

## CHAPTER FOUR

### **DESCRIPTIONS OF EXPERIENCED GRIEF AND EMERGENT NEEDS THROUGH THE EYES OF THE BEHOLDER**

#### **4.1 INTRODUCTION**

AVI individuals' descriptions of their experiences of grief and needs emanating from their adventitious loss of sight are presented in this chapter. The descriptions emerge from the AVI responses to the questions concerned with the key experiential areas pertinent to the research study, namely, the AVI respondents' perspectives of their loss of sight, their experienced emotions, feelings, thoughts and reactions to loss of sight, the emergent needs they experienced and currently experience, and the level of support they experience from family and friends, society and the rehabilitation context. How the AVI perceive their worlds and experiences become explicit and meaningful when the content of their words and actions are analysed. This analysis reveals facts, thoughts, attitudes, emotions and feelings that are idiosyncratically significant to each AVI individual. It is possible, by means of reflection and inference, to reconstruct an AVI individual's phenomenal field, that is, the unobservable, and behaviour, that is, the observable.

In order to understand the meanings of grief and emergent needs experienced by each AVI respondent, the researcher provides the following information:

- (A) Some background on each AVI respondent;
- (B) An account of the AVI respondents' concrete descriptions of the key experiential areas under investigation. This phase accords with step (A) Data Constitution: The Initial Concrete Description {Section 3.8.5.1, p. 112}. The accounts are available on request;
- (C) Phenomenal meaning units arising out of the idiosyncratic

concrete descriptions which have been transformed into psychological structures of meanings. In this phase, the researcher combines the steps of (B) Individual Phenomenal Descriptions: Meaning Units, and (C) Individual (Idiographic) Psychological Structures of Meanings: The Essence of Experience {Section 3.8.5.1., pp. 112-113}; (D) Essential recurrent psychological themes of each AVI respondent's experience of losing sight are highlighted.

What follows is 10 follow-up depth interviews of AVI adults, visually impaired within and beyond 6 years.

#### 4.2 CASE ONE: PETER

##### 4.2.1 **Background Information**

Peter is 27 and has been AVI for 4 years following a suicide attempt. He shot himself through the right side of his head where the bullet severed the optic nerve resulting in him not being able to see out of the eye. He has light perception and is able to see blurred shapes out of the other eye. Concurring with the vision ability classification in chapter one {Section 1.2.1.3, p. 4} Peter can be said to be functionally blind.

He completed grade 11 after a very difficult and troublesome adolescence during which time he was sent to a place of safety. He was then in and out of many diverse jobs, from a miner to a construction worker. His last job did not pay him for 3 months after which he left and was unsuccessful in trying to find another one. It was during this period that he shot himself.

Peter is single and now stays with his mother and youngest brother. A year after the shooting he bought a station wagon, hired somebody to drive it and sold ice-cream. He closed up this business when he came to Optima to attend the independence course. Following rehabilitation he found a job washing dishes in a restaurant and took leave to attend the telephony course.

At the time of the initial interview for this study he had just commenced the course, and the follow-up interview three months later, was two days after he had completed the course.

#### **4.2.2 Phenomenal Meaning Units and Psychological Structures of Meanings**

##### *4.2.2.1 Peter's Perspective of Loss of Sight*

###### *A Second Chance:*

Peter experiences his loss of sight as giving him a "second chance" for a new start in life following his attempted suicide ("I've got a second chance." "My loss of sight has given me a new start in life.") He maintains that his attempted suicide was a mistake and is now motivated to prove himself again ("My attempted suicide was a big mistake." "I have to prove myself, because I made a big mistake to take my own life into my hands.")

###### *Loss and Gain:*

Peter experiences his VI as both a loss and a gain. He maintains that his loss of sight has afforded him a better life than the wild life he had before his loss, that his social interactions have improved, and feels that he is a better person ("I see my blindness as half gain, half loss." "I've come from a wild life." "Drinking, using pills, parties, those kind of things." "Even though there are things that I miss, there are things which are better now." "I now have a king's life." "I am now being spoilt." "Somebody drives me around and I can say "look I want to go there, go that way" and we go that way." "With people interactions I was not as good as what I'm now." "I'm now a much better person.") Peter's present emotional peace and calm is captured by one of his gains from his wild life before his loss of sight ("my loss actually means a great peace and calm for me.") He maintains that through his loss of sight he has gained spiritually because he knows that he is not alone on the road he

walks ("I know that I'm not alone on that road, I'm not walking alone, God is walking with me.") He maintains that life goes on and that he is enjoying his new and better life situation ("life goes on." "I am enjoying it.")

*Opportunity to Learn:*

Peter maintains that his loss of sight as affording him an opportunity to learn more about himself, his life as well as practical issues ("I am learning more." "Things like braille, mobility, telephony and how to study." "I had made a big mistake." "I am enjoying it (life).") He believes that after his loss of sight he has learnt personal interactional skills and more people are interested in him ("many more people are interested in me now." "I have met many people here (Optima) and they talk to me." "I give everybody here in the college a smile on their faces.")

*4.2.2.2 Peter's Emotions, Feelings, Thoughts and Reactions*

*Acceptance:*

Peter maintains that he has made peace with and accepted his attempt to take his own life, and he is emphatic that he has accepted his loss of sight ("I've made peace with it (suicide attempt)." "I have accepted it.") Acceptance is reinforced by his attitude that time heals ("time heals because it goes by, and you forget about it.") Peter's attitude of acceptance is based on his belief that acceptance is expected of people who experience a loss, after which coping and adaptation occur ("it is expected of you, so you just have to accept and then cope." "I really coped very well and adapted very fast.")

*Denial:*

Peter denies any emotions associated with his suicide attempt ("I never felt angry about what I did.") He also denies any

emotions experienced as a result of his loss of sight ("I never felt sad or depressed, never, even up till today." "I never get frustrated.") He denies the limitations and implications of his VI as he sees himself as totally independent, able to do anything, and believes that he can become an architect or civil engineer ("I am a very independent person." "I can do anything." "I want to one day get a civil engineer's diploma, or become an architect or something in the building line.")

His denial of his loss of sight is further reinforced with his belief that "I don't even think I would want to see again." This feeling underscores his belief that he now experiences a "king's life" where he, as an AVI individual, is being "spoilt." Laughter is Peter's way of coping and adapting to his changed situation ("I suppose I am able to cope by laughing.")

*Self-Assertion:*

Peter maintains that he is a totally independent and self-confident person and believes that his loss of sight is no deterrent for him ("I am a very independent person." "If I want to get to a place then I just go." "I can do anything." "I can go to any place wherever I want to, without any difficulties or struggle.")

*Pride:*

Peter was motivated to find a job following his rehabilitation. He now feels proud about having a steady job which he feels is an improvement to his situation before his VI when he was in and out of many diverse jobs ("I got one (job) washing dishes in a restaurant." "I feel good about having a job." "The job is very important for me because it means an improvement in my life.")

**4.2.2.3 Peter's Emergent Needs**

*Need for Independence:*

Independence is expressed through Peter's need for practical

independent mobility and daily living skills, which he believes have been satisfied by the independence course at Optima. With independent mobility Peter has the ability to go wherever he wants to and daily living skills have afforded him the ability to do everything for himself ("after I learnt mobility, if I want to get to a place then I just go." "I do everything for myself, dress myself, bath myself, make food, clean the house.")

*Need for Better Working Skills:*

Peter's hope of getting a job following rehabilitation was thwarted because of his lack of appropriate skills ("when I come out (of Optima) I will have work." "I couldn't find work because I had no skills.") Peter realised that in order to improve himself and get a better job, other than washing dishes, he needs better and more appropriate skills ("I need more skills.")

Goals for skill development in order to procure work, centre around courses at Optima, telephony, computer training and programming. He is motivated to improve and better himself ("I think I can give myself a boost by getting a job in the computer world.") Peter is aware that a better job, using appropriate skills, will provide him with financial security and enable him to fulfil a wish to travel overseas, all of which are tantamount to a "better life" ("I would love to go overseas, especially to Paris, that is my biggest dream.")

*4.2.2.4 Peter's Experiences of Support from Family, Friends, Society and the Rehabilitation Context*

*Positive Support:*

Support is offered by Peter's family who he maintains have accepted him again because he has "proved" himself ("we look after each other." "I have now proved myself again, and they all accept me.") Peter maintains however that he does not need help or support as he is totally independent ("my brother doesn't help

me because I am very independent.")

Support from Optima in realising his need to "learn more" is evident in the skills he has achieved, mobility and telephony. The support from AVI friends doing the same courses as him will be missed ("when I leave I will miss my friends I've made here." )

#### **4.2.3 Emergent Themes: Psychological Structures of Meanings**

Peter views his loss of sight as giving him a "second chance" for a better life to prove himself and become a better person. He has conscious insight that his attempted suicide was wrong and there are overtones that his VI is perceived as retribution for the "mistake." There is an inference that he has gained spiritually and that God is part of his life. His language use of "I know that I'm not alone on that road, I'm not walking alone, God is walking with me," has metaphorical value because there is an implication that god is not only with him on the road but with him all the time , part of his life.

He perceives that following his loss of sight he has gained a "king's life," that he is accepted again by his family, that people are interested in him and that he has been given an opportunity to learn about himself and his world. This learning has given Peter the ability to interact better with people, to procure a steady job with the hope of an even better one with appropriate skills. It would appear that loss of sight is perceived by Peter as a "gain" in all areas of his life rather than a "loss." The descriptions also have psychological symbolic gesture as there is an insinuation that Peter needs attention, acceptance and care, something which he may have never received when he was sighted.

It would appear that Peter is almost content in being AVI, because "seeing again" infers a return to a "wild," incorrigible and out of control sighted life. This contentment is further enhanced by Peter's belief that since his loss of sight he is

being "spoilt" by other people and that he is now enjoying his life. It may be deduced from these descriptions that Peter, because of his VI, has taken control, not only of his life but others as well, and is now getting his needed attention, care and enjoyment, a situation which he cannot contemplate to change.

Denial and acceptance, although contradictory attitudes and emotions, weave their way throughout Peter's descriptions. There was, and still is, denial of any emotion associated with Peter's attempted suicide and his subsequent loss of sight. He distances himself from the reality of his changed life as an AVI individual by not wanting to incorporate the idea of both his suicide attempt and his loss of sight into his perception of himself and "forgets about it." The refusal to face the facts of his loss of sight through attempted suicide are underscored by the frequent repetition of the word "never," and by his perception that "time heals."

Peter's 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. There is a suggestion that Peter believes that with this behaviour, a positive image of a coping and in control person will emerge.

Denial is intertwined with Peter's unrealistic hope that he will become an architect or civil engineer. With this unrealistic belief Peter not only denies the reality of his loss of sight and reveals his total lack of awareness of the implications and limitations of living with a VI, but also suggests maladjustment to his AVI life.

His emphatic acceptance of his loss of sight is based on the social expectation that he must accept his loss and then cope and adapt to his situation. It may be deduced from these perceptions that acceptance, coping and adaptation are feelings and processes that can be conclusively completed and concluded following loss

of sight. There is a suggestion that if Peter's expectation of acceptance is not fulfilled, it would be perceived as a negative reflection of his new self-image of a positive, confident, coping and adapted AVI individual. The acceptance however, connotes denial, as Peter is using it as a way of blocking out the painful reality of his loss of sight, which in turn, enhances his positive self-image.

Conflicting emotions emerge dichotomized as they are difficult to reconcile. The emotion of sadness is not experienced, yet Peter laughs because "it is very hard for me to cry." He describes that he never experiences anger or frustration, yet both were observed by the researcher during the follow-up interview when he was unable to find his money. His out of control interaction with the cleaner implies that his denied emotions may be displaced onto the sighted, in an attempt to reduce his anxiety about the painful reality of his VI.

The rehabilitation course satisfied Peter's need to learn practical independence skills, and with independent mobility, he believes that he is able to go anywhere and do anything. His perceived independence is underscored by the words, "I can," "I want" which indicate Peter's determination to control his life. His independence has nuances of denying a need to be dependent on others for help because this need would be perceived as a negative reflection of his coping and independent image of himself. Dependency would also be perceived as a situation which is completely alien to his psychological structure, as he had lived most of his life as an independent person. Peter's perception that his family needs his help rather than him needing their help and support has overtones of Peter denying his need for help by displacing the need onto his family.

Conflicting attitudes towards the need for independence and dependence emerge dichotomized as they are difficult to reconcile. Peter's overwhelming need was for independence which he believes has been satisfied. He perceives himself to be

totally independent, yet, he is dependent on others to "spoil" him and take him places.

For Peter, the supreme symbol of independence would be to gain appropriate job skills to procure a good job and with it, financial independence. Peter's misconception that he would get a good job with his independence skills was soon realised and his need to improve his work position motivated him to learn new work skills. There is 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. Peter did procure a job washing dishes, and although not a good job, it has "boosted" his self-confidence and self-esteem which has made him feel proud about himself. From Peter's language use it may be deduced that he now perceives himself as a reliable and conscientious person who has "proved" himself. Peter transcends his limited physical condition with his unquestioning acceptance, self-assertion, pride, positivity, coping and adaptation.

#### **4.2.4 Summation**

Peter perceives that his loss of sight has given him a second chance for a better life, and although he is AVI, he hopes for, and is motivated to improve his position in life by learning more skills for a better job, and better social and interpersonal skills. He has accepted, adapted to and is coping with his loss of sight, and sees himself as an independent, self-confident and positive AVI individual.

### **4.3 CASE TWO: MARY**

#### **4.3.1 Background Information**

Mary is 52 and has been AVI for 22 years. At the age of 30 she was involved in a car accident where her right eye's optic nerve was severed. She had partial sight for 10 years when her retina of her left eye detached leaving her with no light perception.

Concurring with the vision ability classification in chapter one {Section 1.2.1.3, p. 4} Mary can be said to be totally blind.

Mary is divorced and has an adult son, who at the time of the first interview, had just left to live overseas. Mary was a home economics high school teacher, and since her loss of sight she has been a mother and a home executive. Approximately 2 years following her accident she attended rehabilitation. At present, she is involved in catering, fund raising for the physically disabled, belongs to the cookery and garden clubs, and attends Bible study. The interviews (5 months apart) were conducted in the house Mary was awarded following the divorce.

#### **4.3.2 Phenomenal Meaning Units and Psychological Structures of Meanings**

##### *4.3.2.1 Mary's Perspective of Loss of Sight*

###### *Power of Faith to Cope:*

Mary's main focus when describing her experience of her loss of sight is her faith which helps her cope with her situation ("when I think about my loss of sight I always quote John 9, verse 25, "I was blind and now I see," and Romans 8, verse 28, "and now we know that in all things, one works for the good of those who love Him, who have been called according to His purpose." "I do believe that I got the grace to just accept it." "God's hand was upon me." "My faith helps me cope." )

###### *Loss has a Purpose:*

Mary 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 social values of serving and caring about people, especially disabled people ("I can say I lived in a fools paradise when I could see." "Now that I'm blind I've got other values." "I've really become more of a peoples person and more of a caring

person than I've ever been." "I don't think that I would ever have worked for disabled people if I didn't have this affliction myself." "Before, I didn't care about the disabled." "It just never featured in my life." "Now I know, I'm aware and there's so much to be done.")

#### *4.3.2.2 Mary's Emotions, Feelings, Thoughts and Reactions*

##### *Acceptance is an Oscillating Process:*

Mary maintains that her initial attitude of acceptance was based on societal expectations that following a loss there is acceptance after which coping and adjustment occur ("it was just something that I accepted." "Everybody expects that you must just accept it, cope with it and just get on with it." "It is just part of our society, a cultural thing.")

She contends that with time, her attitude towards acceptance has changed to that of an oscillating process of non-acceptance and acceptance depending on certain situations and the related emotions. She claims that adjustment is also an ongoing process ("I wonder now about acceptance." "Some days are better than others." "Some days are more frustrating than others." "Some days you don't have to search for help." "I have accepting days and not accepting days." "Each time I lost more sight it was an adjustment right from the beginning again.") For Mary, absolute acceptance is now an impossibility ("time doesn't heal.")

With time, Mary maintains that she has accepted some of the limitations associated with her VI ("I believed I had no limitations." "Maybe it was because I still had that partial sight." "Over the years, I've become aware that I've got limitations and there is just nothing I can do about it.")

##### *Frustration and Anger:*

Frustration continues to be experienced by Mary in specific

situations when she cannot behave as she did before her loss of sight, and when she needs to wait for people to help her in urgent situations ("frustration I had at times." "There were things that you couldn't do any more." "When I need to do or read something now and not to have to wait for somebody to help." "That situation makes me very frustrated." "There are times when you really feel stuck because you don't have anybody to take you right at that moment." "You've got to wait on other people's availability." "That is frustrating." "You've got to phone a few people before one can help you." "Being an independent person, that is when it catches you." "When you cant do what you want to do when you want to do it.")

She contends that the longer she has been AVI the more intense her frustrations ("the longer I have been blind the more frustrated I get with situations when I cant do certain things that I could do before." "It has to do with me knowing my limitations and becoming more aware of them." "I still miss the fact that I had a driver right on my premises." "That I could go at any time to any place I needed to go." "Not being able to do that is still frustrating." "My biggest need (last night) was to make contact with my son." "My friend had no knowledge (of the e-mail)." "That frustrated me, it really made me angry." "He as the sighted person should have taken more care of my needs.") In the specific frustrating situations Mary wishes she could see again ("there are many times I wish I could see again." "I miss just being able to get in the car and go somewhere or do something." "This need is not there all the time." "It is when I need to do or read something now, and not have to wait for somebody to help." "That is when I need to see and that situation makes me very frustrated.")

She claims that she is not angry about her loss of sight but angry with human relationships, and especially her relationship with her ex-husband ("I was never angry about the fact that I'd lost my sight." "Angry and disappointed in human relationships and that was towards my husband." "He couldn't accept the fact

that I'd lost my sight.")

*Self-Confidence and Self-Efficacy:*

Mary contends that she is confident in her capabilities to cope with and carry on with her AVI life ("I just found other skills and other ways of approaching things." "Being a very capable person I think it made it very easy for me." "I've coped with, and carried on with my life." "I have the gift of the gab, and I can ask for snow and I will get it." "I was asked to talk at a school for national women's day." "It was an absolutely incredible experience." "I was asked to address one of the bank's conferences to do a motivational speech." "One of the boys from the first talk told his father how I had inspired him and he asked me to speak." "That was also magic." "It was just after my son left for overseas and I was really in the pits and it lifted my spirits." "I felt good about myself again.")

*Anxiety and Distress:*

Mary claims that she continues to experience anxiety and distress about her divorce more so than with her physical loss of sight ("I went through a divorce." "He just couldn't cope with the fact that I was coping." "Up to today it still stays a traumatic experience more so than the fact that I lost my sight.")

She contends that people and especially friends disappoint and hurt her which causes distress ("they (people in general) are selfish and involved in their own worlds." "They are the ones that hurt and disappoint you the most." "They care for a little while and then find that you've become a burden to them." "When I asked her (a friend) "why can't people just give you an arm and tell you whether there is a step or not," "she said people don't want extra baggage," "that was the most terrible realisation." "As soon as you become baggage to them, they are not interested in helping you or even picking up the phone." "They (people she

knows) stand around me, and they don't greet me." "I find this incredibly difficult to the point that it actually upsets me." "Then I have friends who don't see me as blind and they will just leave me standing talking to fresh air.")

Mary is distressed when she feels insecure and ineffectual in situations when she cannot do things or when she is not kept busy ("I do find that I'm searching for something to do to fill a gap or a void in my life." "In this situation, it is my self-worth that's affected." "I just feel that I could cope a little bit better." "Be able to do things." "I can't use my education, I'm computer illiterate so there is nothing for me to do to keep me busy." "Especially now, with my son overseas I don't have extra chores to keep me busy." "Now when I really need it (computer literacy) I'm not capable of doing it.")

#### *4.3.2.3 Mary's Emergent Needs*

##### *Need for Dependency:*

Mary maintains that although she is an independent person she needs to be able to be dependent on people for help when it is needed ("my greatest need is my dependency on somebody when I go out or when I need to get information." "I don't use a white cane because when I go out I'm always with someone." "I'm never alone." "I am an independent person and I like getting on with things." "There is always a point you get to where somebody has got to help you." "That's not always easy but that is the reality.") This need is being satisfied by her special friends and domestic worker "I have a few wonderful and special friends." "The support of those who really love and care for me have helped me cope." "I have a wonderful domestic who I've trained to cope with things that were not possible for me to do." "She meets quite a lot of my needs." "Checking on paper work, checking on clothes, doing general cooking, there she fulfills those needs.")

Mary is dependent on her telephone for communication, a need

which she claims is very expensive ("another of my very necessary needs is my telephone." "It is my communication, it is my security and my support system, it is my transport." "Everything revolves around contact with others." "I have to phone 6 people to help me with 1 activity." "You phone around to get the best price, then you start looking for people to help you to get there." "That is not only expensive but frustrating.")

*Need for Knowledge and Understanding:*

Mary maintains that all people, including the AVI themselves, need to know and understand the "real story" of adventitious VI and what the impairment entails("there is a need for people who lose their sight to be aware of what their condition entails." "There is a great need for people, the public and communities to be educated so they can become aware about the "ins and outs" of VI and blindness." "The real story." "If they were aware then I'm sure they would get more involved and committed.")

She contends that lack of awareness leads to stereotyping, especially in the employment environment. Employment must be based on abilities and not the stereotypical employment deemed suitable for the AVI ("there is a great need for employment of AVI persons." "The right type of employment for the right person." "I've been educated as a home economist." "I can't go into that field because it needs sight." "I have other abilities." "Although I am financially ok, it would be nice to get paid for it (volunteer fund raiser for the physically disabled)." "The Society for the Blind and the National Council are not pulling their weight." "By promoting VI and what can and can't be done, and they are not selling what blind people can do." "There is this stereotype attitude held by society that if you're blind you must work on a switchboard." "An attitude that needs to be changed immediately.")

*Need for Education, Counselling and Honest Information:*

Mary maintains that during rehabilitation she needed to be made

aware of the real implications and limitations of her eye condition. She feels that with such self-awareness and knowledge about pertinent issues she would have coped better with her situation and would have been better prepared for her future. Such factual and honest knowledge and information could be accomplished through counselling and guidance, especially during rehabilitation ("nobody ever counselled me on what the future maybe holds." "The pitfalls I may encounter later on." "It is important that you should receive guidance." "Especially during rehabilitation." "If you just knew about situations it would help you through difficulties." "They needed to tell me or make me aware of what lies ahead out there in the real world." "To make me aware of what maybe would happen later, the long-term aspect of my condition." "You cope with what you've got and you are not really aware of your disability and what it involves." "When you go into rehabilitation it is then that you should be made aware of what your situation is." "Make you aware of the limitations.") Mary claims that the rehabilitators needed to make her aware of the emotional long-term affects associated with her VI, and that adjustment to VI is a continual process ("it is very important that you are counselled and guided through the stages of partial sight to blindness." "Where better than the rehabilitation centre." "There are times if I had just known what was coming or if I had known what to expect then I would have felt that I was supported." "The knowledge would have helped me through difficulties because each time I lost more sight it was an adjustment right from the beginning again.")

Mary maintains that doctors need to be more humane and be able to pass on honest information to their patients ("let us not forget about doctors." "They need to be aware of the human side of loss of sight." "They need to pass on information to you and explain things." "Tell you where to go for help if they can't help you any more." "Be aware of your needs as a blind person." "All they're concerned with is surgery.")

Mary also feels that people involved in helping the AVI need

to be AVI themselves ("you need people, the instructors who are aware of all these things in the first place." "It is very important that visually impaired people are involved as instructors or counsellors in rehabilitation." "The sighted cannot speak for a blind person." "You've got to be there or have been there to be able to speak with authority." "Must also be those who lost their sight later in their lives and not somebody who was born blind." "I've seen, I know what it's about and how frustrating it is not to be able to see now." "If those born blind are involved in your rehabilitation it would be like comparing apples with pears." "It doesn't work.")

#### *4.3.2.4 Mary's Experiences of Support from Family, Friends, Society and the Rehabilitation Context*

##### *Positive Support from Son:*

The mere presence of Mary's son is positive support ("my son is my pride and joy." "I always had the need to be around, to be available for him and his friends." "I never made him responsible for any of my needs." "I felt he had enough to cope with having a blind mother and being a single child of a single parent." "He had lots to cope with himself." "He has never regarded me as a blind person." "Very seldom did he have to help me.")

##### *Negative Support from Rehabilitation:*

Mary contends that she was disillusioned following her rehabilitation as there was no commitment from the rehabilitators. 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, and being taught braille was meaningless because there were other ways of taking notes ("I came back (from rehabilitation) very disillusioned." "Nobody was really interested in helping or supporting you." "There was no commitment from the instructors." "I was coping (according to the rehabilitators)

because I could walk with a cane." "That was all that mattered." "I came back home and had to relearn it all again in my own area." "I don't need braille to take notes, I just use a tape-recorder." She maintains that the support from the other AVI doing the same course as her was the most beneficial part of her rehabilitation ("the only thing that was OK was that I was with other AVI people." "I got a bit of support and understanding from them." "For the rest it wasn't worth my time."

#### 4.3.3 **Emergent Themes: Psychological structures of Meanings**

Mary believes that her faith has helped her cope with her loss of sight and given her insight into her new purpose in life, that is, doing charitable work for the physically disabled. She perceives that it was following her loss of sight that her self-perception changed to that of a caring and empathetic person, and that there was a motivational change for she now devotes herself to charitable work. She has insight into her self-functioning and now regards herself as knowing and self-aware.

Within the realm of her faith and new spiritual and social values, caring, awareness and empathy, she tends to somewhat glamorize her condition. She belongs to many clubs, does charitable work, and does motivational talks. This "glamorization" helps her cope and adjust "lifted my spirits," and allows a positive image of a coping and competent individual to emerge. Mary's involvement in different clubs and charity work has an overtone 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 vulnerability. There is also a suggestion that Mary experiences rejection from friends, "don't want extra baggage," which distresses and disappoints her. It can be deduced from her language use, "care for a little while, then find that you've become a burden," that Mary needs long-term support, caring, admiration and acceptance. Significant in Mary's verbalizations is her emphasis on doing charitable work for the physically

disabled, possibly reflecting a belief that her need for attention and admiration would be better satisfied by a "blind" person helping individuals with other disabilities.

The glamorization does not help her deal with the reality of her changed condition. She continues to deny the reality of her VI by displacing it onto her son, "he has never regarded me as a blind person." Another part of her denial is in reference to her divorce and loss of her husband. Anger continues to be displaced from the loss of her sight onto her husband, anger at the loss of a companion to help her cope. When confronted with VI issues, and especially emotions such as frustration and anxiety, Mary attempts to deny or block out this painful reality of her situation by keeping herself busy doing charitable work, doing chores in the house, or she displaces her emotions, particularly frustration and anger, onto her ex-husband, son or sighted individuals. The displacement connotes an attempt to reduce the tension associated with her loss and to preserve her self-esteem.

Mary believes that her emotions and attitudes, especially frustration, acceptance and adjustment are oscillating and episodic phenomena. There is an inference that for Mary, acceptance of, and adjustment to, VI are feelings and processes that cannot be conclusively concluded following loss of sight. Acceptance and frustration are intertwined for if Mary is in situations which cause her frustration then she does not accept her VI. Her frustrations appear to centre round issues of perceived loss of control over her life in urgent situations, "when I need to do or read something now," unsatisfied needs, "he as the sighted person should have taken more care of my needs," and loss of spontaneity "not being able to do what you want to do when you want to do it." These "issues" have nuances of non-coping, implying that frustration and non-coping are intertwined.

Mary's descriptions abound with nostalgia especially with her wish to see again in situations which cause her frustration and

anger. This nostalgia impacts on her functioning in the present because there is an overtone of yearning to return to her sighted married life, and to her familiar psychological order of an independent woman. This yearning is transcended by denial of her present situation which in turn results in her searching to "fill a void or gap" in her life.

The dichotomous nature of her attitudes of coping versus non-coping, and independence versus dependence emerge and are difficult to reconcile. She perceives resolutely that through her faith and spiritual and social values she is coping with her VI, which is reinforced by the support she receives from her son and special friends. Her coping is thus reliant on being dependent on her faith and support. There are nuances of non-coping for she describes how she could "cope better" with things. She denies her non-coping with her loss by displacing it onto her ex-husband, son and sighted individuals. Mary perceives herself as an independent person who is realistic when the "point" is reached that she needs to be dependent on others to satisfy her needs. This "point" has an inference of Mary always needing to be dependent as there is a preoccupation with dependency issues. Her dependency is expressed through her need to have somebody as a sighted guide when she goes out or when she needs to get information, her dependence on others for transport, her need never to be alone, and the continuous need to be dependent on her faith and support to cope with her loss of sight. There is an insinuation of a change in Mary's self-functioning from an independent, self-reliant and self-sufficient person to a dependent, vulnerable and reliant person, a dependency which appears to have become a way of life for her. Her need for dependency on others to send her e-mails is justified by her "incapability."

Psychological overtones of symbolic gesture are evident in Mary's descriptions. The loss of her pottery workshop and "letting her (driver) go" suggests a "letting go" of her sighted life and an adaptation to her new way of life as an AVI

individual. It can be deduced from Mary's language use, "I was really in the pits," that she was depressed and vulnerable after her son left for overseas, and "I'm searching for something to do to fill a gap or a void in my life" alludes to her searching for a meaning, purpose and direction in life as an AVI individual. The length of time of Mary's VI has impacted on her self-perception and self-functioning of a "capable and coping person" to feeling incompetent and ineffectual which affects her self-worth.

Mary's description of her relationship with her son reveals her vulnerability. There appears to be feelings of guilt or self-blame, "I felt he had enough to cope with having a blind mother and being a single child of a single parent." Mary's need to be "around and available" for her son, connotes her own need for dependency and for people to be available to help her solve her problems and give her direction in her life.

Mary believes that there is a need for all people, including the AVI themselves, doctors and rehabilitators to be confronted with knowledge and understanding of the "real story" of the implications and limitations of adventitious VI. Knowledge and understanding through honest information about adventitious VI by all individuals ought to make them responsive and sensitive to the needs, issues and problems facing AVI individuals, allowing the "real story" to emerge rather than a fallacious and superficial understanding. This honest knowledge can help alleviate stereotyping about VI, especially in the employment environment. All people, particularly rehabilitators, need to be aware that adjustment to VI is an ongoing process which does not culminate with acceptance. For Mary, living with a VI is an oscillating process having to constantly adjust to her loss of sight.

#### 4.3.4 Summation

Mary perceives herself as a coping, independent, aware and positive person able to carry on with her life despite her adventitious VI. Her faith, spiritual and social values and

support from her son and friends have helped her cope with her continual adjustments she has had to face each time she lost more sight. Her intricate descriptions embrace contradictions and nuances of a non-coping, dependent and vulnerable person.

#### 4.4 CASE THREE: JANE

##### 4.4.1 Background Information

Jane is 53 and has been AVI for 4 years following a crime shooting where shrapnel severed both her retinas. After a period of about a year following many operations, the retina stabilized and she was, and still is, able to see colour and objects through her left eye. She is able to read normal print with the aid of a magnifying glass, and is able to work a computer by using an enlarged font. She does not walk with the white long-cane because according to her, she can identify objects in front of her. Concurring with the vision ability classification in chapter one {Section 1.2.1.3, p. 4} Jane can be said to have low vision.

Jane is not married and has an adult daughter living overseas. Before her loss of sight, she was a high school maths teacher. For the past year she has been giving private tuition from the home of her brother and sister-in-law, where she now lives.

A year following the shooting, Jane went to Optima to do the "mobility course." At the initial interview for this study, she had just commenced the telephony course, and the follow-up interview three months later, was on the final day of the course.

##### 4.4.2 Phenomenal Meaning Units and Psychological Structures of Meanings

###### 4.4.2.1 Jane's Perspective of Loss of Sight

*Loss is an Obstacle Overcome:*

Jane views her loss of sight as an obstacle she has overcome

and maintains that she is coping with her loss. She compares this "obstacle" to an ordinary activity like falling off a bicycle ("I see it as just another obstacle I have overcome." "I can cope with it." "I would say that my loss of sight was like if you're riding a bicycle and you fall off." "You just get back on again.") "I'm on again.")

*Power of Surgery to Heal:*

Jane's central focus is on surgery and what it can accomplish. For her. Surgery is a priority in that it is a means of getting well to having peripheral vision, because without it she would be totally blind ("I was going through lots of operations." "That was the priority." "They were more concerned with operating, trying to heal me." "The operations were essential to give me the bit of peripheral vision I have." "Without the operations it would have been a completely different situation." "I would have been completely blind." "There was improvement in my left eye." "It was just like a dream seeing some image." "Then I started actually seeing shadows." "Later I started seeing colour." "It is now about 18 months since I've been in hospital for any operation." "Everything is still the same.")

*4.4.2.2. Jane's Emotions, Feelings, Thoughts and Reactions*

*Acceptance:*

Jane is emphatic that she has accepted her loss of sight "I have accepted my VI." "In actual fact, I don't even feel as if I have a disability." "I have definitely accepted it.") Jane maintains that acceptance is related to her being independent and in charge of her life again ("acceptance is my feeling of being independent and doing things for myself." "I've taken charge of my life again, that's the acceptance.") Acceptance is reinforced by her attitude that time heals ("I believe that time heals, it does." "It actually makes you stronger." "Especially when you feel that you can do and get something positive out of it.")

*Denial:*

Jane denies the reality of her loss of sight ("I don't even feel as if I have a disability.") She continues to deny emotions associated with her loss of sight, and even when felt, they are difficult to express ("because there was so much else going on your emotional state was put into the background." "It was more the physical part that needed to be dealt with." "With the emotions, I don't know, it is something that is very difficult for me to express." "I have not been for counselling." "I don't even think I want to go for counselling." "Before I came here (Optima) I had already worked through my emotions." "I find it very difficult to express my emotions.")

*Sadness, Bitterness and Frustration:*

Jane maintains that the occasional expressed emotion such as sadness, bitterness, and frustration centre round her loss of her independence ("it was only after about 6 months that I started hurting a lot." "I knew that this really now was my condition." "I realise that it's gone." "I felt sad and bitter and also a lot of hurt that I have now become dependent when I was very independent." "I'd have to ask people to do things for me." "I had to rely on them and their generosity to look after me." "The taking away of the independence is really where I feel it most." "I occasionally feel sad and frustrated and I feel bitter when I find that I can't do something." "Then I try to get away from it by occupying myself.") It is still frustrating for Jane to accept she is not able to drive her motor car ("I miss my car." "I used to drive a lot." "I miss just being able to get in and go where I need to go." "That's frustrating sometimes.")

*Hope:*

For Jane, surgery remains the focus because it promises physical "healing" in that surgery is the means to see again ("they were operating, and your hope is when you come out you're

going to see again.") She claims that during the period of the operations she started giving up hope because the ophthalmologist was frustrated about not getting any positive results ("when the retina started detaching again (after fourth operation) I actually felt at my lowest. "I started giving up hope, mainly because he (the ophthalmologist) was getting frustrated." "You ophthalmologist) said you're going to operate and I'd be able to see." "He said, "no I didn't promise you anything." "That was a crushing blow.")

*Worthlessness, Uncertainty and Anxiety:*

Jane maintains that because she is a private person it is difficult for her to ask for help. She claims that she often feels worthless about needing to ask for help and that she is uncertain about the help offered ("I had to learn that I have to be able to ask for help." "That's a problem because I'm rather a private kind of person." "That is the biggest adjustment that I've found in my life." "Having to be dependent often makes me feel worthless." "I know I can do the things but because of my sight now I need help." "When I ask people for help the third time I get the feeling that I've now overused my privilege.")

Jane is anxious about not being employed and not having a medical aid especially if more operations are in the offing "the only peace of mind was that I had a very good medical aid at the school." "I didn't have to worry about the cost factor." "That of course is a different story now that I am no longer working and don't have a medical aid." "It is a bit of a worry for me.") She claims that in unfamiliar places she is anxious and uncertain ("it (being safe and secure) depends on the circumstances, because there are always times when you are in unfamiliar places." "I'm a bit uncertain and I worry a bit." "If I'm in familiar surroundings I'm completely at ease." "In unfamiliar situations I like people to tell me and I ask them to show me around so that I know where I am.")

***Self-Confidence and Self-Determination:***

Jane contends that she is confident and determined to cope with and carry on with her life despite her VI. She claims that she feels safe and secure and in control of her life, environment and her VI ("I feel safe and secure." "I am very much more confident now." "The mobility course gave me self-confidence to walk alone." "At Optima I learnt to cope with it." "I don't feel vulnerable as a visually impaired person." "I don't feel that my sight is a danger to me." "I can cope with it." "I'm at the stage where I'm in full control of my vi." "I will try and do anything." "It is only when I'm absolutely stuck that I need to get someone to work me through the various stages." "Other than that, I will fumble along and do what I can." "I forced my way and try to do things for myself.")

***Pride:***

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 ("when I found that I needed money for my accommodation at Optima." "I started taking on students to do private lessons." "The money has been coming in." "The word has got around that I'm offering tuition." "The whole area is coming along." "I'm actually busy." "When I came here (Optima) I didn't think I could operate a switchboard." "Today I'm doing it." "I came here not expecting any results and I have results.")

***4.4.2.3 Jane's Emergent Needs***

***Need for Practical and Financial Independence:***

Jane maintains that her needs have changed over time. According to her, the need for practical independence such as, mobility, daily living skills, and being able to read, has been satisfied ("my biggest need, after my loss was to be independent again." "Optima showed me that I can take a cane and walk down the street

on my own." "I am doing my own personal things such as doing my washing." "Another basic need of mine is to be able to read." "I need to be able to get information." "During independence training I was able to get a magnifying glass which helps me to read and write." "If I use font 14 on the computer it is quite comfortable for me to read using the glass." "Optima actually gave me back my independence.") Jane maintains that because of her visual ability she does not need to walk with the white long-cane ("I don't walk with the cane because I have good colour perception." "I can get by quite easily." "I don't see in the distance but immediately in front of me I can identify objects." "I prefer not to walk with it." "I'm quite used to it now.")

For Jane, the supreme symbol of independence is financial independence. She claims that if she could get a job she would be able to afford independent living ("I would love a job." "I feel if I have a job that would probably complete the full circle." "I need to be on my own." "Living in somebody else's house I have always to be in the background." "I can never take advantage of their property." "You have to always think of them before you think of what you want to do yourself." "I feel that I need to try to get my life together again." "Get my independence back." "I will have to look for my own place to stay." "I now need to look around and see if I can get myself my own place to stay." "See if I can find myself a job." "Those are my plans, my aims.")

#### *4.4.2.4 Jane's Experiences of Support from Family, Friends, Society and the Rehabilitation Context*

##### *Unhelpful Support:*

Jane claims that her family tried to over-protect her ("it has been a little bit hard for people I live with." "They wanted to put a cushion round me." "Not allow me to do anything.") Her family will not accept what has happened and silence is their way of coping ("I've noticed some members of my family are finding

it very difficult." "I just sense it." "They are having difficulty with looking at me and accepting.") When independence issues emerge, Jane's family members are "not pleased," but no explanation is offered for the displeasure ("every time I make progress to get on with my life, my independence, they seem not so pleased." "I have no idea why." "I've tried to discuss it but we don't speak about it.")

*Positive Support from Friends, Society and Rehabilitation:*

Jane claims that positive support is offered by sighted friends and a society which is aware of VI issues ("I have very good support from my friends." "These are friends that I've had before I lost my sight." "They help me a lot with satisfying my needs." "Society is very aware of blindness." "There are the institutions which are well established to accommodate the AVI." "There is a lot advertised.") According to Jane, people accept her, but strangers consider her different ("in general, people accept me." "Strangers do consider me a bit different." "I don't go and advertise to everybody wherever I am that I'm partially sighted." "Only after if I need to tell them then I would.")

Optima supported Jane by helping her change her attitude towards VI, and the practical skills offered, mobility, computer and switchboard operation, have far exceeded her expectations, and given her independence and self-confidence ("Optima definitely helped me satisfy my need for independence as far as they could." "Optima actually showed me that I can take a cane and walk down the street on my own." "The mobility course gave me self-confidence to walk alone." "Before I came here I had the idea that I would have to be led by hand everywhere I had to go.") She maintains that she will come back to Optima if there is another course she can attend ("when I leave Optima I will miss nothing." "Unless I find that there is another avenue that I can gain then I will come back." "It has given me computer skills, it has given me the telephony skills.")

#### 4.4.3 Emergent Themes: Psychological Structures of Meanings

Jane views her loss of sight as an ordinary and mundane obstacle she has overcome. She contends that she is coping with and in charge of her loss and life. From her language use it can be deduced that the "obstacle" of loss of sight which she has "overcome" is perceived as a hindrance over which she has triumphed and over which she has full control. There are overtones in these descriptions that Jane perceives her loss of sight to be a mere inconvenience for her.

Jane's hope throughout her experience continues to be focused on the ability of surgery to restore and preserve her sight. This hope of preserving her restored sight is reinforced by "time healing" because it is 18 months since she was last in hospital for surgery, and since then her eye condition has remained stable. With surgery being the "priority" and by focusing on the operations and physical healing helps Jane transcend the emotional trauma of loss of sight. Although she has regained partial sight, there is still an insinuation of fear about losing her remaining sight, "I can't say anything because I would have been completely blind."

Denial and acceptance, although contradictory attitudes and emotions, weave their way throughout Jane's descriptions. There was, and still is, denial of emotions associated with Jane's loss of sight. There is a suggestion that Jane is able to cope with the practical facts of her loss, but cannot cope with the painful emotions. She distances herself from the reality of her changed life as a AVI individual by not wanting to incorporate the idea of her loss of sight into her perception of herself, "I don't even feel as if I have a disability." She further distances her emotions by using impersonal second-person pronouns, "your emotional state," and "your hope." The reality of her loss is also denied because she will not tell people that she has an eye problem, "I don't go and advertise to everybody that I'm partially sighted." The refusal to face the fact of her loss of

sight is underscored by her perception that "time heals."

When emotions, especially frustration, are occasionally expressed they are usually related to her loss of independence. The emotions are in turn, denied when she displaces them onto sighted individuals for having to be dependent on them for help. Frustration and hopelessness are displaced from the loss of her sight onto her ophthalmologist for not fulfilling his promise to restore her sight completely. She displaces her experienced difficulties with her loss of sight onto her family, "little bit hard for people I live with."

Needing to be dependent is a "problem" for Jane and the biggest challenge in adjustment to her changed AVI life for it is contrary to her familiar psychological order of an independent and coping person. Asking for help is something that she has had to "learn," the consequence being that dependence, in some contexts, is accepted, "can you help me?" The word "learning" connotes a process of gaining knowledge, understanding and ability to master or take control of her VI by means of being able to ask for help when it is needed. She blocks out or denies the painful reality and emotions associated with her VI by keeping busy or occupying herself thereby allowing a positive image of a coping and confident person to emerge.

Jane's perceived self-confidence is based on her belief that her independence gained during rehabilitation has enabled her to cope with and accept her VI. There is a suggestion that acceptance of loss of sight is expected so that Jane's independence and her ability to take charge of and adjust to her new AVI life can be guaranteed. It may be deduced from these perceptions that acceptance, coping and adjustment are feelings and processes that can be conclusively completed and concluded following loss of sight. This perception is reinforced with Jane's belief that her loss of sight has been "overcome." The acceptance however, has nuances of denial, as Jane appears to be

using it as a way of blocking out the painful reality of her loss of sight, which in turn, enhances her positive self-image.

Conflicting attitudes and emotions emerge dichotomized as they are difficult to reconcile. The realisation that Jane would not see properly again was "a crushing blow," reflecting overwhelming surrender, yet she perceives herself as taking "charge of" and being in full control of her AVI life. Jane describes how her emotions are "put into the background" and that they are very "difficult to express," yet she perceives herself as having already worked through her emotions before she attended rehabilitation. Jane feels that her VI poses "no danger" to her, that she is not vulnerable but feels safe and secure, and confident. There are however, overtones that these feelings are experienced only in "familiar" places and situations. Jane's experience of feeling safe and secure in familiar situations has been enhanced by her 3 month stay at the familiar environment of Optima, where she has successfully completed the telephony course, which has in turn, heightened her self-confidence.

The dichotomous nature of independence versus dependence emerges. On the one hand, Jane believes that she is independent and able to do things for herself, underscored by her perceived practical independence of mobility, daily living skills and reading. Her acceptance of her loss of sight further supports her independence. On the other hand, time has made Jane aware that as an AVI individual she needs to be dependent on others in certain contexts to help her, and although Jane is aware that she needs to be able to ask for help, there is an insinuation that she perceives this need as a negative reflection of her positive image of an independent person and her self-esteem. Her family's over-protection also reveals that her overwhelming need for independence has been thwarted by their lack of understanding and awareness about her AVI world.

Jane needs employment which would provide her with her needed

financial independence and security to fulfil one of her needs of independent living. The expressed need for her own place to stay alludes to a need for privacy, security, certainty, and freedom to do what she wants to do. The lack of financial security has nuances of Jane becoming uncertain and anxious about her future because a lack of money will not allow her to afford a medical aid, which would give her "peace of mind," if more operations are needed to preserve her sight. There are further assumptions that Jane is not in control of her situation as she claims to be, and that she has not yet fully accepted the fact that she is now not the functioning person she was before her loss of sight, that is, an independent person with a secure job and financial security.

According to Jane, a job would help complete the "full circle" which reflects a final conclusion to regaining the needed independence in all areas of her life. By offering tuition as a means to financial independence and a way to keep busy and escape dealing with the emotional pain of the implications of her loss of sight helps fulfil the goal of independence, practical, financial and personal, and is tantamount to getting her life together. Living with a VI is something Jane has overcome, and she transcends her impairment with her unquestioning acceptance, self-confidence, positivity, and coping.

#### **4.4.4 Summation**

After many operations, Jane can see again, albeit partially, and her hope is that her condition will remain stable. She perceives herself to be practically independent. With the help of rehabilitation and support from her friends, Jane has accepted and is in full control of her VI. For her, this means being independent and in charge of her life again.

### **4.5 CASE FOUR: ANNETTE**

#### **4.5.1 Background Information**

Annette is 56 and has been AVI for 7 years. She has

pseudoxanthoma elasticum and the elasticity in the tissues has caused tears on the retina resulting in the loss of the macular completely in one eye (central vision) and about 50% of the peripheral vision in both eyes. She has had lens implants in both eyes to try to keep as much peripheral vision as possible. She is able to see bright colours, is able to pick up motion, shapes and objects, and can walk without the aid of a white long-cane. Concurring with the vision ability classification in chapter one {Section 1.2.1.3, p. 4} Annette can be said to have low vision.

Annette is divorced and has two adult children, and at the time of the interviews, her daughter was living overseas. She was a maths teacher before the onset of her VI.

Annette was rehabilitated in her own home by a low vision rehabilitator and a social worker from the Society for the Blind in her area. At the initial interview, conducted in her home, she was unemployed, but at the follow-up interview, 6 months later, she had a job as a telephonist.

#### **4.5.2 Phenomenal Meaning Units and Psychological Structures of Meanings**

##### *4.5.2.1 Annette's Perspective of Loss of Sight*

###### *Live Naturally and Normally with VI:*

Annette maintains she is able to live and behave as "naturally and normally" as she did before her loss ("I do things quite naturally and normally." "I still try to live as naturally or as normally as possible as before.") She contends that many people do not know she has an eye problem ( "people don't even realise that I can't see.") It is only when she experiences something out of the ordinary that people remember that she has an eye problem ("every now and then something will happen like I slip or fall." "Everybody will get a fright because they've forgotten that I can't see.")

*Travelling an Uneven Road:*

Annette's experience of her VI is a life journey on an uneven road ("my experience of my VI is more like travelling on an uneven road." "There is a smooth surface, and then there is a gravel surface.") Generally, her AVI life progresses smoothly and normally, but there are also times when she finds it difficult to cope ("from time to time you do fall, fall hard.") She is able to work through these difficulties ("you fall flat in that ditch for a while,") and after that, she is able to continue with her life again ("then you get up and there is the smooth road again.")

*4.5.2.2 Annette's Emotions, Feelings, Thoughts and Reactions*

*Acceptance is a Cyclical Process:*

Acceptance of loss of sight is difficult, if not impossible ("I have not accepted my loss, not even from the beginning, not at all." "The hardest thing to acknowledge was that I could not do what I could do before.") It takes time and effort to accept loss ("you need to work on it emotionally." "Your blindness is something you are confronted with a hundred times a day.")

With time, Annette has accepted some of the limitations associated with her VI ("I had to accept that there are things that I'd never be able to do again." "I've just got to leave them, and don't let them upset me.") Absolute acceptance is an impossibility ("I don't agree with that saying, that time heals." With loss of sight you're confronted everyday with it." "It is not a case of acceptance, because from time to time I fall down." "I then have to start coping again." "It is just like going round in circles, nothing is final.")

*Anxiety and Denial:*

Annette fears losing her remaining vision as she believes that she would not be able to cope with total blindness ("I'm afraid

to lose what I've got." "As long as it (her eye condition) is quiet, I'm happy." "The little bit of vision helps me a lot." "The difference between a little bit of light compared to blindness.") She uses denial to control the threat and fear of "blindness" ("I don't even want to think about it.") And she regularly visits the ophthalmologist ("I still go to the doctor now at this point of time every three months.") Annette also denies her VI by trying to conceal the fact of her vision loss in unsafe and unfamiliar places by not walking with a white long-cane as she perceives that a "blind" person is an easy target for assault ("when my cane is open I am a little bit more open or vulnerable to whatever bad influences are around.") She behaves as "naturally and normally" as before her loss in order to cope with her situation. Annette acknowledges she needs assistance but only in certain situations ("the moment I feel insecure I open it (white long-cane).") "When I go on the plane all by myself I use my cane." "I pretend to be completely blind." "I do this because I now realise that other people do not understand that you can have partial vision.")

*Frustration:*

Annette continues to experience frustration in situations when her VI does not allow her to behave as she did before her loss, the time it takes to complete activities and having to concentrate continually on the task at hand ("I often get frustrated when I'm alone in the house and there is something I really need to do urgently." "I can't do or find something." "I just need to read a document urgently." "Make a phone call and it is such a hassle to find a phone number which I have not got." "I still need to concentrate because the moment I don't I mess up everything." "It takes me so long to do something now which I could do much quicker when I could see.") Her frustrations are not constant but experienced at certain times, places and situations ("I'm not frustrated all the time." "I have to do things immediately, and if you ask me to do something or if I need to do something, I want to do it now." "If I have to wait

for people to help me do something, makes me frustrated." "Frustration also has to do with my emotional state at a particular point in time." "One day something will bother me, and the next day it won't.") It is still very difficult and frustrating for Annette to accept she is not able to drive her motor car "that (not being able to drive) was difficult for me." "Not being able to drive causes me lots of frustration.")

*Fear and Insecurity:*

Annette experiences fear, insecurity, uncertainty and loses confidence when she is alone in unfamiliar and unsafe situations or places ("in unfamiliar places I am very insecure, nervous, and uncertain." "Especially when I'm alone." "I start worrying and I lose my self-confidence.") With the course of time her self-confidence has waned ("it is now 7 years approximately, and I have still not managed to cope with this situation." "My self-confidence to walk to town is not the same as it was before I got the job." "It's a fear that things may have changed.")

*Self-Consciousness, Embarrassment and Withdrawal:*

Annette is sensitive about her VI and feels embarrassed by it ("I am actually glad that I was alone when I lost my sight." "There was no need for me to feel ashamed or embarrassed when I couldn't pour a cup of tea." "I still get very embarrassed when I do something stupid." "I get very embarrassed when somebody speaks and I don't know that they are talking to me." "I would not like other people to think I'm stupid." "I still didn't want to show them that I could not see and wasn't coping.")

For Annette, the longer she has been AVI the more difficult it has become for her to take part in group conversations, and has become more self-conscious about embarrassing herself in front of people ("I have a problem in group conversations." "It is extremely difficult for me to give my input." "I never know when people have finished what they are saying." "I don't want to

interrupt them" because "it is embarrassing for me.") Embarrassment causes Annette to withdraw from group conversations ("I often stay out of the conversation.")

*Self-Esteem:*

Annette believes that her self-esteem has improved the longer she has been VI. At the initial stage of her loss of sight she experienced sadness, helplessness, and worthlessness as everything was unfamiliar to her and she perceived that she was not coping ("I cried a lot." "I didn't know how to do anything." "I just sat in the chair." "I felt worthless.") She took a conscious decision to take control of her life again. By doing crochet and giving her creations to charity she feels worthwhile ("I decided that I must start doing something with my life." "I'll crochet blankets and I always give them away to charity." "When I do this, I feel I'm doing something worthwhile.") Her job has increased her self-esteem and with it, her self-confidence ("not to sit in the chair the whole day thinking about what I'm going to do." "My self-worth and self-confidence has gone up.")

*4.5.2.3 Annette's Emergent Needs*

*Need for Practical and Emotional Support:*

The low vision rehabilitator supported Annette by teaching her practical skills which have helped to make her life easier. These skills include being able to walk with the long-cane and how to read braille, which, because of her visual ability, she does not use ("taught me to walk with the white cane making my life easier." "Being taught braille, which I never use.") What is of greater importance for Annette is her need for a good long-term emotional support system. She needs to have people visit and take her out so that she is not alone, and through these interactions, can maintain a positive attitude towards herself and life. This need is being satisfied by her family, friends, and the social worker at the Society for the Blind ("there is a vital important

need to have a good support system." "I need to have emotional support as well, not just practical support." "I've got friends who visit me and take me out." "The social worker has, and continues, to give me lots of support." "We (low vision lady) became friends." "If I did not have a good support system, I would have become negative in my views on my disability, as well as on life itself.")

For Annette, it is vital to set up a support system as when she loses more of her visual ability she is going to depend on them more ("there is a need for long-term emotional support." "I needed this support every time I lost more sight." "I hope it will be there for me in the future.")

*Need for Sensitivity and Understanding:*

Annette has become aware of the implications, limitations and unique needs associated with the different degrees of visual abilities. She believes that all individuals, including the AVI themselves, society in general, families and friends need to be made aware of and understand what the AVI can and cannot do with different degrees of vision ("they do not know or realise or understand that there are other types of VI, like partial sight." "If you've got total blindness or partial sight, what you can and cannot do." "A completely blind person will be led (by a shop assistant) to whatever he or she is looking for." "I have the ability to walk into a shop and am able to see what I'm looking for." "This does take time, and I feel everything." "The assistants can't understand this.")

For Annette, the lack of knowledge and awareness about VI issues results in stereotyping and misconceptions, particularly in the employment environment, which impacts on her emotionally ("we are not different from them, we just can't see properly." "Maybe people will treat me as a normal human being with a normal intelligence." "I dislike it intensely when people talk to whoever is with me when they actually want to know what I want."

"There is a need for the National Council to go into what jobs are available for persons with all types of VIS." "Not just concentrate on switchboard operators." )

*Need for Honest Information:*

Annette believes that she should have been made aware about the implications and limitations of her eye condition as soon as possible. She feels that with such self-awareness and knowledge about these issues she would have coped better, and would have been better prepared for her future ("there is a need for all visually impaired people to be made aware about the significance of living with their VI as soon as possible." "It was vital right from the beginning that I should have been made aware of what my condition involved and what I could expect in the future." "My life would have been much easier." )

Such truth and honesty could be accomplished through open, clear and sensitive communication between all members of an AVI individual's social network. She also feels that people involved in helping the AVI need to be AVI themselves ("there is a need to teach all people what VI is all about." "It is extremely important that visually impaired persons and their families, together with people like doctors get together so that everybody is clear about what is going on." "I needed somebody to sit down and talk to me." "Ideally, this person should be visually impaired him or herself." "I don't think sighted people actually know what a visually impaired person experiences." )

*Need for Employment and Financial Security:*

Annette's overwhelming need is for employment to give her financial independence and security. She believes such security will enable her to live more comfortably, alleviate some of her emotions like anxiety and hopelessness, and allow her to purchase adaptive devices like a computer to communicate with her daughter ("my pension is just enough to pay my levy, let alone buy food."

"It is something that makes me feel hopeless." "Things like computers that the AVI can use, it is so expensive.") She is currently employed as a stereotypical switchboard operator.

#### *4.5.2.4 Annette's Experiences of Support from Family, Friends, Society and the Rehabilitation Context*

##### *Positive Support from Family and Friends:*

Annette's need to be perceived as a "normal," coping and in control person has been realised by making her family and friends aware of the basic VI issues and what she can and cannot do. Their support has changed from over-protection to accepting her ("they overprotected me." "Now they treat me as a normal person." "They've learnt to live with me and know what I can do and what I cannot do." "They accept me as I am.") Annette also received and continues to receive, support from the Society for the Blind (rehabilitation context) ("the Society for the Blind was there for me in the beginning and is still there for me now.") Annette maintains that people are not supportive and claims it is because they are not aware of VI issues ("people in general are definitely not supportive.") "it is because they are not aware.")

#### **4.5.3 Emergent Themes: Psychological Structures of Meanings**

It is important for Annette to be perceived by others as coping with, and in control of, her VI. She is afraid that if she comes across as not coping and unable to do things other people will see her as "stupid," with nuances of Annette not wanting to be perceived as different, useless or worthless. 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. However, with the support Annette receives from her family and friends she perceives herself able to cope with her impairment, and feel safe and secure. She has gained conscious insight and self-awareness about the complexity and difficulties of living with a VI and

understands that she 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.

The lack of awareness and understanding of the fundamental issues of VI by all people results in stereotypical and prejudicial attitudes towards AVI individuals in all areas of their lives, and in particular, the employment environment. There is a need for Annette to be kept busy so that a positive image of herself as a coping, confident and in control person will emerge. Ironically, Annette is now employed as a switchboard operator, 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 security.

Annette maintains that each AVI individual, depending on their degree of vision loss, has different abilities and needs. Awareness of these facts ought to make people sensitive to the needs, issues and challenges facing the AVI. Annette maintains that her foremost need was to be confronted as soon as possible with the real implications and limitations of her VI which, had it been provided, would have given her the ability to cope better with her condition. This confrontation should have been done in a sensitive manner by an AVI professional.

Annette views her life challenge, because of her physical loss of sight, as an "uneven" life journey with continuous circular emotional adjustments. She perceives that she is confronted on a daily basis with the implications and limitations of her condition. The use of the word "uneven" insinuates that Annette perceives her life to be erratic and unpredictable. She tries to regain "normality" by continually attempting to live as "naturally and normally" as before her loss. Her motivation to live "naturally and normally" reflects low self-esteem. The frequent use of the word "fall" has both literal and metaphorical value: Annette literally does fall, and she also gives in to her

emotions of frustration, fear, loneliness, and worthlessness. Her perceived "unevenness" of her life as an AVI individual is underscored by her belief that her emotions, and especially frustration, are not experienced continually but are episodic and related to specific situations, times and places. Frustration is related to her emotional state at a particular time, or when she experiences loss of control over her life when she cannot read an urgent document or when she cannot drive.

Descriptions of anxiety, self-consciousness, frustration and coping weave their way through Annette's descriptions. She attempts to distance her emotions, especially her fear of losing her sight completely, by not incorporating the idea of "blindness" into her perception of herself. Conflicting attitudes and emotions emerge, dichotomized as they are difficult to reconcile. On the one hand, Annette denies her VI by not walking with the white long-cane, whereas, on the other hand, she always carries her cane and when she feels vulnerable, insecure or when she is in unfamiliar places she opens it and "pretends" to be blind. From Annette's language use, and in particular, the use of the word "pretend," it may be deduced that she needs attention, help and protection whenever she feels vulnerable. Her need for attention in vulnerable situations, which she perceives she does not receive as a partially sighted person, is in contrast to her profound need to be treated as a normal sighted person. These feelings do not last as she deals with anxiety through denial, moves from positions of worthlessness to feelings of worth and self-esteem. Living with a VI is thus a circular process for her, having to constantly cope with and adjust to her loss of sight.

#### 4.5.4 Summation

Annette perceives herself as coping with her VI and living as naturally and normally as before her loss of sight. She has not fully accepted her VI emotionally, but time has made her aware of her limitations associated with her VI. She continues to

experience embarrassment, anxiety and frustration related to issues of VI. Positive support from her family and friends has helped her cope with her continual adjustments she has had to face during the time course of her adventitious VI.

#### 4.6 CASE FIVE: AMANDA

##### **4.6.1 Background Information**

Amanda is 37 and has been AVI for 2,5 years. She has optic atrophy where the nerves behind her eyes have deteriorated to the extent that they are permanently damaged. She still has light perception and is able to distinguish shapes but no fine detail. Concurring with the vision ability classification in chapter one {Section 1.2.1.3, p. 4} Amanda can be said to be functionally blind.

Amanda is married and has 3 children aged 13, 11 and 6. Before she lost her sight, Amanda was a market researcher and is now a home executive. At the time of the initial interview for this study, Amanda was in the final week of her rehabilitation, and the follow-up interview, 4 months later, was at her home.

##### **4.6.2 Phenomenal Meaning Units and Psychological Structures of Meanings**

###### *4.6.2.1 Amanda's Perspective of Loss of Sight*

*Loss is a Learning Process:*

Amanda views her loss of sight as being both a practical and emotional learning experience. She claims that it was precisely her loss which initiated this process for she had to, and continues to, question and analyse both her past and future, ("in these past 2 and a half years I've learnt many things." "I definitely made a u-turn in my life." "I went back in my life and saw what it was like." "Had to make another turn to see where I

was going." "Where is the problem and then work these things out, and analyse them." "I continue to question why this has happened to me.") Amanda adjusts to the experienced changes in her life in order to cope "I had to adjust practically, because things can't be the same as before." "I had to adjust on the emotional side, because I started thinking about things differently." "I had more time to look into myself." "I feel that I'm 10 years ahead of time.")

#### *4.6.2.2 Amanda's Emotions, Feelings, Thoughts and Reactions*

##### *Acceptance:*

Amanda has accepted her VI in order for her to move on with her life ("I have accepted that for now I am blind." "You have to get to a point where you accept in order to move on.") She acknowledges and accepts her limitations ("I can't do what I used to do." "I should function as a blind person." "There are some things that I will never do until I'm able to see again.")

Amanda's attitude of acceptance is based on her belief that acceptance is expected of people who experience a loss, after which coping and adjustment can occur ("accept the things you can't change." "I grew up with that." "It is like I've been through a loss, accept it, and get on with it." "The coping and the adjusting is getting better.") Acceptance is reinforced by her attitude that time heals ("I believe that time heals." "It doesn't hurt so much now." "It is not so intense now." "In the beginning it really hit me hard." "With time, it will never go away, but it definitely gets better.")

##### *Sadness:*

Amanda continues to experience sadness about her loss of sight especially in situations which involve her children. She claims that this sadness will continue to be experienced for a long time. In these situations she wishes she could still see ("I was

terribly sad for my children's sake, and everybody around me, and for myself." "It was the sadness, I felt terribly sad about it." "I have experienced sadness when it comes to things like prize giving or concerts at my children's schools." "It hits me then." "For the sake of the children, I go (to the concerts)." "Then I'm sad, and I'm sure I'll have a lot of those in the future." "I wish I could see just for a moment in these situations.")

*Frustration and Anger:*

Amanda experiences frustration when her VI does not allow her to behave as she did when she could still see. She claims that not being able to drive is frustrating as well as having to plan and organise her life and be dependent on others ("my loss of independence was quite a thing to cope with." "When you want to go to the shops quickly you just can't." "You just can't jump into the car." "Everything has to be so organised and planned." "If you want to do something you need to plan in advance." "That gets to me the most, it is so frustrating." "I need to ask someone to physically take me to where I want to go." "I don't like to ask people, I do if I really have to." "I would prefer to just get on a bus and do my own thing.")

Amanda maintains that she also experiences frustration with her husband's lack of support, his non-acceptance of her loss which she claims has impacted on her negatively in that she is not able to cope ("I thought he should be helping me cope." "In the past I was the positive one, and he would be able to lean on me." "Now the situation has turned around." "I felt that he couldn't be there for me." "He is still battling today and that has a negative effect on me." "I often get frustrated with the situation." "He hasn't got to the point where he has really accepted it yet." "Once you've accepted it you will be able to deal with it in a positive way.")

In addition to experiencing frustration, Amanda claims that she feels angry and continues to question her loss ("anger, yes I had

anger." "I did question "why me?" "I've often wondered and continue to question why this has happened to me.")

*Anxiety and Insecurity:*

Amanda claims that she is anxious and feels unsafe about walking in her area as she is an easy target for assault ("I feel vulnerable and not so safe walking here in the area where I live." "I'm afraid of leaving my home on my own." "I'm a soft target out there.")

Amanda contends that following her loss of sight she is anxious about her husband's reactions towards her, and claims that he often makes her feel insecure about her capabilities. In these situations she wishes she could see again ("his reactions worry me." "He is a person who stresses very easily." "I tend not to overload him." "Wait for the perfect moment and then sometimes it doesn't come." "Everything boils up inside of him and then he almost explodes." "He waits until he can't take it any more and then he gets angry." "I clean the house and maybe there might be a little paper lying there." "He said to me on one occasion, "I'd rather do the whole thing (cleaning the house) myself." "That made me feel bad because I felt that I was incapable of doing anything." "If I could just scan this house once just to know where everything is, it would be much easier for me.")

*Faith and Hope:*

Amanda claims that she had hope that she would see again and with her self-determination searched everywhere for a cure ("I really desperately tried to see again." "I went to every doctor and professor." "I tried absolutely everything, every opinion, because I was determined to see again." "I didn't want to accept it." "I wanted to fight it with everything I had in me.") Amanda continues to have hope that she will see again (for now I am blind, until I'm able to see again." "There are some things that I will never do until I'm able to see again.")

Within the context of Amanda's Christian belief she went to a faith healer in her hope to see again. According to her, this visit was a negative experience and the anxiety it provoked rendered the experience counter-productive ("I even went to a faith healer which ended in a nightmare." "It was very traumatic." "This experience actually put me back." "It was even worse than turning blind." "I experienced it (the faith healer not praying for her) as a rejection." "I started questioning and looking at myself, and wondering what is wrong with me." "I felt worthless, and started doubting myself.") She claims 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. Her renewed faith in God has helped her cope with her situation ("at one stage, I felt like there was a block between me and God." "It was God who kept me going, and all of a sudden, that just wasn't there any more." "After a lot of soul searching, questioning and thinking." "I realise that what I was experiencing was really negative." "I was feeding myself with negative things." "I realised that if I kept on thinking these negative things, I was about to lose everything in my life." "I realised that I wasn't the person I used to be, or the person I was supposed to be." "I then realised it is my choice." "Thank God, He helped me and He is once again keeping me going.")

#### *4.6.2.3 Amanda's Emergent Needs*

##### *Need for Practical and Emotional Support and Open Communication:*

Amanda needs emotional support in the form of her husband listening and communicating openly with her ("support and open communication is very important." "I experience this need even more being blind." "My husband doesn't talk a lot." "He talks when he's cross." "Instead of just sitting down and saying, look this situation is like this and let us do this and this in a civil way." "He waits until he can't take it any more and then he gets angry." "I feel that if he just came to me in a calm way,

we could sort the problems out." "He will rather do things for me than sit and listen and talk to me." "I need this desperately.") Amanda maintains that this need is however being satisfied by a good friend ("I have a friend that I've had for 25 years." "We've always had a good relationship." "I can always talk to her and she understands." "A good support system.")

Amanda maintains that because she is unable to drive a motor car she needs practical support in the form of organised transport for herself and her children ("I feel that my children also have to be at places at certain times." "I would have taken them previously, and my husband isn't always available." "If there was someone who I could just phone up and say please come and pick me up here and take me and my children there.") Because there are financial constraints linked to her being unemployed, practical support is needed in the form of more affordable assistive devices ("the aids for blind people are terribly expensive." "It is expensive to be blind." "I would like to do the e-mail thing but the price has made me not try to want it too much." "It is terribly expensive and with me not having a job any more finances have been cut down.")

*Need for Understanding and Knowledge:*

Amanda feels that society needs to be made aware of and understand the basic issues of VI in order to alleviate misconceptions ("society needs to become more aware of VI and all that is involved." "I do believe that people tend to think that because you're blind you can't do anything.") She maintains that society, the AVI themselves and rehabilitators need to know what the AVI can and cannot do with different degrees of vision. This lack of knowledge impacted on her emotionally ("society and the visually impaired should be made aware of the different types of vi." "There is a huge difference between somebody who can only see a bit, and somebody who can see a lot." "Everyone should know about the differences in what people can see." "Even my friend,(who had a lot of sight) would say "it is there," and I'd

say "where is there?" "It put pressure on me." "It does have an effect on you if you're competing with the person who has a lot more sight than you." "You start feeling stupid, and you think to yourself, "I'm not able to do what she is doing." "From the beginning the people at Optima treated us all as blind people." "They never made any distinctions." "They (rehabilitators) need to distinguish between those who can see and those who cannot." "I'm not sure if they even knew about the differences because if they did they didn't show it.")

*Need for Education and Information:*

Amanda claims that she and her family should have been made aware of the real world of her VI with all its implications and long-term effects. With such self-awareness and knowledge about these issues she and her family would have coped better, and been better prepared for her future ("Optima could have focused on things like what may happen in the future." "Make the students aware about the real world out there." "If the family know exactly what they are dealing with it might be easier." "This is what blindness is all about, and this is what you can do, and this is what the blind person can do, and this is what could happen.") Such knowledge could be accomplished by involving the family in rehabilitation as well as providing education and information ("there is such a need for a place like Optima just to educate the family, to help them to cope." "The more information you have the better you are equipped to cope.")

*Need for More Centres for the AVI:*

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 ("I would have loved to go there (Optima) just during the day and come home at night." "It is easier going there without having a family, a close family

like mine, with young children." "Being away from my family, that was the difficult part." "There is a need for many more places." "I need to be kept busy during the day." "I need to do something creative." "Things like crafts." "To have the company of others." "Which will relax me and that's my need at the moment.")

#### *4.6.2.4 Amanda's Experiences of Support from Family, Friends, Society and the Rehabilitation Context*

##### *Unhelpful Support:*

Practical support and silence is the way for Amanda's husband to cope with her loss of sight. According to her, practical support, although necessary, is unhelpful support given her need for emotional support and communication from her husband to help her cope ("my husband has always been very supportive." "After my loss of sight he became a bit rebellious against the whole situation." "He talks when he's cross." "He would rather do things for me than sit and listen to me." "He would rather be the one to do things and that's the way he thinks he's making it easier for me." "At times all I need is for someone to just sit and listen to me." "I felt that he couldn't be there for me.")

##### *Unconditional and Helpful Support:*

Amanda contends that the helpful and unconditional support she receives from her children helps her cope ("children are wonderful." "Sometimes if we could only be like them." "They react like, ok, there is nothing we can do about it, accept it and carry on." "Our relationship is still fine, and they help me whenever I need help." "I try to keep a very open relationship with them." "Honesty as well.")

##### *Positive Support:*

Support from Optima is evident in the increased self-confidence Amanda experiences after completing the independence course,

especially her mobility skills ("after doing the independence course I got a lot more self-confidence." "I'm able to walk with the -cane in shopping centres." "I'm not so dependent on people guiding me so much.") The support from AVI friends doing the same courses as her will be missed ("I always say it is easy being blind between blind people." "I miss the other blind people at Optima more than anything else." "We used to chat amongst one another and everybody was in the same boat." "There was much more understanding and support amongst everybody.")

#### **4.6.3 Emergent Themes: Psychological Structures of Meanings**

Amanda views her loss of sight as a learning experience. To her, learning with its overtone of education, knowledge, insight and understanding, is the essence of being able to cope with loss of sight, not only for her, but for her family, and especially her husband, and all people who form part of her social network.

Knowledge gained through self-analysis and questioning has given Amanda conscious insight into and understanding of the complexity and difficulties of living with her changed life as an AVI individual, and her need to adjust, both practically and emotionally. There is an inference of Amanda being open to change and willing to learn and adjust to such change, even though adjustment may be difficult. Amanda's language use, "I feel that I'm 10 years ahead of time" has both positive and negative connotations: on the one hand, amanda maturing through the learning and self-analysis process, and on the other hand, the trauma of her loss of sight together with the insight she has gained, especially her knowledge that her loss of sight has negatively affected her relationship between her husband, which has physically aged her beyond her years.

Amanda believes that there is a need for all people, including the AVI themselves, families and rehabilitators to have knowledge of the "real world" of vi, and the unique needs and abilities associated with different degrees of vision loss, rather than a

fallacious and superficial understanding. Knowledge of these facts ought to make people sensitive to the needs and challenges facing AVI individuals and help alleviate misconceptions about vi. 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 individual, with their different degrees of vision, not being addressed during rehabilitation, and a suggestion of stereotyping if all avi individuals are rehabilitated as "blind."

Amanda's relationship between her husband following her loss of sight appears to emerge as her essential concern. Amanda perceives that her role in the relationship has changed from being the positive one and always supporting her husband, to her now being the one needing the support, and particularly emotional support. There is an insinuation that because amanda's husband no longer receives her support, his relationship towards her has changed to that of a negative and difficult one, underscored by his lack of communication and emotional support.

Amanda continues to be anxious and feels stressed and inadequate because she can not live up to her husband's expectations, especially when he finds fault with the way she runs the home. It may be deduced from amanda's language use that her husband has a temper and gets angry, with further nuances of him being impatient and frustrated with her inability to meet his expectations. It appears that amanda is afraid of her husband as she tries not to overload him with her problems for fear of causing him to "explode" with anger. Amanda's need to be kept busy and relaxed during the day alludes to the pressure and stress she is experiencing because of her husband's non-communication and non-support. Significant in amanda's verbalizations is her omission to acknowledge her husband when describing her experienced sadness and her fear of "losing everything," feelings expressed towards her children. This omission appears to reflect a questioning of her husband's role in her life.

Denial and acceptance, although contradictory attitudes and emotions, as well as sadness and frustration weave their way throughout amanda's descriptions. There is denial of the reality of amanda's loss of sight and resolute hope, albeit unrealistic hope, that she will see again. She distances the reality of her loss of sight by not wanting to incorporate the idea of her blindness into her perception of herself as according to her, she will be "able to see again." The refusal to face the facts of her loss of sight is underscored by her perception that "time heals." Contradictory attitudes of "seeing again" emerge. Although amanda emphatically believes that she will see again, she acknowledges that her eye condition will never "go away," which is reinforced by her attitude of having to accept things that cannot be changed, with a suggestion that she will never see again.

Amanda's attitude of acceptance is based on her belief that acceptance is expected of people who experience a loss, after which coping and adjustment occur, and individuals are then able to "move on" with their lives. It may be deduced from these perceptions that acceptance, coping and adjustment are feelings and processes that can be conclusively completed and concluded following loss of sight. This attitude conflicts with her earlier attitude of non-acceptance based on her conviction that she would see again. There is a suggestion that if Amanda's expectation of acceptance is not fulfilled, it would be perceived as a negative reflection of her image of a positive, confident, coping and adjusted AVI individual. The acceptance however, connotes denial, as amanda appears to be using it as a way of blocking out the painful reality of her loss of sight and the related difficulties such as, her negative relationship with her husband. This helps her cope with her loss in the present, as she believes that she will see again in the future. In a conflicting attitude however, Amanda's focus on the here and now, and "living day to day." Has nuances of a blocking out of the painful reality of the implications of not being able to see in the future.

Sadness and frustration are the predominant and all

encompassing emotions which have been experienced throughout the time course of Amanda's VI. Sadness is experienced in situations or events involving her children, and frustration is associated with issues such as her loss of control of her life and having to be dependent on others for transport, loss of spontaneity in not being able to "zip there" in her motor car, and the lack of awareness about VI issues, and in particular, the lack of emotional support from her husband. In these situations, the reality of her VI "hits" home for she has insight that the sadness and frustrations will continue. There is an implication of amanda perceiving her AVI life as being difficult: practically, as when she needs to plan and organise her life and be dependent on others, emotionally, with her continued experiences of frustration and sadness, and financially, "it is expensive to be blind."

Amanda's descriptions abound with nostalgia especially in situations and events which involve her children and her wish to see them again, and her wish to see in situations which cause her anxiety. This nostalgia impacts on amanda's functioning in the present because there is an overtone of yearning to return to her sighted life where she perceives herself to be independent and in control, and to her familiar psychological order of a sighted wife, mother and working woman. Amanda transcends her physical loss of sight by accepting her need to function as a blind person and to live day to day with knowledge of the real implications of her VI which gives her the ability to cope with her condition.

#### 4.6.4 Summation

Amanda perceives herself as a coping, aware and positive person and able to carry on with her life despite her VI. Knowledge, insight and understanding about living with a VI is perceived by Amanda as the essence of being able to cope with loss of sight. Her intricate descriptions however embrace contradictions and nuances of a accepting but denying person, and the continued frustration towards her husband for his lack of emotional support

and his negativity towards her following her loss of sight.

#### 4.7 CASE SIX: GAIL

##### 4.7.1 Background Information

Gail is 43 and has been AVI for 16 years. The cause of her VI is diabetic retinopathy. She had light perception following an operation where one of her retinas was re-attached, but after four years, this retina detached again and she is "unable to see even light." Concurring with the vision ability classification in chapter one {Section 1.2.1.3, p. 4} Gail can be said to be totally blind.

Gail is not married and stays at home with her parents. Before she lost her sight she was a sales consultant for a airline company. She attended Optima College for rehabilitation 2 years following her loss of sight and returned a year later to do the computer courses. At the time of the interviews at her home, 6 months apart, Gail was studying to complete a B.A. degree.

##### 4.7.2 Phenomenal Meaning Units and Psychological Structures of Meanings

###### 4.7.2.1 Gail's Perspective of Loss of Sight

*Loss is a Challenge:*

Gail experiences her loss of sight as a life-long challenge because she feels that she is confronted daily with the difficulties associated with not being able to see ("loss of sight for me is a life-long experience." "My life as a blind person is a great challenge." "I'm confronted continually with difficulties because of my inability to see." "When I cannot get in my car to collect something that is urgently needed." "When I cannot take my mom to the doctor when she is too sick to drive.") She claims that although the difficulties differ from day to day, she still has to meet the challenges in order to carry on with her life ("everyday I am reminded of my loss of

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sight to a greater or lesser degree." "No matter the degree I have to meet the challenge." "Some days not being able to do something or see something will cause me hassles." "On other days this same situation will not bother me." "As long as I can meet this challenge life will go on.")

*Circular and Oscillating Experience of Continuing Losses:*

Gail claims that in certain situations she continues to experience ongoing losses associated with her loss of sight ("these experiences are often like ongoing losses." "I need to get a book urgently in order to complete an assignment." "By me not being able to get into my motor car at that particular point in time to go and fetch it." "I experience it as another loss because I feel like I'm losing out in not being able to do what I need to do.")

Gail maintains that the experience of ongoing losses elicit similar already confronted emotions, which in turn, need to be confronted and challenged again. In this context, Gail views her loss of sight as a circular but oscillating experience, with her greatest challenge being to confront the effects of these oscillating and circular emotions which are experienced in certain situations times and with the particular experienced loss, particularly meaningful to her "when I experience these losses I still feel frustrated, sad, perhaps even angry and often worthless." "When I'm in specific situations when my loss of sight becomes meaningful, I still experience and re-experience those emotions and feelings." "I must stress that it is not all the time." "It often feels like I go round in circles." "I experience a circular thing and go through those emotions relevant to the loss being experienced." "When I need to do something urgently they (family) are surprised that I still get frustrated, which frustrates me more." "My sister got married recently and on her wedding day I felt sad and angry and frustrated that I could not see how she looked." "I experienced this situation as a new loss because I couldn't see her." "In

that important and meaningful situation of her wedding I desperately wanted to see how she looked." "It was my loss in that situation and the emotions associated with that loss." "I think it has to do with how important or how urgent something needs to be seen or done." "It is in these situations that I meet my greatest challenge." "Not being able to do things or see things in important situations will always be there.") It is in these meaningful situations that she wishes she could still see ("I sometimes wish that I could see." "This wish is not there all the time, just in certain times that are especially meaningful to me.")

#### 4.7.2.2 *Gail's Emotions, Feelings, Thoughts and Reactions*

##### *Acceptance is a Circular and Oscillating Process:*

Acceptance of loss of sight is difficult ("I certainly haven't accepted my blindness.") Gail maintains that she has accepted the fact of her VI ("it is not that I don't accept that I am blind because that is the reality." But does not accept the consequences of her condition ("what I don't accept is the effects and hassles that my blindness imposes on me." "Things like the limitations of my blindness, such as having to be dependent on people to read things for me." And the waiting for things to happen." She experiences acceptance as an oscillating and circular process ranging from acceptance to total non-acceptance depending on specific situations ("some days when I walk to the shops and everything goes smoothly then I feel OK, I'm coping, I've adjusted and I suppose then I've sort of accepted." "If I walk to the shops and something goes wrong, like I take a wrong turn, fall off the curb, then I feel totally unadjusted, I feel frustrated, I feel worthless, and by no means do I accept my blindness." "I would describe this situation as a circular thing, where I experience emotions like, accept and then don't accept.") For Gail, absolute acceptance is an impossibility ("I don't believe in that saying of time heals." "Time has not healed the emotions, feelings and thoughts of loss

of sight." "Time has certainly not made it easier for me.")

With time, Gail has accepted some of the limitations associated with her VI, especially with regards to needing to be dependent on people when help is needed ( "the reality set in and I realised that I was not that independent person I believed I was." "I soon realise that in order to survive I have to learn to be dependent on others when I need to be dependent, and ask for help when help is needed." )

*Frustration:*

Frustration directly related to the issues of Gail's VI continues to be experienced ("the emotion that stands out for me when I first lost sight and still now, is frustration." "The frustration I'm referring to is the frustrations related directly to the issues surrounding my blindness." "Issues like having to wait for people to do certain things for me." "Needing people to explain colours of clothes to me." "Those kind of issues that sighted people don't have to experience.") She maintains that she experiences more intense frustrations the longer she has been AVI because she is aware that her situation will never change and that not being able to see in meaningful situations will continue to elicit emotions, including frustration ("the longer I've been blind the more frustration I experience." "The feelings, and in particular frustration, have become more intense." "It is to do with me knowing and understanding that my situation is never going to change." "I'm continually going to be in situations where it would help if I could see." "When I'm in these situations and not being able to see I get frustrated.")

It is still very difficult and frustrating for Gail to accept she is not able to drive her motor car ("I miss being able to drive." "Sometimes just being able to get in my car and go to a movie." "In situations when something is needed urgently and I just can't get in the car to fetch or buy it." "I have to wait for someone else to do it for me is frustrating, very

frustrating.")

*Sense of Humour:*

Gail contends that her sense of humour and being able to laugh at herself helps her and others cope with her VI ("my sense of humour has helped me cope with the difficult world of my blindness." "If I can laugh at myself and if I can laugh at life it makes it easier to cope." "It makes it easier for family and friends to cope." "A sense of humour is often an ice-breaker among new people I come into contact with.") She maintains that laughter helps distance the difficult emotions associated with her blindness ("emotions and thoughts are sort of brushed aside with laughter taking the centre stage.")

*Self-Awareness and Self-Determination:*

Gail maintains that she has gained insight into both herself as a person and about the real world of her blindness. Her sighted life was taken for granted, which has now changed ("before I lost my sight I never gave a thought of not being able to see." "It was just taken for granted that the rest of my life would be a sighted life." "I now try to live each day to the fullest, meet those challenges and not take anything for granted.")

She is aware and accepts the fact that she will always be a blind person and that she needs to be dependent on others in order to survive ("I know I will always be blind." "The reality set in and I realised that I was not that independent person I believed I was." "I had to become dependent on others, and I'm still dependent on them." "To take me shopping, or tell me colours when I buy clothes." "I soon realise that in order to survive I have to learn to be dependent on others when I need to be dependent." "Ask for help when help is needed." "That was a very difficult thing for me." "Having to become dependent on others after always being such an independent person.")

Time has made Gail aware of the real world of her blindness, with all of its implications and limitations ("time has certainly made me aware of the real world of blindness." "I had to become dependent on others." "Over the years I have become more and more aware that my life as a blind person is a great challenge." "I've experienced the loss of sight, I've felt all the emotions, but I'm still continuing to experience those emotions and feelings.")

Initially, Gail was unrealistically determined that she had no limitations, but with her acquired realistic insight she now acknowledges her limitations and is determined to carry on with her life ("I was lead to believe that I could do anything." "Giving me a feeling of unrealistic hope." "You can go back to your last job, which was unrealistic because for that job I needed sight." "In my unrealistic state of mind I thought I can still go overseas alone." "That unrealistic hope made me a very determined person." "Believing that I would show the world and everybody else that I could do everything." "I am still a determined person." "Determined in the sense of getting on with my life despite my blindness." "I now know what I can and cannot do and how to cope with those difficult limitations.")

#### 4.7.2.3 *Gail's Emergent Needs*

##### *Need to Learn to be Blind:*

Gail acknowledges that her needs as a blind person have changed over time. Initially, she needed to "learn to be blind" by acquiring practical skills associated with VI, a need satisfied by being able to walk with the white long-cane. She claims that AVI individuals are expected to know certain skills, such as how to read braille, a skill which she uses in certain situations only ("in the beginning I needed to learn to be blind." "This need was satisfied to the extent that I can walk with a white cane." "I needed to learn how to do braille." "Today I use braille only to mark my CDS." "I learnt it because it was expected of me.")

*Need for Awareness and Understanding:*

With time, Gail has become aware of the real world of VI, and in particular, the implications, limitations and unique needs associated with the different degrees of visual abilities. She maintains that all people need to be made aware of and understand the real world of VI and what the AVI can and cannot do with different degrees of vision ("my biggest need now is for all people, and that includes the visually impaired people themselves, society in general, families, friends, doctors, and in particular the rehabilitation workers to be made aware about the real world of VI." "All people need to be made aware about the different degrees of VI." "All people with a VI are assumed to be blind and unable to see anything." "People should know that you get totally blind people but also partially sighted people." "With the different degrees of sight people can do different things and their needs are different.")

For Gail, the lack of knowledge and awareness of VI issues, and particularly the different degrees of visual abilities, results in stereotyping, confusion, misunderstanding and misconceptions, which impacts on her emotionally ("I think this knowledge would clear up a lot of confusion or misunderstanding." "When a blind person still drives a car." "Sighted society have a complete misconception." "They see visually impaired people as different." "This lack of knowledge can also result in stereotyping." "I often feel very frustrated when I'm compared to a partially sighted person who is assumed to be blind." "The rehabilitation staff also need to know these differences." "When people come in for rehabilitation they can be helped according to their visual ability and their appropriate needs.")

*Need for Honest and Realistic Information:*

Gail believes that she and her family should have been made aware of the real implications and limitations of her eye condition, and the emotional long-term affects as soon as

possible. She feels that with such self-awareness and knowledge about these issues she and her family would have coped better with the situation, would have been better prepared for her future, and that her family would have been able to offer appropriate support ("I needed to have been confronted as soon as possible with the real issues and the long term effects of living with a VI." "Issues like what to expect in the future." "My family needed to be involved in my rehabilitation." "They needed to be made aware of what to expect in the beginning and what to expect in the future." "With this knowledge I'm sure everybody could have coped better." "The support I had in the beginning when I had light perception was no longer there when I kept losing sight." "My family and friends thought I was already totally blind and nobody was aware of the trauma that follows when more sight is lost.")

Gail maintains that the rehabilitators needed to make her and her family aware that adjustment to VI is a continual and life-long process and that she would continue to re-experience emotions associated with her loss ("every time I lost more sight I had to go through all those feelings again." "That experience was not just while I was losing more sight but continues today." "The rehabilitation staff needed to be aware." "The experience of loss of sight with all its emotions is not just a once off experience whereby you adjust and accept your blindness during rehabilitation." "When I'm in specific situations when my loss of sight becomes meaningful, I still experience and re-experience those emotions and feelings." "Nobody can understand this."

Such honest and realistic knowledge and information could be accomplished through open communication between all members of Gail's social network ("I feel that this should have started with the ophthalmologist openly discussing and making me aware." "There has to be rehabilitation staff who are aware of these things in order to pass on the information." "Knowledge and awareness is powerful and is important for coping.") She also feels that people involved in helping the AVI need to be AVI

themselves "a need for some of the rehabilitation staff to be visually impaired later in life." "Sighted persons and people born blind don't really know and understand what those who lose sight in adult life experience.")

*Need for Realistic Employment and Financial Security:*

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 ("I need a job." "I need money for many things." "Being able to afford a medical aid." "To be able to go into a shop and buy things without always having to worry about the price." "The emotions of all this go hand in hand." "It makes me frustrated and angry that the unaffordability of devices is not been seriously addressed.") She claims that employment must be based on her abilities and not the stereotypical employment deemed suitable for AVI individuals ("not the stereotyped switchboard job." "I need to be employed on merit and my abilities." "Time and credible people are needed to research what realistically can and cannot be done by the AVI. ")

**4.7.2.4 Gail's Experiences of Support from Family, Friends, Society and the Rehabilitation Context**

*Positive Support from Family and Friends:*

Gail continues to receive positive support from her family and friends which helps her cope with her VI ("thank goodness for my family when I first had eye problems and still to today." "Without their support I don't know if I'd ever be able to cope." "The true friends who have supported me through thick and thin." "Friends have given me so much support, have laughed and cried with me.") Her relationship with her family is one of openness where she is encouraged to be as independent as possible within her limits ("they (family) also treated me just as they did before I lost my sight." "They help when help is needed but

otherwise allow me to get on with things myself.") Gail claims that people in general are not supportive because they are unaware of VI issues and base their knowledge on misconceptions ("the sighted are often more blind than the blind themselves.")

The support Gail received from her rehabilitation is her ability to "walk with a white cane." The most helpful support Gail received during this period was the understanding she received from AVI friends doing the same course ("the most important thing that Optima did for me was to give me the opportunity to meet others in the same situation as myself." "I got the understanding and much needed support from these friends more so than from the rehabilitation course.")

#### **4.7.3 Emergent Themes: Psychological Structures of Meanings**

Gail views her AVI life as a never-ending challenge. She contends that she continues to be confronted with ongoing losses as well as the implications and limitations associated with her loss of sight. She believes that she has gained insight and is aware of the challenge of the complexity of emotional and cognitive reactions associated with her loss, but is motivated and determined to continually meet the challenges such as, the frustrations associated with her loss, and the lack of awareness of sighted people about VI issues, in order for her to cope with and move forward with her life. The positive support Gail receives from her family and friends reinforces her ability to cope with these challenges.

Coping is also reinforced by Gail's use of humour. She believes that her sense of humour will ameliorate the difficult challenge of interacting with new people and help her family and friends cope with her loss. Her ability to laugh at herself reflects a capacity for self-objectivation and the ability to retain a sense of balance. The use of the word "ice-breaker" has both literal and metaphorical value: the interaction with unaware sighted people is perceived as being a hard or difficult challenge, but

also that unaware sighted people are cold, indifferent and detached from AVI individuals, with laughter helping to break this "ice." There is also an implication that humour is used as a coping mechanism helping her block out or "brush aside" her painful emotions associated with her loss of sight.

Gail's use of the word "challenge" has both negative and positive connotations. There are negative insinuations of an unending confrontation of difficulties and adversities associated with her loss, which is underscored by her language use of "feeling like I've losing out," which has overtones of deprivation and hardship. On the other hand, there are positive nuances of overcoming the difficulties and being able to move forward with her life, with a further reflection of a belief that change rather than stability is the way of life. Length of time of Gail's VI has impacted on and changed her attitudes, emotions and awareness of her VI. Frustration has changed to a more frequent and intense experience, and the denial of her limitations has changed to a more realistic awareness of the limitations of the real world of VI.

Gail has gained realistic self-awareness that in order for her to survive she needs to learn about blindness and be dependent on others to help when help is needed. The frequent use of the word "learn" alludes to the fact that learning is an ongoing process of gaining knowledge, understanding and the ability to master or take control of, and thereby, cope with her VI. It can be deduced from Gail's use of the word "survive" that her AVI life is perceived as being arduous, with further suggestions of endurance, a need to carry on no matter the drawbacks, which in turn, reinforces the notion of her life being a challenge. Gail is determined to remain as independent as she can within the limits of her VI, a balance which is reinforced by the positive support from family and friends. Her willingness to accept help when necessary has an inference of open-mindedness to the reality of AVI individuals needing to be dependent in certain situations.

She believes that her emotions and attitudes, especially frustration and acceptance, are not experienced continually but are oscillating, circular and episodic phenomena. She experiences ongoing losses in meaningful situations such as, her sister's wedding day. These experiences are perceived as losses which are accompanied by a re-experiencing of already experienced emotions. In these situations Gail wishes she could still see. There are nuances of Gail wishing to return to her familiar psychological order of a sighted independent person in these specific meaningful situations. It appears that intellectually, Gail accepts the fact or reality that she has a VI, but emotionally, there is non-acceptance of the continual circular emotions that her VI imposes on her.

Frustration is related to Gail's heightened self-awareness of the irrevocable nature of her VI with all of its implications and limitations. Her frustrations are directly associated with her VI and appear to centre round issues of perceived loss of control over her life, "when I'm in these situations and not being able to see.", Her perceived loss of spontaneity and the lack of awareness from others about VI issues, "when I can't just go into a music shop.") And "they are surprised that I still get frustrated." There is an insinuation that Gail's frustration is often displaced onto her family in an attempt to reduce the tension associated with her loss and to preserve her self-esteem.

Gail believes that there is a need for all people, including the AVI themselves, families and rehabilitators to be confronted as soon as possible with awareness and understanding of the fundamental real issues of VI, and the unique needs and abilities associated with different degrees of vision loss. The use of the word "real" 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. Knowledge of the real facts of adventitious VI ought to make all individuals sensitive to the needs and challenges facing the AVI and help alleviate stereotyping and misconceptions about VI.

Everyone needs to be aware that adjustment to adventitious VI is a life-long and circular process and not a once off experience culminating with acceptance. Living with a VI is thus a circular process for Gail, having to constantly cope with and adjust to the challenge of her loss of sight. There is an inference that for Gail, acceptance of, and adjustment to, VI are feelings and processes that cannot be conclusively completed and concluded following loss of sight.

#### **4.7.4 Summation**

Gail perceives herself as a self-aware and determined person who is able to carry on with her life despite her loss of sight. Her VI is perceived as a continuous and circular challenge with her sense of humour and the support from her family and friends helping her cope with her continual adjustments she has to face as an avi individual.

### **4.8 CASE SEVEN: ALLAN**

#### **4.8.1 Background Information**

Allan is 50 and has been AVI for 5 years. Glaucoma is the cause of his impairment. He has tunnel vision, is extremely light sensitive, has difficulty in depth perception but is still able to see relatively well. He can walk without the aid of a white long-cane and is still able to read and write using an enlarged font size on the computer. Concurring with the vision ability classification in chapter one {Section 1.2.1.3, p. 4} Allan can be said to have low vision.

Allan is married and has two grown up sons, both living overseas. He was a business executive in a large company for 25 years until he experienced eye problems. He has subsequently attended a course to fix braille machines and now gets a small income from this endeavour. He is a professional musician and plays in different bands and teaches music for extra income.

Allan was rehabilitated in his own home environment by a low vision professional and a social worker from the Society for the Blind in his area. The interviews, 5 months apart, were conducted in Allan's cottage.

#### **4.8.2 Phenomenal Meaning Units and Psychological Structures of Meanings**

##### *4.8.2.1 Allan's Perspective of Loss of Sight*

###### *Death of Executive Life and Re-Birth of Artistic Life:*

Allan views his loss of sight as the death of his stressful executive life and the re-birth of his pleasing artistic life ("I would say that my loss of sight has been the death of my executive life and the re-birth of my artistic life." "I became a business executive and did not like my stressful life." "To be able to go out and play music is a God given pleasure.")

###### *Loss is a Gain:*

Allan experiences his loss of sight as a gain. He maintains that he has changed emotionally since his loss of sight, from a stressed businessman with a fiery temper who was too busy to take note of his deteriorating eyesight to someone who is now relaxed and able to enjoy more fully the simple things in life with more time to play music ( "my loss of sight has allowed me to change." "My loss of sight has been my gain." "Before I lost my sight I had a fiery temper but my loss of sight has allowed me to change." "I knew there was something wrong with my eyes but I was too busy to take proper notice." "Today I'm living a life that I enjoy much more." "It has given me the opportunity of appreciating the simple things in life like playing music." "I am able to experience those things more fully.")

He claims that his loss of sight has given him a chance to reflect on his life, for which he now has a greater respect

("I've had a chance now to maybe think about it (AVI life)." "A greater respect for life.") According to him, he is no longer motivated by money but with helping other people which he does through his music. He feels that music reciprocally helps others as well as himself ("I'm no longer motivated by money." "I like to help people." "That (playing music) in itself is nice it does me good, it does other people good.")

Allan also feels that his loss of sight has given him a chance to grow, to explore new things and he feels that he has gained spiritually ("God said that you must grow like a tree, grow lots of branches and prune the ones you don't need." "I've used this as my base." "I keep trying to grow and gain branches.")

#### *4.8.2.2. Allan's Emotions, Feelings, Thoughts and Reactions*

##### *Anxiety and Stress:*

Allan maintains that he experienced, and continues to experience, anxiety with the consequences of losing sight, such as his loss of his job, house and pension, more so than the actual physical loss of his sight ("all the court cases associated with my pension and my house are still continuing." "That is frustrating, annoying and worrying, much more so than my loss of sight.") According to Allan, his heart attack is of more concern to him than losing sight, because he is anxious about not having enough time to do all the things he wants to do in his lifetime ("when I was lying in hospital earlier this year with my heart attack I realised that I'm sort of nearly dead as well as nearly blind." "By comparison the blindness was sort of like chicken feed, because I can live with blindness." "I've always said that my problem in my life is that I'm not going to live long enough to do all the things that I want to do." "I just want to hitch round Europe and play my guitar on the Spanish Steps." "It is just going to take time more than anything else. ")

Allan fears losing his remaining vision as he feels that he

will not be able to operate as a "blind" person ("I would like to keep what I've got because I can still operate like this." "I have hope that my eyes will stay as they are and if they do I'm happy." "It was a frightening realisation that from a business executive I could end up as a potential white stick pusher.") Allan has experienced a deterioration in his eyesight since the initial interview. Intertwined with his fear of losing his remaining vision is the anxiety of not being able to afford an operation to safeguard his remaining vision ("since I last spoke to you my eyes are rapidly deteriorating." "The last resort is an operation." "That is a problem, because I can't afford it." "I'm worried from that angle.")

Allan contends that when he is relaxed he can see better. Although he is trying to remain relaxed by walking, he still experiences stress with the issue of losing more sight ("when I feel relaxed I am able to see quite well." "I'm trying to be relaxed and maybe the pressure in my eyes will come down." "My wife and I are walking a lot and trying to relax and D-stress." "The walking helps the stress and the mental attitude.")

*Denial:*

Allan maintains that he does not feel as if he has an eye problem or that he is blind (I don't feel like I have an eye problem." "I didn't feel like a blind person.") He denies any emotions, especially negative emotions, associated with his loss of sight and maintains that if he does, they are probably pushed into the background ("the shock of realising that I'm going to be blind, I think was pushed into the background." "I never get depressed and never feel sorry for myself, never.")

*Acceptance:*

According to Allan, he has made peace with his loss of sight and is emphatic that he has accepted and adjusted to his condition, and that his life will carry on albeit with a VI ("I'm

at peace with my eyes." "I have accepted it." "I haven't tried to make light of it." "I've just adjusted and carried on.") Acceptance is reinforced by his attitude that time heals ("time heals if you are positive." "I am busy with time healing." "Time has definitely healed the emotional side of me.")

*Self-Confidence:*

Allan feels that he is a confident, positive, optimistic, self-assured and unique person who is able to carry on with his life despite his VI. He maintains that he is not concerned with negativities, and especially negative emotions, associated with his loss of sight because, according to him, these negativities are time wasting ("I think I'm a very positive person." "I think I'm also a very confident person." "I have hope that my eyes will stay as they are." "I can live with blindness." "All the negative emotions is time wasted for me." "I am as happy as can be.")

Allan claims that people take notice of him when he uses his white long-cane when he plays in the band because they see him as an unique blind drummer ("when I play in the band I use it (white long-cane)." "By doing that, people just want to talk to me because now I'm novel you understand, I'm not just a drummer I'm a blind drummer.")

*4.8.2.3 Allan's Emergent Needs*

*Fundamental Basic Needs:*

Allan's 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 ("from my situation my most important needs were the basic ones." "I needed to eat, I needed comfortable surroundings and a roof over my head." "This is the level I had come to because of the problems with the ongoing saga of not getting a pension from the company." "There was just no money." "It got to a stage that we honestly didn't have food to eat.")

According to Allan, these basic needs are continuing to be satisfy through sacrifices, hard work, faith in God, by remaining positive and from the support of his wife ("I converted the garage into our home." "We had to work very hard just to get to this point." "We had to make sacrifices." "God always provides if you are genuine." "The day we were on the bottom rung of the ladder the school for the blind phoned with 30 braillers to be fixed." "I phoned the bank immediately and was so excited to tell them that I was getting money." "I must have sounded so positive that I'm sure I heard her move my repossession file to the bottom of the pile.") Allan maintains that financial independence is needed in order to survive and meet his basic fundamental needs ("so to me, the need to be financially independent, the need for a place to stay, food to eat and a job to do those are my real needs." "It all starts with those fundamental needs, that little bit of financial independence that gives you the ability just to survive." "For me that is now just starting to be realised.")

*Need for Employment:*

Allan contends that he needs a job which is based on his experience and abilities rather than his blindness ("People must not see me as a blind person." "They need to see me as somebody as highly experienced with unique abilities.") On many occasions he has applied for jobs but feels that because of his VI and the misconceptions surrounding blindness he is not even considered ("I've tried and been everywhere." "Nothing comes of it and I get the normal reply, we will phone you back." "If you mention anything about VI you've lost the other person's attention immediately." "You're just not good enough.") He feels that the AVI need to sell their abilities to make people aware of what they can do ("needs to sell himself and make the public aware to get those jobs.")

*Need to be Kept Busy:*

Allan maintains that he has always been a busy person and feels

that this must continue despite his VI. He acknowledges that he needs to be kept occupied, both physically and mentally, in order to remain positive ("I'm a busy type of person and I need to have something to do." "Hence the several musical groups and fixing braillers." "I need a busy mind, I need to be active and positive." "I need to fulfil many dreams.")

#### *4.8.2.4 Allan's Experiences of Support from Family, Friends, Society and the Rehabilitation Context*

##### *Positive Support:*

Allan maintains that the positive emotional and healing support he receives from his wife helps him cope with his loss and helps him satisfy his needs ("having a good partner, my wife, has helped me to cope." "Having that support is probably the most important thing in my life." "I need a bit of tender loving care." "I need to have somebody to understand and to be there for me." "My wife has, and continues to satisfy that need." "She supports me in many ways, like support from a healing perspective." "She has healing hands, and many times she is able to massage away the headaches.")

Support is also offered by Allan's friends ("my wife and I have some very good friends who take us out now and again." "Lots of people visit this house." "There are always comings and goings here.") Positive support continues to be offered by the social worker from the Society for the Blind. Her candid approach made Allan aware of his situation which he feels helped him. He maintains that the turning point in his life was when he attended the braille fixing course ("the person in charge (social worker) gave me, and I must say, continues to give me lots of positivities." "She was straight to the point and she made me aware of my problem which helped me enormously." "She then got me onto this course to mend braillers." "That was the biggest turning point for me, my family, and my friends.") Allan claims that people in general are not supportive because they are not aware of VI issues (people in general are totally unaware about what VI is all about." "They haven't got a clue." "They are not

interested in even knowing what it is all about.")

#### **4.8.3 Emergent Themes: Psychological Structures of Meanings**

Allan views his loss of sight as an emotional and spiritual gain, which has effected many changes in his life. The perceived gains and changes in his AVI life, include: being able to play music again, a new respect for life, his ability to grow, his gaining of a more controlled emotional life, and his appreciation and enjoyment of the simple things in life. He perceives himself as changed from someone who was motivated by money to someone who is now motivated to be kept busy helping both others and himself by playing music. There is an implication that Allan's need to be kept busy is intended so that a image of himself as a positive coping person will emerge.

The descriptions "death of my executive life and "rebirth of my artistic life" have psychological symbolic gesture. The use of the word "death" has overtones of a final conclusion to his emotionally stressful and complicated sighted life, whereas, the use of "re-birth" has overtones of a new start in life, albeit with a vi, with the regaining of an emotionally more enjoyable, simple and familiar existence. It would appear that loss of sight is perceived by Allan as a "gain" in all areas of his life rather than a "loss."

Within the realm of these perceived gains, there is a suggestion that Allan tends to somewhat romanticize his condition. This romanticising is deduced from Allan's language use such as, "rebirth" of his "artistic life," and "hitch round europe and play my guitar on the spanish steps." Although this romanticising is perceived as helping him adjust and cope with his VI it has nuances of him not being able to deal with the reality of his changed condition. Indeed, anxiety and denial of his loss of sight weave their way throughout Allan's

descriptions.

Allan continues to deny the reality of his loss of sight by not wanting to incorporate the idea of his loss into his perception of himself, "I don't feel like I have an eye problem." The refusal to face the facts of his loss of sight are underscored by the frequent repetition of the word "never," and by his emphatic acceptance and his perception that "time heals." It may be deduced from the frequent use of the word "heal" that Allan perceives that coping and adjustment to VI are processes that can be conclusively completed and concluded within a stipulated time period, in his case, 5 years following his loss of sight. The acceptance however, appears to connote denial, as Allan is using it as a way of blocking out the painful reality of his loss of sight, which in turn, enhances his positive self-image.

The continued denial of any emotions, and especially negative emotions, underscores Allan's perception that negative emotions are contrary to his attitude of being a positive person. His expressed emotions of frustration, anger, stress and anxiety appear to have been, and still are, denied by displacing them from his loss of sight onto his loss of his job and house and the inability to obtain a company pension. Allan's attitude of his loss of sight being "chicken feed" when he is confronted with the reality of death through a heart attack alludes to him perceiving his loss of sight as insignificant and inconsequential as compared to death. His description of "live with blindness" has both literal and metaphorical value: Allan believes that he can literally live or cope and function as an avi person, and also that he does not die from a VI but continues to live.

Allan's experience of anxiety and denial are intertwined. His fear about losing his remaining sight is intertwined with his fear of being identified as a blind person using the symbolic white long-cane. He therefore continues to deny his VI by walking without the cane. The dichotomous nature of his attitude to using a white long-cane emerges and is difficult to reconcile. On the

one hand, his perceived fear of becoming a "potential white stick pusher" infers a negative, stereotypical image of a white stick symbolising blindness. This fear of "blindness" is underscored when Allan describes how he does not feel like a blind person and how he needs employment based on his abilities and experience rather than on his blindness. On the other hand, Allan uses a white long-cane when he plays in the band. His fear of "blindness" appears to be pushed into the background as he perceives that blindness makes him an unique blind drummer. There are nuances of Allan using blindness in certain situations to his advantage. These descriptions have psychological symbolic gesture as there is an insinuation that Allan needs attention, approval and to be perceived as a coping and novel or innovative person despite his VI.

There is conflict between Allan's perception of being relaxed and stressed. Before Allan lost his sight he had "a fiery temper" which he is now able to control. He perceives himself to be far more relaxed which allows him to see better. Allan and his wife are walking in order to "relax and D-stress" to reduce the "pressure" in his eyes. It can be deduced from Allan's language use that he is still stressed and not relaxed, "trying to be relaxed." The use of the word "pressure" has both literal and metaphorical value: Allan literally experiences physical pressure in the eyes, but also pressure or stress, anxiety and tension within himself, with further overtones of the two "pressures" being intertwined. There is a suggestion that Allan is, as yet, not fully adjusted to or coping with his VI, as he reacts to stress maladaptively with his displays of excessive anxiety.

Allan's wife supports him in many ways, the most meaningful being her healing. There is psychological symbolic gesture for the description of "healing hands" has both literal and metaphorical value: his wife literally is able to massage away the physical pain of headaches, but also able to massage away the emotional pain of his loss of sight and the associated problems.

Employment, or receiving a company pension, would provide Allan with his needed financial independence in order to satisfy his basic fundamental needs in order to survive. It would also alleviate some of the related emotions, such as, fear and anxiety about his future which Allan experiences as a result of lack of money and more so now that operations are in the offing to safeguard his remaining sight. In order to get employment Allan believes that people need to become aware of the fundamental basic issues of VI and need to move away from the stereotypical attitudes they have of the AVI and become aware of their abilities and similarities rather than their differences. There is a subtle suggestion that Allan himself, has as yet, not moved away from the stereotypical attitudes towards AVI individuals based on his anxiety of being a "white stick pusher."

Attending the braille course is perceived by Allan as the turning point in his life. The word "turning point" connotes a positive new start with a forward motion rather than a turning back motion. It may be deduced from Allan's language use that he is optimistic about resuming his familiar psychological order of a financially independent person, "I can take it a step further, because I've established a steadfast foundation for myself from which to work." Allan transcends his limited physical condition with his acceptance, self-confidence, positivity and adjustment.

#### **4.8.4 Summation**

Allan's perception of his loss of sight being a "gain" has afforded him the ability and opportunity to change emotionally and "grow" and to start afresh with his "artistic" life. Allan's basic needs are beginning to be satisfied with the support from his wife and the income from his music tuition and fixing braillers. He has accepted his loss of sight and is positive and optimistic about going forward with his life despite his VI.

### **4.9 CASE EIGHT: CHANTAL**

#### **4.9.1 Background Information**

Chantal is 49 and has experienced eye problems for 24 years.

She was diagnosed with Stargardts (a childhood macular disease) when she was 25 years old. Up until this diagnosis she had experienced no problems with her eyes, went to a normal sighted school where she finished matric, and then went to college, after which she worked as a secretary. Whilst she was pregnant with her youngest son, 15 years ago, she could still read large print, but after his birth she could no longer read. At present, she still has peripheral vision in both eyes, has light perception and is able to distinguish shapes but no fine detail. Concurring with the vision ability classification in Chapter One {Section 1.2.1.3, p. 4} Chantal can be said to be functionally blind.

Chantal has been divorced for 2 years. She lives in a rented flat with her two sons, aged 19 and 15. She did the independence training earlier this year, that is, 15 years following her almost total loss of sight. The initial interview for this study was at the start of the telephony course, and the follow-up interview 3 months later, was on the final day of the course.

#### **4.9.2 Phenomenal Meaning Units and Psychological Structures of Meanings**

##### *4.9.2.1 Chantal's Perspective of Loss of Sight*

*Loss is a Normal Experience of Confronting Problems and Coping:*

Chantal maintains that because she has had eye problems for so long and because she is so used to it, her VI has become part of her "normal" life ("I'm so used to it." "It has become so much part of my life, part of my normal life.") When faced with problems related to her loss she confronts them and then carries on coping as she cannot change her situation ("I'm faced with many problems because of my loss." "When somebody has moved things around in the kitchen." "I always find this (transport) a problem." "I confront them, try to sort them out, then carry on coping with my life." "I have to live for today." "I've just carried on with my life as I did before." "I think I coped and

still cope." "Everybody says I do." "I can't change the situation, there is nothing I can do.")

*Loss is New Start in Life:*

Chantal claims that it is precisely her loss of sight that has allowed her to complete courses, albeit so many years following her loss, which have effected many changes in her life, and afforded her a new beginning ("after coming here (Optima) to do the independence and now the telephony courses, I feel like I've started a new life again." "A new beginning." "I can't wait to get on with my new life." "I'm so excited about my job which will give a new meaning to my life." "This is a new start for me.")

*4.9.2.2 Chantal's Emotions, Feelings, Thoughts and Reactions*

*Acceptance is an Oscillating and Circular Process:*

Acceptance of loss of sight is difficult ("I'm not sure I've accepted it, it is hard.") Chantal experiences acceptance as an oscillating and circular process of accepting and not accepting, depending on certain situations and her experienced emotions at a particular time ("sometimes I will sit and when I'm feeling sad or frustrated, then I don't accept." "Some days I accept, and then other days I don't." "People talk of stages of emotions." "I certainly feel that I go up and down the stages." "I feel hurt and sad and frustrated, but then I feel better again." "It is like going round in circles." "Acceptance is also like this.") She contends that like acceptance, adjustment and coping are oscillating and circular experiences ("I've learnt to adjust very well." "Some days I cope well and I feel that I've adjusted well." "On other days when I'm confronted with something I can't manage, then I feel that I'm not so well adjusted.")

Acceptance is a societal expectation which Chantal claims she can never fulfil ("it is expected of me to cope and accept." "Mainly my sons, and people out there, but maybe also myself." "Society expects you to." "go through a loss and then you just

have to pick up the pieces, accept and carry on." "The longer I've been VI the more I've realised how difficult this expectation is." "I don't think I will ever fully accept it.")

Chantal feels that time heals, especially after her experiences at Optima ("it feels as if I can do anything." "Doors have been opened." "I think time heals especially in my case it has." "The course has changed my life so much it is exciting.")

*Sadness:*

Chantal continues to experience sadness especially in situations that involve her children. It is in these specific situations that she wishes she could still see ("to today I still feel sad in certain situations." "With my children when they say we wish you could really see what we look like." "They will be proud of some work they did at school, and they want me to see it." "I didn't have a clue what they were doing (in school concerts), that made me sad." "I think the sadness was, and still is, there." "Not all the time, but in certain situations." "I wish I could see again in these situations.")

*Frustration:*

Chantal continues to experience frustration round issues of people interfering with her organised routine, when people try to over-protect her, when she has to wait for somebody to do something for her and when she cannot drive in urgent situations. It is in these situations that Chantal wishes she could see again ("it (frustration) is what I've experienced, and still experience the most." "Especially when somebody has moved things around in the kitchen." "I'm a very organised person, but when someone comes and interferes and puts things in wrong places, then I want to scream." "It is so frustrating." "There are some people who want to do everything for me." "I want to scream, "will you leave me alone." "I can cope, I know what I'm doing, I know where everything is." "I'd bring it in (post) and I just had to sit

there with it in my hand." "Wait for somebody to come to read it to me." "This also makes me frustrated." "When this happens I also wish I could see again.")

It is still very difficult and frustrating for Chantal to accept she is not able to drive her motor car in urgent situations and has to rely on others for transport, another situation which causes frustration ("to be able to get in my car and do everything that I need to do." "In those urgent situations like taking my kids to doctors." "Not being able to do that is very frustrating." "I then also wish I could see in those urgent situations where a car would help." "Transport is the worst, the very worst." "I always find this a problem.")

*Anxiety, Self-Devaluation and Social Withdrawal:*

Chantal claims that during the period following her almost total loss of sight her self-esteem was low, she had no self-confidence and felt insecure and inadequate ("thought that I'm useless, and that I can't do anything." "My self-esteem was low.") She claims that even though her insecurity, self-confidence and self-worth have improved, especially after completing courses at Optima, she is still anxious and insecure especially when she is in unfamiliar environments and with new people ("I still feel vulnerable, but not as much as I used to." "I feel worthwhile when I'm here (Optima)." "It is mainly when I'm in a new environment or with new people." "I worry about them understanding me and my problem." "I'm around sighted people and I know they are watching me." "This makes me very nervous.") Chantal continues to cope by withdrawing from people ("I often crawled into a shell." "I just feel I want to get out of there(home) and go back to Optima.")

*Hope:*

Chantal is optimistic and hopeful that she will get a switchboard job when she has completed the telephony course and

that she will then be able to put her life together. She is hopeful that there may be a cure for her eye condition ("after coming here to Optima anything is possible." "I should say that there is as yet, no cure." "I have to live for today, and do what I can to put my life together." "I think that maybe I've got a job waiting for me." "I can't wait to get on with my new life." "I'm so excited about my job which will give a new meaning to my life.")

#### 4.9.2.3 Chantal's Emergent Needs

##### *Need for Understanding and Knowledge:*

Chantal is aware of the implications of her VI. She maintains that all people need to be made aware of and understand what VI involves and what the AVI can and cannot do with different degrees of vision ("I tried to explain to people (about her eye condition), but they didn't understand." "I don't think that people are aware about what blindness is all about." "When I lost more and more sight people couldn't understand it and they battled with it." "You are either blind or not blind." "I'd catch or get a flash of something small running up the wall." "That baffles people that I can see that, but I can't see that big thing in front of me." "People need to be educated about the different kinds of VIS.") For Chantal, the lack of knowledge and understanding about VI issues results in stereotyping and misconceptions ("they (people) have just avoided blind people." "That is a blind person, and they must just sit down in the corner and stay there.")

According to Chantal, people are not aware of, nor do they understand the problems associated with transport ("people are not aware how problematic transport is for a blind person." "Transport is the worst, the very worst." "I always find this a problem." "They (people) will help with anything but when it comes to transport, they're always busy." "I always need transport, this is the biggest problem and need I have.")

*Need for Explanations and Communication:*

Chantal claims that her family should have been involved in her independence training to help them adjust to her changed life ("the family should be part of the training." "My sons are thrilled about the way I've changed." "Sometimes they say I've changed too much." "They are not used to that (going to the shops herself)." "They are used to doing everything for me." "It is a big adjustment for them as well." "They also need help.") Adjustment and awareness would be facilitated by counselling where explanations can be given through open communication (the family needs to come here to Optima for counselling." "Things can be explained to everybody." "All people involved know what the other one is talking about.") Chantal also feels that rehabilitators involved in independence training need to be AVI themselves ("there is a need for those involved in independence training to be visually impaired." "Not somebody who has been visually impaired since birth, but someone who has lost sight in adulthood." "I believe the needs of those born blind and those who go blind later in life are different." "You need somebody who is able to tell you these things and what to expect.")

*Need for Emotional Support and Follow-Up:*

Chantal needs emotional long-term support from other AVI individuals who can understand her situation ("it is important to have support, and especially emotional support." "I belong to a blind group, this is my emotional support." "It is easier talking to those in the same situation as me, because they understand.") Emotional support was needed during her rehabilitation ("I also needed emotional support as well." "I got this but not enough.")

Emotional support and alleviation of anxiety could be accomplished by follow-up from Optima ("I feel that there is a need for follow-up once you've left Optima." "Just to keep you going emotionally." "During that time (the period between

rehabilitation and the telephony course) I felt like I was getting back into the old rut." "I would have felt much better if the social worker had just phoned to check how I was doing." "If they could phone after the telephony course that would be wonderful." "There should also be a follow-up for a person who starts a new job." "There is going to be a lot to learn and I need to have someone to talk me through it when I'm battling.")

*Need for Employment and Financial Independence:*

Chantal needs employment for financial independence and security, as well as for her own sense of achievement ("I have to have a job." "I need it financially, and for my own sense of achievement." "I don't mind the hours or the travelling but I can't sit at home in a rut.")

*4.9.2.4 Chantal's Experiences of Support from Family, Friends, Society and the Rehabilitation Context*

*Positive Support from Sons and Optima:*

Positive support continues to be offered by Chantal's sons ("my sons have always helped me and will do anything for me." "They are always there for me.") Support from Optima is evident in the skills she has achieved, mobility, braille, computer, telephony skills as well as improved self-confidence ("the independence training has made the biggest difference in my life." "It was focused more on the practical side, mobility and cooking." "Since I've been at Optima I feel things are becoming easier." "When I started with braille I thought I can read and write again and I can work on the computer." "It feels as if I can do anything.") The support and companionship from AVI friends doing the same courses as herself will be missed ("I think when I leave Optima the main thing I will miss is the companionship and support of people in the same position as me.")

*Negative and Unhelpful Support:*

No support is received from Chantal's sister nor her special

friend. She feels that her sister is anxious and not coping with her acquired independence, and silence is the way for her friend to cope ("she (sister) seems not to be coping with me." "She seems afraid." "She will say you can't really do things for yourself." "I've tried to explain things to her." "She is battling and not really supporting me." "He (special friend) changed towards me and he won't talk about it." "I ask him why and he just backs off." "I don't think he is coping with my situation." "He's not supporting me.") Chantal maintains that she experiences unhelpful support when people over-protect her and try to do everything for her ("practical things like cooking and cleaning house I can cope with." "I know what I'm doing." "The support they are trying to give is often no support at all.")

#### 4.9.3 **Emergent Themes: Psychological Structures of Meanings**

As Chantal has had eye problems for a long time she views her loss of sight as a phenomenon which has become part of her "normal" life. It is her loss of sight however, which she perceives as giving her the opportunity to attend and successfully complete courses at Optima. This success has motivated her to go forward with her perceived "new start" in life with increased self-confidence and self-esteem, and a positive feeling about the prospect of a switchboard job, which will give new "meaning" and purpose to her life. There is an overtone that before Chantal came to Optima her life was perceived as being meaningless and pointless, with a further suggestion of a self-devaluating perception of herself being useless and worthless.

Lack of financial independence and emotions are intertwined. A job would give Chantal a sense of mastery over her life, allowing a positive image of a coping and independent AVI individual to emerge. A job would alleviate some of Chantal's related emotions such as, her insecurity, self-doubt, worthlessness and frustration. It must be noted that Chantal's hope of the switchboard job never materialised, a situation which

has undoubtedly impacted on her negatively.

Although Chantal perceives that the courses at Optima have changed her life positively, this conviction does not help her deal with the reality of her condition. There is an inference of denial of the reality of her VI, supposedly more so after her rehabilitation. There is a change from her initial attitude of "no cure" to an attitude of hope, albeit unrealistic hope, for a cure for her eye condition, "after coming to Optima anything is possible." She appears to deny the limitations of her VI for she believes that since being at Optima she can "do anything." Chantal's focus on "live for today" has nuances of a blocking out or denying the painful reality of the implications of not being able to procure a job in the future.

Chantal's situation of going to Optima for rehabilitation 24 years following the onset of her VI and 15 years following her almost complete loss of sight is unique. AVI individuals usually attend rehabilitation on average approximately 2 years following their loss of sight where they are taught independent mobility, daily living skills, and are made aware of their changed functioning and capabilities. Chantal on the other hand, arrived for rehabilitation as a long-term AVI individual who had taught herself daily living skills and ways of coping practically. She perceives however that rehabilitation has made her more independent, positive and motivated to go forward with her life. Within this context, Chantal needed her sons to be involved in her rehabilitation so that they could be made aware of and understand the changes in her functioning and capabilities as a more independent person, as well as the changes imposed on their own lives. There is an insinuation that Chantal's sons perceive her as a "dependent" person, and her new independence is contrary to their perception of having to do "everything" for her.

Despite Chantal's perceived increased self-worth, self-confidence and security, she still feels vulnerable and insecure

especially when she is in unfamiliar environments and with new people. She is anxious that people will not understand her because of her eye problem. Her anxiety is underscored by her belief that sighted people are "watching" her. It can be deduced from her language use that Chantal is sensitive about her VI, is distrustful of people especially sighted individuals, feels susceptible and has self-doubt about her capabilities which in turn, connotes total self-devaluation. There is a suggestion that Chantal is not adjusted to nor coping with her VI, as she reacts to stress maladaptively with her displays of excessive anxiety.

The frequent use of the word "battle" reflects a perception of Chantal's VI being a struggle for both herself and other sighted people. In order to cope with the associated feelings, Chantal withdraws from people and often "crawls into a shell." There is psychological symbolic gesture with the description "crawled into a shell" because it alludes to Chantal creating a barrier between herself, the outside world and people in order to isolate and protect herself from hurt and pain. It may be deduced from Chantal's language use that Optima is perceived as the "shell into which she can crawl," a sheltered place where she feels secure and protected, and a place where she has succeeded in the courses which has increased her self-worth, self-confidence and her sense of mastery and adequacy. Conflicting attitudes emerge as Chantal believes that her self-esteem and self-worth have improved since doing the courses, yet she remains insecure, vulnerable and has self-doubt. Her continued self-devaluation, feelings of anxiety and sadness combined with her social withdrawal has nuances of Chantal experiencing depression.

It is important for Chantal to be perceived by others as coping with her VI, and she is encouraged by this acknowledgement. There is a suggestion that Chantal needs 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.

Chantal believes that her emotions and attitudes related to her VI, especially frustration, sadness, acceptance, adjustment and coping are not experienced continually but are oscillating, circular and episodic experiences related to specific situations and times. Frustration is experienced in situations when Chantal believes that she is not in control of her life or environment having to be dependent on others for transport, and when people offer unhelpful support. Sadness is experienced when situations involve her children. It is in these types of situations that she wishes she could "see again." "Wishing to see again" has nuances of Chantal yearning to return to her familiar psychological order of a sighted and in control mother.

There is an overtone of cognitive dissonance and confusion regarding acceptance. Chantal believes that she is expected to accept, based on society's assumption that following a loss acceptance is required. There is a suggestion that Chantal, because of her vulnerability, insecurity, fear of rejection and need for approval and acceptance from other people accepts her VI because of this expectation. Acceptance is reinforced by her attitude that "time heals." This attitude appears to have emerged in the context of the specific time and place of Optima. Chantal does not accept her VI when she continues to experience emotions, especially frustration and sadness, in certain situations and times. For Chantal, living with a VI is thus a circular process having to constantly cope with and adjust to her loss of sight. It may be deduced from these perceptions that acceptance, coping and adaptation are feelings and processes that cannot be conclusively completed and concluded following loss of sight.

Chantal believes that there is a need for all people to gain knowledge, through open communication and explanations, to understand the unique needs and abilities associated with different degrees of visual abilities. Knowledge of the facts of adventitious VI ought to make all individuals sensitive to the needs and challenges facing the AVI, and help alleviate stereotyping and misconceptions about vi. The stereotypical

attitudes, although expressed in impersonal pronouns, "they must just sit down in the corner," hints at Chantal's own stereotypical blind life she experienced before attending rehabilitation. The words "avoided," and "just sit down in the corner and stay there," have nuances of Chantal's own feelings of rejection, self-doubt, and non-assertiveness.

#### **4.9.4 Summation**

With continued support from Chantal's sons, she perceives that she is coping with and able to carry on with her "normal" life, despite her adventitious vi. Her rehabilitation, almost 15 years following her almost total loss of sight, has afforded her an independent and new start in life. Her intricate descriptions embrace nuances of emotional non-coping and a person who is vulnerable and insecure.

### **4.10 CASE NINE: SUSAN**

#### **4.10.1 Background Information**

Susan is 26 and has been AVI for 1,5 years. Two years ago she was diagnosed with a blood disorder and had a bone marrow transplant. Her eyes started deteriorating after the transplant and she experienced night blindness and glaucoma. According to ophthalmologists, the chemotherapy and radiation treatment she underwent lowered her immune system and a virus attacked and damaged her retinas. Susan is now unable to see "anything." Concurring with the vision ability classification in Chapter One {Section 1.2.1.3, p. 4} Susan can be said to be totally blind.

Susan is not married and stays at home with her parents and 2 brothers. Before her loss of sight she was an insurance clerk for a large company. Ten months following her loss of sight she completed the independence training course at Optima. At the time of the initial interview for this study she had just commenced the telephony course. At the time of the follow-up interview at

her home 4 months later, Susan was still unemployed.

#### 4.10.2 Phenomenal Meaning Units and Psychological Structures of Meanings

##### 4.10.2.1 Susan's Perspective of Loss of Sight

*Loss is Like a Bad Dream:*

Susan experiences her loss of sight as a bad dream from which she still has to wake up ("it feels still like a dream and I must still wake up." "It is like a bad dream that is how I feel." "It definitely feels like a dream, a bad dream." )

*Loss is Deprivation:*

She experiences her loss of sight as deprivation as it has cut her off from everything. She misses what she cannot see, especially the simple things in life ("I feel that I've been cut off from everything." "I miss not being able to see." "I can't see and I miss what I cant see." "I miss just walking in the garden, seeing the rain, the simple things that I can't see any more." "I do miss getting into the car and going to the shops.) She maintains that it is in these situations that she wishes she could still see ("I often wish I could still see." )

*Loss has a Purpose:*

Susan maintains that as a Christian her loss of sight has a purpose, but that she still has to understand and know what it is. Although she knows that she will not "awaken" from her dream and be able to see, there is still hope that healing may occur ("I am a Christian and I've been for healing." "When I wake up I don't think I'll see." "I am here for a purpose." "I just need to find that purpose." But "you never know, maybe healing will occur." )

#### 4.10.2.2 Susan's Emotions, Feelings, Thoughts and Reactions

##### *Acceptance:*

Susan has accepted her loss of sight and contends that she can carry on with her life, albeit with a VI ("I have accepted it." "I don't want to bury my head in a hole." "I've realised that life goes on and I have to make the best of this." Acceptance is reinforced by her attitude that "time heals" (that saying "time heals" is true. "Things have got better for me with time." )

##### *Self-Sufficiency:*

Susan claims that by regaining her independence she is once again self-sufficient and has adjusted to and is coping with her loss of sight ("I've adjusted because I'm independent." "I am able to get around on my own." "Am able to cook again, and able to look after myself." "Have learnt that I must put things in order so that I know what is what." "I'm now coping." "I have adapted.") She maintains that her independence has given her hope for the future ("I can see there is light now." "I feel independent again and I'm more hopeful now." )

##### *Anxiety, Insecurity and Denial:*

Susan experiences anxiety, insecurity and uncertainty about her future. She is anxious about being as independent as she was before her loss and being able to do "normal" things like get married, and get a good job ("I'm worried about my life ahead." "It is that uncertainty of what lies ahead." "How is my life going to progress." "Am I going to get married, am I going to get a good job, am I going to survive on my own?" "The thing that worries me the most is if I am going to be an independent person again like I was before." "This makes me feel very vulnerable.") She uses denial to control her anxiety by trying to conceal the fact of her vision loss by behaving as a normal sighted person ("I just try to stand up a bit straighter." "I try to look as

normal as possible." "Try not to look as if I can't see.")

She continues to be anxious about being in the "dark" and worries that she will never get used to being blind ("I don't know how I'll ever get used to it(being blind)." "I still get scared walking around in the dark." "I hated the dark before and now I'm in the dark all the time.") Susan is anxious when she has to do "blind" things in front of people and this anxiety often results in confusion ("that thing (liquid level indicator) makes me so confused." "My dad insists that I use it." "I tried it and I just felt this pressure." "I poured completely out of the cup." "I just burst into tears.")

*Depression:*

At the initial onset of her VI, Susan was still working and maintains that the stress she experienced round issues of her co-workers not understanding her situation caused her to cry and feel depressed. She contends that the accumulation of many issues such as, her loss of her independence and her bone marrow transplant compounded her depression "I had to go through the stress with everyone at work." "I would go home crying every day." "I was getting depressed." "I was hurting inside a lot." "I was losing my eye sight, I'd gone through a bone marrow transplant and lost my hair through the chemo." "Not being able to see and not being able to drive and my independence gone." "I didn't cope.") Susan's social withdrawal underscores her depression ("I didn't even go to the lounge." "I just lay in my bed." "I withdrew." "I just wanted to cry and be alone.")

Susan continues to experience sadness and hurt claiming that she is not coping with the financial difficulties her family is experiencing and the impact her loss of independence has on her, especially not being able to drive a motor car ("I'm still sad." "I have my days when I get up and I just want to cry my eyes out." "It is just inside me." "I start thinking I can't drive a car any more." "Financially we have problems now." "I just think

I just can't cope with all these things.")

Susan's depression is reinforced by her mother's depression because she feels that she is the cause of it. She claims that she does not feel guilty because according to her, she could not help what happened to her eyes ("my mother is depressed." "I am the cause of her depression I'm sure I am." "She was strong with the transplant, but with the eyes, she doesn't want to talk to me." "That makes me feel heart sore because I've needed my mother." "There are days when I still just want to cry." "I'm not blaming myself because I cant help what's happened." "I don't feel guilty because it is not my fault.") Susan's depression is further reinforced by the feeling of rejection from people close to her, her work colleagues and her mother ("they were (co-workers) like sisters to me." "The rejection from them was hard." "I feel as if she (mother) is rejecting me." "Your mother is the one who must hold you and hug you." "She hasn't been able to do it, and that hurts.")

*Frustration:*

Susan experiences frustration when she has to be dependent on others because of her inability to drive a motor car and when she drops something and cannot find it ("I got frustrated and I still get frustrated sometimes." "I do get frustrated when I have to go and ask someone if they are busy and if they would mind taking me to the shop." "Before it was just a case of jumping in the car." "When I drop something and I have to find it, and I bump myself and hurt myself.")

Susan claims that she is not angry about losing her sight but feels angry with her family because of their lack of understanding and their insensitivity towards her ("I did not feel angry about it." "I get angry with my parents and my brothers because I expected more from them." "They leave doors open and I bang into them." "I just can't understand why they do it." "I get frustrated because by now they know and it is

horrible to walk into a door.")

*Self-Consciousness:*

Susan maintains that she is self-conscious about her blindness when she is with strangers as she feels that she is "different." She is concerned with what other people will think and say about her and tries to act as a "normal" sighted person ("I get self-conscious about my eyes." "It is when I go into an area where I don't know many people." "I wonder what must they be thinking looking at me." "I am conscious about what other people think of me." "That's because I'm different." "Try to look as normal as possible." "Try not to look as if I can't see.")

*4.10.2.3 Susan's Emergent Needs*

*Need for Independence:*

Susan's need for practical independence has been met by doing the independence training course as she now has independent mobility and is able to get around on her own and has daily living skills ("I'm independent and able to get around on my own, am able to cook again, able to look after myself.") For Susan, the supreme symbol of independence would be to gain independent living ("my greatest need is for independence." "I want to live on my own." "I still want to do what every woman wants to do, get married, and have a home.")

*Need for Employment:*

Susan maintains that she needs a job to give her financial independence which in turn, will help her afford "things for the blind," as well as giving her a purpose to her life ("I need to get a job, I need financial independence." "Will at least give me something worthwhile to get up for in the morning.") She is willing to take a telephonist job as according to her, this type of work is the only available jobs for the AVI. She hopes that

with studying she will be able to find other employment in the travel industry ("I don't really want to work on a switchboard all my life." "I can see it can be quite stressful." "That (switchboard operator) seems to be the only job out there for us." "The easiest job you can find as a blind person." "I am going to study the travel management course part time." "It's not so easy studying by tape, so I'll see how it goes.")

*Need for Support and Counselling:*

Susan feels that counselling and support groups were, and still are, needed for herself, her family and friends to make them aware of and understand her AVI world, but to still be treated as a "normal" person ("there is definitely a need for a support group and counselling for the family and the person who loses sight." "I don't think any place has a support group for families and friends of blind people." "They need help so that my family can understand what I'm going through." "What my needs are and not to treat me like a blind person all the time." "I'm still normal." "They must not pamper me.")

*4.10.2.4 Susan's Experiences of Support from Family, Friends, Society and the Rehabilitation Context*

*Unhelpful Support from Family:*

Susan receives no support from her mother with silence being the way for her to cope. No explanation is offered for the silence ("my mother did not, and still does not, support me." "I don't know why because she will not talk to me.") Unhelpful support from Susan's father and brothers has changed over time from not talking about her condition because of their embarrassment, to being more supportive, despite her father being over-protective ("in the beginning my family had difficulty in supporting me." "With time my brothers and dad are far more supportive." "My younger brother was actually embarrassed about it." "In the beginning he would not walk with me." "Today he is so natural with me." "My brothers have adjusted." "Dad is OK,

but men don't talk much." "My dad is a bit over protective.")

*Positive Support from Friends and Optima:*

Susan's friends and her church continue to support her which helps her cope with her situation ("I had very good support from friends and the church." "They were there for me." "I think that is what pulled me out of that (depression)." "They are very good to me." "They still are very supportive.")

Support from Optima in realising her need to be independent and able to cope is evident in the skills she has achieved, mobility and skills of daily living ("there is understanding at Optima more than at home." "I feel independent again and I'm more hopeful now, and I'm coping." "I was so happy here." "It is all geared up for you.") The support from AVI friends doing the same courses as her will be missed ("most of all, I will miss the friends I've made here." "It (Optima) helped me a lot, to talk to other blind people with the same circumstances.")

**4.10.3 Emergent Themes: Psychological Structures of Meanings**

Susan views her loss of sight as a "bad dream" from which she must still "awake." From Susan's language use ("must still awake") it can be deduced that she is not ready to confront the issues of her loss of sight, with further overtones of her denying the reality of her VI. Her perception that her loss of sight has "cut her off from everything" has nuances of her perceiving her loss of sight as a deprivation, with a further suggestion that her loss causes her feelings of isolation and aloneness. It may be deduced from Susan's language use "I don't think" that she will be able to see again when she "wakes up" that there is uncertainty and confusion about the implications of her eye condition, with a further overtone of "hope" that she may see again, a hope which is further reinforced by her attending "healing."

Susan is self-conscious about her blindness and what people will say about her being "different" and it is important for her to be perceived by herself and others as "normal." This perception is reinforced by her needing support where she is treated as "normal" and not over-protected or pampered because she is "blind." There is an insinuation that Susan perceives over-protection as thwarting her gaining total independence. There is a further connotation that Susan's need to be treated as "normal" is actually her need for approval and acceptance from people because of her anxiety about being rejected. She tries to regain "normality" by believing that she can live as she did before her loss of sight. 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. There is a suggestion of Susan yearning to return to her sighted life where she perceives herself to be independent and in control, and to her familiar psychological order of a sighted working woman.

A conflicting attitude of independence emerges dichotomized as it is difficult to reconcile. Although Susan believes that she is independent she still worries about being as independent as she was before her loss of sight. The skills offered by Optima (mobility, skills of daily living, telephony) have enabled Susan to be independent and free again, yet she is anxious about not being able to be independent at home. There are inferences that Susan perceives Optima as a sheltered place where she feels secure, understood, especially by the other visually impaired students, and a place where she has succeeded in the courses which has increased her self-esteem and self-sufficiency.

Although Susan perceives that the independence training has helped her cope with her loss of sight it does not help her deal with the reality of her changed condition. She distances this reality by referring to her loss of sight as "the eyes had gone," which alludes to objectification and detachment. She further distances this reality by not wanting to incorporate the idea of

her blindness into her perception of herself by trying not to look as if she cannot see. The refusal to face the facts of her loss of sight is underscored by her perception that "time heals."

Susan's perceived self-sufficiency is based on her belief that her independence has enabled her to cope with, adjust to, and accept her VI. It may be deduced from these perceptions that acceptance, coping and adjustment are feelings and processes that can be conclusively completed and concluded following loss of sight. The acceptance however, connotes denial, as Susan appears to be using it as a way of blocking out the painful reality of her loss of sight, which in turn, enhances her positive self-image of a self-sufficient person.

Descriptions of anxiety, depression and frustration weave their way through Susan's descriptions. Susan is anxious and uncertain about her future and whether she will be as independent and "normal" as she was before her loss of sight. She is anxious about coping with her VI and this stress often results in self-doubt about her ability to function as a blind person. These descriptions have nuances of Susan not only feeling vulnerable, insecure and inadequate but also that she has not yet confronted the reality of her loss of sight and is not aware of the implications and limitations of living with a chronic VI.

Susan's anxiety is intertwined with her feelings of sadness and depression. Her anxiety about the rejection she experiences from her mother causes her to feel depressed, which is reinforced by her feelings that she is the cause of her mother's depression, which in turn, causes her more anxiety. From Susan's language use it may be deduced that she does feel guilty about her mother's depression, "I must not blame myself," because there is an insinuation that she is indeed blaming herself. In addition, there are conflicting attitudes towards her guilt. On the one hand, she is emphatic that she is the cause of her mothers depression, but on the other hand, she believes that she is not guilty because she is not responsible for what happened to her

eyes. There is a suggestion that Susan is not coping with her situation because of her maladaptive reaction to stress with displays of excessive anxiety.

Susan's frustration centres round issues of her loss of independence and having to be dependent on others for help. The aspect of time becomes meaningful with the frustration Susan experiences with regard to her loss of independence. Susan has been AVI for 1,5 years and attended independence training 10 months following her loss of sight. There are overtones that Susan is using the aspect of "time" ("still new at it") to rationalise her situation of "bumping and hurting" herself so as not to come across as someone who is not independent nor coping. This rationalisation further highlights Susan's vulnerability and insecurity. Susan denies being angry about her loss of sight, and the emotion of anger emerges only when her family does not reach her expectations. There is an implication that anger has been displaced from Susan's loss of sight onto her family, who she perceives as not understanding her condition and because of this lack, are not there to help her cope with her loss of sight. Her rationalisation and displacement has nuances of Susan attempting to reduce her anxiety about her loss and trying to preserve her fragile self-esteem.

Conflicting attitudes of acceptance and coping emerge dichotomized as they are difficult to reconcile. Susan believes that she has accepted and adjusted to her loss of sight yet she believes that she will never get "used to it." Susan believes that she is coping with her loss because she is seeing the "light," yet she is anxious about not coping with all the issues of her loss such as, how scary her loss is for her as she is in the "dark" all the time. These descriptions have psychological symbolic gesture as being "in the dark" have both literal and metaphorical value: Susan is in the dark literally because of her total loss of sight, but also because of her lack of awareness of the implications and limitations of her VI. Susan's perception of telephony being the only job for AVI individuals as well as

perceiving herself as "different" alludes to Susan still sanctioning the stereotypical attitudes towards the AVI and reinforces her lack of awareness and understanding of the implications of her VI and her failure to confront the reality of her situation. She transcends her limited physical condition with her acceptance, coping and adjustment.

#### **4.10.4 Summation**

Although Susan has accepted her loss of sight and perceives herself as coping, independent and self-sufficient the sadness of her mother's rejection of her and the fear of what lies ahead for her in the future are still central concerns. Her intricate descriptions embrace nuances of a person who is unaware of the full-scale implications of living with a chronic VI and that she has, as yet, not confronted the reality of her loss of sight.

### **4.11 CASE TEN: PAUL**

#### **4.11.1 Background Information**

Paul is 47 and has been AVI for 17 years. The cause of his VI is diabetic retinopathy and glaucoma. It was a slow process of sight loss over a period of 6 to 8 months. In the beginning he had light perception but after many operations and laser treatments he had both eyes removed and he now has prostheses. Concurring with the vision ability classification in Chapter one {Section 1.2.1.3, p. 4} Paul can be said to be totally blind.

Paul is divorced and stays with a friend in a house which he has bought. He was a motor car salesman and after his loss of sight he worked on a switchboard for 14 years and then resigned. At the time of the interviews, 6 months apart, he was unemployed. Paul attended rehabilitation approximately 2 years following his loss of sight.

#### 4.11.2 Phenomenal Meaning Units and Psychological Structures of Meanings

##### 4.11.2.1 Paul's Perspective of Loss of Sight

*Loss is an Inconvenience:*

Paul views his loss of sight as an inconvenience. According to him, he is not blind and claims that as he is so used to his situation he is carrying on with and enjoying his normal independent life in the same way as he did before his loss ("my blindness is an inconvenience." "I can still see, in the sense that I feel like the normal person I was before I lost my sight." "A normal person who just happens to be blind." "I think that I'm not blind because I'm so used to it." "I can get around, I don't even need my cane at times." "It is quite natural I just have to feel and see at the same time." "Today it is not dark and I get the light all the time." "I've just had to carry on and enjoy life." "So far I've enjoyed life very much." )

To Paul, his loss of sight is inconsequential, the inconvenience being that he has to deal with the side-effects of his loss, like needing help when he undertakes building changes ("although I'm carrying on with my life as before, I'm having to deal with the side-effects of my loss." "I never asked for help, but now I've got to ask for it." "When something in the house is being done I want to be shown and I want to feel it." )

*Loss is Confronting Problems:*

Paul maintains that he is confronted with problems associated with his loss of sight which are often difficult to solve. He claims that after careful consideration he may attempt to solve the problem in a certain way which may or may not work ("there are times when I hit a wall." "It is often difficult to get around it." "I sit and think about it." "Sometimes I can tackle it on an easy round about way but sometimes I can not." "I want

to know what the problem is because if somebody is battling then I can explain to that person what should be done, because I know what to do.")

#### 4.11.2.2 *Paul's Emotions, Feelings, Thoughts and Reactions*

##### *Acceptance is a Oscillating Process:*

Paul continues to experience acceptance as an oscillating process ranging from acceptance to total non-acceptance depending on specific situations ("at that time I was accepting it one day and then not accepting it the next day." "I accept it on days when everything is good and there are no problems." "On days when it is not good and there are problems, then I don't.") For Paul, absolute acceptance is an impossibility ("time certainly has not healed anything.")

With time, Paul has accepted some of the limitations associated with his VI, especially with regards to needing to be dependent on the sighted when help is needed ("I cant do everything by myself, I have to have help." "I was very independent and I always did things on my own, I never asked for help." "Now I've got to ask for it." "When something in the house is being done I want to be shown and I want to feel it.")

Paul contends that his attitude towards acceptance is contrary to the societal expectation of acceptance following a loss. He claims that acceptance was coerced onto him during rehabilitation ("I think that if you go to Optima they expect you to have already accepted your blindness." "Just as society thinks you must have accepted." "This expectation is sort of forced on you at Optima." "If you haven't accepted then it is your problem.")

##### *Denial:*

Paul denies experiencing emotions associated with his loss of sight. He claims that these emotions are inconsequential but

admits that there could be problems if, and when, he experiences them ("I was never angry about it." "I don't even worry about the emotions." "When they come then I think I might have a problem.")

*Self-Consciousness, Embarrassment and Social Withdrawal:*

Paul maintains that he was initially self-conscious about both his diabetes and loss of sight as he felt "different," and tried to keep them a "secret." In certain situations he still feels embarrassed about issues related to his VI when he attracts attention to himself ("I felt different and embarrassed with no eyes." "Once at work I had my shoes the wrong way round." "In that situation I felt embarrassed.") He claims that it is in embarrassing situations that he wishes he could still see "I wished I could see because what did the people think.")

He maintains that with his attitude of being "different" as well as feeling rejected because the doctors could not give him back his sight, he withdrew from social interactions ("I withdrew a lot." "I felt rejected because he (doctor) couldn't do anything for me. "I did not want to go out, I did not want to go anywhere." "I did nothing, I just wanted to sleep all day." "I just didn't want to meet anybody until I got the prostheses.")

With time, and being in contact with other AVI individuals, Paul claims that his attitude towards his VI changed and he started coping with his loss and was able to interact with other people again ("I had to get to these people (the AVI) to see how they coped." "I started asking and I realised there was nothing to it." "my attitude started changing." "I felt better seeing that some were worse off than what I was." "I felt I could go out again." "I then found that it was easy going." "I did not feel ashamed or embarrassed about my sight and my diabetes any more." "I didn't try to keep it secretive." "I came out of my shell.")

*Frustration:*

Paul continues to experience frustration related directly to

the issues of his VI, and especially in certain situations when he does not feel in control ("in the beginning I can remember getting very frustrated." "Although it is a bit better now I still get frustrated in certain situations." "If I ask someone what the problem is and if he does not give me an answer straight away, then I raise my voice." "If he still keeps quiet, or if he says to me "just wait a bit," that's when I get frustrated." "This is done because of my blindness, because if I could see I would not have this problem." "There is still the frustration, and I think it will always be there." "I don't think you can ever get away from it.") It is in these specific situations that Paul wishes he could still see ("sometimes I wish I could just see again in those situations where it is necessary." "It is not all the time but just those specific situations.")

*Self-Confidence and Self-Control:*

Paul contends that he is a confident and self-assured person who is in control of his life and VI, and is able to carry on with his life despite his loss ("I am confident again and I can do anything now." "I tackle anything even if it takes me the whole day.") He maintains that even though he has to get people to help him with certain things he is still in control of the situation ("when something in the house is being done I want to be shown and I want to feel it." "If it is not right I will know." "I will say "take it out and fix it." "I want to know what the problem is." "If somebody is battling then I can explain to that person what should be done." "I know what to do, how to do it." "It must be the way I want it to be done." "If that's not the way it is done then it is not right.")

*4.11.2.3 Paul's Emergent Needs*

*Need to be Treated as Normal:*

Paul's overwhelming need is to be treated as a "normal" person ("at the time when I first lost my sight up to today my need is

the same, I need to be treated as a normal person who just happens to be blind.") He maintains that because he is blind people treat him as if he is different, stupid or someone who has a contagious disease ("people in general don't treat you like that, they treat you as if you are different." "Besides being blind, treat you as stupid as well." "They ask the other person who is with you, "what would he like to drink" and I'm right there." "They think we've got some contagious disease and they are too scared to shake your hand.")

*Need for Knowledge and Understanding:*

Paul maintains that all people need to be made aware of and understand the real world of VI such as, how to communicate with or approach the AVI. This lack of knowledge impacts emotionally on Paul ("I think there is a great need for everybody to become aware of the real things about blindness." "They do not know about blindness and how to communicate with and approach blind people." "Up until I left work, after 14 years, the people working there still didn't know anything about VI issues and how to cope with somebody who is blind." "I've put my hand out and the other person will just walk away and I stand like an idiot.")

For Paul, the lack of knowledge and understanding of VI issues results in stereotyping, especially in the employment environment ("I needed to be paid a normal sighted person's salary." "Blind people are cheap labour." "This stereotyping of "OK, so you're blind so become a switchboard operator" must be changed." "Treat me as a normal person who can do other kinds of jobs other than switchboard.") He maintains that during his telephony training he was expected to learn the stereotypical braille in order to work on a switchboard. He claims that the trainers were unaware of other methods that could be used to enable him to cope optimally with his work situation ("the expectation that I have to use braille when I worked on the switchboard." "They are wrong." "I managed for 16 years using a tape recorder and managed fine." "I never use braille so that was a waste of time being

taught it." "They need to move away from the expectation that everybody must use braille." "Need to assess what he will need to be able to do it.")

*Need for Proper Training and Honest Information:*

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. He claims that during rehabilitation he should have been made aware of the real implications and limitations of his eye condition, and the long-term affects. He feels that with such self-awareness and knowledge about these issues he would have coped better with his situation, and would have been better prepared for his future ("this was a very basic need for me and it was not met." "On the practical side I came out with a bit more knowledge about mobility but from the emotional side and the awareness side I came out with nothing." "I had to experience many of the things myself and alone that I should have been told about when I was there." "Rehabilitation did not prepare me for all the things to come." "There are so many things you should be made aware of." "Peoples' attitudes, and tell you that you have limitations." "I should have been told about the long term effects." "I was not made aware of the fact that people will still reject me 17 years after I lost my sight.")

Such awareness, truth and honesty could be accomplished through proper training and counselling for all individuals concerned with helping the AVI. A more holistic service could be offered ("I feel that they need to be taught, and taught properly." "How to approach a blind person and how this person functions or how he works." "This must be done by somebody that deals with or knows how blind people function." "They must go into the job situation and explain the truth about VI to everybody. ""They should all go on counselling courses to be able to offer a better service in all the areas." "Anybody can come in and teach but they actually don't know very much about blindness themselves.")

Truth and honesty could be further facilitated through open communication between all members of Paul's social network which would have helped him cope better with his VI ("they (doctors) need to be honest and communicate with their patients." "Just think how better I maybe would have coped." "Maybe I would not have lost so much self-confidence.") He feels that people involved in helping the AVI need to be AVI themselves ("there needs to be staff at Optima who are visually impaired themselves." "Not people who are born blind but those like me who lost their sight later in life." "They know what I'm experiencing far more than what sighted people or those born blind can ever know." )

#### *4.11.2.4 Paul's Experiences of Support from Family, Friends, Society and the Rehabilitation Context*

##### *Positive Support:*

Paul continues to receive positive support from his friend, her son and the others involved in his house, without which, he would not cope ("the support is always there from the person I'm now staying with." "She will phone every day to find out how things are, and if I am all right." "She has helped me a lot and I just feel without her I would not be here today." "Her son is also a great support." "He is able to drive me around to do what I need to do." "Everyone is a great help to me, even the maids and the gardener." )

##### *Negative Support from Friends and Optima:*

Paul maintains that the friends he had when he was sighted are no longer a support for him. He does not mix socially with other visually impaired individuals because according to him, they are scroungers ("when I could still see I had lots of friends, but now that I'm blind nobody phones me." "My friends are the ones at the bowling club." "We meet once a week and that's it." "I have more sighted friends than blind friends." "Some blind people

just take what they can get out of you." "I don't socialise with them because they sponge.")

The only support from rehabilitation is the mobility skills Paul achieved ("rehabilitation did nothing for me and it actually wasted my time." "The only thing which was worthwhile, and which I still use is the mobility." The most beneficial support Paul received during his rehabilitation was the friends he met ("that was most probably the best thing about Optima, the friends I made there." )

#### 4.11.3 **Emergent Themes: Psychological Structures of Meanings**

It is important for Paul to be treated as the "normal" and independent person that he was before his loss of sight. It is also vital that Paul be in control of and coping with his life and his VI, and to be perceived as such by others. He is afraid that if he is perceived as not coping nor in control of his situation, other people will see him as "different" or "stupid," and reject or not accept him. These feelings are reinforced by his belief that he continues to be rejected by people 17 years following his loss of sight. There are overtones that Paul is vulnerable and insecure with his VI and often feels inadequate.

Paul tries to regain "normality" by continually attempting to live as "naturally" and independently as before his loss. The support he receives from his friend facilitates his "normality." His motivation to live as "normal" as he did before his loss of sight possibly reflects low self-esteem which could be rooted in his disparaging attitude towards VI, "blind people just take what they can get out of you." His need to be treated as "normal" is underscored by his need for "normal" employment rather than the stereotypical switchboard job. There is a contradiction in this attitude for Paul was employed as a switchboard operator for 14 years following his loss of sight.

His determination to be in control of his life is underscored by his frequent use of the words, "want," "I know," "it must be the way I want it." There is a suggestion that Paul needs to be in control of his life and blindness but also in control of other individuals to satisfy his needs, with a further suggestion that Paul needs attention, care, acceptance and approval from others.

Paul believes that when he could not cope with or be in control of certain situations he became embarrassed, self-conscious and lost self-confidence. By being fitted with a prothesis which enhanced his physical self-image, Paul nonchalantly claims that his attitude of embarrassment changed because he realised that it was easy for him to cope, which in turn, heightened his self-confidence. The use of the phrase, "coming out of my shell" alludes to Paul creating a barrier between himself and others in order to protect himself from being perceived as "different." It may be deduced from his language use, "in that situation I felt embarrassed," "what did the people think," that he continues to get embarrassed and self-conscious about not being in control of his VI especially when it attracts attention to himself. He continues to cope by withdrawing from and not socialising with people. Paul's continued irritability and agitation towards other people, his social withdrawal and not wanting to interact with other people have nuances of Paul experiencing depression.

Paul denies any emotion associated with his loss of sight and does not "worry" about them. He distances himself from the reality of his changed AVI life by not wanting to incorporate the idea of his loss of sight into his perception of himself, "I am not blind." There is an insinuation that Paul denies the reality of his VI in an attempt to be in control of it, which is reinforced by his attitude that his blindness is a mere "inconvenience."

Conflicting attitudes of experienced emotions emerge dichotomized as they are difficult to reconcile. Paul denies any emotions related to his loss of sight and believes that emotions

do not worry him, yet he gets "annoyed" and continues to get frustrated" with sighted people. Paul's emotions, and especially frustration, centre round his perceived loss of control of his life and environment. He needs to be in control and to dominate situations and people, and even if he cannot do something himself and acknowledges that he needs other people's help, he believes that people should take his advice and listen to him because he "knows." Many of his experienced emotions, including, hopelessness, frustration and annoyance appear to be displaced onto the sighted, such as, the doctors for not giving him a "guarantee" that the operations would help, and for not fulfilling his "hope" of seeing again. There is an insinuation that Paul displaces his emotions in an attempt to reduce his anxiety about his loss and to preserve his self-control.

Paul believes that his emotions and attitudes, and especially frustration and acceptance, are not experienced continually but are oscillating, and episodic phenomena related to specific situations, such as when he is involved in alterations in his house and the person helping does something wrong. It can be deduced from Paul's perceptions that acceptance of, and adjustment to, VI are feelings and processes that cannot be conclusively completed and concluded following loss of sight.

"Wishing to see" is experienced in specific situations as when he is not able to do the practical things he could do when he could still see, or in situations when he feels embarrassed. There are overtones of Paul yearning to return to his familiar psychological order of an independent and in control sighted person. There is a further suggestion of Paul needing certainty and security in his life.

Paul carries on with and enjoys his normal independent life and is helped by his intimate support system. "Enjoyment" centres round Paul being financially independent and being able to purchase his own home and take numerous overseas holidays with his friend. His language use, "I wouldn't be here today," has an

insinuation that Paul may have contemplated suicide without the support from his friend, which in turn, reinforces the suggestion that Paul needs attention and care. A conflict between independence versus dependence emerges. Paul perceives that he can do anything, that he is independent and in control of everything, yet there are implications that Paul needs to be dependent on the support from his small but intimate group of friends in order to cope and carry on with his life. There is an insinuation that Paul is a very private person who depends on his small group of friends which is underscored by him wanting to keep his blindness and his diabetes a "secret."

Paul perceives that with time he has gained conscious insight and self-awareness about the complexity and difficulties of living with a vi. His language use of "not in the dark" has both literal and metaphorical value: although he is in the "dark" literally because of his physical loss of sight, he is not in the "dark but in the light" because he believes he is aware and understands the reality and facts of his vi.

Paul believes that there is a need for all people, and in particular rehabilitators, to be made aware of and understand the truth of the fundamental real issues of VI, and the real implications and limitations of loss of sight. Awareness and understanding of these real facts by all people ought to make them responsive to the needs, issues and problems facing AVI individuals, rather than a fallacious and assumptive understanding. The "facts" will help alleviate stereotyping about adventitious VI, and make individuals, particularly rehabilitators, aware of the different ways or methods of being able to do things in the VI context rather than the stereotypical methods, such as braille. Paul is able to transcend his physical loss of sight by carrying on with, and enjoying his normal independent life with the attitude that his VI is a mere inconvenience which he can overcome. For Paul, living with a VI is a continuous oscillating process having to constantly cope with, adjust to and take control of his loss of sight.

#### 4.11.4. Summation

Paul perceives himself as a normal, coping, independent and in control person who happens to have the inconvenience of an adventitious vi. He carries on with and enjoys his life with support from his friend who helps him cope. His intricate descriptions however, embrace contradictions and nuances of a denial of the VI in order to take control over it, experiences of "denied" emotions, and oscillating attitudes of acceptance and non-acceptance all of which are intertwined with the length of time of his adventitious vi.

#### 4.12 CONCLUSION

It is apt that concluding comments from AVI respondents on how they had experienced the interviews are included here. Although some AVI respondents cried, and some laughed, they were all positive with many making enlightening comments including: "you are the first and only person who has ever asked me about my needs...The interviews were most enlightening, because you touch on aspects that are important to every visually impaired person," and "I think you have made me think about things, which I should have thought about years ago, and it has helped me to understand a bit better," and "after the last interview I thought about what I had said...I think that when one talks about these things you are really confronted with it, and I have looked into myself and thought how can I change things, so you've made me really think," and "it made me think and I enjoyed it because you raised questions that I've never thought about before."

In this Chapter, phenomenal meaning units arising out of the idiosyncratic concrete descriptions of the AVI respondents' perspective of loss of sight, their emotions, feelings, thoughts and reactions to loss of sight, the emergent needs they experienced and currently experience, and the level of support they experience from family and friends, society and the rehabilitation context were transformed into psychological

structures of meanings. Essential recurrent psychological themes of each AVI respondent's experience of losing sight were highlighted.

In the next Chapter, significant findings of the differences and similarities among both the AVI respondents and the two groups, namely, those AVI for less than and beyond 6 years, concerning the key issues under investigation will be discussed, in order to arrive at general conclusions regarding the experience of losing sight.