

**TIME CHANGES EVERYTHING - OR DOES IT? THE GRIEF AND
FRUSTRATIONS OF ADVENTITIOUSLY VISUALLY IMPAIRED ADULTS**

by

SHIRLEY ANNE MURRAY

submitted in fulfilment of the requirements for
the degree of

MASTER OF ARTS

in the subject

PSYCHOLOGY

at the

UNIVERSITY OF SOUTH AFRICA

SUPERVISOR: PROFESSOR RC MCKAY

JUNE 1998

"I declare that TIME CHANGES EVERYTHING - OR DOES IT? THE GRIEF AND FRUSTRATIONS OF ADVENTITIOUSLY VISUALLY IMPAIRED ADULTS is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references."

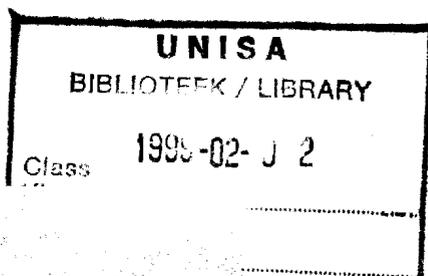
15 June 1998

A rose once grew where all could see,
sheltered beside a garden wall,
And, as the days passed swiftly by,
it spread its branches, straight and tall...

One day, a beam of light shone through
a crevice that had opened wide -
The rose bent gently toward its warmth
then passed beyond to the other side...

Now, you who deeply feel its loss,
be comforted - the rose blooms there -
Its beauty even greater now,
nurtured by God's own loving care.

(Anonymous)



155.916 MURR



0001718123

ABSTRACT

This research focuses on the grief and emotional reactions, especially frustration, of adventitiously visually impaired adults following loss of sight. The traditional grief-following-loss theory with the assumption of a time-limited linear grief process, accompanied by diminishing emotions and culminating with acceptance and adjustment has been challenged. Chronic grief assumes a recurrent and continuous grief process, accompanied by increased emotions associated with continual losses related to a chronic loss, such as visual impairment.

The question of whether there is a relation between length of time of adventitious visual impairment and the healing affect of time on grief and frustrations has been examined by quantitative and qualitative investigations. The answer to the question of whether time changes and heals everything is not necessarily the case. As always there are more questions than answers, and this research provides further insight into the real world of adventitious visual impairment.

ACKNOWLEDGEMENTS

My sincere thanks go to the following persons:

My Mom and Dad for your love, support, concern and encouragement. Mom, without your help I would never have been able to complete this dissertation. Thanks a million Ma.

My niece, Michelle for being there for me with your smile and laughter that has helped me through this dissertation.

Riana Odendaal for your care, help and encouragement and for always being there to listen.

My supervisor, Prof. Robert McKay who with your knowledge, insight and empathy has helped me make this dissertation *beautiful*.

Estelle van Rooyen for all your help with the interviews and the frustrating computer. Thanks for being there with a ready smile.

Neil Crawford for being the e-mail middle-man between America and South Africa and Janet Crawford for being the conveyor of both good and bad news. To both, my sincere thanks.

Merle Werbeloff for your gracious assistance with those dreaded stats.

Sybil Barnard for being so willing to help me with the final reading and encouraging me to jump the final hurdle.

All the volunteers at Tape-aids for reading hundreds of journals, the South African Library for the Blind and the Blindina Library for searching the world for my requested books.

To all the adventitiously visually impaired who so willingly participated in this research study

"...May you build a ladder to the stars and climb on every rung, ...May you always know the truth and see the light surrounding you, ...May you always be courageous, stand upright and be strong, and may you be forever young..."

(Bob Dylan, 1961)

All other friends, too numerous to mention, my grateful thanks.

- The financial assistance of the Centre for Science Development (HSRC, South Africa) towards this research is hereby acknowledged. Opinions expressed in this publication and conclusions arrived at, are those of the author and are not necessarily to be attributed to the Centre for Science Development.

TABLE OF CONTENTS

CHAPTER ONE

INTRODUCTION: CHANGES IN TIME PASSAGES OF ADVENTITIOUS VISUAL IMPAIRMENT

1.1 INTRODUCTION	1
1.2 THE RESEARCH PROBLEM	1
1.3 THE RESEARCH AIMS	4
1.4 CHAPTER OUTLINES	5

CHAPTER TWO

FOR WHOM THE LIGHTS GO OUT

2.1 INTRODUCTION	8
2.2 TYPES OF VISUAL IMPAIRMENT	8
2.3 LEVELS OF VISUAL IMPAIRMENT	9
2.4 CAUSES OF VISUAL IMPAIRMENT	11
2.5 ONSET OF VISUAL IMPAIRMENT	15
2.6 CONCLUSION	15

CHAPTER THREE

LOSS OF SIGHT: A POINT OF NO RETURN OR A TURNING POINT: A LITERATURE AND RESEARCH REVIEW OF LOSS AND GRIEF

3.1 INTRODUCTION	17
3.2 LITERATURE AND RESEARCH:	
LOSS AND GRIEF FOLLOWING DEATH	17
General description of loss	18
Loss through death	19
Death: Models of the grief process	24
Death: Time course of the grief process	33
3.3 LITERATURE AND RESEARCH:	
LOSS AND GRIEF FOLLOWING DISABILITY	35
Loss through disability	35
Disability: Models of the grief process	36
Disability: Time course of the grief process	44
Summation: Critical issues pertaining to the grief process	47
3.4 LITERATURE AND RESEARCH:	
LOSS AND GRIEF FOLLOWING VISUAL IMPAIRMENT	48
Literature on adventitious visual impairment	48
Loss through visual impairment	49
Visual impairment: Models of the grief process	52
Visual impairment: Time course of the grief process	61
The grief process and support	66
Summary	70

3.5	FRUSTRATION AS KEY EMOTION IN VISUAL IMPAIRMENT	72
	Frustrations characteristic of visual impairment	73
3.6	CONCLUSION	75

CHAPTER FOUR

RESEARCH METHODOLOGY: FACTUAL AND MEANINGFUL PROCEDURES

4.1	INTRODUCTION	77
4.2	DESCRIPTION OF TERMS	78
4.3	AIMS OF THIS RESEARCH STUDY	79
4.4	RESEARCH HYPOTHESES AND RELATED SUBSIDIARY INVESTIGATIONS	80
4.5	METHODOLOGY FOR THIS STUDY	83
4.6	SAMPLING RELEVANT TO THE STUDY	84
	Non-probability sampling	84
	The sample used in the present study	84
4.7	DATA COLLECTION	92
	The interview schedule	92
	Standardised tests	95
	Administering the interview schedule	99
4.8	PROCEDURES TO EXAMINE THE DATA	99
	Statistical tests relevant to the study	100
4.9	CONCLUSION	102

CHAPTER FIVE

RESULTS: THE RELATIVE TRUTH

5.1	INTRODUCTION	103
5.2	SECTION 1: THE EXPERIENCE AND MEANING OF FRUSTRATION	104
	Frustration as a personality trait	104
	Analysis of perception of occurrence of frustration	105
	Descriptions of the meaning of frustration	106
	Summation: Results of experience and meaning of frustration	108
5.3	SECTION 2: HYPOTHESIS 1 TESTING AND SUBSIDIARY INVESTIGATIONS	108
	Hypothesis 1	108
	Subsidiary investigation (1A)	110
	Subsidiary investigation (1B)	115
	Summation: Hypothesis 1 and subsidiary results	116
5.4	SECTION 3: HYPOTHESIS 2 TESTING AND SUBSIDIARY INVESTIGATIONS	116
	Hypothesis 2:	117
	Subsidiary investigation (2A)	118
	Subsidiary investigation (2B)	120
	Subsidiary investigation (2C)	120
	Summation: Hypothesis 2 and subsidiary results	121
5.5	SECTION 4: HYPOTHESIS 3 TESTING AND SUBSIDIARY INVESTIGATIONS	122
	Hypothesis 3	122
	Subsidiary investigation (3A)	125
	Subsidiary investigation (3b)	128

Subsidiary investigation (3C)	132
Subsidiary investigation (3D)	133
Summation: Hypothesis 3 and subsidiary results	137
5.6 SECTION 5: HYPOTHESIS 4 TESTING AND SUBSIDIARY INVESTIGATIONS	138
Hypothesis 4	138
Subsidiary investigation (4A)	139
Subsidiary investigation (4B)	142
Subsidiary investigation (4C)	143
Summation: Hypothesis 4 and subsidiary results	144
5.7 CONCLUSION	145

**CHAPTER SIX
MORE THAN WHAT MEETS THE EYE**

6.1 INTRODUCTION	147
6.2 OVERVIEW OF RESULTS	147
6.3 SPECIFIC OUTCOMES	148
Hypotheses 1 and 2: Discussion of results	148
Hypothesis 3: Discussion of results	152
Hypothesis 4: Discussion of results	161
6.4 POSSIBLE EXPLANATIONS FOR DIFFERENCES	165
6.5 SUMMARY: RESEARCH AND THEORETICAL IMPLICATIONS	169
Research implications	169
Implications for theory	172
6.6 CONCLUSION	174

**CHAPTER SEVEN
THE REAL WORLD OF ADVENTITIOUS VISUAL IMPAIRMENT**

7.1 INTRODUCTION	176
7.2 RESEARCH AIMS OF THE STUDY	176
Hypotheses and related subsidiary investigations	177
7.3 MAJOR CONCLUSIONS FROM THE RESEARCH STUDY	178
Suggestions gained from the research	179
7.4 LIMITATIONS OF THE PRESENT STUDY	180
7.5 RECOMMENDATIONS FOR FURTHER RESEARCH	182
7.6 REFLECTION ON THE VALUE OF THE PRESENT STUDY	184
7.7 CONCLUSION	185

REFERENCES	186
----------------------	-----

APPENDICES	195
----------------------	-----

CHAPTER ONE

INTRODUCTION: CHANGES IN TIME PASSAGES OF ADVENTITIOUS VISUAL IMPAIRMENT

1.1 INTRODUCTION

Adventitious loss of sight, no matter the degree of loss, is an impairment that irrevocably changes the course of a formerly sighted person's life. The loss impinges on every facet of the person's life. It affects psychological and emotional reactions as well as practical capabilities and skills, all of which potentially undermine confidence and previously established self perceptions and patterns of behaviour. The question arises of whether these reactions related to the challenge of sight loss change over time. Is there an improvement or deterioration in psychological and emotional reactions to this loss, the longer the visual impairment?

The question to be researched in this study is whether or not there is a relation between different lengths of time of adventitious visual impairment and psychological and emotional reactions in meeting the challenge of visual impairment; in other words, "time changes everything - or does it?" The concept of *time heals* and its influence on emotional and psychological reactions to loss of sight is the focal point in this study.

This chapter will provide a description of the research problem, the aims of the research study and an outline of the contents of the ensuing chapters.

1.2 THE RESEARCH PROBLEM

It is important from the outset to describe how the researcher's personal experience of visual impairment played a role in the instigation of the present study and how it led to

the formulation of the research problem. The process of exploration of the phenomenon of adventitious visual impairment and related psychological and emotional reactions began with a contemplation of the researcher's personal experience of adventitious visual impairment, namely, total blindness which occurred in her adult life. After following the expected passage associated with adventitious visual impairment, the researcher completed the rehabilitation course and then obtained a university degree all of which took approximately 5 inclusive years. It was at this point that the researcher became acutely aware of the *unreality* of the *time heals* ideal that society in general and the rehabilitation context assumes and expects. For instance it is expected that time will heal the pain of loss and therefore change the emotions related to loss of sight; that with time there will be acceptance of the loss of sight; that time will lead to total emotional and practical adjustment to the visual impairment; and with time there will be a return to the independent functioning person as he/she was before the onset of visual impairment with little or no need for continued emotional support. The time passage experience of visual impairment has caused the researcher to question the reality of these idealistic expectations.

These unrealistic expectations were endorsed through discussion with other long-term adventitiously visually impaired adults. The main problem focused on the issue of continued frustrations related to the *real* implications of their visual impairment, involving both their continued loss of independence and the lack of understanding of the sighted world about visual impairment generally and the significance of sight loss. These problems were the starting point of the questioning regarding the presumed "time heals and changes everything" presumption involving the assumptions of diminished emotions, especially frustration; acceptance of the visual impairment; and complete emotional and practical adjustment to the loss of sight. The researcher needed to understand why, if time heals, was there an increase in the level of the emotional reaction of frustration after a

considerable length of time of visual impairment; why was there continuous confrontation of losses associated with visual impairment that had continually to be adjusted to emotionally and practically? Part of the aim of this research study was for the researcher to gain insight into her own experience of visual impairment and then by an in-depth analysis arrive at an essential understanding of the relevant issues concerning the relation between length of time of visual impairment and psychological and emotional reactions of adventitiously visually impaired adults.

An intensive study was provoked by the questions that arose from the inescapable realities of adventitious visual impairment. There have been very few systematic studies done on the reactions to adventitious loss of sight over a long period of time. The paucity of literature and research that is available, generally focuses on the period from onset of visual impairment up to 2 years later, which includes the period during or immediately after rehabilitation. The study of the theme of psychological and emotional reactions related to adventitious visual impairment is based on literature and research of the *loss theory* and the grieving for loss of sight. This literature and research, which tries to understand and explain the phenomenology of loss of sight, is based on the traditional grief-following-loss theory and grief processes after loss through death, which presumes a time-limited linear progress through stages culminating with the final static stage of acceptance. It is inevitable therefore that the available literature on adventitious visual impairment also presumes a time-limited linear progress through the grief process culminating with acceptance of the loss of sight after which adjustment to visual impairment takes place. The researcher's and other long-term adventitiously visually impaired experiences of psychological and emotional reactions to visual impairment run contrary to what is expected and assumed by the traditional grief-following-loss theory and existing literature on the emotional and psychological reactions to loss of sight.

Another inescapable reality related to adventitious visual impairment is that continued loss forms an integral part of visual impairment. This implies that loss and related grief is a continuous process and forms an integral part of the lives of adventitious visually impaired persons.

The main aim of this present study is to begin to fill the gap in the literature and research on this meaningful and significant issue, which can potentially inspire and give insight to many adventitiously visually impaired adults, who are trying to gain understanding about the *real world* of adventitious visual impairment. The overall question in the study is whether there is a relation between different lengths of time of visual impairment and the experience of different psychological and emotional reactions by adventitiously visually impaired adults.

1.3 THE RESEARCH AIMS

The aim in this study is to gain insight into and understanding about the relation between different lengths of time of adventitious visual impairment (specifically, adventitious visual impairment for under and over 6 years) and the psychological and emotional reactions, especially frustration, associated with such loss; acceptance of and adjustment to adventitious visual impairment; and what the need is for continued emotional support. As the aforementioned factors form an integral part of any grief process, the study will investigate whether or not the grief process following loss of sight is comparable to that following loss through death with the implication that with time the grief is resolved.

These are the hypotheses and related subsidiary investigations to be tested in this study:

- **Hypothesis 1: Long-term adventitiously visually impaired persons experience more frequent frustrations than do short-term adventitiously visually impaired persons.**

Hypothesis 1 related subsidiary investigations:

Causes of frustration;
Time intervals and frustration.

- Hypothesis 2: Long-term adventitiously visually impaired persons experience more intense frustrations than do short-term adventitiously visually impaired persons.

Hypothesis 2 related subsidiary investigations:

Changes and frustration;
The healing effect of time;
A less frustrating life.

- Hypothesis 3: Long-term adventitiously visually impaired persons accept the impairment to a lesser extent than do short-term adventitiously visually impaired persons.

Hypothesis 3 related subsidiary investigations:

Adjustment to visual impairment;
Adjustment as a continuous or linear process;
Descriptions of acceptance and adjustment;
Changes in emotions from onset of visual impairment to the present.

- Hypothesis 4: The need for continued emotional support is greater for long-term adventitiously visually impaired persons than short-term adventitiously visually impaired persons.

Hypothesis 4 related subsidiary investigations:

The best person/s to offer support;
Types of helpful support;
Frustrating support.

1.4 CHAPTER OUTLINES

Chapter Two, "For Whom The Lights Go Out", contains a description of the quintessence of adventitious visual

impairment. It will focus on: the meaning of adventitious visual impairment; the difference between the types of adventitious and congenital visual impairment; the different levels of visual impairment ranging from total blindness to the level of partial sight; the main causes of visual impairment; and the rapidity of onset of adventitious visual impairment.

Chapter Three, "Loss Of Sight: - A Point Of No Return Or A Turning Point" contains the literature and research review of loss and grief. There have been few systematic studies of psychological and emotional effects of adventitious loss of sight and the limited amount of available literature and research is based on the *traditional* grief-following-loss theory after loss through death. Therefore traditional loss theory will form the overall basis for all subsequent discussions. The chapter will include three main sections focusing on the literature and research of loss and grief following loss through death, disability and visual impairment. Each section will focus on: models of the grief process; evaluations of the grief process models; the time course of the grief process models. The section on loss through visual impairment will include an additional subsection: the grief process and support. Another main section will outline frustration as a key emotion in adventitious visual impairment.

Chapter Four, "Factual and Meaningful Procedures", contains the research methodology relevant to this present study. It will include: pertinent terms to be used throughout the study; the aims of the present study; the hypotheses and related subsidiary investigations; the methodology of the study including the non-experimental research design involving both quantitative and qualitative data; sampling issues relevant to the study; the interview facilitated by a schedule as the data collection instrument and the standardised tests to be used in the study including the Sixteen Factor Personality Questionnaire (Human Sciences Research Council, 1966) and the Nottingham Adjustment Scale (Dodds, Bailey, Pearson & Yates, 1991); procedures to

examine the data including the statistical tests to be used.

Chapter Five, "The Relative Truth" contains the results obtained from the data analyses. The chapter will consist of 5 main sections. The first section will report on the experience and meaning of frustration. All subsequent sections will report the results and interpretation of the analyzed data from the testing of the hypotheses and subsidiary investigations related to the particular hypothesis under review, namely, the experience of frequency and intensity of frustration, acceptance of visual impairment and the need for continued emotional support.

Chapter Six, "More Than What Meets The Eye", contains the discussion and interpretation of the results obtained from the analyses of the hypotheses and related subsidiary investigations. The discussion will include an overview of the results followed by discussions of specific outcomes obtained from the data analyses. Possible explanations for the results as well as research and theoretical implications of the research study will be discussed.

Chapter Seven, "The Real World Of Visual Impairment", contains the conclusions and recommendations of the present study. The brief discussion will include the following: the research aims of the present study including the hypotheses and related subsidiary investigations; its major conclusions and suggestions; its limitations; recommendations for further research; and a reflection on the value of the present study.

The next chapter "For Whom The Lights Go Out" describes adventitious visual impairment.

CHAPTER TWO

FOR WHOM THE LIGHTS GO OUT

2.1 INTRODUCTION

All people are challenged to a lesser or greater degree throughout their lives. However, a small percentage of people are visually challenged as well and are broadly labelled as *blind*. This label is not conducive to understanding the effects of the impairment on the person's life. The degree of severity, its rapidity of onset and the nature of the impairment are all likely to play a part in how the person reacts to the challenge of sight-loss.

This chapter will present a brief overview of how the notion *visual impairment* is understood: the different types, levels and causes; and the rapidity of onset of adventitious visual impairment.

2.2 TYPES OF VISUAL IMPAIRMENT

Impairment refers to a physical, mental or sensory loss resulting from a bodily disorder or pathology and includes defective limbs (including lack of part or all of a limb), organs or mechanisms of the body (Finkelstein, 1980; Oliver, 1990). *Visual impairment* refers to the sensory loss of the ability to see. Two general types of visual impairment can be distinguished, namely, congenital and adventitious visual impairment. Both involve the loss of vision due to pathological changes in the eye. The congenital visually impaired are those persons born with the pathological changes already present, whereas, the adventitious visually impaired include those persons whose pathological changes have been "acquired later in life through disease or accident" (Metcalf, 1994, p. 4).

There is therefore an essential difference in kind between having seen and lost sight and never having seen, because on the one hand, there is the pain of dealing with *loss* of sight whereas, on the other hand, there is the pain of dealing with *lack* of sight. Rowland (1985, p. XV) states that "between these two groups there remain differences which essentially are unbridgeable." There are many differences between the two groups of visually impaired persons but perhaps the fundamental *unbridgeable* difference is that as congenitally visually impaired persons have never seen, they cannot visualise nor do they form visual concepts, whereas, the sighted and the *once sighted* are able to visualise and form their ideas about reality into visual patterns (Carroll, 1961). This research study will only focus on adventitiously visually impaired adults because of the possible differences in psychological and emotional reactions related to loss of sight as compared to the lack of sight.

To avoid cumbersome repetition, the term *adventitiously visually impaired* will be abbreviated to "AVI" for all further discussions.

2.3 LEVELS OF VISUAL IMPAIRMENT

Vision can be conceptualised as ranging on a continuum from normal vision to total blindness. Visual impairment in turn, includes different *levels* depending on the degree of severity. A person with a visual impairment is often assumed to be *blind* or *sightless*. People in general are not aware of the extreme variation among visually impaired persons and most have the misconception that visual impairment means "blackness and the inability to see" (Murray, 1995, p. 26). Although most visually impaired persons have some degree of residual vision, there is the level of *total blindness*. This level includes those persons who are totally unable to perceive even bright sunshine. Dodds (1993, p.2) states that this small percentage of totally blind people are the "exception rather than the rule." Another level includes those persons who only have light perception or light

projection. These persons have a visual acuity ranging from 20/500 to 20/1000 or less and a visual field constricted to between 10 and 5 degrees or less. The term used to describe this level is *functionally blind*, defined as a "condition of profoundly limited visual capability" (Metcalf, 1994, p. 3). A further level of visual impairment includes the *legally blind*, and includes those persons whose best corrected visual acuity is 20/200 or less in the better eye, or whose visual field is constricted to 20 degrees or less. In order to see clearly the same object, a normal sighted person could stand 60 metres away, whereas a legally blind person would have to stand 6 metres away. Another level of visual impairment includes those persons whose visual acuity with the best correction in the better eye ranges from 20/70 to 20/200. The term used to describe these persons is *partially sighted*, or a person with *low vision*. Table 2.1 shows quantitative criteria to define the different levels of visual impairment. These criteria include visual acuity together with a measurement of visual field in order to describe visual ability (Metcalf, 1994).

Table 2.1 Quantitative Criteria Of The Different Levels Of Visual Impairment (Metcalf, 1994, p. 4)

Normal Vision	20/10 (6/3) to 20/25 (6/7.5)
Near-normal Vision	20/30 (6/9) to 20/60 (6/18)
Moderate Impairment	20/70 (6/21) to 20/160 (6/48)
Severe Impairment	20/200 (6/60) to 20/400 (6/120) or < 20 degrees of field
Profound Impairment	20/500 (6/150) to 20/1000 (6/300) or < 10 degrees of field
Near Total Impairment	< 20/1000 (6/300) or < 5 degrees of field

The use of acuity readings as a description of the visual ability of persons is however a poor explanation because visual impairment is a "functional state rather than a mathematical concept" (Metcalf, 1994, p. 3). Furthermore, the description of residual vision by acuity readings is only one of a complex number of factors contributing to the ability to see. Therefore, in this research study, visual impairment and residual vision

will be described in *behavioral or functional* terms (Hallenbeck, 1967; Perry & Hampton-Roy, 1982; Corn & Sacks, 1994). The level of total blindness will include those persons who are totally unable to perceive even bright sunshine. The level of functional visual impairment will include those persons who only have light perception or light projection and have the ability to pick up changes in light levels and "vaguely see objects that contrast highly with the surroundings" (Perry & Hampton-Roy, 1982, p. X). The level of legal visual impairment will include those persons who are able to count fingers at 0,3 to 3 metres. The level of partial or low vision will include those persons who are able to read normal print with adaptive devices and those persons who are able to travel around in daylight without the aid of special equipment (Corn & Sacks, 1994).

The complexity and uniqueness of visual impairment is evident when visually impaired persons with tunnel vision have a central visual acuity of 20/20 enabling them to read normal print at normal distances but encounter difficulties travelling without a white cane. Other visually impaired persons might have sufficient residual vision to travel without a cane, but be unable to read regular print (Tuttle, 1984). Perhaps the most significant inference to be made from the above outline is that each level, excluding total blindness, is described in terms of lesser or greater degrees of *visual capabilities*. Therefore, the misconception that all visually impaired persons are *blind* or *sightless* is accentuated.

For the purpose of this research study, the term *visual impairment* will be used as an umbrella term to include all the diverse levels of visual loss.

2.4 CAUSES OF VISUAL IMPAIRMENT

The causes of visual impairment are many and varied. They include: congenital conditions, hereditary effects, infections, disease and trauma. To provide some insight into the types of

conditions that may cause visual impairment, some of the more common causes and their characteristics are described (Metcalf, 1994, pp. 4-6).

CATARACT formation is a progressive clouding of the crystalline lens inside the eye which leads to blurred and distorted vision. The amount and direction of light affects vision which can change according to light conditions. Glare causes discomfort and makes the vision worse.

GLAUCOMA occurs as a result of increased intraocular pressure. This results in visual field loss which can lead to tunnel vision and eventual blindness. Vision is affected at night and in dull light.

MACULA DEGENERATION is a condition which produces a blind spot in the centre of the field of view, the part of the eye used for seeing fine detail. Persons with macula degeneration often complain of an inability to recognise faces and difficulty with reading.

DIABETIC RETINOPATHY is a condition that occurs as a result of diabetes. This disease is often accompanied by hypertension, resulting in haemorrhages which discharge onto the retina which may ultimately lead to total blindness. Initially however, the loss of vision may occur in patches.

OPTIC ATROPHY is a deterioration of the optic nerve. Some of the causes are injury, glaucoma, and poisons. The visual acuity is affected and sometimes parts of the visual field are missing.

RETINAL DETACHMENT is an eye disorder where the retina detaches itself either in the form of a tear or a hole from the vascular layer. As the retina begins to buckle and fold over, black areas fall into the path of vision. The retinal film which sends images of what we see to the brain therefore becomes useless and could ultimately lead to total blindness. Retinal detachment may be

caused by disease or injury to the retina or by myopic degeneration. The incidence of this condition increases with age (Sussman, 1986).

CORNEAL DAMAGE is a major cause of impaired vision in developing countries. The cornea may be damaged from infection, injury or disease. The whole cornea can become cloudy, or parts can be damaged by scars. If light cannot pass through the cornea, vision will be affected. The results are the same as those for cataracts; visual acuity is reduced, good contrast is needed, and the amount of light affects vision. Corneal damage can be caused by different diseases such as TRACHOMA which is caused by an infection of the conjunctiva.

RETINITIS PIGMENTOSA is a hereditary condition which results in tunnel vision which could ultimately lead to blindness. Visual acuity may remain normal or deteriorate. Vision is often poor in dull light or at night. However, in good light the person may be able to do many activities that require good vision.

2.4.1 Factors related to causes

Sussman (1986) states that the causes and extent of visual impairment will vary according to the development of the country being studied. According to the SANCB Bureau for the Prevention of Blindness (1995) the statistical estimate of the prevalence of *legally blind* persons (which includes the levels of totally, functional and legally blind) in South Africa is 0,644% of the total population. A further estimated 0,322% are *partially sighted*, giving the estimated South African *visually impaired* as 0,9662% of the total population. However, in contrast to the estimated prevalence of *legally blind* persons in South Africa, the estimated prevalence in developed countries is 0,2% of the total population (SANCB, Bureau for the Prevention of Blindness, 1995).

Costa (in Sussman, 1986) found that the main causes of visual impairment in the under-developed regions of the world are Trachoma, Onchocerciasis or River Blindness, Malnutrition and Cataracts. In developing countries, agricultural and industrial injuries add to the main causes of visual impairment. In advanced urban societies where the lifespan of persons has increased, degenerative diseases are the principal causes of visual impairment (Sussman, 1986). In particular, Cataracts, Chronic Glaucoma, Age Related Macula Degeneration and Diabetic Retinopathy are the more prevalent causes. The main causes of visual impairment throughout the World, including specific reference to South Africa, are shown in Table 2.2.

Table 2.2 Main Causes Of Visual Impairment In the World and South Africa (SANCB: Bureau for the Prevention of Blindness, 1995)

Main Causes	World	South Africa
Cataracts	43,0%	59%
Trachoma	15,0%	*
Glaucoma	12,7%	22%
Age Related Macula Degeneration	5,0%	*
Diabetic Retinopathy	5,0%	*
Other Causes	19,3%	19%

* denotes no available data in South Africa

From the estimated statistics it is clear that as at 1995 Cataracts are the main cause of visual impairment throughout the World. This research study will focus on AVI persons originating from an urban South African society.

Sussman (1986) states that the rates of visual impairment correlate with the different age groups of the population. As age increases, so too will the frequency of AVI persons caused by age-related diseases of the eye. This is supported by the estimated prevalence of Cataracts and Glaucoma as the two main causes of visual impairment in South Africa and the first and third main causes in the World. There are no statistics available in South Africa on the prevalence of visual impairment related

to different age groups. In this research study, the age groups to be interviewed include persons between the ages of 22 and 60 years of age. Robbins and Fonda (in Sussman, 1986) classified visual impairment into different age groups with the corresponding main causes. Their findings showed that in the age group 21 to 40 years the main causes were Diabetic Retinopathy, Degeneration of the Macula, Optic Atrophy, and injuries. In the age group 41 to 60 years the main causes were Diabetic Retinopathy, Cataracts, Glaucoma and Macula Degeneration. One can only assume that the main causes of visual impairment related to age groupings in South Africa will be similar to those of other countries.

2.5 ONSET OF VISUAL IMPAIRMENT

The rapidity of onset of visual impairment can range from: immediate, rapid (up to 1 year) to a gradual and progressive loss of sight. Immediate loss of sight is often traumatic, although not necessarily always total and can occur as a result of accidents or injury. In this research study, *immediate* loss of sight will refer to loss which occurs within 24 hours and *rapid* loss of sight will refer to loss which occurs within a year from the time of onset. Gradual loss of sight can occur as a result of disease, as in diabetes, or infection. In this research study, *gradual* loss of sight will refer to loss which occurs within several years from time of onset. However, loss of sight may be an ongoing, progressive or life long process, as in the case of Retinitis Pigmentosa.

2.6 CONCLUSION

This chapter provided a background to the complex and often misunderstood and misconceived world of visual impairment. It gives insight into the meaning and causes of visual impairment and the extreme variation in the different *levels* which range from total blindness to partial sight. The essential difference between adventitious visual impairment, with the implication of

loss of sight as compared to congenital visual impairment, with the implication of *lack of sight* was discussed.

The next chapter will review the theory and literature pertinent to *grief-following-loss* and the related psychological and emotional reactions by focusing on loss through death, disability and visual impairment.

CHAPTER THREE

LOSS OF SIGHT: A POINT OF NO RETURN OR A TURNING POINT: A LITERATURE AND RESEARCH REVIEW OF LOSS AND GRIEF

3.1 INTRODUCTION

Loss is a universal phenomenon and is faced and experienced at one time or another by every human being. Whether the loss is through the death of a loved one or the loss of sight, the process of coming to terms with loss is complex and involves different psychological, emotional and behavioural reactions. In this chapter, focus will be on the grief process which embodies a person's total reaction to the emotional suffering caused by a loss through death, disability or visual impairment.

The chapter will consist of three main sections focusing on the literature and research of loss and grief following loss through death, disability and visual impairment. All sections will include sub-sections outlining the following: models of the grief process; evaluations of the grief process models; the time course of the grief process. The section on loss through visual impairment will include an additional sub-section: the grief process and support. Another main section will outline frustration as a key emotion in visual impairment. The first section will focus on loss through death, as this loss will form the foundation from which all other discussions of grief-following-loss will flow.

3.2 LITERATURE AND RESEARCH: LOSS AND GRIEF FOLLOWING DEATH

This section on loss and grief following death will focus on:

- the general description of loss;
- loss through death including: descriptions of grief-related

terms;

- models of the grief process including: death: stage models of the grief process; death: task and need models of the grief process; summation and evaluation of the grief process models;
- the time course of the grief process including: death: the time duration of grief; death: the time course of grief-related emotions; summation of time issues pertaining to the grief process.

3.2.1 General description of loss

There are widespread descriptions pertaining to the general concept of loss: deprivation, impairment, misfortune, catastrophe and detriment to name but a few. Generally, a loss, depending on the particular situation and aspect, involves a failure to obtain, cessation to possess, or inability to find (Reber, 1985). Losses occur in many different situations, for example, in a sporting event when a tennis player loses a tennis match and fails to obtain the singles title. Losses also involve a variety of aspects, including: people (when a loved one dies), objects (when a favourite teddy bear is misplaced and is unable to be found) and possessions (when a house and its contents are lost due to a catastrophic fire).

Specific losses involve particular characteristics. Loss of a person through death, for instance, implies the irrevocable and definitive cessation of contact with another person (Cleiren, 1993). In another context, such as loss through disability, and in particular, loss of sight there is the implication of an irrevocable impairment and the cessation of being able to see. Although these divergent losses are not directly comparable (the one involves the loss of another person, whereas, the other involves the loss of a person's sensory ability) the experiences that each elicits (cessation to possess, deprivation and irreversibility) are indeed similar and therefore comparable.

The divergent losses cited in the previous paragraph will be discussed separately, noting both the similarities and the differences. As the literature on *loss* and the related grief process originated from research into the subject of *death*, a discussion on loss through death and the related grief process will form the foundation from which all other discussions will flow.

3.2.2 Loss through death

The death of a loved one is one of the most intense of all human losses. Death implies an irretrievable loss of the *familiar* and the *taken for granted* position which has, up until the loss, given an all encircling meaning to the bereaved person's life (McKay, 1993). For instance, the deceased may have been the principal breadwinner and therefore the assumed source of continuous financial support for the bereaved spouse; an assumption which is challenged after the death. With a drop in the accustomed income and the resultant changes to the *taken for granted* lifestyle, the bereaved spouse may feel uncertain about what the future holds and there may be uncertainty about engaging in new tasks, for example, finding a job, that the bereaved spouse never anticipated before the death. Loss of the spouse may also result in confusion about the bereaved person's new role in the family and society, namely, roles that change from dependent wife and mother to independent breadwinner. Encountering loss through death for the bereaved person means that fundamental life issues such as an unpredictable future and the uncertainty of the ability to protect others and control life events have to be confronted (McKay, 1993).

In trying to cope with the distress of the loss, the bereaved person's emotions, thoughts, attitudes, behaviours and health are affected because every aspect of the bereaved person's life is thrown out of balance. Bereavement by death is a psychological trauma involving subjective reactions to the loss of a person with whom there had been a significant relationship (Stroebe &

Stroebe, 1987; Parkes, 1988; Sanders, 1989; Dershimer, 1990; McKay, 1993). Grief following loss through death is a person's total emotional reaction related to the irreversible loss of a significant social relationship (Stroebe & Stroebe, 1987; Sanders, 1989; Dershimer, 1990; McKay, 1990; 1992, 1993).

In the context of death, a variety of terms are used to describe the phenomenon and processes associated with loss. However, because the experiences involved in loss through disability and loss of sight are comparable to those experienced in loss through death, the same terms will be pertinent to all further discussions of loss. What follows is a description of the relevant terms.

Bereavement

Bereavement is seen as the act of having something or someone go permanently out of another person's control, possession or environment (Cleiren, 1993). In the context of loss through death, it implies the irrevocable and definitive cessation of contact with another person, whereas in the context of disability and in particular visual impairment, it implies the permanent and irrevocable cessation of being able to see. Bereavement includes both subjective and objective components. On the one hand, bereavement is a psychological trauma involving complex subjective responses to the loss of a significant person or to the loss of being able to see, whilst, on the other hand, bereavement is also an objective fact because it represents the experiential state a bereaved person suffers after realising that a loss has occurred (Stroebe & Stroebe, 1987; Parkes, 1988; Sanders, 1989; Dershimer, 1990; De Spelder & Strickland, 1992). As an *umbrella* term, incorporating both subjective and objective components, bereavement describes the actual state of loss involving a variety of changes in behaviour, emotions, thoughts, attitudes and experiences that occur as a result of a loss (Sanders, 1989; Dershimer, 1990).

Grief

Grief is the process that occurs after the loss event and is the manifestation of the bereavement experience (De Spelder & Strickland, 1992; Cleiren, 1993). Essentially, the *grief process* may be described as "making real (inside the self) an event that has actually occurred (outside of the self)" (McKay, 1993, p.3). Grief (in essence a deprivation experience) refers to a person's total reaction to the emotional suffering caused by a loss of any kind and includes internal processes (psychological) and observable physical reactions (Stroebe & Stroebe, 1987; Sanders, 1989; Dershimer, 1990; McKay, 1990; 1992, 1993; De Spelder & Strickland, 1992). Grief is therefore a process encompassing a variety of reactions: psychological (feelings, thoughts and attitudes), behavioural (interactions with others) and somatic (health and bodily symptoms), which are generated by the person's perception of irreversible loss (McKay, 1993). The emotional reactions experienced during grief include feelings of sorrow, anguish, anxiety, anger, frustration, fear and sometimes relief. The observable physical reactions are evident when the body suffers and shows signs of exhaustion, tension, sleeplessness and life generally becomes discontinuous and unbalanced (Sanders, 1989; McKay, 1990, 1992; De Spelder & Strickland, 1992).

Grief emerges from the awareness of a discrepancy between the *world that is* (the external stimulus of death or loss which signals the emotional response) and the *world that should be* (the person's perception of the loss) (Parkes, 1988; McKay, 1993). It is for this reason that bereaved persons often repeat in memory the world that included the deceased person or when the person could still see and are drawn in thoughts and images to the person who is no longer part of their world or to the person who can no longer see (McKay, 1993). Grief is expressed in the form of cognitive-affective processes by which the bereaved person gradually acknowledges, copes with and eventually adjusts to the reality of loss (Rubin, 1984, 1985; McKay, 1993). The grief process is an individual and unique perception of the loss and

culminates when the person regains balance and restores a sense of equilibrium in all aspects of life (Sanders, 1989; McKay, 1990, 1993).

Adjustment

Adjustment is a term closely related to the grief process. In order for bereaved persons to conclude the grieving process and regain a sense of balance and equilibrium, adjustment to the reality of the loss must occur (Sanders, 1989; Conyers, 1992; McKay, 1993). The term *adjustment* has a variety of meanings including: alteration, adaptation, change, shift and modification. All the meanings however, imply a state of change: in the context of death, a state of change and reorganisation to all areas of life affected by the continued absence of the lost person; in the context of loss of sight, a state of change and reorganisation to all areas of life affected by not being able to see, with a need to substitute, modify and alter ways of doing things as visually impaired persons. The process of adjustment embodies the flexibility and ability of persons in assessing, coping with and meeting various changes in situations and demands including: body, self and person-environment interactions imposed by the changes, in order to regain a sense of balance and harmoniousness (Reber, 1985; Carson, Butcher & Coleman, 1988; Gerdes, 1988; Livneh & Antonak, 1991). An example of adjustment is evident when a highly ambitious and committed businesswoman who is totally blinded after a motor car accident (changes in body) and who initially loses self-confidence (changes in self) and is faced with the stigma of being different (person-environment interaction) is able to rehabilitate and rejoin her business career and at the same time balance her need to engage in new projects and still maintain a highly dedicated relationship with her family.

Other terms, instead of adjustment, are often used to denote the end of the grieving process such as *recovery* (Weiss, 1988) and *resolution* (Rubin, 1984, 1985). The term *recovery* means to

heal, improve or to regain, and implies a return to the state as it was before the loss in certain areas of functioning (Rubin, 1984). The term *resolution* assumes a process which leads to a final and certain conclusion of grief. These two terms infer a linear, progressive process with a complete healing or total conclusion of the grieving process and the ability to return to the previous level of functioning as it was before the loss. However, in the context of loss of sight, this *ideal* cannot be realised because it assumes the ability to see again. On the other hand, the term *adjustment*, with its meaning of change, implies a dynamic process where change and therefore adjustment can continually occur in order to gain equilibrium (Tuttle, 1984).

In the context of this research study on loss of sight, *bereavement* will describe the actual state of loss of sight and the psychological trauma and changes in behaviour, emotions, thoughts, attitudes and experiences of persons after the permanent and irrevocable cessation of being able to see. *Grief* will refer to AVI persons' emotional reactions to the suffering caused by loss of sight. Attention will be given to psychological reactions (feelings thoughts and attitudes) and behavioural reactions (interactions with others) which are generated by bereaved persons' perceptions of irreversible loss of sight. Particular attention will be given to the emotional reaction of frustration experienced by the bereaved during the grief process. *Adjustment* will be used in the context of the grief process following loss of sight to denote the process whereby persons are able to cope with and meet continually changing conditions and demands. For example, the ability of AVI persons to adjust to the changed condition of the loss of sight and the need to meet the continuous new demands of this changed condition (Tuttle, 1984).

Attention will now be given to the different ways in which the grief process following loss through death has been conceptualised.

3.2.3 Death: Models of the grief process

A number of models have originated in an attempt to provide comprehensive, conceptual and explanatory frameworks for the various processes involved in grief. Two such frameworks to be discussed in this present study are: to view grief as covering a series of overlapping stages; and to view grief as consisting of different tasks and needs that have to be accomplished (Bowlby, 1969; Kübler-Ross, 1969; Parkes, 1970; Worden, 1982, 1985; Weiss, 1988). Both frameworks imply that the stages and tasks and needs must be concluded and accomplished in order for the grief process to culminate in the resolution and acceptance of the reality of loss resulting in the re-instatement of psychological equilibrium (Conyers, 1992).

3.2.3.1 Death: Stage models of the grief process

A conceptual framework often used to describe the grief process following loss through death is that of overlapping but distinct stages (Cleiren, 1993). The stage model tries chronologically to order and describe how grief functions and what its effect is on grievers. Despite great individual variations in grief reactions a certain general pattern is observable with reactions occurring in three successive, but overlapping stages (Shackleton, 1984; Gerdes, 1988; Dershimer, 1990; McKay, 1993).

In the first stage of *unreality*, there is the initial alarm and numbness of shock, disbelief and denial after the loss (Raphael, 1983; McKay, 1992). Other symptoms in this initial stage of the grieving process can include: appetite loss, physiological high arousal, cognitive illusions and dreams of the dead person and emotional anxiety (Cleiren, 1993). Although shock and disbelief may delay the full emotional reaction, moderate to high levels of anxiety are still experienced. In trying to cope with the distress caused by loss through death, people may either go back through their imagination, memories, dreams or thoughts to the time before the death occurred (approach behaviour and searching

reaction for the deceased), or they might simply ignore the death event (avoidance behaviour and denial reaction) (Parkes, 1972; Marris, 1974; Bowlby, 1975; McKay, 1993).

The second stage in the grief process, according to stage theory, is an intermediate period of *disorganisation* accompanied by acute somatic and emotional uneasiness and social withdrawal (Raphael, 1983; McKay, 1992, 1993). It is usually during this period of intense grief that disruption to personality organisation occurs, as the persistent and insatiable yearning for the lost person is accompanied by overwhelming emotions of pain, sadness, depression, despair and a feeling of helplessness (Parkes, 1972, 1988; Bowlby, 1973, 1975; McKay, 1992). It is also during this period that grieving persons because of despair, apathy and disorganised behaviour, gradually become aware and begin to accept the fact of the loss (Parkes, 1972; Bowlby, 1975; McKay, 1993). Despite the awareness of the reality of loss, the grieving person in trying to discover new goals, experiences difficulty in finding meaning in new activities.

Grieving persons experience overwhelming emotions and need to express those feelings in order to participate emotionally in life (McKay, 1990). Among the many feelings aroused during this second stage, the feeling of anger is significant. The anger reaction of rage, frustration and resentment may be directed towards: those persons close to the grieving person (for still being alive); towards the one who has died (for dying and leaving the grieving person behind); or the anger may be turned on self. McKay (1993, p. 5) states that this *anger* must be broadly interpreted to mean "hurt, frustration, fear and helplessness." This suggestion is supported by Joines (1995) who states that 5 types of anger can be distinguished: rage, anger, frustration, arguing and resentment.

Acute grief gradually declines and the bereaved begin an emotional and social re-integration into the everyday world (Raphael, 1983; Weiss, 1988). Thus begins the third stage of the

reorganisation of the bereaved person's personality (McKay, 1992). This reorganisation refers to the gradual acceptance of the loss, the putting together of life without the *lost* person and coping with the new reality that loss has indeed taken place (McKay, 1992). In this culminating period of reorganisation and the realisation of the permanence of loss, resolution through detachment occurs and grieving persons learn adaptive behaviours for their changed life situations, develop and integrate healthy self concepts and stable world views so that they can once again function in the world and control their environment (Parkes, 1985; Shuchter & Zisook, 1987; Dersheimer, 1990).

The completion of the three stages assumes the conclusion of the grief process with resolution and acceptance of the reality of loss resulting in the re-instatement of psychological equilibrium (Conyers, 1992). It is noted that the terms of reference used to describe the conclusion of the grief process include resolution and recovery; terms which infer a linear, progressive process with a complete healing or total conclusion of the grieving process and the ability to return to the previous level of functioning as it was before the loss.

Kübler-Ross' (1969) *grief stages* originated in her work with the terminally ill. Her model, although concentrating on the grief of the dying person can also apply to the bereaved. She distinguishes five *ideal typical stages* through which the bereaved and dying person proceed. However, Kübler-Ross (1974) acknowledges that the stages are not necessarily sequential, some may overlap and re-occur and each may vary in duration, whilst some may not be negotiated at all. After the initial shock, the first stage of denial is experienced. This may be seen as a necessary reaction, acting as a buffer against a reality that grieving persons are not ready to face (Gerdes, 1988). The second is a stage of anger or protest associated with the admission of impending death and takes the form of anger against this knowledge. It is often manifested in an outcry against it (why me?) and is often displaced onto others. Grieving persons may use

direct and displaced anger as a defence against fear, severe loss of control and as a way of controlling the environment (McKay, 1990). The third stage is associated with negotiating or bargaining with death. The person then experiences one or both types of depression. Reactive depression is a reaction to loss that has already occurred, such as when an organ has been removed. The common denominator in reactive depression is loss (Gerdes, 1988). Depression manifests itself in sadness, despair, hopelessness, poor self-esteem, feelings of helplessness and the loss of interest in life. Preparatory depression is a reaction to anticipated loss of an organ, functioning and life itself. When the person fully recognises the impending loss there is retreat from contact with others (Kübler-Ross, 1969; Gerdes, 1988). If the person has had enough time and assistance in working through the previous stages, there is the fifth and final stage of acceptance and a coming to terms with death after the struggle (Kübler-Ross, 1969; Hughes, 1980). Although Kübler-Ross (1974) acknowledges that the grief stages are not necessarily sequential and may overlap, there is still the inference that the grief process presumes a linear, progressive procedure with the final stage of acceptance as the certain conclusion and resolution of the grief process.

3.2.3.2 *Death: Task and need models of the grief process*

There has been a development away from the *stage models* to a category of *task and need* models to explain the processes involved in grief following loss through death. In these models the grief process is conceptualised as a series of tasks and needs that have to be accomplished in order to conclude the grief process and regain a sense of balance and equilibrium through resolution and acceptance of the reality of loss (Conyers, 1992). In the task models, the grief process following a loss is not conceptualised as an autonomous, natural series of changes (implied in the stage models), but rather an initiated process that involves the bereaved person in accomplishing certain tasks (Cleiren, 1993). Accomplishing the grieving tasks can be viewed

as patterns of growth which persons will experience during the grief process (McKay, 1992). Each task is regarded as a desired outcome in a particular area of functioning and the realisation of each task can be seen as the goal of the adjustment process (Cleiren, 1983). There are many tasks that have to be accomplished and many needs to be met during the grief process, but only four essential tasks and needs will be highlighted.

Task one involves the coming to terms with the reality that loss has occurred by acknowledging, recognising and accepting the finality of the loss (Worden, 1982; McKay, 1992; Cleiren 1993). By acknowledging and accepting the reality of the loss and the changes and re-evaluations of fundamental life issues, bereaved persons will be able to move towards reconstructing a new life for themselves (Worden, 1982).

Task two involves the experiencing and expression of the painful emotions that the loss elicits (Worden, 1982; McKay, 1992; Cleiren, 1993). Bereaved persons need to express the conflicting and overwhelming diversity of feelings that are experienced after a loss (Shuchter & Zisook, 1987; Cleiren, 1993). It is natural to express feelings about the loss, to protest against it and to long to reverse it (Parkes, 1986). In this task there is a need for grieving persons to identify, experience, express and integrate the painful emotions that the loss has elicited by finding means to modulate the painful affects and by finding adequate ways to regulate the pain in order to cope with the demands of daily life (Shuchter & Zisook, 1987; Dersheimer, 1990; Cleiren, 1993). This task is enhanced by an understanding social support system that gives bereaved persons permission to express all aspects of their loss and be helped in practical and concrete ways (McKay, 1993). *Healing* will only occur when grieving persons recognise that what is happening is a normal process and participate in the full range of feelings and their emotional expression because only then will bereaved persons realise the reality of the loss. It is only when the grieving person's personality stabilises and optimal balance

occurs (the third stage of reorganisation in the stage model) that bereaved persons are able to truly feel the pain, loss, anger and fear enough to start integrating the emotional experiences (Rubin, 1984; Shuchter & Zisook, 1987).

Task three involves the emancipation from the bond with the deceased person by integrating the changed relationship through acknowledging the end of its interactive existence (Cleiren, 1993). The coping strategy of redefining the loss in such a way that it can benefit the bereaved is often part of the successful completion of this task (Worden, 1982). The need to assimilate the reality of the loss is seen as the core adaptive goal of the grief process (Rubin 1984, 1985; Worden 1982, 1985; Bailey & Gregg, 1986; Dershimer, 1990; Piper, McCallum & Azim, 1992). This core adaptive goal is comparable with the process of adjustment which embodies the flexibility and ability of persons in assessing, coping with and meeting various changes in situations and demands, in order to regain a sense of balance and harmoniousness (Reber, 1985). Grieving may be viewed as a "process of gaining perspective on losses, of discovering what truly was lost and what was not" (McKay, 1993, p. 3).

Task four is the readjustment of grieving persons in relation to new people, new roles and the changed environment after the death of the person who has helped define their self concepts and situations (Worden, 1982; Shackleton, 1984; McKay, 1992). The bereaved persons need to conserve or adapt their social network; they need to maintain or rebuild meaningful and supportive relationships with others; they need to conserve a positive self image and perceive themselves as being in control; they need to maintain or rebuild psychological and physical health (Cleiren, 1993). When bereaved persons acknowledge that the deceased person is irretrievably lost they proceed through the painful and often resisted process of making conscious all the thoughts and feelings pertaining to the deceased person (Shackleton, 1984; Sanders, 1989). Bereaved persons can free themselves by withdrawing emotional energy from the deceased and reinvesting

that energy in other relationships and activities (Worden, 1982, 1985; Bailey & Gregg 1986; Dershimer, 1990).

In trying to emancipate themselves from the bond with the deceased by reworking relationships and memories of the past, bereaved persons are repeatedly confronted with the reality of the loss. Internal self-definitions and self-representations constantly shift and change and the bereaved have a need for *psychological sanctuary* which homeostasis provides (McKay, 1993). In order to achieve homeostasis (balance and equilibrium) bereaved persons need to accept the reality of the loss and maintain a semblance of continuity in life by discovering what is lost and being able to cope with it, finding out what is left in the present and ascertaining what possibilities, hopes and dreams lie in a reshaped future (Weiss, 1988; Dershimer, 1990). Even though bereaved persons experience devastating loss they have choices and are able to rebuild their world, rebuild meaningful and supportive relationships with others take on a new identity structure and conserve a positive self image and resume a place in the mainstream of life (Shuchter & Zisook, 1987; Sanders, 1989; Dershimer, 1990; Cleiren, 1993; McKay, 1993).

3.2.3.3 *Summation and evaluation of the grief process models*

There are many ways of conceptualising the grief process following a loss but only two models were highlighted in this discussion. The major difference between the two models in the conceptualisation of the grief process appears to be that the *stage models* view the grief process as a natural and spontaneous progression through different stages focusing essentially on emotional reactions, whereas, the *task and need models* conceptualise the grief process as an initiated process of a series of tasks and needs (one of which is the experience of emotions) that have to be accomplished by bereaved persons. Although there is consensus between the two models that acceptance, reorganisation, reintegration and assimilation are integral components of the grief process, each model places

emphasis on different aspects. For instance the stage models, especially that of Kübler-Ross (1969) view acceptance of the reality of the loss as the culminating stage and essence of the grief process. Acceptance is viewed by the task and need models as one of many tasks that have to be accomplished and they view assimilation of the reality of the loss (by emancipation from the bond with the deceased) as the essence of the grief process. However, in both models there is an inference of *recovery* or resolution of a linear, progressive process with a final conclusion of the grief process. The *stage* and *task and need* models are viewed as complementary rather than duplicative and antagonistic (McKay 1993).

Grief however, cannot be judged by a single rigid, objective standard regarded as universally normal as it rarely follows a predictable pattern (Piper et al., 1992). There is therefore an element of risk in trying to describe grief reactions in well-defined and predictable stages as no two persons react in exactly the same way. There will be differences and variations with respect to emotional reactions, their intensity and duration (Zisook & Shuchter, 1985; McKay, 1993).

The term *stage* may misrepresent the grief process in that it may imply that a certain emotion or behaviour must occur for a certain period of time and then disappear as if resolved, or that one stage is more valued than another (Dersheimer, 1990; McKay, 1993). The stages are not necessarily simple, sequential or unidirectional but rather dynamic, flexible and often complex and should therefore not be seen as linear or progressive (McKay, 1992, 1993; Cleiren, 1993). Serious doubts have been raised about the validity of the stage models (Cleiren, 1993). Research by McKittrick (1981/2) found little conclusive evidence of the different stages as proposed by Kübler-Ross (1969).

Conceptualising the grief process as *stages* is valuable when used for descriptive and explanatory purposes for indicating generalised patterns of growth which grieving persons will

experience in trying to accomplish the various grieving tasks (McKay, 1992). The useful insightful knowledge gained about the grief process from the *stage* descriptions has sometimes been distorted. For example, oversimplifications have been indicated when using the stage models as when society in general, and professionals in particular, assume that bereaved persons are in a *stage* when they react with anger or apathy or when they do not respond to a professional intervention. The tendency to over-identify bereaved persons with a *stage label* of *angry or denying*, may avoid the possible legitimacy of their concerns. A too rigid belief in stages may cause non-recognition of the variability among, and within, bereaved persons as they try to cope with the loss. For example, bereaved persons may not experience the stages at the same time or even in the same sequence (Swap in O'Connor & Lubin, 1984).

A conceptual problem with many of the *tasks* is that they implicitly or explicitly define adjustment after the loss in terms of complete recovery (Cleiren, 1993). There is thus an assumption that the level of functioning of the bereaved before the loss is the criterion to be attained at the end of the grief process. This is a difficult assumption because on the one hand, prior to, and independent of the loss, the bereaved may have had severe health, personal and social functioning problems, which could improve spontaneously after the loss, whereas, some bereaved may develop problems only after the loss (Cleiren, 1993).

In both the *stage* and *task and need* models there is a conceptualisation of the grief process that implies a particular course through which grief must progress in order to conclude the grief process. Acceptance of, and assimilation of, the finality of loss, and attainment of psychological balance and equilibrium (homeostasis) is regarded as a process completed.

Another concept closely linked to the grief process is that of *time*. Attention will now be given to the time course of the grief process.

3.2.4 Death: Time course of the grief process

Society in general (including professionals), have in the past viewed and continue, in the present, to view grief as a "time-table of demarcated points along the way with stipulated times for reaching each point" (McKay, 1993, p.4). Each point shows differences and changes over time so that people are able to gauge improvements or deteriorations. The general belief that *time heals* is an important concept in the grief models. There are assumptions of a specified time duration for the completion of the grief process and that psychological and emotional reactions will diminish during the time course of the grief process. These assumptions will now be presented and challenged.

3.2.4.1 *Death: Time duration of grief*

The expected duration of the grief reactions following loss through death can range from weeks, months to years. The most acute and intense experience of grief immediately following a loss usually lasts about four to six weeks and resolution should occur in a matter of weeks after the initiation of grief work (Rubin, 1984; De Spelder & Strickland, 1992). With regard to the time duration of the grief process, one common prescription based on consistent evidence is that for the majority of bereaved adults grieving should be virtually complete one year following a significant loss (Hartz, 1986; Rosenblatt, 1988). Weiss (1988) however, argues that it could take at least four years to gain the phase of adaptation and therefore recovery to occur. Parkes (1985) argues that in the normal course of events the intensity frequency and duration of the *pangs* of grief tend to diminish as time passes.

Research by Zisook and Shuchter (1985) found that the time course of grief was much more prolonged than generally expected. Dysphoric feelings, symptoms and behaviours were most frequent during the first year of bereavement but often remained present even four or more years after the death. In particular, anger,

depression and anxiety tended to diminish over time but not to expected statistically significant degrees (Zisook & Shuchter, 1985). Grief therefore, does not simply end in any circumscribed period of time but rather has a variable course with many interrelated but at least partially discrete dimensions (Zisook & Shuchter, 1985).

3.2.4.2 *Death: Time course of grief-related emotions*

A common expectation among researchers has been that emotions or *feeling states* related to grief will diminish in frequency and intensity with time (Parkes, 1985; Hartz, 1986; Rosenblatt, 1988; Weiss, 1988). However, research by Zisook and Shuchter (1985) found contrary evidence to these assumptions. In their research on widows and widowers who experienced spousal bereavement weeks to years prior to their study, found that a frequently experienced dimension among bereaved spouses is intense feeling states. They found that the most common feeling state or emotion is anger. The anger may be expressed in one or many forms, including irritability and frustration, which may be directed towards a variety of possible objects, or inwardly to self-reproach or guilt, or towards family members and friends for surviving. Feelings of irritability and anger were found to be maximal during the first year and yet contrary to expectations, remained a substantial aspect of grieving for many persons throughout the different time intervals (Zisook & Shuchter, 1985). A variety of other affective and somatic symptoms have been described during the grief process. In general most of these symptoms have traditionally been considered to reach their peak within weeks or months and then gradually diminish in frequency and intensity (Zisook & Shuchter, 1985). Nevertheless it is becoming increasingly recognised that widows and widowers may retain a sense of painful emptiness for years. Apathy, sense of loneliness and social withdrawal seemed to remain relatively persistent over time. Anxiety, symptoms of tension and restlessness were found to be as prominent as depression in the first as well as subsequent years (Zisook & Shuchter (1985).

Somewhat surprising was the fact that many bereaved never fully accepted the fact of their spouse's death and that the percentages of these bereaved persons increased over a four year interval. The bereaved do not forget the past but rather gradually discover which assumptions continue to be relevant in their new life situation and which have to be abandoned (Rubin, 1984). An assumption challenged in the research of Zisook and Shuchter, (1985) is the expected complete acceptance which is assumed to be the final stage in the grieving process.

3.2.4.3 *Summation of time issues pertaining to the grief process*

It would appear that despite the range in the expected time duration of the grief process there is still a subtle, but implicit assumption that the grief process, with diminished psychological and emotional reactions, can be navigated in most cases with the passage of time.

3.3 LITERATURE AND RESEARCH: LOSS AND GRIEF FOLLOWING DISABILITY

This section on loss and grief following disability will focus on:

- loss through disability;
- models of the grief process including: disability: stage models of the grief process; disability: task and need models of the grief process; disability: evaluation of the grief process models including a word on chronic grief;
- time course of the grief process including: disability: time duration of grief; disability: time course of grief-related emotions;
- summation: critical issues pertaining to the grief process.

3.3.1 Loss through disability

In the context of disability, loss implies an irrevocable impairment involving a physical, mental or sensory loss

(Finkelstein, 1980; Tuttle, 1984; Oliver, 1990). This loss also implies a cessation, failure or a reduction in the ability to perform in certain areas of life as was able to be done before the loss. The experiences that loss through disability elicit, for instance, cessation to possess, deprivation and irreversibility, are indeed similar and comparable to the experiences encountered following loss through death.

Disability is regarded as a special case of bereavement, involving the permanent loss of important body parts or functions (Hallenbeck, 1967). Adjustment to disability necessitates that bereaved disabled persons adjust to the reality of the loss in order to regain the sense of certainty, balance and equilibrium (Hughes, 1980). The process of adjustment to disability embodies assessing, coping with and gradually assimilating various changes in body (paralysis after a diving accident), self (loss of self-confidence and self-esteem because of the loss of the ability to do similar things as before) and person-environment interactions (patronising attitude of society because of the disability or the stigma attached to being different) imposed by the disability (Livneh & Antonak, 1991). In addition, adjustment is perceived as a process of dismissing both false hopes and destructive hopelessness in order to give meaning and purpose to living that transcends the limitations imposed by the disability (Wineman, 1990).

Attention will now be given to the models used to explain the grief process after loss through disability, noting both the similarities and differences between the grief processes and associated psychological and emotional reactions following loss through death. The time course of grief and its associated assumptions will also be addressed and challenged.

3.3.2 Disability: Models of the grief process

Research (Parkes, 1975; Hughes, 1980; Bailey & Gregg, 1986) supports the premise that the grief process as experienced by

persons who have suffered major or even minor losses, including loss through bodily injury or illness, is comparable to the loss sustained through death of a loved one.

3.3.2.1 *Disability: Stage models of the grief process*

Psychological research studies relating to disability have indeed shown remarkable similarity to the stages and grief reactions experienced after a loss through death (Falek & Britton, 1974; Parkes, 1975; Hughes, 1980; Livneh & Antonak, 1991). Different researchers (Falek & Britton, 1974; Drotar, Baskiewicz, Irwin, Kennel & Klaus, 1975; Livneh, 1986) argue that a stable sequence of stages defines the process of change in human functioning associated with a disability. Drotar et al. (1975) delineated stages of shock, denial, depression, anger, acknowledgement and reorganisation or adjustment to disability. In this particular study, the researchers conceptualised reactions as overlapping regions of temporary adjacent stages on a linear continuum. Adjustment to disability can be correlated to the final stage of resolution or recovery in the literature on the grief process following loss through death (Drotar et al., 1975).

Falek and Britton (1974, p.5) described a "coping sequence which is a universal reaction to any change in the established steady state" which is great enough to produce stress in any person, from minor or major losses and resultant traumas. The coping sequence consists of four stages: shock and denial; anxiety; anger and/or guilt; and depression. In many of the different types of loss through disability, for example, paraplegia (Falek & Britton, 1974), spinal chord injury (Ray & West, 1983; Elliott, Witty, Herrick & Hoffman, 1991), patients with terminal cancer (Kübler-Ross, 1969) and grieving family members (Parkes, 1972) all, or most of, the characteristics of the coping sequence are present. Parkes (1975) compared widows with amputees in their reaction to loss and found that the symptoms of grief were remarkably similar. The reactions followed

the stages with immediate numbness, shock, and denial. Later both groups experienced periods of sadness, preoccupation with the loss and visual memories of the departed husband or limb. There was however a difference between the two types of losses with regard to the focus of the grief: the widows grieved specifically for their spouses whereas the amputees grieved more for the other losses rather than the loss of limbs themselves. The amputees had not only lost a part of their body, but often their jobs, friends, their sporting skills and the ability to drive a motor car.

Injured athletes go through a process similar to the one described by Kübler-Ross (Quackenbush & Crossman, 1994). However, the Kübler-Ross (1969) grief stages concept when applied to injured athletes is not without its flaws and athletes do not necessarily follow all the stages. For example, the results from the study by Quackenbush and Crossman (1994) showed that denial is not apparent as a stage in the process of recovery from athletic injury as the supporters of Kübler-Ross grief stages propose. What is important is that the athletes move from denial to acceptance as quickly as possible (Quackenbush & Crossman, 1994). The general stages which explain psychological recovery from injury include: shock and denial, increased emotionality, preoccupation with attempts to explore the meaning of the injury and reorganisation through normal routine activities and acceptance of the injury (Quackenbush & Crossman, 1994). Farris (1985) has, however, stated that athletes will go through the cycle of emotions more than once before the rehabilitation process is complete. In the research by Quackenbush and Crossman (1994) there is an assumption that an injury is reversible and that recovery will occur. Therefore, the expected final stage of acceptance in the process of recovery from injury is similar to the expected final stage of recovery and resolution after loss through death. The term *recovery* with the meaning of healing, improvement or to regain, and the implication of a return to the state as it was before the loss in certain areas of functioning appears to be applicable here (Rubin, 1984).

In research by Livneh and Antonak (1991) eight stages of psychosocial reactions to disability in a hypothesised stable temporal order were delineated: namely, shock, anxiety, denial, depression, internalised anger, externalised hostility, acknowledgement and adjustment. Their findings however showed that contrary to the expected invariant hierarchical order of stages, none of which may be missed, disabled persons may indeed skip a particular adaptation stage, as well as regress to earlier stages. This was based on observations often associated with renewed life crises and unexpected medical problems (Livneh & Antonak, 1991). A common psychological reaction mentioned in almost all the grief models is that of denial.

Denial

Denial is an ego coping mechanism meaning an evasive or avoidance reaction (McKay, 1990). The concept has implications of negation, scepticism, disbelief, refutation and rejection.

Research (Elliott et al., 1991) has shown that many persons after an acquired disability engage in a type of psychological denial which include the characteristics of: an absence of anxiety and depression, little acknowledgement of the implications of the condition and expressed optimism regarding the eventual resumption of disruptive social roles and physical functioning. The denial of the reality of the loss can also be interpreted as an attempt to maintain the representation of, or sense of continuity of the lost limb or body function. In the early stages of loss through disability, denial has been found to be related to internal anticipation of control and less psychological distress (Elliott et al., 1991).

However, society and in particular families, often encourage denial on the part of disabled persons (Hughes, 1980). The disabled are often encouraged not to think of their losses and are made false promises that they will improve, resulting in a false hope of recovery (Hughes, 1980). Thus, when denial is

encouraged and when the disabled are urged not to accept their disabilities the healing power of grief will be blocked (Hughes, 1980). Adams and Lindemann (1974) cite the example of a young athlete who was paralysed from the waist down after a car accident. After the accident the young man continued to insist, despite evidence to the contrary (rejection, disbelief and negation of the reality of the loss) that he would completely resume his former active life-style. His parents also insisted that a miracle could occur and that he would walk again if the hospital staff did their jobs properly (scepticism, disbelief, rejection and negation of the reality of the loss). Two years of psychotherapy did little to relieve the young man's depression and hostility and he continued desperately to cling to a false hope of recovery, reinforced by his parents. Hughes (1980) therefore differentiates between denial as a *permanent condition* and denial as a *stage* to be worked through during the grief process.

3.3.2.2 *Disability: Task and need models of the grief process*

The grief process following loss through disability is also conceptualised as a series of tasks and needs that have to be accomplished in order to conclude the grief process and regain a sense of balance and equilibrium (Conyers, 1992). In this section a concise discussion of the essential tasks and needs to be accomplished by disabled persons will be provided.

An essential task involves coming to terms with the reality that loss has occurred by acknowledging, recognising and accepting the finality of the loss (Falek & Britton, 1974; Parkes, 1975; Hughes, 1980; Livneh, 1986; Livneh & Antonak, 1991; Quackenbush & Crossman, 1994). Disabled persons have the task of experiencing, expressing and dealing with all the emotions, pain and problems that their loss has elicited (Hughes, 1980; Livneh & Antonak, 1991; Quackenbush & Crossman, 1994). Only by participating in the full range of feelings and their emotional expression, will bereaved disabled persons realise the reality

of the loss and be able to emotionally participate fully in life (McKay, 1990). The ability to accomplish this task of expressing emotions will be enhanced by an understanding social support system that gives permission for bereaved disabled persons to express all aspects of their loss and be helped in practical and concrete ways (McKay, 1993).

The most fundamental task, as in the case with loss through death, is the need for disabled persons to integrate and assimilate the reality of their losses. People who have sustained permanent physical losses accompanying chronic disease such as multiple sclerosis, or debilitating injuries, have to maintain a sense of self-worth in spite of their losses, as well as behave in ways conducive to optimal psychological and physical adjustment (Elliott et al., 1991). Bereaved disabled persons need to conserve or adapt their social network; they need to maintain or rebuild meaningful and supportive relationships with others; they need to conserve a positive self image and perceive themselves as being in control; they need to maintain or rebuild psychological and physical health (Cleiren, 1993). By acknowledging, accepting and integrating the reality of the loss; by becoming aware of what was lost and what was not (the reality of the implications of loss); by confronting, re-evaluating and acknowledging that changes and adjustments to fundamental life issues must occur, disabled bereaved persons will be able to grow and move towards the task of reconstructing a new life for themselves (McKay, 1990, 1993; Elliott et al., 1991).

3.3.2.3 *Disability: Evaluation of the grief process models*

The stage models of grief are usually based on the period of grieving that follows, or closely proceeds from a death (Davis, 1987). There is no, or little, focus on the long-term experiences of persons who have experienced loss, be it loss through death or loss through disability. Most proponents of stage models generally acknowledge and presume a time-limited, natural and linear progress through the stages culminating with the final

stage of acceptance, adjustment, recovery or resolution. This implies (as in the case with the grief process following loss through death) a final static culmination of the grief process. However, permanent disabilities, chronic illness and degenerative conditions often result in different kinds of grieving that are cyclic or recurrent and that require coming to terms with a continuous long lasting change (Davis, 1987; Livneh & Antonak, 1991; Lindgren, Burke, Hainsworth, & Eakes, 1992).

Although labelling recognisable stages of grief may occasionally encourage the griever to recognise feelings, it may just as easily interfere with the grieving process by implying the appropriateness of progression through the stages (Davis, 1987). This implication can be compared to the oversimplifications and distortions made by society when using the stage models pertaining to grief work caused through death.

Stage theories of grief often distort the grief experience of those who live with disabilities (Davis, 1987). Bowlby (1979) acknowledges that although the stages of grief change over a period of time in most grieving persons, they eventually achieve emotional detachment from the deceased person. Davis (1987) in her research on grieving mothers of mentally disabled children argues that this is an inappropriate resolution for the mother of a living child. Silverman (1981) describes the period of grief as occurring when a person is between roles, for example, between the role of wife and widow. However, Davis (1987) argues that the role of mother to a living disabled child is continuous, even as the grieving continues. Weisman (in Davis, 1987) states that the grief process is completed when the factual loss becomes a significant memory. The disabled child, however, remains physically and psychologically present, regardless how memorable the moment of diagnosis may be (Davis, 1987). Although the mother of a disabled child may describe the crisis as *like a death*, the grief experience cannot be resolved in the same way as can death. The disabled child does not die and to resolve the grief would be to deny the continuity of the child's life (Davis, 1987). The

mother's grief is mixed with confusion, and uncertainty and the passage of time does not permit a resolution of either the uncertainty or grief (Davis, 1987).

Although Davis's research (1987) focuses on the experiences of mothers of disabled children, these experiences can be comparable to the experiences of disabled persons themselves. This is because disabled persons who are grieving for their loss do not themselves die and are physically and psychologically present and to resolve the grief process as in the case of loss after death would be to deny the continuity of disabled persons' lives (Davis, 1987). Disabled persons' attitudes, like the mother's grief, will be mixed with confusion and uncertainty and the passage of time will not permit a resolution of either the uncertainty or grief (Davis, 1987).

Related to the notion of the passage of time not permitting a resolution of grief, the concept of *chronic sorrow* has been used to describe the grief process for people who live with disabilities (Davis, 1987).

3.3.2.4 *A word about chronic grief*

People who live with disability experience grief which is often described as chronic sorrow (Davis, 1987; Lindgren et al., 1992). Losses are an integral part of chronic illness and disability and confrontation of loss is a continual experience for chronically disabled persons because the loss is continually redefined in new situations with new problems (Lindgren et al., 1992). The term *chronic sorrow* is used to describe the emotional pain of the recurring, long term periodic sadness the chronically disabled experience, in reaction to continual losses (Lindgren et al., 1992). They argue that because sorrow is described as "mental suffering caused by loss or disappointment" and because grief is "intense emotional suffering caused by loss, misfortune or injury" the two terms are comparable (Lindgren, et al., 1992, p.30).

The imposition of stage models on the experience of chronic grief distorts the experience and limits the understanding of the psychology of grieving of disabled persons because: the stage models conceptualise the grief process as a time-limited natural progress through the stages culminating with the final stage of acceptance, recovery or resolution; persons with permanent disabilities on the other hand, experience a cyclic or recurrent grief process, implying no time-limited finality of the grief process (Davis, 1987). Thus, if the underlying cause of continual losses is a disability, then grief operates throughout the course of those disabilities (Lindgren et al., 1992).

3.3.3 Disability: Time course of the grief process

As in the case of the grief process following loss through death, society in general (including professionals), have in the past and continue in the present to view grief following loss through disability in terms of a stipulated time duration for the completion of the grief process. Psychological and emotional reactions will diminish during the time course of the grief process.

3.3.3.1 Disability: Time duration of grief

The general belief that *time heals* is an important concept in the grief models related to disability. This is because most of the literature and research on loss through disability is based on the assumptions of the grief process following loss through death and the expectations of a time-limited grief process ranging from weeks, months to years.

Lindgren et al. (1992) describe two categories of grief, namely, resolvable and chronic grief. They argue that in the case of resolvable grief, the grief diminishes in intensity with time as the person reinvests in life and detaches from that which was lost. In chronic grief, the grief continually occurs from new losses and from old losses that are continually brought to mind

(Davis, 1987; Lindgren et al., 1992). Although resolvable and chronic grief are both reactions to loss, the reactions are diverse. Resolvable grief is a reaction to one identified perceived loss, whereas, chronic grief is a reaction to numerous losses that are part of chronic illness or disability (Lindgren et al., 1992). The identifiable attributes in the conceptual analysis of chronic grief according to Lindgren et al. (1992) include: a perception of grief over time in a situation that has no predictable end; grief is cyclic or recurrent and is triggered either internally or externally; grief is progressive and can intensify years after the initial sense of loss, disappointment or fear. The expected time-limited duration of the grief process following loss is challenged by this concept of *chronic grief* which assumes a recurrent, cyclic and continuous grief process.

Elliott et al. (1991) in their study of traumatically acquired spinal cord injury, found an indirect relationship between chronicity and psychosocial adjustment. They argue that empirical research has generally found no meaningful relationship between psychological adjustment of people with acquired physical disabilities and the presumed *healing properties of time*. Years may elapse before persons with disabilities appreciate the full extent and implications of their conditions (Elliott et al., 1991; Livneh & Antonak, 1991). The assumed and expected time-limited duration of the grief process, an assumption in literature and research on the grief process following loss through death, has been challenged in this section with the concept of *chronic grief*.

3.3.3.2 Disability: Time course of grief-related emotions

As in the case of the grief process following loss through death there is a common expectation among researchers that the feeling states of disabled persons will diminish in frequency and intensity with time (Falek & Britton, 1974; Parkes, 1975; Hughes, 1980; Livneh & Antonak, 1991). Lindgren et al. (1992) state that in the case of resolvable grief which is experienced after one

identified loss, as in the case of loss through death, the grief reactions do indeed diminish in intensity with time as the person reinvests in life and detaches from that which was lost. However, in the case of chronic grief, the increasing intensity and frequency of the grief and related emotions may be related to the *build-up* or cumulation of the numerous losses that are a continuous part of a disability and to the impact such losses have on the person (Davis, 1987; Lindgren et al., 1992).

Attention will now be given to the emotional responses of 25 injured athletes described in Quackenbush and Crossman's research (1994). Various emotions, including frustration, were directly measured. As frustration forms the basic emotion in this research, cognisance must be taken of the results.

The instant athletes are injured, most of what they have worked for is taken away. This has a devastating impact, because for athletes, physical condition and athletic ability are the major components of self worth (Farris, 1985; Quackenbush & Crossman, 1994). The athletes subsequently experience feelings of separation, loneliness, guilt and a loss of identity and independence. This could possibly be explained by the fact that the athletes feel that they are no longer contributing to the team and that they are dependent on others in the rehabilitative process (Quackenbush & Crossman, 1994). Emotions such as fear, anger, frustration or depression are normal responses to traumatic injury (Farris, 1985). In Quackenbush and Crossman's (1994) research, the negative emotions of anger, frustration and discouragement decreased from onset of injury to returning to practice, whilst the positive emotional responses such as being hopeful and optimistic increased through the stages (see Table 3.1). However, although the negative emotional response of frustration decreased, it was still apparent at each stage and continued to be experienced after rehabilitation (Quackenbush & Crossman, 1994). One of the causes of frustration experienced by the injured athletes before and after rehabilitation is the athletes' perceived inability to perform at pre-injury levels.

Table 3.1 Frequencies of negative and positive emotional responses after athletic injury (Stage: 1 Initially 2 following day 3 During rehabilitation 4 returning to practice Quackenbush & Crossman, 1994, p. 184)

Responses	Stage 1	Stage 2	Stage 3	Stage 4
Negative				
Angry	16	11	3	2
Irritable	10	11	5	2
Frustrated	16	13	11	7
Positive				
Enthusiastic	0	0	9	12
Happy	0	0	1	12
Hopeful	2	4	13	14

A limitation in this research is the restricted time duration of one year from the onset of the injury to the return to practice. It would be interesting to investigate the long term emotional responses of athletes who are permanently injured. This research does, however, confirm Ray and West's (1983) results on paraplegics' emotional impact of injury. Most paraplegics experienced, and continued to experience over a long period of time, depression or frustration to varying degrees.

3.3.4 Summation: Critical issues pertaining to the grief process

The traditional assumptions that intense emotions will diminish in intensity and frequency with time and that complete acceptance and total adjustment is the final stage in the expected time-limited grief process following loss through disability have been challenged by researchers (Davis, 1987; Lindgren et al., 1992). Most bereaved persons in loss through death, after attempting various strategies, complete the stages of grief, overcome the loss and then come to a point of acceptance which is followed by resolution (Hughes, 1980). In contrast however, descriptions of the grief process following loss through disability, show a course of recurrent, cyclic and continuous grief (Davis, 1987; Lindgren et al, 1991). Disabled

persons, and in fact, all grieving persons, can obtain perspective on grief only when it is acknowledged (Davis, 1987). The ability to be realistic, to know, feel and experience all the emotions and to be able to live with loss, is essential not only for successful bereavement work but also for living with a disability on a continuous basis (Davis, 1987).

In the following section, attention will be given to the literature and research on the grief process following loss through the specific disability of visual impairment.

3.4 LITERATURE AND RESEARCH: LOSS AND GRIEF FOLLOWING VISUAL IMPAIRMENT

This section on loss and grief following visual impairment will focus on:

- literature on adventitious visual impairment;
- loss through visual impairment;
- models of the grief process including: visual impairment: stage models of the grief process; visual impairment: task and need models of the grief process; summation and evaluation of the grief process models;
- time course of the grief process including: visual impairment: time duration of grief; visual impairment: time course of grief-related emotions; summation of time issues pertaining to the grief process;
- the grief process and support including: helpful and unhelpful support; time length of support.

3.4.1 Literature on adventitious visual impairment

Generally, the literature on adventitious visual impairment focuses on the period before and immediately after rehabilitation (Carroll, 1961; Hallenbeck, 1967; Fitzgerald, 1970; Tuttle, 1984; Dodds, 1989, 1991, 1993; Conyers, 1992). There is also a focus on the actual practical process of rehabilitation, for example,

orientation and mobility of AVI people (Carroll, 1961; Dodds, 1993). With regard to general information from research on visual impairment, Rowland (1985) states that although the lists of research are long, analysis shows that the majority of the research projects connected with visual impairment fall into three main categories: technological research to develop and evaluate devices useful to the visually impaired; technical research to develop and evaluate materials, programmes and tests for the assistance or instruction of the visually impaired; perceptual research particularly in the field of reading and of orientation and mobility.

In a guide on research being done on visual impairment (King, 1993), it would appear that the research categories delineated by Rowland (1985) still exist, namely, technological and technical research to develop and evaluate devices, materials, programmes and tests for the assistance or instruction useful to the visually impaired, including: computer speech synthesis, braille devices and production, tactile images and diagrams; aids such as writing and educational aids and games; and perceptual research particularly in the field of reading, cognitive mapping and spatial perception and behaviour in the visually impaired. It is evident that there is a gap in the literature and research on psychological aspects, such as the emotions experienced by long-term AVI adults. This lack of literature is confirmed by Corn and Sacks (1994) when they state that the psychological impact on any visually impaired persons has not been explored in great depth, even in the general literature of disabilities.

3.4.2 Loss through visual impairment

Loss of sight, whether partial or total, constitutes a significant sensory deprivation. In most cases (an exception being loss of sight due to cataracts, a situation which is indeed often surgically restorable), loss of sight implies an irrevocable permanent impairment or deprivation of the sensory function and in many cases cessation of being able to see

(Carroll, 1961; Hallenbeck, 1967; Fitzgerald, 1970; Tuttle, 1984; Dodds, 1989, 1991, 1993; Conyers, 1992).

Loss through visual impairment involves the cessation of the *familiar* and the *taken for granted* positions, which have, up until the loss, been part of, and given an all encircling meaning to a person's life. For example, visual impairment often makes even the simplest activities such as walking, reading or making a cup of coffee (activities the person has been doing automatically since childhood) difficult or impossible and often results in the person running the risk of causing an accident or gaining social disapproval (Dodds, 1991). Situations like these challenge the visually impaired person's assumptive world. For example, the assumption of independent mobility or reading, which if lost may, in turn, result in uncertainty about what the future holds in terms of career and uncertainty about engaging in new tasks at which the person may have had some reasonable expectation of success before the visual impairment. Visual loss may also result in confusion about the visually impaired person's new role in the family or society, discontinuity of mobility by being unable to drive a motor car and imbalance in many areas of life including: on the physical level (mobility); on the personal level (daily living skills); the social level (communication skills) (Carroll, 1961; Tuttle, 1984; Dodds, 1989, 1991, 1993; Conyers, 1992).

Loss of sight as a death

Carroll (1961) interprets the meaning of loss of sight that occurs in adult life as a *death*. He has compared loss of sight to a *dying*, for he argues that when visual impairment comes, it is the end or the death of that sighted life. The *death* may be rapid, resulting from an accident, or from some debilitating disease, such as diabetes, or it may be the slow *death* to a sighted life from a systemic physical ailment as in multiple sclerosis (Carroll, 1961). The *death* may come without warning, the onset often hidden by false hopes or promises of recovery,

or it may come with an inevitable slowness. Carroll (1961) argues that however the loss comes, it is *death* to a sighted way of life and the end of acquired methods of doing things.

Carroll (1961) describes visual impairment as a *multiple handicap*, involving not only the loss of being able to see, but fundamental losses in all areas of persons' lives. Loss of sight is not only a visual loss, but a destructive blow to the self image which people have carefully constructed throughout their lives (Carroll, 1961). Sight gives people a feeling of wholeness, confidence, mobility and orientation (both emotionally and geographically), visual perception of the pleasurable and beautiful, independence, social adequacy and self esteem (Carroll, 1961; Banwell, 1991). When sight is lost many of these characteristics are lost forever, for example, the visual perception of the beautiful, while some can be partially restored, for example, independent mobility by training with a white cane and rehabilitation (Carroll, 1961; Banwell, 1991). According to Carroll (1961), rehabilitation of AVI adults is the process whereby people in varying stages of helplessness, emotional disturbance and dependence come to gain new understanding of themselves and their impairment, the new skills necessary for their new state, and a new control of their emotions and their environment. Therefore, rehabilitation as described by Carroll (1961) is comparable to the process whereby AVI adults learn to adjust to their impairment, with the process of adjustment consisting of assessing, coping with and gradually assimilating various changes in body, self and person-environment interactions imposed by the impairment (Livneh & Antonak, 1991). For example, AVI people have to assess the limitations in mobility and reading imposed by the impairment, be trained to cope with the limitations (being trained to walk with a white cane or read with a computer and voice synthesizer), and then be able to assimilate these changes into their working environment by positive interaction and education of fellow workers and management. In the context of visual impairment therefore, AVI people have to adjust to the reality of the loss of sight in

order to regain the sense of balance and the reinstatement of psychological equilibrium (Conyers, 1992).

Attention will now be given to the models used to explain the grief process following loss of sight, noting both the similarities and differences between the grief processes and associated psychological and emotional reactions after loss through death and disability.

3.4.3 Visual impairment: Models of the grief process

Grief models of loss through death will influence the models used to explain the grief process following loss of sight based on the premise that grief experienced by people who have suffered major or even minor losses, including physical disability and visual impairment, is comparable to the loss sustained through death (Parkes, 1975; Hughes, 1980; Bailey & Gregg, 1986).

3.4.3.1 Visual impairment: Stage models of the grief process

Many psychological research studies relating to visual impairment (Fitzgerald, 1970; Perry & Hampton-Roy, 1982; Tuttle, 1984; Conyers, 1992) are based on the stage models of grief following loss through death (Kübler-Ross, 1969; Parkes, 1975; Rubin, 1984; 1985; Weiss, 1988). Specific research related to the stages of the grief process following adventitious loss of sight will be highlighted in order to discuss the shift in the conceptualisation of the grief process from a linear to a continuous process.

Fitzgerald (1970) studied the reactions to loss of sight in a group of adventitiously blinded adults of working age. He emphasised that normal psychological reactions to loss of sight include, shock, denial, anxiety, anger and depression. The initial stage was absolute disbelief. While most AVI people then moved to the stage of asserting that they had acknowledged the onset of their blindness, various behaviours demonstrated that

a partial denial or protest against their condition was initially present, or persisted with pining for the sighted state (Fitzgerald, 1970). Disbelief, denial and protest were gradually, suddenly or intermittently replaced with the stage of depression or other intra-psychic distress. Of these reactions, depression was found to be the most common reaction occurring in 85% to 92% of all those interviewed. The reactions varied in intensity, from moderate distress to the frequent and severe incapacitating states in which depression with suicidal ideation, anxiety, weight loss, and sleep disturbance occurred. Recovery from depression and other distress began at various times after the onset of visual impairment, with the majority taking many months to recover. The *turning point* was associated with increased self esteem from attempting and mastering self sufficient acts and with the establishment of important interpersonal relationships with care givers and other blind people (Fitzgerald, 1970). He concludes that the distinct stages of reactions which include shock, disbelief or denial, anger or protest and anxiety are essentially healthy responses to the loss of sight. He states that the *stage* reactions seem to occur in the order mentioned above, but without clear dividing lines between them. Fitzgerald (1970) states that his study illustrated that loss of sight results in a dynamically unfolding process and not just a fixed state of depression.

However, it must be noted that Fitzgerald's study did not include people that had been blind for more than 5 years: the average range of blindness was 1,2 years. In addition, his study implies a final state of recovery and acceptance of visual impairment, comparable to the expectations of the grief process following loss through death (Kübler-Ross, 1969; Rubin, 1984, 1985; Weiss, 1988).

While conducting interviews with visually impaired people Perry (Perry & Hampton-Roy, 1982) became aware of the various levels of acceptance and adjustment of these persons to their loss of sight. Some had been visually impaired for a much longer time

than others, but Perry concluded that longevity was not necessarily a measure of acceptance or adjustment (Perry & Hampton-Roy, 1982). This indicates a shift away from the assumptions of the grief process following loss through death with the expectation of total acceptance and adjustment occurring within a time-limit (Parkes, 1985; Hartz, 1986; Rosenblatt, 1988; Weiss, 1988).

Perry evaluated her findings according to the *stage* models of reactions to grief. According to Perry, the initial reaction of AVI persons is a numbing of the remaining senses, which may be a protective device to shield them from the anger, hurt and emotional pain to follow. This numbness may last for several days or several weeks, depending largely on their emotional composition and their adaptability to major life changes. Following the stage of shock, visually impaired people experience denial. In this stage they may refuse to acknowledge their visual impairment by attempting to live as *seeing* persons, often believing that sight may ultimately return. A few visually impaired will attempt to bypass the whole process entirely by remaining in a denial stage and immediately after losing sight attempt to be the best adjusted visually impaired person possible. Once denial is no longer acceptable, a stage of anger will be experienced, often with angry responses such as *why me?* Hostility may be manifested in their responses to others, or inwards toward themselves. The bitterness, anger and frustration exhibited by visually impaired people may cause some relationships with family and friends to deteriorate (Perry & Hampton-Roy, 1982). After the initial shock, denial and anger stages, the AVI may find themselves giving way to feelings of resignation and depression. They begin to face the reality of the situation that sight will not return. Feelings of helplessness, self pity and loss of confidence may overwhelm them. At some point the depression gives way to a positive acceptance of the visual impairment. At this stage the visually impaired recognise that life must go on and that assistance is required if they are to regain independence. There then follows a period of

reorganisation and adjustment.

It would appear that depression and acceptance are seen as essential in the process of grieving for the loss of sight and that adjustment can only begin once grieving has taken place; an expectation noted in the above mentioned research (Dodds, Bailey, Pearson, & Yates, 1991). Although each person is unique, with no two persons following the same grief process, all seem to exhibit some of the symptoms of shock, denial and anger at some time during the adjustment process. Perry and Hampton-Roy (1982) state that moving from one stage of adjustment to another is not a clearly defined process and visually impaired persons may shift back and forth before working through either stage. However, as in the case of the grief process following loss through death, Perry and Hampton-Roy (1982) also envisage a final stage of recovery, acceptance and adjustment to visual impairment. As in the case of loss through death and disability where the basic task of the grief process is to assimilate and adjust to the reality of loss, so too is the concept of *adjustment* a fundamental concept in loss through visual impairment.

Tuttle (1984) describes seven sequential and overlapping adjustment stages to visual impairment. The first stage involves physical (the onset of visual impairment due to accident or disease) or social (the recurring encounter with the social stigma of visual impairment) traumas which are the events, circumstances or crises that precipitate the necessity for adjustment. The next stage involves shock and denial with feelings of *unreality*, detachment and disbelief. There is then the stage of *grieving*. During this stage, people grieve for the "generalised global loss of vision, or the generalised global awareness of being different from others" (Tuttle, 1984, p. 175). Expressions of hostility and anger are common during this stage, often manifesting as constant irritability or occasional outbursts. This reaction may be directly attributed to the frustrating situation imposed by visual impairment (Tuttle, 1984). In the *succumbing and depression* stage, the visually

impaired begin to analyse, either realistically or unrealistically, the perceived losses or incapacities imposed by the impairment. Many grief emotions are also experienced during this stage. In the *reassessment* stage, a re-examination of the meaning of life usually initiates a recovery. In the *coping and mobilisation* stage the desire to live life as independently as possible necessitates the development of techniques and strategies for coping with life's demands as AVI people. There is now acknowledgement of the loss of sight. In the final stage there is self-acceptance and the visually impaired begin to develop or regain self-esteem. It would appear, as in the case of the grief process following loss through death, that acceptance is the *ideal* final condition for adjustment to visual impairment.

Tuttle (1984) initiated a shift from the conceptualisation of a static stage of acceptance and adjustment to loss of sight for he argues that adjustment to visual impairment is not a static condition but rather a continuous dynamic and fluid process. Personal and environmental demands change from situation to situation and from time to time. When certain situations or events produce anxiety or doubt about visually impaired persons' acceptability or worthiness, they are likely to cycle back through some or all of the adjusting stages. As confrontation with another loss is a continual experience for the chronically visually impaired, the cycling back through the stages may occur at any age and whether adjustment is recently acquired or long standing (Tuttle, 1984).

3.4.3.2 *Visual impairment: Task and need models of the grief process*

Tasks and needs have to be accomplished during the grief process following loss of sight. The task of coming to terms with the reality that loss has occurred by acknowledging, recognising and accepting the finality of the loss is essential (Fitzgerald, 1970; Perry & Hampton-Roy, 1982; Tuttle, 1984; Dodds, 1989, 1991,

1993; Dodds et al., 1991; Conyers, 1992). AVI people also have to accomplish the task of experiencing, expressing and dealing with all the emotions, pain and problems that their loss elicits (Fitzgerald, 1970; Perry & Hampton-Roy, 1982; Tuttle, 1984; Conyers, 1992).

The most fundamental task, as in the case with loss through death and disability, is the need for AVI people to integrate and assimilate the reality of their losses. This core goal is comparable with the process of adjustment following loss of sight (Tuttle, 1984). By acknowledging, accepting and integrating the reality of the loss; by becoming aware of what was lost and what was not (the reality of the implications of loss); by confronting, re-evaluating and acknowledging that changes and adjustments to fundamental life issues must occur, visually impaired bereaved people will be able to grow and move towards the task of reconstructing a new life for themselves (Tuttle, 1984; Dodds et al., 1991; Conyers, 1992; McKay, 1993).

3.4.3.3 *Summation and evaluation of the grief process models*

The results obtained from research (Fitzgerald, 1970; Perry & Hampton-Roy, 1982; Conyers, 1992) imply that AVI persons work through a period of grief which culminates in the resolution and acceptance of the reality of sight loss resulting in the reinstatement of psychological equilibrium (Conyers, 1992). Theoretically therefore, being able to accept that one is impaired by reason of visual defect yet nevertheless tolerating this reality and retaining an overall sense of well being, seems to indicate the positive construction of adjustment (Conyers, 1992). There is a subtle but implicit assumption that the grieving process and adjustment to visual impairment can be navigated in most cases with the passage of time. There was however a shift with Tuttle (1984) who conceptualised the grief process as a series of continuous and dynamic adjusting stages through which the visually impaired are able to recycle.

As visual impairment is a *disability* the evaluation of the grief process following loss through disability {Section 3.3.2.3 Disability: Evaluation of the grief process models, p. 41} is relevant to the evaluation of the grief models after loss of sight. This evaluation must therefore be read in conjunction with the discussion that follows.

Most proponents of stage theories generally acknowledge and presume a time-limited, natural progress through the stages, culminating with the task of acceptance, reconciliation or resolution (Carroll, 1961; Fitzgerald, 1970; Perry & Hampton-Roy, 1982; Conyers, 1992). As discussed in Section 3.3.1.3 (Disability grief models: Evaluated) a permanent disability such as visual impairment results in a continuous cyclic and recurrent grief process that requires coming to terms with a continuous long lasting change (Davis, 1987; Livneh & Antonak, 1991; Lindgren et al., 1992). The literature and research on visual impairment emphasises the role of continuous and recurrent adjustment as a fundamental process in grief following loss of sight (Tuttle, 1984).

The stage models proposed in the literature on adventitious visual impairment (Carroll, 1961; Fitzgerald, 1970; Perry & Hampton-Roy, 1982; Conyers, 1992) to describe the grief reactions experienced by AVI persons as they adjust to their new life situation, have been criticised on a number of theoretical and empirical grounds. The conceptual framework provided by the grief-following-loss models with the assumption that complete adjustment requires the AVI to grieve for their loss of sight in a sequence of strong emotions which unfold in a natural order, has been severely criticised on the grounds that it does not accord with the actual experience of disability generally and visual impairment specifically (Dodds, 1989; Oliver, 1990). Dodds et al. (1991) argue that rehabilitation workers who subscribe to some version of the *loss model*, view emotions such as depression or anger as one of the stages through which the AVI must go before they become ready for rehabilitation. They further argue

that not only do some AVI fail to exhibit the stages postulated by the model, but that the model is effectively untestable in that it merely describes stages through which some persons appear to go. If certain AVI persons do not manifest any of the feelings that the *loss model* predicts are appropriate, then loss theorists may claim that grief is being repressed and will surface at a later date. Such a view may lead rehabilitators to see it as their primary aim to offer counselling or even psychotherapy to uncover the feelings of grief if they are not manifested (Dodds et al., 1991).

On the other hand, rehabilitators who do not subscribe to any loss model see it as their task to engage their clients from the start in a programme of skill acquisition. They argue that it is counter productive to allow clients to dwell on the negative aspects of sight loss and that early skill-orientated intervention can prevent clients from becoming helpless and dependent on others.

Dodds (1989, 1991) advocates a move away from the *loss model* and grieving for lost sight, and proposes an alternative model to focus on the AVI persons' self-perception, which have an effect on their willingness to undertake rehabilitation and to apply themselves to the many new tasks and skills which they need to acquire. He states that psychological variables play an important part in adjustment to adventitious visual impairment.

Loss of sight deprives individuals of their usual abilities and normal range of competencies. Perceiving this lack of efficacy and competence is demoralising and the response to this perception is likely to be a loss of self-esteem and negative affect combined with a loss of self-confidence and low motivation to attempt rehabilitation tasks. A major factor in adjustment to visual impairment is the acceptance of the loss of sight, and Dodds (1991) suggests that acceptance of visual impairment may be at the root of the adjustment process. Related to acceptance is attitudes to visual impairment. Individual's previous

attitudes to visually impaired persons when they were sighted might shape their attitude to and expectations about themselves now that they are also labelled as *visually impaired*.

This *adjustment* model focuses on how individuals feel about themselves in relation to the sighted world and its expectations of them (Dodds et al., 1991). The model predicts that certain thoughts and feelings are likely to be found together and that anxiety and depression are produced by the AVI entertaining negative thoughts about themselves and their situation. The "helpless hand of incompetence fits snugly into the glove of negative expectations which give a reassuring validity to the false reasoning" (Dodds, 1993, p. 32). According to Dodds et al. (1991) adjustment to acquired visual impairment is characterised by the following psychological factors: low levels of anxiety, an absence of depression, high self-esteem, a high sense of self-efficacy, a high sense of responsibility for recovery, a positive attitude towards visually impaired people, and a high acceptance of visual impairment. It must be remembered that Dodds and his associates focus on rehabilitating newly AVI persons immediately after loss of sight. It would be interesting to investigate whether negative perceptions persist with time or does this model assume that there is complete adjustment after rehabilitation?

The fundamental differences in philosophy, namely, visual impairment as a loss with the resultant grief reactions or visual impairment requiring practical skill acquisition, result in rehabilitation workers being divided into those who emphasise the need to work through feelings and those who emphasise the need to restore functioning as early as possible (Dodds et al., 1991). Although Dodds et al. (1991) propose that a practical skills-orientated approach to rehabilitation should be taken, they too focus on emotions, feelings and attitudes of the AVI person. It would appear that the main criticism of the loss models focuses on the perception that all stages must be worked through within a certain time frame and conclude with acceptance or resolution before rehabilitation can begin. It would seem that the optimal

approach to rehabilitation of the AVI should adopt a *both and* approach rather than the *either or* approach. By doing this the needs of the whole person will be addressed including both the emotional and practical points of view.

3.4.4 Visual impairment: Time course of the grief process

As in the case of the grief process following loss through death and disability, society in general (including professionals), continue to view grief following loss of sight in terms of a stipulated time duration for the completion of the grief process and that psychological and emotional reactions will diminish during the time course of the process.

3.4.4.1 Visual impairment: Time duration of grief

The literature and research on adventitious visual impairment based on the assumptions and expectations of a time-limited grief process ranging from weeks, months to years following loss through death, has resulted in the belief that *time heals* (Fitzgerald, 1970; Perry & Hampton-Roy, 1982; Conyers, 1992). The description of the two categories of grief reactions as conceptualised by Lindgren et al. (1992): *resolvable* grief to one identified loss and *chronic* grief to numerous losses that are part of chronic disability which includes visual impairment, questions this time-limited grief process. In the case of resolvable grief the passage of time will allow for a diminishment in grief as the person reinvests in life and detaches from that which was lost. However, in chronic grief there is no time limit for grief as it continually occurs from new losses and from old losses that are continually brought to mind (Davis, 1987; Lindgren et al., 1992). It can be argued that the identifiable attributes in the conceptual analysis of chronic grief are relevant to the grief experienced with chronic visual impairment: a perception of grief over time in the situation of chronic visual impairment with no predictable end; grief is cyclic or recurrent and is triggered either internally or

externally. If the underlying cause of continual loss is chronic visual impairment then grief will operate throughout the time course of the impairment (Lindgren et al., 1992). The expected time-limited duration of the grief process is challenged by this concept of *chronic grief* which assumes a recurrent, cyclic and continuous grief process.

Conyers (1992, p. 23) argues that the work of grieving visual impairment may be viewed as an "insidious tidal process." At times of external pressure either from family relationships, financial hardships or lack of social support and status, the effect of grieving lost sight may intensify to diminish later once again. It seems probable that whilst it may superficially appear that working through and adjustment to visual impairment has occurred with the outward resumption of daily and social living skills, there is the growing awareness that at a deeper level, the work of grieving such loss may at best be extended through years (Conyers, 1992).

3.4.4.2 *Visual impairment: Time course of grief-related emotions*

As in the case of the grief process following loss through death and disability there is a common expectation among researchers that the emotions or feeling states of AVI persons will diminish in frequency and intensity with time (Fitzgerald, 1970; Perry & Hampton-Roy, 1982; Tuttle, 1984; Dodds, 1989, 1991, 1993; Conyers, 1992). This assumption is challenged by the conceptualisation of chronic grief (Lindgren et al., 1992). In the case of resolvable grief which is experienced after one identified loss, as in the case of loss through death, the grief reactions do indeed diminish in intensity with time as the person detaches from that which was lost. However, in the case of chronic grief, the increasing intensity and frequency of the grief and related emotions may be related to the *build-up* or accumulation of the numerous losses that are a continuous part of visual impairment and to the impact such losses have on the person (Davis, 1987; Lindgren et al., 1992). The identifiable

attribute in the conceptualisation of chronic grief that grief is progressive and can intensify years after the initial sense of loss, disappointment or fear is relevant to the grief experienced with chronic visual impairment.

Emotional reactions of AVI adults (blind and partially sighted) in the time interval between 6 months to 2 years after onset of visual impairment were described by Conyers (1992). Various emotions were addressed and as the emotion of frustration forms the main focus in this present study, cognisance must be taken of the results. In addition, the present study investigated similar emotions and attitudes as did Conyers (1992).

In her research Conyers (1992) found that overall practical adjustment appeared to be less of a problem for the majority of the respondents than achieving psychological and emotional tolerance of their visual impairment. Anger and sadness were key feelings which showed constant deterioration rather than improvement over the time interval (Table 3.2). Although Conyers does not mention the emotion of *frustration* per se, it must be remembered that Joines (1995) distinguishes five types of anger, one of which is frustration. Therefore, when Conyers refers to anger, it could also include frustration. The ability or inability to accept the reality and permanence of loss of sight has been described as a key factor in assisting or blocking the overall adjustment pattern of the visually impaired individual (Dodds et al., 1991; Conyers, 1992). In her study, Conyers (1992) surprisingly found that the highest level of deterioration in inability to accept loss of sight was found in the visually impaired persons who felt they still *long to see again* after two years of visual impairment (Table 3.2). The surprise that the visually impaired should still *long to see* reinforces society's expectation that when grief occurs, it is expected to occur within a certain time frame and conclude with acceptance and resolution (Davis, 1987). In contrast to these expectations, Zisook and Shuchter's research (1985) concluded that many bereaved never fully accepted the fact of their spouse's death

and maintained a continuing relationship with their deceased spouses in their own way indefinitely and Lindgren et al.'s (1991) assertion that if the underlying cause of continual losses is a disability, then grief, (with the implication of no final stage of acceptance) operates throughout the course of the disability, including visual impairment.

Table 3.2 Incidence of practical and emotional improvement or deterioration after loss of sight (baseline 104 persons) Dimensions 1 Practical 2 emotional
(Adapted from Conyers, 1992, pp. 78-89)

Dimensions	Improvement	Deterioration
1		
difficult getting around alone	1	17
2		
not able to talk honestly	1	25
no meaning & purpose in life	2	23
no hope for the future	3	26
felt angry	4	15
felt sad	3	34
not accepted	3	35
long to see again	2	46
promise anything to get sight back	0	14
try to cover up	0	26
people expect me to be used to the loss	0	33
nobody understands	2	24

One of the recurring issues that appeared striking in Conyers study (1992) was the similar group who apparently tried to block off, shut out or deny any feelings whatsoever about loss of sight. Conyers (1992) calls this phenomenon *negative denial*. It is the mechanism whereby an individual may suppress, deny or block out the painful areas of the reality of sight loss and therefore in consequence, have to hide any affect, emotion or action which reinforces the reality which the person is seeking to deny (Conyers, 1992). This *circular double bind* response, although not constant, may fluctuate and be seen at various

stages in the AVI person's life. Conyers (1992) found that some of the visually impaired in her study attempted to screen off a level of emotion which was felt by them to be unacceptable, while others used a neutral response which appeared to be an absence of any emotion whatsoever. Conyers argues that many factors could account for this response: unacknowledged reactions, fear of losing sight and the subsequent fear of losing control and being overwhelmed by feelings; embarrassment or guilt in having some emotions, especially anger.

The response, attitudes and expectations of society, family and friends to the AVI person's altered capabilities may intensify and influence the emotional and psychological response of the AVI person. These external or social dynamics are simultaneously and continually interacting with the AVI person's internal psychological world (Conyers, 1992). The *meeting* of the external world with the internal, emotional and psychological system will ultimately determine how the individual reacts to the changes which visual deterioration imposes. In Conyers's research, many of the visually impaired felt that since loss of sight, people expected them to have got used to their impairment. Many felt that nobody understood what they were going through and many had difficulties in discussing their anxiety and worries with others.

Conyers (1992) stated that because of the emphasis on practical training and in particular mobility training during rehabilitation, it would be assumed that there would be an improvement in this area. However, in her survey there was no significant improvement over time. Conyers states that the findings suggest that quality of life is markedly affected following visual impairment and that in all areas of response to loss of sight deterioration outweighed improvement. The greatest difficulty experienced by the respondents was in relation to inner emotional needs, the ability to come to terms with what has happened and to accept loss of sight (Conyers, 1992). Whilst practical rehabilitation is obviously important, Conyers (1992) suggests that for too long it has dominated and excluded other

aspects of rehabilitation of AVI people. Enlightening as is Conyers study, it must be remembered that it only included persons who have been visually impaired between 6 months and two years. Research is needed to see whether the emotional responses of persons who have been visually impaired for a longer period of time will be similar to those found in Conyers's study.

3.4.4.3 *Summation of time issues pertaining to the grief process*

Contrary to the assumptions supported in society about the *healing powers of time*, it would appear that chronic visual impairment elicits a *tidal grief process* of continuous, recurring and dynamic adjusting stages through which the AVI recycle when confronting continual losses associated with visual impairment. However, despite these contradictions there is still a subtle but implicit assumption that the grieving process after loss of sight, with diminished emotions, acceptance and adjustment to visual impairment, can be navigated in most cases with the passage of time.

3.4.5 **The grief process and support**

Loss through death, disability and loss of sight impinges on every facet of a person's daily living and affects self-perceptions and self-worth, social relationships, existing patterns of behaviours, life-styles and practical capabilities and skills (Conyers, 1992). How persons react to crises and the range, type and intensity of emotions each person experiences in such a situation, depends on a constellation of factors: pre-existing personality characteristics; relationships to and support from important others and the wider social context; previous experiences of loss and the manner in which these challenges were met (Conyers, 1992). The focus here will be on the effects of support and in particular social support on the grief process.

Social support describes the comfort, assistance, and

information persons receive through formal or informal contacts with individuals or groups, all of which are necessary or helpful in maintaining psychosocial well-being (Vachon & Stylianos, 1988; Cleiren, 1993; Cobb, 1993). Social support refers to the extent of persons' relationships with others and is thus a transactional process requiring for its optimal provision a fit between the persons who provide support, the persons who receive support, and the particular circumstances that require support (Vachon & Stylianos, 1988). Essentially, social support includes: emotional support (enhancement of self-esteem through caring, trust, empathy and acceptance); informational support (advice or information promoting problem solving); instrumental support (practical tangible assistance) (Vachon & Stylianos, 1988; Cobb, 1993; Cleiren, 1993). Wineman's (1990) description of optimal social support encompasses the essential meaning: the degree to which disabled individuals' needs for socialisation, tangible assistance, cognitive guidance, social reinforcement and emotional sustenance are met through interaction with the social network.

3.4.5.1 *Helpful and unhelpful support*

Social support may be perceived as either helpful or unhelpful. Supportive (helpful) social networks help all grieving persons to grieve more easily for the loss; to confirm their sense of integration in the network thereby providing reassurance of their self-worth; to provide a secure and safe environment for the bereaved and in particular bereaved disabled to consider, clarify and facilitate uncertainty, threatening and complex interpersonal issues related to living with a disability (Vachon & Stylianos, 1988; Wineman, 1990). In contrast, unsupportive social networks result in feelings of isolation; increased uncertainty which is associated with greater depths of depression, feelings of being threatened, stress and a lower sense of purpose and meaning in life (Vachon & Stylianos, 1988; Wineman, 1990; Conyers, 1992).

Studies (Ray & West, 1983; Lehman, Wortman & Williams, 1987;

McKay, 1992) have compared bereaved persons perceptions of helpful and unhelpful support. Types of helpful support were: contacts with similar others and the opportunity to express feelings without having them dismissed or being given the message that they were coping badly; listening, acknowledging and validating their experiences as real. Unhelpful support was giving advice or easy solutions; encouraging recovery; pity and patronising attitudes (especially in the case of bereaved disabled persons).

Families and friends help grieving persons to work through their feelings about loss as they are generally more accessible and share the day to day experiences with the grieving persons. However, families and friends experience their own feelings and thoughts regarding the loss. Denial, guilt and regret are common reactions because of their perceptions that they were unable to foresee or prevent the loss and they may feel responsible for alleviating the distress of the grieving person and encourage recovery (Reiss, Gonzalez & Kramer, 1986; Conyers, 1992; McKay, 1992). When grieving persons do not respond to the well-meaning interactions of family and friends, their support might be withdrawn before the grieving person can benefit from their approaches. Conversely, persons may become so invested in helping, that the bereaved is never encouraged or allowed to become self-reliant (Vachon & Stylianos, 1988). The perception of disapproval from significant others can become a source of ongoing strain or conflict that may generate shame, guilt, anxiety, frustration and despair in the grieving person. Negative interaction that is derived from supportive efforts are actually additional stressors. The crisis of loss through death and disability may place pressure on previously adequate support networks and put the entire network group into distress (Worden, 1985; Vachon & Stylianos, 1988). The shared experience of suffering may render the families and friends unable to support the person for whom the loss is most significant and profound (Vachon & Stylianos, 1988; Conyers, 1992).

A pressing need when confronted with loss through death, disability and visual impairment is clear and open communication (McKay, 1990). Grieving persons and their families cannot comfort and support each other, plans cannot be made and the resources of the family cannot be mobilised to support grieving persons until there is open honest and clear communication between all concerned (Raphael & Nunn, 1988; McKay, 1990). Support groups are valuable in allowing people to share and express their grief openly with others and thereby cope with the grief process (Bailey & Gregg, 1986; Sanders, 1989; Conyers, 1992). Grieving persons who are able to share openly and help others in similar situations perceive that they are not alone in their reactions which in turn promotes the feeling of *universality* and installation of hope (Yalom, 1975).

3.4.5.2 *Time length of support*

With regard to length of time of support, Bouwers (in McKittrick, 1981/2) argues that time-limited counselling and support is more effective than more time consuming unlimited counselling and support. The long-term support could encourage dependency. Caylor (in Cobb, 1974) argues that the need for intense follow up or support of the AVI lessens as they develop their skills and confidence. However, recent American research from the National Institute For Disability And Rehabilitation Research, (Gerhardt, 1990) states that it is crucial that educational and supportive interventions form a routine and ongoing part of adequate care of disabled persons. Ideally therefore, the environment should be emotionally and practically supportive to allow the disabled to pursue their work and leisure activities as best possible (Gerhardt, 1990).

Only when society acknowledges chronic grief as a natural reaction to an ongoing experience of loss will appropriate continuous support be available for grieving disabled persons (Davis, 1987). Society in general and families and health care workers in particular overestimate the impact of the initial

crisis and underestimate the impact of later grief episodes associated with chronic grief (Davis, 1987). The expectations of society complicate the process of chronic recurring grief of the disabled (and visually impaired) in two apparently opposite ways: by requiring grieving and by requiring the suppression or denial of grief (Davis, 1987). People with visible disabilities are expected to grieve because the disability is viewed by the rest of society as a tragedy that is analogous to death. On the other hand society prefers that all public displays of grief be controlled especially when the grief is the result of loss other than death (Hughes, 1980; Silverman, 1981; Davis, 1987). It is not surprising therefore that the disabled and visually impaired are pressed to deny chronic grief and the need for continued emotional support (Davis, 1987).

3.4.6 Summary

In this chapter thus far, the literature and research of the grief process following loss through death, disability and visual impairment has been outlined. The *stage* and *task and need* models have attempted to provide comprehensive, conceptual and explanatory frameworks for the various processes involved in grief following a loss of any kind. In both models there is a conceptualisation of the grief process that implies a particular course through which grief must progress in order to conclude the process. Most proponents of stage models generally acknowledge and presume a time-limited, natural and linear progress through the stages culminating with the final static stage of acceptance, adjustment, recovery or resolution. The tasks of acceptance of, and assimilation of the finality of loss, and the attainment of psychological balance and equilibrium is regarded as a grief process completed. Society in general (including professionals), have in the past but continue in the present to view grief following loss of any kind in terms of a stipulated time duration for the completion of the grief process, and assume that psychological and emotional reactions will diminish in frequency and intensity during the time course of the grief process.

Despite the range in the expected time duration of the grief process, there is still a subtle but implicit assumption that the grieving process after loss through death, disability and visual impairment with diminished emotions and acceptance and adjustment, can be navigated in most cases with the passage of time.

However, the expected time-limited duration of the grief process has been challenged by the concept of *chronic grief* which assumes a recurrent, cyclic and continuous grief process. The identifiable attributes in the concept of chronic grief include: a perception of grief over time in a situation that has no predictable end; grief is cyclic or recurrent; grief can intensify years after the initial sense of loss, disappointment, or fear. If the underlying cause of continual losses is a disability (including visual impairment), then grief will operate throughout the course of the disability. The imposition of stage and task and need models on the experience of chronic grief distorts the experience and limits the understanding of grieving of disabled and visually impaired persons. This is because the stage models conceptualise the grief process as a time-limited natural progress through the stages, culminating with the final stage of acceptance, adjustment, recovery or resolution, whereas, persons with permanent disabilities (including visual impairment) experience a recurrent and continuous grief process, implying no time-limited finality of grief but rather a series of continuous and dynamic adjusting stages through which the disabled and AVI are able to recycle.

The effects of support on the grief process were also outlined. Perceptions of both helpful and unhelpful support were delineated with negative interactions that are derived from supportive efforts being perceived as additional stressors for the grieving person.

Attention will now be given to *frustration* as a key emotion in adventitious visual impairment and the characteristic

frustrations experienced by AVI persons.

3.5 FRUSTRATION AS KEY EMOTION IN VISUAL IMPAIRMENT

Frustration is the emotional state assumed to occur when persons' strivings or behaviours are interfered with, disrupted or thwarted, either by obstacles that block progress towards a desired goal, or by the absence of an appropriate goal (Reber, 1985; Carson et al., 1988). A wide range of obstacles, both internal and external, can lead to frustration. Prejudices and discrimination, unfulfillment in a job, death of a loved one are common causes of frustrations stemming from the environment. Physical disabilities, lack of needed competency, loneliness and inadequate self-control result in frustrations from persons' personal limitations (Carson et al., 1988). In the context of visual impairment, the obstacle could be the impairment itself (internal obstacle), that prevents the person from fulfilling a goal of driving a motor car, or it could be the misconceptions of the *sighted world* (external obstacle) that impedes persons from fulfilling a goal such as obtaining an university degree. Frustration is difficult to cope with because it often leads to self devaluation, which in turn, makes persons feel that they are incompetent or have failed in some way (Carson et al., 1988).

A stressor (any adjustive demand that requires coping behaviour) that involves important aspects of persons lives, for example, loss of sight, tends to be highly stressful (Carson et al., 1988). The impact of a stressor depends on its importance, duration, cumulative effect and multiplicity. The longer a stressor operates, the more severe its effects (Carson et al., 1988). Frustration often results from stress, which occurs when the demands of the environment exceed a person's resources. Chronic stress and therefore chronic frustration, occurs when there are prolonged and repeated encounters of the adjustive demands in certain areas of persons' lives (Taylor, 1986). Thus, the repeated and prolonged confrontation of the adjustive demands to cope with the continued losses associated with visual

impairment will often result in chronic frustration. Frustration is known to produce annoyance, irritation and aggression. Stress and hence frustration however can also produce fear, depression and withdrawal (Taylor, 1986; Carson et al., 1988).

3.5.1 Frustrations characteristic of visual impairment

The meaning of *independence* to the visually impaired significant others and society as a whole provides one of the most critical factors influencing the adjusting and in particular, the emotional experience of visual impairment (Rowland, 1985; Conyers, 1992; Dodds, 1993). Throughout life, there are two forces at work: the desire for independence and its freedom and the desire for dependence and its protection (Rowland, 1985). The nature of visual impairment ensures that the areas of dependency of visually impaired persons are more visible than the dependency needs of others, making them more vulnerable to the effects of the negative attitudes, assumptions and expectations placed on them by society. Thus, the sense of loss of control over one's life, the sense of the loss of independence with the sense of a *dependency career* and the perceived lack of understanding of others are factors that have been highlighted as some of the main causes of continued frustration experienced by the AVI (Conyers, 1992; Corn & Sacks, 1994).

Being a non-driver in society today has a long-term impact on persons' lives and life-styles. For some, the impact may be a mere inconvenience, whereas for others, it can become a lifelong challenge to cope with (Corn & Sacks, 1994). Research (Eisenhandler, 1990) has shown that driving a car forms part of social acceptance of the elderly. There is the belief that giving up the ability to drive marks the beginning of what might be called a *dependency career* (Eisenhandler, 1990). The ability to drive gives a person a sense of control, autonomy, independence, spontaneity and the ability to avoid social isolation (Eisenhandler, 1990). It can be expected therefore, that in the case of previously sighted persons who, with the onset of visual

impairment have to give up driving a car, that they too experience loss of control, loss of independence, loss of spontaneity and the sense of isolation. Research by Corn and Sacks (1994) on the impact of non-driving on adults with visual impairment found significant levels of frustration experienced by the respondents in meeting their transport needs. The obstacles rated highest for frustration for both the *blind* and *partially sighted* individuals were "waiting for rides that were late", and "being unable to arrange for a ride on a special occasion" (Corn & Sacks, 1994). These specific obstacles and the resultant frustrations experienced by the visually impaired emphasise the reactions to loss of independence, loss of control over a situation and loss of spontaneity.

It is important in the grieving process that the support network validates, accepts and acknowledges grieving persons' experiences as being real (McKay, 1990). However, grief experienced through loss of sight may be difficult to share with other sighted persons as they have never experienced this type of loss. The visually impaired therefore tend to block open expression of emotions and feelings, often becoming very frustrated which is then further reinforced by the lack of understanding of others (Conyers, 1992). Therefore, until there is open communication between the visually impaired and all persons who form part of their social network, the specific and characteristic frustrations will continue to occur (Rowland, 1985). The research by Corn and Sacks (1994) on the impact of non-driving on visually impaired persons, investigated the perceived understanding and support they received from others. The respondents rated neighbours, the general public, physicians and other health care providers, as having little understanding about the emotional and logistical impact of not being able to drive (Corn & Sacks, 1994). In addition, professionals in the field of visual impairment were perceived to be insensitive to the emotions experienced by those who cannot drive. Conversely, the respondents perceived that spouses or significant others, parents and friends understood the emotional and logistical

impact of being a non-driver.

Loss of sight is made up of the "thousand repeated frustrations in the daily life of the blinded person, which remind him that he is blind" (Rowland, 1985, p. 20). It is inevitable that if confrontation with loss is a continual experience for the chronically AVI which results in a recycling back through some or all of the adjusting grief stages, then frustrations related to visual impairment will also be a continuous emotional reaction (Tuttle, 1984; Lindgren et al., 1992). This inevitability implies that adjustment to visual impairment is a *continual turning point* rather than a *point of no return*. The *turning point* has been appropriately described by Zola (1981) when reflecting on the problems associated with adjustment to his disability states, "...The problems must be faced, evaluated, redefined and readapted to, again and again and again. ...My polio and my accident were not just my past they were part of my present and my future" (Zola, 1981, p. 84).

3.6 CONCLUSION

In this chapter, the grief process and related emotional reactions and in particular frustration following loss of sight has been discussed. The grief process following loss through death formed the foundation from which all other discussions of grief reactions following loss flowed. This was due mainly to the lack of literature and research on psychological and emotional reactions experienced by AVI adults. The grief process and related emotional reactions after loss through disability formed an integral part of the discussion as visual impairment has for many years been described as a *disability*. The concept of *chronic grief* as a continuous and recurrent grief reaction to numerous losses that are part of a chronic disability such as visual impairment is significant in its implications. The concept of chronic grief contradicts the assumptions and expectations put forward in the *traditional* literature on the grief process, namely, the subtle but implicit assumption that the grief process

with a final stage of acceptance, adjustment and resolution can be navigated in most cases with the passage of time. The grief process and final stage of adjustment to visual impairment appears not to be a static condition of acceptance and resolution, but rather a continuous dynamic and circular process. Newly or long-term rehabilitated AVI persons are likely to cycle back through some or all of the adjusting processes, resulting in a continuous and recurring experience of the emotional grief reaction of frustration. Loss of sight should therefore be seen as a continuous, circular *turning point*, rather than the linear *point of no return*.

The next chapter will discuss the research methodology to investigate the grief process and related emotions experienced by AVI adults.

CHAPTER FOUR

RESEARCH METHODOLOGY: FACTUAL AND MEANINGFUL PROCEDURES

4.1 INTRODUCTION

The purpose of research is to find answers to questions, systematically and with the support of related facts (Kerlinger, 1986; Leedy, 1989; McBurney, 1994). In this research study the basic question is whether there is a relation between length of time of adventitious visual impairment and psychological and emotional reactions, acceptance of - and adjustment to - loss of sight.

Research methodology includes firstly, the envisaged overall plan of investigation to obtain answers to the research questions and secondly, an outline of what the researcher will do from writing the hypotheses and their implications to the final analysis and interpretation of the data (Kerlinger, 1986; Leedy, 1989; McBurney, 1994). This methodological procedure has several distinct characteristics: it originates with a question and requires a clear articulation of a goal; it demands a specific plan of procedures; it is guided, in most cases, by inter-relationships between constructs called hypotheses; it uses measurable data in attempting to answer the question that initiated the research (McBurney, 1994).

The process of research is, by its nature, dynamic, circular and is never conclusive. By exploring one area, additional problems that need resolving are encountered and therefore, "research begets research" (Leedy, 1989, p. 9). Research questions may arise from a specific theory and/or from research on that theory, or it may originate from previous research observations which make a researcher aware of unsolved problems in a particular field of study (McBurney, 1994). Research

therefore aims to help fill the gaps in the present knowledge about a particular field of study. The questions requiring research in the study at hand arose from *the grief-following-loss theory* and the unexplored issues related to psychological and emotional reactions following loss of sight.

This chapter will include the following sections: a description of pertinent terms to be used throughout the present study; the aims of the study and related questions; the hypotheses and related subsidiary investigations and their rationale; methodology of the study; sampling issues relevant to the study; data collection; procedures to examine and analyse the collected data.

4.2 DESCRIPTION OF TERMS

The following terms will be used throughout the present study:

Short-term and long-term respondents

According to Optima College (November, 1995) AVI persons reach the rehabilitation centre on average 12 months after application. This time interval does not include the period from the onset of visual impairment, which could in turn, add another 8 to 12 months to the period before AVI persons reach the rehabilitation centre. They then have to learn many new skills, walking with a white cane, learning braille among them. This process of rehabilitation usually takes approximately 3 months. Once AVI persons leave the rehabilitation centre there is a relearning in the home and the outside environment. Thereafter, there is the prospect of getting a job or starting to study. All these factors considered, it usually takes AVI persons on average 5 complete years to reach the presumed true adjustment stage.

Based on this information, the researcher chose a cut-off point of 6 years to delineate the two sample groups of AVI respondents. The term *short-term* refers to those persons AVI for under 6

years. *Long-term* refers to those persons AVI for 6 years and over.

Frustration

The present study will take the meaning of *frustration* as "the emotional state assumed to result from the act of blocking, interfering with or disrupting behaviour that is directed towards some goal. The behaviour may be almost anything from overt physical movement to covert cognitive processes. It is assumed that this emotional state has motivational properties that produce behaviour designed to bypass or surmount the block" (Reber, 1985, p. 288).

4.3 AIMS OF THIS RESEARCH STUDY

The main aim in this research study was to develop a more in-depth body of knowledge than currently exists in the research literature on psychological and emotional reactions of long-term AVI adults in their adjustment to the loss of sight. More specially, the overall aim in this research study was to answer the question of whether or not there is a relation between length of time of visual impairment and the experience of the grief reactions of frustration and adjustment after loss of sight.

The following research questions in this study arose from *the unexplored issues in the grief-following-loss theory related to psychological and emotional reactions experienced by AVI adults*:

- do the frequency and intensity of frustrations experienced by AVI adults change in relation to their length of time of visual impairment?
- is there a change over time in the perceptions of the AVI with regard to acceptance and adjustment?
- does the need for continued emotional support after rehabilitation change over time and if so, who would be the best person/s to offer the support?

- do the causes of frustration change over the length of time of visual impairment?
- do the emotions related to the grief stages change over time?

4.4 RESEARCH HYPOTHESES AND RELATED SUBSIDIARY INVESTIGATIONS

Based on the literature review of the grief process following loss, the following hypotheses and related subsidiary investigations were formulated:

- **Hypothesis 1: Long-term AVI persons experience more frequent frustrations than do short-term AVI persons.**

Subsidiary investigation (1A): Causes of frustration:

To explore whether there is a difference in the causes of frustration of long-term versus short-term AVI persons.

Subsidiary investigation (1B): Time intervals and frustration:

To explore whether certain time intervals of adventitious visual impairment are more or less frustrating.

- **Hypothesis 2: Long-term AVI persons experience more intense frustrations than do short-term AVI persons.**

Subsidiary investigation (2A): Changes and frustration:

To explore the changes in the frustrations of short-term versus long-term AVI persons.

Subsidiary investigation (2B): The healing effect of time:

To explore what the short-term and long-term AVI feel about the saying "time heals" frustrations related to visual impairment.

Subsidiary investigation (2C): A less frustrating life:

To explore what the AVI respondents believe would make their lives less frustrating.

- **Hypothesis 3: Long-term AVI persons accept the impairment to a lesser extent than do short-term AVI persons.**

Subsidiary investigation (3A): Adjustment to visual impairment:

To explore whether there are differences between the long-term and short-term AVI respondents with respect to overall, practical and emotional adjustment.

Subsidiary investigation (3B): Adjustment as a continuous or linear process:

To explore differences between the long-term and short-term AVI respondents' perceptions of adjustment being a continuous or linear process.

Subsidiary investigation (3C): Descriptions of acceptance and adjustment:

To explore the relation between acceptance of and adjustment to visual impairment as described by AVI respondents.

Subsidiary investigation (3D): Changes in emotions from onset of visual impairment to present:

To explore whether emotions that were present at the onset of visual impairment change over time for the short-term and long-term AVI respondents.

- **Hypothesis 4: The need for continued emotional support is greater for long-term AVI persons than short-term AVI persons.**

Subsidiary investigation (4A): The best person to offer support:

To explore who the AVI respondents perceive as the best person to offer continued emotional support and who helped and who is helping the AVI work through their feelings about loss of sight.

Subsidiary investigation (4B): Types of helpful support:

To explore what types of support are perceived by the AVI

respondents as helpful.

Subsidiary investigation (4C): Frustrating support:

To explore whether AVI respondents become frustrated with support and if so, what type of support causes frustration.

The rationale behind Hypotheses 1 and 2 was based on the argument put forward by authors (Davis, 1987; Lindgren et al., 1992) that: if the grief process and related emotional reaction of frustration experienced by AVI adults after loss of sight is chronic, then grief will be a continuous process. The loss of sight is continually confronted by the AVI because the loss is continually redefined in new situations with new problems. The increasing intensity and frequency of chronic grief and the reaction of frustration may be related to the cumulative loss that is a part of visual impairment and to the impact such losses have on the person over time (Davis, 1987; Lindgren et al., 1992).

The rationale behind Hypothesis 3 was based on the argument put forward by authors (Elliott et al., 1991; Livneh & Antonak, 1991) that it takes years before people with disabilities (including visual impairment) appreciate, acknowledge and become aware of the reality and the full extent of the implications and limitations of their condition. The short-term AVI with their presumed lack of awareness may perceive their loss of sight as one identified loss accompanied by resolvable grief (Lindgren et al., 1992). The implication of this perception is that the short-term AVI will follow the traditional stages of the grief process. It is assumed that intense emotions will diminish in intensity and frequency with time and that complete acceptance and total adjustment is the final stage in the expected time-limited grief process following loss of sight. On the other hand, the long-term AVI with a presumed greater awareness about the implications of visual impairment experience the grief process as a course of recurrent, cyclic and continuous grief. It is assumed that there is no final stage of complete acceptance or adjustment but rather

a continuous recycling through the various stages (Davis, 1987; Lindgren et al., 1992).

The rationale behind Hypothesis 4 was based on the presumed differences between the short-term and long-term AVI with regard to the perception of loss of sight involving a resolvable grief process as compared to a chronic grief process (Lindgren et al., 1992). The short-term AVI initially have the emotional support from family, friends and the rehabilitation centre. Their expectation of the completion of the grief process with total acceptance and adjustment and a presumed return to the functioning person as before the visual impairment may elicit a perception that there is no need for continued emotional support after rehabilitation (Elliott et al., 1991). On the other hand, the long-term AVI with their perception of chronic grief and a continuous confrontation of loss may perceive a greater need for continued emotional support.

4.5 METHODOLOGY FOR THIS STUDY

A non-experimental research design involving both quantitative and qualitative data within an empirical research investigation was used in this research study. No attempt was made to manipulate variables and to assign subjects or treatments randomly to experimental or control groups, because the nature of the variables relevant to this research study precluded manipulation (Kerlinger, 1986; McBurney, 1994). The subjects used in this research study already had differing characteristics in tact, namely, being AVI for a certain number of years. The research followed a *criterion groups design* because no treatments were administered and a sample was drawn from each of two actual populations (AVI for under or over 6 years) and already existing differences in the central tendency of these populations were investigated on the basis of the sample data (Huysamen, 1983).

The research study also included an exploratory method which has the major purpose of refining concepts and articulating

questions and hypotheses for subsequent investigations (McBurney, 1994). This research included both quantitative and qualitative data, with the former emphasising measurement, whilst the latter was concerned with meaning (Leedy, 1989; Richardson, 1992).

4.6 SAMPLING RELEVANT TO THE STUDY

This section on sampling issues relevant to the present study will include:

- non-probability sampling;
- the sample used in the present study including: the criteria necessary for inclusion; sample size and selection; characteristics of the sample.

4.6.1 Non-probability sampling

Non-probability sampling involving the technique of purposive sampling was used in this research study and at no stage was any form of random sampling considered. Purposive sampling is characterised by a deliberate effort to obtain representative samples by including presumably typical groups in the sample (Bailey, 1986; Kerlinger, 1986; Leedy, 1989; McBurney, 1994). This sampling method therefore allowed for a relevant group of people to be selected, namely, AVI adults for under and over 6 years, but did not come close to sampling the whole of the envisaged population (Kerlinger, 1986; McBurney, 1994).

4.6.2 The sample used in the present study

The following criteria were adopted for including subjects in the present study:

All persons in the research study had to be AVI adults. In line with the view of Rowland (1985) the congenitally visually impaired (life-long) were not included. According to Rowland (1985) the differences between the two groups are unbridgeable,

one of the main reasons presumably being that congenitally visually impaired adults have to a large extent been *dependent* on others their whole life, whereas this *dependency* is perhaps a new experience for the AVI. This difference could influence the experience of frustration. For example, AVI adults who up until the time of visual impairment were able to drive a motor car, may as a result of the visual impairment experience more frustrations having to be dependent on others for transport than the congenitally visually impaired who have always had to be dependent on others for transport.

As this research was concerned with AVI adults, only those persons between the ages of 22 and 60 years of age were interviewed. According to Gerdes (1988) adulthood begins at the age of 22 years and middle adulthood ends at 60 years of age. However, Gerdes (1988) acknowledges that these divisions are entirely arbitrary as life cannot be separated into distinct stages, as one stage flows into and overlaps the next. AVI persons over 60 years were not included in this study because during this period added age related stressors such as preparation for retirement, physical changes related to ageing, in particular visual sensory deprivation and changes associated with ageing may be stressful and therefore frustrating (Gerdes, 1988).

Each AVI person had to be in the final stages of rehabilitation or an ex-rehabilittee. This criterion was necessary because the literature argues that once an AVI person is rehabilitated, that is, accepted and adjusted to visual impairment, there is a return to previous levels of functioning and frustrations related to the visual impairment should decrease (Fitzgerald, 1970; Perry & Hampton-Roy, 1982; Conyers, 1992).

Only white South Africans were interviewed.

These criteria were seen as a procedure to help *control* or hold constant irrelevant and extraneous variables over the two groups

and therefore give certain unwanted sources of systematic variance minimal opportunity to operate (Huysamen, 1983; Kerlinger, 1986). For example, irrelevant and extraneous variables such as added age related stressors of physical changes, retirement and possible relocation may be stressful for AVI persons over the age of 60 years and therefore the resultant frustrations not related to visual impairment could be unwanted sources of systematic variance.

Another characteristic of the present study was that both *short-term* and *long-term* AVI adults had to be interviewed. As stated in Chapter Three, the majority of literature and research on AVI generally focuses on the period before and immediately after (up to two years) the onset of visual impairment (Carroll, 1961; Hallenbeck, 1967; Fitzgerald, 1970; Tuttle, 1984; Dodds, 1989, 1991, 1993; Conyers, 1992). As this research study was concerned with the relation between length of time of visual impairment and psychological and emotional grief reactions following loss of sight it was necessary to interview those persons AVI for longer than 2 years.

4.6.2.1 *Sample size and selection*

It was envisaged that 40 AVI adults would be interviewed for the research study. This number was considered necessary for empirical testing as the smaller the sample size, the larger the error and deviation from the population values (Kerlinger, 1986). Practical constraints such as, lack of transport to travel long distances to interview respondents and the time taken for the interview, limited the number of AVI respondents for the study. The final number in the research study was 32 white AVI South Africans. The researcher used equal size samples, namely, 16 short-term AVI persons and 16 long-term AVI persons, in order to prevent the breach of the homogeneity of variance assumption from appreciably affecting the obtained results (Huysamen, 1983).

The criteria that each white South African AVI person had to

be in the final stage of rehabilitation or an ex-rehabilitatee necessitated that the sample be selected from an available register of present and past rehabilitated AVI persons from Optima and associated organisations. The register was systematically examined in order to include both long-term and short-term AVI adults.

Optima, in Pretoria, was used to gain particulars of AVI persons as it is the main centre in South Africa that offers courses for the rehabilitation or independence training of AVI adults. Four AVI persons in the final stages of rehabilitation (the last week of the course) were interviewed at Optima. (See Appendices A and B for letter to Optima for permission to use the college for interviews and for names and addresses of ex-rehabilitatees and the subsequent reply). No letter was sent to the potential respondents as each was telephonically contacted to participate in the research. In the light of the selection criteria, 2 congenitally visually impaired persons were excluded.

4.6.2.2 *Characteristics of the sample*

The following characteristics of the AVI sample respondents will be reported:

Age

The average age of the sample respondents was 39,5 years. The age of the respondents ranged from 22 to 60 years.

Education level

The education levels of the sample respondents are as follows: 20 (63%) have secondary school qualifications; 2 (6%) have technical qualifications; and 10 (31%) have tertiary qualifications, including degrees and diplomas. Table 4.1 Provides a detailed breakdown of the various education levels of the sample respondents.

Table 4.1 Education levels of the sample respondents

Education level	Respondents	Percentages
Secondary school		
Standard 6	3	(9%)
Standard 7	1	(3%)
Standard 8	5	(16%)
Standard 9	1	(3%)
Standard 10	10	(31%)
Technical		
NTC3/N4	2	(6%)
Tertiary Degrees/Diplomas		
Bachelor of Science	2	(6%)
Bachelor of Arts	4	(13%)
Bachelor of Arts Honours	1	(3%)
Graduate Diploma of Engineering	1	(3%)
Higher Education Diploma	1	(3%)
Computer Diploma	1	(3%)

The majority of the sample respondents had reached these education levels before the onset of their visual impairment: 27 (87%) of the sample respondents stated that it was obtained before onset; 5 (16%) after the onset of their visual impairment and included 3 persons who obtained their B.A. Degrees and 2 persons who stated that they had experienced visual problems whilst obtaining their school education. It must be stated that all the AVI respondents in this research study had attended *normal sighted* schools.

Occupation

Occupation of the AVI respondents before the onset of visual impairment and occupation at the time of the interview is shown in Table 4.2. It is clear that adventitious visual impairment has had a negative effect, with more than half of the total sample respondents (53%) unemployed at the time of the interview as compared to 0% unemployed before the onset of visual impairment.

The increase in the number of switchboard operators in both the short-term and long-term AVI respondents is not surprising as this profession fits the *stereotyped* employment deemed suitable for visually impaired persons.

Table 4.2 Occupational status of the short-term and long-term AVI sample respondents before the onset of visual impairment and at the time of the interview

Occupation	S-term before	S-term present	L-term before	L-term present
Civ/engineer	0	0	1 (6%)	0
Computer/prog	1 (6%)	0	0	0
Housewife	0	4 (25%)	0	0
Mechanic/al	3 (19%)	0	2 (13%)	0
Military (PF)	0	0	1 (6%)	0
Organiser	0	0	0	1 (6%)
Sales	3 (19%)	0	1 (6%)	0
Secretarial	5 (31%)	0	6 (38%)	0
Student	1 (6%)	1 (6%)	2 (13%)	0
Switchboard	1 (6%)	2 (13%)	0	6 (38%)
Teacher	1 (6%)	0	2 (13%)	1 (6%)
Technician	1 (6%)	0	1 (6%)	0
Unemployed	0	9 (56%)	0	8 (50%)

Causes of visual impairment

The causes of visual impairment were varied and categorised as follows: hereditary causes 11 (34%); injuries to the eyes due to accidents 11 (34%); diseases 10 (32%).

Table 4.3 indicates the most common causes of visual impairment among the sample respondents.

Table 4.3 Common causes of visual impairment among the sample respondents

Causes	Numbers and percentages
Hereditary	
Retinitis Pigmentosa	6 (19%)
Glaucoma	3 (9%)
Other hereditary conditions	2 (6%)
Injuries due to accidents	
Car	3 (9%)
Work-related	2 (6%)
Shooting	3 (9%)
Landmine	1 (3%)
Other injuries	2 (6%)
Diseases	
Diabetes	5 (16%)
Retina-related	4 (13%)
Other	1 (3%)

The most common causes of visual impairment in this research study are similar to the causes stated in the research of Sussman (1987). The main causes, although categorised according to age groups (21-40 and 40-60 years) also included diabetic retinopathy, injuries, glaucoma and retinal related problems including RP and Macular Degeneration.

The sample respondents included 8 (25%) persons who have other disabilities and/or health problems: 5 respondents have diabetes including 1 person with a kidney transplant and bilateral below the knee amputation; 1 person has epilepsy, 1 person has a disabled hand because of a landmine explosion; 1 person has no sense of smell or taste after a suicidal shooting attempt.

Duration of visual impairment

In this research study, the mean duration of adventitious visual impairment for the selected sample was 7,88 years. The

mean duration of impairment for the short-term AVI respondents was 3,26 years. No person impaired for less than one year was interviewed. The mean duration of impairment for the long-term AVI respondents was 12,5 years.

Onset of visual impairment

Table 4.4 gives a detailed breakdown of the time onset of visual impairment for the sample respondents.

Table 4.4 Time onset of visual impairment

Onset	Numbers of respondents
Within a day	12 (37%)
Within a month	1 (3%)
Within 7-12 months	6 (19%)
Within 1-2 years	1 (3%)
2 years and over	5 (16%)
Ongoing	7 (22%)

The time onset of visual impairment ranged from: immediate (37%); rapid (up to 1 year) (22%); gradual (1 year plus) (41%).

The onset of visual impairment correlates with the causes of visual impairment. For example, the immediate onset correlates with the causes of injuries due to accidents and the ongoing loss of sight with the hereditary causes such as Retinitis Pigmentosa.

Visual ability

It is a common misconception that visually impaired persons have no remaining sight as discussed in Chapter Two. The AVI respondents' subjective perceptions of their visual impairment and residual vision were obtained and are shown in Table 4.5. The different levels of AVI were:

- total blindness which included those persons who are totally unable to perceive even bright sunshine;

- functional visual impairment which included those persons who only have light perception or light projection and have the ability to pick up changes in light levels or objects that contrast highly with the surroundings;
- legal visual impairment which included those persons who are able to count fingers at 0,3 to 3 metres;
- partial sight which included those persons who are able to read normal print with adaptive devices and those persons who are able to travel around in daylight without the aid of special equipment.

Table 4.5 Respondents' perceived visual ability at the time of the interview

Visual ability	Numbers of Respondents
Totally blind	13 (41%)
Functionally blind	8 (25%)
Legally blind	1 (3%)
Partially sighted	10 (31%)

It is clear from table 4.5 That the totally blind formed the largest group (41%) in this research study, followed by the partially sighted (31%).

4.7 DATA COLLECTION

This section on data collection includes:

- the interview schedule including: the construction of the interview schedule;
- standardised tests including the Sixteen Personality questionnaire and the Nottingham Adjustment Scale;
- administering the interview schedule.

4.7.1 The interview schedule

A personal interview facilitated by a schedule (questionnaire) was the method and instrument used to gather data from the sample respondents (Kerlinger, 1986; Leedy, 1989; McBurney, 1994). The

schedule was chosen because a great deal of information can be gathered, including, factual information such as education levels and occupation; opinions, attitudes, needs and the reasons thereof (Kerlinger, 1986). In addition, the personal interview was chosen as the method because of the difficulty the respondents (all visually impaired) would have in filling out a questionnaire on their own. All respondents, except the 4 who were interviewed at Optima, were interviewed in their homes.

The interview was used to explore and to identify significant variables and relations relevant to this research study (Kerlinger, 1986). A face-to-face interview has the advantage that the interviewer can establish rapport with the persons being interviewed. In addition, the interviewer when necessary, can explain the meaning of a misunderstood question and can also probe for more complete answers when a respondent gives a brief answer or one that does not respond to the question (Kerlinger, 1986). It must be remembered however, that the presence of the interviewer may create biased responses. The potential for interview effect (social desirability), where a response is chosen even if it does not represent the respondent's true tendency or opinion, is greater with face-to-face interviews than with any other method (Kerlinger, 1986; Leedy, 1989).

4.7.1.1 Construction of the interview schedule

The questions included in the interview schedule were based on the literature study and discussions with many AVI persons, where their thoughts and feelings about visual impairment were all considered when formulating the specific questions. In a interview that is facilitated by a schedule, the questions, their sequence and their wording are fixed, thus allowing for consistency (Kerlinger, 1986).

The schedule consisted of different sections, each related to a specific hypothesis or exploratory question. For example, Sections B and C were constructed to test the hypotheses of

frequency and intensity of the frustrations experienced by the AVI (see Appendix C for the interview schedule). A combination of three types of schedule items were used in the interview: the fixed alternative or closed item, the open-ended item, and the scale item (Kerlinger, 1986). The fixed alternative format was used when there was a choice between two alternatives (Section D, question 9) where a yes or no answer was wanted and where there was a choice of many alternatives (Section A where there was a choice of alternatives to investigate how often certain situations cause visually impaired persons to become frustrated). The scale items had fixed alternatives and placed the respondents on some point on the scale and were found for example, in Section C where the intensity of the visual impairment either decreased or increased.

Authors (Kerlinger, 1986; Leedy, 1989; McBurney, 1994) argue that fixed alternative items achieve greater uniformity of measurement and thus greater reliability. However it can be argued that this type of item and the responses elicited result in superficiality and therefore open-ended questions and probes are needed to get beneath the surface (Kerlinger, 1986). To gain this *insight* open-ended questions were used, for example in Section A, "how would you describe frustration?" Although the content of open-ended questions was dictated by the research problem, no other restrictions on the content and manner of expression were imposed (Kerlinger, 1986). Authors (Kerlinger, 1986; McBurney, 1994) argue that open-ended questions are flexible, have possibility of depth, enable the interviewer to clear up misunderstandings through probing, encourage cooperation and rapport and make better estimates of the respondents true intentions, meanings, beliefs and attitudes. The use therefore of both closed and open-ended questions ensured that in this present study, great depth was gained.

The schedule was checked for consistency. Based on the suspicion that the respondents' answers might have been cautious rather than true, countercheck questions were incorporated into

the schedule. For example, the question of frustrations related to assumptions made by sighted persons were found in Sections A and D, "when people make assumptions about visual impairment without checking to see if they are correct" and "I feel annoyed when people make wrong assumptions about visual impairment"; and contradictory statements in Section D "for total adjustment to visual impairment one has to move through various stages culminating with the final stage of acceptance" and "there is no final stage of acceptance of visual impairment, but rather a continuous recycling through the various stages." The introduction of counterchecks was assumed to verify the consistency with which the schedule was answered (Leedy, 1989). It must be noted however, that the introduction of counterchecks were for informative purposes only and no statistical procedures were applied if inconsistencies were found.

4.7.2 Standardised tests

Standardised tests, such as the Sixteen Personality Factor Questionnaire (Human Sciences Research Council, 1966) and the Nottingham Adjustment Scale (Dodds et al., 1991) were included in the interview schedule. These inclusions enhanced the reliability and validity of the present study and enabled the researcher to explore beyond the surface and gain in-depth knowledge pertaining to psychological and emotional reactions experienced by AVI adults.

The Sixteen Personality Factor Questionnaire

This questionnaire (16-PF) was included in the present study to establish a baseline for the inherent personality trait of frustration (anxiety) amongst the AVI respondents. The intention of this present study was not to measure *trait* frustration but rather the respondents' emotional reactions to their visual impairment which includes the emotional reaction of frustration. The researcher was therefore attempting not to confound *trait* frustration (anxiety) and frustration as a reaction to a

situation (in this case, visual impairment). By establishing that the sample respondents' mean scores on the selected personality factors are comparable to the means of the norm groups, the researcher would be relatively confident that the two are not confounded, in other words, that the sample respondents' levels of trait frustration are comparable to those of the respondents of the norm group.

The 16-PF Questionnaire (Form A) adapted by the Human Sciences Research Council (1966) was based on South African norms and its reliability (split-half and test re-test reliability) compared favourably with those obtained for the original American questionnaire (Huysamen, 1983). The rationale behind the 16-PF is that a questionnaire which is based on revealed traits obtained through mathematical techniques from a large pool of possible personality descriptions is capable of measuring true personality constructs present in humans (Huysamen, 1983). Persons over the age of 18 years can be tested, provided that they have a working understanding of English and that they are adapted to a predominantly western culture and are able to function adequately therein. They should have a formal education of at least Std. 10, or any other equivalent education. Although some of the respondents in this study did not meet this education requirement, their scores were still included, as this test was used only to describe the specific personality characteristic of frustration.

Only three highly correlated factors from the 16-PF were chosen to investigate the selected personality characteristic of frustration, namely, Factor C, Q3 and Q4 (Karson & O'Dell, 1977). A low Factor C score implies that a person is affected by feelings, is emotionally unstable, and is easily upset (lower ego strength), whereas a high score implies emotional stability and reality awareness (high ego strength) (Karson & O'Dell, 1977). Another description of a low Factor C score is that the person could become emotional when frustrated and could have difficulty in adjusting to life's demands (Karson & O'Dell, 1977). A low

score on Factor Q3 implies that a person has a lack of control, and is careless of social rules, whereas, a high score implies that a person has the ability to bind anxiety, is controlled and is socially precise (Karson & O'Dell, 1977). Factor Q3 is most useful as an indicator of ability to control emotions, particularly anger and anxiety (Karson & O'Dell, 1977). A low score on Factor Q4 implies that a person is relaxed, tranquil and unfrustrated, whereas a high score implies that a person is tense, frustrated, driven, and fretful (Karson & O'Dell, 1977). Factor Q4 is the best single indicator of anxiety on the 16-PF (Karson & O'Dell, 1977). The relevant questions related to the selected personality factors from the 16-PF questionnaire (Form A) adapted by the Human Sciences Research Council (1966) were used.

A review shows that the short-term and long-term AVI scores for the selected personality factors compare favourably with the mean scores of the norm group. For factor C, 5 short-term and 4 long-term AVI have higher scores, 2 short-term and 4 long-term AVI have lower scores than the norm mean. For factor Q3, 8 short-term and 7 long-term AVI have higher scores and 1 short-term and 2 long-term AVI have lower scores than the norm mean. For factor Q4, 2 short-term and 4 long-term AVI have higher scores and 4 long-term AVI have lower scores than the norm mean. Appendix F shows the personality factor scores for the AVI respondents.

Nottingham Adjustment Scale

As adjustment to and acceptance of visual impairment are assumed to be a prerequisite for rehabilitation, the Nottingham Adjustment Scale' (Dodds et al., 1991) was administered to all respondents. If the respondents are *adjusted* and have *accepted* their visual impairment, then it would be assumed that the grief reactions and frustrations related to the visual impairment would decrease over time. According to Dodds et al. (1991) adjustment to acquired visual impairment is characterised by the following psychological factors: low levels of anxiety, an absence of

depression, high self esteem, a high sense of self efficacy, a high sense of responsibility for recovery, a positive attitude towards visually impaired people, and a high acceptance of visual impairment.

In researching the literature, Dodds et al. (1991) found a number of questionnaires related to their proposed adjustment scale. These questionnaires included: Goldberg's (1981) General Health Questionnaire that identifies psychological problems which affect a person's perceived health and which also addresses symptoms of anxiety and clinical depression; Linkowski's (1971) Acceptance of Disability Questionnaire; Sherer et al's. (1982) Self Efficacy Questionnaire; Patridge and Johnston's (1989) Recovery Locus of Control Questionnaire; Rosenberg's (1965) Self Esteem Questionnaire; Attitudes to Visual Impairment Questionnaire based on Yaker et al. (1960) Attitude to Disabled Persons Scales; Peterson et al's. (1982) Attributional Style Questionnaire (all mentioned authors appear in Dodds et al., 1991). Except for the Attitudes to Visual Impairment Questionnaire which had to be adapted because many of the items reflected outdated stereotypes of disability and the construction of a new Attributional Style Questionnaire, all other questionnaires, with minor or no changes in the wording, were applicable to visually impaired persons (Dodds et al., 1991).

The final questionnaire was subjected to two analyses and statistical tests including item-total correlations, a cluster and a factor analysis. By reducing the number of items to be included in the scale, the homogeneity of the questionnaire was increased. In addition, the factorial structure of the questionnaire increased the validity of the constructs used (Dodds, et al., 1991).

The Nottingham Adjustment Scale (Dodds et al., 1991) consists of 7 separate sections measuring the psychological factors which characterise adjustment to acquired visual impairment. The sections can be scored separately or when totalled together,

measure the overall adjustment to acquired visual impairment. The request to use the Nottingham Adjustment Scale in the present research study and the subsequent reply appear in Appendices D and E.

4.7.3 Administering the interview schedule

The questions of the interview schedule were read to the AVI respondents and their answers tape-recorded and later transcribed onto a computer by the researcher. As the researcher is herself AVI, a sighted person (including psychology students, nursing sisters and social workers) assisted by reading the questions, but all probing and explaining were done by the researcher.

The following information and instructions were given to each respondent: "Thank you for agreeing to participate in this study. At the outset, I want to assure you that the interview is strictly confidential and that you will remain anonymous. I am conducting interviews to obtain information on how visually impaired persons experience frustrations related to their impairment. Please answer all questions as honestly and openly as possible. There are no *right* or *wrong* answers to these questions, as we are interested in your experiences and feelings. As I myself am visually impaired, the interview will be recorded on audio cassette tape and transcribed after the interview."

At the end of the interview the respondents were asked for their impressions of the interview. They were offered a summary of the results of the research in return for their investment of time and the courtesy of participating in the research.

4.8 PROCEDURES TO EXAMINE THE DATA

The aim in this research study was to investigate whether there is a relation between length of time of visual impairment and psychological and emotional reactions after the loss of sight. Differences between two independent groups of short-term

and long-term AVI adults were examined by means of parametric statistical procedures. The researcher had no control over the independent variable as persons belonged to particular levels of this variable prior to the onset of the study. For example, the independent variable in the present study of *length of time of visual impairment* had two levels, visual impairment for under and over 6 years. The dependent variables either had different categorical levels, such as frequent or infrequent frustrations, or were considered to be continuous, such as the Likert-type measurements of intensity of frustration.

The parametric procedures used to investigate the differences between the two groups followed a pattern. All responses to the relevant questions were tabulated in order to reduce large quantities of data to manageable and understandable form. After this procedure, statistical analysis followed including, percentages, averages, and appropriate statistical tests of significance (Kerlinger, 1986).

4.8.1 Statistical tests relevant to the study

The function of statistical tests is to compare obtained results with those expected on the basis of chance (Kerlinger, 1986). The levels of statistical significance such as the 0,05 and 0,01 levels are the standard levels used in statistical testing and imply that an obtained result that is significant at the 0,05 level could occur at most by chance only five times out of one hundred. Degrees of freedom (df) implies the latitude of variation a statistical problem has (Kerlinger, 1986).

The following statistical tests were used in the present study:

Chi Square Test

A chi square test measures the significance or non-significance of a relation between categorical independent and dependent variables. The test measures the departure of obtained

frequencies from the frequencies expected by chance. The larger the value of chi squared therefore, the greater the obtained frequency deviation from the expected chance frequency and the greater the relation between the variables (Kerlinger, 1986). This method was used in the present study because: the independent variable was categorical comprising two levels of visual impairment of under and over 6 years; many of the dependent variables were categorical, such as frequent and infrequent frustrations and a yes or no response.

t-Test

The central statistical idea behind the t-test is whether there is a significant difference between the mean scores of two groups and whether this difference is within the bounds of chance fluctuations only, or beyond that which is expected by chance (Kerlinger, 1986). This method was used in the present study because: two groups of long-term and short-term AVI respondents were compared; many of the dependent variables were continuous such as, the scores of the Nottingham Adjustment Scale to measure adjustment to visual impairment.

Content Analysis

The purpose of content analysis is to discover common meanings of a specific issue held by different respondents. Content analysis is a method used to measure variables in a "systematic, objective and quantitative manner" (Kerlinger, 1986, p. 477). The quantification involves noting the different mutually exclusive categories that are obtained from the answers to a particular question, and then the summing of the frequencies of similar answers that fall into each mutually exclusive category. This method was used in the present study for the responses to the open-ended or qualitative questions such as "What causes you to become the most frustrated"? The *theme, which is a sentence or proposition related to a particular question*, was the unit of analysis that was used for the content analysis because it came

close to the original content of the respondents' answers to specific questions.

4.9 CONCLUSION

In this chapter, the research methodology (or the envisaged overall plan of investigation into the research problem) was discussed. In complying with the distinct characteristics of research methodology, this research study originated with questions related to unexplored problems in the field of adventitious visual impairment which lead to the formulation of hypotheses and related subsidiary investigations. The characteristics of research requiring a specific plan of *factual and meaningful* procedures were discussed and included: the non-experimental nature of the research; the non-probability sampling method, the characteristics of the selected sample; the interview schedule and standardised tests as the method of data collection; the procedures used to analyze the collected data.

The following chapter reports the results obtained from the hypotheses and subsidiary investigations related to the research problem.

CHAPTER FIVE

RESULTS: THE RELATIVE TRUTH

5.1 INTRODUCTION

This chapter reports on the results of quantitative comparisons of *short-term* versus *long-term* AVI adults with respect to:

- the frustrations they experience;
- their acceptance and adjustment to visual impairment;
- their need for continued emotional support.

It further explores the subjective meanings that AVI persons attribute to these constructs through qualitative analysis.

In this criterion groups design, short-term versus long-term visual impairment is operationalised as less than 6 years versus longer than 6 years of adventitious impairment. Under the assumptions of the normal distribution, homogeneous population variances (that is, the unknown variances of the two populations had relatively similar numerical values) and equal sample sizes, parametric procedures and related test statistics for making inferences about the central tendencies of independent populations are relevant in this research study (Huysamen, 1983; Kerlinger, 1986).

This chapter will consist of 5 main sections each comprising the method and result of the analysis. The first section investigates the experience and meaning of frustration. Section 2 will report the results from the testing of Hypothesis 1 (frequency of frustration) and the related subsidiary investigations. Section 3 will report the results from 5.25 the testing of Hypothesis 2 (intensity of frustration) and the related subsidiary investigations. Section 4 will report the results from the testing of Hypothesis 3 (acceptance of visual

impairment) and the related subsidiary investigations. Section 5 will report the results from the testing of Hypothesis 4 (need for continued emotional support) and the related subsidiary investigations.

5.2 SECTION 1: THE EXPERIENCE AND MEANING OF FRUSTRATION

This section on the experience and meaning of frustration will report the results of:

- frustration as a personality trait;
- the perceived occurrence of frustration;
- the descriptions of the meaning of frustration.

5.2.1 Frustration as a personality trait

As the present study was concerned with the measurement of frustration as an emotional reaction to adventitious visual impairment, it was necessary to ensure that the personality trait of frustration, and frustration as a reaction to the situation of visual impairment, were not confounded.

Method of analysis of personality traits

The obtained raw scores for each AVI respondent on factors C, Q3 and Q4 from the Sixteen Factor Personality Questionnaire were converted to *sten* scores. The means for each factor were calculated and compared to the *sten* scores from the General Public Norm Tables for males and females (HSRC, 1966). The mean *sten* scores of the short-term and long-term AVI respondents and the general public norm tables are shown in Table 5.1.

Results of analysis

The results when comparing the short-term versus the long-term AVI respondents show that the two groups compare favourably with respect to factor Q4 and with respect to the norm mean score

according to the General Public Norm tables.

Table 5.1 Mean sten scores comparing short-term versus long-term AVI respondents and the General Public Norm sten scores for factors C, Q3 and Q4

Factors	C	Q3	Q4
Short-term mean sten scores	5,81	5,88	5,00
Long-term mean sten scores	5,00	5,88	5,06
Total mean sten scores	5,41	5,88	5,03
Norm mean sten scores	5,00	5,00	5,00

The average score on factor Q4 for both groups implies a balance between non-frustration and frustration and anxiety. A slightly higher than average score on factor Q3 was obtained for both the short-term and long-term AVI respondents which implies a satisfactory ability to control emotions particularly anger and anxiety. The short-term and long-term AVI respondents compare favourably with respect to factor C (the short-term having a slightly higher than average score), which implies satisfactory emotional stability and adjustment to life's demands.

If frustration scores on the scales used in this study to measure frustration as an emotional reaction to AVI turn out to be high, it cannot be reflected as a personality trait of high frustration as the AVI respondents do not have higher trait anxiety (frustration) than the norm.

5.2.2 Analysis of perception of occurrence of frustration

To further the investigation into the experience of frustration as an emotional reaction to visual impairment, AVI respondents were asked to state how often they perceive themselves to be frustrated. Frequencies of the response alternatives to the question, "would you say that you are frustrated: most of the time, sometimes, in certain situations, never" (Section B, question 2 of interview schedule) were obtained for the AVI respondents and are shown in Table 5.2.

Table 5.2 Perceived occurrence of frustrations experienced by the short-term versus long-term AVI respondents

Frustrations	Short-term	Long-term	Totals
Most of the time	1 (6%)	1 (6%)	2 (6%)
Sometimes	3 (19%)	2 (13%)	5 (16%)
Certain situations	12 (75%)	13 (81%)	25 (78%)
Never	0	0	0

Results of analysis

The frequencies as shown in Table 5.2 suggest that the majority of both the short-term (75%) and long-term (81%) AVI respondents perceive themselves to be frustrated in "certain situations" related to their visual impairment. This result substantiates the presumption that the measurement of frustration in the present study is an emotional reaction related to visual impairment.

5.2.3 Descriptions of the meaning of frustration

It was investigated whether there was general consensus among the AVI respondents on the meaning of frustration and whether the descriptions came close to the definition described in Section 4.2. {Description of terms p. 78}. As the present study was concerned with the experience of frustration related to visual impairment, diversity in the meaning and therefore understanding of the concept of frustration amongst the AVI respondents would have allowed for invalid results.

Method of analysis

The responses to the qualitative question, "how would you describe frustration" (Section A, question 1 of the interview schedule) were content analysed and thematically grouped in mutually exclusive categories to discover the meaning of the description of frustration that different AVI respondents had in common. As the researcher was interested in establishing whether all the AVI respondents had similar meanings of the concept of

frustration, the analysis of the themes was based on the total sample rather than the separate sample groups.

Results of analysis

Two main themes regarding the meaning of frustration were obtained from the content analysis: "frustration is a feeling which causes problems or difficulties"; "frustration is a feeling that results from being prevented from doing, or the inability to do, something". Both themes comprised negative feelings. The former description had distinct components: frustration causes negative feelings such as depression and aggravation related to visual impairment; frustration causes questioning. Similarly, the latter theme also had distinct components: frustration is a feeling resulting from the inability to do similar things as done before visual impairment; frustration is a feeling resulting from visual impairment preventing independence. There was one description of frustration as a behaviour and therefore was not seen as a main theme. Appendix G shows the different descriptions of the meanings of frustration given by different respondents. Frequencies and corresponding percentages of these themes are shown in Table 5.3.

Table 5.3 Different themes obtained through content analysis regarding the meaning of frustration

Meanings of Frustration	Frequencies and Percentages
Feelings causing problems	15 (47%)
Feelings caused by prevention	16 (50%)
Behaviours	1 (3%)
Totals	32 (100%)

The results show that there was almost total consensus among the respondents (97%) that frustration is a *feeling*. In addition, there was consensus among the respondents regarding the meaning of frustration with only two main themes being described. These descriptions of frustration given by the AVI respondents are

consistent with the meaning of frustration as used in the present study.

5.2.4 Summation: Results of experience and meaning of frustration

The intention of the present study was to measure frustration as an emotional reaction experienced by AVI adults in relation to their impairment. The researcher is relatively confident that this concept of frustration was measured in the study because: content analysis has shown that there was consensus among the AVI respondents regarding the meaning and therefore understanding of the concept of frustration; that the personality trait of frustration, and frustration as an emotional reaction to the situation of adventitious visual impairment were not confounded.

5.3 SECTION 2: HYPOTHESIS 1 TESTING AND SUBSIDIARY INVESTIGATIONS

This section on the testing of Hypothesis 1 (frequency of frustration) and the related subsidiary investigations will report the results of:

- Hypothesis 1 (frequency of frustration);
- causes of frustration;
- time intervals and frustrations.

5.3.1 Hypothesis 1: Long-term AVI persons experience more frequent frustrations than do short-term AVI persons

Method of analysis

Frequencies of the response alternatives to the question, "in the past week how often have you experienced frustrations related to your visual impairment?: Not once, once in the week, once every other day, once a day, several times daily" (Section B, question 1 of interview schedule), were obtained for the two groups and are shown in Table 5.4.

Table 5.4 Frequencies of frustrations experienced by short-term and long-term avi respondents

Frequency of frustration	Short-term	Long-term
Not once	5 (31%)	0
Once a week	6 (37%)	2 (13%)
Every other day	2 (13%)	3 (19%)
Once daily	2 (13%)	6 (37%)
Several daily	1 (6%)	5 (31%)
Totals	16 (100%)	16 (100%)

A chi square statistical test was used to investigate this hypothesis as the variable, frequency of frustration, is categorical. Different levels were combined because the frequencies were too small for a chi squared test based on 5 levels of the variable. *Infrequent frustration* included the levels of not once, once in the week and every other day; whereas *frequent frustrations* included the levels of once a day and several times daily. Frequencies of short-term and long-term AVI respondents experiencing infrequent or frequent frustrations are shown in Table 5.5.

Table 5.5 Frequencies comparing short-term versus long-term avi respondents and the experience of infrequent or frequent frustration

Frustrations	Short-term	Long-term
Infrequent	13 (81%)	5 (31%)
Frequent	3 (19%)	11 (69%)

Results of analysis

Table 5.6 Chi square result of frequent or infrequent frustrations experienced by the short-term and long-term AVI respondents

Chi Square value: 8,13	$p < 0,01$	1 df
------------------------	------------	------

Based on the statistically significant chi squared result the hypothesised relation between the different lengths of time of adventitious visual impairment and the experienced frequency of

frustrations was supported. To investigate the strength of the relation between the categorical variables of frequent or infrequent frustrations experienced by the long-term and short-term AVI respondents, a coefficient of contingency was calculated, with $C = 0,45$. This coefficient indicates a moderate relation.

On the basis of this significant result it can be seen that the majority (81%) of the short-term AVI respondents experience infrequent frustrations as compared to a minority (31%) of the long-term AVI respondents. On the other hand, the majority (69%) of the long-term AVI respondents experience frequent frustrations as compared to a minority (19%) of the short-term AVI respondents. The frequencies as shown in Table 5.4 may be indicative of directional trends between length of time of AVI and frequency of frustrations. Five (31%) of the long-term AVI respondents experienced frustrations "several times daily" as compared to only 1 (6%) of the short-term AVI respondents. On the other hand, 5 (31%) of the short-term AVI respondents experienced frustrations "not once" as compared to none (0%) of the long-term AVI respondents.

The hypothesis that "Long-term AVI persons experience more frequent frustrations than do short-term AVI persons" was supported.

5.3.2 Subsidiary investigation (1A): Causes of frustration

Related to Hypothesis 1 (frequency of frustration) is the subsidiary investigation into the causes of frustration and whether these causes differ between the short-term and long-term AVI respondents.

Method of analysis

The response alternatives to how often selected situations are frustrating were obtained (Section A, question 4 of interview

schedule). A four-point Likert-type scale was used to measure these subjective perceptions. The respondents options were: always, often, seldom and never. The Likert scale was numerically scored from 1 for always, to 4 for never. The lower the score therefore, the more often the situation causes frustration. The dependent variables were considered to be continuous and assumed to approach equal interval scales so that mean scores could be calculated and compared via the statistical t-test.

Results of analysis

The mean scores for the different statements for the short-term and long-term AVI respondents and the subsequent t-tests were calculated and are shown in Table 5.7. The t-test results are not statistically significant.

Table 5.7 Mean scores and t-test results comparing short-term versus long-term AVI respondents on different situations which cause frustration (df = 30)

Mean scores	Short-term	Long-term	t-value
Loss of independence	2,19	2,44	0,78
Lack of understanding	1,81	2,06	0,84
Unable to do things	1,94	1,69	0,09
Visually impaired ignorant	2,00	1,63	1,19
Having to be dependent	1,75	1,56	0,75
Expectations of sighted world	2,13	2,08	0,38
People try to organise visually impaired life	1,87	1,56	0,89
Choice taken away from you	1,75	1,56	0,56
Limitations of the visual impairment	2,01	2,06	0,17
Assumptions taken by sighted world	1,75	1,44	1,11

It is possible that the measuring instrument used in this investigation was not sufficiently sensitive to pick up trends. A further investigation into the causes of frustration was

analysed and will now be discussed.

5.3.2.1 *Further subsidiary investigation: Causes of frustration*

Similar situations causing frustration (situations outlined in Section A, question 4 of interview schedule) were combined to form 3 main categories of causes of frustration: *loss of independence*; *lack of understanding from the sighted*; and *loss of control*.

The category of *loss of independence* included the situations of: "your loss of independence, having to be dependent on others, and the limitations put on you because of your visual impairment."

The category of *lack of understanding* included the situations of: "the general lack of understanding of the sighted world about visual impairment, when people think that the visually impaired are ignorant as well, the stereotyped expectations of the sighted world and when people make assumptions about visual impairment without checking to see if they are correct."

The category of *loss of control* included the situations of: "when you are unable to do things on the spur of the moment, others try to organise your life and when the option of choice is taken from you."

The same four-point Likert-type scale as used in Section 5.3.2 was used in this analysis. t-tests were once again calculated.

Results of analysis

The mean scores for the combined situations causing frustrations for the short-term and long-term AVI respondents and the subsequent t-tests were calculated and are shown in Table 5.8. The overall mean score was the sum of the three categories.

Table 5.8 Mean scores and t-test results comparing short-term versus long-term AVI respondents on different categories of situations causing frustration (df =30)

Mean scores	Short-term	Long-term	t-value
Loss of independence	5,94	6,06	0,16
Lack of understanding	7,65	7,13	0,59
Loss of control	5,56	4,81	0,88
Overall	19,15	18,00	0,56

The t-test results are not statistically significant. However, the differences in mean scores as shown in Table 5.8 may be indicative of a trend with the category of *loss of independence* causing the short-term respondents to become frustrated more often whereas, the other categories of *lack of understanding* and *loss of control* cause the long-term respondents to become frustrated more often.

In order to establish how similar the AVI respondents' descriptions of the causes of frustrations were to the situations delineated in the interview schedule a further investigation was undertaken.

5.3.2.2 *Subsidiary investigation: Descriptions of causes of frustration*

Responses to the qualitative question, "as a visually impaired person, what causes you to become the most frustrated?" (Section A, question 3 of interview schedule) were content analysed and thematically grouped in mutually exclusive categories of concern. It must be noted that this particular question was asked before the question on how often certain situations caused frustration (Section A, question 4), and therefore the answers to the open-ended question given by the respondents could not have been influenced by the statements.

Results of analysis

Two main themes regarding the causes of frustration were

obtained from the content analysis: "loss of independence" and "lack of understanding and support from others." In addition, two other themes, "inability to do things" and a combination of both "loss of independence and lack of understanding" were obtained, but these themes constituted less than 10% of the total sample of responses and were seen merely as secondary causes (see Appendix H for direct transcripts of respondents' descriptions of causes of frustration).

The frequencies of both the short-term and long-term AVI respondents with similar descriptions of the causes of frustration are shown in Table 5.9.

Table 5.9 Different themes obtained through content analysis of the main causes of frustration for the short-term and long-term AVI respondents

Causes of frustrations	Short-term	Long-term
Loss of independence	10 (63%)	7 (44%)
Lack of understanding and support	4 (25%)	5 (31%)
Inability to do things	2 (13%)	1 (6%)
Combination of loss and lack	0	3 (19%)

The results as shown in Table 5.9 show that the majority of the short-term respondents (63%) perceive "loss of independence" as their major cause of frustration. The results suggest that the long-term respondents perceive both "loss of independence" and "lack of understanding" as causing relatively similar amounts of frustration. These results are consistent with the results obtained in 5.3.2 and 5.3.2.1.

The category of "loss of control" (as delineated in 5.3.2.1 did not correspond with the descriptions of the main causes of frustration given by the AVI respondents. Possibly, this category was automatically included in the theme of "loss of independence."

5.3.3 Subsidiary investigation (1B): Time intervals and frustration

The researcher then investigated whether certain time periods of adventitious visual impairment are more or less frustrating than others. This exploratory investigation focused on Hypothesis 1, frequency of frustration. The *time intervals* were divided into periods of 2 years, starting from time of onset and continuing up to 10 plus years of adventitious visual impairment. The same categories of *infrequent* and *frequent* frustrations as outlined in Section 5.3.1 (method of analysis of Hypothesis 1) were used in this investigation.

Results of investigation

Frequencies of infrequent and frequent frustrations that were experienced by the respondents in the demarcated time intervals were obtained and are shown in Table 5.10.

Table 5.10 Frequencies of AVI respondents who experienced frequent or infrequent frustrations according to different time intervals

Years	Infrequent	Frequent
0-2	3 (75%)	1 (25%)
2-4	5 (83%)	1 (17%)
4-6	5 (83%)	1 (17%)
6-8	1 (25%)	3 (75%)
8-10	2 (50%)	2 (50%)
10+	2 (25%)	6 (75%)

The results as shown in Table 5.10 suggest that the time interval from onset to 6 years of adventitious visual impairment is less frustrating as compared to the time interval from 6 years and over which appears to be more frustrating for the AVI respondents. This exploratory result is consistent with the result obtained in Section 5.3.1 where the hypothesis that long-term AVI persons experience more frequent frustrations than do short-term AVI persons was supported.

It is interesting to note that the time intervals, 2-4 and 4-6 years of adventitious visual impairment are the least frustrating (infrequent frustrations) for the short-term AVI respondents. The time intervals, 6-8 and 10+ years of adventitious visual impairment are the most frustrating (frequent frustrations) for the long-term AVI respondents.

5.3.4 Summation: Hypothesis 1 and subsidiary results

The hypothesised relation between length of time of adventitious visual impairment and the frequency of frustrations experienced was supported. The long-term respondents in this study experience "frequent" frustrations as compared to the short-term respondents who experience "infrequent" frustrations. Results obtained from the subsidiary investigation of *causes of frustration* suggest that "loss of independence" is perceived as the major cause of frustration for the short-term respondents, whilst the long-term respondents perceive both "loss of independence" and "lack of understanding" as causing relatively similar amounts of frustration. The results from the subsidiary investigation of certain time intervals of adventitious visual impairment being more or less frustrating are consistent with the Hypothesis 1 result with the time interval from onset to 6 years of adventitious visual impairment being less frustrating than the time interval 6 years and over which appears to be more frustrating for the AVI respondents.

5.4 SECTION 3: HYPOTHESIS 2 TESTING AND SUBSIDIARY INVESTIGATIONS

This section on the testing of Hypothesis 2 (intensity of frustration) and the related subsidiary investigations will report the results of:

- Hypothesis 2 (intensity of frustration);
- changes and frustration;
- the healing effect of time on frustrations related to visual impairment;

- a less frustrating life for AVI persons.

5.4.1 Hypothesis 2: Long-term AVI persons experience more intense frustrations than do short-term AVI persons

Method of analysis

Frequencies of the response alternatives to the question "would you say that since the onset of your visual impairment, the intensity of the frustrations related to your impairment has: decreased a lot or little, remained the same, increased a little or lot" (Section C, question 1 of interview schedule) were obtained for the two sample groups and are shown in Table 5.11.

Table 5.11 Frequencies comparing short-term versus long-term AVI respondents and experienced intensity of frustration

Intensity of frustrations	Short-term	Long-term
Decreased a lot	5 (31%)	1 (6%)
Decreased a little	2 (13%)	2 (13%)
Remained the same	3 (19%)	6 (37%)
Increased a little	6 (37%)	0 (0%)
Increased a lot	0 (0%)	7 (44%)

A five-point Likert-type scale was used to measure the respondents subjective perception of the intensity of their frustrations. The Likert scale was numerically scored from 1 for "decreased a lot", to 3 for "remained the same", to 5 for "increased a lot". A numerical score of 3 was given to "remained the same" as there was no way of knowing whether this description implied an increase or decrease in the intensity of frustrations, but that there are indeed frustrations experienced since the onset of visual impairment. The Likert scale scores were once again considered to be continuous and assumed to approach equal interval scales, so that mean scores could be calculated and compared via the statistical t-test.

Results of analysis

Table 5.12 Mean scores of the AVI respondents and the t-test results of intensity of frustration

Intensity of frustration	Short-term	Long-term	t-value	p-value	df
Mean scores	2,63	3,63	2,11	p <0,05	30

Based on the statistically significant t-test result, the hypothesised relation between the different lengths of time of adventitious visual impairment and the experienced intensity of frustration is supported. On the basis of the direction of the group means, it can be seen that the long-term AVI respondents experienced more intense frustrations than did the short-term AVI respondents.

The results from Table 5.11 show that 7 (44%) of the long-term AVI respondents experienced a large increase in the intensity of frustration as compared to none (0%) of the short-term AVI respondents. On the other hand, 1 (6%) of the long-term AVI respondents experienced a large decrease in the intensity of frustrations as compared to 5 (31%) of the short-term AVI respondents.

The hypothesis that "long-term AVI persons experience more intense frustrations than do short-term AVI persons" was supported.

5.4.2 Subsidiary investigation (2A): Changes and frustration

All AVI respondents were asked the question "from the time of the onset of your visual impairment to now, what has changed to make you feel less/ more frustrated?" (Section C, question 2 of interview schedule). The responses to this qualitative question were content analysed as previously.

Results of analysis

Four main themes regarding the changes leading to more or less

frustration were obtained from the content analysis: awareness of implications of visual impairment; lack of understanding and support from others; learning to cope with the visual impairment; and the changed attitudes of others. As this particular question followed the question of the intensity of frustration increasing, decreasing or remaining the same, the AVI respondents descriptions corresponded with these three categories. Appendix I shows direct transcripts of selected AVI respondents descriptions of the changes. Frequencies and corresponding percentages of both the long-term and short-term respondents with similar descriptions of what had changed to make them more or less frustrated are shown in Table 5.13.

Table 5.13 Different themes obtained through content analysis of what had changed to increase or decrease the frustrations for the short-term and long-term AVI respondents

Themes	Short-term	Long-term
Increase of frustrations		
Awareness of implications	2 (13%)	5 (31%)
Lack of understanding	4 (25%)	2 (13%)
Decrease of frustrations		
Learning to cope	6 (38%)	2 (13%)
Changed attitudes	1 (6%)	1 (6%)
Frustrations remained same		
Learning to cope	3 (19%)	6 (38%)

Awareness of the implications of visual impairment is the reason most often expressed by the long-term AVI respondents for an increase in frustration. The reason most often expressed by the short-term AVI respondents for an increase in frustration is the lack of understanding and support from others. Learning to cope with the visual impairment is the reason most often expressed by the long-term AVI respondents for frustration remaining the same. This reason is most often expressed by the short-term AVI respondents for a decrease in frustration.

5.4.3 Subsidiary investigation (2B): The healing effect of time

The responses to the qualitative question "what are your feelings about the saying, *time heals* with respect to your experience of frustration related to your visual impairment?" (Section D, question 6 of interview schedule) were content analysed as previously (Table 5.14).

Results of analysis

Three main themes were obtained from the content analysis: totally disagree with the saying; time makes it easier but does not totally heal the frustrations; agree that time heals frustrations (Appendix J shows selected direct transcripts).

Table 5.14 Different themes obtained through content analysis of the saying *time heals* for the long-term and short-term AVI respondents

Theme	Short-term	Long-term
Disagree	3 (19%)	10 (63%)
Time makes easier-not totally heal.	4 (25%)	3 (19%)
Agree	9 (56%)	3 (19%)

The results as shown in Table 5.14 show that the majority (63%) of the long-term respondents disagree with the saying that time heals frustrations related to their visual impairment, whereas, just over half (56%) of the short-term respondents agree with the saying.

5.4.4 Subsidiary investigation (2C): A less frustrating life

All respondents were asked the question, "what do you believe would help to make your life as a visually impaired person less frustrating?" (Section G, question 1 of interview schedule). Once again, the responses to this qualitative question were content analysed (Table 5.15).

Results of analysis

Three main themes were obtained from the content analysis: employment; awareness, understanding and acceptance from society; assistance. The theme of "assistance" included practical support such as transport and aids, as well as informational and technical assistance and support. The theme of "awareness, understanding and acceptance" also included specific components, for example, awareness of visual impairment from both society and the visually impaired themselves. Appendix K shows direct transcripts from selected AVI respondents.

Table 5.15 Different themes obtained through content analysis of what would make the short-term and long-term AVI respondents' lives less frustrating

Theme	Short-term	Long-term
Employment	4 (25%)	3 (19%)
Awareness	4 (25%)	9 (56%)
Assistance	7 (44%)	4 (25%)
Don't know	1 (6%)	0

The response most frequently given by the long-term AVI respondents to what would make their lives less frustrating was "awareness, understanding and acceptance from society" (56%), compared to "assistance" (44%) which was cited as the most frequent response by the short-term AVI respondents.

5.4.5 Summation: Hypothesis 2 and subsidiary results

The hypothesised relation between length of time of adventitious visual impairment and the experienced intensity of frustrations was supported. The long-term AVI respondents experience more intense frustrations as compared to the short-term AVI respondents. Results obtained from the subsidiary investigation of changes and frustration suggest that the long-term respondents experience increases in frustration because of their increased awareness of the implications of their condition and although they have learnt to cope, the frustrations still

remain. The short-term respondents however experience a decrease in frustrations because they have learnt to cope with the impairment. The subsidiary investigation into *time heals* frustrations related to visual impairment found that the majority of the long-term respondents disagree whilst the majority of the short-term respondents agree. The subsidiary investigation into what would make the lives of the AVI less frustrating found that the long-term respondents describe "awareness, understanding and acceptance from society" and the short-term respondents describe "assistance."

5.5 SECTION 4: HYPOTHESIS 3 TESTING AND SUBSIDIARY INVESTIGATIONS

This section on the testing of Hypothesis 3 (acceptance of visual impairment) and the related subsidiary investigations will report the results of:

- Hypothesis 3 (acceptance of visual impairment);
- adjustment to visual impairment including: overall adjustment, practical and emotional adjustment;
- adjustment as a linear or continuous process;
- descriptions of adjustment and acceptance of visual impairment;
- changes in emotions that were present at the onset of visual impairment to the present.

5.5.1 Hypothesis 3: Long-term AVI persons accept the impairment to a lesser extent than do short-term AVI persons

Method of analysis

Frequencies of the response alternatives to the question "to what extent have you accepted your visual impairment?" (Section D, question 1 of the interview schedule) were obtained for the two sample groups and are shown in Table 5.16.

Table 5.16 Frequencies of the different levels of acceptance of visual impairment for the short-term and long-term AVI respondents

Acceptance	Short-term	Long-term
Not at all	1 (6%)	2 (12%)
Small extent	0 (0%)	1 (6%)
Moderately	2 (12%)	2 (12%)
Large extent	7 (44%)	7 (44%)
Completely	6 (37%)	4 (25%)

The five-point Likert-type scale was numerically scored from 1 for "not at all", to 5 for "completely". The dependent variable of acceptance of visual impairment was considered to be continuous and assumed to approach equal interval scales so that mean scores could be calculated and compared via the statistical t-test.

Results of analysis

Table 5.17 Mean scores of the AVI respondents and the t-test result for acceptance of visual impairment

Acceptance	Short-term	Long-term	t-value	p	df
Mean scores	4,06	3,63	1,04	>0,1	30

The obtained result was not significant. The results (differences in mean scores) may be indicative of a trend for the long-term AVI respondents to accept their visual impairment to a somewhat lesser extent as compared to the short-term AVI respondents. The results from Table 5.16 show similar trends in the responses of the short-term and long-term AVI respondents.

The hypothesis which stated that "long-term AVI persons accept the impairment to a lesser extent than do short-term AVI persons" was not supported in this analysis. It is possible that the measuring instrument used to test the hypothesis was not sufficiently sensitive to pick up the trends. For this reason, another measure of *acceptance of visual impairment* was analysed

to test Hypothesis 3.

5.5.1.1 Hypothesis 3: Further investigation of acceptance

The Nottingham Adjustment Scale (Dodds et al., 1991) provides 7 separate sub-sections for measuring the overall adjustment to adventitious visual impairment, one of which is acceptance. Section E of the Nottingham Adjustment Scale contains 9 questions measuring acceptance of acquired visual impairment.

Method of analysis

A five-point Likert-type scale is used to measure the respondents' acceptance of visual impairment. The options range from strongly agree to don't know to strongly disagree. The Likert scale is numerically scored from 1 to 5 depending on whether the item is phrased positively or negatively. The higher the overall score, the higher the acceptance of visual impairment. The dependent variable of acceptance of visual impairment was considered to be continuous and assumed to approach equal interval scales so that mean scores could be calculated and compared via the statistical t-test.

Results of analysis

Table 5.18 Mean scores of the two sample groups (and the mean norm score from the Nottingham Adjustment Scale, NAS) and the t-test results for acceptance of visual impairment

Acceptance	Short-term	Long-term	t-test	p	df
Mean scores (NAS 35,00)	35,38	30,88	2,25	<0,05	30

Based on the significant result it can be seen that the long-term AVI respondents accept their visual impairment to a lesser extent as compared to the short-term AVI respondents.

It is interesting to note the difference in the mean score for acceptance of visual impairment between the long-term AVI respondents and the norm mean score of the Nottingham Adjustment Scale. The difference between the long-term AVI scores and the norm group score is greater than the difference between the short-term AVI scores and the norm group score.

The hypothesis that stated that "long-term AVI persons accept their visual impairment to a lesser extent than do short-term AVI persons" was supported by this analysis.

5.5.2 Subsidiary investigation (3A): Adjustment to visual impairment

Acceptance is assumed to be the cornerstone of adjustment to visual impairment. It was investigated whether there were differences, as in the case of acceptance, between the short-term and long-term AVI respondents with regard to adjustment to visual impairment.

Method of analysis

A four-point Likert-type scale is used to measure the respondents' anxiety and depression, as found in Section A of the Nottingham Scale. The respondents' options range from "not at all" to "much more than usual" with higher scores indicating better adjustment (The higher the obtained score, the lower the anxiety and depression).

A five-point Likert scale is used to measure the respondents' self-esteem (Section B), attitudes to visual impairment (Section C), locus of control for recovery (Section D), acceptance (Section E), and self-efficacy (Section F). Options range from "strongly agree" to "don't know" to "strongly disagree". The Likert scale is numerically scored from 1 to 5 depending on whether the item is phrased positively or negatively.

A five-point Likert scale is used to measure the respondent's

attributional style (Section G). Options range from "always" to "never" with the scale numerically scored from 1 to 5. The higher the obtained overall score, the better the adjustment to adventitious visual impairment. The dependent variables are considered to be continuous and assumed to approach equal interval scales.

Results of analysis

The mean scores of the two sample groups (and the mean norm scores from the Nottingham Adjustment Scale, NAS) and the t-test results (Table 5.19).

Table 5.19 Mean scores and t-test results comparing short-term versus long-term respondents on the psychological factors characterising adjustment NAS are mean scores for the Nottingham Scale (df =30)

Means	Short-term	Long-term	t-value	p-level
Overall adjustment (NAS 202,9)	200,5	183,81	2,06	*
Anxiety (NAS 40,9)	42,88	36,94	2,82	**
Self-esteem (NAS 32,7)	35,00	32,56	1,05	
Attitudes (NAS 24,00)	21,13	19,63	1,12	
Locus of control (NAS 18,8)	16,25	16,56	0,4	
Acceptance (NAS 35,00)	35,38	30,88	2,25	*
Self-efficacy (NAS 32,00)	31,56	32,00	0,38	
Attribute style (NAS 19,5)	18,44	18,38	0,04	

* $p < 0,05$

** $P < 0,01$

The inter-group comparisons of overall adjustment to adventitious visual impairment, the experience of anxiety and depression and acceptance of visual impairment are significant. Based on the significant results it can be seen that the short-

term AVI respondents are overall more adjusted to their visual impairment, have lower levels of anxiety and depression and have a higher level of acceptance of their visual impairment as compared to the long-term AVI respondents.

Although the other results were not significant they may be indicative of trends. The short-term respondents have more of the psychological factors characteristic of adjustment to visual impairment as compared to the long-term respondents. For example, they have low levels of anxiety, an absence of depression, high self-esteem, a positive attitude towards visually impaired persons and a high acceptance of visual impairment.

It is interesting to note that the overall adjustment to visual impairment scores for both the short-term and long-term AVI respondents in the present study are below the norm mean according to the Nottingham Adjustment Scale. The short-term respondents are higher than the average norm score for anxiety and self-esteem. The long-term respondents have mean scores for self-esteem and self-efficacy but all other scores are below the norm means (Nottingham Adjustment Scale).

5.5.2.1 *Subsidiary investigation: Practical and emotional adjustment*

Method of analysis

Frequencies of the response alternatives to the questions, "do you feel you have adjusted practically/emotionally to your loss of vision? Not at all, a little, moderately, very well and completely" (Section D, questions 7 and 8 of interview schedule) and are shown in Table 5.20.

Chi square test statistics were used in view of the categorical nature of the variables (results shown in Table 5.21).

Table 5.20 Frequencies of the short-term and long-term AVI respondents' perceived practical and emotional adjustment to their impairment

Adjustment	Practical/ short-term	Practical/ long-term	Emotional/ short-term	Emotional/ long-term
Not at all	0	0	0	2 (13%)
A little	0	0	0	2 (13%)
Moderately	3 (19%)	6 (38%)	3 (19%)	3 (19%)
Very well	9 (56%)	7 (44%)	8 (50%)	7 (44%)
Completely	4 (25%)	3 (19%)	5 (31%)	2 (13%)

In question 8 regarding emotional adjustment, the levels of "not at all" and "a little" were combined to form the category of *poorly adjusted*, as were the levels of "very well" and "completely" which formed the category of *well adjusted* and moderately adjusted remained the same. The different levels were combined because the frequencies were too small for a chi square test based on 5 levels of the variable.

Results of analysis

Table 5.21 Chi square test results for practical and emotional adjustment to adventitious visual impairment

Adjustment	Chi square value	p	df
Practical	1,39	p> 0,1	2
Emotional	4,73	p> 0,05	2

The results of these tests are not statistically significant. It is interesting to note however, (Table 5.20) that both the short-term and long-term AVI respondents appear to perceive themselves as more practically adjusted rather than less practically adjusted to their visual impairment. The short-term respondents appear to perceive themselves as emotionally better adjusted than the long-term respondents.

5.5.3 Subsidiary investigation (3B): Adjustment as a continuous or linear process

The researcher then investigated whether there were differences

between the long-term and short-term AVI respondents with regard to their perceptions of adjustment to visual impairment being a continuous or linear process.

Method of analysis

The respondents had to agree or disagree with certain statements that addressed the pertinent issues at hand (Section D, question 5 of interview schedule).

The following statements focused on the issue of adjustment as a linear process: 1 (complete adjustment), 3 (final stage of acceptance in adjustment), 6 (time-limit for adjustment), 7 (decrease in emotions).

The following statements focused on the issue of adjustment as a continuous process: 2 (adjustment is continuous), 5 (no final stage of acceptance in adjustment), 8 (adjustment is continuous), 10 (increase in emotions).

Frequencies of the response alternatives to the specific statements were obtained for the short-term and long-term AVI respondents (Table 5.22).

Chi square test statistics were used in view of the categorical nature of the variables. A "don't know" response was not included in the analysis. Statement 2 was not statistically analysed because the expected frequency was below 5.

Results of analysis

The frequencies and chi square results comparing the short-term and long-term AVI on adjustment as a continuous or linear process are shown in Table 5.22 {* $p < 0,05$; ** $p < 0,01$ }.

Table 5.22 Results of adjustment (df = 1)

Statement 1	Agree	Disagree	Chi square
Short-term	8 (50%)	7 (44%)	
Long-term	5 (31%)	10 (63%)	
Total	13 (41%)	17 (53%)	1,22
Statement 2			
Short-term	9 (56%)	7 (44%)	
Long-term	14 (88%)	0	
Total	23 (72%)	7 (22%)	
Statement 3			
Short-term	14 (88%)	1 (6%)	
Long-term	6 (38%)	9 (56%)	
Total	20 (63%)	10 (31%)	9,6**
Statement 5			
Short-term	6 (38%)	9 (56%)	
Long-term	14 (88%)	1 (6%)	
Total	20 (63%)	10 (31%)	9,6**
Statement 6			
Short-term	8 (50%)	7 (44%)	
Long-term	4 (25%)	12 (75%)	
Total	12 (38%)	19 (59%)	2,61
Statement 7			
Short-term	11 (69%)	4 (25%)	
Long-term	5 (31%)	10 (63%)	
Total	16 (50%)	14 (44%)	4,84*
Statement 8			
Short-term	7 (44%)	9 (56%)	
Long-term	14 (88%)	2 (13%)	
Total	21 (66%)	11 (32%)	6,8**
Statement 10			
Short-term	5 (31%)	9 (56%)	
Long-term	11 (69%)	5 (31%)	
Total	16 (50%)	14 (44%)	3,29

The results from the analysis of Statements 3 ("for total adjustment to visual impairment one has to move through various stages culminating with the final stage of acceptance"), 5 ("There is no final stage of acceptance of visual impairment but rather a continuous recycling through the various stages"), 7 ("Once visual impairment is accepted, frustration decreases"), and 8 ("Visual impairment involves continual losses that have to be continually adjusted to") are significant.

The majority (88%) of the short-term respondents as compared to the minority of the long-term respondents (38%) perceive a final stage of acceptance for adjustment to visual impairment. The minority of the short-term respondents (38%) as compared to the majority of the long-term respondents perceive that there is no final stage of acceptance but a continuous recycling through the various stages. The majority (69%) of the short-term respondents and a minority (31%) of the long-term respondents perceive a decrease in frustration once visual impairment is accepted. The minority (44%) of the short-term respondents as compared to the majority (88%) of the long-term respondents perceive that visual impairment involves continual losses that have to continually be adjusted to.

The results pertinent to the perception of adjustment to visual impairment as a linear process show half the short-term respondents agree whereas the majority (63%) of the long-term disagree that there is complete adjustment (Statement 1); the majority (88%) of the short-term agree as compared to the majority (56%) of the long-term respondents who disagree that there is a final stage of acceptance for adjustment (Statement 3); half the short-term respondents but the majority (75%) of the long-term respondents disagree that there is a time limit for adjustment (Statement 6); the majority (69%) of the short-term respondents agree whilst the majority (63%) of the long-term disagree that there is a decrease in the emotion of frustration (Statement 7). These results suggest that the short-term AVI respondents more so than the long-term AVI respondents perceive

adjustment to visual impairment as a linear process.

The results pertinent to the perception of adjustment to visual impairment as a continuous process show: the majority of both the short-term (56%) and long-term (88%) respondents agree that adjustment is a continuous process (Statement 2); the majority (56%) of the short-term respondents disagree as compared to the majority (88%) of the long-term respondents who agree that visual impairment involves continual losses that have to be continually adjusted to (Statement 8); the majority of the short-term respondents disagree as compared to the majority (88%) of the long-term respondents who agree that there is no final stage of acceptance for adjustment to visual impairment (Statement 5); the majority (56%) of the short-term disagree as compared to the majority (69%) long-term who agree that there is an increase in the emotion of frustration (Statement 10). These results suggest that the long-term respondents more so than the short-term respondents perceive adjustment to visual impairment as a continuous process.

5.5.4 Subsidiary investigation (3C): Descriptions of acceptance and adjustment

It was investigated whether the AVI respondents differentiate between the concepts of adjustment and acceptance of visual impairment and if so, what their understanding of each are.

Method of analysis

The responses to the qualitative question "what is the difference between acceptance of and adjustment to visual impairment?" (Section D, question 4 of interview schedule) were content analysed as previously.

Results of analysis

Three main themes regarding the meanings of adjustment to and

acceptance of visual impairment were obtained from the content analysis: there is no difference between the two; acceptance is emotional whereas adjustment is practical; acceptance is a finality whereas adjustment is coping, organising, and coming to terms with the impairment (Table 5.23). Appendix L gives the direct transcripts.

Table 5.23 Different themes obtained through content analysis of the meaning of acceptance and adjustment described by the short-term and long-term respondents

Meaning of adjustment and acceptance	Short-term	Long-term
No difference	10 (63%)	5 (31%)
Acceptance is emotional, adjustment is practical	3 (19%)	8 (50%)
Acceptance is finality, adjustment coping	3 (19%)	3 (19%)

The majority (63%) of the short-term AVI respondents perceive that there is no difference between the two concepts of acceptance and adjustment. The long-term respondents perceive a difference between the two concepts with half stating that adjustment is practical whereas acceptance is emotional.

5.5.5 Subsidiary investigation (3D): Changes in emotions from onset of visual impairment to present

It was investigated whether certain emotions or feelings that were present at the time of the onset of visual impairment are still present at the time of the interview. The feelings focused on the stages of the grief process: denial, anger, bargaining, depression and acceptance. The feeling of "longing to see again" was also analysed.

Method of analysis

Frequencies of the response alternatives to the statements that addressed the various emotions (Section D, question 9 of interview schedule) were obtained for the AVI respondents and are

shown after each statement to follow. The two sample groups were analysed separately to investigate any changes in the emotions or feeling states that have occurred over time. It was explained to the respondents that "I used to feel this way" was the period immediately after onset of visual impairment. Suggested trends obtained from the frequencies will be reported as the cell sizes are insufficient for statistical comparison.

Results of analysis

Statement 3: "I try to cover up the fact that I can not see" is associated with the stage of denial (Table A).

Table A Frequencies of "denial" for the AVI respondents

Cover up	Yes	No
Long-term at onset	8 (50%)	8 (50%)
Long-term at interview	5 (31%)	11 (69%)
Short-term at onset	8 (50%)	8 (50%)
Short-term at interview	4 (25%)	12 (75%)

The frequencies as shown in Table A suggest that there has been a decrease in the feeling of trying to cover up the fact of not being able to see (denial) for both the long-term (50% TO 69%) and short-term (50% TO 75%) AVI respondents from the time of the onset of visual impairment to the time of the interview.

Statement 4 deals with the stage of anger: "I feel angry about my loss of sight" (Table B).

Table B Frequencies of "anger" for the AVI respondents

Feel angry	Yes	No
Long-term at onset	5 (31%)	11 (69%)
long-term at interview	9 (56%)	7 (44%)
Short-term at onset	8 (50%)	8 (50%)
Short-term at interview	4 (25%)	12 (75%)

The frequencies as shown in Table B suggest that there has

been an increase in the feeling of "anger" for the long-term respondents (31% to 56%), with a suggested decrease for the short-term respondents (50% to 25%) from the onset of visual impairment to the time of the interview.

Statement 8 deals with the stage of bargaining: "I make promises that if I get my sight back I will do something in return" (Table C).

Table C Frequencies of "bargaining" for the AVI respondents

Make promises	Yes	No
Long-term at onset	8 (50%)	8 (50%)
Long-term At interview	9 (56%)	7 (44%)
Short-term at onset	8 (50%)	8 (50%)
Short-term at interview	9 (56%)	7 (44%)

The frequencies as shown in Table C suggest that there has been an increase in the feeling that something will be done if sight is regained (bargaining) for both the long-term and short-term respondents from the onset of visual impairment to the time of the interview (50% TO 56% for both groups of respondents).

Statement 6 is associated with the stage of depression and hopelessness: "I feel that the meaning and purpose has gone out of my life" (Table D).

Table D Frequencies of "depression and hopelessness" for the AVI respondents

Life is meaningless	Yes	No
Long-term at onset	5 (31%)	11 (69%)
Long-term at interview	3 (19%)	13 (81%)
Short-term at onset	9 (56%)	7 (44%)
Short-term at interview	1 (6%)	15 (94%)

The frequencies as shown in Table D suggest that there has been a decrease in the feeling that there is no meaning and purpose to life (depression and hopelessness) for both the long-

term (69% to 81%) and short-term (44% to 94%) AVI respondents from the time of onset of visual impairment to the time of the interview.

Statement 10 also deals with the stage of depression: "I feel sad about what has happened to me" (Table E).

Table E Frequencies of "sadness" for the AVI respondents

Feel sad	Yes	No
Long-term at onset	12 (75%)	4 (25%)
Long-term At interview	10 (63%)	6 (37%)
Short-term at onset	9 (56%)	7 (44%)
Short-term at interview	7 (44%)	9 (56%)

The frequencies as shown in Table E suggest that there has been a decrease in the feeling of sadness about the loss of sight (depression) for both the long-term (75% to 63%) and short-term (56% to 44%) AVI respondents from the onset of visual impairment to the time of the interview. It is interesting to note that although there has been a decrease in feeling sad for the long-term respondents, the majority still feel sad at the time of the interview.

Statement 15 is associated with the stage of acceptance: "I feel that it gets easier to accept my visual impairment as time passes" (Table F).

Table F Frequencies of "acceptance" for the AVI respondents

Easier to accept with time	Yes	No
Long-term at onset	11 (69%)	5 (31%)
Long-term at interview	6 (38%)	10 (63%)
Short-term at onset	11 (69%)	5 (31%)
Short-term at interview	14 (88%)	2 (12%)

The frequencies as shown in Table F suggest that there has been a decrease in the feeling that it gets easier to accept the visual impairment for the long-term AVI respondents (69% to 38%),

with an increase for the short-term respondents (69% to 88%) from the onset of visual impairment to the time of the interview.

Statement 12: "I long to see again" (Table G).

Table G Frequencies of "longing to see again" for the AVI respondents

Long to see again	Yes	No
Long-term at onset	11 (69%)	5 (31%)
Long-term at interview	12 (75%)	4 (25%)
Short-term at onset	14 (88%)	2 (13%)
Short-term at interview	13 (81%)	3 (19%)

The frequencies as shown in Table G suggest that there has been an increase in the feeling of longing to see again for the long-term respondents (69% to 75%) and a decrease for the short-term respondents (88% to 81%) from the onset of visual impairment to the time of the interview. Although there has been a decrease for the short-term, the majority of the respondents still long to see again.

5.5.6 Summation: Hypothesis 3 and subsidiary results

The hypothesised relation between length of time of adventitious visual impairment and acceptance was supported by one of the two scales used in the analysis. The long-term respondents in this study accept their visual impairment to a lesser extent than the short-term respondents. Results obtained from the subsidiary investigation of adjustment to visual impairment show that the short-term respondents are overall more adjusted to their visual impairment, have lower levels of anxiety and depression and have a higher level of acceptance of their visual impairment than do the long-term respondents. More of the short-term respondents perceive themselves to be practically and emotionally "well adjusted" than do the long-term respondents. The results suggest that the short-term respondents perceive adjustment to visual impairment as a linear process. The long-

term AVI respondents, more so than the short-term respondents, perceive adjustment as a continuous process. The investigation into whether the respondents differentiate between adjustment to and acceptance of visual impairment revealed that while the majority of the short-term respondents do not differentiate, the long-term respondents describe more distinctions between the two concepts. The subsidiary investigation into changes in emotions from onset of visual impairment to the time of the interview suggest that there are increases in feelings of anger, non-acceptance of visual impairment, and longing to see again for the long-term AVI respondents. There are suggested decreases in the feelings of anger, hopelessness, non-acceptance of visual impairment, and sadness for the short-term respondents.

5.6 SECTION 5: HYPOTHESIS 4 TESTING AND SUBSIDIARY INVESTIGATIONS

This section on the testing of Hypothesis 4 (need for continued emotional support) and the related subsidiary investigations will report the results of:

- Hypothesis 4 the need for continued emotional support;
- the best person to offer the continued emotional support and who helped and who is helping the AVI work through their feelings about their loss of sight;
- types of helpful support;
- frustrating support and types of frustrating support.

5.6.1 Hypothesis 4: The need for continued emotional support is greater for long-term AVI persons than short-term AVI persons

Method of analysis

Frequencies of the response alternatives to the question "do you believe that there is a need for continued emotional support after your rehabilitation?" (Section E, question 9 of interview schedule) were obtained and are shown in Table 5.24. A chi square

test was used to investigate this hypothesis in view of the categorical nature of the variables (results shown in Table 5.25).

Table 5.24 Frequencies of short-term versus long-term AVI respondents expressing a need or no need for continued emotional support

Need for emotional support	Short-term	Long-term
Yes	7 (44%)	14 (88%)
No	9 (56%)	2 (12%)

Results of analysis

Table 5.25 Chi square result of continued need for emotional support by the AVI respondents

Chi Square value: 6,79	$p < 0,01$	1 df
------------------------	------------	------

Based on the statistically significant chi square result the hypothesised relation between the different lengths of time of adventitious visual impairment and the need for continued emotional support is supported. To investigate the strength of the relation between the different lengths of visual impairment and the need or no need for continued emotional support, a coefficient of contingency was calculated. A moderate relation was obtained with $C = 0,42$. The majority (88%) of the long-term AVI respondents expressed a need for continued emotional support as compared to the minority (44%) of the short-term AVI respondents.

The hypothesis that "the need for continued emotional support is greater for long-term AVI persons than short-term AVI persons" was supported.

5.6.2 Subsidiary investigation (4A): The best person to offer continued emotional support

Related to Hypothesis 4 is the subsidiary investigation into who the AVI respondents perceive as the best person/s to offer

the continued emotional support. The responses to the qualitative question of "who do you believe would be the best person/s to offer this emotional support?" (Section E, question 10 of interview schedule) were content analysed.

Results of analysis

Four main categories were obtained from the content analysis: friends; family; professional person; nobody. Certain distinctions were made by the AVI respondents with regard to the "professional person". For example, the short-term AVI respondents' descriptions of "professional person" included 2 psychologists and a counsellor. The long-term AVI respondents' descriptions included 2 psychologists and 4 counsellors. However, all the long-term respondents stated that the "professional person" should be AVI as well. One respondent described "spouse" as the best person to provide emotional support (Table 5.26).

Table 5.26 Different categories obtained through content analysis of the best person/s to offer continued emotional support for the long-term and short-term respondents

Emotional support	Friend	Family	Spouse	Professional	Nobody
Long-term	5 (31%)	3 (19%)	1 (6%)	6 (38%)	1 (6%)
Short-term	3 (19%)	2 (13%)	0	3 (19%)	8 (50%)

The results as shown in Table 5.26 show that 50% of the short-term AVI respondents describe "nobody". This result corresponds with the result obtained from the analysis of Hypothesis 4 (Section 5.6.1) where the majority (56%) of the short-term AVI respondents perceived that there was no need for continued emotional support after rehabilitation.

It is interesting to note that the long-term respondents perceive professional persons who are also AVI followed by friends as the best person/s to offer continued emotional support. The short-term respondents focused on nobody to a greater extent and to a lesser extent friends and professional

persons.

5.6.2.1 *Subsidiary investigation: Who is most helpful?*

The next issue of investigation was, who most helped the AVI respondents to work through their feelings about loss of sight at the onset of their visual impairment and who is most helpful now.

Method of analysis

The responses to the qualitative questions of "in the early stage of your visual impairment who most helped you to work through your feelings about your loss of sight?" and "who is most helpful now?" (Section E, questions 6 and 8 of interview schedule) were content analysed.

Results of analysis

Six main categories were obtained from the content analysis: friends; family; spouse; professional person; nobody; rehabilitation centre (Table 5.27). Certain distinctions were made by the respondents with regard to the professional person. For example, the short-term respondents' descriptions of "professional person" at the time of onset of visual impairment included 2 social workers (not attached to the rehabilitation centre) and a psychologist. The long-term respondents descriptions included 2 psychologists and a nursing sister in a hospital. At the time of the interview the professional person described by the short-term respondent was a counsellor.

The results show that at the time of onset of visual impairment both the short-term and long-term AVI respondents describe the "family" as helping them the most to work through their feelings of loss of sight. At the time of the interview, the long-term respondents describe "friends" as the most helpful as compared to the short-term respondents who described the

"family" as the most helpful.

Table 5.27 Different categories obtained through content analysis of who was the most helpful at onset of visual impairment and who is most helpful now for the short-term and long-term respondents

At onset	Friend	Family	Spouse	Prof/p	Nobody	Rehab
Long-term	1	7	1	3	4	0
Short-term	3	5	3	3	1	1
At interview						
Long-term	11	2	0	0	3	0
Short-term	4	5	5	1	1	0

5.6.3 Subsidiary investigation (4B): Types of helpful support

Different types of support perceived as helpful was the next issue considered.

Method of analysis

Frequencies of the response alternatives to the question, "what type of support would be helpful to you as a visually impaired person?: Practical support, emotional support, informational support, no support or any other (Section E, question 1 of interview schedule) and are shown in Table 5.28. The frequencies and corresponding percentages are the number of respondents who answered "yes" to the different types of support perceived as helpful. No respondent stated that "no support" or "any other kind of support" were helpful. Chi square tests were calculated in view of the categorical nature of the variables (Table 5.29).

Table 5.28 Frequencies of types of support perceived as helpful by the short-term and long-term AVI respondents

Types of support	Practical	Informational	Emotional
Short-term	12 (75%)	13 (81%)	4 (25%)
Long-term	15 (94%)	12 (75%)	9 (56%)

Results of analysis

Table 5.29 Chi square results of types of perceived helpful support by the AVI respondents

	chi square value	p	df
Practical	2,13	>0,1	1
Informational	0,18	>0,1	1
Emotional	3,24	>0,05	1

The statistical results are not significant. It is interesting to note that the results (Table 5.28) show that the majority of the long-term respondents 56% as compared to 25% of the short-term respondents perceive emotional support as helpful. This result is consistent with the result obtained from Hypothesis 4 where the majority of the long-term as compared to the minority of the short-term respondents perceive a need for continued emotional support. The majority of both the short-term (75%) and long-term (94%) respondents perceive practical support as the most helpful type of support.

5.6.4 Subsidiary investigation (4C): Frustrating support

The next issues considered were whether the AVI respondents become frustrated with support which is offered and if so, what support causes the frustration.

Method of analysis

Frequencies of the response alternatives to the question, "do you ever become frustrated with support that is offered to you?" (Section E, question 3 of interview schedule) were obtained for the AVI respondents (Table 5.30). A chi square test statistic was used in view of the categorical nature of the variables.

Table 5.30 Frequencies of AVI respondents who perceived support as frustrating

Frustrated with support	Short-term	Long-term
Yes	8 (50%)	9 (56%)
No	8 (50%)	7 (44%)

Results of analysis

The chi square result was not significant (0,13 with $p > 0,1$).

5.6.4.1 Subsidiary investigation: Types of frustrating support

The types of support which cause frustration for the AVI respondents was investigated next. The responses to the qualitative question of "do you ever become frustrated with support that is offered to you?" (Section E, question 3 of interview schedule) was content analysed as previously.

Results of analysis

Three main themes were obtained from the content analysis: unnecessary support; patronising support; empty promise support (Table 5.31). Respondents described unnecessary support as support that is given for something that they are able to do themselves (direct transcripts of selected respondents answers are shown in Appendix M).

Table 5.31 Different themes obtained through content analysis of frustrating support for the short-term and long-term AVI respondents

Frustrating support	Unnecessary	Patronising	Empty promises
Short-term	4 (50%)	2 (25%)	2 (25%)
Long-term	7 (78%)	2 (22%)	0 (0%)

The results show that the most frustrating support of both the short-term and long-term AVI respondents is "unnecessary support".

5.6.5 Summation: Hypothesis 4 and subsidiary results

The hypothesised relation between length of time of adventitious visual impairment and the need for continued emotional support was supported. The long-term respondents perceive a greater need for continued emotional support as

compared to the short-term respondents. The long-term respondents stated that a professional person who is AVI would be the best person to provide the support. Practical support was described by both groups of respondents as the most helpful. The short-term and long-term respondents become frustrated with support offered with "unnecessary support" causing the most frustration.

5.7 CONCLUSION

It is apt that concluding comments from AVI respondents on how they had experienced the interview are included here. All respondents were positive, many making enlightening comments. Most AVI respondents stated that this type of interview should be asked during rehabilitation. A long-term male stated "...interesting interview. These types of questions should definitely be asked to people coming in for rehabilitation because there are many questions here that I needed to ask myself many years ago", and a long-term female stated "...this interview welcomed me to the real world of visual impairment."

In this chapter, the results of the investigation into the experience of frustration by AVI adults, their adjustment and acceptance of their visual impairment and the need for emotional support were reported. Before the hypotheses and exploratory investigations were analysed it was found that the respondents had similar *meanings* of frustration. Furthermore frustration was not found to be a personality trait.

Three of the four hypotheses were supported, while the fourth was supported by one of the two scales used. According to the present study the long-term AVI respondents experience more frequent and intense frustrations, accept their visual impairment to a lesser extent and have a greater need for emotional support as compared to the short-term AVI respondents.

Many of the subsidiary results were based on observations as the cell sizes were insufficient for statistical comparisons.

With regard to the subsidiary investigation into causes of frustration, it was found that the situation of "loss of independence" causes more frustrations for the short-term respondents as compared to the situations of both "lack of understanding" and "loss of independence" which cause more frustrations for the long-term respondents. The statistically significant subsidiary investigation into adjustment to adventitious visual impairment found that the short-term AVI respondents are overall better adjusted to their visual impairment as compared to the long-term respondents. The short-term respondents agree that adjustment to visual impairment is a linear process whereas, the long-term respondents agree that adjustment is a continuous process. There were suggested increases in feelings of anger, non-acceptance of visual impairment, frustrations and longing to see again for the long-term respondents and suggested decreases in feelings of anger, hopelessness, non-acceptance of visual impairment, frustration and sadness for the short-term respondents from the time of onset of visual impairment to the time of the interview. The majority of the long-term respondents disagree with the saying "time heals" frustrations related to the visual impairment as compared to the majority of the short-term respondents who agree. The long-term respondents perceive that a "professional person" who is AVI would be the best person to provide the continued emotional support whereas the short-term respondents perceive that they have no need for continued emotional support after rehabilitation.

The issue that "research begets research" is relevant here because more research is needed to substantiate the results obtained in this study. Larger samples will allow for statistical comparisons.

The next chapter will discuss the implications of the results obtained from the present study and the issue of "time changes everything - or does it"?

CHAPTER SIX

DISCUSSION: MORE THAN WHAT MEETS THE EYE

6.1 INTRODUCTION

In this chapter the results obtained from the analyses of the hypotheses and related subsidiary investigations and the implications thereof will be interpreted and discussed. An overview of the results will be given followed by discussions of specific outcomes. When appropriate the results from this study will be compared to existing research literature. Possible explanations will be put forward to interpret the distinct and different results obtained for the short-term and long-term AVI respondents. The research and theoretical implications of the obtained results from this study will be indicated. Possible suggestions for the modification of the theory to accommodate the results will also be made.

6.2 OVERVIEW OF RESULTS

There is one important thread that runs through the varied data analyses (both quantitative and qualitative) in both the hypotheses and subsidiary investigations, namely, that there are consistent and distinct differences between the short-term and long-term AVI respondents. For example, the results obtained for the long-term AVI respondents (which are in direct contrast to those obtained for the short-term AVI) show that the frequency and intensity of frustrations related to visual impairment have increased, that there is a lesser degree of acceptance of and adjustment to visual impairment and a perceived need for continued emotional support (variables which form an integral part of the grief process). The findings of this research study therefore provided support for the primary hypotheses under examination, namely, that there is a relation between different lengths of time of adventitious visual impairment (AVI for under

and over 6 years) and the experience of frustrations related to visual impairment, acceptance of visual impairment and the continued need for emotional support.

The findings of this research study also challenge the traditional assumptions of the grief-following-loss theory namely, that *time heals* and that adjustment to visual impairment is a time-limited static and linear process accompanied by a decrease in the *feeling states* and which culminates with the final stage of acceptance of the loss of sight.

Specific outcomes related to the hypotheses and subsidiary investigations will now be discussed.

6.3 SPECIFIC OUTCOMES

In this section, the following issues will be discussed:

- discussion of Hypotheses 1 and 2 results;
- discussion of subsidiary investigation (1A): causes of frustration;
- discussion of subsidiary investigations (2A, and 2B): changes and frustration, and the healing effect of time;
- discussion of Hypothesis 3 results;
- discussion of subsidiary investigations (3A, 3B, 3C and 3D): adjustment to visual impairment, adjustment as a continuous or linear process, descriptions of acceptance and adjustment, changes in emotions;
- discussion of Hypothesis 4 results;
- discussion of subsidiary investigations (4A, 4B, 4C), the best person to offer support, types of helpful and frustrating support;
- summation of critical discussions pertaining to the results.

6.3.1 Hypotheses 1 and 2: Discussion of results

The results obtained from Hypotheses 1 and 2 {Section 5.3.1

Hypothesis 1: Long-term AVI persons experience more frequent frustrations than do short-term AVI persons and Section 5.4.1 Hypothesis 2: Long-term AVI persons experience more intense frustrations than do short-term AVI persons pp. 108, 117} show that the short-term AVI (decrease in frequency and intensity of frustration) appear to follow the traditional grief-following-loss theory with the assumption of resolvable grief. The progress through the various *stages* result in a decrease in the frequency and intensity of emotional reactions such as frustration as the loss of sight is accepted and adjusted to within a time-limit (Fitzgerald, 1970; Kübler-Ross, 1969; Falek & Britton, 1974; Hughes, 1980; Perry & Hampton-Roy, 1982; Livneh & Antonak, 1991; Conyers, 1992).

In contrast however, the long-term AVI (increase in frequency and intensity of frustration) appear to refute the traditional grief-following-loss assumptions and appear to support the notion of a chronic grief process (Lindgren et al., 1992). The increasing intensity and frequency of the emotional reaction of frustration as part of chronic grief could be related to the repeated and prolonged confrontation of the adjustive demands to cope with the numerous and continued losses that are part of visual impairment. It would appear that the long-term AVI support the argument put forward by Lindgren et al. (1992) that if the underlying cause of continual losses is a disability (visual impairment) then grief with the accompanying emotions (including frustration) will operate throughout the course of the visual impairment. It is therefore evident that the concept of chronic grief and the related emotions and the concept of length of time of visual impairment are inseparable (Lindgren et al., 1992).

Although the results obtained from the short-term AVI uphold the assumptions as proposed by the traditional grief-following-loss theory they did however challenge the expected duration of the grief process of 1 to 4 years. For example, it is the time intervals of 2-4 and 4-6 years of adventitious visual impairment (short-term category) that are the least frustrating for the AVI

respondents. Overall however, this research study further challenges the assumption of a time-limited grief process with a decrease in the emotional reactions, as it is the time intervals 6-8 and 10+ years of adventitious visual impairment (long-term category) that are the most frustrating for the AVI respondents {Section 5.3.3 Subsidiary Investigation (1B): Time intervals and frustration p. 115}.

6.3.1.1 Subsidiary investigation (1A): Causes of frustration

There are distinct quantitative and qualitative differences between the long-term and short-term AVI respondents with the perceived causes of frustration.

The quantitative results show that *loss of independence* cause the short-term respondents to become frustrated more often whereas, the *lack of understanding* and *loss of control* cause the long-term respondents to become frustrated more often {Section 5.3.2.1 Further subsidiary investigation: Causes of frustration p. 112}. As "loss of control" is perceived only by the long-term AVI as a main cause of frustration and because anger has been shown to be a defence against loss of control (McKay, 1990) could this therefore be the reason for the increased anger shown by the long-term AVI respondents?

The qualitative results {Section 5.3.2.2 Subsidiary investigation: Descriptions of causes of frustration p. 113} show that the short-term respondents once again describe *loss of independence* as their main cause of frustration. The long-term respondents describe both *loss of independence* and *lack of understanding* as causing relatively similar amounts of frustration. The theme of "loss of control" was not qualitatively described as a main cause of frustration, but this theme could have automatically been included in the situations of "loss of independence" or "lack of understanding".

These results support research findings (Eisenhandler, 1990;

Conyers, 1992; Corn & Sacks, 1994) that the sense of loss of control over one's life, the sense of the loss of independence with the sense of a *dependency career* and the perceived lack of understanding of others are factors that have been highlighted as the main causes of continued frustration experienced by the AVI. What is significant in this research is the shift over time from "loss of independence" as the main cause of frustration to both "loss of independence" and "lack of understanding from the sighted". This result could possibly be explained by the fact that the frustrations caused by the initial loss of independence is so overwhelming for the newly visually impaired that all other possible causes are not even considered. However, the realisation by the long-term AVI that confrontation of loss (including loss of independence) is a continuous process that has to be adjusted to continually and will indeed cause further frustration when society, with its traditional assumption that *time heals*, is not aware of this phenomenon. Further research into this aspect is needed.

6.3.1.2 *Subsidiary investigation (2A): Changes and frustration*

The qualitative results obtained from this investigation show that the long-term AVI respondents describe that although they have learnt to cope with their loss of sight, the frustrations have still remained the same. Awareness of the implications of their visual impairment is the reason most often expressed by the long-term AVI respondents for an increase in frustration. On the other hand, the short-term respondents describe that they have learnt to cope with their visual impairment which has resulted in a decrease in frustrations {Section 5.4.2 Subsidiary investigation (2A): Changes and frustration p. 118}.

This result supports the argument put forward by authors (Elliott et al., 1991; Livneh & Antonak, 1991) that it takes years before people with a disability (including visual impairment) appreciate, acknowledge and become aware of the reality and the full extent of the implications and limitations

of their condition. It would appear from this study that it has taken on average 6 years for the AVI to become aware of the implications of their condition. Further research is needed to investigate this important issue of how long it takes to become aware of the reality and implications of loss of sight.

6.3.1.3 *Subsidiary investigation (2B): The healing effect of time*

The qualitative result regarding the assumption that *time heals* the frustrations related to visual impairment {Section 5.4.3 Subsidiary investigation (2B): The healing effect of time p. 120} show that the majority of the short-term AVI support the assumption that *time heals* as compared to the majority of the long-term AVI who totally disagree.

As one long-term totally blind male states, "...The saying *time heals* is a myth, because time doesn't heal anything, especially the frustrations of being blind. This is because you have to live with the blindness and there are always things occurring that make you realise that you are blind and as much as you try to lead a normal life there will always be something that reminds you that you are blind which then causes frustration." This result once again endorses the differences between the short-term and long-term AVI with the short-term supporting the concept of a time-limited resolvable grief process as compared to the long-term who support the concept of a chronic grief process and continuous emotional reactions which are a continuous part of visual impairment (Lindgren et al., 1992).

6.3.2 Hypothesis 3: Discussion of results

Acceptance of loss of sight has been described as one of the key factors in the overall adjustment pattern of AVI (Dodds et al., 1991; Conyers, 1992).

The quantitative results from both the perception of acceptance held by the AVI respondents {Section 5.5.1 Hypothesis 3: Long-

term AVI persons accept the impairment to a lesser extent than do short-term AVI persons p. 122} and the results of actual acceptance from the standardised Nottingham Adjustment Scale {Section 5.5.1.1 Hypothesis 3: Further investigation of acceptance p. 124} show that the short-term AVI perceive a greater extent of acceptance and have a greater actual acceptance of their visual impairment as compared to the long-term AVI.

The results once again show that the short-term AVI appear to follow the assumption of a resolvable grief process with one identified loss which generally acknowledges and presumes a time-limited, natural and linear progress through the *stages* of the grief process culminating with the final stage of acceptance or resolution. The results obtained for the short-term AVI further support the notion that acceptance of visual impairment is correlated to the final stage of resolution in the literature on the grief process after loss through death (Falek & Britton, 1974; Drotar et al., 1975; Hughes, 1980; Livneh, 1986).

This traditional assumption of a final static stage of acceptance of visual impairment is challenged by the long-term AVI. The results, with a lesser extent of acceptance appeared to support the notion that persons with permanent visual impairment experience chronic grief that is cyclic and recurrent. When personal and environmental demands change and when certain situations or events produce anxiety or uncertainty the AVI person is likely to cycle back through some or all of the adjusting stages including the stage of acceptance (Tuttle, 1984).

Taking the notion of a cyclic recurrent and circular grief process it is inevitable therefore, that acceptance of visual impairment will be negotiated and re-negotiated continually. This could therefore also imply that instead of the presumed static nature of acceptance there is rather a circular and changing notion of acceptance which will continually fluctuate between greater and lesser degrees. Further research is needed regarding

this circular notion of acceptance.

6.3.2.1 *Subsidiary investigation (3A): Adjustment to visual impairment*

There are once again consistent and distinct quantitative differences between the short-term and long-term AVI with regard to overall, practical and emotional adjustment to visual impairment.

Overall adjustment

It would be expected (based on the assumptions from the traditional grief-following-loss theory) that persons who experience loss of sight will move through the stages of the grief process culminating with acceptance and adjustment to the visual impairment. This implication that the longer the visual impairment the greater the overall adjustment, was however not realised in this research study.

The quantitative results obtained from the subsidiary investigation into adjustment to visual impairment based on the standardised Nottingham Adjustment Scale {Section 5.5.2 Subsidiary investigation (3A): Adjustment to visual impairment p. 125} show that the short-term AVI are overall more adjusted to their visual impairment as compared to the long-term AVI. The short-term AVI have more of the psychological factors characteristic of adjustment to visual impairment (Dodds et al., 1991) namely, low levels of anxiety, absence of depression, high self-esteem, positive attitudes towards visually impaired persons and high acceptance of visual impairment, which are in direct contrast to the long-term AVI.

The short-term AVI appear to follow the grief-following-loss theory with the assumption of a resolvable grief process which culminates with the final stage of high acceptance and adjustment to visual impairment. The long-term AVI, with low levels of both

acceptance of and adjustment to visual impairment, appear to support once again the notion that persons with permanent visual impairment experience chronic grief that is cyclic and recurrent, implying that adjustment to visual impairment is also a continuous process. When personal and environmental demands change, and when certain situations or events produce anxiety or doubt about the AVI person's acceptability or worthiness (self-esteem), the person is likely to cycle back through some or all of the adjusting stages (Tuttle, 1984). A question which arises from this discussion is whether this is the explanation for the high anxiety experienced by the long-term AVI in this research study.

Taking the notion of a cyclic, recurrent and circular grief process, it is inevitable that adjustment to visual impairment will be negotiated and re-negotiated continually. This could therefore also imply as in the case of acceptance {Section 6.3.2 p. 152} that instead of the presumed static nature of adjustment there is rather a circular and changing notion of adjustment which will continually fluctuate between greater and lesser degrees. Consideration of the concept of a continual *turning point* rather than a *point of no return*, with regard to adjustment to visual impairment is necessary.

The results obtained from this research study question the notion that acceptance of visual impairment may be at the root of the adjustment process, for this implies that before adjustment can take place there must be acceptance of the visual impairment. The results obtained from the short-term AVI (high adjustment and high acceptance) and the results obtained from the long-term (low adjustment and low acceptance) could imply that acceptance of and adjustment to visual impairment are inseparable and reciprocally interact and influence one another. Additional investigation to clarify this notion concerning acceptance and adjustment as inseparable and simultaneously fluctuating from higher to lower degrees is warranted.

A significant and disquieting result regarding overall adjustment to visual impairment is that both the short-term and long-term AVI in this research study are below the norm mean for overall adjustment as delineated by the Nottingham Adjustment Scale (Dodds et al., 1991). Speculation regarding the below average scores is necessary. As the Nottingham Adjustment Scale is concerned with psychological variables affecting the process of adjustment to visual impairment, could the results obtained from this research study (below the norm for overall adjustment) indicate that the rehabilitation of AVI persons is not focusing enough on the identified psychological and emotional variables that do indeed have a bearing on the process of adjustment? Further research into this disquieting issue is necessary.

Practical and emotional adjustment

It would appear from this research study {Section 5.5.2.1 Subsidiary investigation: Practical and emotional adjustment p. 127} that overall practical adjustment is perceived to be less of a problem for the majority of both the short-term and long-term AVI as compared to achieving psychological and emotional adjustment to their visual impairment.

More of the long-term AVI perceive themselves to be moderately practically adjusted as compared to the majority of the short-term who perceive themselves to be practically well adjusted to their visual impairment. As the main intention in rehabilitation is on practical assistance, including practical skills of daily living and mobility, and given that it is the short-term AVI group who have most recently completed their rehabilitation training, it is not surprising therefore that the short-term AVI perceive themselves to be practically well adjusted. The assumption that because great emphasis is placed on practical training during rehabilitation the AVI regardless of length of time of visual impairment, will be practically well adjusted to their visual impairment is not realised in this research study. It is inevitable however, that if the long-term AVI conceptualise

adjustment to visual impairment as a continuous and recurring process then new and unending practical demands will have to be adjusted to continually.

With regard to emotional adjustment, the short-term AVI perceive themselves to be more emotionally adjusted to their visual impairment as compared to the long-term AVI. This result from the short-term AVI once again supports the expectation (based on the assumptions from the traditional grief-following-loss theories) that persons who experience loss of sight will move through the stages of the grief process and that the emotional reactions will diminish as the loss of sight is accepted and adjusted to, implying a final stage of emotional adjustment. Taking the notion as conceptualised by the long-term AVI of a cyclic, recurrent and continuous grief process, it is inevitable that emotional adjustment to visual impairment will also be a continuous process and will be negotiated and re-negotiated continually.

The results obtained from this investigation could also imply that instead of the presumed static nature of practical and emotional adjustment, there is rather a notion of adjustment which will continually fluctuate between greater and lesser degrees. Additional research into this notion is needed.

6.3.2.2 Subsidiary investigation (3B): Adjustment as a continuous or linear process

The results of this investigation {Section 5.5.3 Subsidiary investigation (3B): Adjustment as a continuous or linear process p. 128} show that the short-term AVI, more so than the long-term AVI, perceive adjustment to visual impairment as a linear process. The majority of the short-term perceive that after rehabilitation there will be total adjustment to their visual impairment; that there is a final stage of acceptance for adjustment to visual impairment; and that there is a decrease in the emotion of frustration when visual impairment is accepted.

The implication of these results is a perception by the short-term AVI of a static and final adjustment stage of acceptance of visual impairment and a decrease in the emotion of frustration, key variables in the traditional grief-following-loss theory.

The majority of the long-term AVI perceive that adjustment to visual impairment is a continuous process; that there is no final stage of acceptance for adjustment to visual impairment; that visual impairment involves continual losses that have to be continually adjusted to; that there is an increase in the emotion of frustration. The implication of these results is a perception by the long-term AVI of a continuous and chronic grief process.

It must be noted however, that the short-term AVI agreed with one of the statements related to adjustment being a continuous process. The positive agreement with many statements could be indicative of acquiescent response set or social desirability on behalf of the short-term AVI respondents in an attempt to ward off anxiety and preserve self-esteem (Elliott et al., 1991). Generally however, it would appear that the short-term AVI perceive adjustment to visual impairment as a linear process as compared to the long-term AVI who perceive adjustment as a continuous process. Further research into this significant issue is needed.

6.3.2.3 *Subsidiary investigation (3C): Descriptions of acceptance and adjustment*

As the concepts of *acceptance* and *adjustment* formed an integral part in this research study, it was investigated whether the respondents perceive a relation between the two concepts. There are distinct qualitative differences between the two groups with regard to the meaning of adjustment and acceptance {Section 5.5.4 Subsidiary investigation (3C): Differences in descriptions of acceptance and adjustment p. 132}. The majority of the short-term AVI perceive a relation between the two concepts as they state that there is no difference between the two. On the other hand,

the long-term AVI perceive that there is no relation between the two concepts with the majority stating that acceptance is an emotional issue whereas adjustment is a practical issue.

Given the conceptualisation that acceptance of and adjustment to visual impairment are inseparable and reciprocally interact and influence one another then it is inevitable that emotional (acceptance) and practical (adjustment) issues will also be inseparable and reciprocally interact and influence one another. Once again the point of further research into this conceptualisation is needed.

6.3.2.4 *Subsidiary investigation (3D): Changes in emotions*

The results from the investigation into the emotional reactions experienced by the AVI from the time of onset of visual impairment to the time of the interview {Section 5.5.5 Subsidiary investigation (3D): Changes in emotions from onset of visual impairment to present p. 133} show different results for the short and long-term AVI. Although there are instances of both improvement and deterioration with regard to the emotions experienced over time, the short-term expressed greater overall improvement in their feelings. The most significant improvement for the short-term AVI is the marked decrease in the feeling state of hopelessness. The most significant deterioration for the long-term AVI is the decrease in acceptance of visual impairment.

The short-term AVI showed improvements with decreased anger, sadness, frustration and increased acceptance. They therefore once again support the traditional grief-following-loss theory that the duration of the emotional reactions (feeling states) associated with grief tend to diminish and improve as time passes. The long-term AVI on the other hand, experienced an overall deterioration in their feelings over time. They showed a deterioration with increased anger, frustration, non-acceptance and although there is an improvement with regard to sadness, the majority still feel sad about their visual loss. The long-term

AVI therefore support the contention that chronic grief is associated with a build-up or increase of accompanying feeling states or emotions.

These results differ from those obtained in the research by Conyers (1992). In her research {Section 3.4.4.2 Visual impairment: Time course of grief-related emotions p. 62} there was a deterioration (increase) in anger and sadness for the AVI respondents in the time interval 6 months to 2 years. In this research study however, the short-term AVI (including the 6 months to 2 years time interval) perceive an improvement (decrease) in anger, sadness and frustration. It is the long-term AVI (6 years and over) who perceive a deterioration (increase) in anger, sadness and frustration.

In her study, Conyers (1992) found that the highest level of deterioration in the inability to accept loss of sight is found in the AVI persons who feel they still *longed to see again* after two years of visual impairment. This research study also found a marked increase (implying a deterioration) in the feeling of *longing to see again* for the long-term AVI. Although there is a slight decrease (implying an improvement) for the short-term AVI the majority also feel that they still longed to see again.

The idea of "longing to see again" as a measure of ability or inability to accept the permanence of loss of sight is questioned. For instance, although the majority of the short-term AVI have accepted their visual impairment they still longed to see again. Although the majority of the long-term AVI have a lesser degree of acceptance (still however implying a degree of acceptance) they also still longed to see again. Could it therefore be that this feeling of "longing to see again" is not a measure of acceptance of visual impairment but rather a natural feeling which will occur regardless of length of time of adventitious visual impairment? Perhaps this phenomenon occurs because personal and environmental demands continually change from situation to situation and from time to time and it is

precisely at these times that the AVI long to be able to see again in order to perhaps cope better with the changing situations. The observation made by a long-term AVI female encapsulates this assumption, when she stated that: "...When I'm in a position and I need to do something urgently, I remember when I was able to do what I needed to do, and it's in those situations that I wish I could see again."

6.3.3 Hypothesis 4: Discussion of results

The results from this hypothesis investigation show that the long-term AVI perceive a far greater need for continued emotional support as compared to the short-term AVI {Section 5.6.1 Hypothesis 4: The need for continued emotional support is greater for long-term AVI persons than short-term AVI persons p. 138}.

The perception of the short-term AVI that there is no need for continued emotional support after rehabilitation once again supports the traditional grief-following-loss theory of resolvable grief. They appear to follow the notion that the need for intense follow-up or support of AVI persons will lessen as they develop their skills and confidence (practical and emotional adjustment). It would appear that these results therefore support society's expectation that when loss and the resultant grief process occurs, it is expected to operate within a certain time frame and conclude with acceptance and adjustment with a presumed return to the functioning person as before the loss of sight (Davis, 1987; Elliott et al., 1991). This expectation in turn may elicit a perception that there is no need for continued emotional support after rehabilitation.

The definite need for continued emotional support after rehabilitation as expressed by the long-term AVI supports the notion for the recognition of continual chronic grief and therefore continual interventions and support to help the AVI deal with the numerous and continual losses that are a continual part of visual impairment (Davis, 1987).

6.3.3.1 *Subsidiary investigation (4A): The best person to offer support*

The question of who would be the best person/s to offer continued emotional support after rehabilitation obtained different results {Section 5.6.2 Subsidiary investigation (4A): The best person to offer support p. 139}. Considering that the short-term AVI perceive themselves to be emotionally and practically adjusted, it is therefore not surprising that they perceive a non-need for continued emotional support and that the majority stated that *nobody* needed to support them.

The long-term AVI with their perception of a definite need for continued emotional support stated that a *professional person* will be the best person to offer this emotional support. What is surprising is that the traditional social worker associated with rehabilitation was not considered, but rather a psychologist or counsellor. What is even more significant is that all the long-term AVI stated that this professional person should be AVI. Perhaps the long-term AVI are expressing a need for someone who will understand and be aware of the implications and complexities of visual impairment.

Who is most helpful?

It was also investigated who had most helped AVI persons work through their feelings after loss of sight and who is most helpful now {Section 5.6.2.1 Subsidiary investigation: Who is most helpful? p. 141}. At the time of the onset of visual impairment, it was the family who was perceived by both the short-term and long-term as being the most helpful. This result supports research by Conyers (1992) where the family was also perceived as the most helpful, possibly because they are generally more accessible than anybody else and share the day to day experiences with the AVI person. There was however a shift to the present with regard to the perceived most helpful person. The long-term AVI who perceive friends as the most helpful

whereas the short-term still perceive the family and spouse as the most helpful.

A significant finding from this research study is that persons from both the short-term and long-term AVI perceived that *nobody* had helped or are helping them work through their feelings about loss of sight. It is also disquieting that only 1 respondent from the total sample stated that the rehabilitation centre (with its specialist rehabilitation workers) had helped with feelings about loss of sight. These results are indeed alarming because it is presumed and expected that the rehabilitation centre with its trained specialist workers would be in the best position to help the AVI work through their feelings about loss of sight.

These results did support other research, albeit research into the impact of non-driving on visually impaired persons (Corn & Sacks, 1994). The visually impaired respondents rate amongst others, the professionals in the field of visual impairment, the general public, physicians and other health care providers as being insensitive and having little understanding or support for the emotional and logistical impact of not being able to drive. Conversely, the respondents, as in the case of this research study, perceive that spouses or significant others, parents (families) and friends support them and understand this emotional and logistical impact.

It is apparent that these findings are related to the causes of frustration as delineated by the long-term AVI where the "lack of understanding and support from the sighted" is perceived as one of the main causes. Perhaps this is the reason why the long-term AVI imply that the persons best suited to provide the emotional support will be AVI professionals, precisely because of the perception that only somebody who has experienced adventitious visual impairment will be aware and understand the complex implications; an understanding that the long-term AVI seem so anxious to obtain.

6.3.3.2 *Subsidiary investigations (4B AND 4C): Types of helpful and frustrating support*

It was investigated what type of support is perceived as the most helpful for the AVI {Section 5.6.3 Subsidiary investigation (4B): Types of helpful support p. 142}. There are once again differences, with the majority of the short-term AVI who state that both practical and informational support are the most helpful, whereas, the long-term perceive that practical, informational as well as emotional support are the most helpful. This subsidiary result further substantiates the result from the hypothesis testing where the short-term AVI perceived that there was no need for continued emotional support after rehabilitation as compared to the long-term AVI.

It is apparent that practical and informational support are related to the causes of frustration. The loss of independence of AVI necessitates practical and informational support in order for them to function and participate fully in life and to lessen the frustrations associated with loss of independence.

Frustrating support

It was also investigated whether the AVI become frustrated with support that is offered {Section 5.6.4 Subsidiary investigation (4C): Frustration and support p. 143}. More of the long-term AVI become frustrated with support that is offered as compared to the short-term AVI. "Unnecessary support" is described as causing the most frustration. This result corresponds with the causes of frustration where the long-term describe the lack of awareness and understanding of the sighted about visual impairment as a main cause of frustration.

6.3.4 **Summation of critical discussions pertaining to the results**

The most significant result obtained from this research study

appears to be the different perceptions that the AVI have of the grief process (with accompanying emotions, acceptance and adjustment) based on the length of time of visual impairment. On the one hand, there is the perception of a resolvable grief process (short-term AVI) with diminished emotions and a final static stage of acceptance and adjustment to visual impairment. On the other hand, there is the perception of a chronic grief process (long-term AVI) with a continuous and circular acceptance and adjustment process to visual impairment often accompanied by increases in grief related emotions.

6.4 POSSIBLE EXPLANATIONS FOR DIFFERENCES

Up till now the main thread that has run through the discussion is that of consistent differences between the short-term and long-term AVI with regard to the grief process following loss of sight and the related emotions, especially that of frustration, acceptance, adjustment, and need for continued emotional support. Perhaps the most comprehensive explanation for the differences could be that it takes years before people with a disability (including visual impairment) appreciate, acknowledge and become aware of the reality and the full extent of the implications and limitations of their condition (Elliott et al., 1991; Livneh & Antonak, 1991).

Research (Elliott et al., 1991; Conyers, 1992) has shown that many persons after an acquired disability (including visual impairment) engage in a type of psychological denial which include the characteristics of: an absence of anxiety and depression, little acknowledgement of the implications of the condition and expressed optimism regarding the eventual resumption of disruptive social roles and functioning. The short-term AVI in this research study appeared to have all the above-mentioned characteristics including: decreased emotional reactions, acceptance of and adjustment to visual impairment, an absence of depression and anxiety, a positive optimism about the future with little acknowledgement about the limitations of

visual impairment and a perception that no emotional support is necessary after rehabilitation. Conyers (1992) argues that many factors could account for this phenomenon of denial namely, unacknowledged reactions, fear of losing remaining sight and the subsequent fear of losing control and being overwhelmed by feelings or guilt in having some emotions, especially anger. Admitting to, and owning, powerful emotions such as despair, anger and hopelessness appear to suggest negative implications about self-worth and perceived self-ability. The positive perceptions of the short-term AVI could possibly be an attempt to ward off anxiety and preserve self-esteem.

The longer people are visually impaired the more aware they perhaps become about the *unreality* of the expected time heals ideal and the more aware they become about the reality of the non-ending implications and limitations associated with sight loss. The long-term AVI are possibly more open and more willing to acknowledge and confront issues such as emotional reactions, loss of control and independence, lack of understanding from the sighted world and the negative side of visual impairment, in other words, the real world of visual impairment. All grieving persons, including AVI persons, can obtain perspective on grief only when it is acknowledged. The ability to be realistic, to know, feel and experience all the emotional reactions is essential for living with visual impairment on a continuous basis (Davis, 1987). This greater awareness about the reality of loss of sight is shown in Section 6.3.1.2 {Subsidiary investigation (2A): Changes and frustration p. 151} where the long-term AVI state that it is their awareness about the implications of visual impairment that cause them to become more frustrated.

Resolvable and chronic grief

Taking into consideration this perceived lack of awareness of the short-term AVI about the reality of visual impairment, the comparison given by Lindgren et al. (1992) between resolvable and chronic grief may be significant. Although both are reactions to

loss, resolvable grief involves reactions to one identified loss whereas chronic grief involves reactions to numerous losses that are a part of visual impairment. The short-term AVI with their lack of awareness about the reality and implications of visual impairment may indeed perceive their loss of sight as one identified loss. If so, then it is assumed and expected that the short-term AVI will follow the traditional stages of the grief process with all the accompanying emotional reactions which diminish in intensity and frequency as the loss of sight is accepted and adjusted to within a time limit. The results obtained from the short-term AVI certainly substantiate this assumption.

The long-term AVI with a assumed greater awareness of the reality and implications of visual impairment appeared to support a chronic grief process. They perceive loss of sight as involving numerous and continuous losses which have to be adjusted to continually. The long-term AVI substantiate the assumption that if the underlying cause of continual loss is visual impairment, then grief with the accompanying emotions (including frustration) will operate throughout the course of the visual impairment. It is inevitable that personal and environmental demands will continually change throughout the AVI person's life. When certain situations or events produce further losses resulting in anxiety or doubt about the AVI person's acceptability or worthiness, the person will cycle back through some or all of the adjusting stages. This is a process which the long-term AVI certainly endorse.

Lack of awareness and understanding of the sighted

It became evident from this research study that the AVI and in particular the long-term AVI, perceive a lack of awareness and understanding from the sighted about the reality of visual impairment. Society in general and health care and rehabilitation workers in particular, may overestimate the impact of the initial crisis of loss of sight and underestimate that of later grief

episodes (Davis, 1987). It is not surprising therefore that the AVI are expected to deny or not recognise chronic grief. AVI persons experience a wide variety of emotions related to their visual impairment and they have a need to express those feelings in order to participate emotionally in life (McKay, 1990). Frustrations are often caused when there is external lack of awareness and understanding of a situation and therefore, the recurring encounter with the social stigma and lack of understanding of visual impairment will indeed result in frustration, a condition relevant to the long-term AVI.

A question arises from this discussion which could further explain the differences between the short-term and long-term AVI. Does the perceived lack of understanding of the real world and implications of visual impairment held by society also apply to the persons involved in rehabilitation? If so, then the perception held by the long-term AVI that a professional person who is also AVI will be the best person to provide emotional support is clarified. The long-term perceive that an AVI person would understand the implications and complexities of the *real world* of visual impairment.

In addition, as in the case of society in general, do the rehabilitation workers also presume and uphold the traditional grief-following-loss theory assumption that *time heals and changes everything* and that the resolvable grief process will follow the linear stages and culminate with the final stage of acceptance and adjustment within a time limit? If so, are the short-term AVI encouraged to uphold these traditional assumptions, for it is indeed the short-term AVI who are normally associated with the rehabilitation programme? Is the denial of chronic grief re-enforced during the rehabilitation process and is the *unreality* of visual impairment encouraged? If so, then the newly rehabilitated AVI will indeed come across as adjusted and accepting of visual impairment and therefore totally independent; the traditional loss theory assumptions. The results obtained from this research study clearly indicate that the short-term AVI

live up to these traditional assumptions.

With the passage of time, and in this research study, approximately 6 years, the AVI become to realise and acknowledge that the process of adjustment to visual impairment is a continuous process where losses, limitations and emotional reactions associated with visual impairment have to be continually confronted. Sadly, the lack of understanding and awareness about the implications and real world of visual impairment by society in general and the rehabilitation workers in particular make it extremely difficult for the AVI to become aware of and understand the never ending implications of their loss of sight and it is sadly the AVI who have to travel this long and winding and rocky road alone to discover the real world of visual impairment. The long-term AVI in this research study appeared to have journeyed a long way down this *real* road of visual impairment.

6.5 SUMMARY: RESEARCH AND THEORETICAL IMPLICATIONS

In this section the following issues will be discussed:

- research implications;
- implications for theory.

6.5.1 Research implications

Many significant implications were obtained from this research study.

Implication 1: Relation between time length of AVI and adjustment

The most significant implication from this research study is that there is indeed a relation between different lengths of time of adventitious visual impairment (visual impairment for under and over 6 years) and the experience of psychological and emotional reactions such as frustration related to visual

impairment, acceptance of and adjustment to visual impairment and need for continued emotional support. The 6 year cut off of being AVI for under or over 6 years is significant. It is indeed the long-term AVI (over 6 years) who showed an increase in the intensity and frequency of frustrations related to visual impairment; who showed a lesser extent of acceptance and adjustment to visual impairment; and showed a need for emotional support after rehabilitation (in direct contrast to the short-term AVI under 6 years). In addition, the implication that length of time of visual impairment is indicative of greater awareness and understanding about the implications of the *real world* of visual impairment is significant.

Implication 2: Linear versus continuous grief

The distinct differences between the short-term and long-term AVI with regard to the perception of the grief process is significant. On the one hand, the traditional grief-following-loss theory expectation of a static resolvable grief process with decreasing emotional reactions, acceptance and adjustment to visual impairment is supported by the short-term AVI on the other hand, the long-term AVI support a chronic continuous grief process where confrontation of loss associated with visual impairment is a continuous process and which have to be adjusted to continually. The concept of chronic grief and the related emotions and the concept of length of time of visual impairment are inseparable.

Implication 3: Reciprocal acceptance and adjustment

The notion of acceptance, adjustment and emotional reactions as continually fluctuating between greater and lesser degrees is significant. The notion of acceptance and adjustment as being inseparable, reciprocally interacting and influencing each other is also significant.

Implication 4: Below average adjustment to visual impairment

The below average adjustment to visual impairment scores for both the short-term and long-term AVI in this research study as compared to the norms of the Nottingham Adjustment Scale are disquieting and significant.

Implication 5: Reinforcing resolvable grief

A significant implication from this research study is the suggestion that society in general and rehabilitation workers in particular are reinforcing the traditional grief-following-loss theory of a resolvable grief process. The unrealistic hope, denial and unawareness of the implications of visual impairment amongst AVI adults are thereby enhanced. The need to be confronted with the *real world* of visual impairment with all its implications is a common theme that both the short-term and long-term AVI expressed when asked about the interview. Many stated that this type of interview should be asked during rehabilitation. A long-term male stated, "...These types of questions should definitely be asked to people coming in for rehabilitation because there are many questions here that I needed to ask myself many years ago." Another long-term male commented, "...It should have been done during rehabilitation, not at the beginning of rehab but rather during. People must look at things in cold fact and not let the emotions get in the way. But emotions also have to be dealt with later in the rehabilitation process." A long-term female perhaps encompassed the feelings of many of the AVI when she remarked, "...this interview welcomed me to the real world of visual impairment."

Implication 6: Meeting the basic need?

The implications from this need for being confronted with the *real world* of visual impairment is disquieting for it leads to speculation of whether the rehabilitation context is meeting this basic need. Evidence from this research study, where only 1

person identified the rehabilitation centre as being helpful possibly indicates that the rehabilitation context is not meeting this need. This speculation is further enhanced by the long-term AVI who state that professional persons, and not the rehabilitation workers, would be the best persons to provide continued emotional support deemed necessary by this group. Another significant implication from this research is that the long-term stated that this professional person must also be AVI. This indeed further enhances the notion that long-term view society in general as having no awareness and understanding about visual impairment.

Implication 7: Explaining the gap

The assumption of a resolvable grief process held by both society and the short-term AVI could explain the gap in the literature and research on psychological and emotional reactions of adventitious visual impairment. The bulk of literature and research on psychological and emotional reactions related to adventitious visual impairment has focused on the time period from onset to approximately 2 years later and includes the period immediately before and after rehabilitation. As the results from these investigations have indeed endorsed the resolvable grief process, an erroneous perception may have ensued that there is therefore no need to research beyond the 2 year period of visual impairment.

6.5.2 Implications for theory

Many significant implications for the theory underlying this research study were obtained.

Grieving is continuous

The theory on which this research study is based is that of the grief-following-loss theory. There have been numerous attempts to suggest a move away from the loss model with its notion of

grieving for lost sight.

It is evident however from this research study that the long-term AVI still conceptualise loss of sight as a continuous and chronic grief process. Personal and environmental demands continually change and the AVI are therefore continually confronted with new losses related to their visual impairment. The losses are continually redefined in new situations with new problems which have to be adjusted to continually. The long-term AVI support the notion that if the underlying cause of continual losses is visual impairment then grief with the accompanying emotions (including frustration) will operate throughout the course of the visual impairment (Lindgren et al., 1992).

It is inevitable therefore that the loss theory forms an integral part of adventitious visual impairment regardless of the length of time of the impairment. It is necessary that a new dimension to the already existing loss theory related to loss of sight must be contemplated, namely, a loss theory based on a chronic and continuous grief process. This implies therefore that there must be a move away from the traditional loss theory and related static resolvable grief process to a loss theory involving a chronic and continuous grief process. The identifiable attributes in the conceptual analysis of chronic grief that need to be considered for inclusion in the new dimension of the loss theory related to loss of sight include: a perception of grief over time in a situation that has no predictable end; grief is cyclic or recurrent and is triggered either internally or externally when personal or environmental demands change; grief is progressive and can intensify years after the initial sense of loss, disappointment or fear (Lindgren et al., 1992).

Both grieving and rehabilitation

There are other implications for the theory underlying this research study. Many of the traditional loss models assume that

rehabilitation cannot take place until the grieving process for the loss of sight is completed. However, with the conceptualisation of visual impairment involving a chronic and continuous grief process then this assumption must be challenged. The new dimension to the loss theory has therefore to move away from this traditional assumption of either grieving for loss of sight or rehabilitation to include a new concept of being able to grieve for loss of sight during the rehabilitation process. However, this ability to grieve indeed has to go beyond the rehabilitation context to include the ability to grieve throughout the entire life of visual impairment.

The idea that rehabilitation is seen as an *either or* situation with those rehabilitation workers who emphasise the need to work through feelings and those who emphasise the need to restore functioning as soon as possible after the loss of sight (Dodds, 1987; Dodds et al., 1991) is also challenged with the conceptualisation of a chronic grief process. It is once again inevitable that there has to be a move away from this *either or* approach to rehabilitation to include both the emotional side of working through feelings as well as the practical side to restore functioning as soon as possible. AVI persons cannot begin or be expected to adjust, either emotionally or practically, unless they know what it is they must potentially face and adjust to.

The addition of a new dimension to the loss theory to include the concept of a chronic and continuous grief process that is understood and acknowledged not only by the AVI but by society as well could be the *turning point* that the AVI are so desperately needing and looking for.

6.6 CONCLUSION

In this chapter, the results obtained from the hypotheses and subsidiary analyses were interpreted and discussed. The findings of this research study provide support for the primary hypotheses under investigation; that there is a relation between length of

time of adventitious visual impairment and increased frequency and intensity of frustrations related to visual impairment, a lesser degree of acceptance of visual impairment and a need for continued emotional support. The findings of this research study also challenged the traditional assumptions of the traditional grief-following-loss theory and the related static and resolvable grief process and highlighted the conceptualised concept of a chronic and continuous grief process. Possible explanations were made to explain the differences in the results between the short-term and long-term AVI including, that the short-term AVI lacked awareness, understanding and acknowledgement of the implications of the *real world* of visual impairment. The research and theoretical implications of the research study were discussed. Possible suggestions were made for the modification of the theory to accommodate the results. The results showed that the loss theory still forms an integral part of visual impairment regardless of the length of time of the loss. It was suggested that a new dimension to the already existing loss theory related to loss of sight be contemplated, namely, a loss theory based on a chronic and continuous grief process.

Interpretation of this study has however been limited by the lack of appropriate research regarding psychological and emotional reactions of AVI adults, as well as the concept of a chronic grief process. It is inevitable therefore that more research is needed regarding adventitious visual impairment and related issues which were suggested and hinted at during this research study.

In the next and final chapter, the limitations of this research study, recommendations for further research and the question of whether "time changes everything" will be addressed.

CHAPTER SEVEN

CONCLUSION: THE REAL WORLD OF ADVENTITIOUS VISUAL IMPAIRMENT

7.1 INTRODUCTION

The conclusions and recommendations of the present study will be set out in this chapter. The discussion will centre on the following:

- research aims of the present study and the hypotheses and related subsidiary investigations;
- major conclusions and suggestions from the research study;
- limitations of the present study;
- recommendations for further research;
- reflection on the value of the present study.

7.2 RESEARCH AIMS OF THE STUDY

The main aim in this study was to gain more insight and understanding about the relation between different lengths of time of adventitious visual impairment and psychological and emotional reactions, especially frustration, associated with such loss; acceptance of and adjustment to adventitious visual impairment; and what the need is for continued emotional support after rehabilitation. As the afore-mentioned aspects form an integral part of the grief process the aim of the study was also to gain knowledge of whether the grief process after loss of sight is comparable to that after loss through death with its implication of a time-limited resolvable grief process.

It was hoped therefore that this research study on AVI adults whose loss of sight continued beyond the preferred 2 year time interval (the bulk of the literature on adventitious visual impairment has focused on the grief process up to 2 years after loss of sight) would result in more knowledge and therefore begin

to fill the noticeable gap in the literature and research on the relation between length of time of visual impairment and psychological and emotional reactions of AVI adults.

7.2.1 Hypotheses and related subsidiary investigations

To pursue the main aims of this research study of the relation between different lengths of time of visual impairment and psychological and emotional reactions of AVI adults the following primary hypotheses and related subsidiary research investigations came into focus:

- Hypotheses 1 and 2: that different lengths of time of adventitious visual impairment are related to both the intensity and frequency of frustrations experienced by AVI persons.

Hypothesis 1 related subsidiary investigations:

Different causes of frustration; Certain time intervals of visual impairment that are more or less frustrating.

Hypothesis 2 related subsidiary investigations:

Changes from the onset of visual impairment to the present to make the AVI more or less frustrated; The feelings of the AVI about the saying *time heals* the frustrations related to visual impairment.

- Hypothesis 3: that different lengths of time of adventitious visual impairment are related to acceptance of visual impairment.

Hypothesis 3 related subsidiary investigations:

Overall, practical and emotional adjustment to visual impairment; Perception of adjustment as a linear or continuous process; Descriptions of acceptance of and adjustment; Changes in emotions from the onset of visual impairment to the present.

- Hypothesis 4: that different lengths of time of visual impairment are related to a need for continued emotional support.

Hypothesis 4 related subsidiary investigations:

The best person/s to offer the continued emotional support; Who helped the AVI work through their feelings about loss of sight and who is most helpful now; Helpful and unhelpful types of support; Support that causes frustration.

All the above hypotheses and subsidiary investigations were based on the grief-following-loss theory and the related grief process following loss through death, disability and visual impairment.

7.3 MAJOR CONCLUSIONS FROM THE RESEARCH STUDY

The major conclusion from the results of this research study is that different lengths of time of visual impairment (AVI for under and over 6 years) are significantly related to psychological and emotional reactions of AVI adults. According to this study the long-term AVI experience more frequent and intense frustrations related to their visual impairment, have less acceptance of the impairment and have a greater need for continued emotional support as compared to the short-term AVI. The implication from these results is that the longer the length of time of adventitious visual impairment will cause increases of frustration, decreases of acceptance and greater need for continued emotional support. Longitudinal research is needed to investigate these implications.

The different lengths of time of visual impairment are also a significant factor that influenced the perception of the grief process. On the one hand, the short-term AVI perceive a resolvable grief process which follows the stages with all the accompanying emotional reactions which diminish in intensity and frequency as the loss of sight is accepted and adjusted to within

a time limit. On the other hand, the long-term AVI perceive a chronic recurrent and continuous grief process with continuous emotional reactions (often an increase in intensity and frequency) which have to be adjusted to continually, thus implying no final stage of acceptance of visual loss. These different perceptions will in turn inevitably influence frustrations acceptance and need for continued emotional support.

Additional implications from the divergent perceptions of the grief process is that a new dimension to the already existing grief-following-loss theory with the related resolvable grief process has to be considered to include a chronic grief process. If the underlying cause of continual losses is visual impairment then grief with the accompanying emotions (including frustration) will operate throughout the course of the visual impairment (Lindgren, et al., 1992).

The perception that there is a lack of understanding from the sighted about visual impairment (cited by the long-term AVI as one of their main causes of frustration) effected another speculation of how beneficial the rehabilitation context is for meeting the basic needs of the AVI. It became apparent during the research that one of the basic needs of the AVI is to become aware and understand the reality of the implications of visual impairment. Evidence from this research study indicates that this basic need is probably not being met and this poses great implications because AVI persons cannot begin or be expected to adjust, either emotionally or practically, unless they know what it is they must potentially face and adjust to.

7.3.1 Suggestions gained from the research

Briefly, the suggestions from the present research study include the following:

- that the AVI be confronted with the real world of visual impairment as soon as possible after the onset of loss of sight

and therefore become aware and understand the reality of the implications and limitations of visual impairment;

- that there must be a move away from the perception of the grief process as a linear static process which culminates in acceptance and adjustment as this puts unrealistic expectations on the AVI person;

- that there is a move away from the traditional grief-following-loss theory with its assumption of a resolvable grief process to incorporate a new dimension of a chronic grief process. It is inevitable that personal and environment demands will continually bring about new losses related to visual impairment which will have to be adjusted to continually;

- that a different approach to rehabilitation be considered whereby there is an acknowledgement of chronic grief with all it's implications including a need for continued emotional and practical support. The initial rehabilitation process must therefore be the first stepping stone in a never ending process.

7.4 LIMITATIONS OF THE PRESENT STUDY

Various shortcomings and limitations can be mentioned with regard to the present study.

Perhaps the main shortcoming in this present study is that of small sample groups. The original envisaged number of 20 in each group was deemed necessary for empirical testing as the smaller the sample size, the larger the error and deviation from the population values (Kerlinger, 1986). The final number of 16 respondents in each sample group, although not the *ideal* number, was deemed plausible enough after Huysamen (1984) stated that equal size samples of not smaller than 15 are necessary if parametric procedures are to be used.

Another shortcoming in this research study is that the

conclusions cannot be compared with or supported by other research. This is due to the lack of research into this field of study namely, psychological and emotional reactions of AVI adults, as well as the concept of a chronic grief process.

The non-experimental nature of this research study did not allow for control of extraneous variables. Therefore, variables such as levels of visual ability, onset of visual impairment, age, gender, language differences, educational and marital status, additional health problems, amongst others, could have acted as nuisance variables and cause confounding with the independent variable of length of time of visual impairment. The limitations imposed by the sampling procedure and the ex post facto nature of this research study precludes generalisation of the results to an extended population.

The analysis of data based on categorical measurement (which was used on many occasions in this research study), is a limited application of basic inferential statistics (Babbie, 1992). Although significant statistical results were obtained with the use of categorical measurement more rigorous and advanced inferential statistics are recommended for future research. The majority of the data for the study were respondents self-reports of perceptions, opinions and attitudes to a variety of issues. A potential problem with this type of data analysis could be faking or acquiescence response set where respondents responses to the items may be distorted in their attempts to give a good impression. Generalisability of the results must therefore once again be used with caution. The reliability of the measuring scales developed for the interview (the Likert-type scores) must be further examined and replicated to ensure greater sensitivity.

Although the researcher aimed at maintaining a neutral role and an objective standpoint, which was hopefully achieved in part by using interviewers other than herself, the possibility of subjectivity cannot be ignored. The researcher, being AVI herself and hopefully with insight and understanding of the implications

of adventitious visual impairment possibly encouraged cooperation and rapport with the respondents because of the mutuality of visual impairment. Therefore, the researcher hopefully gained in-depth and better estimates of the respondents true intentions, meanings, beliefs and attitudes.

The main intention in this study was an exploratory investigation into the relation between length of time of adventitious visual impairment and psychological and emotional reactions of AVI adults. The major purpose of exploratory research is to refine concepts and articulate questions and hypotheses for further research based on results, trends and implications obtained from a research study, which was indeed realised in this present study.

7.5 RECOMMENDATIONS FOR FURTHER RESEARCH

Several ideas for further research have emerged from the present study and therefore the notion that "research begets research" (Leedy, 1989, p. 9) is certainly appropriate to this research study. Issues that have been raised and which need to be pursued include the following:

- more research to investigate the relation between length of time of adventitious visual impairment and psychological and emotional reactions and the presumed healing property of time. Results from other research would either endorse or refute the findings from this research study.
- the results obtained from this study show that the long-term AVI are more frustrated, accept their impairment to a lesser degree and need continued emotional support as compared to the short-term AVI. It is possible that frustration and need for continued emotional support increase and acceptance decreases the longer the visual impairment. Longitudinal research is needed to investigate this notion of a progression of increases or decreases the longer the visual impairment.

■ research is needed into the concept of acceptance being the corner stone of adjustment to visual impairment (Dodds et al., 1991). It is evident from this study that if visual impairment is related to a chronic and continuous grief process then acceptance and adjustment will reciprocally interact and influence one another. Therefore the idea that there must first be acceptance before adjustment to visual impairment is questioned.

■ further research is needed into the reasons for the below average overall adjustment scores for the respondents in this research study as compared to the norms of the Nottingham Adjustment Scale. This was a disquieting result which needs explaining.

■ research is needed to investigate whether basic needs of AVI persons, including emotional and practical support, are being met in the rehabilitation context. What emerged from this research study was that the basic need of the AVI to become aware and understand the real world of adventitious visual impairment and all its implications was not being met in the rehabilitation context.

■ the concept of a chronic grief process provided the most insightful and significant contribution to this study. The following issues which need further research include: what are the variables related to increased intensity and frequency of emotions, especially frustration? Is the increase indeed related to added losses or to a changed perspective of loss? Does chronic grief therefore imply chronic acceptance and adjustment which reciprocally interact and influence one another? What type and degree of support are most beneficial with chronic grief? Exploring the incidence and nature of chronic grief and it's related variables will provide comprehensive understanding of the conceptual framework which can then be a basis for developing rehabilitation assessments and interventions to help chronic AVI persons (and families) deal with their losses over a long period

of time. The acknowledgement of chronic grief by both the AVI and society in general could help all concerned become aware and understand the never-ending implications of the real world of adventitious visual impairment and provide a more effective rehabilitation context.

7.6 REFLECTION ON THE VALUE OF THE PRESENT STUDY

It is hoped this present study will act as a stepping stone for future research to help fill the noticeable gap in the literature and research into psychological and emotional reactions related to adventitious, especially long-term, visual impairment. This research study has just touched the tip of the iceberg of the implications of adventitious visual impairment and further research is certainly necessary. Any new information that can educate and inform the AVI as well as the sighted and in particular the rehabilitation workers about the implications of the *real world* of adventitious visual impairment can only but enhance the lives of all concerned.

It is hoped that the information and suggestions from this research study will encourage the rehabilitation workers to reconsider the worth of the rehabilitation context as it now stands. It is hoped that a more effectual process with greater insight and understanding about the *real world* of adventitious visual impairment to meet the basic needs of all concerned will be considered.

It is also hoped that the present research will stimulate reflection on a new dimension to the existing grief-following-loss theory. It is evident from this research that *loss* still forms an integral part of visual impairment regardless of length of time of loss of sight. Consideration will hopefully therefore be given to the concept of a loss theory of chronic grief because if the underlying cause of continual losses is visual impairment then grief with the accompanying emotions will operate throughout the course of the visual impairment (Lindgren et al., 1992).

On reflection however, perhaps the validity and worth of the present study is to be seen not in the answers it has provided (although these were thought provoking and significant) but rather in the pertinent questions it has raised. These questions will hopefully ensure that research into adventitious visual impairment will be a continual *turning point* rather than a *point of no return*.

The aim of research is found at two levels: "problems whose aim it is to increase our knowledge and problems whose prime purpose it is to make life better" (Leedy, 1989, p.48). On further reflection I do believe that this present research has to a small degree fulfilled these aims because greater insight, understanding and awareness about the *real world* of adventitious visual impairment has been achieved.

7.7 CONCLUSION

It is evident from this research study that *time* is the most influential factor affecting all aspects of adventitious visual impairment. Time has and will continue to bring about change, but whether the change will be satisfactory or unsatisfactory for the AVI and as to the question of "time changes everything - or does it?", only *time* will tell.

REFERENCES

- Adams, J.E. & Lindemann, E. (1974). Coping with long-term disability. In G.V. Coelho, D.A. Hamburg, & J.E. Adams (Eds), *Coping and adaptation*. New York: Basic Books.
- Babbie, E. (1992). *The practice of social research*. Belmont, CA: Wadsworth.
- Bailey, K.D. (1986). *Methods of social research*. London: Macmillan.
- Bailey, B.J. & Gregg, C.H. (1986). Grief, pathological grief, rehabilitation counseling. *Journal of Applied Rehabilitation Counseling*, 17(4), 19-23.
- Banwell, V. (1991). Coming to terms with visual loss: The need for counselling services. *The New Beacon*, vol.LXXV(88), 237-240.
- Bowlby, J. (1969). *Attachment and loss. Vol. 1: Attachment*. New York: Basic Books.
- Bowlby, J. (1973). *Attachment and loss: Vol. 2 separation, anxiety and anger*. New York: Basic Books.
- Bowlby, J. (1975). Attachment theory: Separation, anxiety and mourning. In S. Arietty (Ed.), *American Handbook of Psychiatry (2nd ed.)*. New York: Basic Books.
- Bowlby J. (1979). *Making and breaking of affectional bonds*. New York: Meutheun.
- Carroll, T. J. (1961). *Blindness, what it is, what it does and how to live with it*. Boston: Little, Brown.

- Carson, R., Butcher, J. & Coleman, J. (1988). *Abnormal psychology and modern life* (8th ed.). Glenview, Ill: Scott Foresman.
- Caylor, J. (1974). Psychological implications for blindness. In A. Cobb (Ed.), *Special problems in rehabilitation*. New York: Charles C Thomas.
- Cleiren, M. (1993). *Bereavement and adaptation: A comparative study of the aftermath of death*. London: Hemisphere.
- Cobb, S. (1993). Social support as a moderator of life stress. In E. Beyers (Ed.), *Issues in social psychology*. Pretoria: University of South Africa.
- Conyers, M. (1992). *Vision for the future: The challenge of sight loss*. London: Jessica Kingsley.
- Corn, A.L. & Sacks, S.T. (1994). The impact of nondriving on adults with visual impairments. *Journal of Visual Impairment and Blindness*, 89(1), 53-68.
- Davis, B.H. (1987). Disability and grief. *Social Casework*, 68, 352-357.
- De Spelder, I.A. & Strickland, A.L. (1992). *The last dance: Encountering death and dying* (3rd ed.). Mountain View, CA: Mayfield.
- Dershimer, R.A. (1990). *Counseling the bereaved*. New York: Pergamon.
- Dodds, A.G. (1989). Motivation reconsidered: The role of selfefficacy in rehabilitation. *British Journal of Visual Impairment*, 7(1), 11-15.
- Dodds, A.G. (1991). The psychology of rehabilitation. *The British Journal of Visual Impairment*, 9(2), 37-40.

- Dodds, A.G. (1993). *Rehabilitating blind and visually impaired people: A psychological approach*. London: Chapman & Hall.
- Dodds, A.G., Bailey, P., Pearson, A. & Yates, I. (1991). Psychological factors in acquired visual impairment: The development of a scale of adjustment. *Journal of Visual Impairment and Blindness*, 85(7), 306-310.
- Drotar, D., Baskiewicz, A, Irwin, N., Kennel, J., & Klaus, A. (1975). The adaptation of parents to the birth of an infant with congenital malformation: A hypothetical model. *Paediatrics*, 56, 710-717.
- Eisenhandler, E.I. (1990). The Asphalt identikit: Old age and the driver's license. *Journal of Aging and Human Development*, 30(1), 14.
- Elliott, T.R., Witty, T.E., Herrick, S. & Hoffman J,T. (1991). Negotiating reality after physical loss: Hope, depression, and disability. *Journal of Personality and Social Psychology*, 61(4), 608-613.
- Falek, A., & Britton, S. (1974). Phases in coping: The hypothesis and its implications. *Social Biology*, 21, 1-7.
- Farris, G. (1985). Psychologic aspects of athletic rehabilitation. *Clinics in Sports Medicine*, 4(3), 545-551.
- Finkelstein, B. (1980). *Attitudes and disabled people*. Washington: World Rehabilitation Fund.
- Fitzgerald, R.G. (1970). Reactions to blindness: An exploratory study of adults with recent loss of sight. *Archives of General Psychiatry*, 22, 370-379.
- Gerdes, L.C. (1988). *The developing adult* (2nd ed.). Durban: Butterworth.

- Gerhardt, C. (1990). 'Parts of me are excellent': Students with disabilities. *Unisa Psychologia*, 17(2), 33-38.
- HSRC (Human Sciences Research Council) (1966). Catalogue number: 666: *The Sixteen Personality Factor Questionnaire: Form A*. Pretoria: HSRC.
- Hallenbeck, P.N. (1967). *Dogmatism and visual loss*. New York: American Foundation for the Blind.
- Hartz, G.W. (1986). Adult grief and its interface with mood disorder: Proposal of a new diagnosis of complicated bereavement. *Comprehensive Psychiatry*, 27(1), 60-64.
- Hughes, F. (1980). Reaction to loss: Coping with disability and death. *Rehabilitation Counselling Bulletin*, 23, 250-259.
- Human Sciences Research Council (1966). Catalogue number: 666: *The Sixteen Personality Factor Questionnaire: Form A*. Pretoria: HSRC.
- Huysamen, G.K. (1983). *Psychological measurement: An introduction with South African examples*. Pretoria: Academica.
- Joines, S. (1995). A developmental approach to anger. *Transactional Analysis Journal*, 25(2), 112-118.
- Karson, S. & O'Dell, J.W. (1977). Identifying medical risk factors in the 16-PF profile: A clinical approach. In S.E. Krug (Ed.), *Psychological assessment in medicine*. Champaign, Ill: Ipat.
- Kerlinger, F. N. (1986). *Foundations of behavioral research*. New York: Holt, Reinhardt & Winston.

King, S. (Ed.), (1993). *Research for visually disabled people: An international guide*. London: Technical Research Section, Royal National Institute for the Blind.

Kübler-Ross, E. (1969). *On death and dying*. New York: Macmillan.

Kübler-Ross, E. (1974). *Questions and answers on death and dying*. New York: Macmillan.

Leedy, P.D. (1989). *Practical research: Planning and design* (4th ed.). New York: Macmillan.

Lehman, I.R., Wortman, C.B. & Williams, A.F. (1987). Long-term effects of losing a spouse or child in a motor crash. *Journal of Personality and Social Psychology*, 52, 218-231.

Lindgren, C.L., Burke, M.L., Hainsworth, M.A. & Eakes, G.G., (1992). Chronic sorrow: A lifespan concept. *Scholarly Inquiry for Nursing Practice*, 6(1), 27-39.

Livneh, H. (1986). A unified approach to existing models of adaptation to disability. Part 1, A model of adaptation. *Journal of Applied Rehabilitation Counseling*, 17, 5-16.

Livneh, H. & Antonak R.F. (1991). Temporal structure of adaptation to disability. *Rehabilitation Counselling Bulletin*, 34(4), 298-319.

Marris, J. (1974). *Loss and change*. London: Routledge & Kegan Paul.

McBurney, D.H. (1994). *Research method*. Belmont, CA: Brooks-Cole.

McKay, R.C., (1990). *Western cultural metaphors for dying and death: Implications for counselling*. Unpublished thesis for the degree of Doctor of Literature and Philosophy in

Psychology, University of South Africa, Pretoria.

- McKay, R. (1992). Offering support in grief: Some do's and don'ts. *Unisa Psychologia*, 19(2), 31-34
- McKay, R.C. (1993). *Grieving: From stages to needs, a conceptual shift*. Unpublished paper from an Examination of Research Literature and Experiential Workshops attended at the Centre for Living with Dying, Santa Clara, California.
- McKittrick, D. (1981/2). Counselling dying clients. *Omega*, 12(2), 165-187.
- Metcalf, A. (1994). *Low vision services manual*. Pretoria: South African National Council for the Blind.
- Murray, S.A. (1995). Challenging the challenge. *Unisa Psychologia*, 22(2), 25-30.
- Oliver, M. (1990). *The politics of disablement*. London: Macmillan.
- Parkes, C.M. (1970). The first year of bereavement. *Psychiatry*, 33, 440-467.
- Parkes C.M. (1972). *Bereavement: Studies of grief in adult life*. New York: International University Press.
- Parkes C.M. (1975). Psychosocial transitions: Comparison between the reactions to loss of a limb and loss of a spouse. *British Journal of Psychiatry*, 127, 204-210.
- Parkes, C.M. (1985). Bereavement. *British Journal of Psychiatry*, 146, 11-17.
- Parkes, C.M. (1986). *Bereavement*. London: Tavistock.

- Parkes, C.M. (1988). Bereavement as a psychosocial transition: Processes of adaptation to change. *Journal of Social Issues*, 44(3), 53-65.
- Perry, E. & Hampton-Roy, F. (1982). *Light in the shadows: Feelings about blindness*. Little Rock: The World Eye Foundation.
- Piper, W.E., McCallum, M. & Azim, H. (1992). *Adaptation to loss through short-term group psychotherapy*. New York: Guilford.
- Quackenbush, N. & Crossman, J. (1994). Injured athletes: A study of emotional responses. *Journal of Sport Behaviour*, 17(3), 178-187.
- Raphael, B. (1983). *The anatomy of bereavement*. New York: Basic Books.
- Raphael, B. & Nunn, K. (1988). Counseling the bereaved. *Journal of Social Issues*, 44(3), 191-206.
- Ray, C. & West, J. (1983). Spinal cord injury: The nature of its implications and ways of coping. *Journal of Rehabilitation Research*, 6(3), 364-365.
- Reber, A.S. (1985). *The Penguin Dictionary of Psychology*. Hamondsworth: Penguin Books.
- Reiss, D., Gonzalez, S. & Kramer, (1986). Family process, chronic illness and death. *Archives of General Psychiatry*, 43(8), 795-804.
- Richardson, G.A. (1992). *A qualitative investigation into the meaning of work for the South African career women*. Unpublished thesis for the degree of Doctor of Arts in Psychology, University of South Africa, Pretoria.

- Rosenblatt, P.C. (1988). Grief: The social context of private feelings. *Journal of Social Issues*, 44(3), 67-78.
- Rowland, W.P. (1985). *Being blind in the world*. Pretoria: South African National Council for the Blind.
- Rubin, S.S. (1984). Mourning distinct from melancholia: The resolution of bereavement. *British Journal of Medical Psychology*, 57, 339-345.
- Rubin, S.S. (1985). The resolution of bereavement: A clinical focus on the relationship to the deceased. *Psychotherapy*, 22(2), 231-235.
- Sanders, C.M. (1989). *Grief: Dealing with adult bereavement*. New York: John Wiley & Sons.
- Shackleton, C.H. (1984). The psychology of grief: A review. *Advances in Behaviour Research Therapy*, 6(3), 153-205.
- Shuchter, S.R. & Zisook, S. (1987). The therapeutic task of grief. In S. Zisook (Ed.), *Biopsychosocial aspects of bereavement*. Washington: American Psychiatric Press.
- Silverman, P.R. (1981). *Helping women cope with grief*. Beverley Hills, CA: Sage.
- South African National Council for the Blind (SANCB) (1995). Bureau for the Prevention of Blindness Statistics. Pretoria.
- Stroebe, M.M. & Stroebe, W. (1987). *Bereavement and health: The psychological and physical consequences of partner loss*. Cambridge University Press: Cambridge.
- Sussman, D. (1986). *The effect of personal adjustment on the outcome of low vision rehabilitation programmes*. Unpublished dissertation for the Degree of Masters of Arts in Social

Work, University of the Witwatersrand, Johannesburg.

- Swap, S. (1984). Ecological approaches to working with families of disturbed children chapter 7. In W. O'Connor & B. Lubin (Eds.), *Ecological approaches to clinical and community psychology*. New York: John Wiley & Sons.
- Taylor, S. (1986). *Health psychology*. New York: Random House.
- Tuttle, D.W. (1984). *Self-esteem and adjustment to blindness*. Springfield, Ill: Charles C. Thomas.
- Vachon, M.L.S. & Stylianos, D.K. (1988). The role of social support in bereavement. *Journal of Social Issues*, 44(3), 175-190.
- Weiss, R.S. (1988). Loss and recovery. *Journal of Social Issues*, 44(3), 37-52.
- Wineman, N.M. (1990). Adaptation to multiple sclerosis: The role of social support, functional disability, and perceived uncertainty. *Nursing Research*, 39(5), 294-299.
- Worden, W. (1982). *Grief counseling and grief therapy*. New York: Springer.
- Worden, W.J. (1985). Bereavement. *Seminars in Oncology*, 12(4), 472-475.
- Yalom, I.D. (1975). *The theory and practice of group psychotherapy* (2nd ed.). New York: Basic Books.
- Zisook, S. & Shuchter, S. (1985). Time course of spousal bereavement. *General Hospital Psychiatry*, 7, 95-100.
- Zola, I. (1981). *Missing pieces: A chronicle of living with a disability*. Philadelphia: Temporal University Press.

APPENDICES

Appendix A Letter to Optima College for permission to do interviews and to obtain names of ex-rehabilitees

P.O. BOX 27839
YEOVILLE
2143
21 JULY 1995

THE EXECUTIVE DIRECTOR

SANCB
P.O. BOX 11179
BROOKLYN
PRETORIA
0011

DEAR DR. ROWLAND,

FURTHER TO MY TELEPHONE CONVERSATION, I ENCLOSE THE DETAILS OF THE RESEARCH PROJECT I WOULD LIKE TO DO, WITH THE HELP OF OPTIMA, FOR MY MASTER'S PSYCHOLOGY DEGREE AT UNISA.

AS A TOTALLY BLIND PERSON MYSELF, I AM INTERESTED TO SEE HOW ADVENTITIOUSLY VISUALLY IMPAIRED PERSONS EXPERIENCE FRUSTRATIONS, INCIDENTAL TO VISUAL IMPAIRMENT, OVER TIME.

BECAUSE OF THE NATURE OF OPTIMA, NAMELY, THAT THERE ARE PRESENT AT THE SAME TIME BOTH ADVENTITIOUSLY VISUALLY IMPAIRED PERSONS UNDERGOING REHABILITATION AND EX-REHABILITEE UNDERGOING OTHER COURSES, IT WOULD BE A PERFECT PLACE TO DO SOME OF MY RESEARCH. IT WOULD ALSO BE APPRECIATED IF I COULD GET NAMES AND ADDRESSES OF EX-REHABILITEE FROM OPTIMA SO THAT I CAN CONTACT THEM FOR AN INTERVIEW.

I PLAN TO DO A STRUCTURED INTERVIEW WITH AT LEAST 40 ADVENTITIOUSLY VISUALLY IMPAIRED WHITE ADULTS. A FELLOW SIGHTED PSYCHOLOGY STUDENT WILL ASK THE QUESTIONS WHICH I WILL TAPE AND THEN TRANSCRIBE ONTO COMPUTER. EACH INTERVIEW SHOULD LAST APPROXIMATELY 30 MINUTES.

IT WOULD BE GREATLY APPRECIATED IF I COULD OBTAIN PERMISSION TO DO SOME OF THE INTERVIEWS AT OPTIMA AND GET NAMES AND ADDRESSES OF PAST OPTIMA STUDENTS FOR MY RESEARCH PROJECT. ONCE MY RESEARCH PROPOSAL HAS BEEN ACCEPTED BY UNISA, I WILL CONTACT OPTIMA TO ARRANGE DATES FOR THE INTERVIEWS AND COLLECTION OF NAMES AND ADDRESSES.

THANK -YOU FOR YOUR CO-OPERATION. I TRUST THAT THIS RESEARCH WILL BE BENEFICIAL TO BOTH THE VISUALLY IMPAIRED AND SIGHTED WORLD.

THANKING YOU,
YOURS SINCERELY,
SHIRLEY MURRAY.

Appendix B Letter from Optima College

PO Box 11149, Brooklyn
0011 Pretoria, South Africa
514 White Street, Baileys Muckleneuk
0181 Pretoria, South Africa
Telegrams: Blindcare, Pretoria
Telephone: (012) 346 1171
Fax: (012) 346 1149

Suid-Afrikaanse Nasionale
Raad vir Blindes

Our Ref/Ons Verw

1995.08.17
LdP/th

Shirley Murray
P O Box 27839
Yeoville
2143

Dear Shirley

RESEARCH PROJECT

Your request for assistance has been referred to me by Dr Rowland.

We are willing to assist you; however please bear in mind that we only have small numbers of white adults at Optima College and they do not stay for long periods of time.

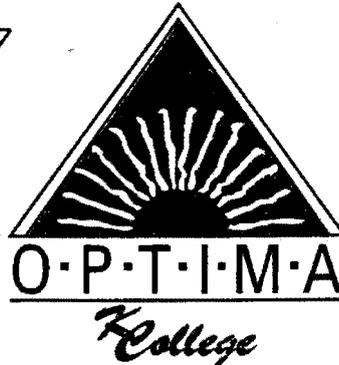
We would like to suggest that you contact each student personally in writing to ask their permission to have an interview with them. Dr Rowland also would like to approve the content of the letter you are going to send to students before you send it out.

Please contact me as soon as possible to discuss practical arrangements.

Sincerely,



LINA DU PLESSIS (mrs)
DIRECTOR



Posbus 11149, Brooklyn
0011 Pretoria, Suid-Afrika
Whitestraat 514, Baileys Muckleneuk
0181 Pretoria, Suid-Afrika
Telegramme: Blindcare, Pretoria
Telefoon: (012) 346 1171
Faks: (012) 346 1149

South African National
Council for the Blind

Our Ref/Ons Verw

Appendix C The interview schedule

Interview Schedule.

Thank you for agreeing to participate in this study. At the outset I want to assure you that the interview is strictly confidential and that you will remain anonymous.

I am conducting interviews to obtain information on how visually impaired persons experience frustrations related to their impairment.

Please answer all questions as honestly and openly as possible. There are no "right" or "wrong" answers to these questions as we are interested in your experiences and feelings.

As I myself am visually impaired, the interview will be recorded on audio cassette tape and transcribed after the interview.

Are there any questions before we begin?

. PERSONAL DETAILS.

1. What is your home language?
 - English
 - Afrikaans
 - Any other - please specify.
2. How old are you?
3. Are you:
 - Single.
 - Married.
 - Separated.
 - Divorced.
 - Widowed.
4. From the time that you were diagnosed with an eye problem to now, how long have you been visually impaired?
5. What was the cause of your visual impairment?
6. Was the onset of your visual impairment:
 - Within a day.
 - Within a week.
 - Within a month.
 - Within 2 to 6 months.
 - Within 7 to 12 months.
 - Within 1 to 2 years.
 - 2 years plus.
 - Still ongoing - Please specify.
7. What is your visual ability now?
 - Only have light perception.
 - Able to vaguely see objects that contrast highly with the surroundings.
 - Able to count fingers at 1 to 10 feet.
 - Able to read normal print with adaptive devices.
 - Able to get around in daylight without special equipment.

Totally unable to see even bright sunshine.

- 8. Do you have any other disability or health problems?
- 9. What is your highest educational level?
- 10. Did you obtain this qualification before or after the onset of your visual impairment?
- 11. What was your occupation before your visual impairment?
- 12. What is your occupation now?
- 13. Did you drive a motor car before your visual impairment?
Yes/No.

****PROMPT:**

Please now administer the following questionnaires:

- 1. The "16PF" Questionnaire.
- 2. The "Nottingham Adjustment Scale".

.SECTION A: FRUSTRATION AND IT'S CAUSES.

- 1. How would you describe frustration?
- 2. By definition, frustration is: "The emotional state assumed to result from the act of blocking, interfering with or disrupting behaviour that is directed towards some goal".(*1)
Do you agree with this definition?
- 3. As a visually impaired person, what causes you to become the most frustrated?
- 4. As a visually impaired person how often do the following cause you to become frustrated?
 - A. Always.
 - B. Often.
 - C. Seldom.
 - D. Never.

Your loss of independence.

The general lack of understanding of the sighted world about visual impairment.

When you are unable to do things on the spur of the moment.

When people think that the visually impaired are ignorant as well.

Having to be dependent on others.

The stereotyped expectations of the sighted world.

Others try to organise your life.

When the option of choice is taken from you.

The limitations put on you because of your visual impairment.

When people make assumptions about visual impairment without checking to see if they are correct.

5. What do you do when you become frustrated?

. SECTION B: FREQUENCY OF FRUSTRATION.

1. In the past week how often have you experienced frustrations related to your visual impairment?
 - A. Not once.
 - B. Once in the week.
 - C. Once every other day.
 - D. Once daily.
 - E. Several times daily.

2. Would you say that you are frustrated:
 - A. Most of the time.
 - B. Sometimes.
 - C. In certain situations.
 - D. Never.

**Prompt:
If the answer is C:

3. What situation makes you the most frustrated?

. SECTION C: INTENSITY OF FRUSTRATION.

1. Would you say that since the onset of your visual impairment, the intensity of the frustrations related to your impairment have:
 - A. Decreased a lot.
 - B. Decreased a little.
 - C. Remained the same.
 - D. Increased a little.
 - E. Increased a lot.

2. From the time of the onset of your visual impairment to now, what has changed to make you feel less / more frustrated?

.SECTION D: ADJUSTMENT.

1. To what extent have you accepted your visual impairment?
 - A. Not at all.
 - B. To a small extent.
 - C. To a moderate extent.
 - D. To a large extent.
 - E. Completely.

2. To what extent have you adjusted to your visual impairment?
 - A. Not at all.
 - B. To a small extent.
 - C. To a moderate extent.
 - D. To a large extent.
 - E. Completely.

3. To what extent have you come to terms with your visual impairment?
 - A. Not at all.
 - B. To a small extent.
 - C. To a moderate extent.
 - D. To a large extent.
 - E. Completely.

4. What is the difference between acceptance of and adjustment to visual impairment?

5. You must now agree or disagree with the following statements.
 - A. Agree.
 - B. Disagree.
 - C. Don't know.
 1. After my rehabilitation I will have totally adjusted to my visual impairment.
 2. Adjustment to visual impairment is a continuous up and down process.
 3. For total adjustment to visual impairment one has to move through various stages culminating with the final stage of acceptance.
 4. Visual impairment imposes certain limitations that have to be acknowledged in order to function optimally.
 5. There is no final stage of acceptance of visual impairment, but rather a continuous recycling through the various stages.
 6. There is a time limit for adjustment to visual impairment.

7. Once visual impairment is accepted, frustration decreases.
 8. Visual impairment involves continual losses that have to be continually adjusted to.
 9. One gets over the emotional grief reaction of frustration within a time limit.
 10. The repeated confrontation of loss associated with visual impairment results in an increase of frustrations.
 11. Visual impairment does not put limits on what a person can do.
 12. Frustration continually occurs from old losses that are continually brought to mind.
6. What are your feelings about the saying, "time heals" with respect to your experience of frustration related to your visual impairment?
 7. Do you feel you have adjusted practically to your loss of vision?
 - A. Not at all.
 - B. A little.
 - C. Moderately.
 - D. Very well
 - E. Completely.
 8. Do you feel you have adjusted emotionally to your loss of vision?
 - A. Not at all.
 - B. A little.
 - C. Moderately.
 - D. Very well
 - E. Completely.
 9. After each statement, please answer yes or no to both A and B.
 - A. I used to feel this way.
 - B. I still feel this way.
 1. I feel that I enjoy life despite my visual impairment.
 2. I feel annoyed when people make wrong assumptions about visual impairment.
 3. I try to cover up the fact that I can not see.
 4. I feel angry about my loss of sight.
 5. I feel that my frustrations have decreased the longer I have been visually impaired.

6. I feel that the meaning and purpose has gone out of my life.
7. I get irritated when it takes long to complete a simple task.
8. I make promises that if i get my sight back i will do something in return.
9. I no longer feel angry about my loss of sight.
10. I feel sad about what has happened to me.
11. I cannot accept the limitations put on me by my visual impairment.
12. I long to see again.
13. I feel positive about the future.
14. I feel frustrated when I am continually confronted with problems related to my impairment.
15. I find it more difficult to make friends now.
16. I feel that it gets easier to accept my visual impairment as time passes.
17. I feel no one can understand what I am going through.
18. I can not see any hope for the future.
19. I feel that people expect me to have accepted my visual impairment.
20. I have difficulty getting around on my own.
21. I feel that I can not talk honestly about my worries and feelings.
22. I feel that despite my visual impairment it is easy to make friends.

.....SECTION E: SUPPORT.

1. What type of support would be helpful to you as a visually impaired person?
Answer one or more.
 - A. Practical support (tangible assistance).
 - B. Emotional support.
 - C. Informational support (advice and suggestions).
 - D. No support.
 - E. Any other support - please specify.

2. Has the type of support most useful to you changed over time?
3. Do you ever become frustrated with support that is offered to you?
4. Are you able to express openly your feelings about your visual impairment with your:
 - A. Family.
 - B. Friends.
5. How do the following persons react to your frustrations?
 - A. Family.
 - B. Friends.
6. In the early stage of your visual impairment who most helped you to work through your feelings about your loss of sight?
7. Is that person or persons still helpful now?
****PROMPT:**
If the answer is negative:
8. Who is most helpful now?
9. Do you believe that there is a need for continued emotional support after your rehabilitation?
Please explain your answer.
****PROMPT:**
If the answer is yes to the above:
10. Who do you believe would be the best person/persons to offer this emotional support?

.....SECTION F: OCCUPATION.

1. Were you able to return to your previous type of occupation after the onset of your visual impairment?
****PROMPT:**
If the answer is no:
2. What are you doing now?
3. Do you feel that you are achieving your potential in your present occupation?

.....SECTION G: CONCLUSION.

1. What do you believe would help to make your life as a visually impaired person less frustrating?

****PROMPT.**

I would like to thank you once again for taking part in this study. The information gained from the interviews will give great insight into how persons experience their visual impairment. This in turn can only benefit those persons who have lost, or are in the process of losing their sight, and for those that interact closely with someone who is visually impaired. Would you be interested in obtaining feedback on the research?

(*1): Reber, A.S. (1985). The Penguin Dictionary of Psychology. Harmondsworth: Penguin Books.

Appendix D Letter to Dr Dodds to obtain a copy of the Nottingham Adjustment Scale

P.O. Box 27839
Yeoville
2143
Republic of South Africa
14 August 1995

Deputy Director
Blind Mobility Research Unit
Department of Psychology
University of Nottingham
University Park
Nottingham
NG7 2RD

Dear Mr. Dodds,

I have just completed my Psychology Honours Degree at the University of South Africa this year. As part of the curriculum, I did a research project on how adventitiously visually impaired adults experience frustrations, incidental to visual impairment, over time. My hypothesis was that the frustrations would increase in frequency and intensity the longer a person is visually impaired. Despite a small sample, the significant statistical results supported this hypothesis. As a totally adventitiously blind person myself, I believe that more research is needed in this area.

Therefore, at present I am preparing my proposal for a research masters in this particular area of visual impairment. I have been doing an extensive literature search and there seems to be a gap in information about the long term rehabilitated visually impaired person. The focus seems to be on the period before, during and immediately after rehabilitation.

I have been reading your books and articles and am very interested in the psychological aspect of many of them. In particular, I am very interested in the article "Psychological factors in acquired visual impairment: the development of a scale of adjustment," written by you and various other researchers in 1991. Unlike other questionnaires, many of the most pertinent psychological factors associated with adjustment to disability are addressed in one questionnaire. Unfortunately, the South African National Council For The Blind does not have a copy of the "Nottingham Adjustment Scale" questionnaire. It would be greatly appreciated if I could get a copy of the questionnaire and scoring for I believe it would help me greatly in my proposed research. By administering the questionnaire I hope to investigate whether adjustment to visual impairment should be seen as a process that occurs during rehabilitation, or if it should be seen rather as a circular process that has to be continually

negotiated and renegotiated throughout the visually impaired person's life. If so, then the implications for the visually impaired person, rehabilitation, and society as a whole are profound.

It would be greatly appreciated if I could obtain a copy of the "Nottingham Adjustment Scale" questionnaire and scoring from you. If this is not possible, could you please advise me where i might obtain one here in South Africa. Any other information that you think might help me with my research would be greatly appreciated.

Thanking you,

Yours sincerely,

Shirley Murray. (Miss).

Appendix E Reply from Dr Dodds

Mansfield Community Hospital, Stockwell Gate, Mansfield, Notts NG18 5QJ
 Telephone: (0623) 22515 Fax: (0623) 635357

Wendy Saviour, General Manager, Mansfield Locality

Our Ref:

Your Ref:

Tel Ext.:

Shirley Murray,
 P.O. Box 27839,
 Yeoville 2143,
 Republic of South Africa.

19.9.95

Dear Ms. Murray,

Thank you for your enquiry regarding the Nottingham Adjustment Scale, a copy of which I enclose. Scoring is straightforward and I also have normative data somewhere if you feel that you would like to have this. I wish you every success with your work.

Yours sincerely,



Dr. Allan G. Dodds, CPsychol, FBPsS, RMIP.

CENTRAL NOTTINGHAMSHIRE
HEALTHCARE

(NHS) TRUST



Acute Services at Newark

Services for Elderly People

Services for People with
 Learning Disabilities

Services for People with
 Mental Health Problems

Clinical Psychology

Child Health Services

Community Nursing Services

Rehabilitation Services

Nutrition and Dietetics

Speech and
 Language Therapy

Chiropody

Family Planning Services

Palliative Care

D J Brotherhood, Chief Executive

G Vere-Laurie, Chairman

NEWARK & SHERWOOD

ASHFIELD

MANSFIELD
 HMSO/T9-904

Appendix F Table showing the obtained mean sten scores for the AVI respondents for the selected 16-PF factors C, Q3 AND Q4 (16-PF mean norm scores = 5)

Short-term	C	Q3	Q4	Long-term	C	Q3	Q4
1	4	7	6	1	5	5	6
2	6	4	4	2	1	2	7
3	7	8	4	3	8	5	4
4	5	6	4	4	7	5	3
5	6	4	5	5	4	8	6
6	3	5	6	6	3	6	6
7	5	5	5	7	9	7	1
8	4	5	4	8	1	4	7
9	6	7	4	9	4	2	8
10	9	8	4	10	5	7	5
11	5	7	4	11	3	7	8
12	3	7	7	12	5	7	2
13	7	2	6	13	8	9	3
14	10	7	5	14	6	9	5
15	8	5	5	15	6	5	6
16	5	7	7	16	5	6	4

Appendix G Direct transcripts of selected AVI respondents' descriptions about the meaning of frustration

Themes	AVI	Descriptions
Feeling causing Problems	F >6	feeling that makes me depressed or aggravated by the situation of vi.
	M <6	feeling that makes me want to break a window or slam a door.
	F >6	feeling that makes me question 'why me?'
	M <6	an inner feeling inside me with a negative drive that I want to release out but I can't.
	M <6	a feeling that makes an impact on your life and causes problems and makes you uneasy, close to stress or anxiety.
	F >6	emotions and feelings that build up inside of you and over which you have no control.
Prevention:	M <6	the inability to do simple things that I could do before.
	M >6	the inability to do something because of a third force, which is out of your control.
	F >6	a feeling resulting from not being able to do things because I'm prevented by my lack of sight; if I had sight I could do it, I'm physically and mentally able to do it but because I can't see I can't do it.
	M <6	the inability to have total control over yourself and no matter how hard you try to do something it doesn't seem to work and there are always new things coming. It's like trying to pitch water with a hole in the bucket.
	F >6	an emotion that results from when you were able to do things and you cannot do them any more because of either your visual impairment or the lack of understanding from the sighted world.
	F <6	feeling from being unable to do something, knowing you can because you've got the ability but there's an obstacle in the way.

	F <6	feeling from my loss of independence caused by my vi.
Behaviour:	F <6	a behaviour resulting from the lack of awareness of the sighted, eg. When guiding me they can't tell me in time when I'm getting to steps.

Appendix H Direct transcripts of the main causes of frustration perceived by selected AVI respondents

Themes	AVI	Descriptions
Loss of independence	M >6	not being able to always do what I would like to do especially when sight is needed eg transport and to do my own shopping by myself, and not being able to see all the beautiful things there is to see.
	F >6	not being able to get to points a and b, eg transport, and having all personal mail to be read for me.
	F >6	not being able to get around, lack of mobility, I can walk around but I need transport and not being able to access things that I need eg information and finding things.
	F <6	when I want to do something and I cannot do it without the assistance of another person
	F >6	having to be dependent on others especially with transport.
Lack:	F <6	lack of understanding and awareness eg things get put in the way when it's not supposed to be there or moving things without telling me.
	F <6	in relationships with people the fact that they tend to see the disability rather than the person, lack of understanding and awareness about vi.
Loss&lack	F >6	when I am in a position and I need to do something urgently and because of my blindness and because of the lack of understanding from the sighted world my goal or what I want to do cannot be reached eg read a book, get to the shop/library.
Inability	M <6	when I put something somewhere and I can't find it.

Appendix I Direct transcripts of selected AVI respondents descriptions of what has changed from the time of the onset of adventitious visual impairment to make them more/less frustrated

Themes	AVI	Descriptions
Awareness	F <6yrs	losing more sight and becoming aware of the continual losses of not being able to read or write anymore.
	M <6yrs	awareness of my different lifestyle, can't do what I used to do, can't do what I want to do and loose out on a lot of things.
	M >6yrs	have become aware of losses, was always independent I had myself and nobody else to depend on which has now changed and I have to be dependent on others.
	M >6yrs	when I first went blind sort of thought oh well but as time has gone on and the more I've tried to do the more I've got frustrated.
	M >6yrs	have become more aware of my continual losses associated with vi such as seeing your friends taking girlfriends out in their own cars and the frustrations get bigger and bigger.
Lack of understanding :	F >6yrs	precisely because things have not changed, despite all the publicity despite all the effort that goes into the awareness into research into everything there's still the ignorance and the apathy towards blindness and the lack of support and the lack of an infrastructure and enabling devices or situations.
	F <6yrs	because of the lack of understanding of others about vi, they look at the disability rather than the person.
Learn to cope:	F <6yrs	I have learnt to cope and do the things I can do and leave the things I can't and accept this.
	M <6yrs	have learnt to cope with the knowledge of what I can do or can't do and do not try to do things that I can't and know I am not able to do.

	F >6yrs	patience, I have learnt patience, tolerance and accepting the situation the way it is for it is not going to change and I've got to adapt to it, so I have learnt to cope.
Attitudes changed:	F <6yrs	the attitudes have changed; people treat me differently because in the beginning they thought I could do nothing for myself but they dont do that anymore.
Learn to cope-frustrations same:	F <6yrs	learnt to cope because it cant get any worse and it also cant get any better.
	F >6yrs	because I have learnt to cope or get used to it and because it's the same frustrations so I cope with it.
	M >6yrs	I have learnt to cope and found ways of getting round the frustrations.

Appendix J Direct transcripts of selected AVI respondents' feelings about the saying "time heals" the frustrations related to their visual impairment

Theme	AVI	Descriptions
Disagree:	F <6yrs	at the moment I don't think I will ever say that time heals, it;s not going to be a case of oh well I'm the same as I was, which is of course what everybody wants and this is frustration.
	M >6yrs	the saying time heals is a myth because time doesn't heal anything especially frustration of vi because you have to live with it and there are always occurring things that make you realise that it is there as much as you try to lead a normal life there will always be something that reminds you and which causes frustration.
	F >6yrs	I believe that time does not heal because you are continually confronted with situations that have to be dealt with and you are being continually confronted with things that remind you of your sighted life for example not being able to drive a car when you need to, so 50 years down the road you are still going to get frustrated.
Time makes it easier but not heal.	F <6yrs	it becomes easier but I don;t know if it ever heals because there is always times that you do think that it would be nice to drive and to be more independent so it is an ongoing thing.
	M >6yrs	frustrations keep coming, keep coming from different quarters so time heals I don't know - time certainly makes you more able to handle it but I wouldn't say it heals.
	F >6yrs	time makes it easier and time is a healer but it is not a cure for frustration.
Agree	M <6yrs	I would totally agree with the statement time heals because I have actually seen the process of myself.

	F >6yrs	true because frustrations do decrease with time.
--	------------	---

Appendix K Direct transcripts of selected AVI respondents
descriptions of what would make their lives less
frustrating

Theme	AVI	Descriptions
Employment	F <6yrs	employment, to be able to earn my own money. I have to rely on other people for, I won;t say charity, but them supporting me emotionally and informationally and I think I would be better off if I could manage on my own.
	F >6yrs	get employment but it must also be like my occupation before I went blind and not just any job.
Awareness	M <6yrs	if people just understand how we feel because people don't understand and if they get more information to understand it will do wonders for me and others as well.
	M >6yrs	to get the world in general to accept the fact that we are people who have a problem rather than see the 'blind' and that they don;t assume to many things. The vi must look for what one can do and yell when you can't.
	F >6yrs	if society in general could accept us more easier because they avoid us and don't know how to treat us.
Assistance	M <6yrs	assistance with a better public transport system; better government grants for blind; sancb subsidies for goods that are costly not cheap things such as watches and canes; information more accessible.

	F >6yrs	I will need adequate public transport so that I don't need to rely on somebody, sufficient funds to buy the equipment needed to put me on a par with the sighted people, and to enable me to do my job. It's frustrating when I have to fight for everything and every cent just to be able to compete for a lesser job than what I am qualified for. The availability of information in a form that I can use and which I can access. General awareness from the society in general. Makes me frustrated to fight to be equal and to fight to have the same opportunity as the sighted people, and if only I was judged on my merits and not on whether I can see or not.
	F >6yrs	more support and assistance in the form of aids to be able to do my job better.

Appendix L Direct transcripts of selected AVI respondents descriptions of adjustment and acceptance of visual impairment

Themes	AVI	Descriptions
No difference	F <6yrs	no difference because they are so closely related.
	F >6yrs	no difference because they are the same.
Emotion/ practical	M >6yrs	acceptance is a mental or emotional thing whereas adjustment is a physical or practical thing.
	F >6yrs	adjusting is how I've picked up the pieces and adapted myself to continue in this new situation, acceptance is whether I'm happy with it and how I cope with it, therefore acceptance is emotional and adjusting is practical.
Finality/ cope	M <6yrs	acceptance when you don't live in a fools garden or thinking of a miracle, a finality, adjustment is when you able to cope and to make use of others senses or just do things differently.
	M >6yrs	acceptance is the realisation that nothing can be done or changed, a finality, whilst adjustment organising things to make things easier for you.

Appendix M Direct transcripts of selected AVI respondents
descriptions of what types of support causes
frustration

Theme Support	AVI	Descriptions
Unnecessary	M >6yrs	when someone wants to do something for me but I'm able to do it myself.
	F >6yrs	when it's irresponsible stupid support eg. When someone comes and picks up the tip of the cane and tries to guide you.
	F <6yrs	unnecessary support when capable of doing it myself, eg family wanting to brush my teeth for me.
Patronising	M >6yrs	if it is patronising support when people do something because they feel sorry and pity for me.
Empty promise	M <6yrs	especially if it is empty promise support, when people promise they will do something for you which never happens.