

## CHAPTER SIX

### MORE THAN WHAT MEETS THE EYE ABOUT ADVENTITIOUS VI: DISCUSSION

#### 6.1 INTRODUCTION

The essential features of the experience of loss of sight and the emergent needs post-grief which have emanated from the AVI respondents' scenarios and which accord with the chief loss of sight issues as outlined in Chapter Two {Chapter Two, p. 12 } will be discussed in this Chapter. Incongruities between the literature and the scenarios are specified. Possible explanations will be put forward to interpret the distinct and different findings obtained for the short-term and long-term AVI respondents.

#### 6.2 OVERVIEW OF THE ESSENCE OF EMERGENT NEEDS POST-GRIEF

The phenomenon researched in this study was the emergent needs post-grief experienced by AVI adults. The research concentrated on specific experiential areas, namely, the perspectives of the AVI respondents' loss of sight, their experienced emotions and attitudes and by implication, their perception of the grief process, the emergent psychological, emotional and practical needs they experienced and currently experience, as well as the support they receive from society, families and rehabilitation in meeting these needs.

Two essential features impressed themselves on the mind of the researcher during the phase of seeking an intuitive holistic grasp of the data of all the AVI research respondents: Although loss of sight is an unique and individual experience which is inextricably linked to the degree of vision loss, many unique but also common psychological, emotional and practical needs are experienced, and that length of time of the adventitious VI has

a profound impact on these needs, emotions and attitudes, and by implication, the grief process. These features emerged as the data were broken down into meaning units and combined again in order to gain a grasp of the essential pattern inherent to the experience of emergent needs post-grief experienced by AVI adults. These essential features will now be highlighted.

### 6.3 COMPOSITE PICTURE OF THE DATA

#### 6.3.1 **Unique and Individual Experiences**

In the face of loss of sight, with the inevitable difficulties and problems, the diverse and unique perceptions and attitudes the AVI respondents have towards their loss of sight give specific meaning to their experience of living with a chronic adventitious VI. The AVI respondents in this research study face their loss of sight in their own particular and unique ways and deal with the issues specific and unique to them. The search for meaning and understanding about loss of sight and life as AVI individuals in the respondents' scenarios reveals that the nature of the search depends on whether human life is viewed as having meaning because of some external source which gives it significance such as, God, or that they themselves make life meaningful through their own goals and efforts (McKay, 1990). These two dimensions will now be discussed.

#### *God, Religious and Spiritual Values*

Religious faith and spiritual values are mentioned by five AVI respondents (Mary, Amanda, Susan, Allan and Peter) as being critical in giving purpose to their lives and helping them cope with and adjust to their loss of sight. God plays a significant function in securing a sense of tranquillity through reconciliation for these AVI respondents. Religious and spiritual values act as a strong unifying influence directing many aspects of people's lives, evident in the five AVI respondents' scenarios (Gerdes, 1988), and substantiates research by Crudden (2000) who

found that spirituality and religious faith were of great importance for adjusting to VI.

### *Meaningful Existences*

The meaning of loss of sight being a continual challenge (Gail and Annette) and a "new start in life" (Chantal) affords new possibilities and probabilities for meaningful human existence. In order to give meaning to life, there must be "a challenge to meet, a goal to strive for, something to live for, and that life has a purpose" (Shantall, 1996, p. 9). The meaning of loss of sight as a mere inconvenience over which Jane and Paul have control affords them the ability to carry on with life as before, thereby making life meaningful through their goals and efforts (McKay, 1990). These findings accord with research (Corn & Sacks, 1994; Rosenblum & Corn 2002a) which, although focusing on the impact of non-driving because of loss of sight, is applicable to the meaning the AVI give to their loss of sight namely, that for some, the impact may be a mere inconvenience, whereas for others, it can become a lifelong challenge.

The AVI should be acknowledged as individuals with their own particular and unique perceptions and meanings of their experience of loss of sight. "Meaning seems to be in the nature of clear vision, much like the liberating effect of a profound truth: "now I see, now I understand..." "Now I know what to do..." (Shantall, 1996, p. 10).

### **6.3.2 Contradictory Positive and Negative Attitudes and Emotions**

All the AVI respondents, regardless of length of time of their adventitious VIS, experience contradictory positive and negative attitudes and emotions simultaneously. This dichotomy is difficult to reconcile.

#### *6.3.2.1 Self-Esteem and Self-Derogation*

Self-esteem is the evaluative aspect of the self-image, the

extent to which individuals admire or value the self, and is related to a sense of worth (Dodds et al., 1991; Gerdes, 1988; van Huijgevoort, 2002). If high self-esteem is associated with feelings of competence, self-satisfaction and feelings of worth then all the AVI respondents in this research study have high self-esteem. Indeed, the AVI respondents evaluate themselves as self-assured, confident, self-efficient, self-aware and worthy AVI individuals who are satisfied with their capabilities to cope with their VIS. They are positive and determined to carry on with their independent lives despite their loss of sight. The AVI respondents perceive and evaluate themselves as having positive self-images and high self-esteem.

In contradiction to, but simultaneous with the AVI respondents' positive self-images and self-esteem they also experience negative emotions and attitudes of self-derogation. They describe feelings of worthlessness when needing to ask for help, or when they are in situations and they feel insecure and ineffectual because of their inability to do things.

Both short and long-term AVI respondents continue to be self-conscious about embarrassing themselves in front of people and are concerned with what other people will think and say about them being "different." In their attempts to conceal their VIS and self-consciousness they try to behave as "normal" sighted individuals, reactions indicative of low self-esteem (Tuttle, 1984). Embarrassment of their VIS causes some of the AVI to withdraw from group interactions and "socialising." These behaviours are contrary to the expectations of individuals with high self-esteem and positive self-images.

The AVI respondents' need for acceptance and approval is indicative of anxiety about rejection and non-acceptance which in turn, reveals self-doubt and self-derogation (Gerdes 1988). As self-efficacy is a subjective estimation of the likelihood of succeeding or failing at tasks, both the short and long-term AVI have a low sense of self-efficacy and by implication, self-

derogation and low self-esteem (Dodds et al., 1991).

Research by Coopersmith (1967) has shown that people who have difficulty in expressing feelings and emotions, especially anger in whatever form, have negative self-images and low self-esteem. Although the AVI respondents perceive and present themselves as positive individuals with positive self-images and high self-esteem there are implicit revelations, including their difficulties in revealing emotions regarding their loss of sight, that they have negative self-images and self-esteem.

It is the functionally and totally blind AVI respondents who experience feelings of rejection and isolation. This finding accords with research by Karlsson (1998) who states that isolation seems to be a function of visual ability with more frequent social isolation associated with higher degrees of vision loss. Given the fact that AVI individuals who are totally or functionally blind, in contrast to the low vision AVI, have greater difficulty with mobility, both practical and social, which in turn, compound feelings of rejection and isolation.

Another explanation for the feelings of rejection, non-acceptance and self-derogation could be the fact that when individuals lose sight, they perceive themselves to be different from what they were before the loss and different from sighted people. Together with society's stereotypes, misconceptions and fear about VI, results in these AVI feeling rejected and isolated (Carroll, 1961; Connor & Muldoon, 1973; Dodds, 1991). In addition, the AVI need to use methods and aids different from those used by the sighted, such as white long-canes, to be able to satisfy many of their needs. It is often precisely this differentness that tends to be distressing to AVI individuals' self-esteem. 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. The lack of knowledge about VI issues and the prevailing devaluating attitudes or social stereotypes about VI held by society in general, and often

by the AVI themselves, compound the low self-esteem (Tuttle, 1984).

The revelation that all the AVI respondents' "real selves" are rather dramatically incongruent with their perceived positive self-images of coping, competent and confident AVI individuals with positive and high self-esteem is interesting but perplexing. AVI respondents' desire for a positive self-image and healthy self-esteem nevertheless, gives rise to hope that the AVI respondents have as yet not exhausted their potentialities.

#### 6.3.2.2 *Tranquillity and Anxiety*

All the AVI respondents perceive and evaluate themselves as positive, independent, confident and coping and by implication, tranquil AVI individuals . In contradiction to, but simultaneous with the AVI respondents' positive emotions and attitudes, they also experience negative emotions like anxiety. This experienced anxiety is expressed both explicitly by the AVI but is also inferred from their scenarios.

Both short and long-term AVI respondents experience anxiety and related emotions like insecurity, uncertainty and a loss of confidence in unfamiliar and unsafe situations or places, or with new and unfamiliar people. Despite perceiving themselves as independent and coping AVI individuals some of the AVI are nonetheless anxious about being as independent as they were before their loss, or they are anxious about being perceived and judged by others as not coping with their VIS and not being in control of their lives and environments.

Anxiety is a multi dimensional construct and each segment of overpowering anxiety must be dealt with to ensure affective equilibrium and functioning (McKay, 1990). Further research into the perplexing continued anxiety is warranted.

#### 6.3.3 **Distinct Emotional and Attitudinal Experiences**

The clear differentiation between the short-term and long-term

AVI respondents concerning experienced emotions (especially frustration) and attitudes (especially acceptance and adjustment, and by implication the grief process), is significant.

#### 6.3.3.1 *Experienced Emotions: Frustration*

##### *Occasional Frustration*

Some of the short-term AVI respondents experience occasional emotions, such as frustration, some have already worked through the emotions associated with loss of sight, whilst some continue to experience no emotions at all. The circumstance that triggers the occasional experienced frustration for the short-term AVI is the loss of independence and their need to be dependent on others. Loss of independence as the only circumstance causing frustration for the short-term AVI could possibly be explained by the fact that this loss is so overwhelming for the new AVI that all other possible causes are not even considered.

##### *Cyclical, Oscillating but Episodic Frustrations*

On the other hand, the long-term AVI respondents experience cyclical, oscillating but episodic emotional reactions, especially frustration, in specific situations or at specific times which are particularly meaningful to them. Frustration usually exacerbates in meaningful situations when the AVI become acutely aware of the irrevocable limitations of their VIS. The long-term AVI respondents' experienced frustration could be explained by research (Elliott et al., 1991; Gerber, 2003; Hewson, 1997; Lindgren et al., 1992; Teel, 1991) which found that the longer the adventitious VI the more the AVI become aware of the implications and limitations of their VIS, are aware of exactly what they are missing as they are confronted with regular reminders of what can no longer be done.

Three specific circumstances foster the frustration for all of the long-term AVI, namely, perceived loss of control over their

lives and environments (especially in urgent situations), perceived loss of spontaneity, and lack of awareness from the sighted about the basic VI issues. Anger (which includes frustration) has been shown to be a defence against loss of control (McKay, 1990).

Frustration is often caused when there is external lack of awareness and understanding about a situation, like loss of sight (Carson et al., 1988). Therefore, the recurring encounter with the social stereotyping and lack of understanding of VI issues by society in general will indeed result in frustration, a condition relevant to the long-term AVI. These respondents do not specify loss of independence per se as a cause of frustration, but this loss could be implied in their perceived loss of control and spontaneity over their lives and environments.

The experienced frustrations of the long-term AVI have increased in intensity and frequency the longer they have been AVI. Their explanation for the increase is their heightened awareness of the irrevocable nature and limitations of their eye conditions. One long-term AVI respondent describes the increased frustrations as being associated with the experienced ongoing losses and the related continual confrontation of emotions that are a part of living with a chronic VI.

#### *Frustration and Not Being Able to Drive*

A central mitigating factor for triggering frustration in the circumstances of perceived loss of independence and needing to be dependent on others, especially for transport, as well as the perceived loss of control and spontaneity in the AVI respondents, regardless of length of time of adventitious VI, is no longer being able to drive a motor car. This finding accords with research (Eisenhandler, 1990; Cherry et al., 1991; Conyers, 1992; Corn & Sacks, 1994; Horowitz, 2001; Rosenblum & Corn, 2002a, 2002b) that the sense of loss of control over AVI individuals' lives, the sense of the loss of independence with the sense of



a dependency career, and the perceived lack of awareness and understanding of others about not being able to drive a motor car are factors that have been highlighted as the main causes of continued frustration experienced by the AVI.

It is interesting that none of the men in this research study mention the inability to drive as a cause of frustration. Possible explanations could be that the men, unlike many of the women, have drivers ready and available at any time to take them where they need to go. Men may not be willing to own emotions, especially anger (which includes frustration) as admitting to powerful emotions could appear to suggest negative implications about their self-worth and perceived self-abilities (Conyers, 1992; Elliott et al., 1991).

#### 6.3.3.2 *Experienced Attitudes: Acceptance and Adjustment*

##### *Absolute Acceptance and Adjustment*

The short-term AVI respondents experience absolute acceptance of, adjustment to and coping with their VIS. Acceptance for these AVI respondents is related to being independent, coping with and in charge of and adjusted to their AVI lives. It would appear that with this absolute acceptance and adjustment these short-term AVI still lack the awareness about the reality of living with a chronic VI.

The short-term AVI have accepted their loss both intellectually and emotionally. Their experiences of absolute acceptance and adjustment accord with research (Parkes & Weiss 1983; Wortman & Silver, 1987) which state that individuals who have experienced an irrevocable loss, like loss of sight, must intellectually be able to understand and accept what has happened and make sense and meaning of the loss. In addition, when reminders of the loss can be confronted without intense emotional pain and when the intensity of the distress is diminished, then emotional acceptance has occurred.

*Cyclical, Oscillating Acceptance and Adjustment*

The long-term AVI respondents on the other hand, experience cyclical, oscillating but episodic attitudinal reactions of acceptance and adjustment. As in the case of experienced frustration, it is precisely in specific situations or at specific times when the long-term AVI become acutely aware of the irrevocable limitations of their VIS that they experience non-acceptance and non-adjustment. It is inevitable therefore, that absolute acceptance of, and adjustment to loss of sight is difficult, if not impossible, and never final for these AVI. Oscillation of any kind, reflects the changes in abilities to cope with reality at any given time (McKay, 1990).

The long-term AVI accept intellectually the fact that they have lost their sight. With their attitudes of cyclical, oscillating but episodic emotional and attitudinal reactions, none have as yet, accepted their loss of sight emotionally.

With time and a better understanding and awareness of the implications and limitations of their adventitious VIS, some of the long-term AVI respondents' psychological denial of the limitations of their VIS have changed to acknowledgement and acceptance. These changes accord with research (Elliott et al., 1991; Ray & West, 1983) which claims that years may elapse before the AVI appreciate the full extent of the limitations of their conditions.

*Reciprocal Acceptance and Adjustment*

The observations obtained from this research study challenge the notion that acceptance of loss of sight is at the root of the adjustment process (Conyers, 1992; Dodds et al., 1991). This assumption implies that before adjustment can take place, there must be acceptance of the VI. It is inevitable however, that with the cyclical, oscillating but episodic attitudinal reactions that both acceptance and adjustment to VI will be negotiated and re-

negotiated continually. In addition, it would appear that acceptance and adjustment are inseparable reactions, and reciprocally interact and impact on one another. Additional research to clarify this notion concerning acceptance and adjustment as inseparable is warranted.

#### 6.3.3.3 The Grief Process

In this research study, the grief process was considered in terms of experienced emotions and attitudes, especially acceptance and adjustment. The comparison given by Lindgren and her associates (1992) between resolvable and chronic grief is meaningful in the context of this research study. Although both are reactions to loss, resolvable grief involves reactions to one identified loss whereas, chronic grief involves reactions to numerous losses. These differences are significant when reflecting on the distinct experiences of grief between the short-term and long-term AVI.

##### *Resolvable Grief*

The short-term AVI respondents with their perceived lack of awareness about the reality of the implications and limitations of their VIS may indeed perceive their loss of sight as one identified loss. If so, then it is assumed and expected that the short-term AVI will follow the traditional resolvable grief process of a linear, sequential and time-bound procedure during which time the emotional reactions diminish in intensity and frequency, and where acceptance of the reality of the loss is the final state of conclusion to the grief process. Following this resolvable grief process and the recognition that acceptance is the necessary emotional milieu for adjustment to adventitious VI, there is an expectation of the re-instatement of psychological and emotional balance and equilibrium, and the ability to return to the previous level of functioning as it was before the loss (Atkinson, 1990; Conyers, 1992; Dodds, 1993a; Dodds et al., 1991; Fitzgerald, 1970; Horowitz & Reinhardt, 2000; Kubler-Ross, 1969;

Reinhardt & Benn, 2000). All the short-term AVI substantiate these assumptions.

The short-term AVI respondents' experiences accord with research by Atkinson (1990) who states that the grief process must be concluded before AVI individuals are able to resume a normal existence. In addition, society and rehabilitators and many of the AVI themselves assume that they, the AVI, after accepting their loss are adjusted to and coping adequately with their loss of sight, something which the short-term AVI certainly uphold.

### *Chronic Grief*

The long-term AVI respondents, with a assumed greater awareness of the reality and implications of their VIS, challenge the traditional assumptions of a resolvable grief process. The longer individuals are AVI, the more aware they perhaps become about the unreality of the expected time heals ideal and the more aware they become about the reality of the non-ending implications, limitations and emotions associated with sight loss.

The long-term AVI are aware of the inevitability of personal and environmental demands constantly changing and producing further losses. Indeed, 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 occur in relation to the loss (Hewson, 1997; Teel, 1991). In these problematic loss situations, the long-term AVI could re-experience anxiety or doubt about their acceptability or worthiness, emotions and attitudes which in turn, need constant emotional and psychological adjustment. On reflection, this scenario could be the explanation for the high anxiety experienced by the long-term AVI in this research study.

These experiences do however, accord with research (Tuttle, 1984; van Huijgevoort, 2002) which has found that acceptance and

adjustment to adventitious VI is not a static condition but rather a life-long, dynamic and fluid process. The cycling back through the emotional adjustment stages may occur at any age and whether adjustment is recently acquired or long standing.

The increasing intensity and frequency of the grief related emotions, especially frustration, may be related to the build-up or cumulation of the numerous losses that are a continuous part of a VI (Davis, 1987; Lindgren et al., 1992). The long-term AVI experiences certainly substantiate the afore-mentioned research findings and assumptions.

Accordingly, as in the case with the emotional and attitudinal reactions which are experienced in certain meaningful times and situations, so too is chronic grief not constant and unrelenting. It is experienced many times. Feelings are expressed not simply to repeat the past but rather to rework them in a new context or deal with loss from a new or different perspective. These feelings are exacerbated at critical periods, at different times and situations in the life of AVI individuals. It is in these specific situations and times that the AVI recognise more acutely the disparity between being able to see and not being able to see, highlighting the acknowledged irrevocable limitations of their VIS (Davis, 1987; Lindgren et al., 1992; Webb, 1992).

The long-term AVI sanction the identifiable attributes of chronic grief as conceptualised by Lindgren and her associates (1992). They have perceptions of grief over time with no predictable end as they are aware that their VIS are chronic eye conditions that cannot be changed or reversed. Grief is recurrent and cyclical and is triggered either internally (as the loss endures new situations with new problems and new loss responses arise), or externally (the recurring encounter with the lack of awareness of VI issues and the stereotypical attitudes of society towards VI). Grief can intensify years after the initial sense of loss (related to the cumulation of the numerous losses confronted by the AVI). Consequently, the long-term AVI uphold

the assertion that if the underlying cause of continual loss is the VI, then chronic grief, with recurrent episodes of both positive and negative emotions and attitudes, which vary in intensity at different times and situations, will operate throughout the time course of the VI (Lindgren et al., 1992).

It can be argued that what the long-term AVI respondents achieve in the grief process is a state of recognition that sight has been lost, an acceptance of this fact, and a cyclical, oscillating but episodic process of emotional adjustment to this recognition. It is evident that the concept of chronic grief and the related cyclical, oscillating but episodic emotions and attitudes, and the concept of length of time of adventitious VI are inseparable and reciprocally impact on one another. More research into this phenomenon is definitely needed.

The findings of this research study with regard to resolvable versus chronic grief supports research by Murray (1998). Murray's (1998) study 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, 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.

The long-term AVI respondents need all individuals to be aware and understand that they experience chronic grief with cyclical, oscillating but episodic emotions and attitudes. This need accords with research (Conyers, 1992; Davis, 1987) which states that 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. 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 however, the growing awareness that at a deeper level, the work of grieving such loss may be extended through years (Conyers, 1992). 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. With acknowledgement of chronic grief and the related emotional and attitudinal reactions the AVI may be able to cope better with this grievous phenomenon in their lives, something which the long-term AVI respondents certainly endorse.

Another point to ponder is whether society's lack of awareness and knowledge about the real world of adventitious VI, as well as the concept of chronic grief, coerce the AVI, and especially the long-term AVI, to conceal their cyclical and oscillating emotions and attitudes of the loss experience. If so, then it is inevitable that this concealment could perpetuate the long-term AVI respondents' need for acceptance, nurturance and esteem, both from others and self-esteem. More research into this fascinating phenomenon is warranted.

#### **6.3.4 Coping Strategies**

Many of the AVI respondents in this research study use defence mechanisms or coping strategies as adaptive buffers to reduce their overwhelming negative emotions (anxiety and frustration) and to help preserve their self-images of coping and positive AVI individuals (Atkinson, 1990; Hewson, 1997).

More short-term than long-term AVI respondents use the defence mechanism of psychological denial as a coping strategy. They, the short-term AVI, have the characteristics of psychological denial, namely, their perceived absence or decrease in emotions, including anxiety and frustration; little acknowledgement of the implications and limitations of their conditions, and a positive

optimism, albeit unrealistic hope, about their futures with the resumption of disruptive social roles and sensory functioning (Conyers, 1992; Elliott et al., 1991; Roy & Mackay, 2002). In addition, the absolute acceptance experienced by all the short-term AVI connotes denial, as they all appear to be using it as a way of blocking out the painful reality and emotions of their loss of sight. Research by Conyers (1992) shows that many factors could account for this phenomenon of denial namely, unacknowledged reactions, anxiety about losing remaining sight and the subsequent anxiety of losing control and being overwhelmed by feelings or guilt about having emotions, especially anger (in whatever form). Admitting to and owning powerful emotions such as anger and anxiety appear to suggest negative implications about self-worth and perceived self-ability (Conyers, 1992; Elliott et al., 1991). The positive attitudes of the AVI respondents, particularly the short-term AVI, could be an attempt to ward off anxiety and preserve self-esteem.

The psychological defence mechanisms require a certain amount of self-deception to reduce negative emotions and to preserve self-esteem (Gerdes, 1988; Tuttle, 1984). This self-deception appears to be happening with many of the AVI respondents in this study, with their denial of the disagreeable reality of loss of sight, rationalising in an attempt to excuse behaviour, and projecting or displacing blame onto the sighted. Extensive use of these defence mechanisms, or coping strategies, by many of the AVI respondents are indicators of poor adjustment and low self-esteem (Tuttle, 1984).

The low vision AVI respondents in this research study manifest contradictions in their coping strategies. They refuse to use adaptive aids such as the white long-cane as they could be denying or rejecting the symbolism of blindness that the aids represent (Dodds, 1993a; Emerson, 1981; Tuttle, 1984). They also deny their remaining amount of residual vision in order to perhaps be perceived as being totally adjusted and coping with their "blindness." On the other hand, when they use their white



long-canes they are perhaps attempting to avoid being labelled as "frauds," and therefore "fake" worse than they really are. One AVI respondent describes this behaviour as "pretends to be blind," possibly because of guilt about the apparent contradiction between the label they have been given by society, namely, blind, and the level of their social performances which may be predominantly visual (Dodds, 1993a). A possible explanation for the denial of residual vision or the denial of the symbols of blindness could be the result of the sighted not being aware of the different degrees of visual abilities. More research into this interesting phenomenon is needed.

### 6.3.5 **Emergent Needs**

The essential needs for optimal coping and psychological, emotional and physical well-being faced by the AVI respondents following their loss of sight focus on three fundamental needs, namely, independence, understanding and awareness, and support. Although idiosyncratic and unique needs are experienced by the individual AVI respondents, there are distinct differences between the short and long-term respondents' expressed needs.

#### 6.3.5.1 *Need for Independence*

Loss of sight deprives AVI individuals of considerable amounts of their already acquired competencies, particularly their personal independence (Conyers, 1992; Dodds, 1991, 1993a; Rowland, 1985; Roy & Mackay, 2002; Tuttle, 1984). The loss of independence inevitably guarantees the need for dependency, a situation which is contrary to AVI individuals' (especially the new AVI) psychological orders of independent individuals. Independence is one of the characteristics of self-esteem which, when lost, also means the loss of feelings of dignity and worth, and the sense of competence, capability, adequacy and personal strength (Dodds, 1991; Maslow, 1987; Miller et al., 1994; Oishi et al., 1999; Rowan, 1998; Tuttle, 1984).

It is inevitable that the overwhelming need for the short-term AVI respondents is to regain what personal independence they can. None of the long-term AVI explicitly experience this need. According to the short-term AVI, this need has been satisfied during rehabilitation. Rehabilitators regard mobility and braille as the cornerstone for personal independence, and given the assumption that when the AVI have mastered the white long-cane together with competence in braille, they are once again independent. It is not surprising therefore that the short-term AVI perceive themselves to be independent, coping with and adjusted to their VIS. With their perceived independence they experience feelings of self-confidence, self-worth and mastery over their lives and VIS (Atkinson, 1990; Dodds, 1991, 1993a; Dodds et al., 1991; Rosenblum & Corn, 2002b; Roy & Mackay, 2002).

A possible explanation for the overwhelming need for independence by the short-term AVI respondents is that they are so enveloped in this "new" world of VI and are desperately trying to regain their lost independence in order to return to their previous level of functioning as before their loss of sight, that other needs are not even contemplated. The overwhelming need by some of the short-term AVI respondents to be totally independent and not have to be dependent on the sighted for help is an unrealistic need which will never be satisfied. This need reveals a total lack of insight about the implications and limitations of adventitious VI.

#### 6.3.5.2 *Inferred Independence Needs*

Although the long-term AVI respondents (unlike the short-term AVI) do not explicitly describe a need for independence per se, there is, at a deeper level, a desire to return to their psychological orders of independent individuals. This need is infer from subtle descriptions, such as, needing to be treated and to be able to behave as "normal" individuals.

This inferred need for independence, as in the case of 25

experienced emotions and attitudes of frustration and acceptance respectively, is a cyclical, oscillating but episodic need. It exacerbates only in specific situations or at specific times when the long-term AVI become acutely aware of the irrevocable limitations related to their loss of independence and their need to be dependent on others (needing transport in urgent situations). A possible explanation for not expressing this need explicitly, is that length of time of the adventitious VI has increased the AVI respondents' self-awareness about the realities, implications and limitations of loss of sight, specifically, the reality that they will never be as "independent" as they were before their loss of sight. They do however, acknowledge a balance between the need for independence and the need for dependence in order to function optimally with their chronic VIS.

#### *Need to See Again*

The researcher included the need or wish to see again, expressed by many of the AVI respondents, regardless of length of time of their adventitious VIS, as an inferred need for independence. This was based on the assumption that seeing again would give these AVI individuals back their independence. What is interesting however, is that it is only the AVI respondents who are totally or functionally blind who express this need.

Wishing to see again, as with emotional and attitudinal reactions is not experienced continually but is a cyclical, oscillating but episodic phenomenon. Wishing to see again is dependent on specific meaningful situations or times where the AVI recognise more acutely the disparity between being able to see and not being able to see (not able to participate in activities with children).

The argument put forward by researchers (Conyers, 1992; Dodds et al., 1991; Schainholz, 2000) that "longing to see again" is a measure of the inability to accept the permanence of loss of

sight is challenged by the revelations of this research study. It is the functionally and totally blind, which includes both short-term and long-term AVI respondents, who wish to see again. Given the fact that both groups of respondents in this study have accepted their loss of sight to varying degrees, ranging from absolute to oscillating acceptance respectively, stimulates the challenge. This finding accords with research by Murray (1998) who states that this feeling of wishing to see again is probably not a measure of acceptance of VI but rather a natural feeling which will occur regardless of the length of time of the adventitious VI. This research however, gives additional insight into this phenomenon for it reveals that it is those AVI respondents with higher degrees of vision loss who express this cyclical, oscillating but episodic need. The phenomenon may occur, especially with the long-term AVI, who are more aware of being confronted with personal and environmental demands which continually change from situation to situation and from time to time. It is precisely at these times that the AVI long to be able to see again in order to perhaps cope better with the changing situations and related emotions.

It therefore becomes critical that all people, including the AVI themselves, are made aware of the different degrees of visual abilities so that they can understand and be sensitive to the diverse experienced needs, like needing to see again. Knowledge and understanding will avoid this need being judged as pathological. The degree of visual ability, that is, higher degrees of visual loss, and the length of time of the adventitious VI are related to the need, or wish to see again. Research into this interesting phenomenon is needed.

#### 6.3.5.3 *Specific Independence Need*

Many of the AVI respondents, regardless of length of time of their VIS, need financial independence and security. Loss of sight increases everyday expenses for the AVI to supplement the diverse areas of loss. For instance, medical expenses to try to

preserve sight, and expenses associated with purchasing adaptive aids, like white long-canes for travel or adapted computers with voice synthesizers. These expenses in turn, result in even more financial dependency to meet these needs, feelings described by many of the AVI respondents in this research study.

Employment would satisfy this need. Only one long-term respondent has procured a "stereotypical" telephonist job during the time course of the two interviews. The thwarting of the AVI respondents' need for employment is perceived to be associated with the misconceptions or stereotypes of the sighted world that AVI individuals are incapable and therefore not employable. On the other hand, employment as the stereotyped telephonist is deemed suitable for VI individuals. These misconceptions regarding employment result in great frustration for all the AVI respondents regardless of length of time of the adventitious VI. An interesting observation for the researcher was the number of respondents, especially the short-term AVI, attending the telephony training course. This occurrence however, accords with research by O'Day (1999) who found that society, and in particular, rehabilitators, tend to counsel the AVI into a narrow range of stereotypical vocational roles, such as switchboard operators. More research into this phenomenon is warranted.

For the low vision AVI respondent who has regained employment, the financial rewards of being employed are inextricably intertwined with psychological and emotional reactions. She has greater self-esteem and feelings of competence, self-efficacy and self-confidence. What is interesting however is how the attitude of this long-term AVI respondent changed over time from being totally against a stereotypical telephonist job to accepting employment as one. The implication here is that the dire need for financial security overrides the dreaded stereotypical employment deemed suitable by society for AVI individuals.

#### 6.3.5.4 *Need for Understanding*

None of the short-term AVI respondents in this research study

express the need for understanding about VI issues. On the other hand, the long-term AVI respondents' overwhelming need is for all individuals, including the AVI themselves, and all those who form part of their social networks, such as, families, friends, Ophthalmologists and rehabilitators, to acquire knowledge and understanding through honest information and real facts about adventitious VI.

All individuals need to be made aware of and understand the real world of adventitious VI rather than a fallacious and superficial understanding. With such honest knowledge and real understanding of the implications and limitations of living with a chronic VI, they, which of course includes the AVI themselves, can become responsive and sensitive to the needs, issues and problems facing AVI individuals. This need accords with research by Rosenbloom and Goodrich (2000) who found that the low vision diplomates survey data for their rankings of the highest priority need in low vision research was the need for improved public and professional awareness of VI issues.

Significant for the researcher is the long-term AVI respondents use of the word real world of VI which has implications that what is needed by these long-term AVI is knowledge that is accurate, genuine, factual and true. There is thus an implication that it is only with time and living the experience of the real world of adventitious VI for themselves, that these AVI respondents have become aware about the fallacious, assumptive and superficial understanding they initially had of their VIS.

Related to the lack of awareness and understanding about basic VI issues, is the long-term AVI respondents' expressed need for all individuals, including the AVI themselves and in particular, rehabilitators, to know and understand that acceptance and adjustment and especially, emotional adjustment, to living with a chronic VI is a cyclical, oscillating but episodic process which is never final. As the long-term AVI respondents were not made aware of this fact during rehabilitation, there is an

inference that society, including rehabilitators, are not aware themselves of this process. There is thus, an need for all individuals, including the AVI themselves, to be made aware and understand this phenomenon.

A possible explanation for the non-expressed (short-term AVI) versus the expressed (long-term AVI) need for understanding and awareness is given by researchers (Dodds, 1991; Elliott et al., 1991; Epstein, 1993; Tuttle, 1984) that years may elapse before the AVI become aware of the reality and the full extent of the implications and limitations of living with an adventitious VI. Sadly, the lack of understanding and awareness about the implications and real world of adventitious VI by society in general and rehabilitators in particular, make it extremely difficult for the AVI to become aware of and understand the never ending implications and limitations of their loss of sight. It appears that it is the AVI themselves who have to travel this long and winding and rocky road alone to discover this real world of VI. The long-term AVI in this research study appeared to have journeyed a long way down this real road of adventitious VI.

#### 6.3.5.5 *Need for Knowledge of Different Degrees of VI*

Only one short-term AVI respondent in this research study expressed the need for people to be made aware of the different degrees of visual abilities. On the other hand, all the long-term AVI respondents need people, including the AVI themselves, society in general and the rehabilitators to have knowledge and understanding of the real facts about the different degrees of visual abilities. The different degrees impact on AVI individuals' needs, abilities, expectations, as well as the associated limitations.

The extreme variation and different degrees of visual ability among AVI individuals is little understood by society in general, and unfortunately, often by the AVI themselves, and often becomes the basis for misunderstanding and confusion. 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 as AVI individuals, depending on their degree of vision loss, have different abilities and needs. The totally and functionally blind for example, need to walk with white long-canes, whilst the low vision AVI are often able to walk without any assistive device, and some are still able to drive motor cars; some AVI individuals with tunnel vision are able to read normal print at normal distances but encounter difficulties travelling without a white long-cane, or on the other hand, those AVI with sufficient residual vision can travel without the cane, but are unable to recognise faces at two paces (Dodds, 1993a; Lund & Dietrichson, 2000; Tuttle, 1984).

The degree of visual ability is important in the employment environment. Only one low vision AVI respondent procured employment during the time course of the interviews. This occurrence accords with research (Crudden, 2002; La Grow, 2003; Leonard & D'Allura 2000) which showed that when the numbers of visually impaired individuals in paid employment were broken down according to degrees of visual ability, those with the least amount of vision are less likely to be in paid employment than those with a little or lot of usable vision.

Awareness of the real facts of the different degrees of visual abilities ought to make all people sensitive to the diverse needs, issues and challenges facing AVI individuals. The impact of the lack of knowledge about the different degrees of visual abilities is evident in many of the situations already described in this research study, namely, the emotions experienced especially frustration because of this lack of knowledge and the related stereotyping that goes hand in hand with the lack; the described "faking" about visual abilities by the low vision AVI respondents precisely because of this lack of knowledge and understanding; the AVI respondents with higher degrees of vision loss who express the cyclical, oscillating but episodic need to see again, and feelings of isolation and rejection; and the only



AVI person employed has low vision. To the researcher, this need was the most significant finding from the research study for it highlights the total lack of knowledge, understanding and sensitivity towards one of the most basic or fundamental issues of VI, namely, is there any residual vision and if so how much? With this knowledge, appropriate support can be given as well as pertinent and factual information being passed onto the naive new AVI person. There is a need for this issue of the lack of knowledge of the different degrees of visual abilities to be definitely researched further.

#### 6.3.5.6 *Need for Timely Confrontation*

None of the short-term AVI respondents in this research study expressed the need to be confronted as soon as possible with VI issues. On the other hand, all the long-term AVI respondents expressed the need to be confronted as soon as possible with honest information and the real facts about the real world of their VIS. All the psycho-social and physical implications, limitations and long-term effects of living with a chronic adventitious VI needed to be shared with them as soon as possible. AVI individuals need to be confronted with the realistic world of adventitious VI as soon as possible, because they 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). Familiarity of the facts does not necessarily destroy hope and degenerate despair, rather, awareness of facts and openness in communication can advantageously affect AVI individuals' abilities to confront their various objectives and goals with deeper insight and understanding (McKay, 1990).

Involving the family in rehabilitation, as well as providing education, counselling and honest information and explanations through open communication, would reciprocally help the AVI and all members of their social networks to cope better with living with a chronic adventitious VI. This need is emphasised by a

comment from a long-term AVI, "knowledge and awareness is powerful and is important for coping." Had this need been confronted as soon as possible and satisfied during rehabilitation, the AVI respondents and their families, or support systems, would have had insight and knowledge to cope better with their situations, would have been better prepared for their futures, and families would have been able to offer appropriate support.

#### 6.3.5.7 *Need for Long-Term Emotional Support*

An explicit, but also inferred, need for appropriate long-term emotional support is expressed by both the short and long-term AVI respondents. This long-term emotional support is needed by the AVI respondents to help them cope optimally with their situations, and to feel accepted, cared for and loved.

Some of the families of the AVI provided, and continue to provide positive support, both practical and emotional. There are those families however, who provide no support at all to the AVI. This situation impacts negatively on both coping and emotions. Overall, it is the friends of both the short and long-term AVI who meet their need for long-term emotional support. This finding accords with research by Reinhardt (2001) who found that instrumental support (practical and tangible assistance) from family members of AVI individuals was associated with better adjustment and coping, whereas, affective or emotional support (caring, trust, empathy and acceptance) from friends was associated with better adjustment and coping with vision loss and greater life satisfaction.

The emotional manner in which family and friends try to adjust to AVI individuals, such as, over protection, rejection, unrealistic expectations, and misconceptions about adventitious VI result in negative interactions (Connor & Muldoon, 1973; Dodds, 1991; Tuttle, 1984). These negative interactions are actually additional stressors for the AVI respondents (Conyers,

1992; Vachon & Stylianos, 1988).

Emotional support in the form of listening and communication is needed by the AVI. This emotional need accords with research (McKay, 1990; Raphael & Nunn, 1988; Webb, 1992) which found that 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, both practically and emotionally.

The need for emotional long-term support could possibly be explained by the fact that whilst it may appear that working through and adjustment to adventitious VI following rehabilitation has occurred with the outward resumption of practical daily and social living skills, an inner felt experience of powerlessness may be belied by a superficial outer confidence (Conyers, 1992; Roy & Mackay, 2002). In Conyers' research, (1992) the greatest difficulty experienced by the AVI respondents, during and following rehabilitation, was in relation to inner emotional needs, a situation relevant to many of the AVI respondents in this research study.

The need for long-term emotional support goes hand in hand with the long-term AVI respondents' perception of a chronic grief process, with cyclical, oscillating but episodic emotions, attitudes and needs. Consequently, the issue of continued emotional support must be considered in terms of whether family members and friends perceive the grief process as the traditional resolvable and time-limited process, or a chronic, cyclical, oscillating but episodic process. Those families or friends who uphold the assumptions of a resolvable grief process may encourage and expect the AVI to recover from their loss and satisfy completely their emergent needs. Associated with this expectation is an inference that continued emotional support is no longer needed (Conyers, 1992; Reiss et al., 1986; Webb, 1992).

On the other hand, those family members and friends who perceive a chronic, cyclical, oscillating but episodic grief process, and thus by implication, ongoing ascent and descent process of need satisfaction will be able to offer appropriate long-term emotional support (Davis, 1987; Lindgren et al., 1992; Tuttle, 1984; Webb, 1992). The need for long-term emotional support is there because it would appear that families and support systems are not aware of chronic grief. More research into this important phenomenon is needed.

#### 6.3.5.8 *Need for Awareness Within Rehabilitation Context*

The researcher deemed it necessary to discuss in more depth the awareness of VI issues and the satisfaction of needs within the rehabilitation context, given the pivotal role it has to play in making AVI individuals understand the implications and limitations of living with a chronic adventitious VI.

#### *Effective and Ineffective Rehabilitation*

The short-term AVI respondents feel that the rehabilitation process was effective as they all perceive themselves to be independent and adjusted, both practically and emotionally, to their adventitious VIS. It is inevitable therefore, that the short-term AVI as well as the rehabilitators uphold the ideal of rehabilitation being a goal-directed and time-limited process. The main aim of rehabilitation is to emphasise the restoration of maximum personal and practical independence to allow AVI individuals to adjust to their acquired VIS by learning and acquiring new skills, techniques and adaptive aids which they need to function independently within their total psycho-social and physical environments (Atkinson, 1990; Conyers, 1992; Del Carmen & Marzo, 2000; Miller, 2002; Miller et al., 1994).

On the other hand, the long-term AVI respondents perceive the rehabilitation process as being ineffective and a negative experience. These perceptions are disquieting because it is

presumed and expected that the trained specialist rehabilitators would be in the best position to help the AVI to become aware of and understand the real world of their VIS. The negative experiences were evident in the following areas: the rehabilitators not being committed to their responsibilities; their lack of awareness and knowledge of the real fundamental issues of loss of sight, and especially the different degrees of visual abilities; not being aware that adjustment to adventitious VI is a life-long, cyclical and oscillating process; the lack of emotional support following rehabilitation; as well as being given unrealistic hope for the future. All these afore-mentioned matters of the lack of knowledge and understanding about the real fundamental issues of adventitious VI, not only from the rehabilitators but society in general, are the main circumstances causing the experienced frustrations as well as the overwhelming needs for understanding and awareness to allow optimal coping and functioning for the long-term AVI.

The long-term AVI respondents uphold the perception of rehabilitation as defined by Moore (2003) who 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. The belief by researchers (Lund & Dietrichson, 2000; Robertson & Brown, 1992) that the rehabilitation process must be conducive to inner growth for AVI individuals to which the whole atmosphere of the rehabilitation setting must contribute was not realised for the long-term AVI in this research study.

#### *Realistic Awareness of Rehabilitation Process*

Rehabilitators need to become aware that the acquisition of independent mobility skills and braille, which are presumed to be the corner stones of rehabilitation, depends on AVI individuals' abilities, level of interest and personal aspirations. They need to be aware that the complex interaction

of psychological and emotional factors impact on the likelihood of AVI individuals benefiting from these skills (Berndtsson, 2000; Dodds, 1993b). It would appear that the rehabilitators did not consider the degree of visual abilities, the level of interest and personal aspirations, nor the psychological and emotional impact, especially frustration, that this lack of consideration or inquiry had on the AVI respondents, and in particular, the long-term AVI. There are some AVI respondents in this research study who refuse to use a white long-cane because they deny or reject the symbolism of blindness that the aid represents, or they do not have to use the long-cane because of their visual abilities. Many AVI respondents do not have to use the stereotypical and assumed medium of braille as they themselves have found alternative methods for communication and information collection.

Rehabilitation must be based on the unique needs and requirements (both emotional and practical) of each individual AVI person. It is vitally important for rehabilitators to know how meaningful achievement is for the AVI in the various areas of rehabilitation, and to what degree achievement can lead to them becoming more content and experiencing increased quality in their lives.

The AVI respondents, especially the long-term AVI, in this research study endorse the notion that whilst practical rehabilitation such as, the acquisition of mobility skills 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 (Conyers, 1992; Roy & Mackay, 2002).

#### *Trained Rehabilitators*

The long-term AVI, as opposed to only one of the short-term AVI, stress how important it is that rehabilitators receive proper training and counselling so that competent and aware

rehabilitators can convey factual and honest knowledge and information to the new AVI during rehabilitation. It is alarming that the AVI respondents, both short-term and long-term, perceive the rehabilitators not being aware of the different degrees of visual abilities and that all were treated as "blind." The rehabilitators' perceived lack of knowledge and awareness of the different degrees of VI has an assumption of the uniqueness and individuality of each AVI person, with their different degrees of vision, not being addressed during rehabilitation. There is a further implication of stereotyping if all AVI individuals are rehabilitated as blind. More research about this disturbing matter is warranted.

All the long-term AVI, as opposed to none of the short-term AVI, state that the rehabilitators best suited to provide the honest and factual information about adventitious VI should be AVI professionals. This is based on the perception that only individuals who have experienced loss of sight in their adult years will be aware of and understand the complex implications and limitations of living with a chronic adventitious VI, an understanding that the long-term AVI seem so anxious to obtain. The need for competent and aware rehabilitators accords with research (Abner & Lahm, 2002; Butler et al., 2002; Wolf & Spungin, 2002) which (although describing training in assistive devices, is applicable to all areas of training for the AVI) found that in order to provide high quality services and instruction it is vital that certified instructors of the AVI be well versed in the training, selection and application of current access technologies; be able to train the AVI to master the various technologies so that they can enter the work place (or society) skilled in their use.

*Fellow Rehabilitees Providing Support*

An interesting finding from this research study is that all the AVI respondents, regardless of length of time of their adventitious VIS, stated that the most beneficial part of

rehabilitation was the friends they met and the support and understanding they received from them. The implication here is that when AVI individuals are together in groups (the rehabilitation training course) and experience the same emotions and needs, they are able to understand and offer appropriate support to each other, more so than the rehabilitators. This situation further endorses the long-term respondents' need for AVI professionals to be involved in rehabilitation. This finding supplements research by Fitzgerald (1970) who found that the AVI respondents in his study attributed the positive changes in their feelings to their leaving home to spend several months in a residential rehabilitation centre. This present research takes the suggestion further to add that positive feelings were encouraged by the support and understanding that the AVI respondents got from fellow AVI rehabilitees. These findings support research, albeit research into the impact of non-driving on AVI individuals (Corn & Sacks, 1994; Rosenblum & Corn, 2002b) whose research respondents rated amongst others, the professionals in the field of adventitious VI, the general public, physicians and other health care providers as being insensitive and having little understanding or support for the emotional impact of not being able to drive.

#### *Research Questions Confronted*

Research by Murray (1998) questioned whether rehabilitators presume and uphold the traditional resolvable grief process and if so, is it reinforced onto the AVI during rehabilitation, and whether the unreality of VI is encouraged. From the findings of this research study it would appear that the rehabilitators presume a resolvable grief process, and that the short-term AVI, who are normally associated with rehabilitation, are encouraged to uphold the traditional grief assumptions. It is the short-term AVI respondents who perceive themselves to be independent, accepting of, adjusted to and in full control emotionally and practically, of their VIS, the traditional loss theory assumptions. The rehabilitators encouraging the traditional



resolvable grief process and the unreality of VI were further sanctioned by two interesting findings from this study. One long-term AVI respondent felt that the rehabilitators expected him to have accepted his loss of sight before he commenced rehabilitation. Another long-term AVI respondent who only recently completed rehabilitation 24 years following her initial loss of sight, now feels that time heals, that she is once again independent, has an attitude of hope, albeit unrealistic hope, for a cure for her eye condition, and appears to deny the limitations of her VI. These emotions and attitudes must be considered in the context of the specific time and place of her rehabilitation. The need to research resolvable and chronic grief is accentuated.

#### 6.3.6 AVI Needs and Maslow's Hierarchy of Needs

Many of the emergent needs, both expressed and inferred, of the AVI respondents in this research study reflect those needs as described on Maslow's (1987) need hierarchy. The researcher deemed it necessary to discuss in more depth these hierarchical needs given the crucial role that rehabilitators place on AVI rehabilitees being able to realize their full potentials.

##### 6.3.6.1 *Physiological Needs*

The unsatisfied basic physiological needs for food and shelter continues to be experienced by one short-term AVI respondent. The cyclical, oscillating but episodic need to see again, expressed by the totally and functionally blind AVI respondents accords with the physiological need for sensory stimulation in Maslow's need hierarchy. The researcher included this need as an inferred need for independence based on the assumption that seeing again would give these AVI individuals back their independence {Section 6.3.5.2 Inferred Independence Needs, p. 299}.

##### 6.3.6.2 *Need for Safety*

Safety needs, in the form of needing security, continue to be

experienced by those AVI respondents who feel anxious, fearful, and insecure when they are alone in unfamiliar and unsafe situations or places, or with new and unfamiliar people.

The unsatisfied need for financial security and independence from lack of employment continues to be expressed by many of the AVI respondents regardless of length of time of their VIS {Section 6.3.5.3 Specific Independence Need, p. 300}.

#### 6.3.6.3 *Need for Love and Belonging*

The majority of the AVI respondents in this research study continue to experience unsatisfied needs on this level of Maslow's (1987) need hierarchy. They continue to need acceptance, nurturance and support from family, friends and society in general {Section 6.3.5.7 Need for Long-Term Emotional Support, p.306, and Section 6.3.5.4 Need for Understanding, p. 301}. Included in this level of the need hierarchy are those AVI respondents who continue to be self-conscious about embarrassing themselves in front of people in case they are rejected or not accepted; those who feel insecure and rejected need acceptance; and those who need to be accepted by others as coping AVI individuals. The negative support AVI respondents (both short and long-term) receive from their families and friends is indicative of needing acceptance and nurturance.

This need accords with research (Conyers, 1992; Miller et al., 1994) which found that the need for love and belonging becomes most prominent for the AVI following their loss of sight. This need could possibly be explained by the fact that the unawareness of the basic VI issues impacts on the responses, attitudes and expectations of society, family and friends to AVI individuals' altered capabilities. These attitudes may intensify and influence the emotional and psychological responses of the AVI (needing acceptance as VI individuals) as the external or social dynamics are simultaneously and continually interacting with their internal psychological and emotional world (Conyers, 1992). These

dynamic inextricably interrelated personal, psychological and social forces that operate upon the AVI make their sense of worth and competence especially vulnerable (Tuttle, 1984).

#### 6.3.6.4 *Need for Esteem*

##### *Need for Esteem from Others*

Many of the AVI respondents (both short and long-term) need to be respected by others as coping with and in control of their AVI lives and environments. It would appear that the AVI respondents involved in charitable work for the disabled, and playing healing music need respect and recognition from others for the work they are doing. These needs accord with the need for esteem from others as described by Maslow (1987) which includes the need to be respected by others who recognise and appreciate achievements and competencies.

##### *Need for Self-Esteem*

Need for self-esteem as described by Maslow (1987) includes stable, firmly based high and positive evaluations based on achievements, feelings of dignity and worth, a sense of competence, capability and adequacy, and a sense of personal strength and independence. Based on both the short-term and long-term AVI respondents' contradictory but simultaneous experiences of both self-esteem and self-derogation {Section 6.3.2.1 Self-Esteem and Self-Derogation, p. 283}, it would appear that the AVI respondents' need for self-esteem remains unsatisfied. In addition, some of the criteria for self-esteem as described by Maslow (1987) such as, the need for independence, and particularly financial independence, remains unsatisfied for many of the AVI respondents {Section 6.3.5.3 Specific Independence Need, p. 300}.

The long-term AVI respondents' need (not expressed by the short-term AVI) for grater understanding, awareness and knowledge

about the real world of adventitious VI issues from society in general, the AVI themselves and rehabilitators {Section 6.3.5.4 Need for Understanding, p. 301, and Section 6.3.5.5 Need for Knowledge of Different Degrees of VI, p. 303} is a need not described explicitly by Maslow (1987). This need could however, be the long-term AVI respondents' continued need for both acceptance (need for love and belonging on Maslow's hierarchy) and self-esteem (need for esteem on Maslow's need hierarchy).

#### 6.3.6.5 *Need for Self-Actualization*

If the researcher adheres to the principle as conceptualised by Maslow (1987) that higher needs, namely, self-actualization, cannot be fulfilled until all the basic needs are met, then all the AVI respondents in this research study have not reached this level of functioning. This conclusion is based on the fact that all the AVI respondents continue to experience unsatisfied deficiency needs on all levels of Maslow's (1987) need hierarchy.

Nonetheless, certain questions need to be clarified regarding the notion of self-actualization. If the need to know and understand (which includes the need for truth and meaningfulness), is a meta or higher need on the level of self-actualization (Maslow, 1999; Moore, 1989a), then the long-term AVI respondents are indeed functioning at this level. This assumption is based on their overwhelming needs to know and understand the truth about the real world of their VIS.

An interesting point to reflect upon is Maslow's (1987) reason why people, including the AVI, do not reach their potential. He claims that it is because of individuals' lack of self-knowledge and self-insight which results, as in the case of the short-term AVI respondents, not being aware of their own needs and needing to be dependent on external directives, like advice or suggestions from others, such as, the AVI being dependent on rehabilitators for advice about their VIS, or rules, especially the expectation of a resolvable grief process, a rule emulated

by the short-term AVI respondents. If AVI individuals cannot identify their own needs they cannot realise their potentials (Moore, 1989a).

#### 6.3.6.6 *Maslow's Good Society*

From the AVI respondents' scenarios it would appear that Maslow's (1987) envisaged good society with its institutional arrangements organised in such a way as to foster, encourage and effect optimum good human relationships and where experienced needs can be satisfied is not being realised for the AVI respondents. 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; Dodds, 1991, 1993a; Tuttle, 1984; van Huijgevoort, 2002).

The experienced needs of the AVI respondents support research (Connor & Muldoon, 1973; Tuttle, 1984; van Huijgevoort, 2002) which states that experienced needs are caused not only by AVI individuals' physical limitations but also by the lack of awareness, negative attitudes and the emotional manner in which society attempts to cope with the AVI. There is therefore a need to challenge society's existing negative attitudes towards AVI individuals and to debunk stereotyping, misunderstandings and prejudices for as Keith (in Duru, 2000, p. 685) States that "society suffers from innocent ignorance and needs a massive dose of blindness education."

#### 6.3.6.7 *Maslow's Hierarchy of Needs Shifting*

There has been a move away from Maslow's (1987) notion of the hierarchy of needs as being a one-way linear and invariant trend, an ascent from lower to higher levels, to a recognition that there is both ascent and descent in the need hierarchy (Rowan, 1998; 1999; Wilber, 1995). It is evident from this research study

that the AVI respondents endorse this new notion of both ascent and descent. Those AVI who have reached a certain level of functioning on the need hierarchy but when confronted by circumstances at particular meaningful situations or times that once again produce anxiety or doubt about their acceptability, capabilities or worthiness (self-esteem) descend to lower levels in the need hierarchy. Many of the AVI respondents (especially the totally and functionally blind) descend to the physiological level of needing to see again {Section 6.3.5.2 Inferred Independence Needs, p. 299}. When the AVI have confronted and adjusted to the feelings and attitudes associated with this descent, they are able to once again ascend to their previous level of functioning on the need hierarchy.

It is further evident that the AVI respondents' behaviours are not necessarily motivated by needs on only one level of the need hierarchy as previously assumed. They are motivated on different levels simultaneously, such as, their needs for safety, acceptance and self-esteem. It needs to be questioned whether the cyclical ascent and descent in the need hierarchy and the re-experiencing of already satisfied needs at certain times or situations is analogous to the experiences of the cyclical, oscillating but episodic emotions and attitudes, and by implication, chronic grief, experienced by the long-term AVI.

#### 6.3.6.8 *Maslow's Hierarchy Challenged*

Frankl (1978) rejects Maslow's hierarchy of needs and his view that the lower needs must first be satisfied before higher needs such as, self-actualization, can emerge. He argues that Maslow's distinction between higher and lower needs does not take into account that when lower needs are not satisfied, a higher need, such as, the will to meaning, will become more urgent. The more meaning individuals attain in their lives the more they will be actualised (Frankl, 1978). There is meaning in all of life's circumstances, even in suffering, and those who can find a meaning for a reason to life, despite adversities and

afflictions, are "capable of taking up the challenge to live with courage and dignity" (Shantall, 1989, p. 429).

Frankl (1978) points out that meaning in life can be found in three types of experiences, the creative things individuals do, the uplifting things they experience, and the kind of attitude that they have to situations of inevitable suffering. "To live is to suffer to find meaning in life is to find meaning in suffering. If there is a purpose in life at all, there must be a purpose in suffering and in dying" (Frankl, 1959, pp 10-11). It can be argued therefore, that loss of sight becomes another one of life's tasks which offers a challenge (Shantall, 1989). Gaining insight into life's meaning of living with a chronic VI can contribute to the significance of life with this loss, but only if the AVI individuals' personalities have ego strength, function appropriately, and if there is a good family or support system (McKay, 1990).

The researcher believes that although all the AVI respondents in this research study continue to experience unsatisfied needs, they are according to her, self-actualisers as they all experience meaning in their lives as AVI individuals, are functioning appropriately and are able to go forward with their challenging lives with courage and dignity. Further research into this phenomenon of the meaning AVI individuals give to their lives is certainly needed.

#### 6.4 SUMMATION OF DISCUSSION OF EMERGENT NEEDS POST-GRIEF

The most significant finding from this research study is that length of time of the adventitious VI impacts profoundly on experienced emotions and attitudes, and by implication, the perception of the grief process, and emergent needs.

The short-term AVI respondents experience occasional emotions and absolute acceptance and adjustment to their VIS, and by implication, resolvable grief. On the other hand, the long-term

AVI experience cyclical, oscillating but episodic emotions (frustration and anxiety), and attitudes (acceptance and adjustment), and by implication, chronic grief.

Length of time of the adventitious VI impacts on realistic awareness of the implications and limitations of the chronic VI, which in turn impacts on experienced needs. The overriding need for the short-term AVI respondents is to regain what personal independence they can and thereby reciprocally maximise their self-esteem. The overwhelming needs for the long-term AVI respondents on the other hand, is for understanding, awareness and knowledge about the real world of their VIS with all its implications and limitations, and their need for emotional long-term support. Specific needs are emphasised, with the short-term AVI experiencing practical needs (practical independence) with the long-term experiencing psychological (awareness and understanding) and emotional (emotional support) needs. One of the illuminating insights gained from this research study is that behind the positive masks of coping, independent and confident AVI individuals are shades and shadows of anxious, often non-coping, individuals desperately determined to cope, by whatever means, with the implications, limitations and their unique needs of living with a chronic adventitious VI.

The different degrees of visual abilities is a central and disquieting need experienced by the long-term AVI respondents in this research study. The different degrees of visual abilities and their specific and unique limitations and the different elicited needs must be acknowledged and understood by all individuals, including the AVI themselves. Nevertheless, in order to satisfy these needs the prevailing negative attitudes, stereotypes and misunderstandings about VI held by society in general, rehabilitators and the AVI themselves need to be challenged. People need to become aware of and understand the reality and the full extent of the implications and limitations of living with a chronic adventitious VI.



It is evident from the discussion that the real experience of adventitious loss of sight has to be described in terms of the interaction of four factors, namely, the practical, psychological and emotional needs of AVI individuals, the degree of sight loss, the physical and social environment of these individuals, and the common conception of VI (Tuttle, 1984).

## 6.5 CONCLUSION

In this Chapter, the findings obtained from the phenomenological inquiry into the emergent needs post-grief experienced by AVI adults following their loss of sight were described and discussed. The overwhelming finding is: Although the AVI respondents have individual and unique perspectives and meanings of their loss of sight, the length of time of the adventitious VI, and the realistic or unrealistic awareness of the reality, implications and limitations of living with a chronic VI, as well as an understanding about the different degrees of visual abilities, profoundly impacts on experienced emotions and attitudes (the perception of the grief process) and emergent experienced needs. The findings of this research study also challenged the traditional resolvable grief process and highlighted the conceptualised concept of a chronic grief process. Possible explanations were made to explain the differences in the findings between the short-term and long-term AVI respondents.

Interpretation of this study has however been limited by the lack of appropriate research regarding psychological, emotional and attitudinal reactions and needs of AVI adults, as well as the concept of a chronic grief process. More research is needed regarding adventitious VI and related issues which were suggested and hinted at during this research study.

In the next and final Chapter, the conclusions of the study, its limitations, recommendations for further research and the question of whether insight leads to ability will be addressed.