

CHAPTER FIVE

FINDINGS FROM THE TAPESTRY OF THE EXPERIENCES OF LOSS OF SIGHT

5.1 INTRODUCTION

The ten AVI respondents' perspectives of their loss of sight, their experienced emotions and attitudes, and by implication, their perception of the grief process, their experienced emergent needs and the level of support they experience in meeting these needs, all of which are represented in this chapter, provide a mere glimpse of the entire tapestry of the experience of loss of sight. The specific degree of vision loss, the length of time of the adventitious VI of each respondent, together with their personalities, challenge their lives in particular ways and determine the nature of individual responses to loss of sight. Although psychological, emotional and factual insights into the AVI respondents' experiences are gained by focusing on certain segments only, they do not do justice to the uniqueness of every person's experience of loss of sight.

In the discussion of the findings to follow, the similarities and differences between the AVI respondents' experiences of their loss of sight as well as the similarities and differences between the two groups of AVI respondents, namely, those AVI for less and beyond 6 years, with special reference to similar experienced needs as conceptualised by Maslow (1987), together with general statements regarding the experience of losing sight are presented. This strategy will complete the final phase of the phenomenal explication {section 3.8.5.1 (D) General (Nomothetic) Psychological Structures of Meanings, p. 115}.

5.2 AVI RESPONDENTS' PERSPECTIVES OF LOSS OF SIGHT

After a rigorous analysis of the data emanating from the AVI

respondents' narratives regarding their perspectives of their loss of sight, one central theme emerged: loss of sight is an unique, individual and idiosyncratic experience. Within this central theme however, three sub-themes were identified with the AVI respondents expressing similar connections to at least one of the sub-themes.

Loss of Sight has a Purpose:

Peter, Chantal, Allan and Mary each in their own idiosyncratic contexts, perceive their loss of sight as having a "purpose." Peter, within the context of his suicide attempt and subsequent loss of sight, perceives that the purpose of his loss of sight was to give him a "second chance" for a new start in life with a new found faith in god, something which he understands as a "gain." Chantal, within the context of her attending rehabilitation and courses many years following her loss of sight and particularly now with the prospect of a switchboard job, claims that it is precisely her loss of sight which has given purpose to her life by allowing her to complete different courses which have afforded her a new beginning and start in life, "i'm so excited about my job which will give a new meaning to my life." Within the context of Allan being able to start afresh with his "artistic" and more relaxed and enjoyable life, he believes that he has gained both spiritually and emotionally, and that the purpose of his loss of sight is to help both others and himself by playing "healing" music. Mary, within the context of her doing charitable work for the disabled, claims that she is now aware that her loss of sight has a purpose for it is only since her loss that she has different spiritual and social values of serving and caring about people, especially disabled people.

Loss of Sight is a Challenge:

Susan, Annette, Amanda and Gail, each in their own idiosyncratic contexts, perceive their loss of sight as a challenge. Susan, within the context of her christian belief,

contends that her loss of sight has a purpose, but that she is challenged to understand and know what it is, "I am here for a purpose, I just need to find that purpose." Annette's experience of her VI is the challenge of a life journey on an "uneven road" and despite being able to live and behave as "naturally and normally" as she did before her loss, she is confronted with "circular" and oscillating challenges associated with her loss. Amanda claims that it was her loss of sight which initiated her "learning" process for she had to, and continues to, be challenged by questioning and analysing both her past and future. Gail experiences her loss of sight as a life-long challenge because she continues to experience ongoing losses associated with her loss, and in this context, views her loss of sight as a circular but oscillating experience which elicit similar already confronted emotions, which in turn, need to be challenged again.

Loss of Sight is an Inconvenience:

Paul and Jane perceive their loss of sight as mere "inconveniences." Although Paul perceives himself as being able to carry on with and be in control of his normal independent life as before, he experiences the inconvenience of having to deal with the "side-effects" of his loss. Jane views her loss of sight as an inconvenience in the sense that she perceives the loss as an ordinary mundane "obstacle" she has "overcome."

The AVI respondents' perspectives of their loss of sight and their self-images, or better perhaps, the imagined self that they suppose themselves to be are closely intertwined and impact reciprocally on each other. All the AVI respondents in this study appear to have positive images of themselves which can be deduced from both their perspectives of their loss of sight and by their language use with regard to their coping with their loss. The AVI respondents describe positive perspectives of their experiences of their loss of sight which is evident in the emanating sub-themes which appear to have positive connotations, the only

exception possibly being the perspective of "loss is an inconvenience," and Susan's perspective of her loss being a "challenge" which perhaps portray neutral or negative connotations. The respondents' images of themselves as positive, coping, in control, adjusted and confident AVI individuals can be deduced from their language use, such as, "I think I'm a very positive person" (Allan), "I really coped very well and adapted very fast" (Peter), "I think I coped and still cope" (Mary), "i'm at the stage where I'm in full control of my VI" (Jane), and "I am confident again and I can do anything" (Paul). By maintaining positive images of themselves, the AVI respondents continue to be able to go forward with their lives despite their VIS, and amidst a multitude of losses.

The awareness gained from the data of the 10 AVI respondents is that they all face their loss of sight in their own particular and unique ways and deal with the issues specific and peculiar to them. The diverse and unique perspectives the AVI respondents have towards their loss of sight give specific meaning to their experience of living with a chronic bi. Their individual and unique perspectives of their loss of sight, together with their positive self-images determine to a large extent their responses and attitudes towards their loss of sight, what life direction to follow and the decisions to be made about their futures. It would appear that the AVI respondents are able to move beyond the difficulties of the visual loss experience and are able to create new and unique ways for approaching life.

5.3 EMOTIONAL AND ATTITUDINAL REACTIONS TO LOSS OF SIGHT

As loss of sight is an individual and unique experience for each of the AVI respondents in this study, it is inevitable that unique and idiosyncratic emotional and attitudinal reactions will be experienced. Nevertheless, both similar and different emotions and attitudes were expressed by all the AVI respondents, but a certain pattern emerged with a clear distinction between the short-term and long-term AVI with regard to certain reactions.

After a rigorous analysis of the data emanating from the AVI respondents' narratives, one central theme emerged: length of time of the adventitious VI, together with a heightened awareness about its implications, impacts on emotions and attitudes to loss of sight, as well as the perception of the grief process. Within this central theme however, sub-themes were identified with the AVI respondents expressing both similar and different connections to them (Table 5.1).

5.3.1 **Summary of Delineated Sub-themes and Related Emotions and Attitudes**

5.3.1.1 *Emotions and Attitudes Related to Realistic Awareness Versus Unrealistic Awareness of the Reality and Implications of Loss of Sight*

A significant finding from this research study is that the length of time of the adventitious VI impacts on the realistic awareness of the reality, implications and limitations of the impairment which in turn, impacts on experienced emotions and attitudes towards loss of sight.

The Use of Denial:

All the AVI respondents in this study have used denial at some stage during the time course of their adventitious VIS. Nevertheless, more short-term than long-term AVI respondents continue to use unrealistic denial of the reality, limitations and emotions associated with their loss of sight as a means of coping. Jane, Allan and Peter deny any emotions associated with their loss, with Jane and Allan believing that they do not have eye problems. Peter denies the implications, limitations and reality of his loss of sight and believes that he can "do anything." Susan denies the reality of her loss of sight as she believes that she must still awaken from a "bad dream" to be able to see again, and attempts to look as "normal" and sighted as possible. Amanda denies the limitations of her loss because of

her hope that she will see again.

Paul and Chantal (long-term AVI respondents) deny the limitations of their loss of sight as they believe that they can "do anything." Paul denies experiencing emotions associated with his loss of sight and describes that these emotions are inconsequential to his loss.

Table 5.1 Self-reported emotional and attitudinal reactions to loss of sight for the two groups of AVI respondents, those AVI within and beyond 6 years, arranged under the delineated sub-themes

Emotion/attitude	Nos < 6	Nos >6
Unrealistic emotions/attitudes:		
Denial	5	2
Unrealistic hope	5	1
Emotional coping:		
Displacement	5	4
Faith	4	1
Cyclical & episodic emotions/attitudes:		4
Hope & contentment	3	4
Pride	2	2
Self-esteem	5	5
Negative emotions/attitudes:		
Anxiety	4	4
Embarrassment	1	3
Frustration	3	5
Sadness	3	1
Ambivalent emotions/attitudes:		
Acceptance	5/absolute	5/cyclical

Unrealistic Hope:

All of the short-term as compared to the long-term AVI in this

study describe unrealistic hope about their futures as AVI individuals. Unrealistic hope is the desire to have life circumstances as the way they were without incorporating the fact of a changed reality and substantiates the short-term respondents' use of denial about the reality of their loss of sight. Amanda and Susan continue to have unrealistic hope that they will see again, sanctioned with Amanda's comment, "until I'm able to see again." Peter has unrealistic hope that he will become an architect or civil engineer despite his functional blindness, heightening his lack of awareness of the implications limitations and reality of his VI. Jane's hope throughout her experience continues to be focused on the ability of surgery to preserve her sight, a hope reinforced by "time healing" because for 18 months her eye condition has remained stable. Allan's hope is that his "time healing" will also preserve his sight. Within these contexts, both Jane and Allan have, to a certain extent, unrealistic hope that their sight will remain constant.

Chantal is the only long-term respondent who has unrealistic hope of a cure for her eye condition, "as yet there is no cure." Her "unrealistic" hope, together with her denial of the limitations of her VI, appear to have intensified following her rehabilitation years following her initial loss of sight.

5.3.1.2 *Positive and Negative Emotions and Attitudes*

A significant finding from this research study is that the AVI, regardless of length of time of their adventitious VIS, continue to describe more negative than positive emotions and attitudes towards their loss of sight. The short-term AVI however, describe more positive emotions whereas, the long-term AVI describe more negative emotions (Table 5.1).

Positive Emotions And Attitudes

Hope and Contentment:

Susan and Peter (short-term respondents) describe hope about

their futures, with Susan's comment, "I can see there is light now;" and Peter's hope for a better job with appropriate skills. Chantal (long-term respondent) expresses hope and excitement about her future and is optimistic and hopeful that she will get a switchboard job and that she will then be able to put her life together. Chantal's present hope must be seen in the context of her attending rehabilitation and courses many years following her loss of sight and particularly now with the prospect of a switchboard job. Peter, Allan and Paul are positive, optimistic and contented with their lives as AVI individuals, with descriptions such as, "I am as happy as can be," and "I'm enjoying my life."

Pride:

Only two short-term AVI respondents expressed pride about their achievements as AVI individuals. Jane feels proud about being able to offer private tuition to bring in extra money and about succeeding in the courses she has attended at Optima. Peter feels proud about having a steady job which he feels is an improvement to his situation before his loss of sight when he was in and out of many diverse jobs, a situation which now enables Peter to "enjoy" his life.

Self-Esteem:

Positive self-esteem and its concomitant attributes continue to be experienced by all the AVI respondents in this study regardless of the length of time of the adventitious VI. The positive "self-esteem" enhances the AVI respondents' perceptions of independent and coping AVI individuals.

Self-Confidence, Self-Determination, Self-Assurance, Self-Efficacy, Self-Control, Self-Awareness and Self-Worth:

Jane and Mary are confident in their capabilities to cope with their VIS and are determined to carry on with their lives despite

their loss of sight. Amanda is determined to carry on with her life as an AVI person with the hope that she will see again. Peter, Allan and Paul perceive themselves to be independent, self-assured and self-confident AVI individuals who believe that they are in control of their lives and VIS and are determined to move forward with their lives. By regaining her independence, Susan perceives herself to once again be self-sufficient and adjusted to and coping with her loss of sight. With time, Gail has gained self-awareness of the real world of her blindness, with all of its implications and limitations and is determined to meet the "challenge" of her blindness in order to carry on with her AVI life. Annette believes that her self-esteem has improved the longer she has been AVI, and especially now with her new job and her increased self-confidence and self-worth. Chantal perceives herself as an independent and coping AVI person whose self-worth has improved after completing courses at Optima.

Negative Emotions And Attitudes

Sadness:

Sadness continues to be experienced more so by the short-term AVI respondents than the long-term AVI respondents. In this study, Amanda and Chantal (short-term and long-term respondents respectively) continue to experience sadness especially in situations which involve their children and their inability to participate in activities with them because of their loss of sight. Amanda also continues to experience sadness with her husband's lack of support and his negativity towards her. Susan and Jane continue to experience sadness because of their loss of independence and having to be dependent on others. In addition, Susan experiences sadness with her non-coping of the financial difficulties her family is experiencing, and the non-understanding and rejection by her mother.

Anxiety:

Anxiety and its concomitant emotions and reactions continue to

be experienced by all the AVI respondents in this study, regardless of length of time of the adventitious VI.

Anxiety, Fear and Distress:

Jane, Allan and Annette (all low vision respondents) fear losing their remaining vision because they believe that they will not be able to operate as "blind" individuals and that their self-identities of independent, coping and "normal" individuals will be replaced with a stereotypical identity of dependent, non-coping and different "white stick pushers." In these particular cases, anxiety and denial are intertwined as they all use denial by not walking with the symbolic white long-cane in an attempt to control the threat and fear of "blindness."

Amanda, Susan, Annette, Mary and Paul fear being perceived and judged by others as not coping with their VIS and not being in control of their lives and environments. In addition, Annette, Susan, Chantal and Paul fear that other people will perceive them as being "different," or "stupid," because they are AVI. In order to control their anxiety and fear about "blindness," Susan, Annette and Paul try to conceal the fact of their vision loss by behaving as "naturally and normally" as before their loss, and Jane fails to disclose the extent of her visual ability.

Mary continues to experience anxiety and distress about her divorce more so than her physical loss of sight, and people, and especially friends, because of their lack of awareness of VI issues, disappoint and hurt her which causes anxiety and distressed. Allan continues to experience anxiety and distress with the consequences of losing sight, such as, his loss of his job, house and pension, and his heart attack is of more concern to him than his physical loss of sight because he is anxious about not having enough time to fulfil all his life dreams.

Jane, Susan, Allan and Annette experience anxiety and distress about not being able to cope financially because of their loss

of sight. Jane and Allan's lack of money is anxiety provoking especially if more surgery is in the offing.

Insecurity, Uncertainty, Loss of Worth and Confidence:

Jane, Amanda, Annette and Chantal experience anxiety, fear, insecurity, uncertainty and a loss of confidence when they are alone in unfamiliar and unsafe situations or places, and Chantal also feels anxious and insecure when she is with new and unfamiliar people. Susan experiences anxiety, insecurity and uncertainty about her future and being as independent as she was before her loss and being able to do "normal" things as before. Jane often feels worthless when she needs to ask for help because being a private person, it is difficult for her. Mary is anxious when she feels insecure and ineffectual in situations when she cannot do things or when she is not kept busy and it is in these situations that she loses her self-worth, "I'm searching for something to do to fill a gap or a void in my life."

Self-Consciousness, Embarrassment and Withdrawal:

A significant finding from this research study is that more of the long-term than short-term AVI respondents in this study continue to be self-conscious and feel embarrassed about their VIS. Annette, Paul, Chantal and Susan continue to be self-conscious about embarrassing themselves in front of people. They are concerned with what other people will think and say about them being "stupid" or "different" and try to act as "normal" sighted individuals. Embarrassment causes Annette and Susan to withdraw from group interactions, Paul reacts by not "socialising" and Chantal continues to cope by withdrawing and "crawling into a shell." As depression manifests itself through behaviour such as sadness, and in particular, continued experiences of sadness, and social withdrawal and apathy, it would appear that Chantal and Paul reveal a form of depression with their social withdrawals. For Susan, her continued sadness, her withdrawal and her feeling of guilt for the pain that both

her cancer and her loss of sight have cause her parents, and especially her mother, and the drain she has put on their financial resources are all indicative of depression.

Frustration:

Frustration is the one emotion that continues to be experienced by many of the AVI respondents in this study. Although there are similar experiences of frustration between the individual AVI respondents, the more significant finding is the difference in the attitude towards frustration between the two groups of short and long-term respondents.

Frustration is an Episodic, Cyclical and Oscillating Emotion:

The overwhelming emotion which continues to be experienced by all the long-term AVI respondents is frustration. For Mary, Gail and Paul their frustrations have increased in intensity and frequency the longer they have been AVI, their explanation being a heightened awareness of the irrevocable nature of their eye conditions, and the accumulation of the implications and limitations of living with a chronic VI.

All the long-term AVI respondents describe how their experienced frustrations are not constant but episodic, cyclical and oscillating and experienced in specific situations or at specific times which are particularly meaningful to them, and where they become acutely aware of the limitations of their adventitiousVIS. It would appear that three specific circumstances foster frustration for all of the long-term AVI respondents, namely, perceived loss of control over their lives and environments, perceived loss of spontaneity, and lack of awareness of VI issues. For example, Annette and Paul get frustrated when they perceive themselves not to be in control of their lives and situations when for instance Annette cannot do things that she could do when she could still see and the increased time it takes to complete activities; Paul gets

frustrated when he is not in control of building alterations when he has to rely on others to do them; and Chantal gets frustrated when people try to take control of her life by interfering with her organised daily routine. It would appear that the crucial circumstance for the triggering of frustration for Mary, Chantal, Annette and Gail is their perceived loss of control over their lives in urgent situations such as having to wait for urgent things to be read to them and needing transport in urgent situations. Mary and Gail get frustrated in situations when they experience loss of spontaneity, such as, not being able to do what they want to do when and how they want to do it. All the long-term AVI respondents experience frustration because of the lack of awareness from others about VI issues and the associated stereotyping and misconceptions.

Occasional Frustration:

Occasional frustrations are experienced by Jane, Amanda and Susan (short-term AVI respondents). It would appear that the overwhelming circumstance that fosters frustration for the three short-term AVI respondents is their perceived loss of their independence and their need to be dependent on others for help. Amanda does however, experience frustration with her perceived loss of control over her life and her loss of spontaneity at not being able to do the things she could do when she could see and having to plan and organise her life well in advance. Amanda also experiences frustration with her husband's lack of awareness about her life as a VI person and his lack of support.

Frustration and Not being Able to Drive:

It is still very difficult and frustrating for many of the AVI respondents, regardless of length of time of their adventitious VI, to accept they are not able to drive their motor cars. No longer being able to drive a motor car is 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, the perceived loss of control and spontaneity in the AVI respondents' lives in not being able to get in a car and be able to go and do things where and when they want. It is interesting that none of the men in this research study mention the inability to drive as a cause of frustration, possibly because both Paul and Peter have drivers and in Paul's case, living in the same house as himself, who are able to drive them anywhere and at any time. According to Allan, he and his wife walk to wherever they need to go.

5.3.1.3 *Ambivalent Experience of Emotions and Attitudes*

A significant finding from this study is the ambivalence in the described experiences of emotions and attitudes between the two groups of AVI respondents.

Cyclical, Oscillating and Episodic Emotions and Attitudes:

Episodic, cyclical but oscillating reactions of re-experiencing already experienced emotions, especially frustration, in specific situations or at specific times have been expressed by many of the long-term AVI respondents, an experience not described by any of the short-term respondents. Each time Mary lost more sight she became aware that adjustment to VI is a continual process and a re-experiencing of already experienced emotions. Annette believes that she is confronted "a hundred times a day" with the "circular" emotional effects of her VI which she perceives as a never-ending alternation of emotions. Chantal experiences a continuous "up and down" motion of stages of emotions. Gail is confronted with continual losses related to her VI with continuous circular emotions which she experiences and re-experiences. All the afore-mentioned AVI respondents however, express emphatically that the reactions of "cyclical" emotions, as in the case of frustration, are experienced and re-experienced in specific situations or specific times which are particularly meaningful to them, and especially in situations where they become acutely aware of the implications and limitations of their

loss of sight.

Ambivalent Attitude of Absolute Acceptance Versus Cyclical and Oscillating Acceptance:

A significant finding from this research study is the distinct difference in attitudes towards acceptance between the two groups of short and long-term AVI respondents.

Acceptance is an Oscillating and Cyclical Process:

Absolute acceptance of loss of sight is difficult if not impossible for all the long-term AVI respondents in this research study. They all describe how they experience acceptance as a cyclical and oscillating process which is never completed. The cyclical and oscillating process of acceptance and non-acceptance is experienced in specific situations or at specific times which are particularly meaningful to them, and especially when they become acutely aware of the irrevocable limitations of their VIS. It would appear that specific circumstances foster this oscillating and cyclical process. For example, in specific situations or at specific times which cause certain emotions, especially frustration and sadness, Mary, Chantal and Gail do not accept their VIS, and Paul does not accept when he experiences problems related to his VI. Acceptance for Annette and Gail is experienced as a cyclical but oscillating process that is never final because Annette is confronted with the implications of her loss a "hundred times a day" and Gail is confronted with ongoing losses associated with her loss of sight. Absolute acceptance being an impossibility is reinforced with the attitude that "time does not heal." This finding reinforces the experiences of the cyclical, oscillating and episodic emotions and attitudes which are experienced by the above mentioned AVI respondents.

For Chantal, acceptance is perceived as a societal expectation which she knows she can never fulfil. Paul believes that the societal expectation of acceptance following a loss of any kind

was coerced onto him during rehabilitation.

With time and a better understanding of their adventitious VIS, Annette, Paul, Mary and Gail have accepted some of the limitations associated with their loss of sight. For Mary and Gail, acceptance of their limitations have changed over time from believing that they could do anything and that they had no limitations to acknowledging that there are indeed limitations associated with their loss of sight. Paul and Gail have accepted their limitations of needing to be dependent on others for help when help is needed, and Annette acknowledges and accepts that she will never be able to do things that she could do when she could see. Chantal however, denies her limitations by believing that she can do anything, an attitude which has emerged in the context of the specific time and place of rehabilitation.

The long-term AVI respondents also experience adjustment and coping as an ongoing oscillating and cyclical process, the implication being that acceptance, adjustment and coping are intertwined and inter-related. For all these AVI respondents, acceptance of and adjustment to, VI are chronic, oscillating and cyclical feelings, attitudes and processes that cannot be conclusively concluded following loss of sight. Oscillation of any kind, reflects the changes in these long-term AVI respondents' abilities to cope with reality at any given time.

Absolute Acceptance:

All the short-term AVI respondents in this research study have accepted their loss of sight. Jane, Susan and Allan believe that acceptance is related to being independent, coping with and in charge of and adjusted to their AVI lives. Amanda and Peter's attitudes of acceptance of their loss of sight are based on the social expectation that following a loss of any kind, there is acceptance after which coping and adjustment occur. Absolute acceptance is reinforced by all the above mentioned respondents' attitude that "time heals." Acceptance of, adjustment to and

coping with adventitious VI are feelings, attitudes and processes that can be conclusively completed and concluded following loss of sight.

All the short-term AVI respondents' emphatic acceptance of their loss of sight infers denial, as they all appear to be using it as a way of blocking out the painful reality of their loss of sight, which in turn, enhances their positive self-images. In this context, the attitudes and emotions of acceptance, denial and unrealistic hope are all inter-twined and inter-related.

5.3.1.4 *Linear Versus Chronic Grief*

The AVI respondents' perception of the grief process is inferred from their descriptions of their experienced emotions and their attitudes towards acceptance of their VIS, from the time of their initial loss to the present. The significant finding from this study is the distinct diverse perceptions of the grief process between the two groups of AVI respondents.

Linear Grief:

All the short-term AVI respondents in this research study are emphatic that they have accepted their loss of sight. According to them, this attitude means that they perceive themselves to be independent, coping and adjusted to their loss of sight. In addition, they all believe that they have worked through their experienced emotions associated with their loss of sight, or that they only experience occasional emotions, such as frustration or sadness. Acceptance has occurred within a limited time frame ranging from 1,5 to 5 years. These experiences reflect the process of grief as experienced by these short-term AVI respondents as being a linear and time-bound process involving the completion of emotions associated with loss of sight and a final acceptance and certain conclusion of the grief process.

Chronic Grief:

All the long-term AVI respondents experience acceptance as a cyclical and oscillating process. In addition, they all experience oscillating, cyclical and episodic emotions associated with their loss, with many experiencing more intense and frequent frustrations the longer the adventitious VI. These experiences reflect the process of grief as experienced by these long-term AVI respondents as a chronic and ongoing process, involving cyclical and episodic experiences of more intense and frequent emotions related to their VIS, and no final acceptance nor certain conclusion of the grief process.

5.3.1.5 Strategical Emotional Coping

In an attempt to cope with their loss of sight many AVI respondents, regardless of length of time of their adventitious VIS, react by using some form of denial or blocking of painful emotions. Jane, Allan and Annette react to fear of losing more sight by denying that they have eye problems. Mary glamorizes and Allan romanticizes their situations in order to cope. In addition, Mary, Jane, Allan, Annette and Amanda keep busy to deny or block out the painful reality and emotions associated with their VIS. Paul and Peter have become preoccupied with taking control over all situations and people in an attempt to cope and be in control of their lives.

Some AVI respondents, regardless of their length of time of their adventitious VIS, describe how their faith has helped them cope with their loss of sight. Within the context of their Christian beliefs, Amanda describes that following her trauma of the faith healing experience she questioned her relationship with God, but after much soul searching she realised that she was being negative and her renewed faith in god has helped her cope with her situation; Peter believes that he is no longer alone but that his new found faith in God has helped him gain self-confidence and cope with his loss of sight: Susan believes that

her loss of sight has a purpose, but that she is challenged to understand and know what it is; and Mary is now aware that her loss of sight has a purpose for it is only since her loss that she has different spiritual and social "values" of serving and caring about people, especially disabled people. Allan describes how his loss has given him an opportunity to grow spiritually and how "healing" has occurred within him by his being able to play music and help others. Faith underscores all the above mentioned respondents' perspectives that their AVI lives have a purpose.

Sense of humour revealed itself in only two interviews, those of Peter and Gail. Although Peter believes that laughter is his way of coping and adapting to his changed situation, his use of inappropriate laughter throughout the interviews emphasises his denial-like avoidant coping which helps him distance himself from the painful emotional reality of his loss of sight. Gail on the other hand, believes that the appropriate use of her sense of humour and being able to laugh at herself helps her and others cope with the difficult world of her blindness.

In an attempt to cope with their VIS, many of the AVI respondents, regardless of length of time of their VIS, react by displacing their emotions onto the sighted in an attempt to reduce the tension associated with their loss, and thereby, preserve their perceived positive self-images. Jane, Allan, Peter and Paul, who deny emotions associated with their loss of sight, inadvertently expose displacement of emotions. Jane displaces her occasional expressed emotions, like frustration, onto sighted individuals for having to be dependent on them, Allan's frustration, anger, stress and anxiety are displaced onto sighted individuals for he blames them for his loss of his job and his inability to obtain a company pension, Paul's emotions, especially frustration are displaced onto the sighted who will not listen to him, and Peter's anger and frustration was displaced onto the cleaner for his inability to find his money. Mary and Amanda displace their frustration and sadness onto their respective ex-husband and husband because of their lack of

support to help them cope, Susan displaces and rationalises her sadness, embarrassment and frustration onto her parents, especially her mother, for not supporting her, whilst Gail displaces her frustration onto her family because of their lack of understanding of the ongoing implications of living with a VI.

5.3.1.6 *Paradoxical Experiences of Emotions and Attitudes*

An important finding from this research study is that all the AVI respondents, regardless of length of time of adventitious VI, experience both congruent and incongruent emotions and attitudes, effecting paradoxical existences lived simultaneously.

Congruencies:

All the AVI respondents in this study perceive and evaluate themselves as independent and coping AVI individuals with positive self-images {Section 5.3.1.2 Positive and negative emotions and attitudes, p. 239}. These perceptions or self-evaluations, in turn, are congruent with many of their perspectives or meanings of their loss of sight. Jane has emphatically accepted her loss of sight, believes that she is independent, self-confident, coping with, adjusted to and in full control of her VI and life reflecting her perspective that her loss of sight is an inconvenience of a "obstacle" she has "overcome." Mary's perspective of her loss of sight having a purpose reflects how her faith has helped her cope with and adjust to her loss of sight and her somewhat glamorization of her condition allows a positive image of a coping and competent person to emerge. Gail's self-awareness of the difficulties of the real world of her AVI life, supports her perspective that living with loss of sight is an ongoing challenge. Paul perceives himself as a coping, independent and in control AVI person who happens to have the "inconvenience" of an adventitious VI.

Incongruencies:

With deeper analysis and reflection, the more significant

finding from this study is the incongruencies of experienced emotions and attitudes. Each AVI respondent's narrative reflects contradictions which are indeed difficult to reconcile.

Behind the Positive Masks:

Many of the AVI respondents' "real selves" are rather dramatically incongruent with their perceived positive self-images. A deeper analysis of both the described and inferred emotions and attitudes of the AVI respondents negate their evaluated positive self-images resulting in their lives being paradoxes lived simultaneously.

Susan is anxious, insecure and uncertain about her future and being as independent as she was before her loss, and the sadness of her mother's rejection of her and the fear of what lies ahead for her in the future embrace nuances of a person who is unaware of the full-scale implications and limitations of living with a chronic VI and that she has, as yet, not confronted the reality of her loss of sight. Susan's need to be treated "normally" is actually her need for approval and acceptance from people because of her anxiety about being rejected. Mary is anxious when she feels insecure and ineffectual in situations when she cannot do things or when she is not kept busy and it is in these situations that she loses her self-worth. Her need to be involved in many different clubs suggests that she needs attention and to be accepted, noticed and admired by others, with a further inference that this involvement is a mask to cover up her insecurity and non-coping. Paul and Peter need not only to be in control of their lives and blindness but also in control of, and in a contradiction of terms, dependent on other individuals to satisfy their needs, implying a need for attention, care, acceptance and approval from others, implications based also on their inferred insecurities and feelings of inadequacy and rejection. Despite Allan's perceived competence there is a need for him to be accepted by others as a coping and innovative AVI individual.

Jane, Amanda, Annette and Chantal, despite their perceived independence and coping, are anxious and insecure when they are in unfamiliar and unsafe situations or places or with unfamiliar people. In addition, Chantal is distrustful of people, especially sighted individuals, feels susceptible and has self-doubt about her capabilities or in other words, is totally self-devaluating. Jane feels worthless when she needs to ask for help because being a private individual it is difficult for her.

Annette, Susan, Chantal and Paul are anxious that other people will perceive them as being "different," or "stupid," because they are AVI. All three try to conceal their VIS and act as normally and naturally as before, a reaction indicative of low self-esteem. Both Paul and Chantal continue to feel self-conscious about their VIS and cope by "crawling" into a shell or not socialising, with nuances of non-coping and insecure AVI individuals. Excessive use of the coping mechanism of displacement or rationalising used by many of the AVI respondents is indicative of poor adjustment and low self-esteem.

Both Allan and Annette are anxious about losing sight completely, and in order to deny this fear of "blindness" they do not walk with the symbolic white long-cane. On the other hand, Allan uses the cane when he plays in the band, perceiving that blindness makes him an "unique" person, hinting that he feels insecure and needs attention, approval and to be perceived as a coping AVI person. When Annette feels insecure she opens the cane and "pretends" to be blind, inferring a need for attention, help and protection whenever she feels insecure and uncertain. It would appear that as yet, many of the AVI respondents are not coping optimally with their VIS, as they continue to react to the stress of their situations maladaptively with their displays of anxiety, denial and unrealistic emotions and attitudes.

Familiar Security Versus Unfamiliar Insecurity:

Jane, Susan and Chantal feel that in familiar situations and

places they are safe, secure and confident. Their experience of feeling safe and secure in familiar situations has been enhanced by their recent stay at the familiar environment or shelter of Optima, where they have successfully completed the different courses, which has in turn, heightened their self-confidence, self-efficacy and self-worth.

Independence Versus Dependence:

A conflicting attitude of independence versus dependence emerges in many of the AVI respondents' scenarios which are difficult to reconcile. Paul and Peter perceive that they can do anything, that they are independent and in control of everything, yet there are implications that they need to be dependent on the support from friends in order to cope and carry on with their lives. Jane believes that she is independent and able to do things for herself, yet her description of how she has had to learn to ask for help, has consequences that dependence, in some contexts, is accepted. Although Mary perceives herself as an independent person who is realistic about needing to be dependent on others in certain situations, there is an insinuation of a change in her self-functioning from an independent, self-reliant and self-sufficient person to a dependent and reliant person, a dependency which appears to have become a way of life for her. Although Susan believes that she is independent she still worries about being as independent as she was before her loss of sight.

5.3.2 Summation

The awareness gained from the data of the 10 AVI respondents in this study with regard to emotional and attitudinal reactions to loss of sight, is that length of time of adventitious VI and the realistic or unrealistic awareness of the implications of living with this chronic impairment profoundly impacts on experienced negative, positive and ambivalent emotions and attitudes which in turn, influences strategic emotional coping strategies, as well as the perception of grief as either a linear

and resolvable process, or a chronic and recurrent process, all of which are enveloped in paradoxes lived simultaneously. It would appear 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 and limitations of living with a chronic adventitious VI.

5.4 EMERGENT NEEDS FOLLOWING LOSS OF SIGHT

As loss of sight is an individual and unique experience for each of the AVI respondents in this study, it is inevitable that unique and idiosyncratic needs will be experienced. Nevertheless, both similar and different needs were expressed by all the AVI respondents, but a certain pattern emerged with a clear distinction between the short-term and long-term AVI respondents with regard to certain experienced needs. After a rigorous analysis of the data emanating from the AVI respondents' narratives, one central theme emerged: length of time of the adventitious VI, together with a heightened awareness of the reality, implications and limitations of the impairment, and especially the different degrees of visual abilities, impacts on experienced needs. Within this central theme however, sub-themes were identified with the AVI respondents expressing both similar and different connections to them (Table 5.2).

5.4.1 **Summary of Delineated Sub-Themes and Related Emergent Experienced Needs**

5.4.1.1 *Basic Fundamental Needs*

Basic Needs Continuing but Abating:

Only one short-term AVI respondent in this research study, Allan, experienced, and continues to experience, basic fundamental needs. His consequent losses following the onset of his VI such as, the loss of his job and house and his inability

to procure a pension, necessitated him satisfying fundamental basic practical needs such as, food and shelter for him and his family. These basic needs continue, but are being satisfied through hard work, faith, positivity, the support from his wife, as well as through his "turning point" of an income from fixing brailers and playing music in bands, which has afforded him the ability to convert a garage into his home.

Table 5.2 Self-reported and inferred needs and perceived satisfaction thereof from the respondents AVI within and beyond 6 years, arranged under the sub-themes

Needs	<6	>6	Satisfied
Basic fundamental needs:			
Basic: food & shelter	1		no
Continuing need for independence:			
Practical independence	4	1	yes
Independent living	2		no
Inferred independence/normality	1	3	no
Inferred independence/see again	2	4	no
Financial independence & security	4	3	no/lyes
Continuing need for support:			
Emotional support	2	2	no/lyes
Acceptance from others	4	4	no
Awareness needing awareness:			
Knowledge & understanding about the real world of adventitious VI	1	5	no
Knowledge & understanding of degrees of visual abilities	1	4	no
Honest information to reduce stereotyping	1	5	no
Factual & honest information: rehabilitation context			
Timely confrontation about the real world of VI	0	4	no
Adjustment is a cyclical process	0	4	no
AVI rehabilators	0	5	no

5.4.1.2 *Continuing Need for Independence*

An important finding from this research study is that the length of time of the adventitious VI impacts on the realistic awareness of the reality, implications and limitations of the impairment which in turn, impacts on experienced needs for independence.

Explicit Need for Independence Versus Explicit Need for Dependence:

When individuals loose sight in their adult years they have reached a certain level of functioning and coping within their psycho-social, family and work environments. In this research study, all the AVI respondents were employed at the time of the onset of their VIS, and all were able to drive a motor car. In essence, all the AVI respondents, before their loss of sight, were independent and coping optimally with their lives. Loss of sight however deprived these AVI considerable amounts of their already acquired competencies and in particular their personal independence. It is not surprising therefore, that the most pressing and explicit need for the short-term AVI respondents, more so than the long-term AVI respondents, is to regain their level of independence as before their loss. Independence is a sweeping and ambiguous word with many diverse meanings, but for Jane, Peter, and Susan independence means practical independence such as, independent mobility, practical skills of daily living, like being able to cook, and being able to read and write, as in Jane's case through the use of a magnifying glass. Although Amanda does not explicitly describe her need for independence it is however inferred from her descriptions of her increased self-confidence in being able to walk independently with her white long-cane. Allan does not highlight practical independence as a need because of his visual ability and not needing to use a long-cane, and being able to read and write by merely enlarging the font size on his computer.

An interesting finding from this research study is that only one long-term AVI respondent, Chantal, explicitly describes the benefits of her regained practical independence such as being able to walk to the shops with her long-cane and being able to read and write again with the aid of braille. This regained independence must be seen in the context of Chantal attending rehabilitation 24 years following her initial loss of sight.

According to all the above mentioned AVI respondents, their need for practical independence has been satisfied after completing the independence training course. As Optima focuses on independent mobility with a white long-cane, being able to read braille, and competent daily living skills as the corner stone for independence, it is not surprising that the individuals having recently completed the rehabilitation course perceive themselves to be "independent," emphasised by Jane's comment, "Optima actually gave me back my independence."

The explicit and pressing need for practical independence by the AVI immediately after their loss of sight is upheld by the long-term AVI respondents in this research study. Initially, Gail, Paul, Mary and Annette needed to "learn to be blind" by acquiring the expected practical skills associated with VI, needs which have been satisfied by being able to walk with the white long-cane or read braille. There is however acknowledgement that their needs as AVI individuals have changed over time with their greater awareness about the implications of living with a VI. Gail uses braille in certain situations only like marking her cds, Paul and Mary have found alternative methods, like using tape-recorders to take notes, and because of Annette's visual ability, she does not use the white long-cane nor braille.

In total contrast to the short-term AVI respondents need for independence, is the long-term AVI respondents acknowledgement of needing to be dependent. Needing to be dependent is a "problem" for all the short-term AVI respondents and the biggest challenge in adjustment to their changed lives as AVI individuals

for it is contrary to their familiar psychological orders of independent and coping individuals. On the other hand however, Paul, Gail and Mary (long-term AVI) acknowledge a greater self-awareness about the reality of the limitations of living with a VI and are determined to remain as independent as possible within their limits but acknowledge the need to be dependent on others to help when help is needed. This attitude ensures a healthy balance between needing independence and dependence.

Independence Needs Shifting:

Independence needs remain the focus for the short-term AVI respondents but have shifted from the satisfied need for practical independence to needing independent living, and being able to procure appropriate skills for better jobs. Susan and Jane's supreme symbol of independence would be to gain independent living, emphasised by Jane's comment, "I now need to look around and see if I can get myself my own place to stay." For Peter, the supreme symbol of independence would be self-enhancement by gaining appropriate job skills to procure a better job and with it, financial independence. An interesting finding from the study is that Peter had a misconception that he would get a good job with his independence skills, which leads to an insinuation of rehabilitees leaving Optima with unrealistic hopes because of the lack of awareness about the implications and limitations of VI issues in the real world.

Enigmatic Needs for Independence:

The long-term AVI respondents in this research study do not explicitly express a need to regain their independence. More of the long-term as compared to the short-term AVI respondents infer this need with subtle descriptions.

Paul, Annette and Chantal need to be treated as "normal" and to be able to behave as "normally and naturally" as before their loss of sight, with an inference of a yearning to return to their

psychological orders of independent and sighted individuals. Susan (short-term AVI respondent) also expresses this need which reinforces her already described need for practical independence. These are the same respondents who continue to be self-conscious about embarrassing themselves in front of people because they are concerned with what other people will think and say about them being "different" and try to act as "normal" sighted and independent individuals.

Another important finding in this research study is the need or wish for some of the AVI respondents to see again which in turn, has overtones of them needing to be as independent as they were before their loss of sight. 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 is not experienced continually but is an episodic, cyclical and oscillating phenomenon and experienced in specific situations or at specific times which are particularly meaningful to the AVI respondents and where they become acutely aware of the irrevocable limitations of their adventitious VIS. This finding underscores the findings that emotions and attitudes, especially frustration and acceptance, experienced by the long-term AVI respondents in this research study are episodic, cyclical and oscillating experiences. In specific frustrating situations Mary wishes she could see again, in meaningful situations or times associated with Gail's ongoing losses she wishes she could see again, and Susan wishes she could see the simple things in life like the rain. Amanda and Chantal (short-term and long-term respondents respectively) continue to experience sadness especially in situations which involve their children and their inability to participate in activities with them because of their loss of sight, and in these situations they wish they could see again. It is in embarrassing situations and situations where it is necessary to see when doing practical work that Paul wishes he could see again. Not being able to drive a motor car in urgent situations results in Mary, Amanda, Susan and Gail "wishing they could see again." There are overtones of these AVI yearning to

return to their familiar psychological orders of independent and sighted individuals. Wishing to see again, experienced emotions and attitudes are intertwined and reciprocally interact on one another.

Need for Financial Independence and Security Continues:

An important finding in this research study is the continued need for financial independence and security achieved through employment which is experienced by all AVI respondents, regardless of length of time of their adventitious VIS. Allan needs permanent employment and the consequent financial independence and security in order to survive and meet his basic fundamental needs. Susan needs a job to give her financial independence and security to help her afford the very expensive adaptive aids, as well as to give her a purpose to her life, "will at least give me something worthwhile to get up for in the morning." Being able to fulfil the need for independence, both financial and personal, is tantamount to Susan being able to return to the "normal" an independent person she was before her loss of sight. For Jane, the supreme symbol of independence is financial independence and security. Lack of money will not allow her to afford a medical aid which causes her to become uncertain and anxious about her future especially if more operations are needed to preserve her sight. A job would give her the ability to afford independent living, and would help her complete the "full circle" which reflects a final conclusion to regaining the needed independence in all areas of her life. Peter is aware that a better job, using appropriate skills, will provide him with financial independence and security and enable him to fulfil a wish to travel overseas, all of which are tantamount to a "better life." Annette's overwhelming need was for employment to give her financial independence and security to enable her to live more comfortably, alleviate some of her emotions like anxiety and hopelessness, and allow her to purchase the expensive adaptive devices like a computer to communicate with her daughter. Annette is currently employed as a switchboard operator. Chantal needs

employment for financial independence and security, as well as for her own sense of achievement and mastery over her life. Gail needs employment which according to her, would give her financial independence and security and alleviate some of her negative emotions associated with lack of money such as, anxiety about not being able to afford a medical aid. It is interesting to note that the three AVI respondents who do not express a need for employment and financial independence and security are Amanda (short-term AVI respondent who is married and does not need to work), Mary and Paul (long-term AVI respondents who are both financially independent and secure already).

Annette, Mary, Gail and Paul, (long-term AVI respondents) and Allan (short-term AVI respondent) are emphatic that employment needs to be based on their experience and abilities rather than on the VI per se, or the stereotypical jobs deemed suitable for AVI individuals by society namely, switchboard operators. Ironically, despite Annette's resistance to stereotypical switchboard jobs, she is now employed as one, which has overtones that even this stereotypical job with the implication of under-employment is perceived as being better than no job to satisfy her basic need for financial independence and security. Paul's need for "normal" rather than stereotypical employment is a contradiction in terms as he was employed as a switchboard operator for 14 years following his loss of sight.

Peter, Susan and Jane (short-term AVI respondents) and Chantal (long-term AVI respondent) who are training to become switchboard operators appear willing to take on this kind of stereotypical job, with an implication that under-employment, except in Peter's case, which would be an improvement, is perceived as being better than no job to satisfy their needs for financial independence and security. There is however, a further implication that together with the Centre that sanctions this type of employment training that the AVI respondents themselves are also continuing to sanction the stereotypical employment deemed suitable for the AVI, emphasised by Susan's comment, "that (switchboard operator)

seems to be the only job out there for us." These perceptions reinforce the above mentioned AVI respondents (mainly the short-term) lack of awareness and understanding of the real world of adventitious VI.

5.4.1.3 *Continuing Need for Support*

All the AVI respondents in this study, regardless of length of time of their adventitious VIS, continue to need support.

Need for Long-Term Emotional Support:

Emotional support is needed by the AVI respondents to help them cope with their situations, and to feel cared for and loved. Of great importance for Annette is her need for a good long-term emotional support system as she needs to have interaction with people to maintain a positive attitude towards herself and life. She also needs long-term emotional support in order for her to cope optimally with her situation, especially if more loss of sight is in the offing. Her fear of being alone in unfamiliar and unsafe places is underscored by her expressed need for a good long-term support system which will ensure both company and protection. This need is being satisfied by her family and friends after she made them aware of the basic VI issues and what she can and cannot do. Chantal needs emotional long-term support from other VI individuals who can understand her situation. In addition to practical support Chantal needed emotional support during her rehabilitation. Emotional support and alleviation of anxiety could be accomplished by follow-ups from Optima, both during and following the completion of courses.

Susan feels that counselling, by implication, emotional support, and support groups were, and still are, needed for herself, her family and friends to make them aware of and understand her world as an AVI person. Amanda needs emotional support in the form of her husband listening and communicating openly with her to help her cope with her situation. Although

practical support, which is given by her husband, is necessary, it is perceived as unhelpful support in the context of her overwhelming need for emotional support.

Tacit Support:

An interesting finding from this research study is the hidden needs for support not explicitly expressed by the respondents, especially the long-term AVI respondents. This finding substantiates the finding that many of the AVI respondents' "real selves" are rather dramatically incongruent with their perceived positive self-images of coping and independent AVI individuals {Section 5.3.1.6 Paradoxical Experiences of Emotions and Attitudes, p. 252}. It can be deduced from Mary's language use, "care for a little while, then find that you've become a burden," and "don't want extra baggage," that she experiences rejection and non-acceptance from friends, and needs long-term emotional support, caring, and acceptance. It is important for Chantal to be perceived by others as coping with her VI and there is a suggestion that she needs support in the form of approval, acceptance and understanding from others. These needs in turn, highlight her lack of emotional coping which is underscored by her need for continued long-term emotional support which she perceives as being essential for Optimal coping. Paul and Peter need to be in control of other individuals to support them in satisfying their needs. Susan needs support where she is treated as "normal" and not over-protected or pampered because she is "blind."

Positive Support Satisfied:

Many of the AVI respondents, regardless of length of time of the adventitious VI, continue to receive positive support without which they would not be able to cope: from Paul's friend, her son and the others involved in his house; from Peter's family who he maintains have accepted him again because he has "proved" himself; the mere presence of Mary's son is positive support as

well as being able to be dependent on her domestic worker and friends for support; from Jane's sighted friends and a society which is aware of VI issues; from Annette's family and the Society for the Blind in her area; the helpful and unconditional support Amanda receives from her children; from Gail's family and friends with the relationship with her family being one of openness where she is encouraged to be as independent as possible within her limits, which in turn, reinforces her ability to cope with the challenges of living with an adventitious vi; the long-term support and healing Allan receives from his wife, and the continued support from the social worker at the Society for the Blind; from Chantal's sons; from Susan's friends and her church.

Positive support from Optima is evident in the skills the AVI respondents have achieved: the mobility and telephony skills Peter has achieved in order to "learn more;" helping Jane change her attitude towards VI, and the practical skills achieved, mobility, computer and switchboard operation, which has given her independence, self-confidence and the ability to cope with her VI; the increased self-confidence Amanda experiences after completing the independence course; the mobility, braille, computer, telephony skills Chantal has achieved as well as improved self-confidence; Susan's need to be independent and able to cope was satisfied through mobility and daily living skills.

An interesting finding from this research study is that all the AVI respondents describe how the positive support and understanding from AVI friends doing the same courses as themselves was, and will be the only thing they will miss when they leave Optima, emphasised by Susan's comment, "most of all, I will miss the friends I've made here." Allan and Annette who received rehabilitation from the Society for the Blind in their areas describe how they continue to receive positive support from those involved in the Society.

Continuing Negative Support:

Many of the AVI respondents, regardless of length of time of

the adventitious VI, continue to receive negative support which impacts negatively on them. Susan receives no support from her mother with silence being the way for her to cope and no explanation is offered for the silence. Susan's father continues to over-protect her, situations which underscore her need for counselling and support groups. Not only does Jane's family try to over-protect her but they will not accept what has happened, and silence is their way of coping. There is an inference that Jane needs this acceptance because when independence issues emerge, her family members are "not pleased," but no explanation is offered for the displeasure. No support is received from Chantal's sister nor her special friend because her sister is anxious and not coping with her acquired independence, and silence is the way for her friend to cope with her VI. Amanda receives no emotional support from her husband which is needed for her to cope optimally with her loss of sight.

According to Annette, Gail and Allan, people in general are not supportive and claim it is because they are not aware of VI issues and base their knowledge on misconceptions and stereotyping, emphasised by Gail' comment, "the sighted are often more blind than the blind themselves."

Negative experiences from rehabilitation were experienced by many of the AVI respondents. According to Mary, there was no commitment from the rehabilitators and their support in helping her cope with her VI by instructing her to walk with the white long-cane was ineffective as she had to re-learn everything when she returned home; the only support Paul received from rehabilitation is the mobility skills he achieved "rehabilitation did nothing for me and it actually wasted my time;" and according to Gail, she was given unrealistic hope about being able to return to her previous line of work for which she needed sight.

5.4.1.4 *Awareness Needing Awareness*

The most significant finding from this research study is the

distinct difference between the short and long-term AVI with regard to needing awareness about adventitious VI issues. It is clear that length of time of the VI has impacted on a heightened awareness of the reality, implications and limitations of the impairment, which has in turn, impacted on experienced needs.

Need for Knowledge and Understanding about the Real World of Adventitious VI:

All the long-term AVI respondents and Amanda (short-term respondent) believe that there is a need for all individuals, including the AVI themselves, families, friends, Ophthalmologists and rehabilitators to be confronted with honest knowledge so that they can be made aware of and understand the basic issues of the real world of adventitious VI, with all its implications and limitations, including how to communicate with or how to approach AVI individuals. This particular lack of knowledge impacts emotionally on Paul, emphasised by his comments, "they (people in general) do not know about blindness and how to communicate with and approach blind people," and "up until I left work, after 14 years, the people working there still didn't know anything about blindness, and how to cope with somebody who is blind."

Knowledge and understanding through honest information and real facts about adventitious VI by all individuals ought to make them responsive and sensitive to the needs, issues and problems facing the AVI, allowing the real world of adventitious VI to emerge rather than a fallacious and superficial understanding. Many of the AVI respondents use the word real world of VI which insinuates an awareness about VI issues that are accurate, genuine, factual and true, with a further overtone that what individuals are aware of is often fallacious and assumptive.

Need for Knowledge, Understanding and Sensitivity about the Different Degrees of Visual Abilities:

An important finding from this research study is the emphasis

many of the AVI respondents placed on all individuals needing to know about the different degrees of visual abilities, and the impact these differences have on AVI individuals' needs and capabilities.

With time, Amanda, Mary, Annette, Gail and Chantal have become aware of the real world of adventitious VI, and in particular, the implications, limitations and unique needs associated with the different degrees of visual abilities. All individuals, including the AVI themselves, society in general, families and friends as well as rehabilitators need to be made aware of and understand what the AVI can and cannot do with different degrees of vision, and not as in the case as described by Chantal "you are either blind or not blind." Each AVI individual, depending on their degree of vision loss, have different abilities and needs, as in the case of the most basic need of totally and functionally blind needing to walk with a white long-cane whilst the AVI with low vision not needing to do this. Awareness of these facts ought to make people sensitive to the needs, issues and challenges facing VI individuals.

Awareness of the different degrees of vision and the related needs and abilities is relevant for all AVI individuals regardless of visual functioning. From Annette's context, she is aware that people in general do not know that there is something like "low vision" and that people assume that she is "blind" and unable to do anything for herself. This situation impacts on her emotionally, especially the frustration associated with this lack of awareness. During rehabilitation Amanda was not aware of the different degrees of visual abilities, and started feeling "stupid" when she could not accomplish the same tasks as somebody who had low vision. Gail gets frustrated when she is compared to a partially sighted person who is assumed to be blind. According to Amanda and Gail, rehabilitators also need to know the different degrees of visual abilities so that those who come in for rehabilitation can be helped according to their appropriate needs. Amanda claims that all rehabilitees 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, and a suggestion of stereotyping if all the AVI are rehabilitated as "blind."

Need for Honest Information to Prevent Stereotyping:

For all the long-term AVI respondents and Amanda (short-term respondent), the lack of knowledge, awareness and understanding about the fundamental issues of adventitious VI, and in particular, the different degrees of visual abilities, result in confusion, misconceptions, stereotypical and prejudicial attitudes towards AVI individuals in all areas of their lives, and especially, the employment environment. This lack of knowledge impacts on them emotionally, emphasised by Annette's comment, "maybe people will treat me as a normal human being with a normal intelligence."

Employment must be based on abilities and not the stereotypical employment deemed suitable for VI individuals. Honest and factual knowledge can help alleviate stereotyping about adventitious VI, with the "facts" making individuals, particularly rehabilitators, aware of the different ways of being able to do things in the VI context rather than the stereotypical methods, like braille.

Need for Timely Confrontation about the Real Implications of Adventitious VI:

Annette, Mary, Gail and Paul's (long-term AVI respondents) foremost need was to be confronted as soon as possible with honest information about the real implications and limitations of their eye conditions, which, had it been provided, would have given them insight and knowledge to cope better with their conditions. Such truth and honesty could be accomplished through open, clear and sensitive communication between all members of

an AVI person's social network, starting with the Ophthalmologists. Doctors and Ophthalmologists need to be more humane and be able to pass on honest information and explanations to their patients as the first step in an ongoing process of gaining knowledge and understanding of the real world of VI, emphasised by Mary's comment, "they (Doctors) need to be aware of the human side of loss of sight."

Need for Factual and Honest Information: Rehabilitation Context:

Mary, Amanda, Gail, Paul, Chantal and their families needed to have been made aware of the real world of their VIS with all the psycho-social and physical implications, limitations and long-term effects as soon as possible during rehabilitation. They believe that with such self-awareness and knowledge about pertinent issues they and their families would have coped better with their situations and would have been better prepared for their futures, and that families would have been able to offer appropriate support. It must be remembered that Annette and Allan were rehabilitated in their own homes, and continue to receive positive support from the social worker in their areas.

Mary coped with her situation in her own idiosyncratic way but was not aware and had no knowledge of what to expect and how to move forward with her life. Paul maintains that it was only with time and having to experience the real world of VI by himself that he became aware of the truth of his condition. Factual and honest knowledge and information could be accomplished during rehabilitation by competent and aware rehabilitators including mobility and braille instructors as well as social workers. Paul describes how such awareness and honesty could be accomplished through proper training and counselling for rehabilitators in order to offer a more holistic service to the new AVI.

Involving the family in rehabilitation, as well as providing education, counselling and honest information where explanations can be given through open communication, would reciprocally help

AVI individuals and all members of their social networks to cope with the adventitious VI, emphasised by Gail's comment, "knowledge and awareness is powerful and is important for coping."

Within the context of Amanda's situation, that is, a wife and mother with small children, she maintains that more centres should be established where she could have attended both rehabilitation and creative activities in the companionship of other AVI individuals on a daily basis.

Need to Know Adjustment is a Cyclical Process:

Mary, Annette, Gail and Chantal needed to be made aware of and understand the emotional long-term affects of living with a chronic adventitious VI and that adjustment, and particularly emotional adjustment, is a life-long, cyclical and oscillating process. As they were not made aware of this phenomenon there is an inference that society and in particular, rehabilitators are not aware themselves of this process. There is thus, an need for all individuals, including the AVI and especially, rehabilitators, to be made aware and understand this phenomenon. Mary and Gail needed to be counselled about this phenomenon during rehabilitation so that they could have known and been aware of and prepared for this ongoing confrontation of emotional adjustments and the associated episodic, cyclical and oscillating emotions.

It is important that all individuals, particularly rehabilitators, are aware that adjustment to adventitious VI is an ongoing process which does not culminate with acceptance. This need accentuates the long-term AVI respondents' perception of the process of grief as being a chronic and ongoing process, involving more intense and frequent cyclical and episodic experiences and re-experiences of emotions related to their VIS, and no final acceptance nor certain conclusion of the grief process {Section 5.3.1.4 Linear Versus Chronic Grief, p. 248}.

AVI needing AVI:

A significant finding from this research study is the perception by all the long-term as compared to none of the short-term AVI respondents, that for rehabilitation to be successful the rehabilitators need to be AVI themselves. By experiencing first hand the process of losing sight with all its implications and limitations, honest and real information can be passed on in a sensitive manner to the new AVI individuals.

A further interesting point made by the long-term AVI respondents is that these rehabilitators must have lost their sight in their adult lives rather than being congenitally blind, as these individuals do not know what it is like to have seen and lost sight, eloquently described by Mary, "I've seen, I know what it's about and how frustrating it is not to be able to see now," and "if those born blind are involved in your rehabilitation it would be like comparing apples with pears."

5.4.2 **Summation**

The awareness gained from the data of the 10 AVI respondents in this study regarding experienced emergent needs following loss of sight, is that length of time of the adventitious VI, with a deeper awareness of the reality, implications and limitations of the chronic impairments, as well as an understanding about the different degrees of visual abilities, profoundly impacts on experienced needs for independence, awareness and support, with distinct differences between the short and long-term AVI respondents' need for awareness about adventitious VI issues. Many of the needs, especially the need for practical independence have been satisfied, many have changed over time with heightened awareness especially, from needing independence to needing to be dependent, and many are being satisfied with the basic needs continuing but abating. The overall finding however, is that the majority of needs, and especially awareness needing awareness of the real world of adventitious VI continue to remain unsatisfied,

which in turn, impacts on experienced emotions negatively.

5.5 MASLOW'S NEED HIERARCHY COMPARED TO AVI RESPONDENTS' NEEDS

The findings of the emergent needs which have to be satisfied in order for the AVI respondents in this study to function and cope with the psychological and practical demands of life, reflect many of the needs as described by Maslow (Table 5.3).

Table 5.3 Maslow's hierarchial needs and corresponding numbers of AVI respondents expressing similar unsatisfied needs

Maslow's Hierarchial Needs:	AVI
Self-actualises	7
Esteem:	
Self-esteem	6
Esteem from others	6
Love & belonging:	
Acceptance	8
Safety:	
Safety & security	4
Financial security	7
Physiological:	
Food/shelter	1
Sensory stimulation	6

Physiological needs such as the basic need for food and shelter is evident in Allan's need to satisfy the fundamental practical needs for himself and his family {Section 5.4.1.1 Basic Fundamental Needs, p. 255}. The physiological need for sensory stimulation or the wish to see again expressed by the totally and functionally blind AVI respondents is an episodic, cyclical and oscillating phenomenon and it is to this level of functioning that the AVI return when they become acutely aware of the limitations of their adventitious VIS in particular meaningful situations or at specific times {Section 5.4.1.2 Continuing Need

for Independence, p. 259}.

Safety needs in the form of needing security are 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 {Section 5.3.1.2 Positive and Negative Emotions and Attitudes, p. 240}. The need for financial security and independence through employment continues to be experienced by all AVI respondents, regardless of length of time of their adventitious VIS {Section 5.4.1.2 Continuing Need for Independence, p. 261}.

The love and belonging needs as described by Maslow (1987) focus on the need for acceptance, nurturance and concern from family, friends and society in general. Based on this description, the researcher included the AVI respondents who continue to be self-conscious about embarrassing themselves in front of people in case they are rejected or not accepted by them; those who are insecure and feel rejected need acceptance and approval from others; and those who need to be accepted by others as coping and innovative AVI individuals {Sections, 5.3.1.6 Paradoxical Experiences of Emotions and Attitudes, p. 252; Section 5.4.1.3 Continuing Need for Support, p. 264}. The negative support some of the AVI respondents receive from their families and friends is indicative of needing acceptance {Section 5.4.1.3 Continuing Need for Support, p. 265}.

The need for esteem from others as described by Maslow (1987) includes the need to be respected by others who recognise and appreciate achievements and competencies. Based on these criteria the researcher included Amanda, Susan, Annette, Mary and Paul on this level because of their need to be respected by others as coping with, and in control of their lives and environments. Mary's involvement in doing charitable work for the disabled, and Allan's healing music to help others have overtones that they need respect and recognition from others for the work they are doing {sections 5.3.1.2 Positive and Negative Emotions and

Attitudes, p. 241; Section 5.3.1.6 Paradoxical Experiences of Emotions and Attitudes, p. 252}.

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 these criteria the researcher included the following AVI respondents: Jane who often feels worthless when she needs to ask for help, Mary who feels worthless in situations when she feels ineffectual, and Susan who is anxious, and uncertain about her future as an AVI person and being as independent as she was before her loss {Section 5.3.1.2 Positive and Negative Emotions and Attitudes, p. 240}. Because of Annette, Susan, Chantal and Paul's anxiety that other people will perceive them as being "different," they try to conceal their VIS and act as normally and naturally as before, a reaction indicative of low self-esteem {Section 5.3.1.6 Paradoxical Experiences of Emotions and Attitudes, p. 252}.

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 deficiency needs are met, then all the AVI respondents in this research study are not functioning at the level of self-actualization given the fact that they all continue to experience unsatisfied deficiency needs. However, if the researcher bases her findings on the criteria for self-actualization as described by Maslow (1987; 1999) of individuals becoming more of what they idiosyncratically are and doing what they are capable of doing, seeking fresh stimulation and new experiences, a spontaneous zest for life, qualities of individuality and strength, the researcher can include Mary, Allan and Gail as functioning on this level based on them fulfilling some of these criteria. In Allan's case, his starting afresh with his "artistic" and more relaxed and enjoyable life, his belief that he has gained spiritually to help both others and himself by playing "healing" music, and in Mary's

case, doing charitable work for the disabled with different spiritual and social "values" of serving and caring about people. In Gail's case, her determination with increased self-awareness and a belief in her ability to meet the ongoing challenges of living with an adventitious VI and to maintain the healthy balance between needing both independence and dependence.

5.5.1 **Summation**

Important issues emanating from this discussion of comparing Maslow's need hierarchy with the emergent needs experienced by the AVI respondents in this research study reveal interesting findings. More of the AVI respondents in this study continue to need acceptance from family, friends and society (the need for love and belonging on the need hierarchy), followed by their need for financial security (the need for safety on the need hierarchy). The AVI respondents' needs reveal both ascent and descent in the need hierarchy, as well as experiencing needs on different levels simultaneously. It would appear that as yet, many of the AVI respondents are not coping optimally with their VIS, as they continue to experience many unsatisfied needs.

5.6 RESEARCH QUESTIONS ANSWERED

The research aims relevant to this study centred round the grief experiences of the AVI respondents, 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, and the influence of the length of time of adventitious VI (VI within and beyond 6 years), on these experiences of the AVI respondents.

The research questioned the following:

What are the AVI respondents' perspectives of their loss of sight?: All the AVI respondents, no matter the length of time of the adventitious VI, have different, unique and individual

perspectives of their loss of sight which are closely intertwined with their self-images.

Whether the AVI respondents experience grief after their loss of sight as a linear or chronic process?: The overall awareness gained from the 10 case scenarios, is that the length of time of the adventitious VI is significantly related to grief being experienced as either a linear and resolvable process, or a chronic and recurrent process. The AVI respondents AVI for less than 6 years perceive a linear and time-bound process involving the completion or diminishment of emotions associated with loss of sight, a final emphatic acceptance and a certain conclusion of grief. On the other hand, the respondents AVI for longer than 6 years perceive grief as a chronic and ongoing process, with more intense and frequent cyclical and episodic experiences and re-experiences of emotions related to their VIS, and no final acceptance nor certain conclusion of the grief process.

Whether there are similar and/or different needs between those who experience grief after loss of sight as a linear or chronic process?: The AVI respondents who perceive a linear grief process experience to a large extent diminished and completed emotions related to their loss of sight with emphatic acceptance of their loss. They perceive themselves to be adjusted and coping individuals who do not need support to satisfy needs because of their perceptions that they are independent. On the other hand, the AVI respondents who perceive a chronic grief process are confronted with continuous experienced and re-experienced emotions associated with their adventitious VIS, no final acceptance of nor adjustment to the loss. These AVI respondents therefore need to continually work through the experienced emotions. It is these AVI who need to have all individuals, including the AVI themselves and the rehabilitators made aware that adjustment to adventitious VI is a life-long and continuous process, that is, that they experience chronic grief.

Are there different or similar emotions and reactions experienced

by the AVI respondents?: A significant finding from this research study is that the AVI respondents, regardless of length of time of their adventitious VIS, continue to describe more negative than positive emotions and attitudes towards their loss of sight. The short-term respondents however, describe more positive emotions whereas, the long-term respondents describe more negative emotions. The long-term AVI respondents experience episodic, cyclical but oscillating reactions of re-experiencing already experienced emotions, especially frustration, in specific situations or at specific times which are particularly meaningful to them, and especially in situations where they become acutely aware of the implications and irrevocable limitations of their loss of sight. Acceptance for the long-term AVI is a cyclical and oscillating experience with absolute acceptance of loss of sight being difficult. The short-term experience absolute acceptance which is related to being independent, coping with and in charge of and adjusted to their AVI lives.

What emergent needs are experienced by the AVI following their loss of sight, whether they have changed over time and whether they have been satisfied?: There is a significant differentiation between experienced and currently experienced needs by the AVI respondents, with length of time of the VI significantly related to the experienced needs. The need for practical independence is the overwhelming need experienced by the respondents AVI for less than 6 years, a need which has to some extent been satisfied through rehabilitation and the acquiring of independent mobility skills. The need for awareness of fundamental basic issues of the real world of adventitious VI and in particular the different degrees of visual abilities, by all individuals, including the AVI themselves and in particular, rehabilitators, is the overwhelming need experienced by the respondents AVI for longer than 6 years, needs which as yet, have not been satisfied. The majority of all AVI respondents need both practical and emotional support to help them cope with their adventitious VIS. Families and special sighted friends form caring and supportive network systems for some of the AVI respondents and help to satisfy some

of their experienced needs, especially support. Unsatisfied needs are closely intertwined with experienced emotions and reactions, especially frustration.

Whether the same needs are experienced by the AVI with different degrees of visual abilities?: There is a difference in certain experienced needs unique to the degree of visual ability. Those AVI respondents who are functionally or totally blind need to be dependent on the sighted to satisfy their needs more so than the low vision AVI respondents, especially in the areas of independent mobility and reading and writing. The need or wish to see again is only experienced by the functionally and totally blind AVI respondents.

5.6.1 General Statements

Based on the findings from this research study the following general statements can be made:

Although the AVI respondents have individual and unique perspectives of their loss of sight, the length of time of the adventitious VI, and the realistic or unrealistic awareness of the implications of living with this chronic impairment profoundly impacts on experienced emotions and attitudes, as well as the perception of grief as either a linear and resolvable process, or a chronic and recurrent process, which are enveloped in paradoxes lived simultaneously.

Length of time of the adventitious VI, with a deeper awareness of the reality, implications and limitations of the chronic impairments, as well as the different degrees of visual abilities, profoundly impacts on experienced needs for independence, awareness and support, with distinct differences between the short and long-term AVI respondents' needs for independence versus awareness about the real world of adventitious VI respectively. The majority of needs, and especially awareness needing awareness of the real world of

adventitious VI continue to remain unsatisfied, which in turn, impacts on experienced emotions negatively. Insight into the real world of adventitious VI will give AVI individuals the ability to cope better with their loss of sight.

5.7 CONCLUSION

In this Chapter, the findings from the research study of the perspectives of loss of sight, emotional and attitudinal reactions to loss of sight, grief as either a linear or chronic process, and the emergent needs following loss of sight were discussed. The similarities and differences between the AVI respondents' experiences of their loss of sight as well as the similarities and differences between the two groups of AVI respondents, namely, those AVI for less and beyond 6 years, with special reference to similar experienced needs as conceptualised by Maslow (1987), together with general statements regarding the experience of losing sight were presented.

In the next Chapter, 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 principal loss of sight issues as outlined in Chapter Two will be presented.