

CHAPTER TWO

SHEDDING LIGHT ON THE MATTER: A LITERATURE REVIEW OF PARTICULAR NEEDS AFTER LOSING SIGHT

2.1 INTRODUCTION

Loss of sight, no matter the degree, irrevocably changes the course of formerly sighted individuals' lives. The loss affects their feelings of well-being and deprives them of many of their former abilities. Loss is defined as irrevocable when a life-changing event involves permanent change over which there is little, if any, control and the situation cannot be reversed, altered or undone (Wortman & Silver, 1987, 1989; Wortman, Silver & Kessler 1993). Losses considered irrevocable include, among others: the permanent loss of bodily and sensory functioning, loss of particular bodily parts, loss of a loved one, or a person's own terminal illness (Hewson, 1997; Wortman & Silver, 1989). Loss of sight is irrevocable and constitutes a permanent impairment and deprivation of the sensory function. People who have lived with good visual function and who then experience irrevocable loss of sight in their adult years will go through emotions and psychological reactions associated with grief (Atkinson, 1990; Schainholz, 2000).

This Chapter presents firstly, a brief critique of the traditional models of the grief process as applied to adventitious loss of sight, secondly, an exposition of literature supporting the notion of chronic grief as being a more appropriate a model in understanding the grief process after losing the ability to see, and thirdly, a review of the needs which emerge as AVI individuals try to adapt to their changed and chronic conditions.

2.2 CRITIQUE OF TRADITIONAL MODELS OF GRIEF

Grief is the process that occurs after a loss event and refers

to individuals' total response to the emotional suffering caused by a loss of any kind (Cleiren, 1993; Cook & Oltjenbruns, 1998; De Spelder & Strickland, 1992; McKay, 1993). For all individuals, including those who have lost sight, grief is a complex process encompassing both internal processes and observable physical reactions. These reactions involve psychological, somatic and social elements (Dershimer, 1990; De Spelder & Strickland, 1992; Hewson, 1997; McKay, 1990, 1993; Shuchter & Zisook, 1993; Stroebe & Stroebe, 1987).

Central to the concept of grief is that it is a highly complex and individualised process, that there are many and varied ways individuals grieve, that even one individual's grief varies from moment to moment and potentially culminates when the person regains balance and restores a sense of equilibrium and coping in all aspects of life (McKay, 1990, 1993; Parkes, 1993; Shuchter & Zisook, 1993; Stroebe, Stroebe & Hansson, 1993). Since grief is such a complicated phenomenon, many theoretical models have emerged to explain and understand the phenomenon better.

2.2.1 Overview of Traditional Models

The diverse traditional models of grief after loss (Bowlby, 1969, 1973, 1980; Kbler-Ross, 1969; Parkes, 1972, 1986; Raphael, 1983; Worden, 1982, 1985) which try to provide comprehensive, conceptual and explanatory frameworks for the various processes and reactions involved in the grief process have often been applied to grief following loss of sight. The rationale here is based on the premise that grief experienced by people who have suffered major or even minor losses, including adventitious loss of sight, is comparable to the loss sustained through death (Bailey & Gregg, 1986; Hewson, 1997; Hughes, 1980; Webb, 1992; Wortman & Silver, 1989). The stage models of emotional reactions of grief and the task and need models represent influential approaches on how people should grieve and cope with an irrevocable loss (Cleiren, 1993; Hewson, 1997; Shuchter & Zisook, 1993; Stroebe et al., 1993; Webb, 1992; Wortman & Silver, 1989;

Wortman et al., 1993).

2.2.1.1 *Stage Models of Grief*

Despite great individual variations in grief reactions a certain general pattern is assumed with reactions occurring in three sequential but overlapping stages (Dersheimer, 1990; Gerdes, 1988; Hewson, 1997; McKay, 1993; Shuchter & Zisook, 1993).

The first stage of unreality is characterised by varying degrees of shock, disbelief and denial (Bowlby, 1980; Cleiren, 1993; McKay, 1992; Raphael, 1983; Shuchter & Zisook, 1993). The second stage is an intermediate period of personality disorganisation characterised by social withdrawal and accompanied by acute and complex feeling states generally occurring in periodic waves of intense emotional and often somatic discomfort (McKay, 1992, 1993; Raphael, 1983; Shuchter & Zisook, 1993). Feelings can include sadness, depression, despair, helplessness, and anger at the loss (Bowlby, 1973, 1980; McKay, 1992, 1993; Parkes, 1972, 1986). The complexity of feeling states is evident with anger because the form it takes is diverse and can be felt as anger, resentment, frustration, envy, hurt or a sense of unfairness (Joines, 1995; McKay, 1993; Shuchter & Zisook, 1993). Grieving individuals do however, gradually become aware and begin to acknowledge the fact of the loss cognitively and emotionally (Bowlby, 1980; Parkes, 1986; Shuchter & Zisook, 1993). As the acute grief gradually declines, griever's can begin an emotional and social re-integration into the everyday world with feelings of well-being and the ability to cope and go on living (Raphael, 1983; Shuchter & Zisook, 1993; Weiss, 1988). Thus begins the third stage of the reorganisation of grieving individuals' personalities (McKay, 1992). This reorganisation refers to the gradual acceptance of the loss, the putting together of life and coping with the new reality that loss has indeed taken place (McKay, 1992). In this culminating period, griever's 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 optimally in their environments (Bowlby, 1980; Cook & Oltjenbruns, 1998; Dersheimer, 1990; McKay, 1993; Parkes, 1986, 1993; Shuchter & Zisook, 1993).

2.2.1.2 *Evaluation of Stage Models*

The notion of stages is a heuristic one and should not be taken too literally. Grief cannot be judged by a single rigid, objective standard regarded as universally normal as it rarely follows a predictable pattern (Hewson, 1997; McKay, 1993; Piper, McCallum & Azim, 1992; Wortman & Silver, 1989). There is therefore an element of risk in trying to describe grief reactions in well-defined and predictable stages as no two individuals react in exactly the same way and there will be differences and variations with respect to emotional reactions, their intensity and duration (McKay, 1993; Shuchter & Zisook, 1993; Wortman & Silver, 1989; Wortman et al., 1993).

Conceptualising the grief process as stages is however valuable when used for descriptive and explanatory purposes for indicating generalised patterns of growth which griever will experience in trying to cope and accomplish the various grieving tasks (McKay, 1992; Shuchter & Zisook, 1993). Nevertheless, the insightful knowledge gained about the grief process from the stage descriptions has sometimes been distorted and oversimplified (Hewson, 1997). Perhaps it is for this reason that serious doubts have been raised about the adequacy of the stage models for the conceptualisation of grief and in particular, the assumptions regarding the inevitability of stages, the length of time considered normal to continue grief reactions, and that resolution and conclusion of grief is ultimately achieved (Hewson, 1997; Wortman & Silver, 1989; Wortman et al., 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 it

may lead individuals to expect to proceed from one clearly identifiable reaction to another in an orderly fashion, or that one stage is more valued than another (Dersheimer, 1990; Hewson, 1997; McKay, 1993). Society in general, and professionals in particular, may make assessments of where individuals are, or ought to be, in the grieving process as when they assume that individuals are in a stage when they react with anger, or when they do not respond to a professional intervention (Osterweis, Solomon & Green, 1984). A too rigid belief in stages may cause non-recognition of the variability among, and within individuals as they try to cope with the loss (Hewson, 1997; Swap, 1984).

There is no evidence that grief reactions occur in the clear-cut, sequential stages as assumed (McKittrick, 1981/2; Wortman & Silver, 1989; Wortman et al., 1993). It is logical that certain reactions dominate at particular times such as, shock, which is likely to occur earlier rather than later, but it is rare for any response to be the exclusive experience at any one time in the grief process (Hewson, 1997). Kubler-Ross (1974) acknowledges that the stages of grief are not necessarily sequential, some may overlap and re-occur and each may vary in duration, whilst some may not be negotiated at all.

2.2.1.3 Task/Need Models of Grief

In these models, the grief process is conceptualised as a series of tasks and needs that have to be accomplished and satisfied in order to conclude the grief process and regain a sense of balance and equilibrium through resolution and acceptance of the reality of loss (McKay, 1993; Worden, 1982). Only three of many essential tasks and needs that have to be accomplished and met during the grief process will be highlighted because of their relevance to adventitious vi.

The first need is to come to terms with the reality that loss has occurred by acknowledging, recognising and accepting the finality of the loss (Cleiren, 1993; McKay, 1993; Worden, 1982).

The painful emotions that the loss elicits need to be identified, experienced, expressed and integrated (Cleiren, 1993; McKay, 1990, 1992, 1993; Worden, 1982). Only by participating in the full range of the conflicting and overwhelming diversity of feelings and their emotional expression, will griever realise the reality of the loss and be able to emotionally participate fully in life (McKay, 1990). There is a need for grievers to find adequate ways to regulate the pain and emotions in order to cope with the demands of daily life. This task is enhanced by an understanding social support system that gives grievers permission to express all aspects of their loss and be helped in practical and concrete ways to once again feel safe and secure in their environments (McKay, 1993).

A second essential need is to integrate the loss and redefine it in such a way that it can benefit grievers. This 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 (Bailey & Gregg, 1986; Dersheimer, 1990; Piper et al., 1992; Rubin, 1984; Worden, 1982).

The third need that grievers have is to readjust their relationships with people, assume new roles and adapt to the changed environment because individuals define their self-concepts and situations through relationships with others and their environments (McKay, 1993; Worden, 1982). Grievers need to conserve or adapt their social networks, maintain positive self-images and perceive themselves as being in control, re-evaluate fundamental life issues, maintain or rebuild psychological and physical health, and resume a place in the mainstream of life (Cleiren, 1993; McKay, 1993; Shuchter & Zisook, 1993; Worden, 1982).

2.2.1.4 *Evaluation of Task/Need Models*

A conceptual problem with many of the tasks in the task/need models of grief 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 grievors 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 individuals may have had severe health, personal and social functioning problems, which could improve spontaneously after the loss, whereas, some individuals may develop problems only after the loss (Cleiren, 1993).

Although labelling recognisable stages of grief and the tasks and needs that have to be accomplished may occasionally encourage grievors to recognise feelings, it may just as easily interfere with the grieving process by implying the appropriateness of progression through the stages or tasks with the expectation of a time-bound conclusion to grief (Davis, 1987). There is thus a subtle, but implicit assumption that the grief process can be navigated in most cases with the passage of time. Notwithstanding the above mentioned appraisals, the theoretical conceptualisations of the stage and task/need models have been influential in explaining and understanding the phenomenon of grief following loss through death as well as loss of sight.

2.2.2 Stage Models versus Task/Need Models

The stage and task/need models are viewed as complementary rather than duplicative and antagonistic (McKay, 1993). 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/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 grievors. Although there is consensus between the two models that acceptance and assimilation are integral components of the grief process, each model places emphasis on different aspects. For

instance, the stage models, especially that of K•bler-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/need models as one of many tasks that have to be accomplished and they view assimilation of the reality of the loss as the essence of the grief process. Nevertheless, in both grief models there is an inference of recovery or resolution and a final conclusion to grief.

In both the stage and task/need models there is a conceptualisation of the grief process that implies a particular course through which grief must progress in order to reach conclusion, namely, a linear, sequential and time-bound process characterised by a diminishment in the frequency and intensity of psychological and emotional reactions. Acceptance of and assimilation of the finality of loss, and attainment of psychological balance and equilibrium (homeostasis) is regarded as a process completed.

2.2.3 Assumptions Emanating from Traditional Grief Models

Emanating from both examples of the grief models presented in this Chapter are common assumptions and notions about peoples' emotional reactions and how they are expected to grieve and cope with their irrevocable loss (Hewson, 1997; Wortman & Silver, 1987, 1989). These assumptions about the grief process are not only prevalent in the grief-following loss theories, but they are also espoused by society, psychologists, health-care and rehabilitation professionals and are reflected in cultural beliefs about coping with loss, including loss through death and loss of sight (Hewson, 1997; Webb, 1992; Wortman & Silver, 1987, 1989; Wortman et al., 1993). These assumptions include among others: Grief ends and Grief is time-limited.

2.2.3.1 *Grief Ends*

An assumption of both the stage and task/need models is that

individuals who experience an irrevocable loss will ultimately achieve a final state of conclusion to the grief process. The grief process is conceptualised as a linear, sequential and time-bound process and after individuals have actively worked through and completed the three generalised stages, or the ideal-typical five stages as conceptualised by Kubler-Ross, (1969), or accomplished the tasks and needs, the final and certain conclusion of the grief process is assumed (Hewson, 1997; Wortman & Silver, 1987, 1989).

The terms of reference used to describe the conclusion of the grief process include: acceptance (Kubler-Ross, 1969), assimilation (Worden, 1982, 1985), recovery (Weiss, 1988), resolution (Rubin, 1984, 1985), or reorganisation (Bowlby, 1980; Parkes, 1986). Resolution for example, is assumed to be achieved by accepting the loss intellectually and emotionally (Wortman & Silver, 1987, 1989). Individuals who have experienced an irrevocable loss must intellectually be able to understand and accept what has happened and make sense and meaning of the loss (Parkes, 1986; Parkes & Weiss, 1983). Emotional acceptance is reached when the lost person can be recalled and reminders of the loss can be confronted without intense emotional pain (Parkes & Weiss 1983; Wortman & Silver, 1987). Parkes and Weiss (1983, p. 157) have argued that for a state of emotional acceptance to be reached, "there must be a repeated confrontation with every element of the loss until the intensity of the distress is diminished." Consequently, the diverse terms used to describe the conclusion of the grief process imply a complete healing and reinstatement of psychological balance, equilibrium and coping, and the ability to return to the previous level of functioning as it was before the loss (Sanders, 1989; Wortman & Silver 1989). Acceptance and the assimilation of the reality of the loss is not only the assumed essence of the grief process, but also the psychological reactions necessary for the culmination of grief (Kubler-Ross, 1969; Wortman & Silver, 1987, 1989). Attempts to deny the implications of the loss or block feelings or thoughts about it, and failure to accept the loss within a reasonable time

period will, according to virtually every major theory of the grieving process, lead to unresolved, chronic or pathological grief (Bowlby, 1980; Osterweis et al., 1984; Parkes, 1986; Parkes & Weiss, 1983; Raphael & Middleton, 1990; Wortman & Silver, 1989).

The assumption that psychological and emotional reactions will diminish in intensity and frequency during the time-bound grief process has been challenged by research. Zisook and Shuchter (1985) found that although dysphoric feelings and behaviours were most frequent during the first year of grief, they continued to be present four years after the death. In particular, anger, depression and anxiety tended to diminish over time but not to expected statistically significant degrees. The sense of loneliness, painful emptiness, and social withdrawal remained relatively persistent over time. In addition, many grievors never fully accepted the fact of their spouses' death, and the percentages of non-acceptance among grievors increased over a four year interval. Grieving individuals do not forget the past but rather discover which assumptions continue to be relevant in their new life situation and which have to be abandoned (Rubin, 1984). Hewson (1997) argues that what many grievors experience and achieve may be a state of recognition that loss has occurred, and an adaptation or adjustment to this recognition.

2.2.3.2 *AVI Research on Assumption that Grief Ends*

Applied to the stage models of grief following loss of sight is the assumption that AVI individuals will proceed through the sequential, linear emotional stages of denial and anger, and will then experience intense depression when they confront the reality of their loss (Atkinson, 1990; Fitzgerald, 1970; Horowitz & Reinhardt, 2000; Schainholz, 2000). Denial and denial-like responses such as, rationalisation and unrealistic hope of recovery, anger and depression are inevitable and expected reactions following loss of sight and these reactions are essential in the grieving process (Atkinson, 1990; Conyers, 1992;

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Fitzgerald, 1970; Greenough, Keegan & Ash, 1978; Hewson, 1997; Perry & Hampton-Roy, 1982; Schainholz, 2000). Psychological denial includes such characteristics as: 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 or sensory functioning (Conyers, 1992; Elliott, Witty, Herrick & Hoffman, 1991). After working through and successfully completing all the grief stages (denial, anger and depression) the final stage of acceptance of the reality of the loss of sight is experienced (Atkinson, 1990; Conyers, 1992; Schainholz, 2000). Acceptance is not only the assumed essence and conclusion of the grief process but is the necessary emotional milieu for adjustment to adventitious VI (Atkinson, 1990; Conyers, 1992; Dodds, 1993a; Dodds et al., 1991; Reinhardt & Benn, 2000; Schainholz, 2000). Adjustment to adventitious loss of sight embodies the flexibility and ability of assessing, coping with and gradually assimilating various changes in body (the VI due to accident or disease), and social (the recurring encounter with the social stigma of vi), and where both false hopes and destructive hopelessness are dismissed in order to give meaning and purpose to living that transcends the limitations imposed by the VI (Hughes, 1980; Lambert, West & Carlin, 1981; Livneh, 1986; Livneh & Antonak, 1991; Reber, 1985; Tuttle, 1984; Wineman, 1990). Consequently, there is the assumption that when AVI individuals have actively worked through and completed the ideal-typical stages or accomplished the tasks and needs (such as, integrating, assimilating and accepting the reality of the loss) the final conclusion of the grief process is achieved, followed by adjustment and a complete healing and re-instatement of psychological balance and equilibrium, and the ability to return to the previous level of functioning as it was before the loss (Atkinson, 1990; Conyers, 1992; Fitzgerald, 1970; Perry & Hampton-Roy, 1982; Schainholz, 2000). Atkinson (1990) states that the grief process must be concluded before AVI individuals are able to resume a normal existence, for it is only following the grief process that the AVI will be able to deal with blindness

issues and not allow the issues to disrupt their lives. Attempts to deny the implications of the loss of sight and failure to accept the loss will ultimately lead to unresolved or pathological grief (Atkinson, 1990; Conyers, 1992; Webb, 1992). 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).

The terms of reference used by the stage and task/need models to denote the conclusion of grief following loss of sight such as recovery and resolution, assume that the level of functioning of the grieving AVI before the loss is the criterion to be attained at the end of the grief process. This is a difficult assumption because in the context of loss of sight, this ideal cannot be realised because it assumes the ability to see again (Murray, 1998). In addition, the most commonly used term for the completion of grieving for both loss through death and loss of sight is acceptance. The term however appears to be a misnomer for the process that K•bler-Ross (1969) describes. Acceptance should not be mistaken for a happy stage of healing or recovery and the statement of the "...Struggle is over" (K•bler-Ross, 1969, p. 100) is merely describing the acceptance of the physiological inevitability of imminent death (Hewson, 1997). Similarly, the term acceptance following loss of sight should not imply a stage of healing or recovery and neither should it imply that AVI individuals should be happy or satisfied about being visually impaired. Rather, acceptance should be seen as a state where AVI individuals are aware and understand the full extent and implications of the reality of their loss of sight, are able to acknowledge and appreciate the limitations imposed by the loss, but are nevertheless still capable of making the best use of their remaining strengths and abilities (Dodds, 1993a; Tuttle, 1984). It can therefore be argued that what many of the AVI achieve in the grief process is a state of recognition that sight has been lost, an acceptance of this fact, and an adjustment to this recognition (Hewson, 1997).

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 AVI (Conyers, 1992; Dodds et al., 1991; Schainholz, 2000). Conyers (1992), in her study of AVI respondents (blind and those with low vision for 6 months to 2 years), surprisingly found that the highest level of deterioration in the ability to accept loss of sight was found in the AVI who felt they still long to see again after two years of adventitious VI. The surprise that the AVI 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 the acceptance of the loss (Davis, 1987). Murray (1998) investigated whether AVI adults who have suffered loss of sight within and beyond a six year time-frame accepted their loss of sight and whether they still long to see. The results showed that the respondents who have been AVI for less than 6 years have a greater acceptance of their loss of sight as compared to the respondents who have been AVI for longer than 6 years, but that both groups still long to see. Murray (1998) argues that the feeling of "longing to see again" may not be a measure of acceptance of adventitious VI but rather a natural feeling which will occur regardless of length of time of adventitious VI. Hull (1990, p. 42) debunks the expectation that AVI individuals must accept their loss of sight when he states, "...Of course I want my sight back. I will never accept the loss of my sight...I will never accept the human losses involved in blindness."

The conceptual framework provided by the stage models of grief which assumes 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 criticised on a number of theoretical and empirical grounds as it does not accord with the actual experience of disability generally and adventitious VI specifically (Dodds, 1991, 1993a, 1993b; Dodds et al., 1991; Finkelstein, 1980; Oliver, 1990). Dodds and his associates (Dodds, 1991, 1993a, 1993b; Dodds et al., 1991) argue that rehabilitators who subscribe to some version of the grief and

loss models, view emotions such as depression or anger as stages through which the AVI must go before they become ready for rehabilitation. They 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 AVI appear to go.

Further research has indeed shown that there is no evidence that grief reactions following loss of sight occur in the clear-cut, sequential stages as assumed. For example, in research by Livneh and Antonak (1991) eight stages of psychosocial reactions to physical impairment, and by implication, adventitious VI, 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, impaired individuals may indeed skip a particular adjustment 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). Research by Horowitz and Reinhardt (2000) which investigated the prevalence and persistence of significant depressive symptomatology among AVI individuals at an initial interview and at a two year follow-up, found that 62% of the AVI respondents were free of significant symptoms at both the baseline and follow-up interviews. They argue that although depression is a pervasive problem that cannot be ignored (for in fact 28% of the AVI respondents were consistently depressed at both interviews), it should not be seen as an inevitable, normal or expected stage to be worked through during the grief process. This finding is in contrast to the traditional grief approaches to vision loss in which the stage of depression was viewed as both an expected and an essential part of the grief process, and a stage which could not be missed (Horowitz & Reinhardt, 2000). In her study, Perry (Perry & Hampton-Roy, 1982) found that some AVI individuals continued to deny their loss of sight and attempted to live as

seeing individuals, often believing that sight may ultimately return, and a few of the AVI attempted to bypass the whole grief process entirely and immediately after losing sight attempted to be the best adjusted AVI individuals possible.

In light of these criticisms of the grief and loss models, dodds and his associates advocate a move away from the loss model and grieving for lost sight, and propose an alternative adjustment model which focuses on AVI individuals' self-perceptions and psychological variables 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. According to dodds and his associates, adjustment to acquired VI 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 the loss. This adjustment model focuses on how AVI 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 such as anxiety and depression which are produced by the AVI entertaining negative thoughts about themselves and their situation. Acceptance of the loss of sight is assumed to be at "the root of the adjustment process" (Dodds et al., 1991, P. 308). Dodds and his associates see it as their task as rehabilitators 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. Although dodds and his associates propose that a practical skills-orientated approach to rehabilitation should be taken, rather than a grief and loss approach, they too focus on emotions, feelings and attitudes of the AVI. Dodds and his associates focus on rehabilitating newly AVI individuals immediately after loss of sight and it would be

interesting therefore to investigate whether the positive psychological and emotional attributes deemed necessary for successful adjustment persist with time, for there is a subtle but implicit assumption of a time-limited, final and complete conclusion to the adjustment process as envisaged by Dodds and his associates.

Pursuing the evaluation of the grief stages, Davis (1987) argues that stage theories of grief often distort and oversimplify the grief experience of those who live with disabilities, including adventitious VI. An important element in working through a loss in the context of loss through death, is dealing with the attachment to the lost object. Bowlby (1979) acknowledges that although the stages of grief change over a period of time in most grievers, 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. Weisman (in Davis, 1987) states that the grief process is completed when the factual loss becomes a significant memory. Davis argues however, that regardless of how memorable the moment of diagnosis, the disabled child remains physically and psychologically present. 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 experiences of mothers of disabled children in Davis' (1987) research are comparable to the experiences of AVI individuals themselves. This is because the AVI who are grieving for their loss of sight do not themselves die, 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 AVI individuals' lives. The loss of sight remains an integral part of AVI individuals' daily lives and while the griever following loss through death must learn to close the "gap left by the dead, the person with a disability must learn to live with

the gap left by the disability" (Webb, 1992, p. 204).

2.2.3.3 *Grief is Time-limited*

Society in general has in the past viewed and continues, 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). There are assumptions of a specified time duration for the completion of the grief process and that psychological and emotional reactions will diminish in frequency and intensity during this time course (Shuchter & Zisook, 1993).

The most acute and intense experience of grief immediately following a loss is expected to last for approximately four to six weeks and resolution should occur in a matter of weeks after the initiation of grief work (De Spelder & Strickland, 1992; Rubin, 1984; Wortman & Silver, 1989). Other authors (Hartz, 1986; Rosenblatt, 1988) suggest that for the majority of individuals, grieving should be virtually complete one year following a significant loss, whereas, Weiss (1988) argues that it could take at least four years for recovery to occur.

Most of the affective and somatic symptoms have traditionally been considered to reach their peak within weeks or months after the loss and then gradually diminish in frequency and intensity with time (Hewson, 1997; Zisook & Shuchter, 1985). Parkes (1986) argues that in the normal course of events, the intensity, frequency and duration of the pangs of grief tend to diminish as time passes. The assumption that grief is time-limited has been challenged by research which has shown that full resolution does not occur for a large number of individuals, and that grief is more prolonged than generally expected (Lehman, Wortman & Williams, 1987; Parkes & Weiss, 1983; Shuchter & Zisook, 1993).

2.2.3.4 *AVI Research on Assumption that Grief is Time-limited*

The belief that time heals held by society in general, and

professionals in particular, is an important concept in the grief models related to adventitious VI. The belief originates from the assumptions of the grief process following loss through death and dying, and the expectations of a time-limited grief process with diminished psychological and emotional reactions (Conyers, 1992; Schainholz, 2000). Literature and research has shown for example, that the most acute and intense experience of grief immediately following the loss of sight may last for several days or several weeks, depending on AVI individuals' emotional composition and their adaptability to life changes (Atkinson, 1990; Dodds, 1993a; Emerson, 1981; Schainholz, 2000). Fitzgerald (1970) states that the majority of the AVI adults in his research took months to reach the stage of recovery whereas, Lindemann (1981) suggests that one to two years post-trauma is the typical length of time required for adjustment to loss through disability, and by implication, loss of sight.

The affective and somatic symptoms following loss of sight have, as in the case of loss through death, been considered to reach their peak within weeks or months after the loss and then gradually diminish in frequency and intensity as time passes (Conyers, 1992; Emerson, 1981; Schainholz, 2000). Fitzgerald (1970) states that the AVI adults in his research took months to experience a decrease in the intensity of depression and other intra-psychic distress. Research has however challenged the assumed time-limited grief process accompanied by a decrease in the intensity and frequency of psychological and emotional reactions following loss of sight. Perry (Perry & Hampton-Roy, 1982) became aware of the various levels of acceptance and adjustment of the AVI 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. This conclusion indicates a shift away from the assumptions of the traditional grief process following loss through death with the expectation of total acceptance and adjustment occurring within a time-limit. There was another shift from this assumption when Tuttle (1984) conceptualised the grief

adjustment process as a series of continuous and dynamic adjusting stages through which the AVI are able to continuously recycle, implying no final conclusion to the grief process. Elliott and his associates (1991) found an indirect relationship between chronicity and psychosocial adjustment to spinal cord injury. They argue that empirical research has generally found no meaningful relationship between psychological adjustment of people with acquired physical disabilities (and by implication, adventitious vi) and the presumed healing properties of time. Years may elapse before individuals with disabilities appreciate the full extent and implications of their condition (Elliott et al., 1991; Ray & West, 1983). In her research, Conyers (1992) found that overall practical adjustment appeared to be less of a problem for the majority of the AVI respondents than achieving psychological and emotional tolerance of their vis. Emotions, and in particular, anger (in whatever form) and sadness were key feelings which showed constant deterioration rather than improvement over the time interval of 6 months to 2 years of adventitious VI (Table 2.1).

Research by Murray (1998) pursued this line of investigation when she compared the emotional reactions of AVI adults who have suffered loss of sight within and beyond a six year time-frame. The major conclusion arising out of the research is that different lengths of time of adventitious VI are significantly related to the psychological and emotional reactions involved in the grief process. The study revealed that respondents AVI for longer than 6 years experience more frequent and intense frustrations related to their VI, have less acceptance of, and are less adjusted to the impairment, are more anxious and depressed, felt more angry and sad about their loss of sight than those respondents AVI for less than 6 years.

Conyers (1992, p. 23) States that the work of grieving the loss of sight 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 and then diminish later. Whilst it may superficially appear that working through and adjustment to adventitious VI 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).

Table 2.1 Incidence of emotional improvement or deterioration after loss of sight (baseline 104 individuals)
(adapted from Conyers, 1992, pp. 78-89)

Dimensions	Improvement	Deterioration
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
Try to cover up	0	26

2.2.4 Summation of Critical Issues Pertaining to Traditional Grief Models

Most proponents of stage and task/need models generally acknowledge and presume a time-limited, natural and linear progress through the stages concluding with the final stage of acceptance, adjustment, or assimilation. Thus, when AVI individuals have worked through and concluded their grief within a time-limit, have accepted their loss of sight, have resolved any psychological or emotional reactions to the loss, are realistic about the limitations imposed by the loss and are psychologically adjusted, then society, psychologists, health-care and rehabilitation professionals and many of the AVI themselves assume that they, the AVI, are coping adequately with their loss of sight.

The stage and task/need 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 individuals who have experienced loss, be it loss through death or loss of sight. The traditional assumptions that grief ends and that it is a time-limited process has been challenged by researchers (Conyers, 1992; Davis, 1987; Dodds et al., 1991; Hewson, 1997; Murray, 1998; Tuttle, 1984). The notion of the passage of time not permitting the conclusion of grief, and that there is no linear progress through stages, has led to another grief process, namely chronic grief, being used to describe the process for people who live with permanent disabilities, including adventitious VI, chronic illness or degenerative conditions that require coming to terms with a continuous long lasting change (Davis, 1987; Lindgren, Burke, Hainsworth, & Eakes, 1992; Livneh & Antonak, 1991).

2.3 CHRONIC GRIEF: DEEPER INSIGHT

People who live with chronic disabilities (including adventitious VI) experience grief which is often described as chronic sorrow (Davis, 1987; Lindgren et al., 1992). Olshansky (1962) used this concept to illustrate that ongoing and repeated episodic sadness can be part of the long-term reactions of parents caring for a mentally or physically disabled child. Chronic sorrow is a pervasive psychological reaction, a natural, normal and changing phenomenon, rather than a neurotic, static response to a tragic fact (Olshansky, 1962). Walker and Avant (1988) describe the essential criteria of chronic sorrow as: episodic pain and sadness that is variable in intensity at different times and situations for an individual and between individuals; is permanent and reoccurs throughout the lifetime of the individual; is interwoven with periods of neutrality, satisfaction and happiness. Lindgren and her associates (1992, p. 30) State 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.

2.3.1 The Notion of Chronic Grief

Confrontation of loss is a continual experience for AVI individuals because as the loss endures new situations with new problems or crises, and therefore new loss responses arise repeatedly in relation to the loss (Flagg-Williams, 1991; Hewson, 1997; Teel, 1991). There are regular reminders of what can no longer be done, and a new awareness of the impact of the loss (Elliott et al., 1991; Hewson, 1997; Lindgren et al., 1992; Teel, 1991). Grief may therefore be experienced many times, not in order to repeat past feelings but to rework them in a new context or deal with the loss from a new angle (Webb, 1992). The grief is not constant and unrelenting, but exacerbates at critical periods and at different times and situations during the lifetime of the AVI (Teel, 1991). For example, the grief with reactions of sadness which an AVI mother experiences when her son is born and she cannot see what he looks like. At these specific times, the AVI recognise more acutely the disparity between being able to see and not being able to see (Webb, 1992).

Lindgren and her associates (1992) describe two categories of grief, namely, resolvable and chronic grief. 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 an integral part of chronic disability, including adventitious VI. In chronic grief, the grief continually occurs from new losses and from old losses that are continually brought to mind (Bailey & Gregg, 1986; Davis, 1987; Lindgren et al., 1992). Thus, unlike the finality of death, the full impact of loss of sight cannot be faced and resolved at any given point in time, and there is no foreseeable end to grief or its closure (Hewson, 1997; Webb, 1992). Lindgren and her associates (1992) 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 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 an impairment, and to the impact such losses have on the person (Davis, 1987; Lindgren et al., 1992).

The identifiable attributes of chronic grief as conceptualised by Lindgren and her associates (1992) are relevant to the grief experienced with chronic adventitious VI, namely, a perception of grief over time with no predictable end (adventitious VI is a chronic eye condition that cannot be changed or reversed); grief is recurrent and circular and is triggered either internally (confrontation of loss is a continuous experience because as the loss endures new situations with new problems and new loss responses arise), or externally (the recurring encounter with the stereotypical attitudes of society towards VI, or the stigma attached to being different); grief can intensify years after the initial sense of loss, disappointment or fear (increasing intensity and frequency of the grief emotions related to the cumulation of the numerous losses confronted by AVI individuals). Consequently, if the underlying cause of continual loss is chronic adventitious VI, then grief will operate throughout the lifetime of the AVI.

Society in general, and families, health-care and rehabilitators in particular, tend to overestimate the initial crisis of loss of sight, but underestimate the impact of later grief episodes associated with chronic grief (Conyers, 1992; Davis, 1987). Grief reactions are also often ignored by health-care professionals as they focus on individuals' physical care and on getting them well enough to leave the hospital setting, and not on addressing their changed quality of life (Webb, 1992). In addition, the expectations and assumptions of society complicate the process of chronic recurring grief of the AVI in two apparently opposite ways: by requiring grieving and by requiring the suppression or denial of grief (Davis, 1987; Wortman & Silver, 1989). 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 frowns upon open displays of grief and prefers that grief be controlled especially when the grief is the result of loss other than that of death (Davis, 1987; Hughes, 1980; Wortman & Silver, 1987, 1989). It is not surprising therefore that the AVI are pressed to deny chronic grief and because of the societal expectations, the need to grieve may be "masked behind a determination to improve" (Webb, 1992, p. 206). The very act of trying to conceal aspects of the loss experience is likely to perpetuate the misconception that grief is time-limited (Wortman & Silver, 1989). Only when the AVI themselves, society in general and professionals in particular, acknowledge chronic grief as a natural and normal reaction to a continuous experience of loss, will appropriate and long-term support be available for grieving AVI individuals (Davis, 1987). The AVI may then reach an understanding and awareness about the reality of living with a chronic impairment and thereby cope better with this grievous phenomenon in their lives (Davis, 1987; Hewson, 1997; Lindgren et al., 1992).

2.3.2 Evaluation of Critical Insights Pertaining to Chronic Grief as a Model

The word chronic in chronic grief could imply that grieving is unresolved and thus pathological rather than a common response to the ongoing stress of a loss (Hewson, 1997). The term chronic is probably somewhat less accurate than are the terms, recurrent or episodic, but the term chronic does suggest continuance over time (Davis, 1987; Hewson, 1997). Adventitious VI is a chronic eye condition in that it is continuous over time (long-term), and not a temporary situation which can be changed. If the underlying cause of continual loss which has to be continually confronted is chronic adventitious then it is reasonable to assume that grief, with intermittent and recurrent episodes of both positive and negative emotions and reactions which vary in intensity at different times and situations for each AVI person, will also be

chronic and operate throughout the time course of the impairment.

Chronic grief offers an alternative insight into the grief which could potentially be experienced by AVI individuals rather than the one episode of time-limited resolvable grief as assumed by the traditional grief-following-loss models (Danrosch & Perry, 1989; Hainsworth, Eakes & Burke, 1994; Lindgren et al., 1992). Researchers (Tuttle, 1984; van Huijgevoort, 2002) initiated a shift away from the conceptualisation of a linear grief process with a static stage of acceptance and adjustment to loss of sight for they argue that adjustment to adventitious VI is not a static condition but rather a life-long, continuous, dynamic and fluid process. Tuttle (1984) states that personal and environmental demands change from situation to situation and from time to time. When certain situations or events produce anxiety or doubt about AVI individuals' acceptability or worthiness (self-esteem), they are likely to cycle back through some, or all of the adjusting stages. As confrontation with another loss is a continual experience for AVI individuals, the cycling back through the stages may occur at any age and whether adjustment is recently acquired or long standing (Tuttle, 1984). Research by Murray (1998) showed that adult respondents AVI for less than 6 years perceive the grief process to be resolved after completing the various stages of grief and anticipate the accompanying emotional reactions as diminished in intensity and frequency as they accept, and adjust to, loss of sight within a certain time-limit. By contrast, adult respondents AVI for longer than 6 years perceive their grief to be a chronic, recurrent and continuous process demanding constant emotional adaptation since there is no expectation of a final stage of acceptance. Understanding loss reactions that are continuous and of extreme significance to the grieving AVI requires a conceptual shift from the traditional linear grief-following-loss models to a less restrictive and circular model of reactions to ongoing loss which supports people in their recurrent experiences of grief rather than to hold acceptance and resolution as the ultimate goal for all victims of loss (Cook & Oltjenbruns, 1998; Teel, 1991).

2.3.3 Summation

The current literature shows an awareness that grief responses are much more complex, multidimensional, socially constructed and meaning-context based than the traditional grief-following-loss models seem to acknowledge (Averill & Nunley, 1993; Hewson, 1997; Shuchter & Zisook, 1993). The expected and assumed linear progress through stages and a time-limited grief process has been challenged by the concept of chronic grief. AVI individuals can potentially experience a recurrent, circular and continuous grief process which implies no time-limited finality of grief but rather, a series of continuous and dynamic adjusting stages through which the AVI are able to recycle when confronted by the numerous ongoing losses associated with adventitious VI (Tuttle, 1984; van Huijgevoort, 2002; Webb, 1992).

2.4 NEEDS EMANATING FROM LOSS OF SIGHT

Arising out of the notion of chronic grief is that AVI individuals experience constant challenges to which they are required to adapt. These challenges may be depicted as needs which emerge as they attempt to adjust to the fact that their sight is irrevocably affected. Particular needs that emanate from loss of sight are experienced by AVI individuals. These needs will now be addressed.

2.4.1 General Description of Needs

There are widespread descriptions pertaining to the general concept of needs. The term need could mean a condition of wanting something necessary, useful or beneficial, such as help in times of need. The term need could also mean a state of lacking or being deprived of something, such as, not enough money, or it could mean something which is required in order to do a job, solve a problem or achieve a particular result such as, a medical clinic answering the needs of sick people (Collin's Dictionary, 1987). In fact, Reber (1985, p. 465) Defines a need as "something

or some state of affairs, which if present would improve the well-being of an organism (or person)." A need in this sense may be something basic such as the need for food, or the need for sensory stimulation (physical), or it may involve social and personal factors, such as the need to achieve success in a job or the need for support and friendship from others. A need may also therefore reflect an internal state of an organism (or person) and thus, the word need can be as a synonym for such diverse terms as motive, incentive, wish or desire. Maslow's theory of need hierarchy captures well the many nuances of attempts to define the word need. His theory is especially important in the adventitious VI context and the adaptations AVI individuals have to make to their changed life situations.

2.4.2 Maslow's Need Hierarchy

Maslow (1987) maintains that human motivation, behaviour, emotions and well-being can be explained in terms of need gratification. Needs are arranged in a hierarchy of lesser or greater priority or potency, and the gratification of these needs is not only a means of relieving tension or frustration, but is also the basis for growth and the realisation of individuals' full potential through self-actualization (Maslow, 1987).

Maslow's hierarchial arrangement of basic deficiency needs include: physiological needs (such as, food and shelter) which are the most basic of all the needs; followed by safety needs (involving security and stability); love and belonging needs (especially affection and acceptance); esteem needs (including both esteem from others, and self-esteem embracing self-respect and independence); and at the top of the hierarchy, the growth needs for idiosyncratic self-actualization, such as needs for self-fulfilment (Maslow, 1987; Oishi, Diener, Lucas & Suh, 1999). If there is a need or lack of something or some state of affairs on any of the basic deficiency levels, then the need will continue unabated until satisfied (Gerdes, 1988; Jordaan & Jordaan, 1989; Maslow, 1987; Moore, 1989a). Deficiency needs

depend to a large degree on the physical and social environment for satisfaction, for example, employment to enable individuals to buy food and shelter, and acceptance by others in a community following re-location (Gerdes, 1988; Maslow, 1987). Individuals at the top of the need hierarchy are relatively independent of others and their environment, are more realistic about their situations, and the satisfaction of self-actualization needs depend on the realisation of their own values, aspirations, talents and abilities (Chiang & Maslow, 1977; Gerdes, 1988; Maslow, 1987; Moore, 1989a; Stevens-Long, 1988).

Maslow's (1987) notion of the hierarchy of needs has a subtle but implicit assumption that it is a one-way linear and invariant trend, an ascent from lower to higher levels (Rowan, 1998, 1999). There has however been a move away from this linear thinking to recognise that there is both ascent and descent in the need hierarchy (Wilber, 1995; Rowan, 1999). Ascent is about rising to whatever heights individuals are capable of and acquiring insight with the ability to be independent of the world (what Maslow (1987) calls self-actualization), whereas, descent is about coming down from the procured heights and using the insight as a new way of life and connection with the world (Rowan, 1999). This conceptualisation implies a circular ascent and descent activity of need gratification with both deficiency and growth needs existing side by side at every level of the need hierarchy (Rowan, 1999).

It must be remembered that when individuals lose sight in their adult life they have already reached a certain level of functioning in the need hierarchy as described by Maslow (1987). Wortman and her associates (1993) suggest that those individuals, including the AVI, who have reached a high level of self-esteem, feelings of mastery and the belief that the world is a safe and secure place, and have high intellectual and financial resources, may be particularly vulnerable to an uncontrollable life event such as, loss of sight. AVI individuals who have reached the levels of having their needs for love and belonging or self-

esteem satisfied, but are confronted by certain situations or events that once again produce anxiety or doubt about their acceptability, capabilities or worthiness may descend at these times to lower levels in the need hierarchy, such as, needing to feel safe and secure in their worlds again. AVI individuals who had been motivated by higher ideals and goals in their career may, after their loss of sight, return to a lower level in the need hierarchy such as, needing to feel accepted and respected as AVI individuals (the levels of need for love and belonging and the need for esteem from others). Once these needs have been satisfied they can ascend again to the level of needing to feel competent and adequate (the need for self-esteem) in careers that utilize their optimal qualifications and abilities, thereby fulfilling their potential. Rowan (1999) further states that individuals' behaviours are not necessarily motivated by needs on only one level on the need hierarchy. For example, when AVI individuals' needs to feel safe and secure and to belong to and be accepted by society and significant others around them remain unfulfilled, their self-esteem suffers reciprocally (Tuttle, 1984). All individuals, including the AVI, need to be aware that they can experience both satisfied and unsatisfied needs simultaneously, and can re-experience already satisfied needs in their everyday living (Rowan, 1999).

2.4.3 AVI and Emergent Idiosyncratic Needs

Although the AVI experience the same needs as all human beings that are essential to optimal coping and psychological, emotional and physical well-being such as, the need for food and shelter, for love and acceptance, for freedom and independence, for respect, responsibility and productivity, and to be recognized and acknowledged as unique and worthy individuals, they do however, need to acquire new and particular psychological, emotional and practical skills and methods in order to substitute their numerous losses (Berndtsson, 2000; Gerhardt, 1990; Miller, Houston & Goodmans, 1994; Murray, 1995; Shantall, 1993; Tuttle, 1984). To understand AVI individuals' idiosyncratic needs

emanating from their adventitious loss of sight, it is necessary to understand the numerous losses they experience which elicit these particular needs. Loss of sight consists of fundamental losses that occur in all the areas of AVI individuals' lives including among others: the physiological loss of sight with the different degrees of vision loss, such as total or partial loss; the loss of personal independence and in particular, the loss of independent mobility, and the loss of communication such as reading, writing and information collection; the loss of safety and security and in particular, the loss of financial security through loss of vocations; the loss of feeling accepted and respected by others; the loss of self-esteem; and the loss of being able to self-actualize (Atkinson, 1990; Tuttle, 1984). When contemplating the many losses experienced by the AVI and the emergent idiosyncratic needs which have to be satisfied in order for them to function and cope with the psychological and practical demands of life, it becomes clear how many of the emergent needs reflect those needs as described by Maslow (1987).

2.4.4 AVI Idiosyncratic Needs: Review of Research

Generally, the literature and research on adventitious VI concentrates on the period before and immediately after rehabilitation, and focuses mainly on practical issues and needs such as orientation and mobility (Dodds, 1993a). There is also a focus on technological and technical issues such as the development, evaluation and refining of devices, tests and programmes for the assistance or instruction useful to the visually impaired, including: braille devices and production, tactile images and diagrams, magnifying devices, computer technology; new low vision enhancement systems based on video computer technology; educational and perceptual aids and tests particularly in the field of reading, cognitive mapping and spatial perception (Dodds, 1993a; King, 1993; May, 1993; Rosenbloom & Goodrich, 2000; Rowland, 1985; Tuttle, 1984).

In spite of these research undertakings, other challenging

issues emerge. Among these are firstly, the psychological and emotional reactions and needs of AVI individuals following loss of sight, secondly, the social environment of these individuals and the common conception of VI. All these factors interact and impact on the understanding of the experience of adventitious VI (and particularly long-term adventitious vi), and have yet to be fully articulated within research literature on adventitious loss of sight (Cherry, Keller & Dudley, 1991; Corn & Sacks, 1994; Rosenbloom & Goodrich, 2000; Roy & Mackay, 2002).

Drawing on literature and research on needs, including Maslow's (1987) need hierarchy, consideration will be given in this section to the particular idiosyncratic psychological, emotional and practical needs experienced by the AVI following their loss of sight.

2.4.4.1 *Research Focus: Setting the Stage*

There have been relatively few need assessment endeavours directed towards visually impaired individuals, and in particular, AVI adults (Connor & Muldoon, 1973; Cherry et al., 1991). One such need assessment was undertaken by Rosenbloom and Goodrich (2000) when they conducted research to improve their understanding of research needs and to identify the current research emphasis in the field of adventitious and in particular, low vision. They reviewed the current low vision literature published between 1990 and 1996 in the publication, *Low Vision: - The Reference* (3rd ed.) (Goodrich & Jose, 1996) and compared the results to those obtained from interviews with 20 low vision diplomates attending the 1997 Academy of Optometry Conference. The comparison of the frequency of topics in the low vision literature with the research priorities of the sample of low vision diplomates is meaningful as the diplomates describe research priorities which are significantly different to the current themes of the low vision literature (Table 2.2). For example, the results showed that low vision devices and aids are the most frequent subjects dealt within the low vision literature

survey, and that citations regarding children and childhood development are the most frequent age group addressed.

Table 2.2 Rankings of research needs by data from the literature survey and low vision diplomates (adapted from Rosenbloom & Goodrich, 2000, pp. 20-21).

Ranking	Literature Survey	Diplomates Survey
1.	Low vision devices	Improved public & professional awareness of low vision/Development of outcome & efficacy measures
2.	Children and child development	
3.	Ocular health & pathology	Develop new low vision devices
4.	Vision evaluation & assessment	Study effect of low vision across lifespan
5.	New services & professional training	Establish low vision centres of excellence

The content areas of ocular health and pathologies, vision evaluation and assessment, services and professional training are each addressed in over 10% of the citations. The remaining content areas of ageing and the elderly, psychological and social issues, and employment issues are addressed in less than 10% of citations (Rosenbloom & Goodrich, 2000). On the other hand, the low vision diplomates survey data for their rankings of the highest priority needs in low vision research were the need for improved public and professional awareness of VI and in particular, low vision, the need for the development of outcome and efficacy measures, the need for the establishment of VI centres of excellence, and in particular low vision centres, and the need to be aware of and understand the effects of VI across the lifespan. Rosenbloom and Goodrich (2000) state that the apparent disparity between perceived research needs and the current research literature to be cause for concern as it seems to suggest a gap between needs and current practice where important areas of needs of the AVI are not being addressed.

When individuals lose sight, they lose one of the most basic of all the physiological needs in the hierarchy described by Maslow (1987) namely, sensory stimulation. The loss of sensory stimulation in the form of loss of sight in turn, inhibits or thwarts AVI individuals' previous level of activity and functioning as sighted persons. It can be argued therefore that as loss of sight impinges on every facet of the affected individuals' lives in an extreme way, it is most likely that the major motivation or need in these AVI, at least in the early period after loss of sight, will be the physiological need for sensory stimulation or the need to see again rather than any other. If AVI individuals are dominated by this need, all other needs may become nonexistent and behaviour may become determined by the one purpose of satisfying this need, such as AVI individuals' incessant search for a cure (Atkinson, 1990; Maslow, 1987). In addition, if loss of sight means loss of a job and loss of an income, then physiological needs such as the need for food or shelter can also emerge (Atkinson, 1990; Carroll, 1961).

Maslow (1987) states that when gratified, the physiological needs along with their partial goals cease to exist as active determinants or organisers of behaviour. The gratification of the need for sensory stimulation, or in other words, the ability to see again, cannot be realised by the AVI. In this extreme case of loss of sight, AVI individuals need to acquire appropriate adaptive behaviours and coping skills in order to function and cope with not being able to see (Berndtsson, 2000; Dodds, 1993a; Tuttle, 1984). A point to consider is whether the AVI do experience this basic physiological need of longing to see again, and if so, is the degree of visual ability significant?

2.4.4.2 *Loss of Personal Independence and Emergent Needs*

Loss of sight deprives AVI individuals of considerable amounts of their already acquired competencies such as their personal independence, another of the basic needs as described by Maslow (1987). The meaning of independence to the AVI, significant

others and society as a whole provides one of the most critical factors influencing how the AVI adjust to and cope with their loss of sight and in particular, the emotional experience of adventitious VI (Conyers, 1992; Dodds, 1991, 1993a, 1993b; Rowland, 1985; Roy & Mackay, 2002; Tuttle, 1984). The nature of VI ensures that the dependency needs of the AVI are more visible and obvious than the dependency needs of the sighted. These visible dependency needs signal the AVI out from the predominantly sighted society which means a loss of anonymity and privacy which in turn, often exposes AVI individuals to embarrassment and public pity especially because the label blind carries with it a set of negative assumptions and expectations (Carroll, 1961; Dodds, 1991, 1993b; Roy & Mackay, 2002; Tuttle, 1984).

Although the International Classification of Impairment, Disability and Handicap (1999) emphasises how people function with regard to the different dimensions, in this case, dimensions of VI, with interventions aimed to increase independence and optimum participation in life situations, it does not offer any insights into how the impairment affects people's wellbeing and what it means to the individuals involved. What is important is to find out what role VI plays in AVI individuals' lives, how they construct some kind of meaning out of their impairments and which tasks, needs and challenges have to be faced (van Huijgevoort, 2002). AVI individuals' perception of their lack of efficacy following their loss of sight, and their need to be dependent on others to meet some of their needs which they were able to satisfy themselves when they could still see is demoralising, and the response to this perception is likely to be a loss of self-esteem and competence combined with negative affects such as, frustration and depression among others (Dodds, 1991; Roy & Mackay, 2002; Weaver-Moore, 2000). The overriding need for the AVI is to regain what personal independence they can within the limits of their VI (Dodds, 1991, 1993a). In order to satisfy this need however, AVI individuals need to acknowledge the degree of their visual ability, and become aware of the

reality of the implications and limitations of living with a VI (Berndtsson, 2000; Elliott et al., 1991; Epstein, 1993; Murray, 1998).

Loss of independent mobility: The loss of personal independence is experienced when the AVI lose the ability to travel through and interact independently with their physical and social environments (Cherry et al., 1991; Connor & Muldoon, 1973; Golledge, 1993; Tuttle, 1984). The need to regain the independent mobility can be partially satisfied through instruction in orientation, which is the ability to create and maintain a mental map of the environment, and mobility, which is the ability to travel independently, safely and efficiently through that environment by means of a white long-cane or guide dog (Banwell, 1991; Connor & Muldoon, 1973; Dodds, 1993a; Miller, 2002; Tuttle, 1984). Most people, and in particular rehabilitators, regard mobility as the cornerstone of personal independence and it is assumed that when AVI individuals have mastered the white long-cane then they are once again independent (Dodds, 1993b). This need for training in mobility and orientation is assumed to help develop a sense of personal independence, personal and social adequacy, self-control and control over the environment, self-esteem and self-confidence (Cherry et al., 1991; Connor & Muldoon, 1973; Dodds, 1993a, 1993b; Rosenblum & Corn, 2002b; Tuttle, 1984). Rehabilitators nevertheless need to become aware that the acquisition of independent mobility skills depends on AVI individuals' aptitudes, abilities, level of interest and personal aspirations, or in other words, the complex interaction of psychological factors which have an impact on the likelihood of the AVI benefiting from these skills (Dodds, 1993b). There are some AVI individuals who refuse to use a white long-cane because they deny or reject the symbolism of blindness that the aid represents (Berndtsson, 2000; Tuttle, 1984).

Neither the dog nor cane, as good as they are, provide the freedom of mobility to which society, including the AVI, have become accustomed, for example, the independence experienced by

being able to drive a motor car (Corn & Sacks, 1994; Rosenblum & Corn, 2002a). Being a non-driver in society today has a long-term impact on AVI individuals' personal, social and economic well-being, and for some, the impact may be a mere inconvenience, whereas for others, it can become a lifelong challenge (Corn & Sacks, 1994; Rosenblum & Corn, 2002a).

Research by Eisenhandler (1990) has shown that driving a motor car forms part of social acceptance of the elderly and there is the belief that giving up the ability to drive marks the beginning of what might be called a dependency career. The ability to drive gives individuals a sense of control over their lives and environments, a sense of self-worth, autonomy, independence, spontaneity, and the ability to be active and avoid social isolation (Eisenhandler, 1990; Rosenblum & Corn, 2002a, 2002b). It can be expected therefore, that in the case of previously sighted individuals who, with the onset of VI have to give up driving a motor car, that they too experience loss of control over their lives and environments, self-worth, independence, spontaneity, and experience decreased levels of activity and a sense of social isolation, despair and hopelessness (Corn & Sacks, 1994; Horowitz, 2001; Rosenblum & Corn, 2002a, 2002b).

Research (Corn & Sacks, 1994; Rosenblum & Corn, 2002a, 2002b) on the impact of non-driving on AVI adults found significant levels of frustration experienced by the participants. Frustration is the emotional state which occurs when AVI individuals' needs or behaviours are disrupted or thwarted, either by obstacles that block progress towards a desired goal, or by the absence of an appropriate goal (Carson, Butcher & Coleman, 1988; Reber, 1985). The obstacle that thwarts the needs of the AVI could be the impairment itself (internal obstacle), that prevents the AVI from fulfilling a need such as driving a motor car. The findings of the research (Corn & Sacks, 1994; Rosenblum & Corn, 2002a, 2002b) found that frustration related to non-driving was associated with various issues including, the

AVI participants need to rely on others for transportation and their loss of spontaneity or not being able to go where and when they wanted to with responses such as "I can't hop into my car." Another key frustration was related to the loss and control of time with statements such as, "I always have to be ready on time, but some drivers are late." The AVI respondents felt frustrated at no longer being able to help others such as, not being able to take care of family members in an emergency (Rosenblum & Corn, 2002b).

Research by Cherry and her associates (1991) found that very few of the AVI respondents in their need assessment study were as independent as they would like to be, and that transportation problems were most often cited as the primary obstacle to independence. Research by Marston and Golledge (2003) on why VI individuals report limited use of public transportation has found that the most important thing that is lacking for this group is access to information. This lack of information, especially in unfamiliar places, includes positive identification at locations, directional cues to distant locations, and lack of cues in open spaces which result in the individuals getting lost or disoriented, which in turn, leads to emotional anxiety. The need to preplan (and by implication, loss of spontaneity) and to arrange for motorised travel especially when public transport is inadequate has the effect of limiting the quality of a wide range of experiences for the AVI including among others, spontaneous shopping and visits to friends (Cherry et al., 1991; Rosenblum & Corn, 2002b). Rehabilitators who provide services to the AVI attempt to promote and maximize high levels of independence by means of the white long-cane, yet when they promote independence without dealing with the psychological and emotional impact of being non-driving AVI adults, some of the AVI may be subject to greater psychological and emotional obstacles and have less control over their lives (Corn & Sacks, 1994; Horowitz, 2001; Rosenblum & Corn, 2002a, 2002b).

The practical loss of independent mobility is intertwined with

psychological and emotional reactions such as feelings of frustration, isolation, a sense of loss of self-control and control over the environment, a sense of loss of personal and social adequacy and competency and a loss of self-esteem (Dodds, 1991, 1993b; Roy & Mackay, 2002; Tuttle, 1984). Research by Karlsson (1998) found that feelings of isolation were related to degree of visual ability, with the blind group experiencing significantly more isolation than the low vision group, given the fact that many low vision individuals can move independently through their environments. The need to regain independent mobility albeit pedestrian travel, can be partially restored by the AVI training with a white long-cane or guide dog which in turn, enables them to regain some personal independence and self-esteem (Dodds, 1991, 1993b; Tuttle, 1984). A point to consider is whether the need for independent mobility ever totally satisfied especially in the long-term, given that the built environment is constantly changing, there is increased traffic density, impatient motorists and vehicles that can accelerate at alarming rates (Dodds, 1993b).

Loss of communication: Other practical losses associated with the loss of personal independence are experienced with the loss of communication which includes the loss of the ability to read and write and the loss of acquiring information through reading or from observing others (Carroll, 1961; Connor & Muldoon, 1973; Tuttle, 1984). Hull (1990, p. 65) says "...any blind person is to some extent, starved of information. I run short of facts, my brain demands something new to know. I can be plunged quite suddenly into such feelings of deprivation through some little incidence or other."

Loss of being able to read is not just the loss of the power to read books or newspapers but also the humiliation, frustration and loss of privacy when private letters or accounts have to be read for the AVI (Carroll, 1961; Lambert et al., 1981). When intermediary persons such as volunteers need to read letters, or text books for the AVI, the time lag involved often results

in them experiencing intense frustration in having to wait for the material. This situation further poses a problem for AVI individuals wanting to remain current in a specialised field.

The need to be able to communicate, that is, to read and write and acquire information can potentially be satisfied using alternative skills, adaptive equipment or assistive technology, such as, braille, talking books or computers with synthetic speech (Berndtsson, 2000; Croser, Garrett, Seeger & Davies, 2001; Hopkins, 1998). AVI individuals who have to learn braille in their adult years however, often find it "a slow and irritating substitute for visual reading" (Tuttle, 1984, p. 30). Some of the AVI may confine their use of braille to identify important articles or to keep telephone numbers which may in turn, assist them in regaining some personal independence, a sense of control over their lives and the environment, and to minimise some of the experienced frustrations directly attributed to loss of sight (Connor & Muldoon, 1973; Croser et al., 2001; Hopkins, 1998). The importance of being able to read and write braille is emphasized by rehabilitators because it is assumed that it will maximize AVI individuals' independence (Connor & Muldoon, 1973). It can however be debated whether braille is a satisfactory way for the AVI to communicate with the sighted, as the majority of these individuals cannot read braille. Rehabilitators need to once again become aware that the acquisition of communication skills, especially braille, depends on AVI individuals' abilities, level of interest and personal aspirations, or, the complex interaction of psychological factors which have an impact on the likelihood of the AVI benefiting from this skill (Dodds, 1993b).

Advances in technology such as, computers with synthetic voice or optical magnifiers, have provided the AVI with access to information which in turn, enhances their knowledge, has given them new opportunities to be independent at work or at home with personal access to information, enhanced their social networks, and have allowed them to compete successfully with sighted individuals and to have equal access to printed information

(Abner & Lahm, 2002; Gerber, 2003; Kapperman, Sticken & Hinds, 2002). This communication technology is however, very expensive and often out of financial reach for many AVI individuals especially if they are unemployed (Croser et al., 2001; Duru, 2000; Gerber, 2003; Hopkins, 1998). Low vision individuals are often able to use regular print and standard writing tools without modification such as felt pens, or by simply holding the material closer or by using magnifiers which enables these individuals direct access to print and computers. There is thus, no need for some low vision individuals to have to purchase expensive adaptive equipment as in the case with the totally or functionally blind.

Loss of sight also means the loss of the ability to observe other people (Tuttle, 1984). The essential role of gestures and facial expressions in clarifying or modifying the meaning of speech is lost to the AVI, more so for the totally and functionally blind, as those with low vision can often still see these gestures (Metcalfe, 1994; Tuttle, 1984). Not being able to observe and communicate with other people often results in the AVI feeling embarrassed, humiliated, frustrated and being out of control of the environment, such as when AVI individuals carry on a conversation with someone who is no longer there, a situation obviously more relevant to the totally and functionally blind as compared to individuals with low vision (Carroll, 1961; Dodds, 1991; Roy & Mackay, 2002; Tuttle, 1984). To eliminate some of the emotional reactions associated with not being able to observe other people, a need which will never be realistically satisfied, the sighted need to become aware of how to interact with the AVI and the implications of what adventitious VI entails and the consequences of not being aware of them (Murray, 1998). As Hull (1990, p. 72) says, "...for the sighted, people have an abiding presence, they are there all the time, every day. For the blind, people are not there unless they speak. Many times I have continued a conversation with a sighted friend only to discover he is not there. He may have walked away without telling me, he may have nodded or smiled thinking the conversation was over.

From my point of view, he had suddenly vanished."

AVI individuals need to acquire new methods or strategies such as braille or computers in an attempt to substitute their numerous losses in the areas of reading, writing and information gathering. If these needs are satisfied AVI individuals will be able to regain some sense of personal independence, and feel more in control of their lives and the environment, as well as feeling more socially adequate and competent (Lambert et al., 1981; Roy & Mackay, 2002; Tuttle, 1984). A barrier in meeting the communication needs, especially for the totally and functionally blind, is the great expense involved in purchasing the adaptive equipment or assistive technology, a situation which makes the satisfaction of this need very difficult for a large number of the AVI (Duru, 2000; Hopkins, 1998). Professionals, and in particular, rehabilitators who provide services to the AVI to maximize their levels of independence by instruction in braille or computers, need to be aware of the psychological and emotional obstacles these AVI are confronted with such as feelings of frustration, incompetence, and worthlessness, when they are taught these skills during rehabilitation and then have to carry on with their lives empty handed because of financial constraints (Duru, 2000; Lambert et al., 1981). Being unable to read or observe people and things directly, severely hampers the AVI in their means of obtaining information and their knowledge suffers cumulatively (Carroll, 1961; Tuttle, 1984).

2.4.4.3 *Loss of Safety and Security and Emergent Needs*

The need for safety and security in the world is seen in the preference for familiar rather than unfamiliar things or for the known rather than the unknown (Maslow, 1987). With loss of sight, safety and security needs are indeed thwarted because the familiar and known worlds of the AVI become unfamiliar, the security about the future and the confidence in AVI individuals' internal and life worlds is lost and there is a tendency to doubt and lose confidence and security in the information of the other

senses (Carroll, 1961; Conyers, 1992; Dodds, 1991, 1993b; Miller et al., 1994; Tuttle, 1984).

All individuals, including the AVI, tend to respond to danger of any kind with realistic regression to the safety need level and will defend themselves against any threat (Maslow, 1987). As earlier discussed, loss of sight means the loss of the ability to travel independently through the physical and social environment and to anticipate and therefore, to exercise some control over potential hazardous situations (Cherry et al., 1991; Tuttle, 1984). This need to avoid external dangers or anything that may threaten or harm the AVI is often a difficult need to satisfy because of AVI individuals' inability to see, especially in the case of the totally or functionally blind (Cherry et al., 1991; Tuttle, 1984). In fact, Dodds (1993b, p. 34) States that the "environment is becoming continually less user-friendly" for the AVI. The relentless increase in crime such as muggings, render AVI individuals vulnerable and present a deterrent to their wish to travel independently through this unsafe environment (Dodds, 1993b).

Loss of financial security and independence: Oishi and his associates (1999) argue that safety needs are an indication of financial and job satisfaction. Losing sight effectively means losing control over the environment and many of the AVI lose their jobs, career or long-term vocational goals. for instance, a person in the middle of training to become a medical doctor (Dodds, 1991, 1993b; Roy & Mackay, 2002). This loss in turn, means that the economic underpinnings of AVI individuals' lives are removed, producing uncertainty and fears for the future (Dodds, 1991; O'Day, 1999; Roy & Mackay, 2002). Loss of sight increases everyday expenses, for instance, medical expenses to try to preserve sight, and expenses associated with purchasing aids, for example, white long-canes for travel, to supplement the diverse areas of loss, which in turn, results in even more financial dependency to meet these needs (O'Day, 1999).

Research (Houtenville, 2003; La Grow, 2003; Leonard, 2002; Leonard & D'Allura, 2000; O'Day, 1999; Wolffe & Spungin, 2002) has shown that the rates of employment among individuals of working age who are visually impaired are significantly lower than those among individuals in the general population as well as among individuals with other disabilities, particularly hearing impairments. Reasons for the high rate of unemployment and underemployment (AVI individuals employed in positions utilising less than their optimal qualifications and abilities) among visually impaired individuals include various employment related barriers such as: lack of sufficient funds or resources which restrict access to training opportunities, adaptive equipment for seeking and performing jobs such as, computers with voice output, screen readers and magnification equipment; employers' negative attitudes and their lack of awareness of the abilities of individuals with VIS which in turn, restricts employment opportunities; a lack of systematic occupational research to devise improved means of performing more jobs without sight; and transportation and mobility issues (Butler, Crudden, Sansing & Le Jeune, 2002; Crudden, 2002; Kapperman et al., 2002; La Grow, 2003; Leonard, 2002; Malakpa, 1994; O'Day, 1999; Tuttle, 1984; Wolffe & Candela, 2002; Wolffe & Spungin, 2002). In addition, society and in particular some rehabilitators, tend to counsel AVI individuals into a narrow range of stereotypical vocational roles, such as switchboard operators, or they (the AVI) are given mixed messages such as being told that they can do any job they choose, but received no practical or concrete guidance on reaching their employment goals, nor are they challenged to think realistically about the skills they would need for employment (O'Day, 1999). To provide high quality services and instruction it is vital that certified instructors of AVI individuals be well versed in the training, selection and application of current access technologies, and be able to train the AVI to master the various technologies so that they can enter the work place skilled in their use (Abner & Lahm, 2002; Butler et al., 2002; Wolf & Spungin, 2002). With improved quality of assistive training for the AVI the "looming threat of abandoning

many of the nations' visually impaired citizens on the wrong side of the digital divide would be abated" (Kapperman et al., 2002, P. 108).

Research (Crudden, 2002; Houtenville, 2003; La Grow, 2003; Leonard & D'Allura 2000) found that when the numbers of visually impaired individuals in paid employment were broken down according to degrees of visual ability, individuals with the least amount of vision are less likely to be in paid employment than those with a little or lot of usable vision. Leonard and D'Allura (2000) also found that a high percentage of the employed visually impaired in their study were congenitally VI as compared to the high percentage of unemployed who were AVI. The degree of vision loss becomes critical when contemplating the needs of AVI individuals in the employment field.

Besides the financial rewards of being employed, the benefits of paid employment to individuals with or without a VI is inextricably intertwined with psychological and emotional reactions such as, greater self-esteem and feelings of competence, adequacy, self-efficacy and feelings of being in control of the environment (Duru, 2000; Leonard, 2002; Leonard & D'Allura, 2000). Unemployment has been found to negatively affect various aspects of AVI individuals' lives including, increased dependency on others to meet financial needs, loss of self-confidence, self-worth and self-esteem as well as feelings of frustration and depression, which can in turn, lead to conflict among family members and friends (Leonard, 2002). Frustration related to the thwarting of AVI individuals' need for employment can be associated with the misconceptions or stereotypes of the sighted world (environmental or external obstacle) that impedes the AVI from fulfilling the need for employment because of the misconception that they are incapable and therefore not employable. Living with an adventitious VI is a "life-long process, and a life-long challenge to struggle against other peoples' prejudices and representations about visually impaired and blind persons as being incapable"

(Berndtsson, 2000, p. 643).

Insecurity, unpredictability inconsistency and uncertainty as a consequence of the thwarting of safety and security needs affect AVI individuals' emotional reactions such as feelings of fear, anxiety, frustration, and distrust, as well as affecting the AVI psychologically such as lowering their self-esteem and self-confidence (Conyers, 1992; Dodds, 1991; Tuttle, 1984). The AVI need to feel safe and secure, both personally and financially, and confident in order to cope and function optimally with life's changed demands as AVI individuals, a need which may potentially never be satisfied for many of the AVI.

2.4.4.4 *Loss of Feeling Accepted and Respected by Others and Emergent Needs*

On Maslow's (1987) third level of the need hierarchy, issues related to love, characterised by the need for acceptance, nurturance and concern from family, friends and society in general, and belonging, characterised by the need to achieve acceptance through membership of and identification with a group or another person, may become most prominent for the AVI following their loss of sight (Atkinson, 1990; Carroll, 1961; Miller et al., 1994). The response, attitudes and expectations of society, family and friends to AVI individuals' altered capabilities may intensify and influence the emotional and psychological responses of the AVI as the external or social dynamics are simultaneously and continually interacting with their internal psychological and emotional world (Conyers, 1992).

Moore (1989a) states that many societies take care of physiological needs but people seem to be less caring about one another, with time only for superficial relationships. The lack of intimacy results in a sense of loneliness, isolation and rejection. This situation is often more profound for the AVI because of society's prejudices, stereotypes, misconceptions and fear about individuals who are visually impaired (Connor &

Muldoon, 1973; Dodds, 1991). Visually impaired individuals represent a small number in any community and when individuals lose their sight they, and society in general, often perceive themselves to be different from what they were before the loss and different from the sighted, which in turn, often results in the AVI feeling rejected and isolated (Carroll, 1961; Dodds, 1991; Tuttle, 1984). Isolation however, seems to be a function of visual ability (Karlsson, 1998). More frequent social isolation is associated with higher degrees of vision loss, given the fact that AVI individuals who are totally or functionally blind have greater difficulty with mobility, both practical and social, they are not always able to choose their companions for conversation and often need to wait to be spoken to first (Karlsson, 1998; Tuttle, 1984). In a social group, the AVI frequently find it difficult to know when comments are directed to them, a situation which is often a result of the uncertainty of the sighted on how to approach AVI individuals (Tuttle, 1984). In Conyers's research (1992) many of the AVI felt that since their loss of sight, people expected them to have got used to their VI, many felt that nobody understood what they were going through and many had difficulties in discussing their anxiety with others.

When AVI individuals' basic need to belong to the world around them and when their need to feel recognised and accepted as unique and worthy individuals by significant others and society in general remain unfulfilled their self-esteem suffers and often causes the AVI to feel acutely the pain of depression, anger or frustration, rejection, loneliness and ostracism (Conyers, 1992; Tuttle, 1984). As Carver (1961, p. 178) Poignantly says "...I was experiencing what most blind people experience sooner or later, the want, but want isn't strong enough, need is a better word, they need to belong to the world around them. Consciously or sub-consciously we long to be useful and accepted regardless. Regarded with favour. Loss of sight does not change this I discovered, I needed to find a way to belong. What could I do?"

2.4.4.5 *Loss of Esteem and Emergent Needs*

Maslow (1987) classifies the need for esteem into two categories, the need for esteem from others and the need for self-esteem.

Loss of Esteem from Others: According to Maslow (1987) individuals, including the AVI, who are at the level of needing esteem from others no longer need acceptance but rather need to be respected by those with higher status in the structure that they themselves respect. AVI individuals need others to recognise and appreciate their achievements and competence thereby satisfying the need for confidence, worth, capability and adequacy (Dodds, 1991; Gerdes, 1988; Maslow, 1987; Tuttle, 1984). This need for esteem from others is an ego need, and the ego can be boosted or lowered by the opinions of others (Rowan, 1998). Society often hides its fear of VI with reactions of pity, patronisation and stereotyping and there is often devaluation of AVI individuals' capabilities and worth, which in turn, results in the AVI feeling inferior, helpless, useless and unnecessary in the world (Carroll, 1961; Dodds, 1991; Gerdes, 1988; Maslow, 1987; Miller et al., 1994; Tuttle, 1984). The essential needs of feeling accepted, respected and valued as unique individuals by significant others and society in general are indeed difficult needs to be satisfied for the AVI (Miller et al., 1994).

Loss of Self-Esteem: All individuals, including the AVI, have a need for self-esteem which includes a stable, firmly based high and positive evaluation of themselves based on their achievements, feelings of dignity and worth, a sense of competence, capability and adequacy, and a sense of personal strength and independence (Dodds, 1991; Maslow, 1987; Miller et al., 1994; Oishi et al., 1999; Rowan, 1998; Tuttle, 1984; van Huijgevoort, 2002). In order to satisfy some of their needs, the AVI need to use methods and aids different from those used by the sighted, such as white long-canes in order to be able to walk around independently in the environment, and it is often precisely this differentness and strangeness that tends to be

distressing to AVI individuals' self-esteem (Tuttle, 1984). AVI individuals' self-esteem is further negatively affected by the recognition that they are not totally self-sufficient, that they are dependent on the sighted to meet some of their needs even with the best adaptive aids, techniques, behaviours and coping skills. In addition, feelings of self-consciousness may result from the realisation that as AVI individuals using unique coping skills and aids, they are seldom able to blend into the crowd, and remain anonymous (Tuttle, 1984). If self-esteem is measured in terms of feelings of competence or adequacy then the AVI are frequently made to feel anything but competent, worthy or adequate because of the prevailing derogatory, devaluating attitudes or social stereotypes or stigmas about VI held by society in general and often by the AVI themselves (Dodds, 1991, 1993b; Dodds et al., 1991; Tuttle, 1984). How the AVI feel about themselves, how they feel about their VI and how they feel about the attitudes of others towards them are as important determiners of their self-esteem and personal adjustment as are the adaptive behaviours and coping skills they acquire (Conyers, 1992; Dodds, 1991, 1993b; Dodds et al., 1991; Tuttle, 1984).

The response to loss of self-esteem is likely to give rise to basic discouragement and low motivation to cope with and challenge the challenge of sight loss (Atkinson, 1990; Carroll, 1961; Dodds, 1991; Tuttle, 1984). The need for AVI individuals to regain their self-esteem and self-acceptance is critical in order to function and cope successfully in meeting the practical and psychological day to day demands of living with a VI. This is a difficult and complex need to satisfy because the dynamic, inextricably interrelated personal, psychological and social forces that operate upon the AVI make their sense of worth and competence especially vulnerable (Tuttle, 1984).

2.4.4.6 *Loss of Self-Actualization and Emergent Needs*

Even if all the basic needs in the need hierarchy are satisfied, individuals, including the AVI, may still experience

a new discontent or restlessness if they are not becoming more of what they idiosyncratically are and doing what they are capable of doing (Maslow, 1987). Self-actualization is a process where individuals are motivated towards growth, self-fulfilment, and the achievement of personal and life goals (Maslow, 1987). According to him, these growth motivations, or meta-needs, are innate like the basic needs and have to be satisfied to ensure growth. The need to know and understand is one of many meta-needs and includes the need for truth, justice and meaningfulness (Moore, 1989a). Self-actualizing individuals seek actively fresh stimulation and new experiences, have a spontaneous zest for life, qualities of individuality and strength, which in turn, evoke peak experiences of unique intensity, insight and revelation (Maslow, 1999; Rowan, 1999). These individuals are able to see reality more clearly and see human nature as it is, and not as a mass of human made concepts, expectations, beliefs and stereotypes, and as Maslow (1987, p. 131) Says, "their eyes see what is before them without being strained through spectacles of various sorts to distort or shape or colour the reality."

Need gratification is dependent on the nature of the AVI individuals' needs and the discrepancy between what is desired and the extent to which they feel the desires are met (Gerdes, 1988). One of the reasons according to Maslow (1987) of why individuals, including the AVI, do not reach their potential seems to be the lack of self-knowledge and self-insight. The result is that the AVI are not aware of their own needs and depend on external directives like advice or suggestions from others, or rules and programmes. Thus, the AVI need to become aware of the full extent of the implications and limitations of living with an adventitious VI and realize what they are capable of becoming. This realization however needs an environment of an understanding and aware society which does not "distort or colour" the reality of adventitious VI and the desired goals of the AVI, needs which are indeed difficult to be satisfied (Conyers, 1992; Dodds, 1991; Elliott et al., 1991; Livneh & Antonak, 1991; Miller et al., 1994; Tuttle, 1984). In the final

analysis, every person, including the AVI, "want to live their own very unique lives in a free and highly authentic way" (Shantall, 1993, p. 40). Moore (1989a, p. 358) argues that few "people in our imperfect society actually achieve the ideal of self-actualization," and it remains to be seen how many of the AVI do indeed reach this echelon.

2.4.4.7 *Summation of Experienced Losses and Emergent Needs*

The overriding need for AVI individuals is to regain what personal independence they can within the limits of their adventitious VI and thereby reciprocally maximise their self-esteem (Dodds, 1991, 1993a; Tuttle, 1984). In order to satisfy this need however, the prevailing negative attitudes, stereotypes and feelings about VI held by society in general, rehabilitators and the AVI themselves need to be challenged. All individuals need to become aware of the reality and the full extent of the implications and limitations of living with an adventitious VI (Dodds, 1991; Elliott et al., 1991; Epstein, 1993; Tuttle, 1984).

The different degrees of vision loss with their specific and unique limitations as well as the different elicited needs must be acknowledged by all concerned. For example, the totally or functionally blind who need white long-canes for mobility, as compared to some low vision individuals who need no assistance or aids for mobility (Cherry et al., 1991; Dodds, 1991; Tuttle, 1984). Society in general, professionals and rehabilitators who provide services to the AVI should be aware of these differences and not make generalisations such as, all visually impaired individuals are blind, and that they experience the same generalised needs (Murray, 1995). Rehabilitators, in their attempt to maximize high levels of practical independence such as, independent mobility and being able to read braille, must simultaneously deal with the complex interaction of psychological and emotional needs which have an impact on the likelihood of AVI individuals benefiting from these skills or being confronted by greater obstacles and less control over their lives (Conyers,

1992; Corn & Sacks, 1994; Dodds, 1993b; Tuttle, 1984).

It is evident from the discussion that the experience of adventitious loss of sight should be described in terms of the interaction of four factors, namely, the practical, psychological and emotional needs of the AVI, the degree of sight loss, the physical and social environment of these individuals, and the common conception of VI (Tuttle, 1984). Much research is still needed to investigate whether the needs experienced by the AVI such as, regaining personal independence, and making society, and the AVI themselves, aware of the reality of adventitious ever totally satisfied, especially in the long-term.

Human needs do not emerge in a vacuum and neither are they satisfied in a void. As social beings, people function within many strata in society. The societal strata that influence AVI individuals in discovering their needs, and the satisfaction thereof, have to be incorporated in any discussion around AVI people's adaptation to their situation.

2.5 SOCIETY AND THE AVI WORLD

2.5.1 **The General Society**

Maslow (1987) states that all individuals, including the AVI, need good societies to satisfy their experienced needs, and to enable them to realise their potential. A good society is one that gives to its members the greatest possibility of becoming sound, healthy and self-actualising human beings by having its institutional arrangements organised in such a way as to foster, encourage and effect optimum good human relationships (Maslow, 1987). A good society is synonymous with a psychologically healthy society whereas, a bad society is synonymous with a psychologically unhealthy society where basic needs are thwarted and where there is not enough love, acceptance, protection, respect and trust, and too much hostility, humiliation, fear, stereotyping, prejudice and oppression (Maslow, 1987).

The complex field of adventitious VI is linked to prejudices, stereotypes and misconceptions about VI which in turn, elicits a wide divergence of predominantly negative attitudes, feelings and experiences in both society and the AVI themselves (Berndtsson, 2000; Connor & Muldoon, 1973; Dodds, 1991, 1993a; Dodds et al., 1991; Tuttle, 1984; van Huijgevoort, 2002). Watermeyer (in Bosman, 2000) states that an oppressive social environment is encountered by the AVI when they are devalued, humiliated and disrespected. The stereotypical attitudes in turn, influence the satisfaction of AVI individuals' emergent needs because they are confronted not only with the psychological, but also with the social implications of the VI. The experienced needs of the AVI are caused by their physical limitations but also by the attitudes and emotional manner in which society attempts to cope with AVI individuals (Connor & Muldoon, 1973; van Huijgevoort, 2002). People fear VI because it evokes in them negative emotions such as, vulnerability and helplessness (Watermeyer in Bosman, 2000). The negative feelings need to be normalised by sighted people admitting and dealing with their fears and not projecting them onto the AVI, nor resorting to a "confining benevolence which cares for but also segregates them from sighted society" (Connor & Muldoon, 1973, p. 353).

The extreme variation and different degrees of visual ability among AVI individuals is little understood by society in general and often becomes the basis for misunderstanding and confusion, as most sighted individuals have the misconception that VI means "blackness and the inability to see" (Murray, 1995, p. 26). The complexity and uniqueness of VI is evident when AVI individuals with tunnel vision are able to read normal print at normal distances but encounter difficulties travelling without a white long-cane, or when AVI individuals have sufficient residual vision to travel without the cane, but are unable to recognise faces at two paces (Dodds, 1993a; Lund & Dietrichson, 2000; Tuttle, 1984). The lack of understanding about the different degrees of visual abilities may result in AVI individuals with low vision denying their remaining amount of residual vision and

use this denial in the form of passing as sighted, refusing to use adaptive aids, or covering their loss of sight with other explanations as ways of coping (Dodds, 1993a; Emerson, 1981). On the other hand, in order to avoid being labelled as frauds, some AVI individuals with residual sight may fake worse than they really are. Even the AVI who are registered as legally blind, yet possess good central vision, can feel guilty about the apparent contradiction between the label they have been given by society and the level of their social performance, which may be predominantly visual (Dodds, 1993a).

There is therefore a need to challenge society's existing negative attitudes towards AVI individuals and to debunk stereotyping, prejudice and labelling (Berndtsson, 2000; Bosman, 2000; Conyers, 1992; Hull, 1990; Tuttle, 1984). According to Keith (in Duru, 2000, p. 685) "The public is a prisoner of past stereotypical thinking. It suffers from innocent ignorance and needs a massive dose of blindness education."

2.5.2 The Particular Society

AVI individuals do not exist in a vacuum and must live out their difficulties in relation to others, especially those who are emotionally significant to them (Webb, 1992). Families and friends are generally more accessible and share the day to day experiences with the AVI and serve as personal support infrastructures and help the AVI to work through their grief and feelings about their loss of sight, help them manage the uncertainties associated with their loss and increase self confidence and a sense of personal control over the environment, as well as helping to satisfy some of their experienced idiosyncratic needs (Conyers, 1992; Gothelf, Petroff & Teich, 2003; Grundlingh, 1993; Horowitz & Reinhardt, 2000; Webb, 1992). Loss of sight to one member of the family can affect the stability and typical means of satisfaction of needs for the whole family unit, as when financial insecurity is experienced by all family members when the breadwinner is the person who

loses sight (Miller et al., 1994).

Families and friends of the AVI experience their own feelings and thoughts regarding the loss and must also struggle with their own grief reactions and needs (Webb, 1992). Family adjustment to a member who has lost sight may be difficult because their grief is similar and parallel to that of the AVI person (Sutton, 1985). If family members and the AVI person are in different stages of grieving, for example, if the AVI person is struggling with the anger about the loss and the family is still denying that it will have a significant impact on family life, little assistance can be given to each other and there will be little room for open and constructive communication (Webb, 1992). A pressing need when confronted with loss of sight is honest, clear and open communication between all members of the affected families because without it, there can be no comfort and support, plans cannot be made, needs cannot be satisfied and the resources of the family cannot be mobilised to support the AVI (McKay, 1990; Raphael & Nunn, 1988; Webb, 1992).

Feelings experienced because of loss of sight may however, be difficult to share with other sighted individuals as they have never experienced this type of loss (Hughes, 1980; Webb, 1992). AVI individuals may therefore block open expression of emotions and needs, often becoming frustrated which is then further reinforced by the lack of understanding of others (Conyers, 1992). Families and friends therefore need to become aware and understand the fact that the AVI may be reluctant to seek their support and assistance as they may fear that the requests they make will reflect negatively on their self-image and self-esteem (Miller et al., 1994). When AVI individuals do not respond to the well-meaning interactions of family and friends, their support might be withdrawn before the AVI can benefit from their approaches, whereas on the other hand, families and friends may become so invested in helping, that the AVI are never encouraged or allowed to become self-reliant (Vachon & Stylianos, 1988). Research by Reinhardt (2001) found that instrumental support

(practical and tangible assistance) from family members was associated with better adjustment by AVI individuals whereas, affective support (caring, trust, empathy and acceptance) from friends was associated with better adjustment to vision loss, greater life satisfaction and fewer depressive symptoms. Connor and Muldoon (1973) argue that the needs of the AVI are caused not only by their physical conditions but also by the emotional manner in which family and friends try to adjust to them. Many of the needs of AVI are occasioned by restrictions, over protection, rejection, unrealistic expectations, and misconceptions about adventitious VI (Connor & Muldoon, 1973; Dodds, 1991; Tuttle, 1984). Negative interactions that are derived from misunderstood supportive efforts are actually additional stressors (Vachon & Stylianios, 1988). The crisis of loss of sight may place pressure on previously adequate support networks and put the entire network group into distress and may render the families and friends unable to support the AVI individuals for whom the loss is most significant and profound (Conyers, 1992; Goodwin & Holmes, 1988; Vachon & Stylianios, 1988). Research by Corn and Sacks (1994) on the impact of non-driving on AVI individuals investigated the perceived understanding and support they received from others. The AVI respondents rated 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. In addition, professionals in the field of VI were perceived to be insensitive to the emotions experienced by those who can no longer drive.

Consideration must also be given to whether family members and friends perceive the grief process as the traditional, linear, resolvable and time-limited process with abated and satisfied needs, or a chronic, recurrent and circular process with ongoing and unabated needs (Hewson, 1997; Rowan, 1999). Denial, anger and guilt are common reactions experienced by family members and friends during the grief process because of their perceptions that they were unable to foresee or prevent the loss of sight.

They may therefore feel responsible for alleviating the distress of the grieving AVI person and encourage and expect the person to recover and satisfy their particular emergent needs (Conyers, 1992; Reiss, Gonzalez & Kramer, 1986; Webb, 1992). On the other hand, those family members and friends who perceive a chronic grief process, and thus by implication, ongoing ascent and descent or a circular process of need gratification, will be able to offer appropriate long-term support (Davis, 1987; Lindgren et al., 1992; Webb, 1992).

The initial priority of AVI individuals and their families is therefore to acquire a clear and sensitive explanation of their conditions as well as realistic expectations of what might be expected in terms of progress (Miller et al., 1994). Support from family and friends based on realistic expectations is of critical importance for successful long-term adjustment to the limitations of living with an adventitious VI (Wortman & Silver, 1987). In addition, the family and the AVI themselves need to be confronted as soon as possible with the reality of adventitious with all its implications, including such issues as degree of sight loss and remaining abilities; realistic and unrealistic limitations, needs, aspirations, expectations and fears (Miller et al., 1994). Only with insight, awareness and understanding about adventitious VI will the lives of family members friends and the AVI themselves be enhanced.

2.5.3 The Rehabilitation Society

A broad range of rehabilitative measures are required to meet the many unique needs experienced by the AVI following their loss of sight in the form of acquiring adaptive aids and skills in order to cope with their changed lives (Asp & Johansson, 2000; Connor & Muldoon, 1973; Dodds, 1991, 1993a, 1993b; Lund & Dietrichson, 2000; Miller et al., 1994; Ryan, Culham, Hill, Jackson, Jones, Bird & Bunce, 2000; Tuttle, 1984). The United Nations' World Programme of Action concerning Disabled Persons (1983, p.3) Defines the term rehabilitation as, "a goal-directed

and time-limited process aimed at enabling an impaired person to reach optimum mental, physical and/or social functional levels, thus providing her or him with the tools to change her or his own life." Rehabilitation of AVI adults should therefore be a process whereby these individuals come to gain awareness and understanding of themselves and the implications of their adventitious VIS, adjust to their new situations by learning and acquiring new skills, techniques and adaptive aids, take control of their emotions and their social and physical environments, and assimilate the various changes into their lives (Carroll, 1961; Del Carmen & Marzo, 2000; Livneh & Antonak, 1991). On the other hand, Moore (2003) states that rehabilitation is a never-ending process where the need for on-going independent living evaluations and assessments of rehabilitated AVI individuals' changing needs on all levels, technical, employment and psychological, must be ensured.

One of the main aims of the rehabilitation process is to emphasise the restoration of maximum personal independence to enable the AVI to regain the skills they need to function independently within their total psycho-social and physical environments (Miller, 2002; Miller et al., 1994; Millman, 2000). According to Del Carmen and Marzo (2000) rehabilitation to regain personal independence must cover the following areas: psychological and social support tasks, orientation and mobility, low vision skills, communication by access to information, as well as personal independence appliances or aids, such as white long-canes. Furthermore, rehabilitation must also be a process of inner growth for AVI individuals to which the whole atmosphere of the rehabilitation setting must contribute (Robertson & Brown, 1992). In the rehabilitation context, the restoring of AVI individuals' self-esteem should begin with a realistic appraisal by the AVI, with the active participation of all rehabilitators, of their situation, what their prospects are for the future and what difficulties lie ahead (Robertson & Brown, 1992).

While many studies have often concentrated on measuring the

direct effect of rehabilitation within certain areas of achievement such as, the speed of reading braille or performing different tasks in mobility, a more effective approach would be to measure results in relation to how the rehabilitation has affected AVI individuals' total life situation, both practically and emotionally (Lund & Dietrichson, 2000). For example, achievement in increased braille reading skills have little value for AVI individuals who do not see braille as important. Research by Fitzgerald (1970) showed that achievement of acceptance of loss of sight was associated with AVI individuals' increased self-esteem from attempting and mastering self-sufficient acts such as mobility, whereas, other AVI respondents attributed the positive change in their feelings and the acceptance of their loss of sight to their leaving home to spend several months in a residential rehabilitation centre and the forming of important interpersonal relationships with other AVI individuals.

Whilst it may appear that working through and adjustment to adventitious VI following rehabilitation has occurred with the outward resumption of daily and social living skills, an inner felt experience of powerlessness may be belied by a superficial outer confidence (Conyers, 1992; Roy & Mackay, 2002). Conyers (1992) found that in her research the greatest difficulty experienced by the AVI respondents, during and following rehabilitation, was in relation to inner emotional needs, the ability to come to terms with what has happened and to accept loss of sight. Roy and Mackay (2002, p. 263) State that the danger for the AVI is that any further traumatic personal event of whatever sort, is likely to "blow the fragile confidence apart" because the issue of loss of sight has not been resolved within the self. Whilst practical rehabilitation such as, the acquisition of orientation and mobility and basic activities of daily living are obviously important, there is a suggestion that for too long it has dominated and excluded other aspects of rehabilitation, such as psychological and emotional issues (Banwell, 1991; Conyers, 1992; Roy & Mackay, 2002). Dodds (1991, p. 38) States that "perhaps those who have worked for many years

with blind and visually handicapped people have had to protect their own emotional lives from the explicit recognition of real tragedy by avoiding the psychological realities of visual loss." An important need during rehabilitation is for rehabilitators to make the AVI aware of the reality of their situations and conditions through clear and sensitive explanations, to focus on both the practical and emotional needs of these individuals, and to point out the available options and resources. The AVI need to be active participants in all decision making and in determining what needs ought to be addressed, rather than the mere preconceived notions about needs from the rehabilitators (Banwell, 1991; Craig, 2000; Lund & Dietrichson, 2000; Miller et al., 1994; Robertson & Brown, 1992; Webb, 1992). The mismatch between rehabilitators' expectations for the AVI, and the AVI individuals' own expectations can often be a considerable one (Dodds, 1993b).

AVI individuals need to be confronted with the realistic world of adventitious VI as soon as possible, be helped to become aware and understand the full impact of the reality of the implications and limitations of their loss, because the AVI cannot begin or be expected to adjust, either emotionally or practically, unless they know what it is they must potentially face and adjust to (Dodds, 1993a). It is essential that family members should participate in the rehabilitation process because a secure rehabilitation setting will allow open communication between all members of the affected families and allow them to express their diverse emotions, obtain practical advice on how to cope with the acquired VI, and gain a better understanding and awareness of the realistic needs and expectations of the AVI living with a chronic VI (Webb, 1992). The rehabilitation process should be most concerned about the multiplicity of levels of needs of the AVI, the changing needs of their family members, and the interrelatedness of these needs (Miller et al., 1994).

All rehabilitators must address and be comfortable with their own reactions to grief, loss and needs before they can be helpful

and facilitative to the AVI who need their support to achieve adjustment (Dodds, 1991; Webb, 1992). Rehabilitators may feel guilty for not having a VI themselves, or for being luckier than their clients, and since these are feelings that will be shared by others in the context in which the AVI individuals move, it is extremely important for rehabilitators to be clear about this aspect of themselves, and not allow it to intrude on their work (Webb, 1992). Dodds (1991, p. 38) states that it is up to all rehabilitators to "decide whether or not they can cope with the feelings unleashed by asking probing questions. If they think they can, they should go ahead; if they have any doubts, they should pass their client on to a psychologist."

It is important that rehabilitators are aware of and understand their perceptions and assumptions of the grief process because these assumptions can affect how they respond to AVI individuals who have encountered loss of sight (Webb, 1992; Wortman & Silver, 1987, 1989; Wortman et al., 1993). If rehabilitators presume and uphold the traditional grief-following-loss theory assumptions that time heals and that the resolvable grief process will follow the linear stages and culminate with the final stage of acceptance and adjustment and that all emergent needs will be satisfied within a time limit, and if these assumptions are reinforced on the AVI during rehabilitation, then the expectation will be that newly rehabilitated AVI adults are adjusted and accepting of their vis, that they are totally independent, that their experienced needs have indeed been satisfied, and that they are able to return to the functioning individuals they were before their loss of sight (Atkinson, 1990; Murray, 1998). If on the other hand, rehabilitators acknowledge that AVI individuals can potentially experience a chronic, recurrent and circular grief process, that they will indeed be confronted with continual losses and recurrent needs directly related to their adventitious vis, which in turn, will have to be continually satisfied, will they, the rehabilitators, be able to make the AVI aware of the long-term and realistic implications and limitations of living with a chronic adventitious VI (Davis, 1987; Lindgren, et al.,

1992; Moore, 2003). The initial rehabilitation process must be the first stepping stone in a never ending process (Murray, 1998).

2.6 CONCLUSION

In this Chapter, the grief process and the needs emanating from adventitious loss of sight have been discussed. What emerges is that adventitious VI issues are complex and varied. The grief process following loss through death formed the foundation of the discussion of adventitious VI grief. The concept of chronic grief, with its emphasis on the circular nature of the grief process, emerged as a more appropriate model to the traditional models which focus on linear and resolvable processes. Maslow's need hierarchy provided the platform for the discussion on the emergent needs following loss of sight. The satisfaction of the emergent needs were discussed in terms of general social support, particular support from families and friends, and support from the rehabilitation community.

The next Chapter will discuss the research methodology to be used in accessing the experiences of AVI adults following their loss of sight, their idiosyncratic emergent needs and their perceived support from the community's to which they belong.