

## CHAPTER SEVEN

### THE REAL WORLD OF ADVENTITIOUS VI: CONCLUSION

#### 7.1 INTRODUCTION

The final conclusions and recommendations of the present study will be set out in this Chapter. A brief and critical discussion will focus on the following: The research aims of the present study; conclusions from the research findings and the theories underlying the study; its limitations; recommendations for further research; and a closing reflection on the value of this study.

#### 7.2 RESEARCH AIMS OF THE STUDY

The primary aim of this research study was to gain more insight and understanding about what meanings AVI adults have of their loss of sight; their experiences of grief as a resolvable or chronic process; the emergent psychological and emotional needs they experienced, and currently experience; and the impact that the length of time of the VI has on these experiences. Answers to these questions will be addressed in the major conclusions gained from the research study {Section 7.3, p. 323}.

The use of the phenomenological approach in the present study allowed access into the inner worlds of AVI adults and provided an in-depth understanding of the meaning of their loss and experienced emotions, attitudes and needs from the AVI respondents' own unique perspectives. The researcher trusts that with the revelations from this research study, the AVI and all members of their social networks, including rehabilitators, will be able to confront and deal with the difficult and painful issues of loss of sight in a more meaningful way.

It was hoped therefore, that this research study on AVI adults

whose loss of sight continued beyond the preferred 2 year time interval (the bulk of the literature on adventitious VI has focused on experiences up to 2 years after loss of sight) would result in more knowledge and therefore begin to fill the noticeable gap in the literature and research on the relation between length of time of VI and experienced psychological and emotional needs and the experience of grief of AVI adults. The lack of research and literature in these areas of adventitious VI seems to suggest that important areas of psychological, emotional, and attitudinal reactions, as well as emotional and to a lesser degree, practical needs, of AVI individuals, particularly the long-term AVI, are not being addressed. Insights from this research study were therefore not from adventitious VI literature and research but from the AVI respondents' inner experiential worlds of the meanings they give to their loss of sight and experienced emotions attitudes and needs.

### 7.3 MAJOR CONCLUSIONS FROM THE PRESENT STUDY

Significant conclusions emerged from this research study which are embraced in the core themes of the essence of the structures of the experience of loss of sight.

#### *Unique and Individual Perspectives and Meanings*

Loss of sight is an unique, individual and idiosyncratic experience. Each AVI respondent gives specific unique meaning to living with a chronic adventitious VI. The implication is that all people, including professionals and rehabilitators, should respect this individuality and not make generalisations, often based on stereotypical attitudes and misunderstandings, such as, all visually impaired individuals are blind, and that they experience the same generalised needs.

#### *Length of Time of the Adventitious VI Impacts on Attitudes and Emotions*

The length of time of the adventitious VI impacts on the

unrealistic or realistic awareness of the implications and limitations of living with a chronic VI, which in turn, profoundly impacts on experienced emotions and attitudes, as well as the perception of grief as a resolvable or chronic process.

The short-term AVI experience occasional emotions, such as frustration, some have already worked through the emotions associated with loss of sight, whilst some do not experience any emotions at all. They however, all experience absolute acceptance of, and adjustment to their VIS. The long-term AVI experience cyclical, oscillating but episodic emotional, (especially frustration) and attitudinal (especially acceptance and adjustment) reactions in specific situations or at specific times which are particularly meaningful to them. These emotional and attitudinal reactions usually exacerbate in meaningful situations when they become acutely aware of the irrevocable limitations of their VIS.

Despite all the AVIS' positive self-images of coping, confident and independent individuals they continue to experience more negative than positive emotions towards their VIS, and at a deeper level, experience ongoing tacit anxiety about living with this chronic impairment. The implication is that they experience paradoxical emotions and attitudes which are lived simultaneously.

#### *Resolvable and Chronic Grief*

The length of time of the adventitious VI is related to the distinct differences between the short-term and long-term AVI with regard to the experience of the grief process. On the one hand, the traditional grief-following-loss theory expectation of a static, resolvable grief process with decreasing emotional reactions, acceptance and adjustment to the VI is embraced by the short-term AVI. On the other hand, the long-term AVI embrace a chronic, cyclical, oscillating but episodic grief process. Confrontation of ongoing loss associated with the VI continues

to be a cyclical and episodic process which has to be adjusted to continually. The implication of these observations is that length of time of the adventitious VI, chronic grief and the related cyclical, oscillating but episodic emotions and attitudes are inseparable. This notion implies phenomena which reciprocally interact and influence each other.

A significant conclusion from this research study is the suggestion that society in general, and rehabilitators in particular, are reinforcing the traditional grief-following-loss theory of a resolvable grief process. The unrealistic hope, denial and unawareness of the real implications and limitations of adventitious VI amongst AVI adults are thereby enhanced. The assumption of a resolvable grief process held by both society and the short-term AVI in this research study could explain the gap in the literature and research on the psychological, emotional and attitudinal reactions and needs of AVI individuals, and particularly, of the long-term AVI. The bulk of literature and research on psychological and emotional reactions and needs related to adventitious VI focus on the time period from onset up to approximately 2 years following the loss, and includes the period immediately before and after rehabilitation. As the short-term AVI in this inquiry have endorsed the resolvable grief process, as in the case of many other research inquiries, an erroneous perception may have emerged that there is no need to research beyond the 2 year period of adventitious VI, given the fact that the rehabilitated AVI are once again independent, coping with, and accepting of and adjusted to their VIS.

#### *Length of Time of the Adventitious VI Impacts on Needs*

The length of time of the adventitious VI, together with a deeper awareness of the reality, implications and limitations of the chronic impairment, as well as the different degrees of visual abilities, profoundly impacts on experienced needs. The overwhelming needs experienced by the AVI respondents are the needs for independence, understanding and awareness, and long-

term emotional support. There are distinct differences between the short and long-term AVI respondents' specific needs for independence (short-term AVI) and awareness about the real world of adventitious VI (long-term AVI). It can be concluded that specific needs are emphasised, with the short-term AVI experiencing practical needs (practical independence), and the long-term AVI experiencing psychological (awareness and understanding) and emotional (emotional support) needs.

The need for practical independence has been satisfied for all the AVI during rehabilitation, many needs have changed over time, especially for the long-term AVI, because of their heightened awareness about the real implications and limitations of living with a chronic VI, and particularly, changes from needing independence to needing both independence and dependence. The significant conclusion however, is that the majority of needs, and especially the need for awareness and understanding of the real world of adventitious VI continue to remain unsatisfied. These unsatisfied needs in turn, impact on experienced emotions negatively.

The long-term respondents' need for all individuals, including the AVI themselves and rehabilitators, to be aware of and understand the unique abilities, needs and limitations which challenge the AVI with different degrees of visual abilities is disquieting. The conclusion which can be made from this lack of awareness is that one of the fundamental and basic issues of living with an adventitious VI is not being addressed, namely, is there any residual vision and if so, how much, so that pertinent and factual information, as well as appropriate support can be given to the new AVI and their families. A further implication of the lack of knowledge about these different degrees of VI could be one of the reasons for the stereotyping and misunderstandings that society has towards blind individuals.

Another conclusion from this study is that the AVI need to be confronted as soon as possible by aware and competent

rehabilitators with the real world of adventitious VI and all its implications, limitations, as well as its possibilities, and the prospect of experiencing chronic grief. The long-term AVI had to gain awareness, knowledge and understanding by experiencing the unique needs, abilities, limitations and challenges of their own particular visual ability by themselves, highlighting their accentuated need to be confronted with the real world of their adventitious VIS as soon as possible. The long-term AVI respondents' need for competent AVI rehabilitators further enhances the notion that these AVI view society in general, including rehabilitators, as having no awareness nor understanding about the real world of their VIS. The conclusions from this need for being confronted with the real world of adventitious VI is disquieting for it leads to speculation of whether the rehabilitation context is indeed meeting this basic need. Evidence from this research study suggests that this need is not being met.

Related to the lack of awareness and understanding about basic VI issues, is the long-term AVI respondents' expressed need for all individuals, including the AVI themselves and in particular, rehabilitators, to know and understand that acceptance and adjustment, especially emotional adjustment, to living with a chronic VI is a cyclical and oscillating process which is never final, integral aspects of chronic grief. As the long-term AVI were not made aware of this fact during rehabilitation, it can be concluded that society, including rehabilitators, are not aware themselves of this process. In addition, the continued need for acceptance from everybody who forms part of the AVI respondents' social networks, as well as the need for self-esteem, are probably linked to the lack of awareness, knowledge and understanding about the real world of adventitious VI with all its implications, limitations, different degrees of visual abilities, and the experience of chronic, cyclical and oscillating grief by all individuals who form part of the social network of the AVI. There is thus, a need for all individuals, including the AVI, to be made aware of and to understand these

phenomena.

The research findings supported the premise of this study that if length of time of the adventitious VI impacts on different experiences of grief as either a resolvable or chronic process, then diverse emotions, attitudes and needs will also be experienced. Lack of knowledge and understanding about these differences by all individuals impact negatively on AVI adults. An illuminating finding from this research is that behind the positive masks of coping, independent and confident AVI individuals are shades and shadows of anxious, often non-coping individuals, desperately determined to cope, by whatever means, with the implications, limitations and unsatisfied needs of living with a chronic adventitious VI.

### 7.3.1 Conclusions about Theories

Many significant conclusions about the theories underlying this research study were revealed.

#### *Grieving is Chronic, Recurrent but Episodic*

It was concluded from this research study that the theory of the traditional resolvable grief process, expected by society in general and in particular, rehabilitators, following loss of sight needs to be challenged. In addition, the suggestions to move away completely from a loss model theory with its notion of grieving for lost sight also needs to be challenged.

It is evident from this study that the loss model of grieving for loss of sight continues to be experienced by the long-term AVI. The grief which is experienced is however, not the traditional and assumed resolvable grief but rather, chronic grief. The long-term AVI with their greater awareness, understanding, and insight into the reality of the implications, limitations and needs of living with a chronic adventitious VI know that personal and environmental demands constantly change

in different situations and at different times, and that because of these changes they will be confronted with new losses associated with their VIS. It is in these specific situations, which are however, not constant and unrelenting, but which exacerbate at critical times and situations, that recurrent emotions and attitudes are experienced which have to be adjusted to continually. If the underlying cause of unending loss which has to be continually confronted is chronic adventitious VI, then it is reasonable to assume that the cyclical and recurrent episodes of both positive and negative emotions and reactions, which oscillate in intensity at critical times and situations for each AVI individual is chronic grief. This grief will operate throughout the time course of the adventitious VI.

The researcher however, needs to augment the concept of chronic grief to the concept of chronic, recurrent and episodic grief. Chronic, because the grief is continuous over time; recurrent, because it is cyclical, oscillating, reappears and is repeated; and episodic, because it is not constant or unrelenting, but exacerbates at critical times and situations.

It can be concluded from the research findings that it is inevitable that the loss theory of grieving for loss of sight forms an integral part of adventitious VI. It is however, necessary that a conceptual shift be made from the traditional resolvable grief models of loss of sight to a less restrictive model of chronic, recurrent and episodic grief which supports individuals in their recurrent experiences of loss rather than holding acceptance and resolution as the ultimate goal for the AVI. There is also a need to move away from the assumptions that the word chronic implies unresolved and pathological grief, to a new notion that chronic grief is a pervasive psychological reaction, and a natural and normal response to the ongoing anxiety of loss of sight.

#### *Both Grieving and Rehabilitation*

It can be concluded from the findings of this research study

that the theory behind the need to have accepted loss of sight (by implication, completing the resolvable grief process) before rehabilitation can begin the adjustment process, needs to be challenged. In this research study, the challenge has begun with the conceptualisation of adventitious VI involving a chronic, recurrent and episodic grief process, with no final acceptance nor adjustment to the VI. There must be a move away from the traditional assumption of either grieving for loss of sight or rehabilitation, to include a new concept of being able to grieve for loss of sight during the rehabilitation process. Rehabilitation must include both the emotional side of working through feelings as well as the practical side to restore functioning as soon as possible.

Individuals cannot begin or be expected to adjust, either emotionally or practically, unless they know what it is they must potentially face and adjust to. Competent rehabilitators with awareness, knowledge and understanding about the real world of adventitious VI involving chronic, recurrent and episodic grief need to make the AVI aware about the real implications and limitations they will face during the time course of their VIS.

A further conclusion regarding rehabilitation is that rehabilitators, in their attempt to maximize high levels of practical independence such as, independent mobility and being able to read braille, must simultaneously deal with the complex interaction of psychological and emotional needs which have an impact on the likelihood of the AVI benefiting from these skills.

#### *Hierarchy of Needs*

It was concluded from this research study that Maslow's (1987) need hierarchy theory, which was used in this research study, needs to be challenged. The notion of the satisfaction of needs following a linear and invariant process was questioned with the AVI respondents satisfaction of needs being both an ascent and descent experience in the hierarchy, indicating a cyclical,

oscillating and episodic motion of need satisfaction. In addition, needs from different levels, such as the need for acceptance, esteem as well as the physiological need to see again are experienced simultaneously by the AVI. The insights gained from this research study imply that the satisfaction of needs experienced by the AVI respondents is analogous to the chronic, recurrent and episodic grief process. It can be concluded therefore that there be a conceptual shift from the traditional linear need hierarchy to a notion of a chronic, cyclical and episodic need hierarchy to understand the process of the satisfaction of needs.

It was further concluded from this study that although the use of Maslow's (1987) need hierarchy to determine unsatisfied and satisfied needs, which are essential for optimal coping, well-being and quality of life, is beneficial for understanding AVI individuals' functioning, there needs to be a shift in this conceptualisation to include the notion of what meaning AVI individuals give to their lives. Indeed, Frankl (1978) challenged Maslow's concept of the linear need hierarchy with his notion that when lower needs are not satisfied, a higher need, such as, the will to meaning, will become more urgent, and that the more meaning individuals attain in their lives the more they will be actualised. Thus, when it comes to understanding well-being and quality of life it is essential that both Maslow's need hierarchy and Frankl's will to meaning be used simultaneously. The need for meaning will in turn, give meaning to life for the AVI, and those who can find a meaning despite afflictions, are "capable of taking up the challenge to live with courage and dignity," something which all the AVI respondents in this research study continue to achieve (Shantall, 1989, p. 429).

This research study challenges the International Classification of Functioning and Disability (1999) emphasis on how people should function with regard to the dimensions of VI, with interventions aimed to increase independence and optimum participation in life situations. It does however, not offer any

insights into how the VI affect individuals' well-being and what it means to those involved. It is important to find out what role VI plays in AVI individuals' lives, how they construct meaning out of their lives as AVI individuals, and which tasks, needs and challenges need to be faced.

### 7.3.2 Summation of Major Conclusions

The major conclusion from this research study is that the length of time of adventitious VI (within and beyond 6 years) has a profound impact on experienced emotions, attitudes and needs. The longer the adventitious VI, the more insight and awareness the AVI gain about the reality, implications and limitations of the real world of their adventitious VIS, which in turn, profoundly impacts on experienced emotions, attitudes and needs. The divergent needs of the two groups of AVI respondents were, the need for independence by the short-term AVI, and the need for awareness and understanding of the real world of adventitious VI with its implications and limitations, especially the different degrees of visual abilities and that emotional adjustment is a cyclical, episodic and oscillating process, which in turn, effected the need by these long-term AVI for continued emotional support. The different lengths of time of VI are also a significant factor that influenced the perception of the grief process, with the short-term AVI embracing a resolvable process, and the long-term AVI embracing a chronic, recurrent and episodic process.

### 7.4 LIMITATIONS OF THIS RESEARCH STUDY

Various shortcomings and limitations can be mentioned with regard to the present research study.

The phenomenological approach involving single case studies is particularly useful for gaining insight into a particular phenomenon. The descriptive or qualitative data obtained from this type of research are however difficult to test empirically,

so the conclusions of this study will in all likelihood be modest. However, the use of several AVI respondents in this study not only negated possible undetected idiosyncrasies of an individual AVI respondent (which would make it more difficult to arrive at a valid general description of the phenomenon) but it also facilitated a greater flexibility with the phenomenon given the greater variability provided by several respondents. In addition, the interpretations of the findings in this research study drew their validity from exercising a systematic and rigorous phenomenological approach, and a fidelity at all times to immediate experience.

Another shortcoming in this research study is that the conclusions cannot be compared with or supported by other research. This is due to the lack of pertinent research into this field of study namely, psychological and emotional reactions and needs of AVI adults, as well as the concept of a chronic grief process. Although the findings from this study compared favourably with the research by Murray (1998) it is inevitable that more research is needed regarding adventitious VI and the related issues which were suggested and hinted at during this research study.

Phenomenology is but one of the many research methods within the Humanistic research paradigm that can be employed in illuminating and seeking a broader vision of the phenomenon of the emergent needs post-grief experienced by AVI adults. Therefore, different perspectives should be applied and other avenues of research used in subsequent research to highlight the varied ways that emotions and needs of AVI adults can be experienced.

Although the researcher aimed at maintaining a neutral role and an objective standpoint, the possibility of subjectivity cannot be ignored. The researcher dealt with powerful emotions during the interviews and in these situations it was difficult to remain emotionally aloof, detached and objective. Strong feelings were

evoked in her during the interviews as she identifies with the reality of loss of sight and she cried and laughed with many of the AVI respondents. The researcher however, hopefully encouraged co-operation and rapport with the respondents because of the mutuality of their VIS. She hopes that she gained rich descriptions and insight into the AVI respondents' meanings, beliefs and attitudes of the phenomena being investigated.

#### 7.5 RECOMMENDATIONS FOR FURTHER RESEARCH

Several ideas for further research have emerged from the present study and therefore the notion that "research begets research" (Leedy, 1989, p. 9) is certainly appropriate to this research study. Issues that have been raised and which need to be pursued include the following:

More research to investigate the relation between length of time of adventitious VI and realistic or unrealistic awareness about the fundamental issues of the real world of VI and the experienced emotions and attitudes is needed. The notion that it is at critical periods and at specific times and situations that cyclical, oscillating and episodic emotions and attitudes are experienced needs further research. Other research would either endorse or refute the findings from this research study.

Research is needed into the concept of acceptance being the corner stone of adjustment to adventitious VI. It is evident from the findings of this study that if adventitious VI is related to a chronic, recurrent and episodic grief process then acceptance and adjustment, besides being inseparable, a notion which in itself needs further research, will also be cyclical, oscillating and episodic.

The phenomenon of the need or wish to see again needs further research. The conclusion from this research study is that the need or wish to see again is not a measure of acceptance of VI but rather a natural feeling which occurs, mainly for the AVI

with higher degrees of vision loss, when they are confronted with changing personal and environmental demands and it is precisely at these times that the probably long to be able to see again in order to perhaps cope better with the changing situations and related emotions. Findings from other research would either endorse or refute the findings from this study.

Research is needed to investigate whether the basic needs of the AVI are being met in the rehabilitation context. What emerged from this research study is that the basic need of the AVI to be made aware of and to understand the real world of their adventitious VIS, with all its implications and limitations is not being met in the rehabilitation context.

Further research is definitely needed on the impact that the different degrees of visual abilities has on experienced needs, emotions, limitations and abilities. The general lack of knowledge by all people about this basic VI issue, indicated by the lack of research and literature on this aspect of VI, is disquieting.

The concept of a chronic, recurrent and episodic grief process provided the most insightful and significant contribution to this study. Not only is the concept of a chronic, recurrent and episodic grief process related to experienced emotions and attitudes towards adventitious VI, but to experienced needs, both practical and emotional, as in the need for continued emotional support. More research into this critical phenomenon in adventitious VI is certainly needed. The acknowledgement of chronic grief by both the AVI and society in general could help all concerned become aware and understand the never-ending implications and needs of the real world of adventitious VI and provide a more effective societal, familial and rehabilitation context for AVI individuals.

#### 7.6 REFLECTION ON THE VALUE OF THE PRESENT STUDY

It is hoped this present study will act as a stepping stone for

future research to help fill the noticeable gap in the literature and research on the psychological, emotional and attitudinal reactions and needs which emerge following loss of sight, and the concept of chronic, recurrent and episodic grief related to adventitious (and especially long-term) VI. This research study has just touched the tip of the iceberg about the awareness of the real world of adventitious VI, with its implications and limitations, and further research is certainly necessary. Any new factual information that can make all individuals, including the AVI themselves and the rehabilitators, aware of the real implications and limitations of living with a chronic VI, can only but enhance the lives of all concerned.

It is hoped that the information and suggestions from this research study will encourage the rehabilitators to reconsider the worth of the rehabilitation context as it now stands. It is hoped that a more effective and holistic process with greater insight and understanding about the real world of adventitious VI to meet the basic needs of all concerned will be considered.

It is also hoped that the present research will stimulate reflection on a shift away from the existing resolvable grief theory. It is evident from this research that loss still forms an integral part of adventitious VI. Consideration will hopefully therefore be given to the concept of a loss theory of chronic, recurrent and episodic grief, because if the underlying cause of continual loss, and of course, the continuing confrontation of needs, is the VI, then grief with the accompanying cyclical, oscillating and episodic emotions and attitudes, as well as emergent needs, will operate throughout the time course of the VI. In addition, when trying to understand well-being and quality of life in the AVI, particularly in the rehabilitation context, it is hoped that both Maslow's need hierarchy and Frankl's will to meaning be used simultaneously. It is important to find out what role VI plays in individuals' lives, the meanings they give to their AVI lives, and which needs and challenges have to be faced.

On reflection however, perhaps the validity and worth of the present study is to be seen not in the answers it has provided (although these were thought provoking and meaningful) but rather in the pertinent questions it has raised. These questions will hopefully ensure that research into adventitious VI will be a chronic and cyclical process. As Maslow (1988, p. 86) states, "It is the ones who choose to work with the crucial, unresolved human questions who have taken on their shoulders the fate of mankind."

The aim of research is found at two levels: "problems whose aim it is to increase our knowledge and problems whose prime purpose it is to make life better" (Leedy, 1989, p.48). On further reflection, I do believe that this present research has to a small degree fulfilled these aims, because greater insight, understanding and awareness about the real world of adventitious VI has been achieved. With this new insight the lives of AVI adults will hopefully be better.

#### 7.7 CONCLUSION

Length of time of adventitious VI has certainly given many of the AVI, especially the long-term AVI, awareness and understanding about the implications, limitations and needs of living with a chronic VI. Timely confrontation with the fundamental issues of adventitious VI will give AVI adults insight into the real world of VI and give them the ability to cope optimally with their loss, and with psychological and emotional well-being live their own unique lives in their own authentic ways.