 2 Before only
- 3 Now only
- 4 Before and now
- 9 Missing/Don't Know

(1) Reason:

D. Attended a church or synagogue service?

- 1 Never
- 2 Before only
- 3 Now only
- 4 Before and now
- 9 Missing/Don't Know

(1) Reason:

E. Gone to meetings of church or other groups or clubs?

- 1 Never
- 2 Before only
- 3 Now only
- 4 Before and now
- 9 Missing/Don't Know

(1) Reason:

F. Gone to the movies, theater, concert, or lectures?

- 1 Never  
 2 Before only  
 3 Now only  
 4 Before and now  
 9 Missing/Don't Know

(1) Reason:

G. Gone to a sporting event?

- 1 Never  
 2 Before only  
 3 Now only  
 4 Before and now  
 9 Missing/Don't Know

(1) Reason:

H. Participated in a sport, played cards, bingo, pool, or some other game?

- 1 Never  
 2 Before only  
 3 Now only  
 4 Before and now  
 9 Missing/Don't Know

(1) Reason:

I Taken care of house plants or done outdoor gardening?

- 1 Never  
 2 Before only  
 3 Now only  
 4 Before and now  
 9 Missing/Don't Know

(1) Reason:

J. Worked on a hobby or handwork like knitting or woodworking?

- 1 Never  
 2 Before only  
 3 Now only  
 4 Before and now  
 9 Missing/Don't Know



(1) Reason:

K. Painted pictures or played a musical instrument?

- 1 Never  
 2 Before only  
 3 Now only  
 4 Before and now  
 9 Missing/Don't Know

(1) Reason:

L. Eaten out at a restaurant for a special occasion with relatives or friends?

- 1 Never  
 2 Before only  
 3 Now only  
 4 Before and now  
 9 Missing/Don't Know

(1) Reason:

M. Babysat for grandchildren or other children?

- 1 Never  
 2 Before only  
 3 Now only  
 4 Before and now  
 9 Missing/Don't Know

(1) Reason:

N. Visited a friend or relative out of town for overnight or longer?

- 1 Never  
 2 Before only  
 3 Now only  
 4 Before and now  
 9 Missing/Don't Know

(1) Reason:

O. Gone out of town for a vacation?

- 1 Never  
 2 Before only  
 3 Now only

- 4 Before and now  
 9 Missing/Don't Know

(1) Reason:

P. Had a visit from a friend or relative out of town for a night or longer?

- 1 Never  
 2 Before only  
 3 Now only  
 4 Before and now  
 9 Missing/Don't Know

(1) Reason:

Q. Taken adult education courses?

- 1 Never  
 2 Before only  
 3 Now only  
 4 Before and now  
 9 Missing/Don't Know

(1) Reason:

R. Reading?

- 1 Never  
 2 Before only  
 3 Now only  
 4 Before and now  
 9 Missing/Don't Know

(1) Reason:

S. Television?

- 1 Never  
 2 Before only  
 3 Now only  
 4 Before and now  
 9 Missing/Don't Know

(1) Reason:

## T. Other?

- 1 Never  
 2 Before only  
 3 Now only  
 4 Before and now  
 9 Missing/Don't Know

(1) Reason:

34. Have you discovered any new activities or interests that I did not mention since the onset of your vision loss ?

- 1 Yes  
 2 No  
 9 Missing/Don't Know

If yes, could you explain? Write in.

35. Has anyone close to you, for example a relative or friend, moved away since the onset of your vision loss?

- 1 Yes  
 2 No  
 9 Missing/Don't Know

If yes,

(a) What was the relationship? \_\_\_\_\_

(b) How long ago did this occur? \_\_\_\_\_

Write in any additional information.

36. Has anyone close to you become seriously ill since the onset of your vision loss?

- 1 Yes  
 2 No  
 9 Missing/Don't Know

If yes,

(a) What was the relationship? \_\_\_\_\_

(b) How long ago did this occur? \_\_\_\_\_

Write in any additional information.

37. Has anyone close to you died since the onset of your vision loss?

- 1 Yes
- 2 No
- 9 Missing/Don't Know

If yes,

(a) What was the relationship? \_\_\_\_\_

(b) How long ago did this occur? \_\_\_\_\_

Write in any additional information.

Now, I'm going to ask some questions about how you manage your daily activities.

38. Did you use paid help for housekeeping or other services before the onset of vision loss?

- 1 Yes
- 2 No
- 9 Missing/Don't Know

If yes,

(a) Please describe the service(s)

39. I am going to read you a list of daily activities with which some older people need help. If you no longer do any activity or need help with any activity, please tell me if it is primarily because of your vision loss or primarily because of another health problem.

	Never did	Does w/no help	Does w/help	Does no more	VL	AHP
A Dress and put on your shoes	—	—	—	—	—	—
B Take a bath or shower?	—	—	—	—	—	—
C Prepare a simple meal?	—	—	—	—	—	—
D Clean your apartment/house?	—	—	—	—	—	—

	<i>Never Did</i>	<i>With No Help</i>	<i>With Help</i>	<i>Does No more</i>	<i>VL</i>	<i>AHP</i>
E Climb stairs?	—	—	—	—	—	254—
F Get around the apartment/ house?	—	—	—	—	—	—
G Manage eating?	—	—	—	—	—	—
H Go for short walks outside?	—	—	—	—	—	—
I Ride in a regular bus?	—	—	—	—	—	—
J Shop for groceries?	—	—	—	—	—	—
K Make your own bed?	—	—	—	—	—	—
L Take your medications?	—	—	—	—	—	—
M Do the laundry?	—	—	—	—	—	—
N Manage your money?	—	—	—	—	—	—
O Take care of your own appearance?	—	—	—	—	—	—
P Get in and out of bed?	—	—	—	—	—	—

40. Do you use any low vision aids to assist you in daily activities?

\_\_\_ 1 Yes

\_\_\_ 2 No

If yes, which of the following do you use? (Interviewer read and circle on list.)

A Watch, timer

B Cane

C Special glasses and magnifiers

D Kitchen aids

E Playing cards and puzzles

F Talking books

G Large print books or papers

H Writing guides

I Medical devices

J Other (Specify) \_\_\_\_\_

41. Have you made any changes in the physical arrangement of your house/apartment to accomodate your vision loss?

- 1 Yes  
 2 No

If yes, which of the following have you changed?

(Interviewer read and circle all response choices)

- A Stairways or ramps  
 B Furniture  
 C Kitchen appliances or fixtures  
 D Bathroom appliances or fixtures  
 E Other (Specify) \_\_\_\_\_

42. Have you made any color changes in your house/apartment to accomodate your vision loss?

- 1 Yes  
 2 No

If yes,

(a) Please describe.

43. Have you made any lighting changes in your house/apartment to accomodate your vision loss?

- 1 Yes  
 2 No

If yes,

(a) Please describe.

44. Many older people receive help from private pay services and social agencies. What agencies have you received services from since your vision loss?

- 1 The Lighthouse  
 2 Other agency for the blind  
 3 Senior Center activities, meals, or transportation  
 4 Medicare or Medicaid Home Care or transportation  
 5 Private Pay Services Home care or transportation  
 6 Other (Specify) \_\_\_\_\_

45. Next, we would like to know about the help you currently receive from your family, friends, and outside agencies and how often they help you.

(Interviewer: Use this coding:

- 1 Almost every day (6+)  
 2 Several times a week (2-5)  
 3 At least once a week (1)  
 4 Every other week (2-3 times a month)  
 5 At least once a month

- 6 Less than twice a year  
 7 Less than once a month  
 8 Not Applicable  
 9 Missing/Don't Know

For each question ask: Has anyone helped you when....? How often....? Anyone else....? How often....?

	<u>Spouse</u>	<u>Child/Rel</u>	<u>Neigh/Fr</u>	<u>Pvt.Pay</u>	<u>Soc.Agcy</u>
A Help out when you are sick?	—	—	—	—	—
B. Help out with shopping or errands	—	—	—	—	—
C. Help you with house-cleaning?	—	—	—	—	—
D. Cook for you?	—	—	—	—	—
E. Fix things around the apartment?	—	—	—	—	—
F. Give advice when you have a problem or worry?	—	—	—	—	—
G. Provide transportation or go with you to the doctor, or social visits, or other places you go?	—	—	—	—	—
H. Other (Specify)	—	—	—	—	—

46. What do you think about the amount of help you receive?  
 (Interviewer read all response choices)

- \_\_\_ 1 Just about right  
 \_\_\_ 2 Too much  
 \_\_\_ 3 Too little  
 \_\_\_ 8 Not Applicable  
 \_\_\_ 9 Missing/Don't Know

(a) If too much or too little, could you explain? Write in.

47. What do you think about the quality of help you receive?  
(Interviewer read all response choices)

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor
- 6 It varies
- 8 Not applicable
- 9 Missing/Don't Know

(a) If it varies, could you please explain?

48. Are there disagreements in your family as to the type or amount of help you need?

- 1 Yes
- 2 No
- 8 Not applicable
- 9 Missing/Don't Know

(a) If yes, could you please explain?

49. Now, I am going to read you ten statements. For each one, please say if you strongly agree, agree, disagree, strongly disagree.

	SA	A	D	SD
A I feel that I'm a person of worth, at least on an equal plane with others.	—	—	—	—
B I feel that I have a number of good qualities.	—	—	—	—
C All in all, I am inclined to feel that I am a failure.	—	—	—	—
D I am able to do things as well as most other people.	—	—	—	—
E I feel I do not have much to be				



	<u>SA</u>	<u>A</u>	<u>D</u>	<u>SD</u>
proud of.	—	—	—	—
F I take a positive attitude toward myself.	—	—	—	—
G On the whole, I am satisfied with myself	—	—	—	—
H I wish I could have more respect for myself.	—	—	—	—
i. I certainly feel useless at times.	—	—	—	—
j. At times I think I am no good at all.	—	—	—	—

258

Now, I have just a few more questions to ask.

50. Does your income come from? (Interviewer read all response choices)

- 1 Income only
- 2 Social Security and Pension Only
- 2 Social Security, Pension, and other income
- 8 Not Applicable
- 9 Missing/Don't Know

51. What was the last grade in school you completed? (Interviewer read all response choices)

- 1 \_\_\_\_\_
- 2 12 - High School Graduate
- 3 Some College
- 4 College Graduate
- 5 Post College
- 9 Missing/Don't Know

52. What is your ethnicity (racial background)?

- 1 White
- 2 Black
- 3 Hispanic
- 4 Asian
- 5 Other

53. Finally, what is your religion?

- 1 Jewish
- 2 Catholic
- 3 Protestant
- 4 Other
- 5 No response

Thank you very much for your time and willingness to participate. Do you have any questions or comments?

Note:

INTERVIEWER REACTION - This section is to be completed by the interviewer at the completion of the interview.

1. Total length of interview \_\_\_\_\_ minutes

2. Was the respondent \_\_\_\_\_

- 1 Female
- 0 Male

4. Were there any persons present during the interview other than the respondent?

- 1 Yes
- 0 No

4a. IF YES: Did this person (any of these people present) take part in the interview or did the respondent seek advice or opinions from (any of) them?

- 1 Yes
- 0 No

5. Was there anything unusual about the respondent's family or living situation not covered by the interview questions?

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6. Were there any answers given by the respondent which you felt were contradicted by other answers, comments, stories, or apparent life circumstances?

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(PLEASE USE THE WORD-PAIR TECHNIQUE TO GIVE THE FOLLOWING RATINGS ON THE BASIS OF YOUR OBSERVATION OF THE RESPONDENT, THE RESPONDENT'S HOME AND NEIGHBORHOOD. CIRCLE ONE ANSWER CODE FROM EACH ROW.)

7. Respondent in interview situation:

- a. Not smart 1 2 3 4 5 6 7 Smart
- b. Friendly 1 2 3 4 5 6 7 Hostile
- c. Slow 1 2 3 4 5 6 7 Quick
- d. Silent 1 2 3 4 5 6 7 Talkative
- e. Cheerful 1 2 3 4 5 6 7 Depressed

8. Respondent's speech:

260

- a. Correct grammar 1 2 3 4 5 6 7 Incorrect grammar  
b. Difficult to understand 1 2 3 4 5 6 7 Easy to understand

9. Respondent's home:

- a. Neat 1 2 3 4 5 6 7 Disorderly  
b. Dirty 1 2 3 4 5 6 7 Clean  
c. Rich 1 2 3 4 5 6 7 Poor

10. Please note the general physical condition of the respondent:

	Yes	No	Can't tell
a. Hands shake	1	0	2
b. Immobilized--cannot walk without help	1	0	2
c. Difficulty hearing	1	0	2
d. Difficulty seeing	1	0	2
e. Paralysis	1	0	2
f. Cane	1	0	2
g. Walker	1	0	2
h. Wheelchair	1	0	2
i. Confined to bed	1	0	2

(CHECK BY OBSERVATION)

11. Furnishings are generally sound (not dilapidated)

- 1 Yes  
0 No  
9 Not ascertained

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**Burack-Weiss, Ann, D.S.W.**

**Columbia University, 1990**

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