

CHAPTER ONE

LIGHT, SHADOWS AND DARKNESS: THE COLOURS OF LIFE

1.1 INTRODUCTION

Human beings are unable to escape the experience of anguish after a loss, one of the inescapable realities of life. Loss of sight, no matter the degree of loss, is one such inescapable reality. Visual impairment is a phenomenon with complex, multiple and irrevocable effects and challenges on human life. The loss impinges on every facet of life and affects psychological, emotional and attitudinal experiences, practical capabilities and skills, and emotional and practical needs. The phenomenon to be explored in this research study is whether length of time of the adventitious visual impairment affects experienced emotions and attitudes, and by implication, the grief process, and whether these experiences impact on needs, in other words, the phenomenon of emergent needs post-grief experienced by adventitiously visually impaired adults.

This chapter will provide a description of the quintessence of visual impairment, the origins and aims of the present research study, and an outline and orientation of the contents of the ensuing chapters.

1.2 THE QUINTESSENCE OF VISUAL IMPAIRMENT

To acquire some feeling of what it is like to be visually impaired, imagine for a moment a life with little or no vision, a world limited to what is heard, touched and smelt. This world differs from the world of those who can see. It is true that all people are challenged to a lesser or greater degree throughout their lives, but a small percentage of people are visually challenged in addition to everything else.

Visual impairment is a phenomenon with complex and multiple effects on human life and functioning and the degree of severity and the nature of the impairment are all likely to impact on how the person reacts to the challenge of sight loss. This section will present an overview of how visual impairment is understood.

1.2.1 The Notions Visual Disability, Visual Handicap and Visual Impairment

There are three terms used more or less synonymously and interchangeably that refer to individuals with a visual loss, namely, visually impaired, visually disabled or visually handicapped (Lund & Dietrichson, 2000; Sacharowitz, 1998; Tuttle, 1984). The World Health Organisation's Model of Disability, defined by the International Classification of Impairment, Disability and Handicap (ICIDH2, 1999) emphasises how people function with regard to different dimensions of an impairment, disability or handicap, with interventions aimed to increase independence and optimum participation in life situations. There are, however, subtle differences between the three terms.

1.2.1.1 Visual Disability

Visual disability is a limitation of a person's ability to perform certain visual tasks (Lund & Dietrichson, 2000; Sacharowitz, 1998; Tuttle, 1984). The degree of visual disability depends specifically on the person's habitual visual tasks, as well as the degree of visual impairment (Sacharowitz, 1998). The most common visual tasks are reading, writing, orientation and mobility.

1.2.1.2 Visual Handicap

A visual handicap is the disadvantage a person experiences because of a visual disability (Lund & Dietrichson, 2000; Sacharowitz, 1998). The visual handicaps that may arise depend not only on the degree of disability, but also on the

individual's own expectations, society's expectations and environmental demands (Lund & Dietrichson, 2000; Sacharowitz, 1998). If the impairments and disabilities are severe, the visual handicaps may manifest as loss of independence, loss of self-esteem, loss of friends, inability to obtain or keep employment among others (Nosek, Fuhrer & Howland, 1992; Sacharowitz, 1998). The term handicap expands the context from the individual to the environment in which the individual resides (Lund & Dietrichson, 2000). The determination of a visual impairment as a handicap could either be self-imposed or imposed by others. A visually compromised lawyer may give up the position because of an erroneous belief that blind individuals are incapable of being successful lawyers. On the other hand, the blind person's desire to practice law may be thwarted because a law firm discriminates against blind individuals. Thus, a visual impairment can be a handicap in one of two ways, "unrealistic goals in view of the realistic impact of blindness, and unrealistic restrictions ascribed to blindness" (Tuttle, 1984, p. 14).

1.2.1.3 *Visual Impairment*

Impairment is conceptualised as the residual effects of defect, disease or injury and refers to the physical, mental or sensory loss resulting from a bodily disorder or pathology and includes defective limbs, organs or mechanisms of the body (Finkelstein, 1980; Lund & Dietrichson, 2000). A visual impairment describes anatomical and functional changes within the organ, indicated here by the eye, and is considered to be an uncorrectable limitation of visual functions (Lund & Dietrichson, 2000; Sacharowitz, 1998). The most common visual functions are, visual acuity, visual fields, colour discrimination, contrast sensitivity, and dark adaptation. A visual impairment is therefore an irrevocable permanent impairment or deprivation of the sensory function and in many cases cessation of being able to see (Conyers, 1992; Dodds, 1993a; Tuttle, 1984).

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 congenitally visually impaired are those individuals born with the pathological changes already present, whereas, the adventitiously visually impaired include those individuals whose pathological changes have been acquired later in life through disease or accident (Metcalf, 1994). There is therefore an essential difference in kind between having had sight and losing sight and never having had sight. 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 individuals but perhaps the fundamental unbridgeable difference is that as congenitally visually impaired individuals have never seen, they cannot visualise nor can they form visual concepts and images and share a sensory experience with others. The adventitiously visually impaired however, having had and lost sight are able to visualise and form their ideas about reality into visual patterns and images (Carroll, 1961; Dodds, 1993a).

Visual impairment also includes different degrees of visual ability depending on the severity of the anatomical and functional changes within the eye (Karlsson, 1998). Quantitative criteria such as, visual acuity together with a measurement of visual field are most often used to describe visual ability. These criteria are, however, poor explanations because visual ability is a "functional state rather than a mathematical concept" (Metcalf, 1994, p. 3). Behavioural or functional terms allow for a more understandable description of visual ability (Corn & Sacks, 1994; Fitzmaurice, Osborne & Kendig, 2000; Hallenbeck, 1967; Perry & Hampton-Roy, 1982). Generally therefore, totally blind individuals have a complete absence of any visual experience and are unable to perceive even bright sunshine (Bolt, 2003; Dodds, 1993a). Functionally blind individuals have light perception or light projection and have

the ability to pick up changes in light levels and "see vaguely objects that contrast highly with the surroundings" (Perry & Hampton-Roy, 1982, p. X). Legally blind individuals have a severe impairment but are able to count fingers at 0,3 to 3 metres (Metcalf, 1994; Perry & Hampton-Roy, 1982). Individuals with low vision have reduced levels of visual functioning which they use to accomplish daily tasks, at least to some extent, and are able to read normal print with the aid of adaptive devices and/or are able to travel around in daylight without the aid of special equipment (Corn & Sacks, 1994).

This research study will focus on adventitiously visually impaired adults because of the possible differences in psychological and emotional reactions and experienced needs related to loss of sight. Visual impairment will be used as an umbrella term encompassing all the diverse degrees of visual abilities. To avoid cumbersome repetition, the terms adventitiously visually impaired will be abbreviated to AVI, and visual impairment to VI.

1.3 ORIGIN OF THIS RESEARCH STUDY

It is important from the outset to describe how the researcher's personal experience of VI, namely, total blindness which occurred in her adult life, played a role in the instigation of the present study and how it led to the formulation of the research aims. After approximately 5 years of adventitious VI the researcher became acutely aware of the unreality of the time heals ideal that society in general and the rehabilitation context assumes and expects following the loss of sight. The expectations, for instance, time will heal the anguish, that acceptance and emotional and practical adjustment to the loss will occur and allow the AVI to return to their previous levels of functioning as before the loss, were contrary expectations to what the researcher was experiencing. Questioning the reality of these idealistic expectations prompted the researcher to undertake research and explore precisely these

issues. The study (Murray, 1998) compared the emotional reactions of AVI adults who have suffered VI within and beyond a six year time-frame, with the major conclusion being that different lengths of time of adventitious VI impact significantly on psychological and emotional reactions involved in the grief process following loss of sight which in turn, affects adjustment to living with a chronic VI.

The researcher was fascinated by the paucity of literature and research especially long-term research, on psychological and emotional reactions to loss of sight, and in particular, grief reactions. An unexplored issue emerging from the study was the needs experienced by the AVI following their loss of sight. Once again, the researcher was fascinated by the paucity of literature and research on the psychological and emotional needs, and especially long-term needs, of AVI adults. The bulk of the literature and research focuses on practical needs such as, mobility and technology among others. The researcher was however inspired by the insight she herself gained from the research study, and felt it necessary to continue exploring these unexplored areas of adventitious VI. New levels of insight must be reached about the reality and full extent of emotional and attitudinal reactions, and by implication, the grief process, as well as the psychological and emotional needs experienced by AVI adults. This necessity of knowing and understanding AVI adults' meanings of their experiences in these particular areas was the origin of the inquiry into the phenomenon of emergent needs post-grief experienced by AVI adults.

Society in general (including psychologists and rehabilitators) need to explore and deal with difficult and painful issues and thereby, help unfold the meaning of bewildering issues in human reality, like loss of sight. Researching the meanings AVI individuals have of the experience of loss of sight and the emergent needs experienced post-grief is an important undertaking because any new insight and knowledge that can inform and educate the AVI, society in general and professionals involved in the

field of adventitious VI about the real experiences of living with an adventitious VI and the related emergent needs can only but enhance the lives of all concerned.

1.4 RESEARCH FOCUS

This research study will focus on the unexplored issues regarding the grief experience of AVI adults as a linear or chronic process; the unexplored issues of the psychological and emotional needs of AVI adults; and the influence of the length of time of adventitious VI on the afore-mentioned segments of these individuals' lives.

The focus will be on the premise that if length of time of the adventitious VI impacts on the experience of grief as a linear or chronic process, then diverse emotions, attitudes and needs will also be experienced. Lack of knowledge and understanding about these differences by all people could in turn, impact negatively on AVI adults.

In order to compare, but more importantly, to augment the findings from the quantitative research (Murray, 1998) the researcher will use an adapted phenomenological research approach involving case studies so that following the in-depth inquiry an essential understanding of the phenomenon under investigation can be achieved. Researching these issues of loss of sight phenomenologically means trying to make sense of the meanings AVI adults have of their lives, and what emotional and attitudinal reactions and needs they experience within the context of this AVI existence. The complex field of VI is linked to stereotyping and misconceptions and the way people typically speak of loss of sight include generalised labels where all AVI individuals are labelled as blind, and where society (and sometimes the AVI themselves) assume that experiences and needs of AVI individuals must conform to those of the sighted (Berndtsson, 2000; Carroll, 1961; Connor & Muldoon, 1973; Dodds, 1991, 1993a; Dodds, Bailey, Pearson & Yates, 1991; Tuttle, 1984; van Huijgevoort, 2002). AVI

individuals, by allowing people to "look into and beyond our windows to the world" (Murray, 1995, p. 29) Can reveal their own needs, thoughts and feelings about the loss experience. In these revelations, the AVI, society (including rehabilitators and psychological researchers) can confront and deal with difficult and painful issues and begin to unfold the complex meaning of living with loss of sight.

1.4.1 Research Problem and Aims

The problem of the lack of knowledge about the psychological and emotional experiences of AVI adults, and in particular, their experiences of the grief process and their emergent needs will be addressed in this research study. The study therefore aims to achieve deeper understanding and insight into AVI adults' meanings of loss of sight, experiences of the grief process, the emergent needs experienced after the loss, and the influence that the length of time of the adventitious VI has on these experiences. Questions to be addressed to gain insightful knowledge about the phenomenon include:

Whether grief is experienced as a linear or chronic process. In order to understand the notion of grief the researcher will focus on questions related to experienced emotions and attitudes over the time course of the VI;

What emergent needs are experienced by the AVI; whether these needs have been, and are continuing to be satisfied; whether there are similar and/or different needs between those who experience grief as a linear or chronic process; whether the needs change over time; whether the same needs are experienced by the AVI with different degrees of visual abilities;

Whether length of time of the adventitious VI impacts on the experience of grief and emergent needs.

Another aim in this research study is to develop a more in-

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depth body of knowledge than currently exists in the research literature on adventitious VI, and in particular, long-term adventitious VI. Any new knowledge and insight into this complex world can only enrich the lives of AVI individuals and all those who form part of their social networks.

The present study is not meant to be all inclusive since one can never reveal or discover the reality and enigmas of loss of sight in its entirety. This research aims to explore the questions which reflect the paradoxes of living with loss of sight so that new levels of insight can be reached. With new insights, understanding and knowledge it is hoped that a new approach to researching adventitious VI that is both sensitive to personal experience and responsible towards broader currents of thought will emerge.

1.5 OUTLINE AND ORIENTATION of the present study

According to Elden (1988) the researcher, when undertaking a research study in psychology must be clear about at least the following 4 important issues:

1. The research problem and aims must be clear.

The overall theme of this thesis concerns the phenomenon of the emergent needs post-grief experienced by AVI adults. The problem of the lack of knowledge of the psychological and emotional experiences of AVI adults will be addressed. The aim is to achieve insightful understanding of AVI adults' meanings of loss of sight, experiences of the grief process, the emergent needs experienced and the influence that the length of time of the adventitious VI has on these experiences.

2. How the problem is to be studied or what method will yield the required information must be specified.

CHAPTER TWO, "SHEDDING LIGHT ON THE MATTER," deals with the

literature and research on emergent needs post-grief following loss of sight. This chapter presents a brief critique of the traditional models of the grief process as applied to adventitious loss of sight, an exposition of literature supporting the notion of chronic grief as being a more appropriate a model in understanding the grief process, and a review of the needs, with particular reference to Maslow's (1987) Need Hierarchy, which emerge as AVI individuals try to adapt to their changed and chronic conditions.

CHAPTER THREE, "ILLUMINATING THE DESCRIPTIVE UNDERSTANDING OF MEANINGS," deals with the research methodology relevant to this present study. The chapter focuses on the diverse approaches to conducting psychological research, the phenomenological approach to be used in this study, and the technicalities of this research such as, criteria for inclusion in the study and the depth interview as the method of data collection.

3. The meaning of the derived information must be explicated.

CHAPTER FOUR, "DESCRIPTIONS OF EXPERIENCED GRIEF AND EMERGENT NEEDS THROUGH THE EYES OF THE BEHOLDER," presents the case scenarios of 10 AVI adults, 7 females and 3 men, between the ages of 26 and 56, AVI within and beyond 6 years and their experience of emergent needs post-grief following their loss of sight. Since the loss of sight in children and adolescence is a study in its own right they are not included in this research study.

CHAPTER FIVE, "FINDINGS FROM THE TAPESTRY OF THE EXPERIENCES OF LOSS OF SIGHT," presents the findings from the data obtained from the different case scenarios of the experiences of the needs post-grief. The similarities and differences between the AVI respondents, as well as the similarities and differences between the two groups of AVI respondents (AVI within and beyond 6 years) with special reference to similar experienced needs as conceptualised by Maslow (1987) are considered.

CHAPTER SIX, "MORE THAN WHAT MEETS THE EYE ABOUT ADVENTITIOUS VI," discusses the findings from the research, specifying the similarities and incongruities between the literature and the scenarios, with explanations to interpret the distinct and different findings obtained.

4. How these findings can be used must be indicated.

CHAPTER SEVEN "THE REAL WORLD OF ADVENTITIOUS VI," discusses the conclusions from the research outcomes with a closing reflection on the value of the present study for the AVI themselves, rehabilitators and all individuals who form part of the social network of the AVI. With greater awareness it is hoped that people, including the AVI themselves, will see more clearly and understand more insightfully the experience of the grief process and the emergent experienced needs and thereby give the AVI the ability to cope optimally with their chronic VIS.

1.6 CONCLUSION

This chapter provided insight into the extreme variation in the different degrees of visual abilities which range from total blindness to low vision. The essential difference between adventitious VI with loss of sight, as compared to congenital vi with lack of sight was discussed.

The origin of the present research study, together with its focus, that is, a phenomenological approach, and aims, that is, an inquiry of the phenomenon of emergent needs post-grief experienced by AVI adults, was presented.

Following the outline and orientation of the present study, the next Chapter will review the theory and literature pertinent to the phenomenon of grief following a loss, including loss through death and loss of sight, and the emergent needs experienced by AVI adults, with particular reference to Maslow's (1987) Need Hierarchy.