GIVE SORROW WORDS: THE MEANING OF PARENTAL BEREAVEMENT

by

ANNE-MARIE LYDALL

Submitted in partial fulfilment

of the requirements for the degree

DOCTOR OF LITERATURE AND PHILOSOPHY

in

PSYCHOLOGY

in the

FACULTY OF ARTS

at the

RAND AFRIKAANS UNIVERSITY

Promoter : Professor H.G. Pretorius

Co-Promoter : Professor A.D. Stuart

October, 2004

Declaration

I hereby declare that this thesis is my own, unaided work and that recognition has been given to the references used. It has not been submitted for any degree of examination at any other university.

……………………………. …………………..

Anne-Marie Lydall Date

Dedication

To my husband

Terry

and our children,

Peter, Stephen, Jonathan, Geoffrey and David

who make each day begin and end

and

in loving memory of Julie-Anne

(9.10.1978 - 19.2.1979)

"Soave sia il vento,

Tranquilla sia l'onda"

Così fan tutte
Mozart

Acknowledgements

I am grateful to my promoters for their enthusiasm, support and direction. I am especially indebted to Professor Pretorius for her unstinting support, constructive reviews and pertinent suggestions. The professionalism, wisdom and dedication of Professor Stuart provided steadiness and guidance. I am particularly appreciative of the honour and blessings of the work I am privileged to do and for which they have assisted in equipping me.

My thanks also go to the Johannesburg chapter of The Compassionate Friends (TCF) for allowing me access to their many resources. I have been deeply privileged and greatly honoured by those many people, members of TCF for their kindness and support. A special expression of gratitude goes to Madge Rix for her continued caring, encouragement and assistance, which cannot be specified in words.

I am deeply grateful to the participants in my study and the stories of their children that they have shared with me, for all that they have contributed to this work. I owe them an immeasurable debt of thanks, and they live on in my mind through that which we have shared. Their courage and generosity went far beyond that which I could have asked for or expected.

The richness of life's experiences has been bestowed on me by those dearest to me who have brought a rich texture to the tapestry of my life. Their love and affection provides the reason for all I do, and in practical ways their unfailing support has sustained my efforts. Finally, I give thanks for the small and the mundane, the comfort of tea and the endless games of solitaire, which provided sustenance and the space to reflect and compose my thoughts.

Summary

This study explores the process of meaning-making for parents who have lost an adult child where the cause of death was a stigmatised illness. In order to shed light on the phenomenon under review, an investigation of existing research literature was undertaken. A particular focal point in respect of the review as a whole, is the exploration of how the experience of parental bereavement motivates the search for meaning and the possible significance of this meaning in the continued life of the bereaved parent. The review comprises an overview of theoretical approaches to bereavement and the various factors which determine the grief experience. These include an examination of factors surrounding the loss, personal factors and coping skills, as well as an outline of familial, cultural and social aspects. A further focus of the review, is on the process of meaning making especially with regard to death and suffering. The review explores the issues of stigma and the process of stigmatisation. How stigma attaches to an attribute and issues of disclosure are areas of focus, in particular the effect of stigma in respect of HIV/AIDS.

The focus of the study is on the world of the lived experienced as it is interpreted by participants in order to produce an understanding of the participants' experience. Hence the study is sited within a phenomenological framework. Six participants were interviewed with the intention to act as informants who are able to give rich and abundant descriptions of their experience. All participants have experienced the loss of an adult offspring as a result of a long-term illness. The children of three of the participants died as a result of an AIDS-related illness, which is currently a stigmatised illness in South Africa, and the children of three participants have died as a result of cancer, which is a long-term terminal illness which is not currently stigmatised in South Africa. The interviews were recorded and transcribed. An interwoven analysis was presented in order to identify the themes and experiences of such bereavement which emerged from the transcripts. An attempt was made to understand how the various phenomena relating to parental bereavement were reflected by participants in the interviews. The study also sought to compare areas of commonality and divergence between participants whose children have died from cancer and those who have died as a result of AIDS, so as to present an integrated delineation of themes.

Finally the study presents a reflection of the experience of the researcher and recommendations for therapeutic practice which arise from the conclusions of the study. There is an evaluation as regards the strengths and limitations of the study and recommendations for future research. The unique contribution of the study to the field of psychology is also addressed.

Table of Contents

Chapter 1 .... **1**

1. Introduction, motivation, aims and terminology **1**

1.1 Introduction **1**

1.2 Motivation for the present study **3**

1.3 Aims and objectives of the present study **4**

1.4 Definitions of terminology **5**

1.5 Overview of the present study. **8**

Chapter 2 .... **9**

2. Bereavement **9**

2.1 Introduction **9**

2.2 Characteristics of the grief response **9**

2.2.1 Somatic symptoms 9
2.2.2 Emotional sequelae 11
2.2.3 Cognitive sequelae 12
2.2.4 Behavioural sequelae 12
2.2.5 Patterns of grief 13
2.2.5.1 Anticipatory Grief 14
2.2.5.2 Complicated mourning 15

2.3 Theories of bereavement **18**

2.3.1 Psychoanalytic approaches 18
2.3.2 Stage and phase theories of bereavement 22
2.3.3 Behaviourally and cognitively-based approaches 25
2.3.4 A move away from traditional theoretical frameworks 31
2.3.5 Post-modern and constructivist approaches 31
2.3.6 Towards an integrated approach 33

2.4 Psychosocial determinants of grief **34**

2.4.1 Relationship of the deceased to the bereaved person 34
2.4.2 Circumstances surrounding the loss 36
2.4.3 Personal factors 39
2.4.4 Coping skills 43

2.5 Cultural and social aspects of bereavement **43**

2.5.1 Socio-economic aspects of the HIV/AIDS epidemic in South Africa and the impact on bereavement 48
2.5.2 The effect of bereavement on the family system 48
2.5.3 The family system and the effects of HIV/AIDS in South Africa as it impacts on bereavement. 53

2.6 Parental bereavement through loss of offspring 54
2.6.1 Parental bereavement as a result of cancer 55
2.6.2 Parental bereavement as a result of an AIDS-related illness 57

2.7 Conclusion 59

Chapter 3 60

3. Meaning-making 61

3.1 Introduction 61

3.2 Reality and meaning 61
3.2.1 The need for meaning-making 63
3.2.2 Meaning construction 66
3.2.3 Language and meaning 68

3.3 Death, suffering and meaning 69
3.3.1 Meaning-making and HIV/AIDS 79
3.3.2 Meaning-making and parental bereavement 81

3.4 Religion and spirituality in meaning-making 90

3.5 Conclusion 99

Chapter 4 100

4. Stigma and stigmatisation 100

4.1 Introduction 100

4.2 The stigmatisation process 101
4.2.1 Courtesy stigma 102
4.2.2 Structural discrimination 103
4.2.3 Stigma consciousness 103
4.2.4 Stigma acquisition 105

4.3 Stigma and disclosure 107

4.4 Enacted stigma 109
4.4.1 Scapegoating 110
4.4.2 Stigma, social death and physical death 111

4.5 Felt stigma 113

4.6 Stigma and illness 115

4.7 Stigma and death 117

4.8 Stigma and HIV/AIDS 119

- 4.8.1 Instrumental stigma versus symbolic stigma 124
- 4.8.2 The social contamination reaction 125
- 4.8.3 Grieving a stigmatised death 131

4.9 Conclusion 135

Chapter 5 136

5. Research approach: A phenomenological investigation 136

5.1 Explication of selection of the methodology 136

- 5.1.1 Phenomenology as a research method 138
- 5.1.2 Focus of the research 140
- 5.1.3 The role of the researcher 140
- 5.1.4 Fundamentals of the phenomenological enquiry 142
  - 5.1.4.1 The nature of lived experience 142
  - 5.1.4.2 Investigation of the lived experience 144
  - 5.1.4.3 Reflection of essential themes 145
  - 5.1.4.4 Writing up the research 146
- 5.1.5 Issues of validity and reliability 146

5.2 An overview of the development of phenomenology 148

- 5.2.1 Definition and introduction of phenomenology 148
- 5.2.2 Phenomenology at its inception 148
- 5.2.3 From Descartes to Husserl 149
- 5.2.4 Husserl's contribution 152
  - 5.2.4.1 Eidetic reduction 153
  - 5.2.4.2 Phenomenological reduction 155
  - 5.2.4.3 The structure of perceptual experience 156
  - 5.2.4.4 The life-world 159
  - 5.2.4.5 The concept of intentionality 162
  - 5.2.4.6 Meaning and language 165
- 5.2.5 The transition to existential phenomenology 165
- 5.2.6 An overview of the three phases of phenomenology 165
- 5.2.7 Heidegger 167
  - 5.2.7.1 Dasein 167
  - 5.2.7.2 Being-in-the-world, ontological anxiety and throwness 168
- 5.2.8 The existentialist contribution 171
  - 5.2.8.1 Sartre 173

5.2.8.2 Marcel 175
5.2.8.3 Merleau-Ponty 176
5.2.9 Phenomenology and hermeneutics 180
5.2.9.1 A comparison between phenomenology and hermeneutics 180
5.2.9.2 Phenomenology as hermeneutics 180
5.2.10 Phenomenology in the postmodern context 186

5.3 The research problem and the aims of the study 187

5.3.1 General aims 188
5.3.2 Specific Aims 188

5.4 Research procedure 188

5.4.1 Selection of participants 189
5.4.1.1 Selection of participants in phenomenological research 189
5.4.1.2 Criteria for selection of participants in the study 189
5.4.2 Data collection 190
5.4.3 Method and Analysis 192
5.4.4 Steps in the analysis 192
5.4.5 Ethical considerations 195

5.5 Conclusion 196

Chapter 6 197

6. Analysis and discussion of the experiences of participants 197

6.1 Introduction 197

6.2 Parental bereavement through cancer 197

6.2.1 Introduction to Vasalisa 198
6.2.2 Researcher’s impression of Vasalisa 198
6.2.3 Introduction to Kevin 198
6.2.4 Researcher’s impression of Kevin 199
6.2.5 Introduction to Ella 199
6.2.6 Researcher’s impression of Ella 199

6.3 Analysis of themes of participants whose children have died as a result of cancer 200

6.3.1 Temporality 200
6.3.1.1 The chronology of events 200
6.3.1.2 The temporal nature of the experience 201
6.3.1.3 Observing the changes wrought by the illness 202
6.3.2 Disbelief, denial and dissociation 203
6.3.3 Signs and portents 209
6.3.4 Doing it their own way 212
6.3.5 “Good things in the bad things” 214

6.3.6 Relating to the person, dying and deceased 216
6.3.7 Rites and rituals 224
6.3.8 Innerscape and outerscape: bodiliness and spatiality 225
6.3.9 The illness itself: Cancer 228
  6.3.9.1 A dread-provoking illness 228
  6.3.9.2 Treatment and suffering 229
  6.3.9.3 Illness metaphors 230
6.3.10 Change and transformation: the world since the loss 230
  6.3.10.1 A different world, a changed family 230
  6.3.10.2 Effect on personal philosophy 231
  6.3.10.3 Searching, maybe to find 233
  6.3.10.4 New values for life 233

6.4 Parental bereavement as a result of an AIDS-related illness 237
6.4.1 Introduction to Selinah 237
6.4.2 Researcher's impression of Selinah 238
6.4.3 Introduction to Rosemary 238
6.4.4 Researcher's impression of Rosemary 238
6.4.5 Introduction to Lorraine 238
6.4.6 Researcher's impression of Lorraine 239

6.5 Analysis of themes of participants whose children have died as a result of AIDS 239
6.5.1 The chronology of the events 239
6.5.2 Reaction to the news 240
6.5.3 The illness itself: AIDS 244
  6.5.3.1 Dichotomies: Illness vs health; HIV vs AIDS 244
  6.5.3.2 A changed existence 246
  6.5.3.3 Watching the suffering with horror 247
6.5.4 Disclosure 249
6.5.5 Relating to the person, dying and deceased 252
  6.5.5.1 Frail hope against hopelessness 253
  6.5.5.2 Taking care of the ill 254
  6.5.5.3 The final departure 256
6.5.6 Doing it their own way 257
6.5.7 The grief landscape 261
6.5.8 The role of God 264
  6.5.8.1 The changing relationship with God 264
  6.5.8.2 Reconciling retribution and forgiveness 265
  6.5.8.3 Reconciling Divine goodness and evil death 265
  6.5.8.4 AIDS as a test 269
6.5.9 Powerlessness 269

6.5.10 On being alone 273

6.5.11 The pain of the loss 275

6.5.12 Rites and rituals 279

6.5.13 Change and transformation: the world since the loss 281

6.5.13.1 Hoping for a restoration of hope for living 281

6.5.13.2 Forging a new relationship with the deceased 283

6.5.13.3 Existential fear arising from vulnerability and impotence 284

6.5.13.4 Being thankful for small mercies 285

6.5.14 Relating to others 287

6.6 Conclusion 288

Chapter 7 290

7. Discussion and integration of results 290

7.1 Comparison of themes in the interviews with the literature 290

7.1.1 The sequelae of grief 290

7.1.2 Anticipatory grief 293

7.1.3 Denial 296

7.1.4 Acute mourning 298

7.1.4.1 Intensity of the loss 299

7.1.5 Psychosocial factors and their effect on grief 300

7.1.5.1 Coping strategies 300

7.1.5.2 Relationship to the deceased and personal factors 301

7.1.5.3 Regulation of emotion 304

7.1.6 The impact of grief on meaning frameworks 304

7.1.7 Altruistic orientation after the experience of grief 310

7.1.8 The emergence of existential concerns 311

7.1.9 Renegotiating relationships after bereavement 312

7.1.10 Finding meaning versus constructing meaning 314

7.1.11 The continued presence of the child in the parent’s life 321

7.1.12 Issues relating to stigma and the stigmatisation of HIV/AIDS 324

7.1.12.1 Felt stigma 326

7.1.12.2 Issues of disclosure 327

7.1.13 The view of HIV/AIDS as a latter-day plague 329

7.1.14 The trauma of witnessing the suffering of the person with AIDS 329

7.2 Comparison of themes 331

Chapter 8 337

8. Personal reflection, evaluation, recommendations and conclusion 337

8.1 A personal reflection on the experience as researcher 337

8.2 Implications for therapeutic practice 340

8.2.1 To accept the invitation 342

8.2.2 To witness 342

8.2.3 To validate 342

8.2.4 To accompany 342

8.2.5 To encourage linkages 342

8.2.6 To offer hope 343

8.3 The unique contribution of the study 344

8.4 Recommendations and implications for future research.......................................344

8.5 Strengths of the study..345

8.6 Limitations of the study 345

8.7 Conclusion...346

References 347

Appendix A: Interview with Vasalisa ……………………………………..……………..A1-18

Appendix B: Interview with Kevin ………………………………………….…………..B1-20

Appendix C: Interview with Ella ……………………………………..…………………..C1-14

Appendix D: Interview with Selinah ……………………………………………………… D1-11

Appendix E: Interview with Rosemary ……………………………………………………..E1-12

Appendix F: Interview with Lorraine……………………………………………………..F1-19

Chapter 1

1. Introduction, motivation, aims and terminology

1.1 Introduction

From its earliest dawn humanity, as indeed is the case with all that is living, has always been beset by loss and death. Sometimes loss happens with unexpected suddenness, at other times it occurs slowly but inexorably. Some losses can be borne and overcome, others mark a final point that alters forever the life of the person who has suffered the loss. The pain of the loss of someone who is loved is difficult to deal with because it is an irretrievable loss and so the experience of loss is profound because of its life-altering quality.

Themes of loss can be found throughout literature and were a prevalent theme in Greek tragedy. The work of Shakespeare, great English playwright and wordsmith of the sixteenth century, is still relevant today because of his ability to express universal and timeless constants of human experience. The words spoken by Malcolm on receiving the news of the death of Macduff's wife, children and servants, vividly call out the human need to express his pain or suffer greater anguish: "Give sorrow words: the grief that does not speak whispers the o'erfraught heart, and bids it break" (Shakespeare, Macbeth, Act IV, Scene iii).

In his autobiographical account of the loss of his wife, Lewis (1978) has indeed attempted to give sorrow words. He describes how he believed it would be possible to describe the state of loss and, “make a map of sorrow” (p. 47). He finds however, that it is not a state but a process, not a map but a history. He describes the landscape of grief, constantly changing yet echoing past experience. This experience was interpreted cinematically as *Shadowlands*, in the 1993 film produced by Attenborough and Eastman in a complex and moving portrayal of the marriage between Lewis and his wife. This relationship enriched Lewis’ life to the extent that even the loss of his wife brought a sense of joy in the knowing of her, rather than regret of the loss of her. The volumes that have been written on the subject of loss bear testimony to the injunction to give sorrow words. Perhaps it is in doing this that people are able to find a meaning that makes sense of their loss.

Death and dying, as a process, has been much studied in the last quarter century especially since the publication of Becker's *The denial of death* in 1973 and *On Death and Dying* by Elizabeth Kübler-Ross' in 1974. The influence of the latter work lives on today in the strength of the Hospice movement, which it inspired, focussing as it did on humanising the process of dying for the person who is undergoing it. The following few decades were marked by a plethora of publications regarding dying, death and bereavement. Neimeyer (2001a, p. 1) terms this the, "'death awareness movement', a cultural shift toward greater acknowledgement of the place of death in human life." From a review of literature, it appears that much of the initial interest in this field was directed at spousal loss and at the experience of children who lose a parent. Attention was also directed at parental bereavement through loss of a child especially after the early 1980s. For people living in earlier times, the prevalence of illness and increased rates for mortality, also for the young, was common, so that people were exposed to death from a young age. In contrast to this, in the current era, improved sanitation and the availability of health care has resulted in a greater life-expectancy. Hence there are fewer opportunities for learning about this human event which affects all and it is possible for many people to reach adulthood before being exposed to the death of a loved one (Corr, 1979a).

The search for meaning appears to be a central aspect in humanity as is evidenced from mythology and early written texts to current philosophical endeavours. The loss of a sense of meaning in life creates a sense of inner desolation and spiritual barrenness that spurs the search for meaning. The experience of bereavement has been linked with the search for meaning as individuals seek to understand what has occurred and make sense of a world that does not conform to previously-held convictions. Such a search may be a means for bereaved individuals to try to integrate the death into their lives through assembling a novel understanding of the events surrounding the death with a view to restoring a sense of having some agency in the world. Davis and Nolen-Hoeksema (2001) have found that people coping with significant loss tend not to be satisfied with a causal understanding of the death but seek a deeper, philosophical meaning for their loss. While causal attributions such as the explanation that a physician can provide, can be an aid in the search for meaning, finding such an explanation rarely provides the reason sought by the bereaved person.

In contrast to many previous pandemics, HIV (Human Immunodeficiency Virus) and AIDS (Acquired Immune Deficiency Syndrome) afflict primarily adults and young adults, at a time in their lives when their parents are still expected to be alive. It is likely then, that a greater proportion of parents is facing the loss of adult children than has been the case heretofore. In addition, it appears that losing a child as a result of an AIDS-related illness may be a difficult loss intrinsically, because of the confluence of factors that are likely to complicate the bereavement process and also because of the stigmatising nature of the illness.

1.2 Motivation for the present study

According to the Medical Research Council (Galloway, 2001), South African hospitals are experiencing an alarming increase in caseloads as a result of HIV/AIDS. Orphanages and child-care facilities are reporting an increase in “AIDS orphans” and so-called “child-headed households”, and most South African families have been affected by the epidemic. Reliable statistics for South Africa are not available as AIDS deaths are still often misreported probably due in part to the fact that many people are not diagnosed at the time of their death and, because of the stigma of dying of AIDS, it is often not recorded as the actual cause of death. Galloway reports that,

> "While there is inevitably some degree of uncertainty because of the assumptions underlying both the model and the interpretation of the empirical data, we estimate that about 40% of the adult deaths aged 15-49 that occurred in the year 2000 were due to HIV/AIDS and that about 20% of all adult deaths in that year were due to AIDS. When this is combined with the excess deaths in childhood, it is estimated that AIDS accounted for about 25% of all deaths in the year 2000 and has become the single biggest cause of death. The projections show that, without treatment to prevent AIDS, the number of AIDS deaths can be expected to grow, within the next 10 years, to more than double the number of deaths due to other causes, resulting in 5 to 7 million cumulative AIDS deaths in South Africa by 2010.”

The Department of Health in South Africa (Soul City, 2004) estimates that of the 40 million people who are living with HIV globally, more that 10% are in South Africa, which highlights the severity of the epidemic in this country. What makes AIDS a unique disease is the fact that it infects people at the peak of their productive years, at a time when they would not normally require medical care: the incubation period is long and the condition is fatal. The extent of the AIDS pandemic in South Africa thus is such that many parents are likely to face the loss of their adult children. However, most of the research available in regard to bereavement as a result of an AIDS-related illness, has focussed on the person living with

HIV/AIDS, the surviving partner or offspring, or the caregiver. Crossley (2000a) has conducted research on the effect of living with the diagnosis on HIV-positive individuals. Walker, Pomeroy, McNeil and Franklin (1996) have studied the impact of social stigma on the grief process of caregivers who were primarily the partners of the person with AIDS. The focus in research by Bower, Kemeny, Taylor and Fahey (1998) was on bereaved HIV-seropositive men. In South Africa too, the focus appears to be primarily on the effect of bereavement on partners and children of those dying from an AIDS-related illness. For example, Katz (1999, p. 6) asserts that, "the disease is tearing apart families and communities, turning wives into widows and children into orphans".

The focus of much of the research done earlier in the field of bereavement has been on the pathological aspects of the grieving process. (Bailey & Gregg, 1986; Goalder, 1983; Hodgkinson, 1982; Mawson, Marks, Ramm & Stern, 1981; Rubin, 1985; Walker et al., 1996; Zisook & DeVaul, 1985). More recently, however, the focus has been on understanding how the bereaved person seeks to reconstruct a sense of their life-story and the life of their loved one, (Balk, 1999; Crossley, 2000b; Davis, Wortman, Lehman & Silver, 2000; Davis & Nolen-Hoeksema, 2001; Harvey, 2001; Neimeyer, 1999; Niemeyer, 2000; Stroebe, 2001; Wheeler, 2001).

The HIV/AIDS infection also confers on the individual a spoiled image and identity and it is the stigma that therefore attaches to the illness that partly accounts for the difficulty in establishing the full prevalence of the disease. In addition it is possible that the stigma that attaches to HIV/AIDS might result in bereaved parents not being able to receive the social support that would otherwise be available to them during such a bereavement (Henderson, 2001; Herek, 1999; Link & Phelan, 2001; Pryor, Reeder & Landau, 1999).

1.3 Aims and objectives of the present study

The research aims to acquire a fuller understanding of the process of meaning-making after the parental loss of an adult child as a result of a stigmatised illness, where the important meanings of a significant loss might not be accessible in terms of straightforward linguistic constructs, but rather lie in the realm of metaphor, simile and story. In particular, the aim of this phenomenological study was to interview on an individual basis six parents who have lost an adult offspring. The cause of death for the adult child for three of the participants was cancer, a long-term illness, currently not stigmatised in South Africa, and for the children of three participants it was an AIDS-related illness, a long-term illness which is currently stigmatised in South Africa. The interviews were recorded, transcribed and analysed within a phenomenological framework and an attempt will be made to understand more fully the lived experience of the participants of the study. The focus of the study was to explore and understand how the parents of the child, that has died in the ways described, make sense or meaning from the event.

From a broader perspective, the objective of the current research is to enhance the construction of theory, to generate knowledge and greater insight into the field of psychology, in the areas of meaning-making around parental bereavement, and more specifically, where the cause of death for the offspring of the bereaved parent is an AIDS-related illness. It also seeks to explore the links between existing literature and this research, and reveal inadequacies in such literature. Finally, it aspires to generate topics that may spark future research, as well as to provide some guidelines for therapeutic intervention for bereaved parents.

1.4 Definitions of terminology

The use of terminology pertaining to bereavement, grief, mourning and loss in the literature can be confusing as these terms are used interchangeably. In order to ensure clarity, for the purposes of this study, the term **bereavement** refers to the occurrence of the loss of someone with whom there is a close relationship and the reaction of the bereaved person to the loss. The state of having suffered a loss is bereavement. According to Rando (1993) the etymological origin of the word **bereavement** shares a root with “rob” which is descriptive of the shared sense of deprivation against one's will. The person who suffers such a loss is described as bereaved or as a griever.

Stroebe and Stroebe (1992) propose that the meaning of the terms **bereavement** and **grief** be differentiated, with **bereavement** referring to the objective situation of an individual who has recently experienced the loss of a significant person through death, and **grief** referring to the emotional response of the individual to such a loss. Worden (1988) also defines grief as the personal experience of loss. Grief includes sadness, anger, guilt, despair and hopelessness and constitutes a part of the bereavement process. Another defining characteristic is the “experience of suffering” (Wright, 1992, p. 101). Parkes (1988) notes that awareness of the difference between how things are, and how they were, or should be, triggers grief. In this sense grief is a natural occurrence consequent upon loss and forms a complex and coherent pattern of reactions. These include psychological reactions, which include feelings, thoughts and attitudes; social reactions (interactions with others) and physical reactions with attendant bodily symptoms (Kleber & Brom, 1992).

Loss is defined as an event that leads to the permanent unavailability of a person or object that is emotionally significant to an individual and to which the individual was attached (Martin & Doka, 2000). Loss always results in deprivation of some kind and losses are generally perceived as being unpleasant. Loss is concomitant with change as each transition, whether pleasant or not, involves some loss. For instance, even where marriage follows on a happy decision, it entails the loss of some freedom. The meaning of loss differs from person to person and it is the idiosyncratic meaning of the loss which influences the grief reaction. The griever may also experience secondary losses which are the physical or symbolic losses that develop as a consequence of the death of the loved person. This is as a result of changes to relationships with other family members, loss of activities that were linked to the deceased and other experiences in the life of the bereaved on a day-to-day basis. Where the understanding of one's role in life changes, such as a change of self-perception from adequate parent to inadequate parent, a symbolic loss may be experienced.

The terms **grief work**, **mourning** and **grieving** are often used to denote the process which occurs following a loss. Using the term **grief work** (Lindemann, 1944) illustrates the active nature of the grieving process highlighting that there are tasks and processes to be completed in order to resolve the grief. The terms also refer to the conscious and unconscious processes that gradually undo the psychological ties that bind the bereaved to the deceased, thereby facilitating adaptation to the loss (Rando, 1988). As part of the work of grieving, the bereaved person mourns not only the actual deceased person and the needs that they fulfilled, but also the hopes, expectations, ambitions and dreams held in connection with the deceased. Self-identity needs to be redefined as well as the assumptive world of the bereaved person. Martin and Doka (2000) reflect that current thinking emphasises the continued connection of the bereaved person to the deceased although the nature of the connection changes, finding expression in memories, legacies and spiritual beliefs.

HIV/AIDS is an illness with profound and serious implications for human well-being. HIV is an acronym for the Human Immunodeficiency Virus, which is transmitted through bodily fluids. The virus utilises the immune system of the infected person in order to replicate itself, in particular CD4 cells which ordinarily co-ordinate the immune system, and these are destroyed in the process. Over a period of time, numbering some years, the person's ability to resist illness declines, with consequent emergence of various illnesses. Being infected with the virus is termed being HIV-positive, which implies the presence of the virus, as opposed to being HIV-negative. AIDS is an acronym for the Acquired Immune Deficiency Syndrome and is the most severe expression of the HIV-infection. Once the immune system is so weakened by HIV that it is no longer able to protect the person from the multitude of disease-causing pathogens present in the environment, the person with HIV may fall prey to a wide spectrum of opportunistic infections which are caused by bacteria, viruses and fungi. There is currently no cure for the disease, although anti-retroviral treatment may moderate its severity, extending the life-span of the perosn who has the illness (Soul City, 2004).

Meaning, for the purposes of this study, refers to the exploration of the purpose and significance of the existence of the individual. According to Frankl (1964a) the search for meaning is unique for each individual and constitutes a primary motivational force in the existence of that person. It is precisely and exclusively the unique nature of the definition of meaning for the individual that provides a satisfactory response to a search for meaning. Not only are individuals driven to seek meaning in their lives, but there is also "a desire for a life that is as meaningful as possible" (Frankl, 1964a, p. 100). According to Fabry (1967), a phenomenological analysis demonstrates that meaning can be found in the creation of something of merit. The experiences that life proffers, including those that are painful or that cause suffering, are rich with meaning as is the knowing, respecting and appreciating of the value of others. Grappling with issues of meaning is thus a central precept that enables an individual to relate, not only to the present, but also directs the individual towards the future.

The etymological roots for the meaning of **stigma** lie in ancient cultures. The origin of the word stigma (plural: stigmatos) is from the Greek meaning the mark made by a pointed instrument or brand. The Latin word for the tattoo used to mark slaves and criminals was a stigma, and it was seen as a slur on one's character to have such a mark (Finan, 2002). The word came to denote the state of people who are not fully socially acceptable as a result of their bearing a specific undesirable attribute or characteristic. The oft-quoted standard is frequently based on the definition that Goffman (1963, p. 3) proposed in his seminal work on the subject, *Stigma: Notes on the management of a spoiled identity*, which defines stigma as, “an attribute that is deeply discrediting” and which reduces the bearer “from a whole and usual person to a tainted, discounted one.”

1.5 Overview of the present study.

This chapter constitutes the beginning of the study, offering an introduction to the present study, and setting out the motivation and aims of the present study. It has also defined the terminology which is utilised in the study. The following three chapters examine the literature pertaining to those areas which impact on the study. **Chapter 2** investigates the various issues of bereavement from the grief response to the theoretical approaches that have held sway in this field. There is an examination of psychosocial factors, and the effect of cultural issues and a brief exploration of the possible impact of specific deaths, such as those which result from cancer or an AIDS-related illness. **Chapter 3** is concerned with the process of meaning-making, especially as it occurs in the context of death or suffering. The role of religion and spirituality in meaning-making is considered, and there is also an exploration of possible factors relating to meaning-making which may impact on parental bereavement and HIV/AIDS. **Chapter 4** explores the literature regarding stigma and the stigmatisation process. Various aspects are explored and these include consciousnessness of, and acquisition of stigma, and an examination of the issues surrounding disclosure of a stigma. Enacted and felt stigma are reviewed and particular attention is focussed on these issues as they impact on attitudes towards HIV/AIDS and how the grieving process may be affected by this. The paradigmatic framework for the research is presented in **Chapter 5**, followed by a survey of the development of phenomenology. The operational aspects of the research are also defined and elucidated in this chapter. **Chapter 6** presents an interwoven analysis of themes and in **Chapter 7** these are discussed in light of the literature survey. There is also a comparison of themes from the participants whose adult children have died as a result of cancer, a long-term illness which is currently not stigmatised in South Africa, and of those participants whose adult children have died as a result of AIDS, which is currently stigmatised in South Africa. **Chapter 8** is the final chapter, and by way of conclusion provides the personal reflection of the researcher, an evaluation of the study, recommendations for therapeutic practice and for future research.

Chapter 2

2. Bereavement

This chapter examines the various characteristics of the grief response, from the symptomatology of grief, to a range of sequelae of a significant loss. There is an overview of various theoretical approaches to grief, from the inception of the field of psychology to the current time. Psychosocial determinants of grief are explored to understand how they affect the grief process, including the relationship of the deceased to the bereaved person, the circumstances surrounding the loss, personal factors and coping skills. Cultural and social aspects that impact on the grief process are also examined. Finally, there is an attempt to understand some of the specific factors which could impact on parental bereavement where the death occurs as a result of cancer or of an AIDS-related illness.

2.1 Introduction

The bereavement process has been much studied in the last quarter century. However, much of the interest was initially directed at spousal loss and it is only relatively recently that the focus has begun to be directed at parental bereavement through loss of a child. In contrast to many previous pandemics, AIDS afflicts primarily adults and young adults, at a time in their lives when their parents are still expected to be alive. It is likely then, that a greater proportion of parents is facing the loss of adult children than has been the case heretofore. In addition, it appears that losing a child as a result of an AIDS-related illness may be a more difficult loss, because of the confluence of factors that are likely to complicate the bereavement process and also because of the stigmatising nature of the illness. In light of this, a greater understanding of bereavement following on the loss of a significant other, would serve a useful purpose. Where pertinent, specific attention will be focussed on parental bereavement following on the loss of offspring.

2.2 Characteristics of the grief response

The symptoms and the sequelae of grief are examined in the following section as well as patterns of grief and anticipatory and complicated mourning.

2.2.1 Somatic symptoms

Many patterns of grief have been observed and described in the literature. Littlewood (1991) describes a wide range of somatic symptoms that may occur in grief, though these are not necessarily experienced by everyone equally. These include a sense of hollowness in the stomach or abdomen, a sense of tightness in the throat, chest and shoulders, dry mouth, muscular weakness, fatigue, tiredness and lack of energy, frequent sighing and breathlessness. Oversensitivity to light and noise stimuli is also a common experience. Other symptoms frequently include appetite and sleep disturbances, visual and auditory hallucinations and dreaming of the dead person.

The impact of the physical nature of the symptoms is confirmed in various studies: Holmes and Rahe (1967) found that loss of a spouse has the highest life stress rating. From an historical perspective, grief was accepted as a cause of death Dr Heberden's 1657 Bill classifying the causes of death in London listed causes such as flox, small pox, gout, griping, suicide and "griefe", and many bereaved people do in fact seek medical advice after a bereavement (Parkes, 1972). Stroebe, Stroebe and Domittner (1988) confirm that the risk of suffering a variety of ailments is significantly raised for a considerable period of time following bereavement. This could be attributed to the fact that raised levels of corticosteroids are common during periods of active mourning, which includes anniversaries of the death or birthdays of the deceased. Although plasma cortisol was not found to be raised in parents who suffer a sudden bereavement, T-suppressor cells were significantly decreased and T-helper cells significantly increased. They also showed non-significantly elevated blastogenesis in mitogen-stimulated cells (Spratt & Denney, 1991). Raphael and Dobson (2000) highlight the association of higher levels of separation anxiety distress a month after the loss with higher urinary free cortisol excretion which could be indicative of raised levels of adrenocortical activity. These findings suggest that further investigation of immune system changes be undertaken. Decreased immuno-competence in bereaved persons has been found to be associated with more severe depressive symptoms, and neuroendocrine changes with the impact of loss. This research serves to differentiate between the sadness of grief, and the depression which may follow loss.

The impact of the loss which manifests in these physical symptoms, is also evident in the increased mortality and morbidity rates of bereaved people: research carried out at the Mount Sinai Hospital in New York indicates that of the people who die within a year of losing a spouse, 20 percent die as a direct result of the loss. Hafen, Karren, Frandsen and Smith (1996) conclude, on the strength of various studies, that parents who lose children are at a particular risk for illness, especially where this is coupled with being divorced or being widowed. Following a longitudinal study from 1980 to 1996 of 314 807 parents, 21 062 of whom had lost a child, researchers concluded that the death of a child is associated with an overall increased mortality from both natural and unnatural causes in mothers, and an early increased mortality from unnatural causes in fathers (Jiong, Precht, Mortensen & Olsen, 2003). Although the greatest impact of the loss occurs during the first three years, increased mortality rates were noted to the termination of the study. Redding (1979) suggests that possible mechanisms for such outcomes may include both physiological changes including hypertension, and psychological changes which impact on health, such as those resulting from personal neglect or increased consumption of medication, alcohol or drugs.

2.2.2 Emotional sequelae

The range of emotional experiences described by Littlewood (1991) includes shock, numbness and disbelief. A sense of anxiety is exacerbated by fears of feeling unsafe, or of being alone and of being overwhelmed by grief. Fears of becoming insane are made worse by confusion and an inability to concentrate. Such disorientation tends to become most intense in the period between 4 and 6 months subsequent to the bereavement, and this may be accompanied by a negative effect on health maintenance (Davidson, 1979). There may be rumination and preoccupation with thoughts of the deceased and the events leading up to the death, especially where there is a lack of clarity over what led to the death. Sadness is a pervasive emotion even when it is not associated with crying. The extent of crying is not necessarily indicative of the intensity of the grief, especially when social or cultural constraints are considered. For example, it may be less acceptable for men to cry, and this is especially more so after the first short period after the loss. Anger, too, is commonly experienced, and can be directed at the self, those believed to be responsible for the death, society, fate and God. Other feelings include loneliness, restlessness, apathy, a yearning to be with the deceased person and searching for them.

Vance, Najman, Thearle, Embelton, Foster and Boyle (1995), found lower levels of depression and anxiety for fathers after 8 months than for mothers, but for both mothers and fathers these levels were higher in bereaved parents than in a control group. However, according to Boyle, Vance, Najman and Thearle (1996) research would indicate that the majority of mothers escape serious impairment even after such a highly traumatic event. While distress may be acute or chronic, and lasts for a least 30 months after the loss, the response to such distress is normally self-limiting. For a smaller sub-group however, such a death may herald serious and chronic distress, particularly if it is still prevalent at 8 months after the loss.

2.2.3 Cognitive sequelae

Worden (1988) describes some common thought patterns or cognitions of the newly bereaved person, some of which may trigger feelings that lead to depression or anxiety if they persist for a considerable period of time. Disbelief is generally the first thought on being faced with the news, and this gives way to a sense of confusion where concentration is impaired. There may be a preoccupation with thoughts of the deceased which may include obsessional thoughts on how to retrieve the deceased. Magical thinking is described as being characterised by thinking of all the alternative possibilities mentally playing out the event so that the ending is changed. Another common thought pattern is the belief that the deceased is somehow still present. Visual and auditory hallucinations may also occur, normally in the first few weeks following the loss.

Searching and yearning, according to Davidson (1979) tends to peak in the first few weeks following a bereavement and then again at the time of the first anniversary of the death. Despair and a sense of meaninglessness of life and living can contribute to a desire for life to end and suicidal ideation is not uncommon. There is often a sense of guilt, especially over acts or omissions, even if these are not necessarily based in reality.

2.2.4 Behavioural sequelae

Worden (1988) has also enumerated various specific behaviours which are associated with a grief reaction. As described earlier, sleep and appetite disturbances are common. The newly bereaved person may behave in an absent-minded way, thereby causing themselves inconvenience or harm. Social withdrawal is also common and can include a loss of interest in events outside. Other common behaviours are dreaming of the deceased, searching and calling out, restlessness and hyperactivity, crying and sighing, and visiting places or carrying objects that are reminiscent of the deceased. Martin and Doka (2000) have also added the following possible changes from pre-loss behaviours: increase in the use of alcohol, smoking or other chemical use, in order to alleviate anxiety or depression, as well as observable changes in religious or spiritual behaviours and accidents.

2.2.5 Patterns of grief

Lindemann (1944) in his classic study of the survivors of the Coconut Grove night-club fire in Boston, described the symptoms exhibited by this group. These included somatic symptoms including pain in the chest; shifts of sensory perception (for some people auditory or visual hallucinations of the deceased); preoccupation with the deceased; disruption of normal day-to-day activities; and emotions such as guilt and hostility. His conclusion that the acute symptomatology as well as the grief process could be resolved within four to six weeks, however, has not been borne out by researchers in subsequent studies (Parkes, 1988; Rando, 1986; Weiss, 1988; Wortman & Silver, 1989). Moreover, Shapiro (1994) quotes the case of one survivor of the Coconut Grove fire who, on being interviewed once again about her experience of the fire in 1989, described continued grief and flashbacks.

Shapiro (1994) finds that the initial response to bereavement is overwhelmingly physiological. Symptoms described often refer to a chronic pain located in the chest, and difficulties in breathing and swallowing. Sleep and appetite disturbances are prevalent, as is a decline of the immune response. Initially there is a sense of unreality followed later by a sense of divided consciousness, as there is a refusal to believe the news of the death on one level, though understanding about it on another.

Worden (1988) construes the function of the mourning process as being task orientated. The first task is to accept the reality of the loss. As the searching fails to retrieve the deceased, continued searching behaviour, as described by Bowlby and Parkes (1972) is geared towards the facilitation of this first task. During this time, denial, varying from distortion to full-blown delusion, can persist as a form of protection against the full impact of pain which would result from a fuller acceptance of reality. This can present in various ways such as a denial of the meaning of the loss, selective forgetting or a denial of the irreversibility of the loss.

The second task is to experience the pain of the grief. In this regard, Parkes (1972) contends that where the emotional and behavioural pain of grief is avoided or suppressed, the mourning process is drawn out. Strategies to avoid the pain can be to avoid thinking about it either by thought-stopping or replacing unpleasant thoughts by more pleasant ones such as idealising the deceased. Other strategies involve changing the environment or moving (Worden, 1988).

The third task is to adjust to an environment without the deceased. Having to develop new skills and take on new roles may form part of this task. Friends, relatives or colleagues may feel resentful of the bereaved person, believing that they are refusing to adapt to the loss by promoting their own helplessness. The final task for the bereaved person is to withdraw emotional energy from the deceased and reinvest it in another relationship. Worden (1988) suggests that this may be the most difficult task to achieve, as the prospect of reinvestment can be a frightening one, in the light of the bereaved person's sense of vulnerability to pain following attachment.

According to Davidson (1979) such reorganisation as a phase is characterised by a sense of release from the loss; an objective increase in energy levels; greater ability to make judgements and handle complex issues; improved habits as regards to eating and sleeping. It appears that these characteristics often emerge after about 18 to 24 months, “even though the intensity of the loss is still great and the memories associated with the deceased are still present” (p. 179). He emphasizes these latter features will remain present, and in fact dominate the mourner’s existence for a, “much longer period of time than is commonly believed” (p. 179).

2.2.5.1 Anticipatory Grief

In an expected death, anticipatory grief has an effect on the mourning process subsequent to the death of the child. The term anticipatory grief was conceived of by Lindemann (1944) who found that prior knowledge of the anticipated death can result in mourning prior to the actual death, rather than after it. Worden (1988) suggests that awareness of the impending demise facilitates an acceptance of it, even though this acceptance alternates with denial. Separation anxiety is also common and may be exacerbated by existential anxiety as identification with the dying person causes the soon-to-be-bereaved person to face the fact of their own mortality. The task of adjusting to living without the deceased is rehearsed during this period of anticipation.

While there is agreement that anticipatory grief does have an effect on the mourning process, there does not appear to be consensus as to whether the effects of anticipatory grief are beneficial or detrimental once the bereavement occurs. Walker et al. (1996) found that for caregivers the sense of commitment, loyalty and attachment which is developed during the process of caring for the sick individual, tended to increase the intensity of the post-death grief experience. A further difficulty is that the pace of the mourning process may differ for the patient and family members placing additional strain on their interactions. As different family members are at different developmental stages, with differing needs, may also complicate matters (Boyd-Franklin, Drelich & Schwolsky-Fitch, 1995b). Attig (2000) suggests that anticipatory mourning facilitates learning to balance the pain of missing those who will die with the cherishing of their legacies and memories in lasting love. In this respect he believes that it is a time of transition and one which is not characterised by a premature “letting go” in anticipation of death.

While some researchers have found that anticipatory grief can ease postdeath grief, others have found that it is unrelated to the postdeath grief process (Walker et al., 1996). It is possible that other factors account for these discrepant findings and according to Rando (1986), it would appear that there is optimal period for anticipatory grief of about six to 18 months (Walker et al., 1996). In the case of HIV/AIDS, the course of the illness can last for longer than this period so that some of the possible benefits of the anticipatory grief experience may be nullified.

Boyd-Franklin et al. (1995b) comment on the profound and lengthy experience of anticipatory loss that is experienced by the family members of the person with AIDS. The repugnant physical symptoms and possible progressive neurological or cognitive degeneration of the illness resulting in prolonged deterioration and suffering can cause family members to feel overwhelmed and so withdraw. This may result in intense guilt and depression after the patient's death.

2.2.5.2 Complicated mourning

Since the distinction first made by Freud (Richards,1984) between mourning and melancholia, much of the literature has focussed on attempting to differentiate between “normal” and “abnormal” grief which has been variously called pathological, unresolved, chronic or exaggerated grief. Shapiro (1994) cautions that a review of Freud's work may suggest that Freud's view was influenced by his own personal losses at an historical nexus where the active participation of his three sons in the First World War had caused him to fear that they might have died. After the war "two significant and crushing losses … would affect the remainder of his adult life: the death … of Sofie, the second of his three daughters, … and the death of Hennele," who was Sofie's son (Shapiro, 1994, p.8). Worden (1988) suggests four categories of complicated grief. Prolonged grieving, without the prospect of a satisfactory conclusion is chronic grief. Delayed, inhibited or suppressed grief may occur where a sufficiently significant grief response does not follow at the time of the loss. In this case a later loss may activate the grief of an earlier loss. According to Bowlby (1969), grief of this kind can be triggered by the attempt of the newly bereaved person to seek comfort from an earlier attachment figure, who may have died some time previously. As it is not possible to join with this figure the loss of that attachment is felt afresh. Exaggerated grief is marked by an excessive and disabling reaction to the death which manifests as a phobia centred around death, or irrational despair persisting for an extended period of time. Masked or repressed grief presents as a physical symptom or as aberrant behaviour. In this case, the symptom or the behaviour can be symbolic of the grief reaction, which is suppressed (Worden, 1988). Absent or delayed grief is identified where the usual manifestations of grief are delayed for at least two weeks. The grief itself may be delayed for a substantial period of time, sometimes years, though less serious subsequent experiences of loss may trigger grief responses. Chronic grief is marked by the significant persistence of grief symptoms for a prolonged period. Chronic grief may be preceded by a grief response which is markedly or unusually severe. Worden (1988) conceptualises this as a lack of adjustment to the loss of the loved one and a consequent inability to return to normal living. Inhibited or distorted grief is characterised by an erratic pattern of emotional responses and thoughts. Somatic complaints are common, as is depression, anxiety, hostility, anger and overidentification with the deceased (Catalan, 1995). Raphael and Dobson (2000) report that the incidence of chronic grief occurs in about 9% of a community population of bereaved people. Other criteria have been proposed to identify Complicated Grief Disorder and Traumatic Grief, both of which would confirm the value of attachment theory as separation distress and yearning, are central features of such disorders.

According to Worden (1988) there are various factors which can precipitate complicated grief. The type of relationship that existed between the bereaved person and the deceased can be significant. Ambivalent, narcissistic or highly dependent relationships appear to be difficult to grieve. The circumstances surrounding the loss such as multiple losses, or an unconfirmed death, are factors to be taken into consideration. The personality of the bereaved person and their specific history especially as regards depression, are additional significant determinants. As grief is a social process occurring within the context of a social setting, social factors are also important determinants. Factors which could exacerbate the process include: a lack of social support; a loss that is negated from the perspective of the social setting; and finally a cause of death, such as suicide or AIDS, which may be considered socially unacceptable.

Kalish (1981) agrees that the type of death has a bearing on how difficult it will be for the bereaved to resolve their grief. The following are examples of deaths that are more likely to be complicated:

- Unconfirmed death where no body has been found.
- Homicide.
- Death where the bereaved person feels a sense of responsibility for the death such as drowning or neglect. This may also include those deaths where there is no actual culpability especially in the case of stillbirth, perinatal death or SIDS.
- Suicide or death due to self-neglect and carelessness.
- Untimely death, as in the case of young people, people just married, or people about to achieve something significant.
- Death that required the bereaved person to care for the dying person in a manner that proved to be distressing.
- A drawn out dying process where the survivors become impatient for death to occur.

The last four factors enumerated above would tend to be implicated in the case of the death resulting from an AIDS-related illness.

In another perspective on the impact of multiple losses, Kastenbaum (in Kalish, 1981) suggests that there are two facets to the question of multiple loss which he has termed bereavement overload. Firstly, a single bereavement may signal many other losses, practical and economic as well as emotional. Secondly, where AIDS is concerned, the prevalence of the disease suggests that in one social group or family there may be multiple deaths. Biller and Rice (1990) have examined multiple loss and how it is associated with the progression through grief stages. They suggested that people experiencing multiple loss would vacillate among the grief stages and never establish a pattern of accepting loss because they face another loss in a brief amount of time. This new loss would disrupt the resolution process of the previous loss. Their findings suggested that after each new loss, survivors seemed to further grieve the loss they identified as most significant, as if that particular loss were the only loss. As a result, other losses were not dealt with and resolved. This may result in the outward appearance of acceptance and resolution of the bereavement, but leave them vulnerable to experiencing an overwhelming amount of grief when issues related to those unresolved bereavements are triggered. In addition, Biller and Rice suggested that survivors have a tendency to turn inward, reducing their opportunities for social support and increasing their vulnerability to distress.

2.3 Theories of bereavement

The next section explores the understanding of bereavement which arises from different theoretical frameworks including psychoanalytic approaches, behaviourally and cognitively-based approaches and more recent frameworks based in post-modern and constructivist ideology.

2.3.1 Psychoanalytic approaches

Although an integrated theory of bereavement has not yet been achieved, several theories have attempted to explain this phenomenon. According to Freud (Richards,1984), normal grief is the person's reaction to the loss of a loved one which may be resolved after unspecified time and after serious departures from everyday life. A person's libido is attached (cathected) to the loved object: the beloved person and their loss requires all thoughts about the deceased person to be brought to consciousness in order for the libido to be detached from them (decathected). The mourner's struggle to maintain the original attachment means that completing this grief work, or catharsis, is long, difficult and painful, hence the term 'grief work'. Decathexis ensures that the love object does not offer gratification to the bereaved person any more, and that the libido is freed for investment in a new attachment object.

In his seminal work "Mourning and melancholia", Freud (Richards,1984) differentiated between normal mourning and its pathological counterpart, which was termed 'melancholia'. While melancholia resembles grief, it is initiated by psychological object loss rather than the actual loss of the beloved. The inability or refusal to relinquish the love object may result from narcissistic or ambivalent attachment where the love object is both loved and hated. Remorse, guilt and self-criticism are a way for the ego to express this ambivalence. Although the differentiation between normal and abnormal grief seems to have given rise to a view of grief as an illness, according to Freud, the human psyche is adequately equipped for accomplishing the bereavement process, which is a crucial task, irrespective of its duration. Although the veracity of Freud's definition of grief as a slow and painful process of re-evaluation, almost as an embodiment of the reality of the loss, is self-evident for those who have experienced it, it has led to two unfortunate outcomes. In the first place, it has led to a tendency to see normal grief as pathology, and secondly it perpetuates the erroneous belief that the final (successful) outcome of bereavement is the dissolution of ties to the lost attachment object (Shapiro, 1994). Freud himself reviewed this second belief, as his personal experiences led to the understanding that important attachments cannot be so dissolved. As this was not formalised in later writings, these important revisions tended to be discounted until more recent research highlighted their importance (Shapiro, 1994).

Since Freud, the object relations approach has been a major development in psychoanalytic theory, with the focus on the interpersonal relationships that people develop so that the objects of desire in object relations are people, rather than targets of libidinal drive, as in Freudian theory (Cashdan, 1988). Arguing from an object relations perspective, Rubin (1999) suggests that the internal representations of others, while based in reality, are also influenced by internal object schemata. It is these internal representations that affect the perceptions and interactions of the individual. However, after the death of a person who is significant to the individual, interactions in the real world come to an end as regards any present and future relationship between the bereaved and the deceased. This means that any further interaction with the deceased person moves solely into the realm of the internal world of the bereaved. Secondly, the representation of the deceased in the world of the bereaved person affects their self-perception, affective functioning and psychological well-being. In an effort to manage the internal equilibrium of the individual's self-image, memories and past relationships are continually reworked at both conscious and unconscious levels.

For this reason, Rubin (1999) suggests that it is not sufficient to look at function, and that the quality of the recollected and remembered relationship with the deceased must also be acknowledged. In the Two-track model of bereavement posited by Rubin (1981), the bereaved person's functioning is taken into account, as well as the nature of the continuing attachment to the deceased, thus separating the analysis of personality function from the object detachment aspect of the bereavement process. Aspects of the continuing relationship with the deceased that must be considered include: imagery and memory; emotional distance; positive and negative feelings in respect of the deceased; preoccupation with loss; idealisation; conflict; shock; searching; disorganisation and reorganisation. The goal for true recovery from bereavement thus requires a new integration of the internalised relationship of the bereaved person with the deceased. This relationship continues to exist as a valuable inner resource, though not detracting from the capacity of the bereaved to establish or continue other relationships with the living.

According to Bowlby (1969) grief is essentially separation anxiety following on an unwanted separation from an attachment figure and follows on his work that examines childhood separation responses. In the case of children, a threat of separation from the caretaker or mother evokes a range of responses, the most common of which are crying, protest and searching for the lost attachment figure. The magnitude of this reaction depends on the potential for loss in the situation. Attachments form in respect of specific others, and last for a large part of a person's life. These bonds, or attachments, develop early in life and are a consequence of a need for safety and security. The goal of attachment behaviour is the maintenance of the attachment bond between the individual and specific others and in an evolutionary sense, it has survival value. According to Worden (1988), there is evidence to support the contention that all human beings grieve loss in an effort to be reunited with their attachment object.

Shapiro (1994) suggests that, for adults, cognition in the early phase of bereavement may be reminiscent of a more child-like response. In the initial period of grief which is characterised by disbelief, denial and protest are sustained by searching for a cause to explain the death: "It is as if they are reasoning that knowing exactly what happened can somehow, magically, enable them to take the moment back and create new circumstances in which the death is averted" (Shapiro, 1994, p. 35). This magical, concrete and self-blaming conceptualisation of the cause of death can persist even as the reality of the death becomes clearer.

The same principle underlies attachment bonds to spouses and children, hence the similarity of the grief reactions as evidenced by adults to the reaction to separation experienced by children (Bowlby, 1969). Initially there is brief period of protest at the separation, before searching behaviour occurs. As the individual realises that these fail at restoring the lost attachment figure, despair and depression follow. When considered in the context of the grief process, he maintains that separation does not signify an end to the relationship with the deceased person, and that part of the task of restructuring is to include a sense of the deceased person into the sense of self. Indeed, there is a phase of reorganisation during which time the individual restructures their situation in a cognitive sense.

Bowlby suggests, and Weiss (1988, p. 43) agrees, that "all the emotional systems underlying the attachment relationships of adult life will eventually be shown, to be derived from the emotional system underlying attachment in children." Weiss notes that grief does not necessarily follow every loss experienced by a person. For instance, the loss of a colleague may evoke sadness and a sense of diminished community, but will not result in the protracted distress of grief which is characterised by numb disbelief, searching and pining, and depression. The characteristics of those relationships which tend to produce grief reactions by their loss, are those where:

- The presence or availability of the attachment figure fosters a sense of security.
- If the attachment figure is not present or available, a belief of being reunited with the attachment figure can also foster a sense of security.
- Conditions of threat or danger cause the attachment feelings and behaviours to emerge.
- If reassuring contact cannot be re-established separation distress follows. This is characterised by searching behaviour, a sense of apprehension and anxiety, as well as vigilance and an inability to focus on other matters.
- The attachment figure is unique and it is not possible to substitute someone else for them.
- The distress following separation cannot be removed through strategies such as distraction, as it is not under conscious control.
- Attachment to specific people does not diminish with habituation.
- Attachment persists regardless of the nature of the experience of relationship wih the attachment figure.

In common with Freud's theory, Bowlby's attachment theory (1969) is also a cathexis theory, demonstrating how the childhood bond plays a crucial role in later relationships and stressing the instinctual and congenital aspects of the grief process. In a marked departure from Freud however, Bowlby contends that mourning is not a pathological process (unless it is suppressed or delayed) and that the relationship with the deceased does not cease in healthy bereavement. Moreover, the continued sense of presence of the deceased is of comfort to the bereaved person and is helpful in the cognitive restructuring of the life of the bereaved person.

2.3.2 Stage and phase theories of bereavement

Bowlby (1969) proposed four stages of mourning: numbness, yearning and searching, disorganisation and despair, and reorganisation. Numbness may last for a variable period of time, followed by a period of intense sadness. During this emotional time there may be feelings of rage, guilt and anger particularly where the relationship that has ended was ambivalent. Searching behaviour is also prevalent during this period that may last for periods of up to some years. The stage of disorganisation and despair is characterised by a sense of meaninglessness and a sense that life is not worth living. The detachment phase of separation, characterised by an acceptance of the loss and investment in new attachments, is echoed in the final phase of mourning which is termed the reorganisation phase. Mourning ceremonies and rituals can facilitate the process by drawing in support from the community.

In a model influenced by Bowlby, Parkes (1972) also suggests four stages: shock, protest, despair followed by a long period of adaptation. The phase of shock offers a temporary moratorium from the pain of the loss and buffers the individual from experiencing the full impact of it. During the protest phase, the bereaved person attempts to 'retrieve' the deceased through a kind of “magical thinking” (if only something else had or had not been done or happened). It is an intensely painful phase where the bereaved individual also experiences fear and anxiety with episodic bouts of panic.

The urge to search for the lost attachment figure can be understood in terms of the attachment feelings which are activated by the loss. The pain is exacerbated through understanding that it is impossible to find the attachment object and this leads to a sense of despair, which is characterised by withdrawal and depression. Although the sequence of phases is generally in the order described above, this is not incontrovertibly the case.

Adaptation is characterised by cognitive and emotional acceptance of the bereavement and a change of identity. Central to the cognitive acceptance is that an individual develops a subjective understanding of the events surrounding the loss. Through a process of re-visiting the memories of the deceased, the emotionality associated with these memories is reduced to a level where the person is able to function without being overwhelmed by pain. Identity change requires that an individual develop a new understanding or image of themselves in a different relationship to the attachment figure. According to Weiss (1988) this aspect of recovery seems more difficult after the death of a child than after other significant losses, including loss of a spouse. Kübler-Ross (1974) in her research of the dying has proposed a model which roughly follows the same pattern as those proposed by Bowlby and Parkes. Five stages are posited in this model: denial, anger, bargaining, depression and acceptance.

As in many of the later psycho-analytic approaches to bereavement, the idea that grief is determined by intrapsychic processes remains a central tenet in these models. In the models proposed by Bowlby and Parkes (1972), cognitive functioning and goal-orientedness in adaptation are stressed. According to Parkes (1972), the restructuring that occurs during the grief process enables the bereaved person to re-acquire a sense of control over life so that recovery from bereavement is marked by the attainment of a new level of functioning. As in Bowlby's approach, the theory is to some extent cathartic and views grief as separation anxiety. The model is a medical one and attempts to classify grief in terms of a medical diagnosis. A number of other stage or phase theories have been proposed which share a number of common features with the earlier models. Zisook and DeVaul (1985) describe three stages of grief and the symptoms of typical grief as comprising:

- An initial period of shock, disbelief and denial. This stage is characterised by sighing and sobbing, tightness in the throat, a shortness of breath, an empty feeling in the abdomen, fatigue and restlessness with aimless activity and exhaustion, weakness and a sense of sorrow.
- An intermediate acute mourning period of acute physical and emotional discomfort coupled with social withdrawal. This stage is characterised by anger and irritability, an emotional distancing from people, avoidance of friends and/or work.

- A period of resolution where the attention of the bereaved person begins to return to the world around them once more.

In the phase model proposed by Rando (1993), the goal of the grief process is to adapt to the loss. In the avoidance phase the aim is the recognition of the loss which entails acknowledging that the death has occurred. The confrontation phase follows, characterised by the experience and expression of the psychological reactions to the loss and the identification of secondary losses. Other elements of this phase are remembering and re-experiencing the relationship with the deceased, and the letting go of the old attachment to the deceased and the old assumptive world. In the accommodation phase, readjustment is marked by an adaptive move into the new world that does not forget the old, and areinvestment in new relationship. Rando’s approach describes clearly the dynamic aspects as revealed in fluctuations of emotions and Cheadle (1998) suggests that this conceptualisation of grief could be enhanced through the incorporation of cybernetic principles. This could be achieved through the inclusion of description of loss as punctuation, through the drawing of descriptive distinctions of the experience and through the revelation of the stability/change dynamic. Thus it would demonstrate how the parent moves a new stability forming a new identity which takes into account the changes in the assumptive world.

However, since the extended period of ascendancy of stage or phase models of bereavement, Wortman and Silver, (1989) have questioned their value and usefulness as very little evidence has been found to support this thesis in empirical research (Cleiren, 1991). Braun and Berg (1994) also believe that stage models are inappropriate for bereaved parents as they fail to account for the lasting difficulty that some parents experience in the area of finding meaning in their child's death. This suggests that defining recovery as a return to a pre-loss state is inappropriate. A further criticisms of stage theories of bereavement is that they have led, paradoxically, to another form of depersonalisation where bereaved people who are believed to have *regressed* to an earlier stage are evaluated negatively as suffering from abnormal or pathological grief.

A more contemporary view, regards stage or phase models of bereavement as descriptive heuristic tools, rather than prescriptive rules (Stroebe, Van den Bout & Schut, 1994). According to this view, grief can be understood more as a process where the early experience differs from that later on. Recovery can last an unspecified amount of time, although the intensity of the grief typically gradually diminishes. Feelings of grief may surface even years later in response to cues or stressful situations. The concept of recovery has also been questioned. Weiss (1988), for instance, suggests that a more correct terminology would be to refer to 'adaptation' or 'accommodation', rather than seeing an end-point to bereavement.

Most recently, the zeitgeist of the era has signalled a move away from the standard normative psychoanalytic model of mourning, to one that incorporates elements from current thinking and reflects the conclusions drawn from research over three-quarters of a century. Hagman (2001) suggests that the psychoanalytic model has largely been replaced by one that incorporates the role of relationships and meaning. The role of the analyst too has transformed from the observer and researcher to a more interpretive participatory role. Hagman suggests that this move is so significant as to constitute a “paradigm shift” (p. 20) and is characterised by an understanding which is unique and idiosyncratic. This then has significant implications regarding evaluations of normality and pathology. In the traditional model the goal of mourning was decathexis or the relinquishing of the attachment to the beloved. However the current focus is on the process of meaning reconstruction and in this context even pathological grief may be evidence of such a process. Finally the intersubjective nature of the process is given due importance and pathology may be symptomatic of the failure of a community rather than the individual.

2.3.3 Behaviourally and cognitively-based approaches

In contrast with the psychoanalytically-oriented models, behaviourally-oriented theories tend to view grief as a natural phenomenon which can be reinforced or inhibited by external stimuli rather than by intrapsychic processes. Their approach is characterised by a more clinical viewpoint with a focus on abnormal or pathological grief processes and intervention strategies. Empirical evidence for these approaches, however, is also limited (Corr, 1979a). Ramsay (in Cleiren, 1991), a proponent of this approach has emphasised the role of reinforcement, and environmental factors such as social support. Gauthier and Marshall (in Cleiren, 1991) have also stressed the importance of social environment in conjunction with disposition, abruptness of the loss and its significance to the bereaved person.

Crisis theory (Moos & Schaefer, 1986) has been shaped by various approaches that attempt to provide an understanding of life crises: evolutionary theory; psychoanalytic concepts about personal fulfilment and growth; a developmental life-cycle perspective and information on the process of coping. It examines the general determinants of outcome of a"situation so major that habitual responses are not sufficient" (Moos & Schaefer, 1986, p. 6). Crises provide the momentum to develop new cognitive and personal skills in order to ensure effective adaptation and as such may be an essential condition for psychological development. Five major adaptive tasks have been identified in managing a crisis:

- To establish the meaning of the situation and to understand the personal significance of the situation. After the initial stage of shock and confusion, the individual is faced with assimilating the event and its aftermath. In the case of death, there is a need to accept the loss intellectually, and also to explain it;
- To confront reality and respond to the requirements of the external situation;
- To sustain relationships with family members, friends and others who can be of assistance in resolving the crisis and its aftermath. It is paradoxically at precisely the time when the support of close personal relationships is most necessary as a source of emotional support in a period of crisis, that it can be most difficult to achieve this and find or maintain such relationships;
- To preserve a reasonable emotional balance by managing upsetting feelings aroused by the situation. Guilt, a sense of failure, self-blame and anger are common emotions following the death of a child. The ability to sustain hope is important in coping with depression;
- To preserve a satisfactory self-image and maintain a sense of competence and mastery. Changes in the life circumstances of the individual must be assimilated so as to produce a revised self-image. This 'identity crisis' may require a shift in behaviour or values. Rando (1983) found that the best coping styles of bereaved parents were active and externally directed and comprised altruism or altruistic activities.

A variety of emotions is experienced when facing a crisis, and the attribution of meaning follows later in the experience. As Moos & Schaefer (1986) notes, some crises are more challenging than others, and the death of a child is one of the most profound losses because of the unique parent-child bond.

Janoff-Bulman (1992) reflects that the bereaved or traumatised person fluctuates between denial and emotional numbing and the recalling of the events with the emotional re-experiencing of the trauma. The function of denial is to minimise the threat inherent in the event which is so severe that it brings about a shutting-down of the cognitive emotional system so that day-to-day coping is able to continue enabling individuals to manage the pace of the process. She contends that this concept is borne out empirically as the denial lessens as the event recedes into the past. This is distinct from the kind of denial which can be regarded as a form of dissociation such as amnesia with regard to the traumatising event. In these cases although the event is kept out of the conscious realm, the individual continues to react to new stress in a way which reflects the experience of the trauma. It would seem therefore that the cognitive processing the traumatic event is also an important aspect of recovery and important in the construction of new schemas or world-views that are able to accommodate the traumatic event. Klass (1993) agrees that the modification of worldviews is a major component of grieving and suggests that it provides a link between a parent and child that supports the sense of meaningfulness that existed in the relationship prior to the death. The goal of such modification is to provide a continuation in this sense of meaningfulness despite the death.

The central question inherent in the salutogenic perspective posited by Antonovsky (1979), is to establish that which enables people to recover from stress and not to succumb to extreme strain. Antonovsky criticised the basic assumption of the biomedical model where disease is viewed as a deviation from health. According to this model, pathogenic conditions and agents must be identified, and the aim of therapeutic intervention is to eliminate them. The salutogenic approach endeavours to strengthen resources in order to make the organism more resilient and more able to resist weakening influences. Within this paradigm, health and illness are opposite ends of a continuum, so that even a high level of health contains a measure of ill-health, and vice versa. While external events, such as the experience of trauma can be detrimental to health, different individuals respond differently to these events in terms of health and coping. A major role is played by the cognitive and affective-motivational outlook of the individual, as this determines the extent to which the individual is able to utilise available resources to maintain well-being. This outlook is termed the sense of coherence and it includes the sense of consistency, congruence and harmony. It encompasses a, "feeling of confidence that one's internal and external environments are predictable and that there is a high probability that things will work out as well as can reasonably be expected" (Antonovsky, 1979, p. 10). The three dimensions of experiencing the world as coherent and meaningful are:

- The sense of comprehensibility. This refers to a cognitive processing pattern and means that stimuli are experienced as ordered, consistent and structured, irrespective of whether they are familiar or not. This dimension is formed through experiences of consistency in life which reinforce the understanding that experiences can be classified and structured in an orderly fashion.
- The sense of manageability. This refers to a cognitive-emotional processing style and includes the individual's belief that difficulties can be solved as a result of using either one's own or other resources and competencies as required. The sense of manageability develops through experiencing balanced strain, and avoiding both overload and underload.
- The sense of meaningfulness. This refers to the extent to which the individual experiences life as making sense when seen from an emotional point of view, such as whether tasks are viewed as challenges or are seen as burdens. This motivational component is considered the most significant of the three as it determines whether or not an experience will have a high sense of coherence. The feeling of having influence on the outcome of events fosters a sense of meaningfulness (Antonovsky, 1979).

Bengel, Strittmatter and Willmann (1999) conclude that the sense of coherence is dynamic because it is affected by life experiences, and also influences the kind of life experiences that will be encountered. A well-defined sense of coherence facilitates flexibility in meeting life demands (as opposed to rigidity) so that the coping strategy that is selected by the individual will be the most appropriate one for dealing with the stressor that confronts the individual. Another contributory element to the sense of coherence is the dynamic feeling of confidence that the outcome of events will in all likelihood be good or for the best. They suggest that the strength of the sense of coherence determines whether a stimulus is defined by the individual as a stressor or not. Once a stressor is detected, it can be differentiated as either a favourable or an irrelevant one, which leads to a diminution of tension without the use of resources, or it can be defined as threatening. Even tension-engendering stressors will not be threatening if the individual's sense of coherence is strong because of their belief that the situation will resolve itself. However, where the sense of coherence is weak, individuals tend to react with diffuse emotions (such as rage) that are difficult to control. Their lack of confidence in their ability to resolve the situation tends to immobilise them (Bengel, Strittmatter & Willmann, 1999).

The variables that facilitate successful coping with tension are termed Generalised Resistance Resources (GRRs). These include individual factors such as intelligence, social factors such as social support as well as cultural factors such as cultural stability. They can be effective in many different situations (Generalised) and function as potentialities which are activated during a state of tension. They increase resistance by helping the individual make sense of the stressors which assail him or her. This quality makes life experiences coherent and this forms the basis for the individual sense of coherence. As is the case for the health-illness dichotomy, it is possible to consider resistance resources and resistance deficits as poles on a continuum with the negative pole representing those experiences that weaken the sense of coherence, and the positive pole representing those experiences that strengthen the sense of coherence (Antonovsky, 1979). While losing a child is always a significant stressor, the effect of the sense of coherence in managing the subjective experience of the bereaved individual is significant as it can provide buffers and mobilise resources, enabling the bereaved parent to make choices that promote health. The sense of coherence also acts as a filter in information processing, and thus plays a central role in the way the individual assigns meaning to the experience, which is a significant contributor to coping with an event of this magnitude.

Tedeschi and Calhoun (1995) have enumerated the themes common to those who cope with loss in a creative way. These include, "a willingness to take up challenges and a persistently active approach to experiences and problem solving" (p. 55). The proviso to this is that this approach should be balanced by flexibility and a realistic awareness of personal limitations. The relationship between the personal characteristic and effective coping not clear cut, however, it appears that growth is more likely for those people who are resilient, optimistic, hardy and adaptable.

Updegraff and Taylor (2000), in a review of coping styles, have grouped these into three categories: active coping, acceptance and positive reinterpretation and avoidance coping. Active coping strategies seek to resolve a problem and reduce the effects of the stressor. In acceptance and positive reinterpretation, while the stressor is viewed as both true and inescapable, there is an attempt to connote it positively. In avoidance coping the stressor itself is either avoided or denied, although the pernicious aspects of the situation are unchanged. In situations that are subject to modification, active coping styles may be the most effective, but in the case of loss of a child, the situation essentially cannot be modified. In these cases, Updegraff and Taylor (2000) contend that acceptance and positive reinterpretaiton may be more effective and become a significant predictor of growth subsequent to stress and may contribute to the development of a sense of finding benefit. Avoidance coping may be paradoxically linked to better coping for a short term stressor, but in response to a longer-term stressor appear to be associated with distress and unsettling cycling through intrusive thoughts and avoidance. Updegraff and Taylor (2000) have also examined the role of optimism in adjustment to stressful life experience when combined with an accepting coping style with reinterpretation. This combination is associated with better adjustment, greater growth and fewer symptoms. Pessimism tends to be associated with less adaptive coping style and greater vulnerability to stressful life experiences, and with greater levels of both physical and psychological symptoms such as distress and depression, as well as maladaptive cycles of avoidance and intrusion.

There is evidentiary support for the notion that talking about the event, whether to self or other, while bringing about distress at the time of doing so, is associated with better long-term health outcomes (Pennebaker, Hughes & O'Heeron, 1986). It is postulated that disclosure reduces long-term stress-related disease by inhibiting the short-term autonomic activity precipitated by the active inhibition of denial. At the same time, transforming the experience in a linguistic sense may make it understandable, and sets limits to it, as can be seen in the fact that while it is possible to replay an event in one's mind countless times, it is not possible to recount it repeatedly to the same person. Rather than as viewing this behaviour as an abnormal set of responses, Janoff-Bulman (1992) posits that it is important to view it as an adaptive effort that seeks to facilitate recovery with the individual alternating between a need for protection and the need to process the event conceptually. Seemingly in contrast to this, Bonanno, Holen, Keltner and Horowitz (1995) note that findings support the theory that emotional avoidance during bereavement may serve adaptive functions. Emotional avoidance is defined as an emotion-focussed process directed at the dissociation of awareness of distress related to the loss. It is therefore possible that there needs to be a balance between the two positions, where a measure of disclosure is followed by emotional avoidance. In a similar vein, Keltner and Bonanno (McBroom, 1997) believe that the experiencing of positive emotions such as amusement, love, compassion, pride and desire provides an important path out of trauma. In particular, laughter can contribute to the creation of meaning and positive transformation. This does not mean denying negative emotions, but rather being able to set them aside for a while in order to have a brief respite from the pain. They conclude from their research that those grievers who are able to do this have a better outcome later. They conjecture that the positive effects from laughter could also result from the social bonding that it facilitates because other people are drawn to laughter and it is this which could provide greater levels of support for the bereaved.

2.3.4 A move away from traditional theoretical frameworks

Satel (1999) remarks on how grief has been transformed almost into a commodity, with phrases such as "working through it" and "getting closure" being common currency. She suggests that all the theories of grief and grief work have spawned a Grief Industry, equipped with its own texts and prescriptions. Other researchers have also questioned the validity of traditional theoretical frameworks in understanding the grief process: Harvey and Miller (2000), Nolen-Hoeksema, McBride and Larson (1997), Stroebe and Stroebe (1991) as well as Wortman and Silver (1989) have all failed to find evidentiary support for traditional perspectives on grief and loss. In spite of this, understanding based in these traditional approaches continues to form a basis for training of therapists and counsellors in the field.

2.3.5 Post-modern and constructivist approaches

Neimeyer (2001a) argues that the accumulation of evidence from clinicians who have worked in this field is in direct contradiction of the Freudian perspective. Instead, he believes that the evidence gathered fits more accurately the post-modern perspective which gives due importance to the power of subjectivity in the lives of people. He suggests therefore, that as a result of this evidence, a paradigm shift is occurring among practitioners and theorists within this field, and that this shift mirrors the profound alteration of worldview that the bereaved individual experiences in making sense of the loss.

Neimeyer (1998) also challenges the notion that resolution of grief is signalled by letting go of the deceased. Neimeyer uses a constructivist approach which takes into account of individual dynamics in the way people find significance in their loss. Hence grieving is viewed as a process of, "relearning the world in the wake of loss" (Russel, 2002, p. 110). Grief theory should be unique to each bereaved individual, with each individual seen as an active agent in the shaping of their world. This view of grief suggests that grief is essentially a process of meaning reconstruction and narrative revision. According to him, "meaning reconstruction in response to a loss is the central process in grieving" (p. 110). Three phases: avoidance, assimilation and accommodation are conceptualised as typical of a life-long grief-cycle. Prescriptive definitions that would classify any deviations as pathological are shunned. Instead, the rich description of experience, with personal and social meaning being central to the process, is preferred to prescription. In contrast to traditional stage or phase models, Neimeyer concludes that it is not time in itself that assists the bereaved person, but rather what the bereaved person does with the time. Talbot (1996) in a study of mothers who have lost their only child, finds that because motherhood becomes an integral aspect of the construct of self, to survive after such a loss, it is necessary to find a means to not relinquish this construct through a continued relationship with the child.

The act of retelling the story is a social one and through it the bereaved can step out of the isolation of grief. In this sense it can be understood as a dialectical challenge to balance the need to focus inward and the need to restore social connection. Through personal and communal rituals there is a possibility of self-transformation, as well as the conversion of the relationship between the bereaved person and their social world with the deceased to one where an ongoing connection to the deceased is possible. Grieving, then, is understood as a process of reconstructing the world of meaning and the relearning of the self (Neimeyer, 1998).

Rosenblatt (2000) concurs that evaluating bereaved people in terms of pathology can blind the researcher to the way that bereaved parents find healing. Instead he has considered the narratives of bereaved parents finding that these reflect the significant themes of the experience. Common domains in the narrative include the dying process, the actual death, funerary rituals, religions and relationships. Areas that do not appear to become domains are the larger societal context of the death or relating the death or experience to current events. Apart from the common domains mentioned above, a chasm appears to form between the bereaved parents, the world as it was, and the world around them, originating from the devastating feelings experienced by the bereaved parents and the fragmentation and anonymity of society which means that few other people in society even know about the death. How to deal with this chasm constitutes a large part of what is said by bereaved parents.

Organising the narrative into a limited number of domains seems to promote a sense that it is possible to make sense of the event. Another explanation is that the number of culturally dominant domains offer a rhetoric which is meaningful and shared by others in constructing a reality that gives a sense of validity for themselves and others around them. In this respect then, these narratives are a product of the culture and time in which they are embedded. A grief theory is itself a narrative offering a low level empirical generalisation which does not account for the depth of the subjective experience.

According to Neimeyer (2001a) new and constructivist approaches to bereavement are characterised by their rejection of a universal pattern of a predictable responses to loss and of cathexis models of loss. Hence there is a greater appreciation of the individuality and complexity of adaptive responses and for the value of continued connection to the deceased in symbolic form. Such an understanding may necessitate a greater appreciation of grief as precipitating a modification to the bereaved person’s sense of self and identity because the responses of significant others act as a mirror that provides verification for the self-narrative of the person. The loss of such a significant other may leave a vacuum that the bereaved person is obliged to fill in other ways, by seeking out new listeners to mirror back the new self-narratives as they evolve (Neimeyer, 2001c). For instance, the individual may integrate the loss through seeing it as a contribution to personal growth (Neimeyer, 2001a).

2.3.6 Towards an integrated approach

Although there is at present no model of bereavement which fully integrates these different aspects, attempts are being made towards this end. In attempting to develop a more integrative approach to bereavement, Bonanno and Kaltman (1999) have taken into account four perspectives which currently inform research in this area. These include the attachment models, cognitive stress approaches, the social-function and trauma perspectives. The focus has been on those elements within these approaches which have evidentiary support such as, “contextual factors, the continuum of subjective meaning, the changing representations of the lost relationship and the regulation of coping and emotion” (Bonanno & Kaltman, 1999, p. 771). They conclude that this process is less like the grief work model, but rather it is an attempt to evolve a way of living subsequent to the bereavement, where this would cover the full spectrum of existence, as indeed is the case for life in general.

2.4 Psychosocial determinants of grief

This section will attempt to understand how various specific factors, such as the relationship of the bereaved person to the deceased, the circumstances surrounding the death, personal attributes and coping skills affect the process of bereavement.

Beginning with Parkes, there have been various attempts to determine the personal or other psychosocial factors that influence grief (Rando, 1984; Sanders, 1988; Worden, 1988). The Harvard Bereavement Study (Parkes, 1972) was one such attempt to identify the significant determinants of the grief process. As a result of these studies a number of factors were examined including the relationship to the deceased, circumstances surrounding the loss, personal characteristics and types of coping skills. Two important factors serve to differentiate Parkes' theory and highlight the psychosocial aspect of bereavement. Stigma refers to the attitude of society to the bereaved person, while deprivation refers to the absence of those psychological benefits which the deceased had provided to the bereaved person during their lifetime. These factors also play a significant part in the overall outcome of the grief process. Recognition of these psychosocial factors can be important when providing therapeutic intervention to parents as they may exacerbate the intensity of the grief process.

2.4.1 Relationship of the deceased to the bereaved person

The degree of consanguinity between the deceased and the bereaved is a significant determinant of the grief process, so that the death of an acquaintance or work colleague is grieved less intensely than the death of a close family member. According to Arnold and Gemma (1994, p. 9), "the loss of a child is a loss like none other [because it] signifies the loss of the future, of hopes and dreams, of new strength and of perfection." For this reason the loss of a child is believed to be the most difficult and significant adult bereavement (Arnold & Gemma, 1994; Cleiren, 1991; Rando, 1986; Sanders, 1988). Schwab (1990) notes that parents insist that the grief experienced on the loss of a child is unlike any previous loss, although many may have experienced other losses, such as that of their own parents. Moreover many initially report that they believe they would not be able to survive such a loss. Middleton, Raphael, Burnett and Martinek (1998) in a comparative study between bereaved spouses, adult children and parents found that bereaved parents exhibit a greater and more intense grief reaction than bereaved spouses whose reaction was more intense than that of adult children losing a spouse. Leahy (1992) similarly noted this amongst bereaved mothers.

Rando (1986, p. xiii) cautions that, "the traditional critera commonly used for identifying and classifying pathological grief are themselves normal components of parental bereavement and so cannot be used to detect abnormality within parental bereavement." This is a conclusion drawn from empirical studies and should serve to assist clinicians in their assessments of bereaved parents. According to Arnold and Gemma (1994) it highlights the importance of understanding the subjective experience of such a bereavement.

The nature of the relationship is also important as regards the strength and security of the attachment. A relationship characterised by a small degree of attachment is easier to grieve than one characterised by a greater degree of attachment. According to Rando (1984) the type of role which the dead child filled and the function that they performed in relation to the bereaved, will be transformed after the death into important symbolic secondary losses, which also need to be identified and grieved. Another factor influencing the grief reaction is the amount of "unfinished business" in the relationship between the child and the parent which are the issues that were never addressed or settled during the lifetime of the child. Where the relationship is highly ambivalent, there may be a great deal of guilt and anger (Rando, 1984). Where the relationship between parent and child had broken down prior to the death, there can be a sense of regret for the lost opportunities and the future loss of the possibility to re-establish a warmer relationship. Bowen (1978) notes that where the family is fused, family triangulation is common which implies some level of undifferentiation. The lower the level of differentiation, the more difficult becomes the process of separation. Where the relationship with the deceased had been characterised by anger or alienation, it may be difficult to acknowledge this aspect subsequent to the death (Kander, 1990).

The relationship with the child is one of the major constellations of meaning for the parent. Consequently the death of a child creates a major disequilibrium in the psychic structure of the parent which requires complex reorganization. The characteristics of the living relationship are part of the search for equilibrium after the death of the child. For instance, where the child is an inner representation of another relationship, the energy from that relationship is also invested in the relationship with the child (Klass, 1988). If the inner representations of the child within the parental psyche have a conflicted relationship, the task of separating these inner representations from one another may require purging the representation of stressful memories so that the representation can be an idealised one (Klass, 1988).

The unique constellation of characteristics which are joined in a specific child can make certain aspects of the grief more difficult. Death of an only child equates to loss of the parent's role as parent (Kander, 1990). Role or gender-identification may establish a particular bond between child and parent, making the loss of the child a central loss. The loss of an only son or daughter can also result in a particular sense of loss. Losing a child who is handicapped can leave the parent feeling relieved or ambivalent, which may exacerbate feelings of guilt. Twinship has particular dynamics and so has the grief experience as the parent has to adjust to having one child, with all the concomitant anxiety about the possibility of losing the surviving twin, at a time when it is perhaps expected that having a surviving child ought to provide a measure of solace. If the deceased child is an adult, the death severs a long-established relationship with many degrees of interconnectedness even though some appropriate separateness had been achieved prior to the death as a result of the child's independence (Kander, 1990).

2.4.2 Circumstances surrounding the loss

Some deaths are more 'appropriate' than others such as that of an elderly person whose death is expected. Worden (1988) suggests that accidental deaths may increase feelings of helplessness which expresses itself as anger and blame. Sudden deaths may be associated with greater difficulties as may deaths which occur at a removed locality. Calhoun and Tedeschi (2001) have found that bereaved parents had greater difficulties adjusting to the loss when the cause of death was suicide, when the death was unexpected and sudden and when there are no surviving children. Research by Brotherson (2000) confirms that the circumstances surrounding the death of a child have a significant impact on the nature of the grief experience of the parents.

Sudden, violent deaths such as through homicide and suicide which by their nature have a traumatic element, have also shown to have a very slow rate of reduction in distress over time, irrespective of intervention. This manifests as higher mental distress and greater trauma, concomitant with lesser loss accommodation and poorer physical health (Murphy, 1997). According to Séguin, Lesage and Kiely (1995), parents of suicide victims experience greater feelings of shame and are more depressed than those whose children died in car accidents in the first period after the loss. Later, however, this difference tends to disappear. Guilt experiences also tend to be more marked in these parents than in those where their children died as a result of an accident or chronic disease (Miles & Demi, 1991). Trolley (1993) posits that the sudden loss of a child especially as a result of suicide may impose a lifelong sentence of suffering for bereaved parents, who find it almost inconceivable to reach out for help.

Other deaths that present difficulty are those that occur at critical life junctures of people, deaths which cannot be blamed on others, and deaths which evoke a sense of loss of control (Tedeschi & Calhoun, 1995). Bailley, Kral and Dunham (1999) confirm that where the cause of death is suicide, the bereaved experience more frequent feelings of rejection, responsibility and more total grief reactions which they link to the increased levels of shame and perceived stigmatisation associated with such a mode of death. When the outcome of an event cannot be altered such as occurs with a death, control is out of reach. The survivor is then faced with altering the meaning of the situation and their emotional response to it (Moos & Schaefer, 1986).

Holmes and Rahe (1967) have hypothesised regarding the cumulative effect of losses and their “Schedule of recent experience” is geared towards being able to calculate the effect of losses that follow each other within a short space of time. However, Worden (1988) comments that this has not been borne out in research, possibly because different events are understood differently by people.

Neugarten (1968) has proposed an interpretation in terms of a life events framework. According to this, it is important to understand how the sociohistorical context influences the timing of important life events. In terms of such a context, it is easier to cope with an event if others in the cohort of the affected individual are experiencing similar events. Where events have strong correlation to age, the person is able to anticipate the development of coping strategies that may help to alleviate some of the expected stresses. Conversely, an idiosyncratic event has a low probability of occurring so that there is little preparation for it psychologically. In this respect, it is easier to cope with the loss of an elderly parent than of an offspring.

An AIDS-related illness as a cause of death, may not be idiosyncratic in terms of the sociohistorical context pertaining in South Africa at the present time, however, according to Kelley (1997) the following factors tend to complicate the grief:

- The experience of suffering a multiplicity of losses such as the deaths of others in the community, loss of health or employment and a subsequent lowering of economic status;
- The age of the deceased, which in the case of AIDS sufferers tends to be young;
- Distressing symptoms such as pain, or disfigurement;
- Difficult treatments which cause the infected person to struggle or suffer;
- Social isolation resulting from a fear of contamination and the stigma attaching to the illness.

In addition to the above, bereavement overload may result in a reduction of funerary or other rituals which are costly or time-consuming due to insufficient resources. Many communities now lack the human and material resources to bury their dead according to culturally prescribed mourning rituals, which historically allowed community members to grieve their losses deeply and meaningfully.

Stamm (1999) points out that there has been a notable shift in the understanding of a traumatic stress with the focus now on the interaction between the event and the person who experiences it at the most inclusive level. Many experiences of bereavement, as described in Section 2.2, resemble those of stress reactions or Post-traumatic Stress Disorder (PTSD). In a study by Oliver and Fallat (1995) to assess the prevalence of pathologic grieving in parents after a traumatic death of a child, grieving tended to be pathologic where there was a lack of a support network beyond the extended family, where an avoidant stance to grieving was employed and where God was viewed as distant and punitive. Figley (1995) has differentiated between a traumatic stress reaction, which implies that the event provokes a reworking of one's fundamental belief system, and traumatic stress disorder, where the demands elicited by the stressful event exceed personal resources thus resulting in pathology. PTSD can then be understood as one type of traumatic stress disorder where the bereaved person suffers, "a self-loss, a wound to one's identity and damage to other parts of one's self-theory" (Hyer & Brandsma, 1999, p. 131). According to Neimeyer (2001b) traumatic losses, which include deaths resulting from violence, disfiguring deaths or deaths at an inappropriate life-stage, are characterised by, “a chronically hyper-aroused limbic system and susceptibility to intrusive memories alternating with attempted avoidance”. As a result of the high arousal surrounding the circumstances when these memories are formed, they tend to couple the overwhelming affective state, such as overwhelming fear, guilt or anger to the event. A “re-programming” of trauma cues as neutral events can occur through revealing the associations which make them traumatic, and through a gradual reconstruction of the event in meaning terms. As has also been posited by Tedeschi and Calhoun (1995) trauma can not only be healed, but it can lead to a transformation resulting in growth if the self-schema is changed in order to accommodate the traumatic event. This transformation occurs once the person is able to recognise some good arising from this event.

Janoff-Bulman and Berger (2000) concur, and note the effect of a “psychological immune system” that attempts to create value in the life of survivors of trauma. Whilst the negative effects of trauma and loss have been well-documented, negative effects in survivors tend to co-exist with other more positive effects. An increase in appreciation, defined as a perception of increased value from a psychological perspective, is commonly reported. This applies to greater appreciation of others, self and life itself and these domains form a counterpoint to the shattering of three basic assumptions of the world as postulated by Janoff-Bulman (1992). These assume that the world is benevolent, that the self is worthy and that the world is meaningful. In terms of these assumptions the meaning of life rests on issues around control and comprehensibility which is shattered by the experience of trauma by making the trauma survivor acutely aware of personal vulnerability to random events. In contrast, after trauma, the meaning of life tends to result from a re-evaluation of living through appraisals centred around value and worth, which offers a sense of appreciation of life. Such increased appreciation also extends to others, through a perceived increase in the value of those who offer caring and support. A self-perception which is more realistic about personal limitations but which is also more appreciative of personal abilities and competencies in surviving is also an outcome of increased appreciation.

2.4.3 Personal factors

The age and gender of the bereaved person can be significant: the impact of bereavement might be greater for older individuals who may be coping with age-related health and personal losses (Rando, 1986; Sanders, 1988). An inability to attribute meaning to life in general is exacerbated, for some older parents, by the loss of a child, so that their ability to cope with the bereavement is lessened (Arbuckle & de Vries, 1995). Older parents may also have diminished resources as regards strength and options for reinvestment and nurturance following the death of their child. Miles and Brown Crandall (1986) notes that involvement in altruistic causes may be helpful in assisting recovery, but this may not be an option for the older bereaved parent. It would seem then that the bio-psychosocial situation of these parents might make the grief process more difficult and impede resolution and subsequent growth.

There is disagreement in the literature about whether mothers suffer more than fathers after the death of a child (Shapiro, 1994). It is believed that their more intimate emotional connection to the child makes mothers more vulnerable, as does the more central role that motherhood plays in the life of women as compared with the less central role of fatherhood in the life of men. Moriarty, Carroll and Cotroneo (1996) examined the differences in distress within couples after the sudden death of a child, whereas Vance et al. (1995) and Boyle et al. (1996) studied such differences in parents of very young infants. In all of these studies, women revealed higher levels of distress with regard to most symptoms and measures. In a study of gender differences in parental grief, Schwab (1996) notes that mothers' scores on a Grief Experience Inventory were significantly higher than fathers on many scales including despair, anger and hostility, guilt, loss of control, rumination, depersonalisation, loss of vigour and physical symptoms. Lang, Gottlieb and Amsel (1996) have found that husbands experience less guilt, meaninglessness, yearning and morbid fear after infant death than their wives. For both spouses however grief reaction tended to lessen within two to four years.

Zinner (2000) suggests that (especially American) men tend to be marginalised in grief and loss. The social constructionist view of grief posits that society has a 'template' for how grief should look, and hence how it ought to be expressed. The accepted 'look of grief' as portrayed in the media is characterised more by qualities associated with femininity such as sighing, crying and slowness, rather than those associated with masculinity such as anger, irritability and impatience. Some of the 'masculine' or instrumental style characteristics, quoted by Zinner (2000), which are in opposition to the conventionally-accepted or intuitive style of grieving are:

- A reluctance to confront the emotional tasks of grief.
- A reluctance to access social and professional support.
- Rejecting help as a show of strength.
- Lesser expectation of society of the need for social support.

Golden (in Zinner, 2000) notes that it took him many years to understand that conventional grief therapy is designed for women, partly because there are more female clients than male. Women do not necessarily feel their loss more painfully than men, but there is evidence that they are far more prepared to express it. After researching some of the causes for marital splits after the loss of a child, Brubaker (1985) suggests that role expectations may be significant in this respect. The bereaved person may enact the role assigned to such a person by the cultural context and society. These socially defined roles might define the expression of grief and the desirability of such expression. Other research (Carr-Gregg & Lennox, 1993) highlights that because men grieve differently from women, interventions may also need to differ. In research carried out by Riches and Dawson (1996), the willingness of mothers to talk about painful events and personal experiences contrasts with their husbands' greater reticence and more considered accounts of events. For masculine-style grievers, the need to reject help in order to be seen as strong and as a survivor, seems fitting in a society that values stoicism and strength in males. However, by not displaying grief in the conventional manner, the male griever is less acknowledged by society as being a legitimate griever, something that Doka and Martin (2000) label a "double-disenfranchisement". Strategies employed by the male griever in coping with the emotional pain of loss, include:

- Shelving thoughts and feelings to meet work and personal obligations;
- Expressing grief externally by active means and by 'doing' rather than 'sharing'. An example of this would be to build something which is meaningful in the context of their relationship with the deceased;
- Indirect expression of feelings, perhaps using humour;
- Private ventilation of feelings in a journal or through music;
- Retreating to a private space like working alone on a hobby.

Bonanno (1999a) suggests that in general clinical intervention around the expression of the emotional meanings of loss generally centres around mainly negative emotions and more especially anger. However there is little empirical evidence to support this approach

(Stroebe & Stroebe, 1991, 1992; Stroebe, Stroebe & Hansson, 1993; Wortman & Silver, 1989). Research by Bonanno (1999a) points to the adaptive value of positive emotion during bereavement which is associated with less grief over time. In this context he posits that by engaging positive emotions it is easier to access support from significant others, which in itself, will reduce some of the distress associated with grief. In support of this view, he quotes cross-cultural studies which illustrate other approaches to grief, such as the use of humour. A further interesting outcome of research by Bonanno (1999b) is the identification of the repressor personality style as being associated with an earlier reduction in grief symptomatology. Repressors are defined as using a, "relatively automatic or habitual 'perceptual avoidance schema' that allows them to ignore or to discretely process threatening information" (Bonanno, 1999b, p. 41). Bonnano (1999a) has researched the adaptive value of emotional dissociation and self-deception and this study provides evidence about the value of positive emotion. Although this has traditionally been associated with maladaptive denial, Bonanno (1999a) found that minimising negative emotion can foster connection to important others and garner support from them.

Personality disorders also affect the course of the grief process, especially as regards the ability of the bereaved person to cope with the anxiety or stress of the bereavement. In this respect, those classified with borderline personality disorder or narcissistic personality disorder, find it more difficult to cope with such a loss. This is also the case for persons who have a history of depressive illness (Worden, 1988). Recent research by Martin and Doka (2000) has found that the most predictive factors for positive bereavement outcome were positive self-esteem and personal competencies in managing the tasks of daily living.

Other personal factors which can affect the grief process include cognitive and emotional maturity, ego strength and self-confidence as well as the experience of coping in earlier crises. While resilience and self-confidence can positively affect the outcome of a stressful events, a sense of invulnerability may increase the difficulty if illusions are confounded by the enormity of the crisis. Philosophical or religious frameworks help to define the crisis as well as assist in their resolution (Moos & Schaefer, 1986). Parkes (1972) has also examined the effects on coping of past experience. However, at present it is still unclear what implications these factors may hold for adjustment to bereavement.

2.4.4 Coping skills

What determines how any crisis can be coped with, is not simply the precipitating event and its nature, but also the coping style of the individual (Hafen et al., 1996). Moos & Schaefer (1986) suggests that various coping skills are used when dealing with the adaptive tasks necessary for managing a crisis. The choice of skills employed may vary according to the requirements of the situation, as not all are equally well suited. Three domains of coping skills are identified:

- Appraisal-focussed coping encompasses the process of appraisal to understand or modify the meaning of the situation. This requires logical analysis, mental preparation, cognitive redefinition, cognitive avoidance or denial;
- Problem-focussed coping deals with the tangible issues so as to create a better outcome. This entails seeking information and support, taking problem-solving action and identifying alternative rewards;
- Emotion-focussed coping aims to manage the feelings that a crisis sets off so as to maintain a balance in the emotional sphere. It requires affective regulation, emotional discharge and resigned acceptance.

2.5 Cultural and social aspects of bereavement

This section explores some of the cultural and social determinants of the bereavement process, in an attempt to clarify some of the issues which confront bereaved parents, and the families of which they are members. The impact of HIV/AIDS on these issues is examined as are some of the specific considerations for parents whose child dies of cancer and for parents whose child dies as a result of an AIDS-related illness.

Stroebe, Stroebe and Hansson (1993) have found that to respond to grief is a universally ubiquitous phenomenon. However the specific nature of the response tends to differ in respect to the culturally-defined norms of that culture as they pertain to beliefs and customs. Hence these manifest as specific rituals and procedures arising from those central understandings, expectations and etiquette (Schuchter & Zisook, 1993). Thus it could be surmised that although grief is a universal experience, its expression is variable. While all such expression provides a culturally-sanctioned means for coping with the experience of grief, it would appear that some are more useful than others as regards long-term psychological well-being (Parkes, 1972).

Not only does culture define patterns of kinship and relationship, but it also defines the quality and nature of relationships at many levels. For instance, the degree of attachment may be culturally determined so that in societies where there is little expectation for the survival of a child, attachment is limited until adolescence (Martin & Doka, 2000). Society also has norms regulating the expression of emotion and these define who may grieve, what one may grieve and how to express such grief. Wright (1992) notes that society has unrealistic expectations for the duration of grief, to which is assigned a period of months or even weeks. There is acute pressure to cease displaying any signs of mourning after this culturally-sanctioned period of time. Subsequently to this, emotions relating to grief are interpreted as a loss of control and so the bereaved person is confronted with a dilemma because the negation of these emotions feels like a denial of the loss. When the individual experiences grief which is beyond socially accepted parameters, it is termed disenfranchised grief (Martin & Doka, 2000). Societal and cultural norms also divide tasks according to gender, and men in Western society have tended until recently to live life in the public sphere and women in the private sphere, so that the loss of a child may impact more severely on a woman. (Malacrida, 1998) has also commented on the issue of disenfranchised grief. Where the grief of the loss is not socially validated, parents may be instructed on the appropriate way and length of time for the grief, how they ought, or ought not to, feel. A paradoxical outcome of such lack of legitimisation of the grief process, is that it tends to be complicated by shame, isolation and alienation.

Shapiro (1994) notes that since the publication of *Death and Dying* by Kübler-Ross (1974), many people are cognisant with the stages of grief. She also contends that where culture prizes personal mastery over adversity, the experience of loss is profoundly unwelcome as it exposes the vulnerability of the individual to the vagaries of fate. It is this that brings about a shattering of those assumptions regarding the sense of control that human beings have over living and dying. There is a sense of solidarity among those who share some of the devastation of the loss and of the changed view it gives of the world. Outside of this culture are those who fail to appreciate the enormity of their loss, or who deny its significance, or who expect them to return unchanged to the everyday routines of so-called normal living. Others have described how the unwillingness of other people to confront the reality of death can create, "a conspiracy of silence surrounding the death" (Yorkstone, 1981).

For the bereaved person, the emotions of grief are often subjectively experienced in spite of their wishes. These reactions appear to be universally applicable, and may be necessary to activate biologically determined adaptive purposes (Bowlby, 1969). This is not necessarily well understood. For instance, estimates of the duration of typical grief range between 24 and 36 months, however, people surrounding the bereaved person consistently underestimate the duration of grief (Doka & Jendreski, 1986). This also applies to clergy who could be an important source of support for the bereaved. In a survey of the clergy, Doka and Jendreski (1986) found that thirty percent of them believed that the normal duration of grief to be six months, and a further 46 percent about a year. Parkes (1972) suggests that by prescribing periods for mourning, churches could alleviate some of the difficulties described here because as Parkes (1972) noted, the value of the prescribed rituals of any religion is only valuable insofar as there is a concomitant faith. The symptomatology of grief is also not well known, even among the clergy, and there is a tendency to label common symptoms of grief abnormal. Lack of empathy, and the failure to validate both the symptoms and duration of the grief, may increase psychological pain for the bereaved. The medical profession too tends to underestimate the suffering caused by grief which can lead to unnecessary interventions which themselves increase suffering, also as a result of the pathologising of the situation.

After the death, families and friends will offer help to the bereaved in the form of comfort as well as practical assistance for the arrangements that need to be made such as funerals and legal procedures. According to Bonanno (1999b) perceived availability of support from friends and relatives is linked to fewer depressive and somatic symptoms but does not show buffering effects with respect to bereavement. However, for the bereaved person, the initial period is marked by a sense of numbness and shock, which only later gives way to intense grief, and this is the vulnerable time where support may be less available, leaving the bereaved at risk if unsupported (Yorkstone, 1981). Hence funerary rituals may assist the broader community to connect with its own sense of loss. It is interesting to speculate whether the public reaction to the death of personages such as that of Princess Diana in 1997 may have had this effect. The bereaved themselves however, may be numb at this time and may believe that the funeral merely sets into motion a process which will unfold over a long period of time (Shapiro, 1994).

Kastenbaum (in Martin & Doka, 2000), suggests that in cultures where the rate of infant and childhood mortality is high, attachments to offspring are limited by social norms and cultures. Today in Western cultures however, few have experienced the loss of a close family member and find it difficult to acknowledge the depth of pain that a bereaved person experiences. In 1900, one half of all parents would have experienced the death of a child but by 1976 only 6% would have done so. The socio-historical context of bereaved parents in Western society is such that a child's death is statistically less prevalent than in earlier historical periods (Farnsworth & Allen, 1996). As a result of this, the experience of the bereaved person is one of intense isolation. With these shifts in occurrence, the death of a child has come to be viewed as a devastating loss from which a parent may never fully recover, instead of a normal hazard of parenthood.

Janoff-Bulman (1992) highlights the importance of social support in the matter of coping with a traumatic event and, among the bereaved, is associated with better emotional adjustment as well as providing a bulwark that protects people from the deleterious effects of stressful events. The understanding and appreciation of others is valuable in helping the bereaved maintain a positive sense of self-worth at a time when it appears to be crumbling. Types of support resources that have been identified include: esteem or emotional support which emphasises that the person is esteemed, valued and accepted; instrumental support provides material assistance or other necessary services; informational support provides advice or knowledge of resources; social companionship which provides friendship for leisure or pleasure. These resources are especially important at a time when the person is attempting to reconstruct a conceptual understanding of their world. Lack of social support at this time is the ultimate demonstration of the malevolence of the world and the lack of worth of the bereaved person. For the bereaved individual a particular, and almost incomprehensible, difficulty is how untouched others are by the events which have shattered both outer and inner worlds. For those around them, the bereaved individual poses an enormous threat which could destroy their own inner world of assumptions.

Lazare (in Worden, 1988) has highlighted the importance of the social setting as this is the context of the grief process. Three social conditions have been identified that may serve to complicate the grief reaction. Where the cause of death is seen as socially unacceptable to the extent that it cannot be spoken of, it might result in a ‘conspiracy of silence’ that isolates the bereaved person who may be needing to talk about the event. A second factor that can complicate the grief process is a situation where the loss is socially negated, as could happen in the case of abortion, where others may not recognise the magnitude of the event for the person who has sustained the loss. Thirdly, a social support network is made up of people who knew the deceased and who can be supportive of one another. Social isolation through relocation, can result in an absence of the social support network and this increases the risk for a complicated grief process. Research by Oliver and Fallat (1995) has highlighted the value of a support network beyond the extended family and its ability to lessen pathological grief responses.

However, although social support is an important determinant of the grief process, it is only a moderate predictor of bereavement outcome (Martin & Doka, 2000). While the support that social networks can offer has a positive impact on the grief process, unrealistic expectations can diminish this benefit. In Africa the scale of the HIV/AIDS epidemic places constraints on the extent to which a community can support the bereaved. In areas which have already suffered economic hardship as well as social and political upheaval, HIV/AIDS is another affliction visited on a populace whose resources are already diminished (Seeley & Kajura, 1995).

The cultural construction of bereavement and its attendant rituals serves to highlight a social transition during which time the bereaved are separate from ongoing structures, before re-entering at a later time in different social form. This period of transition or liminality, was first introduced by Von Gennep in anthropological studies (Shapiro, 1994). Transition in this sense also applies to the period between life and death and provides a means to resolve the preoccupation surrounding mortality. Hence funerary customs and rituals allow for the ventilation of emotions, and comfort for the community who is discomfited by such ventilation. Such discomfort is also addressed by meaningful constructions about death and the existential dilemmas pertaining to human life. Death initiates change in the life of a community, and the concept of liminality means that social roles are redefined in order to accommodate the loss (Shapiro, 1994).

The social disconnection that characterises the modern Western lifestyle has been compensated for by the mental health system. Such 'professionalisation' of grief has led to a focus on 'closure', 'coming to terms' with the loss or 'letting go' where reminiscing about the person who has died may be seen as dysfunctional. Yet, Niemeyer rejects this terminology and comments that, “closure is for bank accounts, not for love accounts” (Brody, 2003). In this way normal developmental processes are pathologised. In contrast to this, Worden (1988) argues that remembering the beloved and creating new connections to him or her, may be more useful. Moreover, this should take precedence over the expression of sadness or anger. The effectiveness of groups such as The Compassionate Friends relies on the fellowship of a shared experience rather than on professional help.

2.5.1 Socio-economic aspects of the HIV/AIDS epidemic in South Africa and the impact on bereavement

Goldblum and Erickson (2000) have observed that those communities most severely affected by the AIDS epidemic have developed responses of appropriate magnitude. While this observation holds true for some communities in the United States and Europe (such as gay middle-class men), this has not always been the response in South Africa so that establishing support networks has been slow. Barolsky (2003) notes that the extent of the epidemic in South Africa is such that deaths are now so frequent and so numerous that prescribed funerary rites are too onerous for many people to attend, so that attending is becoming a matter of choice. In this way then, death has become a routine phenomenon and as the traditional rituals for according signification to a particular human life are thus a paradoxical, "corrosion of critical affirmation of life which are implicit in formal acknowledgement of death" (Barolsky, 2003, p. 66). This lack of communal acknowledgement of death is in marked contrast to the prominence that funerals were accorded during the Apartheid era, when political deaths were seen as a unifying factor propelling people towards a common goal.

2.5.2 The effect of bereavement on the family system

Shapiro (1994) argues that grief for the death of a family member is twofold: it is both a crisis of attachment and a crisis of identity impacting on the family's interactions and social roles which may need to be renegotiated. The first priority for the family is the necessity to re-establish the equilibrium necessary for allowing the family to continue functioning. This occurs at a time of intense emotionality for the family members. Paradoxically, while sharing one's grief experience would be important in order to allow family members to feel understood and to re-establish a coherent sense of the continuity of the family over time, members refrain from doing so, fearing that this sharing might threaten the family's emotional stability. A study by Kiser, Ostoha and Pruitt (1998) confirms that the stress and trauma that families experience as a result of unexpected stressors such as a death of a child may make family adaptation more difficult at such a time and suggest that intervention could be beneficial. A study by Najman, Vance, Boyle, Embleton, Foster and Thearle (1993) indicates that there is an increased rate of dissolution of marriage following the death of an infant. Even for those whose marital relationship remains intact, there is a deterioration of the relationship for both partners for the first six months after the death. Wortman and Silver (1989) have also found an increased likelihood of divorce in couples subsequent to the loss of their child, while others find the incidence is no greater than that in the general population (Rando, 1986).

Rando (1985, 1986) argues that the death of a child impacts on the marriage of the parents as it alters the dynamics of the marital relationship disrupting the habitual patterns of communicating and relating. Although the loss of the child initiates each parent into the grieving process, the individual experience of their grief can be as different for each parent as was their relationships with the child. At a time when each partner is in need of the support of their spouse, their spouse is equally in need of support. Thus the co-ordination of the ebb and flow of grief is not necessarily synchronised and it may be difficult for the various family members to permit these different timetables when another's pain heightens their own grief (Shapiro, 1994). While some studies appear to support the belief that mothers experience greater distress after the death of a child, Moriarty et al. (1996) note that hostility scores, are equivalent in both genders. They posit that these findings may indicate why bereaved parental couples are at greater risk for the marital difficulties which have been observed. In a study by Ditchik (1991), marital dissatisfaction was associated with anger and somatisation in the wife, and despair in the husband. Interestingly, both spouses displayed a lack of awareness of how their grieving affected their partners.

The sexual relationship of a bereaved couple may be affected as a result of lack of desire or energy, adding to intimacy difficulties (Johnson, 1984). Some of the difficulties resulted from the meaning of intercourse as the means of having conceived their child or from the pleasuring of intercourse being inconsistent with the experience of grief and grieving (Hagemeister & Rosenblatt, 1997). It can also highlight differences between partners as they differ in what the sexual relationship means to them, and what they need and want (Schwab, 1992).

The impact of the loss affects the homeostatic balance of the family as family members attempt to adapt to the new constellation. Each family member responds idiosyncratically and this can be a source of difficulty as each family member grieves within the context of the family (Rando, 1986). Although each member is affected individually and uniquely, the grief reaction of each individual is fashioned also by the needs and reactions of others, as well as by the availability of emotional resources which are strained at this time. For parents who have other children, their capacity to parent them is greatly affected and is reflected in reduced emotional and physical availability. Ponzetti (1992) has found that parents find they feel and act differently towards surviving children and that their reactions were governed by their focus on the deceased child. The length of the grief process means that this may have consequences for surviving children for many of their growing years (Shapiro, 1994). Siblings are particularly vulnerable and are almost overlooked as grievers. If the cause of death is a long-term illness, the nursing of the sibling can also be stressful giving rise to ambivalent feelings about their ill sibling. These emotions can include anger, envy and shame at a time when parents are emotionally unavailable to them (Martinson, Papadatou, Pask & Stevens, 1998). Where families impose rigid structures for relating in order to bring stability back into the family system, they may find themselves ill-equipped to cope with new demands as the family moves through new developmental stages within the family system. Many families however, demonstrate significant levels of creativity and resilience in dealing with the difficulties which face them if sufficient support can be given to them (Shapiro, 1994).

For the bereaved parent, the loss of a child, ushers in a period of crisis wherein the parent reviews his or her role as a parent. This radical life-review occurs in parallel with other family members who are themselves undergoing a process of similar magnitude so that the collective burden of the family to provide support to one another is significant at this time (Shapiro, 1994). According to Shapiro (1994), losing a child initiates a transformative life-cycle transition. During this process the love-bond for the child that has died is not forsaken, but a new internalised relationship is forged which is both enduring and important to the remaining family members. Shapiro (1994) argues that in the context of a systemic developmental framework, grief is considered a family developmental crisis that reshapes the future course of shared family development. The family needs to marshal all resources for this kind of crisis which touches on both attachment and identity in order to re-establish the necessary equilibrium for ongoing family development. Integration of the reality of the death continues throughout the family life cycle with each new developmental stage ushering in new opportunities for integration. In order to reintegrate the deceased into the family, it is necessary to develop an evolving spiritual and psychologically supportive presence that goes forward with the family with the passage of time.

Gilbert (1996) takes a constructivist/interpretive view of grief within the meaning-making system of the family. He suggests that grief results from the loss of meaning that resided within a significant relationship. The degree of grief felt is directly related to the importance of the lost relationship for the bereaved. The grief process then, can be construed as the reconstruction of a predictable and manageable ‘new-normal’ world in which the bereaved person will be able to function. In addition, the sets of assumptions that the individual held prior to the loss need to be re-evaluated and reconstructed into a new assumptive world. This process entails the questioning of the assumptions which underlie beliefs and behaviours, and this emotional upheaval impacts on interpersonal, relational and social systems.

Seen from the perspective of the individual in the family, Gilbert (1996) believes that family members construct a common reality for the family through the confirmation or otherwise of the beliefs of the family members. This reality is then accepted and acted upon unless contradictory evidence is produced to disconfirm such beliefs. This is a collaborative and ongoing process which occurs continuously in the life of the family, and at the time of the loss serves as a basis for interaction between family members. This that makes it possible for family members to believe that they share a view of the situation, even though each member's subjective reality is individually determined. It appears that there is a strong desire for family members to share a particular view of their common loss, to the extent that it is hard for spouses to accept that their partner's style of grieving differs from their own.

In terms of the functioning of the family, once the nature of the loss has been recognised, the family needs to reorganise itself to function without the now-deceased member. Rituals can serve to facilitate the passing-down of a role from the deceased to a surviving family member. Eventually family members are able to transform the memory of the lost family member so as to continue with their lives and invest in the new family with a continuing sense of connection to the deceased (Gilbert,1996).

In a study of the narratives of bereaved parents, Rosenblatt (2000) has found that death rituals were prominent. Rituals which help to give meaning to the child's death include rituals of baptism, autopsy, police inquiry and organ donation. Funerary rituals include wakes, funerals, memorial services and burials, and these help to define the child, the death and changes in the parent-child relationship. According to Rando (1988) the quality of social experiences, as well as the interactional processes with the dying child, have an influence on the mourning process, and impact on the emotional and psychological processes of the bereaved parent. The acceptance by, and assistance from, of the parent's social support system is also an important factor, as are the funerary rituals utilised. (Rando, 1986).

Both attachment theory and role developmental theory have attempted to find an explanation for the scale of the experience that parents undergo at the loss of a child (Rando 1986; Raphael, 1983; Weiss, 1988). The death of a child re-activates internalised aspects of the parent's own early relationships. In addition, the child represents, for the parent, an investment in the future so that the loss of a child can be equated to a loss of aspect of the parent herself or himself, almost like an amputation (Klass, 1988).

Bowen (1978) emphasises the importance of taking into account at least two generations of family history, because postponed mourning from an earlier loss impacts on the current loss. Important areas that need to be considered are the role the deceased played in the family, the emotional integration of the family, and how that emotional integration is achieved. Worden (1988) suggests that the stress of losing a child impacts heavily on family equilibrium.

A further source of difficulty, for both the parents and family of the deceased child, can be the attitude of society to the loss of a child. The loss of a child is a stigmatising event to the extent that there is no word to describe the altered status of a bereaved parent which corresponds to words such as orphan, widow or widower (Hicks, 1995). Parkes (1972) notes that association with the bereaved can confer the taint of death so that expressions of sympathy and offers of help may be spurious. In his autobiographical account of the experience of loss, Lewis (1978, p. 13) notes that as a result of awkwardness around the topic of death, people avoid the bereaved so that he suggest that, "perhaps the bereaved ought to be isolated in special settlements like lepers."

Patterns of social relationships may change resulting in a sense of abandonment for the bereaved parents and family, at a time when the need for social support is great. Boston and Tresize (1988) suggest that others fear the bereaved person, and that once the socially recognised period of mourning, of perhaps six weeks, has passed, considerable pressure is exerted on the bereaved person to pretend to be well again. As a result the bereaved feel that their misery makes them socially unacceptable as their presence spoils the fun of others. The finding by Rando (1983) that the grief of bereaved parents worsened during the third year, highlights the gap between the social expectation and the experience of the bereaved, accounting to some degree for the sense of isolation. Calhoun and Tedeschi (2001) also found that a significant change in bereaved parents is not exhibited until at least two to five years following the death of their child.

Marginalisation of the bereaved parent can occur when the bereaved parent serves as a reminder that, contrary to expectation, a child may predecease its parents. For the bereaved parent this marginalisation accentuates their feelings of guilt (Rando, 1986). Society may exhort the bereaved parent to 'be strong' or 'have courage', so that the bereaved parent may believe that expression of grief in a manner appropriate to the depth of feeling, is not socially acceptable. Liiceanu (2000) has suggested that a conceptualisation of parallel selves is useful, where a more active coping self is shown in public, but that this may co-exist with a parallel aspect that allows for the ventilation of grief in more select circumstances.

2.5.3 The family system and the effects of HIV/AIDS in South Africa as it impacts on bereavement

Ziel (2001) notes that despite social, political and historical influences that have impacted upon the traditional system of the extended family, the philosophy of the extended family is still strong in South African society and indeed has been merged in the nuclear family. This is apparent in the multi-generational nature of the majority of households as a preponderance of the elderly reside with the families of their offspring. The life-task for grand-parents within the extended family traditionally meant that they took on the responsibility for the acculturation and socialisation of the younger generation. More recently, for many families, their very survival has become dependent on the financial support provided by the pensions of grandparents, and this coupled with the pooling of resources through the network of kinship has enabled families to overcome the challenges imposed by severely straitened economic circumstances.

The prevalence of the HIV/AIDS epidemic in the young adult population has increased the burden of those responsibilities that have traditionally fallen onto the shoulders of grandparents and has additionally also fallen on the children of those who are so afflicted. There has therefore been a significant increase in the number of households headed by children or grandparents.

2.6 Parental bereavement through loss of offspring

Grief does not result equally in the case of all losses and this section examines some specific elements which apply to bereavement through loss of a child, with emphasis on parental loss as a result of cancer and of AIDS. Where the loss of a relationship leads to a grief reaction marked by intense and lasting distress as a result of the absence of the individual, such a relationship is termed a relationship of attachment (Weiss, 1988). In the case of such relationships, the distress (grief) cannot be diminished even if another individual takes the place of the deceased person within a relationship: another spouse or a child cannot replace the one that is lost. Such relationships are characterised as attachments as a result of their similarity to the relationship of the child in respect of the parents. The availability of the attachment figure fosters feelings of security which is verified through visual, tangible or auditory contact with the attachment figure, or through the promise of future contact. Apart from the fact that such an attachment figure cannot be substituted, other common factors are that the attachment is not conditional upon the treatment of the individual by the attachment figure and that these attachments persist over time (Weiss, 1988).

According to Weiss (1988) conditions that threaten either the self or the continuation of the relationship will trigger the demonstration of attachment feelings and behaviours and if these are thwarted then separation distress will inevitably ensue as it is not a matter of volition. This state is characterised by a sense of anxiety, vigilance and searching for the attachment figure that is consuming for the bereaved person to the extent that it gives rise to sleep disturbances and an inability to focus on other concerns.

He has identified four relational bonds that fit these criteria and parental attachment to children is one such bond. Furthermore, the reaction of parents elicited in response to a threat to the well-being of their child is evidence supporting the argument that the emotional systems underlying the relational bond of a parent for a child is derived from their own attachment relationship in childhood. Significant others within the social milieu provide a context for a person to understand, define and validate feelings and experience and are important for one's definition of self. The loss of such a person therefore, can lead to a loss of the foundation for dealing with experience, as well as to a sense of uncertainty about one's sense of self.

Although loss of a child has been less researched than conjugal loss, some researchers believe it is perhaps the most difficult adult bereavement (Arnold & Gemma, 1994, Braun & Berg, 1994; Jacob & Scandrett-Hibdon, 1994; Sanders, 1988; Singh & Raphael, 1981). Leahy (1992) has found that depression is greater for bereaved mothers than it is for widows or women who have lost a parent. Rando (1986) describes various idiosyncratic factors that can influence the grief experience. These include the nature of the relationship between parent and child prior to the death and the meaning that the child had for the parents; characteristics of the deceased child as well as characteristics of the bereaved parent such as coping behaviour, personality and socio-cultural background; characteristics of the death event, whether it was sudden or expected and the perception as to whether or not it was inevitable; social factors such as the extent of social support available to the parents; physiological factors such as the health of the parents.

McIlwraith (1998) suggests that feelings of guilt are a significant component of the grief experience of bereaved parents. Feelings of having failed or having done something wrong can be overwhelming. Perhaps this is related to a belief that as the parents are responsible for having brought the child into the world, they should be able to ensure the survival of the child. Hence the inability to ensure the continuation of their child's life, however illogical, may result in feelings of failure as a parent and by extension, of feelings of failure as a person.

2.6.1 Parental bereavement as a result of cancer

Death as a result of cancer tends to occur subsequent to unsuccessful attempts to effect a cure, and as such the care of the person so afflicted can be a lengthy process. Thus caring for these family members is frequently, “exhausting and heartrending for all family members. It is an experience characterized by periods of hope and optimism, alternating with periods of despair and fear.” (Martinson et al., 1998, p. 301). The experience affects all family members though in different ways, with enormous strain being placed on resources at all levels: psychological, energy, economic, time, relationship and employment. Roles tend to change with mothers often taking on the burden of nursing, thus requiring other family members, often other children, to take up those roles that she has vacated. Fathers, as highlighted by the studies of Martin and Doka (2000), tend to assume instrumental roles and yet the very process of the child’s dying tends to undermine their sense of family protector especially when dealing with the health-care system. However in research by Martinson et al. (1998, p. 308), this assumption is questioned as it emerged that fathers, “may be more involved in expressive and caretaking roles than assumed.”

Much of the sense of guilt and regret for parents results from a sense of failure over the treatment options pursued. A particular source of difficulty for mothers subsequent to the death of the child, relate to difficulties arising in their relationships with their husbands, as a result of different coping styles, and with their surviving children who often appear unwilling to talk about their deceased sibling (Martinson et al., 1998). In research of mothers of terminally ill children, Martinson et al. (1998) have found that over half of them seek spiritual nurturance during the last month of the child’s life. Spiritual support is not necessarily from a religious perspective, but implies a transcendent dimension of experience and signifies a certain ease with the knowledge of imminent mortality. It is possible that this also applies to fathers, and to parents of people dying from other long term illnesses.

According to Benoliel (1979), situations that can make a death from cancer difficult for both family and staff is a lingering, suffering death, as it is characterised by watching and waiting, knowing that the final outcome is bound to be death. Patients also may be anxious fearing a painful death or abandonment, and this elicits feelings of helplessness, anger, guilt, sadness and depression in those who are involved in their care. This context which may strain the kind of communication that occurs between the patient, the family and the medical staff, for instance with all concerned exhibiting a forced and spurious cheerfulness.

2.6.2 Parental bereavement as a result of an AIDS-related illness

Shapiro (1994) notes that although terminal illness affords relatives for a chance to make farewells, a chronic illness such as AIDS can add to the stress which the family experiences. Rando (1983) suggests that if the period between diagnosis and death extends more than six months this will further strain the parent-child relationship as the nursing or care-taking responsibilities which are placed on family members reduce available resources. In the case of a terminal AIDS-related illness there may be some pressure on the family to expel the dying family member as a punishment for shameful behaviour in contracting the illness. In South Africa, for instance, AIDS sufferers may be relegated to a shack outside of the family dwelling (Barolsky, 2003).

Shapiro (1994) also highlights how many parents will normally distort details of the circumstances of the death in the belief that surviving family members will be saved from greater pain. This tendency may well be augmented where the cause of death is an AIDS-related illness as there may already be a need to avoid disclosure to protect the family from social taint or discredit. Thus it may be understood that loss of one child is not merely an intra-psychic event but rather an event which may contribute to the future shaping of the family. Family patterns may arise to cope with the loss that may be rigid or inflexible, aimed at preserving more desirable images than the ones that an AIDS-related death will precipitate. Such incomplete mourning affects family adjustment perhaps for a long period also because "the integration of a complex sense of self requires a high tolerance for contradiction and difference" (Shapiro, 1994, p. 147). An example may be the inability to discuss unresolved issues pertaining to the deceased, or the means of death so that difference is not addressed but deferred so that integration of this event into the historical narrative of the family is stunted or shelved, perhaps permanently. Symptomatic behaviour by family members may thus be a (creative) attempt to improve family adaptation and may represent meanings which are not permitted to emerge more honestly. Shapiro (1994) posits that the ability to integrate change depends on the balance between stress and support. Inadequate support with great stress may put the family at risk for fragmentation or dysfunctional symptoms.

The age groups most severely affected in the HIV/AIDS epidemic are the 25-29 year age group (with a prevalence of 31%) and the 20-24 year age group (with a prevalence of 28%).

Prevalence by age group tends to decline, except for the 45-49 age group where it increases once more to a level of 18%. Thus it can be surmised that parents whose offspring die of an AIDS-related illness will frequently fall into an older age group. Brubaker (1985) notes that bereavement has a number of implications for the bereaved parent. As people age, their social network may narrow, through loss of friends and this may result in a diminution of potential resources for support. Other children may try to shield them from the full impact of the information surrounding the death which may make them feel even more isolated. For the older parent, there may also be a loss of an instrumental relationship if the adult child had contributed to the functioning of the parent by helping them particularly in the event of stressful situations such as illness. Thus the loss of those services previously rendered by the now-deceased child intensify the feelings of grief especially where there is no one else to provide these services. As a result the parent might become dependent on social services over which he or she has less control, thus reducing their sense of autonomy. Such a loss also may make the parent more aware of their own impending mortality especially if the reality of old age and death has not been addressed prior to this point (Brubaker, 1985).

In addition, families who lose a family member are already vulnerable to isolation. It is therefore postulated that where shame attaches to an AIDS-related cause of death, there will be an increased tendency towards isolation. The scope of therapy in these cases is the to intervene in expanding the openness of the family system (Shapiro, 1994).

However traumatic the course of the disease and the death of their child, Wiener (1998) has found that most bereaved parents report wishing to have that period back, even if only briefly, in order to see and hold their child once again because after all the activity that precedes the death makes the subsequent calm all the more dissonant. At least during that period there is a sense of being needed and useful and the lack of such activity later exacerbates the devastating feelings of loneliness and futility. A common experience of bereaved parents is the sense of not feeling comfortable in the world outside of the AIDS community. Issues around secrecy and disclosure also became more significant as does ostracism as a result of stigma.

Kalish (1981) has examined the types of relationships between the dying person and others with regard to the management of the information about the terminal nature of the illness. In a closed-awareness context the attempt is made to keep information from the dying person, even though the knowledge may be common ground among family members and medical personnel. For some people, this may be a successful strategy, but for others the need for deceit may negatively affect the quality of the relationships. Where the patient begins to suspect the nature of the illness, a suspicion-awareness context may develop as the dying person attempts to discover more, while others conspire to keep it from the patient. Where it is decided to continue the deception, circumlocution and deflection of questions tends to become the norm so that an atmosphere of distrust may evolve. In cases where both patient and others know of the situation, all, or some may decide to pretend that it is not the case. The open-awareness context, which has become more common in recent years, is where the prognosis and condition are known by all parties and openly admitted. In many cases there may also be vacillation between denial and acceptance, hope and despair so that over the course of time shifts tend to occur. These findings may have a bearing for the families of a person with AIDS, especially where the patient is very young. Generally however, the adult patient tends to know of their condition before the rest of the family, so that a curious reversal of these options plays itself out. Deciding whether or not to disclose to member of the family of origin may pose a substantial dilemma for the person with AIDS.

2.7 Conclusion

"Life is filled with loss. It is the inevitable in the experience of living. It is inescapable yet necessary for growth" (Arnold & Gemma, 1994, p. 3). Loss is probably an inescapable issue in the life of most people, be it the loss of a precious or meaningful possession, a relationship, or even of a hoped-for event. However, losing someone who is beloved can be so traumatic, intense and shocking, that it can alter the course of existence for the bereaved person for a considerable period of time if not for ever. This chapter has explored various issues of bereavement from the grief response and sequelae of bereavement, to the theoretical frameworks that have been utilised in attempting to describe and provide an understanding of it. Psychosocial factors, the effect of cultural issues and a brief exploration of the possible impact of specific deaths, such as those which result from cancer or an AIDS-related illness, were also explored. From the literature examined in this chapter, it appears that the approaches to bereavement are diverse and this is indicative of the diversity of conceptual and philosophical constructs from which they stem and which underlie them. Despite the differences between approaches, there is general agreement that bereavement provides a notable biographical disruption in the life of the bereaved individual. Furthermore, there is support for the idea that loss of a child is an idiosyncratic discontinuity in the course of a parent's life and that such an event overturns the underlying sense of coherence of existence.

As the focus of the study is on understanding the process of meaning-making for parents who have lost a child, this chapter has examined the various characteristics of the grief response, and some of the theoretical approaches to them. The next chapter will explore meaning-making, especially as it occurs in the context of death and suffering.

Chapter 3

3. Meaning-making

This chapter seeks to explore some of the issues pertaining to meaning-making. These include an attempt to understand whether there is a need for it, the construction of meaning and the role of language in meaning-making. There is also an exploration of possible factors relating to meaning-making which may impact on parental bereavement and HIV/AIDS. Finally, the role of religion and spirituality in meaning-making is considered.

3.1 Introduction

Throughout history humankind has attempted to make sense of human existence. The tendency to attempt to create meaning is so central to humanity that, when coupled with humanity's capacity for symbolisation, it appears to be inherent to the human condition. From an historic perspective, myth and the introduction of religious frameworks can be understood as formalised ideas regarding an attempt to find an understanding of the meaning of life. The power of such frameworks to provide meaning has waned since the rise of empiricism. The meaning of life which had been so clear, became indistinct, producing an existential vacuum. The loss of these fundamental assumptions, which are the cornerstones of individual can also occur following a cataclysmic event, such as a major personal loss and this too may initiate a search for new meaning.

3.2 Reality and meaning

The aim of the Cognitive Revolution was to bring a more interpretative approach to meaning-making (Bruner, 1990). The focus was on the attempt to, "discover and to describe formally the meanings that human beings created out of their encounters with the world, and then to propose hypotheses about what meaning-making processes were implicated. It focussed upon the symbolic activities that human beings employed in making sense not only of their world, but of themselves" (p. 2). These symbolic activities are embedded in culture and language, so that their usage not only reflects something of the nature of the community, but is also a significant aspect of the way the individuals within that community construct their consciousness. Implied in this concept, therefore, is the conviction that in order to understand the individual, it is necessary to understand how the intentional states embedded in the symbolic system of the culture contribute to the formation of the experiences and acts of the individual.

Crossley (2000b) asserts that the sensory and perceptual faculties of human beings do not serve merely as conduits enabling an experience of the world, but also act interpretatively to create meaning of events in terms of their interconnectedness. Accordingly, "it is in the connections or relationships among events that constitute their meanings" (Crossley, 2000b, p. 11). Furthermore, cultural meaning systems, such as language, provide the context for the creation of meaning.

Berger and Luckmann (1967) argue that reality can be understood by individuals as their lived experience. Common sense can be understood as the knowledge of routines and habitual behaviours that are acted out by individuals and which give them a sense of their objective reality. Experiences are interpreted in terms of this objective reality and become meaningful for the individual when they are perceived as making sense in terms of that objective reality. Events that cannot be explained and are outside of these bounds, however, negate the sense of an objective reality by virtue of invalidating the structure that has been put in place to justify such reality. In response to this kind of crisis, individuals have to reconstruct their reality so that it will be able to accommodate this new experience because it cannot fit into their previously-held understanding of the world.

According to Janoff-Bulman (1992) a belief system may be necessary in order for individuals to accommodate new information as it provides a framework into which it is possible to slot such information. Not being able to assimilate or adjust to the new situation results in a state of unresolved tension. Existential theorist Frankl (1964a) observed that the need for meaning is a fundamental human motivational factor and that there is no reason to go on living in a world in which there is no meaning. This may be one reason for the high rates of mortality and physical illness among the bereaved (Stroebe & Stroebe, 1992). Yalom and Lieberman (1991) and Jaffe (1985) concur that bereavement sets off existential concerns regarding meaning in life and its transience. Furthermore, Frankl (1964a) believes that the ability for people to survive is dependent on their ability to derive meaning and purpose for their suffering. Suffering and tragedy may bring a person to seek for existential meaning, even if they had not done so prior to the event.

3.2.1 The need for meaning-making

According to Janoff-Bulman (1992), core beliefs are constructed over years of experience and these guide an understanding of the world. These abstract beliefs are about the self, the external world and the relationship between them, and form the core of an assumptive inner world. Janoff-Bulman (1992) has proposed that there are three fundamental assumptions that most, if not all people, tend to hold. The first of these core beliefs in respect of the world holds that their lived world is benevolent and that there is a preponderance of positive outcomes over negative outcomes in their own lives, even though the world at large may not be perceived so optimistically. She suggests that this assumption arises from people's own, relatively limited experience of the world.

The second core belief in respect of the world is that it is meaningful. This means that there is a relationship between the individual and what happens to the individual and that events make sense. While science seeks to provide explanatory models for events, it does not provide the reason for their occurrence and people look to socially constructed explanatory 'laws'. According to these 'laws' goodness will be 'rewarded' with a good life and, conversely, a wicked life will deserve negative outcomes. Corr (1979a) observes that the Protestant ethic of faith and hard work fitted well into these constructs, by providing a set of values which provide a sense of security in the uncertainty of life. He notes that it is a human characteristic to attempt to deal with manageable problems by assuming that to all difficulties there exist answers that are simple and universally applicable.

Janoff-Bulman (1992) has coined the term of a principle of personal deservingness in order to describe the process which underlies the above-mentioned endeavour. Lerner and Simmons (1966) found that when people hear of the misfortune of others, they are confronted by a threatening sense of vulnerability to random events which do not make sense. Hence, an arbitrary or random event is in stark contrast to the ability to make sense of the world and it negates the possibility of protecting oneself against negative events through appropriate and careful behaviour, so that the person is open to the vagaries of fate. Through a process of negative judgement of the behaviour of the victim and the devaluation of his or her character, people are able to maintain a sense of the justness of the world and the deservingness of events, and this provides a sense of safety, predictability and control. Goffman's (1963) concept of a 'spoiled identity', where the stigma attaching to one attribute is transferred to a person who is believed to be associated with it, clarifies the significance of this process of judgment and devaluation. The attitudes of people towards those who have HIV/AIDS is an exemplar in this respect as contracting the illness is seen to be a consequence of morally reprehensible behaviour of the person who is associated with the illness.

The third core belief is that the self is worthy. An evaluative process enables people to judge themselves in terms of character and whether one is good and moral, as well as judging themselves in terms of behaviour and whether one's actions are effective and competent. Not only do people tend to evaluate themselves as being above average as regards competencies and qualities, but people also tend to attribute positive, desired outcomes to personal agency (Janoff-Bulman, 1992).

From these fundamental assumptions arises a sense of trust, security and invulnerability that is so universal as to be seen as an inherent aspect of human nature. During infancy when the mother is able to accommodate the needs of the child a sense of safety and security begins to develop. Positive generalisations based on these experiences of need satisfaction from a caregiver can thus be generated by the child regarding the nature of the world. Over time these generalisations are extended and applied to an ever-widening circle of life experiences so that the sense of being cared for and protected persists throughout the child's developmental phases. The resultant effect is one of a general optimism about the outcome of life events and the person's ability to prevail in spite of being surrounded by many tragic or threatening events and is reflected in a deeply-held conviction of the person's own invulnerability. Although such over-generalisations may not be based in reality the effects of such beliefs may have adaptive value enabling better physical, mental and social functioning. It is also suggested that a sense of basic trust, safety and security in both self and environment is integral to the person's confidence to test and explore their world especially in situations where there is insufficient knowledge about possible outcomes.

The core beliefs discussed earlier serve to underpin this conviction through the understanding that in a benevolent world, those negative events that occur, do so in a predictable pattern with bad things happening to bad people. Kushner (1981) picked up on this theme in his book 'When bad things happen to good people'. So potent is this belief, that Janoff-Bulman (1992) has found that people tend to consistently underestimate their risk for experiencing negative events such as illness, death or natural disaster.

It seems then that maintaining a sense of meaningfulness and coherence in a chaotic or unpredictable world requires some sort of framework into which the individual is able to fit new experiences. New information, as well as pre-existing information, is both perceived and interpreted in the light of what is already known in a way that makes sense to the person and could be termed a 'paradigm' (that is a conceptual framework). Cognitive conservatism refers to this tendency and implies that it is easier to reinforce pre-existing beliefs than it is to change them. Expectations give rise to specific behaviours which are likely to elicit expected outcomes so that the process is self-confirming and self-perpetuating (Janoff-Bulman, 1992). Not only is it easier to reinforce pre-existing beliefs than it is to change them, but they are remarkably resistant to change even in the face of inconsistent evidence or lack of substantiation.

The paradigms that people construct enable them to make sense of their world and make it comprehensible and therefore manageable and to a great extent confer the illusion that it is controllable providing for stability even in a continually changing environment. The changes that occur tend to be gradual with change to the basic conceptual framework being atypical. The exception to this tenet is the impact of trauma which causes the individual to reconsider the fundamental assumptions and beliefs which underlie an understanding of life. This kind of change could be termed a 'paradigm shift'. As in scientific circles, such a degree of change is marked by severe crisis as the existing paradigm is unable to accommodate new information. Janoff-Bulman (1992) has termed the trauma that leads to such change as one that causes a “shattering” of the person's assumptive world.

Characteristics of such traumatic events are that they are outside of the person's expectations and that all people would find them greatly upsetting. Such experiences may include confrontation with possible annihilation, direct attack or threat of attack either to self or to a loved one. Threats to both physiological and psychological survival can be the result of natural disasters, serious illness or accident, as well as the result of criminal intent. In the aftermath of such an event, the positively biased beliefs that the person holds, become untenable and their illusory nature is revealed in so stark a manner that previous beliefs can no longer be salvaged or retained. In the light of the new experience human existence is revealed not as safe and predictable but as fragile and whimsical leaving the person vulnerable and exposed. Once the core beliefs underlying the person's very existence cease to be valid, the person may feel that nothing that they had previously believed is of value and that their judgement is deeply flawed and unreliable. The perceived sense of control previously experienced over the outcome of events is also understood to be delusion. The world itself becomes 'terra incognita' and the person feels lost, unprepared, fearful and defenseless. The previously assumed benevolence of the world takes on a malevolent aspect and nothing makes sense any more. In addition to the dangerous external environment, the internal world is shaken to its core which is intensely and pervasively filled with anxiety. Earlier it was mentioned that optimistic and somewhat illusory core beliefs have an adaptive value in terms of functioning. The emotional climate of the person who has lost these beliefs may be more realistic but it is also a depressive one and over time deepening depression may be characterised by an all-pervasive sense of pessimism.

3.2.2 Meaning construction

The hotchpotch of life experiences is used by people to construct a coherent and unified life-story in a way that takes cognisance of the temporal aspect. McAdams, Diamond, de St. Aubin and Mansfield, (1997) have studied the effect of this process in understanding how stories become a vehicle for people to make sense of their lives to tell others about themselves. By recounting these stories to themselves as well as to others, people are able to construct a sense of their identity. Life events are woven into an integrated life-story and meaning is ascribed to all events through the connotation they attach to past events or experiences and the anticipation of future ones. In this way the present event is embedded in both the past and the future (Crossley, 2000a). Crisis and trauma that shatter the assumptive world of the individual tend to result in pessimism, a profound loss of hope in the world itself. With regard to Erikson’s (1997) theory there is a re-working at a more mature level of the developmental crisis between trust versus mistrust originally resolved in early childhood. Erikson in expounding the Epigenetic principle makes clear that successful resolution of each developmental crisis needs to be re-attained at each new level, as age-related limitations will inhibit this occurring earlier.

Creating a story through the integration of discrete and sequential experiences requires establishing connections between them and other past and future experiences so as to achieve ownership of the story and hence to take responsibility for one's life. This story creation is always current, rather than retrospective and there is a continuous process of editing experiences so as to render them comprehensible. Like a miner panning for golden fragments in the river to combine into ingots, the individual 'sifts out' the elements that create the story. From the vast array of continuously occurring events and experiences, which occur almost in disordered fashion over time, the person selects and omits certain of them so as to produce a story that can hold together. Neimeyer (2001c) suggests that this holds practical implications for therapeutic practice as the bereaved person seeks assistance when this process stalls as the therapist supplies an audience for whom the bereaved person must construct a story that hangs together in a way that makes sense. Rhetoric is thus a useful tool for indicating areas of unprocessed emotion, and meaning which is neither patent or covert, but rather suggestive, inviting further exploration.

Spence (1984), in differentiating between historical truth and narrative truth, suggests that rather than recovering the past, individuals create a new narrative that is close enough to reality in order to serve their purpose at that time. The narrator is at the centre of the narrative, and the object of the narrative is not its 'truth' but its ability to make meaning of the sense of self of the narrator within the narrative. Hence self is not a fixed entity but rather a continuously reconfigured amalgamation of that which has occurred and that which is yet to happen (Polkinghorne, 1988).

While the narratives that individuals construct are a reflection of the culture in which they are embedded, the narrative also provides for the renegotiation of meaning. (Bruner, 1990). Hence narrative becomes the vehicle for instituting associations between the ordinary and the exceptional by making the exceptional comprehensible. When events occur in accordance with that which is expected, then an individual needs no further explanation. However, departures from the expected course of events trigger off a search for the meaning of the event, in order to construct a reality that is able to contain such meanings.

The personal story of each individual is also important when seen from the perspective of salutogenesis, because it is only in the awareness of the circumstances of the individual's life that the resources that contribute to recovery can be found and fostered (Antonovsky, 1979). This process is particularly significant when considering the central role that the sense of meaningfulness plays within the sense of coherence. Without the experience of meaningfulness, even life itself becomes a burden.

3.2.3 Language and meaning

The notion of 'mimesis' first expressed by Aristotle, was the capturing of 'life in action' (Bruner, 1990, p. 46). Ricoeur (in Bruner, 1990) expanded on this notion of mimesis by noting how it is a metaphor for reality which is born out of reality but understood in a new way. The capacity of the individual to create symbolic structures is thus dependent on the mimetic function of interpretation.

Symbolic meaning itself depends on the capacity of the individual to use language so that a symbol can represent another reality. While these representations are malleable, they are 'fitted' into the individual's personal theory of the world, and consequently their predisposition to construe the world in a particular way. Crossley (2000b) also emphasises the role of language as the vehicle for making the lived experience meaningful, and that "individuals understand themselves through the medium of language, through talking and writing, and it is through these processes that individuals are constantly engaged in the process of creating themselves" (p. 10).

Segal (1999) has demonstrated the use of metaphor in psychotherapy as an appropriate vehicle for providing symbolic meaning. In this sense, metaphor can be used to integrate the worlds of emotion, thoughts and beliefs. Furthermore, using metaphors provides an element of 'safety' where it comes to dealing with emotionally charged issues enabling the exploration of ideas which would otherwise be less accessible. In a sense it provides an entry point through which elements of the world of the unconscious can enter into the conscious.

Rosenblatt (2000) has observed that the narratives of bereaved parents include many metaphors. Metaphors for grief make it easier to talk about grief as an entity which has substance and impact. Some of the metaphors used to explain the grief process are: 'draining', 'emptiness and holes' and 'part of me died'. Talk about dying is often also expressed in metaphor and death can be seen as a battle, struggle or resistance against something harmful. 'Passing away', 'loss', 'letting [the child] go', 'could not get [the child] back' are metaphors used to describe dying (p. 59). However, as he points out, while the metaphors used reveal something of the experience, they also obscure something else of the experience. For instance, using the metaphor of emptiness and holes obscures how much the child and the child's death fills the parent to overflowing with suffering.

Husserl (in Mohanty, 1969) contends that while it is possible to find the meaning-function in the absence of speech elements, the converse is not possible. Because the essence of a communication exists in the meaning, it is possible that a representation of reality is as valid for fulfilling the meaning function as the existence of an actual reality. Husserl argues that just as many meanings can be attributed to the same object denoted by a word, so one perceived thing may be related to many things as they are perceived. These are termed perceptual noemata. It is immaterial whether these noemata are real or unreal, physical or mental. In other words, there is a concern with the analysis of the individual's experience of meaningfully using a specific expression. However, the meaning-intending act may not be obvious and may only become so subsequently in the act of reflection. Understanding in this sense, then, is the grasping of meaning (Warnock, 1970).

According to Kierkegaard (Palmer, 1996) indirect communication and metaphor are unbalancing in that they destabilise the smug complacency that stands between the individual and the truth. This kind of communication leads back into the self and of necessity reveals something of the subjective world of the one using the communication. There are no objective criteria for establishing subjective truth, and yet subjective truth is essentially related to the existence of the individual, the values and the foundation of such values of the individual. Hence values and morals, be they religious or aesthetic, originate from the sense of self of the individual.

3.3 Death, suffering and meaning

Suffering and death have been held to have a bearing on meaning-making and this is considered in this section, specifically where they are occasioned by parental bereavement and HIV/AIDS.

Davis (2001) has observed that although many authors have described that meaning attribution as a contributor to the resolution of grief after a significant loss, there is little clarity as to a definition of the process, or the means for achieving it, with a variety of different understandings. While some authors, such as Frankl (1964a) suggest meaning is primarily accessible through an emotional response others such as Moos & Schaefer (1986) understand it in terms of an intellectual understanding; some focus on the transformative aspects (Tedeschi & Calhoun, 1995), or on the explanation one produces for the event (Janoff-Bulman, 1992). Davis has found that being able to make sense of the loss and uncover some benefit to self-growth is associated with greater emotional adjustment to the loss. Attig (2001) takes a different approach in terms of which he understands “soul” as that which roots human being in the world. Hence he describes the experience of loss as “soul pain” (p. 37) and the suffering which causes the bereaved person to lose contact with this sense of rootedness leading to feelings of being dispirited and demotivated, as life appears to have lost the meaning that provided spiritual sustenance.

Corr (1979a) traces some of the attitudes that have been associated with death and dying through the ages. In this he examines the work of the French social historian Ariès who observed how in antiquity the suddenness and ubiquity of death in everyday life made it a familiar event, demanding resignation. However in the late Middle Ages death, the religious zeitgeist of the era, focussed as it was on the divine judgement that would follow death, transformed death into the opportunity to prepare to meet God. This gave rise to the cult of the ars moriendi (art of dying) such that the suffering of life was viewed as preparation for death. Hence the losses associated with both dying and grieving could find consolation in the knowledge that one had prepared with the gravity appropriate to the situation. Over the centuries however, a shift occurred which transferred the emphasis from the person dying to the death of the other. This manifested itself in the public observances around death, such as the erection of memorials and was accompanied by a change of perceptions surrounding death, where it ceased to be viewed as a normative life event and was viewed as a break with life evoking fear and obsessive morbid attention. More recently, in the last 100 to 150 years, death transformed into a shameful and taboo event to the extent that even the dying person was seen as needing to be protected from the unpleasant knowledge of the prospective demise. Much of the responsibility for caring for those near to death was transferred to professionals and institutions so that death if at all possible was separated and removed from the daily business of living. Death, in a tangential manner, forms part of much of entertainment, as portrayed in the mass media. Yet there is a “peculiar mindlessness” (Corr, 1979a, p. 37) which characterises these portrayals of death which paradoxically serve to maintain the viewer’s distance from it through an alienation of the experience of it. Gorer (1965) argues that death has become the new pornography. Just as in times past matters related to human sexuality and reproduction were not discussed openly and directly, so it is the case for death which is inherently abhorrent to be discussed through the use of euphemisms. Thus it can be seen that the relationship to death and dying is governed by the socially defined constructs around these issues at the historic intersection in time, which creates the context of the individual experience.

According to Simpson (1979), in the current era, the attitude with regard to death is one of fear and such fear can take various forms. Firstly, a fear of dying would encompass all those physiological and psychological processes that may accompany dying, ranging from pain to shame. Secondly, death itself is fear-provoking heralding the possibility of non-being and existential angst. The conjectured consequences of death can also inspire apprehension both as regards the future of those people or possessions which will be left behind, and for the unknown ahead. Finally there may be a fear of the death of others, especially loved ones which may be exacerbated in the case of negative past experiences.

Most recently, there is evidence that society is attempting a more realistic approach to death with concomitantly more honest representations of death in the mass media. A fairly recent example was the film *Wit* (2001) directed by Mike Nichols with Emma Thompson as the protagonist in a moving and realistic look at a renowned professor's struggle after a diagnosis with ovarian cancer. In Attenborough's (1993) *Shadowlands*, the leading actor, Anthony Hopkins succeeded in capturing fine subtleties of C.S. Lewis' experience after the death of his wife, as could be deduced from his autobiographical book. Death and dying have become common topics for study and research with many seminars and symposia. Simpson (1979) has enumerated the number of books (over 700) and articles (thousands) that he has in his possession on the topic of death, dying and bereavement. Considering that none date back to before the 1960s, it can be viewed as a remarkable and recent phenomenon. Satel (1999) in an article which condemns the overabundance of grief counselling is very critical of the (so-called) commodification of the grief industry with its plethora of books and counsellors doing work which research has not indicated to helpful especially after major events such as the Columbine killings. Simpson (1979) suggests that such an abundant interest in the subject may be indicative of denial, by making it something that is tackled by professionals in the field, once again removing it from the communal sphere.

The transience of life is made evident by death. If meaning lies in existence, lack of existence implies lack or destruction of meaning. Hence death can be viewed as an event which has the power to deprive life of meaning. Knowledge of imminent death can also bring with it knowledge for the ending of the possibility of amelioration, and thus a cessation of hope, where a person believes their life to have been unfulfilling or wasted. Hope is a multi-faceted phenomenon which is not to be equated with a desire for unrealistic outcomes, but is rather a state of being with a wide variety of presentations. Thus hope can co-exist in spite of the harsh realities of the situation that encompasses it. The value of hope is such that it may be subverted to uphold the human tendency to avoid finality in a way that results in a pretence-filled falseness which while providing momentary solace is revealed to be hollow and insubstantial. Thus, as Corr (1979b) notes, this laudable wish to lessen suffering may itself become the instrument for suffering itself through encouraging an isolating aloneness of the person who is comforted by such spurious hope.

Death as the extinction of existence, and more especially as the extinction of consciousness, is considered untenable by many. Research in this area has yielded support for the idea that understanding death as a passage from one to another form of existence is preferable to the idea of death as extinction. Philosophers such as Kafka as well as leaders such as Bismarck, have postulated that the belief in an afterlife or some form of continued existence is necessary for continued survival on a day-to-day basis (Kalish, 1981). Heidegger notes that at the base of anxiety is the ever-present fear is of non-being in the form of the threat of death (Vander Hoeven, 1964). At the same time there is also an ever-present anxiety of being-in-the-world, so that the fear of death is concurrent with the fear of life. Although Kierkegaard does not employ terminology such as 'defense mechanisms', 'denial' or 'repression', he proposes that the task of psychology is to expose the strategies that a person employs to avoid the anxiety that accompanies the sense of terror and annihilation that underlies the threat to existence posed by death (Becker, 1973). Camus too, from an existential phenomenological viewpoint, observes that the consciousness that enables humanity to distinguish itself from the non-human realm, is a double-edged sword in that it also makes humanity aware that it too will be subject to death, as are all animals. The ultimate paradox is that while people are driven to understand the purpose and meaning of life, this can never be resolved with certainty and hence people are doomed to live in an "abyss of absurdity" (Moller, 2000, p. 128).

Becker (1973) suggests that the fear of death has been the source of humanity's endeavour to overcome this potential extinction by denying that death is a being's final destiny. While Becker believes that fear of death is both natural and present in every human being, many people believe that this is not the case because it rarely manifests itself (doing so only once in a lifetime). He argues that the reason that it so seldom appears illustrates the effectiveness of repression. An implication of the existential paradox of existence resulting from the human nature which is both animal and conscious, means that one of the central dilemmas of consciousness is how to grasp the fact that life, and therefore symbolic identity itself, is evanescent. So difficult is this, that Becker suggests that, as Pascal stated, “not to be mad would amount to another form of madness” (Becker, 1973, p. 27). In light of this, repression offers a more honourable option for dealing with this dilemma, especially when this form of 'madness' is a socially agreed-upon, shared one. Repression thus permits the person to feel a sense of inner value and basic security.

Reflecting on the difference between fear and anxiety or dread, 'no-thing' is not nothingness but depends on its not being some-thing in order to be so defined. Hence no-thing itself is only possible as a part of the world as such and that which Dasein dreads then is also the being-in-the-world itself (Kockelmans, 1967). In contrast to the reaction where fear is involved, dread or anxiety results in the loss of the meaning of everything.

Death can also be seen as a signifier of loss. Apart from loss of life as it is now known and understood, it is a loss of consciousness, which may be considered ultimately all that anyone can call their own and which denotes a human being as that particular person. For both the dying and the bereaved, death brings knowledge of the loss of dear ones, as well as concerns as to how the survivors will continue after the loss of the person who has died. This may be of particular concern where the dying or dead person played an integral role in the economic survival of others. For the dying person death can also be seen as a release from pain or suffering, as well as heralding the hope for reunion with others who have already died. Other perceived losses are those of control, as has also been highlighted by Janoff-Bulman (1992), loss of material comforts, loss of body and of self, loss of future, dreams and hopes (Kalish, 1981).

Attig (2001) also pays attention to cognitive processes surrounding the loss describing how it is necessary for the bereaved person to “relearn the world” (p. 38). Such relearning includes the necessity of coming to terms with the physical elements that surrounding the deceased such as possessions, preferences or values as well as the physical spaces and places that had connection with the deceased. Occasions too, serve as reminders of not-being of the loved one and these include actual events as well as hoped-for ones such as absence at a graduation. Thus events, objects and places have meanings attached to them which transcend their intrinsic value. The absence of the loved one changes the meaning of existence. Similar changes of meaning also occur in the area of social relationships, both casual and intimate which make the person need to relearn how to relate to them. The relationship with self is another area that needs to be relearnt as the historical events reshape the bereaved person’s understanding of him- or herself. Finally the relationship with the deceased is altered and needs a renewed understanding. Although the relationship is no longer characterised by the same type of reciprocity, it continues to be reciprocal to the extent that the deceased give a legacy of their lives, and the survivors sense their support. There is a transition in memory towards a lasting love through which the living can confer a kind of symbolic immortality to the dead. Thus it is clear that Attig goes beyond understanding such re-learning as a cognitive process because many of these processes are inextricably linked with every aspect of being and living. The final aspect of the process of relearning the world is the “re-weaving [of] lasting love into life’s fabric,” through which the deceased are given new presence in the life of survivors (Attig, 2001, p. 51).

Frankl (1964b) has demonstrated the power of the individual's perceived meaning of an event to allay pain and suffering, even where the situation includes experiences which are horrifying and degrading. He has classified values into three groups in terms of creative, experiential and attitudinal values. This reflects the way in which individuals are able to find meaning in life as values must be lived in a manner which makes sense for the individual. Frankl (1964a) contends that the meaning of existence is not invented by the individual, but rather is discovered. In this journey of discovery, values act as a pull, which emphasises the role freedom as a central dimension of the process. The individual is thus not obliged to fulfil or reject the potential of meaning. As the search for meaning yields answers that are idiosyncratic and specific, what is important is the particular meaning at an identifiable moment in the life of the individual. It is possible that, as Frankl (1964a) reminds us, the fact that the question is asked at all, in the search for meaning, is more significant than the content of the question that is posed, because it demonstrates clearly the capacity of the individual for assuming responsibility for his or her own life. The consequence for such assumption of responsibility is for the individual to confront the finiteness of life and self.

Frankl (1964a) sees love as one of the ways through which meaning in life can be found and suffering is another. While suffering is not sought, once it occurs it opens the door to understanding the transitory nature of human existence. He contends that being brought face-to-face with an immutable reality motivates the individual to seek for life's meaning with transformed resolve. He states that "suffering ceases to be suffering … at the moment it finds a meaning". (Frankl, 1964a, p. 115). Self-transcendence is seen as a necessary adjunct to this process, making the spiritual dimension central to finding meaning in life.

It is possible then to find meaning in life by what a person gives the world in terms of his or her creations, by what the individual takes from the world as regards experiences and encounters, and the position that the individual decides to take in the face of an inexorable event. It is the human capacity to form and re-form oneself that enables the person to transform suffering from pain to meaning. In a longitudinal study of bereavement Davis, Nolen-Hoeksema and Larson (Nolen-Hoeksema, 2000) interviewed several hundred adults, aged between 18 and 84 years, at intervals, after the death of a close loved one. When asked whether they had found something positive in the experience, 65% of them responded affirmatively and described the areas of growth that they had experienced. This echoed the findings of research by Tedeschi and Calhoun (1995).

While death can be seen as an event that takes meaning away from life, Frankl (1964a) emphasises that the only potentialities in life are in fact the transitory aspects of life. As soon as they occur then they become part of the past where they are not lost but can be given meaning. In this way the transient aspect of life does not make it meaningless but rather presents a selection of choices or possibilities where past deeds, joys and suffering can be salvaged or redeemed through memory. Jung (1964) too believed that being brought face-to-face with the reality of death, as happens when one is witness to death, concentrates the mind on the meaning of life and the values that are attached thereto.

As pointed out by Havenga Coetzer (1997) the spiritual sphere is central to understanding Frankl's concept of the will to meaning as faith can be understood as an, "unconditional trust in ultimate meaning" (Frankl, 1964a, p. 156). This does not indicate a need for meaning which must be satisfied, but rather something that is discovered. Meaning then is a final explanation which is external to the individual rather than internal, and that, "the meaning which a person has to fulfill is something beyond himself, is never just himself" (Frankl, 1967, p. 11). Meaning then, has the capacity to draw the individual towards a concern for life that is directed towards the future, so that the nature of meaning is inspirational (Fabry, 1967).

Gergen (1982) suggests that in the process of interpretation of experience, the individual is reflexive in that his or her understanding of the past can be altered in view of present experience, and the present altered in terms of the past. In this sense the past is fluid and so presumably then, is the future. Moreover, the individual has the capacity to imagine alternative ways of being or behaving. Through these twin processes the individual is able to re-evaluate and reformulate what is prescribed by the culture.

Rowe (1991) claims that in constructing an inner understanding of the world it is necessary to deal with the issues of life and death, the purpose of life and the supposed existence and nature of God. Maintaining the idea of the continuity of existence after death is made possible by a symbolic extension of life into an after-life. In a sense, what makes this possible is the metamorphosis of the fear of death into hope for continued existence.

In an observation arising from clinical experience, Klass (1988) notes that although the symptomatic descriptions which are common currency are accurate representations of the bereavement experience, they did not help to explain the long term changes to the self that manifest in the bereaved. Moreover, the models that are available, do not assist in understanding the intricate workings of the grief resolution within the social-support network and the complex life history of the individual. Equally significantly, the way that the individual integrates the multiplicity of his or her symbol systems into their social environment is not adequately explained. It seems, therefore, that models which do not contain these elements are not able to wholly reflect the totality of the grief experience and this further highlights the importance of incorporating the central role of meaning-making into any theory or model of bereavement.

Davis and Nolen-Hoeksema (2001) conjecture that the reason people seek meaning in loss arises from an inability to acknowledge the inevitability of death, and the possibility that it may occur at any time within the life span. Kalish (1981) refers to this as the phenomenon of the 'horse on the dining room table' where diners are discomfited, puzzled and disturbed by its presence, yet no one is able to comment on its presence because of its inherent impoliteness. However, this does not imply finding a reason or causal attribution for the death. Rather it appears that the search is to find a transcendent meaning in the loss so as to make sense of it (Davis & Nolen-Hoeksema, 2001). Normative life events such as an age-appropriate death, and having spiritual beliefs are two factors which tend to facilitate making sense of the loss for survivors of a loss. However, although not all people express a need for meaning, an inability to find meaning, when it is sought, can result in despair.

According to Janoff-Bulman (1992), an event is traumatic if it is able to challenge fundamental assumptions and indeed to shatter them. When previously-held positively-biased assumptions can no longer be maintained, the self appears impotent against a world which now appears malevolent and meaningless. This conceptual disintegration of the inner world requires a creative reformulation in terms of a survivor perspective whereby the traumatic experience is re-interpreted and re-evaluated with the focus on the benefits that have accrued from the experience. The magnitude of this task is all the greater considering the fundamental nature of the assumptions that are now being contradicted. It also means that people have to overcome a preference to persevere in the maintenance of their theories rather than change them (cognitive conservatism), as is evidenced by the degree of confounding information that they are willing to fit into their theories before considering their dissolution. While to accept new and threatening assumptions of the world's malevolence and meaninglessness and personal powerlessness and frailty would provide a stable conceptual system which accommodates their experience of victimhood, the intensely negative emotions which are an adjunct to such a world-view, militate against it. Finding an answer to the arbitrary impermanence of life, requires a move away from a universal, simple and accessible formulation to one that has personal value. In order to achieve this, it needs to be appropriated and made one’s own (Corr, 1979a). According to Janoff-Bulman (1992), successful re-formulation is characterised by an emphasis of benevolence over malevolence, meaningfulness over lack of meaning and self-worth over self-abasement. Hence, there is an interplay between two evaluative systems one of which is cognitive and rational while the other is emotional and experiential and successful coping meets the requirements of both. The early response of self-blame, whether behavioural or characteriological, is an attempt to reestablish a sense of meaning and non-randomness in the world through a belief in control that could have been exerted that could have averted the event.

In order to reestablish a belief in the benevolence of the world and the individual's self-worth, a different type of interpretation is required which enables a transformation of the experience through the identification of positive elements in the experience or arising out of the experience so that while this experience would not have been chosen, it nonetheless has, almost as by-product, some valuable outcomes. Janoff-Bulman (1992) suggests that possible positive interpretations of a traumatic event are to find benefits for self and benefits for others. Both of these are instances of being able to add a deeper meaning to life by choosing to interpret certain aspects of suffering in a positive light. Benefits to self can include a sense of appreciation for life and reassessment of life values born out of a confrontation with death or possible death. An awareness of one's strength, endurance and the ability to survive in a dangerous world can also stimulate a sense of self appreciation and the experience may be viewed in retrospect, as having been character-building. A more refined sense of compassion, caring and patience is also attributed to this experience. The value of life and living is also more keenly felt and appreciated as are other loved ones.

Another way of adding a deeper meaning to the experience is turning the experience into a motivation for altruism. Whether or not an individual can find a meaning for himself or herself in suffering, there is nonetheless the possibility of finding a deeper meaning through an altruistic outcome. While the individual who has suffered recognises that the experience was unwanted and unplanned, and that it is one that would gladly be reversed if possible, these are not available choices. The option to choose lies only in their willingness to establish a deeper sense of meaning for the event (Janoff-Bulman, 1992).

Tedeschi and Calhoun (1995) agree that an increased sense of the ability to survive and sense-reliance can emerge as positive outcomes after trauma. Other positive outcomes can include changes in interpersonal relationships such as greater emotional expressiveness and a greater willingness to accept help and social support. Increased compassion, sensitivity to the needs of others and the ability to support others, have also been cited in this respect. In the sphere of a changed life philosophy, a positive outcome is a greater awareness of the value of life, time and relationships. The degree of introspection which this process entails may also foster a new life philosophy or spur the individual with renewed vigour into a more spiritual direction.

3.3.1 Meaning-making and HIV/AIDS

Crossley (2000a, p. 519) posits that a life-threatening illness such as HIV/AIDS is a 'biographical disruption' that threatens the most basic existential assumptions that people have of themselves and their world. This challenges the concepts that the individual holds of the self, body, the world and the likelihood of a future existence. There is an enormous disruption in the sense of lived time, as opposed to time left to live, that results from the deconstruction of that which was previously taken for granted. In spite of this, most of the research has focussed on the physical burdens of disease on the sufferer and caregiver and of the psychological aspects of stress that it entails (Carlisle, 2000).

Receiving a diagnosis of a life-limiting illness for the persons diagnosed, and those close to them, means that normal life ends and another takes its place where the planning for living is replaced by planning for dying. "Hence, an HIV-positive diagnosis has the capacity to fundamentally disturb one of the central characteristics definitive of the contemporary human being's existence; the fact that s/he lives in and for the future" (Crossley, 2000b, p. 36). Accepting AIDS as a terminal illness while maintaining a hope for a cure can be a major challenge in finding meaning for both the sufferer and their parents (Barroso & Powell-Cope, 2000). Perhaps the most difficult aspect for the parents of a child with HIV is the sense of not knowing how long their child will survive, and this relates to Frankl's observation that not knowing the length of the term of their imprisonment was the most depressing factor for a prisoner, reducing life to a provisional existence (Frankl, 1964a).

The long asymptomatic phase and the high degree of certainty of an AIDS following HIV at some point, can give rise to an anticipatory grieving process in the person diagnosed as being HIV-positive. Finding meaning by accepting the presence of the virus was one specific active existential strategy. The desire to work in the HIV field as a professional caregiver or volunteer is another strategy that helps caregivers find meaning (Crossley, 2000a).

Wheeler (2001) concurs that the great majority of the bereaved parents in her study could identify meanings in their lives resulting from the bereavement. The most common areas of meaning-making or meaning acquisition were in terms of contact with people and helping others. Some of the positive changes arising from finding meaning in values and beliefs were valuing life, accepting that which cannot be changed, caring more about people, valuing the spiritual above the materialistic, and finding new religious-spiritual beliefs. Some bereaved parents found meaning from personal growth, such as feeling better about oneself, becoming a better person, and pursuing further education.

Many caregivers felt that they did not survive the experience of caring for a loved one who was terminally ill with AIDS as the persons that they had been before the advent of the illness. However, surviving the experience appears to confer a sense of success that gives new meaning to life in spite of the death (Carlisle, 2000). While for some sufferers and caregivers the experience was marked by crisis, such as attempted suicide, Carlisle (2000) notes that many sufferers believe that HIV and AIDS had brought a positive and permanent contribution to their personal lives through initiating a reappraisal of their feelings and the ways in which they acknowledged and expressed them, both to self and to others. While it may not remove the pain of the experience, the ability to engage in a restructuring of life beliefs in the face of a challenging reality can reduce stress for caregivers. Hence, the finding of meaning can be a powerful way to redress the balance of the costs of caregiving with personal rewards (Carlisle, 2000).

For some parents, learning of the diagnosis leads to a knowledge, or exposure, of the lifestyle of their child, which may be especially intolerable to them (Kander, 1990). This is exacerbated where the child has contracted the illness as a result of homosexual contact, drug abuse or prostitution, as there may be exposure to moral condemnation by society, church and even the media. Moffatt (1986) describes the experience of shame as a 'What-will people-think syndrome' so that the climate of understanding and support that the mourner seeks during their grief process may be denied to them, even to the extent that mourners may themselves be reluctant to ask for the support of others.

Barroso and Powell-Cope (2000) have found that for some people the diagnosis of HIV or AIDS leads to a dissolution of social networks that were previously supportive. For some people, such a diagnosis also leads to a severing of family ties. Families may not overtly reject the person living with HIV; however, keeping the diagnosis secret or adopting extreme measures to avoid contagion may lead to a reinforced sense of stigma because such covert behaviour could be interpreted as a subtle form of backing away (Barroso & Powell-Cope, 2000). For others, however, news of an HIV diagnosis could also bring families closer together or end previous conflict as a result of the process of evaluation, or 'value-ation' (Janoff-Bulman & Frantz, 1997, p. 98) and the subsequent re-ordering of life priorities.

A basis for the sense of shame that is experienced by some people can be found in the Just World theory (Lerner, 1980) which suggests that people believe that they get what they deserve and deserve what they get. ‘Common wisdom’ also supports this view and sayings such as ‘what goes round, comes round’ tend to support this world-view. Seen from this point of view, it would seem that if a person is good, or leads a moral life, they should be spared misfortune. By contrast, misfortune would tend to happen to people who are not good, perhaps as a kind of punitive justice. In essence then, the question with regards to HIV/AIDS becomes more about why it occurs to specific people than why it occurs at all.

3.3.2 Meaning-making and parental bereavement

Braun and Berg (1994) suggest that it is part of the natural order of life that parents should pre-decease their children. A natural corollary to this is the common sense belief that children do not die. The death of a child challenges this assumptive world order, and the world now appears to be out of control, unjust and unfair. Hence the death of a child threatens the very meaning structures associated with being a parent. In order to make sense of the occurrence, the world view needs to be changed so as to accommodate the new reality which can incorporate knowledge both of the child's death and of the continuity of life.

The current generation is the first one to be ‘death-free’ in the sense of a lack of direct contact with natural human death (Corr, 1979a). This serves to distance human beings from their involvement in the community of living creatures, all of whom are destined to die. Hence the opportunities for reflecting on the meaning of death in order to understand something about one's own mortality are limited. As mortal beings, humans cannot be impartial observers in respect to confrontation with death, and the knowledge of death rouses many deep-seated emotions and fears in the survivors.

Confronting the harsh reality of a disturbing death, such as loss of offspring, violates an implicit sense of the continuity of life. Kalish (1981) lists an extensive collection of commonly used phrases such as “drop dead”, “dead end” and “dead weight”, to mention but a few, and suggests that this is indicative of how death and dying are at the forefront of human consciousness. Yet these phrases do not refer to literal death. Paradoxically, it seems, in the case of literal death, a variety of euphemisms are used in common parlance for referring to death perhaps because death itself seems almost unspeakable. Language patterns appear reflect this understanding so that one of the reasons for using such words is the fear that to talk of death, although even to use the words, would be tantamount to courting death (Boston & Tresize, 1988; Kalish, 1981). Capps and Bonanno (2000) have also emphasised the role of language especially in the way a narrative is grammatically constructed. Grammar can construct a particular view of the narrator in relation to it and reveal perspectives that might not be fully accessible to narrators themselves.

Kalish (1981) suggests that in order to cope with the significance of death humour, alcohol, drugs, denial and anger may be employed. The feeling of intense anxiety or dread which is part of the experience of disintegration when faced with a seriously traumatising event such as bereavement or a life-threatening illness was termed 'angst' by the Existential philosopher Heidegger (1962). If meaning for individuals exists in the connections and relationships, then the loss of a significant constituent in this chain causes the whole complex configuration to fragment. In this respect, existential crises produce a sense of groundlessness as the person suffering a loss finds that nothing makes sense any more, rather like the vertigo experienced when faced with an abyss (Crossley, 2000b).

All facets of human functioning including the physiological, psychological and the social aspects are affected by the impact of a significant loss such as the loss of a child, as this kind of loss is frequently of a traumatic nature. It shatters the bereaved person's sense of being able to manage their emotions and relate to others, as well as shattering their world-view, which is their customary pattern of understanding their world. The sense of safety or trust in the world is dramatically affected as most people assume that their own death will precede that of their child (Janoff-Bulman, 1985; 1992).

The search for meaning is a way for bereaved individuals to try to integrate the death into their lives by constructing an understanding of the events surrounding the death.

Understanding helps to restore a sense of being in control, rather than being powerless and helpless, even if this means resorting to self-blame (Shapiro, 1994). Davis and Nolen-Hoeksema (2001) have found that people coping with loss tend not to be satisfied with a causal understanding of the death but seek a deeper, philosophical meaning for their loss. While causal attributions such as the explanation that a physician can provide, can be an aid in the search for meaning, finding such an explanation rarely provides the reason that the bereaved person seeks.

For most bereaved people there also appears to be a reconstruction of the relationship with the deceased beloved and this occurs through a novel narrative which interweaves multiple connections of the person's life to the experience of the death and the now-dead beloved. Thus anniversaries are particularly apt to trigger memories, tied as these are to significant dates, many of which have ritual or religious associations. Anniversaries also becomes milestones which are missed by the deceased, so that other children grow, other events occur, while the dead remain behind and, in a sense, static, confined to the totality of their existence prior to the death.

Boston and Tresize (1988) have found that each individual tends to have vastly different meanings regarding death. Depending on one's belief, it can be construed as a beginning, a transition or an end. Where there is a belief in an eternal existence, death becomes the doorway for re-unification with the beloved child who has died, and so death appears to contain all life's meaning. On the opposite end of the continuum, others attempt to describe death as nothingness, seeing it as an ordinary and insignificant event. Between these two extremes, bereaved persons must craft their own personal meaning of death. In the absence of a predominant religious belief, people draw on many traditions and religions to construct their own understanding of the meaning of the death.

Rando (1986) believes that the child is an extension of the parents psychologically, and the loss of the child leads to a sense of loss of part of themselves, sparking an existential crisis, so that the process of grieving becomes a means to re-create their sense of meaning of self. Brotherson (2000) too has found that parents struggle with a sense of parental identity after their loss of a child. When a child dies, idealistic assumptions about motherhood may rapidly turn to self-blame and feelings of failure. Mothers, under these circumstances, are likely to feel marginalised by failing to live up to the benchmark family ideal where they are principally responsible for outcomes relating to the child's life (Farnsworth & Allen, 1996). The child embodies for the parents possible immortality and continuity of life beyond their own life-span, so that the loss of a child disrupts the sense of an orderly universe where the oldest die first (Rando, 1986).

Davis et al. (2000) argue that a significant proportion of well-adjusted bereaved individuals do not search for meaning after a significant loss. However, the Leiden Bereavement Study (Cleiren, 1991) has found that the bereaved group most likely to be concerned with issues of meaning is that of parents who lose a child. In addition, bereaved mothers appear to experience greater levels of guilt and anger as well as greater social isolation. Those parents who lose an only child suffer more guilt than those who have surviving children. Janoff-Bulman (1992) differentiates between behavioural self-blame and characteriological self-blame. In the former blame is located on acts of omission or commission that may have contributed to the loss whilst in the latter the blame is focussed on the character of the person. The use of characteriological self-blame is linked to depression, but the development of behavioural self-blame can contribute to the reestablishment of meaning through the structuring of beliefs about control. The ability to shun the use of characteriological self-blame enables the person to believe that they have done something which in retrospect is ill-judged, even though their judgement is not impaired. According to Janoff-Bulman this is indicative of the individuals effort to find benevolence, meaning and self-worth. By interpreting events so that a sense of control is enhanced, meaningfulness is enhanced as the event is not random but rather dependent on particular contingencies which could have been different. This is a vital aspect to the reestablishment of a new and viable assumptive world.

In contrast to Rubin (1981), who argues that the goal of the bereavement process is the restoration of pre-loss levels of functioning, or Worden (1988) who sees it as 'working through' the grief, phenomenological theory suggests that there cannot be a return to a pre-traumatic state (Golsworthy & Coyle, 1999). This is supported by findings that bereavement and other threatening events can be catalysts for substantive changes within the individual. In this regard the goal of the bereavement process could be the creation of a new representation of the individual's reality. Research by Braun and Berg (1994) has focussed on the process of meaning reconstruction employed by bereaved parents. Where the explanation of the death cannot be made to fit the assumptive world-view, there is an extreme disorientation or shattering of previously-held beliefs, assumptions, values and norms. At its most extreme, such a degree of disorientation is incompatible with continued existence, so that the bereaved parent begins the process of adjustment to the prior meaning structure in order to restore a sense of meaning and purpose in life that is compatible with its continuation. Themes which were identified as properties of the meaning structure of parents prior to the death of the child that cannot account for the death, are:

- Centrality of the child's life in the parent's sense of meaning and purpose in life. This also refers to the way in which the child's life was central to the parent's experience of self and their vision of the future.
- Nature of life beliefs that include a sense of the goodness and justness of life, and include beliefs about immunity to tragedy.
- Personal control refers to the sense of being able to influence the outcome of events in their lives.
- External control refers to the belief about the existence of an external control such as God, and the power that is attributed to such a being.
- A belief in the existence of order in the world and that there are reasons for what happens.

An additional possible belief that is not able to account for a child's death, is where there is a belief that existence ceases at death, because this signifies that a premature death nullifies the ability to make meaning of life.

Braun and Berg (1994) suggest also that social factors contribute to the development of these meaning structures that are incompatible with the death of a child. Planned parenthood does not include a plan for losing the child. It also means that a parent has fewer children, in whom there is much personal and emotional investment. There are also beliefs that life should be good, and that people are themselves responsible for outcomes. In addition the general denial of death of Western society where death only occurs to the elderly (after removal to a hospital, an old age or nursing home), makes the death of a child seem incomprehensible.

Where meaning structures fail to account for the child's death and the discontinuity it represents in the life of the bereaved person, there is a severe sense of disorientation. This sense of disorientation is characterised by feelings of being disconnected from the world, of a fragile life with consequent fear and distrust. Loss of hope for the future, a sense of powerlessness, loss of personal control and loss of purpose in living also contribute to the sense of disorientation. It is clear then, that the extent of discontinuity is what differentiates the loss of a child from other losses, as an entire collection of assumptions about life is undermined, and this strikes the parent at the level on which their whole existence is based.

The findings of Brotherson (2000) about parental behaviour in relation to parental identity suggest that connecting with and remembering the child in diverse ways are fundamental aspects of parental behaviour after a child's death. Possessions including clothing, photographs, letters and mementoes relating to the dead child may take on particular significance. More recently, the Internet has provided a further means of creating memorials, through dedicated web sites (Roberts, Bruce, Izarraz & Soni, 2000). According to Rosenblatt (1990) this is because the meaning inherent in them can assist in the definition of the relationship to the deceased.

In the Two-Track Model of bereavement (Rubin, 1981), Track I comprises the overt symptomatology of the individual's biopsychosocial function of the bereaved person, and Track II comprises the more covert aspect of the bereaved person's continued relationship with the deceased. In a later study, Rubin (1999) has found that whereas functioning for bereaved mothers on the basis of Track I improved as a result of more time having passed since the death, there was no difference between the two groups regarding their concern for the deceased (Track II). He notes that it is difficult to capture the essence of their experience in statistical findings, and highlights the importance of considering both Tracks because death does not necessarily bring to finality the bereaved person's attachment bond for the deceased.

Stroebe et al. (1994) also offer a dual process model where it is suggested that although bereaved people often attempt to make meaning of their experience, they also struggle to restore the lost order, using avoidance to cope with painful feelings. While traditional models view resolution of the grief as the ultimate goal, Stroebe et al. (1994) examine the different approaches used by bereaved parents to reconstruct their worlds to reflect a new and different view and how these efforts occur simultaneously with attempts to achieve some sense of resolution of the loss.

Neimeyer (2000) makes a cogent point that the focus of the meaning-making process tends to shift over time. The course of the life-story of the bereaved person is changed as a result of the death and there is an attempt to find new meaning for both the bereaved as well as some meaning in the death. The construction and integration of meaning occurs within a personal as well as social and cultural context and is particular to that individual, his or her history and the relationship that existed between him or her and the deceased. Although the social milieu also provides an audience for those new meanings to be tried out, the process of meaning-making is nonetheless highly personal and idiosyncratic. In contrast to Frankl's (1964a) belief that meaning must be discovered, there is no global ‘meaning-to-be’, but rather a process of creating or constructing a significant new understanding.

The purpose of these new understandings, and the narratives employed to such an end, is to facilitate the process of healing and reconstruction. As such, these narratives provide an entry point into the subjective reality of the person who creates them and can become powerful vehicles for clinical intervention (Neimeyer, 2001). Capps and Bonanno (2000) also understand a narrative to be a pervasive and powerful tool for reconstructing personal experience, and thus contend that a narrative approach is warranted given the tendency for bereaved persons to repeatedly revisit this event over the course of their lives.

Rando (1986) has found that losses may accumulate in the wake of bereavement, each one compounding the other, making the bereavement process more difficult. In the case of a parent whose child has died as a result of an AIDS-related illness, it would seem from the above discussion, that there are various factors that might increase the need for finding meaning. Where a parent knows their child is suffering from a life-limiting illness, there is a face-to-face confrontation with death, pain and loss. The sense of repugnance both for the way the illness is transmitted as well as for the physical ravages of the illness can also complicate the grief process and in this way the AIDS-sufferer becomes a metaphor for these fears about disease and death. It is possible then that the search for meaning that is experienced by these parents is more significant than it would be if the terminal illness were non-stigmatised.

The idea that it is possible to experience growth after a devastating loss is not new. In *The Prophet' Gibran* (1973) asks, "Shall it be said that my eve was in truth my dawn?" Research by Miles & Brown Crandall (1986) has indicated that bereaved parents quoted positive outcome categories more frequently than negative ones. Positive outcome categories included statements such as being more grateful, compassionate, appreciative, serious about life, aware of the importance of loved ones, aware of the fragility of life and having a greater understanding of life and death. Negative responses included not being able to forget the loss, recover, or resolve the loss.

While Miles and Brown Crandall (1986) caution that the self-selection aspect of the sample could mean that it may not be possible to generalise from the results, it is interesting to note that many of the parents indicated that they had found some meaning and grown since the death of their children. The existence of support groups such as The Compassionate Friends and Mothers Against Drunken Drivers among others, indicates the attempt by bereaved parents to channel the pain and rage of the loss into meaningful endeavours. It is also possible that through this involvement the search for meaning can affect the outcome of the grief process positively. Ramsey and Blieszner (2000) also emphasise the communal aspect of the search for meaning and that it is more than a solitary activity. Groups are mentioned as a way for people who have shared similar experiences to make meaning of an event and build the resilience necessary for transcending suffering. Ramsey and Blieszner (2000) also emphasize the communal aspect of the search for meaning, and that it is more than a solitary activity. Groups are mentioned as a way for people who have shared similar experiences to make meaning of an event and build the resiliece necessary for transcending suffering.

Tatelbaum (1983) has found that using affirmations for personal growth can provide the beginning for changes. Previewing possibilities enables the bereaved parents to imagine desired opportunities as a first step to transformation. Loss can launch the bereaved person into a new life in which making grief meaningful can act as an antidote to despair and suffering. It also becomes a springboard to personal growth and achievement (Calhoun & Tedeschi, 1990; Polatinsky & Esprey). Many bereaved parents go on from grief to become counsellors or healers for the suffering of others. They are then able to enhance their own lives through the compassionate helping of others. Shanefield, Benjamin and Swain (1984) found that over half of bereaved parents in their study reported having experienced personal growth, becoming more emotionally expressive and more productive and were able to talk about sensitive emotional issues. There was also a commitment to living life more fully and meaningfully. Other studies have shown that bereavement may be associated with personal growth (Edmonds & Hooker, 1992). Kessler, (1987), Schwartzberg and Janoff-Bulman (1991) and Ulmer, Range and Smith (1991) have found that participants in their studies believe that their grief has led to a deeper appreciation of life and their surviving loved ones.

Creativity is used by some bereaved parents as survivors of trauma, to forge a new sense of reality and to rework the symbols and images of the trauma through working with others. There is also a transformation that occurs in the values, goals and assumptions that are held about the nature of the world and of the self (Baures, 1996). Tedeschi and Calhoun (1995) found that areas of growth after traumatic loss included growth in character and an enhanced capability of being able to survive, strengthened relationships and an increased sense of connectedness, characterised by a greater capacity for compassion. Other perceived areas of growth are a changed philosophy in life with a greater appreciation for life, and new understanding of spiritual beliefs. Davis and Nolen-Hoeksema (2001) however, differentiate the meaning-making process from that of finding benefit from the loss, because, irrespective of the ability to make sense of the loss, people may be able to report some benefit to have accrued from the loss, which facilitates emotional adjustment over time.

Parental meaning-making is evident in much of the narrative presented by bereaved parents (Rosenblatt, 2000). This includes attempts to understand reality which becomes necessary where the child predeceases its parents because this is seen as an unnatural event which shakes the orderliness of life and hence is meaningfulness. An accounting for the multiplicity of losses encompassed in the loss of a child can also serve as a foundation for meaning-making by defining what must be given meaning to. Loss of an imagined or envisioned future is an example of this (Rando, 1986). Some parents seek comfort in recounting or enumerating how things could have been worse, or how the child is now free of a worse fate such as prolonged suffering. Searching for positive meanings is part of a process of reinvestment in life, not through negating the enormity of the loss, but by finding something in it that was not negative. Allied to this, is identifying the good that has come from the death, which is a legacy of their child (Rosenblatt, 2000).

Nadeau (2001) has reflected on the intersubjective nature of grief within the context of the family, noting that it is through the sharing with other family members the nature of the common loss, that people attach meaning to the loss. While some meanings are agreed on shortly following on the death, others evolve over time. A factor which may enhance such a process include the presence of in-laws who by definition are somewhat freer from the rules which govern the interaction of family members. Another factor is the family's eagerness to share meanings and the opportunities for doing so in the frequency of contact between members. A significant strategies for meaning-making is storytelling, also through reaching a common theme for the family story. Some themes, however, appear more likely to bring comfort than others, such as a theme of the death being a good one, versus a death being in vain. Other common strategies are the comparison with others who have suffered losses, and the sharing of dreams, especially of the deceased.

3.4 Religion and spirituality in meaning-making

This section focusses on the role of religion and spirituality on meaning-making. While religion can be defined as a particular socially organised system of faith and worship based on human recognition of superhuman power, spirituality can be defined as the human propensity to find meaning in life through self-transcendence. According to Kalish (1981) religious and cultural belief systems have given credence to the belief that death is a transitory phase in an immortal life and this has been the case since time immemorial. Corr, (1979b) notes that some authors have argued that religion is an attempt to deny death by offering the hope of an immortal existence. Each belief system has its own understanding in regard to the mechanisms behind these beliefs which provide a more satisfactory solution to the finality of death. In support of this, is the observation that spirituality often becomes particularly salient as people age and move closer to death (Golsworthy & Coyle, 1999). In essence, while recognising the impossibility of continued life, belief systems offer their followers the possibility of spiritual immortality. Moreover the redemptive possibilities of death are emphasised in many religions such as Judaism, Islam and Christianity. Within the context of religious or spiritual belief, the bereaved is also given access to various rites and rituals in regard to death which in addition to hope for some form of immortality, may provide comfort through the social support which is evidenced. Tedeschi and Calhoun (1995) concur that there is a tradition in philosophical and religious thought that tragedy may lead to exploration of meaning and hence spiritual growth. Religious beliefs can provide higher-order cognitive schemas that serve to provide meaning even where the event itself appears to have none. This is made possible by the provision of universal truths and values that provide a "sacred canopy" which shelters the bereaved person from the chaos that follows a traumatic event (Tedeschi & Calhoun, 1995, p. 73). This is especially helpful where God is seen as benign as it can be used to minimize the crushing aspects of an event, by incorporating them into something larger. Mantala-Bozos (2003) suggests that from her research some aspects of the Orthodox-Christian rituals associated with death correspond to positive predictors of successful bereavement outcome as defined by Worden. These include the facilitation of a strong social support system while also giving the bereaved permission to grieve openly in the early stages following the loss. Both of these qualities are identified in the literature as primary tasks of grief counselling and grief therapy (Worden, 1988).

Simpson (1979) finds conflicting evidence regarding the role of religion in determining the course of the grief process, but concludes that the significant aspect may be having faith, rather than following a particular religion. However it appears that, "major philosophical debates are less prominent among the dying than might be expected; they may be more the prerogative of the healthy" (Simpson, 1979, p. 121).

With respect to parental bereavement, there is an ongoing debate about whether the fear of death is diminished by religion or whether in certain cases fear and anxiety may be exacerbated. The punitive face of religion which presents God as a righteous judge who seeks retribution or ideas of hell may serve to increase fear. Kalish (1981) suggests that the group that has the greatest difficulty in respect of fear and anxiety related to death may in fact fall in neither the staunchly religious group nor that which determinedly rejects religious belief. Rather it is the group who is undecided about what to believe.

A different kind of immortality proposed by Kalish (1981) is that of social immortality where the individual continues to exist for others albeit symbolically. Ways of preserving the person who has died for those who continue living include: memories of individuals or groups to whom the deceased belonged or made contributions; oral traditions, which can include audio-visual recordings and written items; a family name or tradition; ancestor recognition, which is of great importance within certain cultures; achievements that out-live the deceased and by entering the annals of recorded history.

According to Antonovsky (1979) the sense of meaningfulness is very significant as it determines whether or not an experience will have a high sense of coherence. The feeling of having influence on the outcome of events fosters a sense of meaningfulness and it refers to the extent to which the individual experiences life as making sense when seen from an emotional point of view. Yalom (1980) differentiates between secular and cosmic meaning. Secular meaning refers to meaning resulting from the belief that life is purposeful. Cosmic meaning refers to the belief in an overall order of life and sense of coherence about life events which may express itself as a belief in a higher power such as God. This is also echoed in Janoff-Bulman's (1992, p. 11) assertion that, "belief in a God who rewards a moral existence also reflects belief in a meaningful world, despite the fact that direct control does not rest with the individual performing the deeds but rather with a God responsible for making the ultimate judgement about one's outcomes." Thus the belief in the existence of a relationship between an action and an outcome provides a sense of control. The apparent effectiveness of certain strategies in producing specific outcomes leads people to believe that they have a greater control than is in fact the case, especially when it applies to chance events and may form the basis for superstitious behaviours. This may also include self-blame in the form of seeing the event as divine retribution for past transgressions.

A variety of other strategies are employed in justifying suffering in a religious context. Kushner (1981) suggests the following are commonly utilised: a belief in the instrumental nature of the misfortune such as God using this event to teach a life lesson in much the way a parent would discipline a child through deprivation or punishment; seeing the event as God's righteous punishment for wickedness; a belief that God does not send more suffering than a person can bear; trying to understand death as the liberation of the person who has died from existence which can be fraught with difficulty or suffering. When people have maintained faith and hope in the face of suffering, death can appear as God not answering their prayers. Common responses to, or reasons for, not receiving the wished for outcome include: the person's lack of merit; inadequacy in praying; another's more worthy prayer with conflicting interest; non-existence of God; inability of prayer to change events; God's wisdom in not granting all human desire. As he points out many of these justifications appear more suited to the defence of God's good name (or even fate's) than as comfort for the victim. In this sense, they assist to preserve the illusory security of others confronted by the seemingly senseless nature of a catastrophic event. He suggests also that it would appear that accepting the randomness of the universe as the residual chaos of creation, is more than many people can confront, therefore, "they look for connections, striving desperately to make sense of all that happens" (Kushner, 1981, p. 54).

The final chapter which is titled, 'What good, then, is religion?' Kushner (1981) explains the sense he has himself made of the event of the suffering and death of his son, Aaron. Indeed the entire book is a reflection of the reasoning he employed and process he underwent to reach such meaning. That this meaning is essential for his own continued survival is clear in the final words of the book, "I think of Aaron and all that his life taught me, and I realise how much I have lost and how much I have gained. Yesterday seems less painful, and I am not afraid of tomorrow" (p. 155).

In this regard, Corr (1979a) argues that religion can be understood as an attempt by society and the individual to deny the reality of death or to somehow 'manage' it. Thus in many religions death is perceived as merely a stop on the way of an eternal existence which may variously incorporate doctrines of immortality, resurrection or reincarnation. However, faced with such a devastating confirmation that death involves the cessation of life, the bereaved person might be left to ruminate how even if the deceased is continuing to exist, they are no longer available in this current existence. Hence, Balk (1999) contends that some bereavements present a life crisis that forces the bereaved person to review the meaning of life and one's place in the universe, and in so doing, provide the medium for spiritual change.

Crisis provokes questioning about the meaning of existence which can lead to a conversion of belief. Shanefield, Benjamin and Swain (1984) found that almost two-thirds of participants in their study experienced an increased sense of spirituality. As Kushner (1981) points out, questioning of faith is not restricted to those of lesser faith, and a repudiation of religion is as valid an outcome of the process as is the embracing of religion.

Research by Davis and Nolen-Hoeksema (2001) appears to indicate that having religious or spiritual beliefs appears to facilitate the process of meaning-making after loss. This is possibly a result of the fact that having a pre-existing world-view makes it easier to make sense of the loss, sooner rather than later in the process. The Stanford Bereavement Project (Davis & Nolen-Hoeksema, 2001) found that people who are unable to make sense of their loss within 6 months of the loss, appear to be unable to make sense of it later. However, finding meaning early does not put an end to the process of searching for meaning and this searching persists.

Watson (1986) contends that people who suffer behave as though there is meaning in suffering, and that this is evidenced by their search for answers to questions that they pose. The meaning sought is whether any good can come of the suffering, and whether there is any meaning inherent in the suffering. The framework for establishing meaning comes from the world-view of the individual, which fits on a continuum of epistemologies ranging from the secular/scientific worldview to the sacred/religious worldview. In the former, the cosmos is seen as autonomous from supernatural forces, while in the latter, the cosmos is wholly dependent upon them. The former is an evolutionary model and emphasises the survival of the fittest and extinction of that which is maladaptive, while the latter describes existence in creationist terms of divine salvation. There is a tension between these antithetical worldviews that the individual needs to resolve so that science can admit a purpose to life beyond the observable limits of physics and religion can admit the possibility of organic etiology for illness and death. Archetypes for the meaning of suffering are naturalism (where death is seen as a part of human destiny), altruism (a belief that others may benefit as a result of the loss), correction (the loss as punishment) and affirmation (loss as the way to spiritual growth). The image of God in the correction and affirmation archetypes is as the direct saviour/mediator of life with the focus falling on the individual as sufferer, while the image of God in the altruistic and naturalistic archetypes is as the indirect creator/nature of life with the focus falling on humanity as sufferers. A positive orientation to suffering can be assumed in the affirmation and altruism frameworks while correction and naturalism tend towards a negative orientation.

Golsworthy and Coyle (1999) concur that human beings create a structure of meaning that gives a sense of order and purpose to their existence and to death through religious and spiritual beliefs. However, it is important to also take into account the complexity of the phenomenon, such as the interactions between an individual's belief system and his or her response to loss. Hope appears to be a significant component of religion that imbues a sense of purpose to the loss, and for many bereaved people, meeting the deceased again in the next world is a significant aspect of hope in the midst of despair over the loss.

Meaning can be sought after bereavement through asking, “why did this happen?”, as well as through wider searching reflected by attempts to answer the question, “what does my life mean now?” Questioning is a common theme in the search for meaning following bereavement and appears to result in an oscillation between the support gained from their prior meaning structure and a sense of uncertainty following the loss. However, what appears to be important is to challenge definitions of reality, including the explanations provided by others, which are rejected or resisted (Braun & Berg, 1994). This concurs with recent bereavement theory which focuses on the oscillation between an approach versus an avoidance of grief (Stroebe, Stroebe, & Hansson, 1993). This process of oscillation seems for many to be a constructive process assisting in the development of a reintegrated religious meaning structure (Golsworthy & Coyle, 1999). There is also a measure of consensus regarding the positive implications of the loss in that bereaved persons found they developed. These include a greater capacity for empathy and understanding of others and an increased sense of the importance of, and involvement with, relationships and human life.

Negativity or anger toward a higher power may indicate the mourner's inability to derive a sense of meaning from of the death. When assumptions about the nature of God (as just and benevolent) are contradicted, this incongruity leads to feelings of anger and blame which are directed towards God. However, finding meaning from the death, helps to mitigate some of the sense of anger and is thus able to lessen the severity of the grief response (Williams & Gamino, 1998).

In their research Golsworthy and Coyle (1999) found that a key element of faith was the nature of relationship or connection with God. For some this relationship was intimate and built around trust, while for others their experience of bereavement appeared to shake their faith, leading to questioning and doubt. For most participants, there appeared to be a link between personal support and feeling spiritually supported. In some instances, God was seen as instrumental in the provision of the support, be it from within the family or outside of it, and this increased their sense of spiritual connection.

Klass (1997) has traced the spiritual consolidation of the 'inner representation' bereaved parents make of the child and its validation by the community of others who have suffered similarly tragic losses, which supports the idea that meaning reconstruction is as much a social practice as it is a cognitive process. Bereaved parents are able to get others to know their deceased child through the process of sharing stories and experiences with others. In a sense this is a process of constructing a biography of the deceased and enables the parents to mould the representations they have of their deceased child so that these can have a sense of constancy and stability. Fleming and Belanger (in Neimeyer, 2001) discuss bereavement as 'losing what you have' and how the creation of 'having what has been lost' is the legacy that connects the bereaved to the deceased.

Golsworthy and Coyle (1999) found evidence of a sense of continuity arising through an experience of an ongoing relationship with their partner after death for bereaved spouses. The participants' accounts of their experiences suggest that ongoing relationships with the deceased were not necessarily dependent on being with them but rather on intrapersonal factors. The extent to which there was a feeling of spiritual support and a sense of ongoing presence depended on the meanings attached to these ongoing relationships which can only be regarded as spiritual rather than social in nature.

Klass (1997) has found that parents do not forget the child who died, nor do they wish to. These memories can comfort, but are also painful. They connect the parent to the child and emphasise the importance to them of their role as parents. Rosenblatt (2000) also notes the continued presence of the child in the parent's life in the narratives of bereaved parents. This is achieved through keeping reminders of the child, creating reminders, memories and memorials which are symbols honouring the life of the child.

Continued interaction of parent and child is a common theme in the narratives of bereaved parents. This interaction is quite diverse, sometimes involving feelings and a sense of presence, or having mental conversations with the child. Parents also tend to keep track of the child's timeline as a way of remaining connected to their child, and this may set off recurrent bouts of grief as new losses are encountered, as the parents become aware that each new developmental milestone is yet another that will not be attained by their child. Grieving can also be a way of continuing to be connected with the child and attempts to silence the grieving may be construed as an attempt to break the connection with the child (Klass, 1997). The continuing communication with the child means that the child is still alive somewhere and there is therefore a hope for being reunited with their child in heaven. Interestingly however, the sense of spiritual support and the connection to God and to the deceased does not appear to lessen the pain of loss. While spirituality or religion may assist the bereaved person in living with the loss it does not reduce the experience of grief. Moreover there is a belief in the permanence of the loss, and an acceptance that henceforth there will be permanent change (Golsworthy & Coyle, 1999).

According to Marrone (1999) psychological and spiritual transformation for a bereaved parent is likely to occur for the parent after the loss of a child because of the nature of the parent-child bond. He considers this bond to be a sacred rather than contractual bond, which cannot be abandoned if the relationship ceases to be satisfactory, as can happen in marriage through divorce. Even where a parent and child cease to have any contact with one another, they are still connected by virtue of this bond, which defines each participant by the nature of the relationship to the other. The parent employs three rationales in this process of transformation: reunion, where the parent hopes to be reunited with their child in an after-life; reverence, where the child's death is deemed to serve a higher, perhaps inspiring altruistic social service; and retribution, where the child's death is viewed as punishment for the sins of the parent thus validating the sense of guilt which is commonly experienced (Marrone, 1999).

After the loss of their child, parents are confronted with the task of re-defining the meaning of their own lives, the meaning of the life of their deceased child and the meaning of their relationship to them. In their research Riches and Dawson (1996) found that religious belief was a major support and source of reassurance, especially if there is a conviction of an eternal existence. Some parents find that visiting a medium can be valuable in constructing a sense of the specialness of their child, especially regarding some kind of pre-cognition of the impending death or a signal which marked the death. Moreover, those parents who were originally sceptical of these beliefs, admit to revising their original rejection of the possibility of life after death. Sharing of information of mediums and their abilities is one of the more common topics for bereavement support groups (Riches & Dawson, 1996).

According to Rosenblatt (2000) it is to be expected that religion is central in the narratives of bereaved parents because it is a major area of discourse in the culture for dealing with death and the meaning of life. Death is seen as a challenge to religious belief and so the resolution of this challenge can form a significant aspect of the narrative. While not all bereaved parents reach resolution, he has identified seven ways in which this conflict is resolved:

- An affirmation of religious belief while still questioning the death.
- Not seeing God as responsible for the death, and believing that the child is with God.

- Understanding the death as part of God's plan, and that the child's task on earth was completed.
- Not seeing God as responsible for the death, but believing that God chose not to intervene.
- A sense that only a belief in the existence of God makes the loss bearable.
- A rejection of religious language in that death is seen as an arbitrary event.
- A lack of belief in God, in the light of the event.

Common to religion is the use of funerary rituals as a response sense of fear that is engendered by death both to the individual and the community. Fulton (1979) suggests that the function of funerary rites is to acknowledge the death, restoring confidence and social cohesion. According to Fulton, the funeral facilitates both the expression and sharing of grief, as well as acknowledging and confirming the existence of the deceased prior to the death. Seeing that the loss is also mourned by others in the community has a positive effect on the bereaved person. The attitudes of funeral directors or others associated with the burial is also important in providing a sense of comfort to the bereaved and religious frameworks are also the common context for funerary rituals with communally accepted structures for burial. Burials appear very early in human history and Fulton remarks that there is evidence of such rites since paleolithic times. Tribal cultures too, appear to place importance on such rituals, and it appears that there is a sense that the style of such rituals reveals a great deal of the nature of the social group that practices it (Jackson, 1979). As a result of this, it is a well-studied phenomenon especially as regards anthropological research, which contends that funerary rituals promote group cohesion and the emotional welfare of the members of the group. Aspects of the ceremony such as processions, the sharing of food, social exchanges increase the bereaved person’s sense of communal participation. Other rituals enhance the sense of passage from life to death and affirm the continuance of existence in another realm. While the death of a loved one always evokes strong emotions, the death of some prominent public figures has a similar affect especially where the death was violent in nature or unexpected. Fulton refers to the deaths of such American luminaries such as President Kennedy and Martin Luther King among others. More recently the death of Princess Diana after a road accident, appeared to provoke a national crisis in England, with Queen Elizabeth earning much opprobrium from her subjects, for, what was judged to be, an inappropriate response. South African history too has many such heroes. In the last thirty years, the sudden and violent deaths deaths of personages such as Steve Biko, Hector Petersen and Chris Hani have evoked powerful emotions of grief and anger and precipitated social disturbance of such magnitude that imperilled the future of the nation. Such emotions need to be expressed and perhaps calmed. In this respect, the voice of Nelson Mandela, appealing for calm, subsequent to the assassination of Chris Hani, changed the possible trajectory for events. Research of a representative sample of adults conducted within a week of the assassination of President Kennedy showed a general preoccupation with the death which was accompanied by physical symptoms and crying. People reported feeling anxious, tense and numb and the sense of grief was personal rather than ideological (Fulton, 1979).

3.5 Conclusion

This chapter has explored aspects of meaning-making in general, and specifically meaning-making in the context of suffering and death, with an additional focus on the possible role of religion and spirituality in this undertaking. There is a tendency within human existence to attempt to create meaning within the framework of a narrative structure so that a sense of stability, coherence and identity can be created for an individual over a life span. Bereavement, which is a severe disruption of this sense of stability, is the springboard for a process where the individual seeks to re-establish or reintegrate a sense of the meaning of life and of identity in a unified whole. Through the derivation of new meaning or purpose, the extent of suffering is ameliorated. It is through the reconstitution of meaning structures that transformation is wrought into a new understanding of life for the bereaved person without which it would seem difficult to continue to invest in living. The next chapter will address the issues surrounding stigma and the stigmatisation process, with a particular interest on the issue of HIV/AIDS which is currently a stigmatised illness in South Africa.

Chapter 4

4. Stigma and stigmatisation

Continuing with the literature review which explored bereavement in Chapter 2, and which addressed meaning-making in Chapter 3, this chapter explores the issues of stigma and the stigmatisation process. Various aspects are explored and these include consciousnessness and acquisition of stigma, and an examination of issues surrounding disclosure of a stigma. Enacted and felt stigma are reviewed and particular attention is focussed on these issues as they impact on attitudes towards HIV/AIDS and the experience of bereavement which follows a stigmatised death. Relevance to HIV/AIDS will remain a particular focus throughout the chapter.

4.1 Introduction

In current times the focus of stigma is on the shame that attaches to the stigmatised quality rather than on the physical attribute or mark characterising the stigma, as was originally the case. According to Link and Phelan (2001) there is considerable variance in the definition of stigma, possibly because it varies according to the wide range of situations to which it has been applied. This broad spectrum of circumstances to which stigma is applied has resulted in different ways of conceptualising stigma. However, common to most definitions, is that the stigmatised person is connected in some way, for instance, has or is seen as having, a trait or characteristic or feature that is socially denigrated.

Goffman (1963) describes stigma as a characteristic which profoundly harms the reputation of the person or persons believed to be connected to this characteristic thus conferring upon them a ‘spoiled identity’. A stigma can attach to an individual through a physical stigma, such as a deformity, or through a stigma of character, such as drug abuse or homosexuality, or can even attach to entire social groupings such as communities or races where stigma attaches to an individual by virtue of his or her descent (Goffman, 1963; Haour-Knipe, 1993). Lack of social acceptability is then used to seemingly justify the exclusion of the stigmatised individual or group from normal social interaction. Through this marginalisation and isolation social control can be exerted on this group, which then absolves society to an extent from responsibility for the stigmatised group (Malcolm, Aggleton, Bronfman, Galvão, Mane & Verrall, 1998). They also note that stigma can be experienced by a person either as ‘felt’ stigma which relates to the potentially stigmatised individual's own perceptions about the stigmatised event or characteristic, or as 'enacted' stigma which is the experience of discrimination by others as a result of the stigmatising event or characteristic.

4.2 The stigmatisation process

This section explores how stigma comes to be attached to a specific attribute, and the factors which contribute to, and result from, this process. The process of stigmatising an attribute, event, person or group of persons, initially involves distinguishing and labelling various characteristics which have negative connotations. This then becomes a means of categorising a person that may determine how an individual is judged or thought of, even prior to meeting that person. In a sense, it is a process whereby the stigmatised person is dehumanised and this provides a spurious justification for the kind of discrimination that will negatively impact upon the human rights of the person. The kind of thinking which causes people to righteously proclaim that prisoners deserve limited, if any, sympathy or even medical assistance, is an example of this type of discrimination, and highlights how the life chances of the person may be reduced as a result of stigma-related discrimination. Linking negative connotations to certain persons then becomes the basis for the creation of ‘us’ and ‘them’ groups where the latter suffer from loss of status and discrimination (Link & Phelan, 2001; Malcolm et al., 1998).

According to Herek (1999), a challenge for researchers in this field, is that much of the focus of stigma research has been on the perceptions of individuals and the consequences of these perceptions, and hence directly on the carrier of the stigma. Studies examining the sources and consequences of the socially determined exclusion of the stigmatised individual or group from social and economic life are needed to attend to Goffman's injunction that in studying stigma it is necessary to develop a, “language of relationships, not attributes” (Goffman, 1963, p. 3). When seen from this perspective, the focus shifts to those who create and define units of stigma and stigmatising attributes so that discrimination needs to be a central focus for attention. The process of stigmatisation, seen from this perspective, to begin with, entails the identification of existing human differences and, consequently, the labelling of these persons. Dominant cultural beliefs that link the labelled person to undesirable characteristics result in negative stereotypes of certain people or groups. An example would be that a migrant does not speak the local language well thus being mistaken for being stupid. The resultant categorisation is then applied to the whole group and facilitates the separation between us and them where the them group is believed to be fundamentally different in a negative way from those who are not similarly labelled. The labelling and categorisation leads to the devaluing and rejection of this group and they experience a reduction of status. According to Link and Phelan (2001), a loss of status is associated with a lack of equality within social interactions through the creation of performance expectations which are determined by the group or individual who has the greater social power. Allied to the loss of status, discrimination results in differential, and lesser, access to resources. In the above example, the migrant may be denied access to jobs requiring greater intelligence and be thus limited to manual labour where the pay is much less favourable.

4.2.1 Courtesy stigma

Goffman (1963) has identified the concept of courtesy stigma. Once stigma spreads from its bearer to those with whom the bearer is associated, the associates are said to carry a 'courtesy stigma'. It is possible that an individual, group or even an entire population can be stigmatised through the bestowal of courtesy stigma. Once this occurs, the disgrace which attaches to specific individuals, can also be attributed to the group, race or class to which they belong, or are perceived to belong. This is significant in the case of HIV/AIDS where those people who are associated with the person who is known to be HIV-positive, or who has AIDS, are themselves tainted with the same stigma that attaches to HIV/AIDS itself. The implications of this for family members and other associates of the person with AIDS are multiple and significantly affect their treatment by society.

Walker et al. (1996) have described how the social stigma that attaches to HIV/AIDS is transferred to the person who is diagnosed as being HIV positive or having AIDS. There already is a stigma which attaches to those groups, already marginalised in society, which are seen to be at risk for contracting the disease such as prostitutes, homosexuals, immigrants, prison inmates and intravenous drug users and this is transferred to the disease. As the disease was originally most prevalent in these groups, it became identified with individuals who were already seen as 'rejects' of society, so that it confirmed and reinforced the pre-existing prejudices and practices of discrimination against these groups.

4.2.2 Structural discrimination

Link and Phelan (2001) have considered how structural discrimination can result in the stigmatised person experiencing the effects of discrimination even in the absence of overt discrimination or individual prejudice. Structural discrimination would also be at the basis of the NIMBY (Not In My Back Yard) syndrome where isolation following upon stigmatisation can physically limit the locations that a stigmatised person can practically occupy in areas where the available resources or facilities are fewer or lesser in quality. Stigma can thus influence the societal and economic structure around the person which in a way that also effectively prevents him from changing these circumstances. It can thus be surmised that the role of the dominant culture is essential in all phases of this process and that the development of all aspects of stigma is embedded within this so that, "stigma processes have a dramatic and probably a highly underestimated impact on life chances" (Link & Phelan, 2001, p.381).

4.2.3 Stigma consciousness

The stigmatised person is generally well aware of the attributes associated with a particular stereotype and consequently may develop a sensitivity to it that can make social interaction a minefield for the stigmatised individual, particularly so where the stigma is visually evident. Stigma signs denote information with social value or significance (Goffman, 1963). While some signs of AIDS can be ambiguous, others are less so. In central Africa, AIDS is known as 'slims disease' so that weight loss for whatever reason can carry stigma. Being a caregiver of a sick person who displays some signs of the illness, can be also be clear indication of the presence of the infection. A point made by Goffman about the socially informative nature of signs, is that an individual may be defined as being 'with' another, and through courtesy stigma may themselves be stigmatised.

A visible sign means that the stigmatised attribute itself can be seen irrespective of whether or not the information has been disseminated officially. Goffman (1963) also refers to the degrees of obtrusiveness of the visible sign. In some cases, once the implications of having the stigma sign have been noted, the stigmatised situation can be allowed to escape from notice. What becomes critical at this point is the perceived focus of the stigma which may result in the disqualification or rejection of the person carrying the stigmatising attribute. Thus a child at school who is HIV-positive may be asked to leave, or, as happened in the case of Nkosi Johnson when his adoptive mother attempted to enrol him at a nearby school, may be denied entry (Fox, 2002) Conversely while the person is well, even if HIV-positive, the lack of visible signs, coupled with a lack of disclosure may make it less likely that they will be seen as having the stigmatised attribute, thus facilitating an avoidance of rejection.

The personal identity of an individual is such that information about that person which is specific to him or her serves as a distinguishing feature. The signs which become associated with an individual also contribute to their personal identity. Then as Goffman (1963, p. 61) observes, the, "biography attached to documented identity can place clear limitations on the way in which an individual can elect to present" himself or herself. For the person who is known to be stigmatised, various forms of social control may be invoked. In the case of the person with AIDS, this may mean lack of access to work, housing or even medical care. In order to avoid this personal identification the person may maintain physical distance by concealing the situation from certain people, while telling a (smaller) group that can be relied on to maintain confidentiality.

Goffman suggests that entering a social situation can make the individual cower defensively, or approach it with hostile bravado (which in itself may provoke a range of negative responses). If nothing else, these types of responses are in themselves indicative of the extent to which untried social interaction can be a source of anxiety for the stigmatised individual who understands clearly the meaning of being associated with the stigmatised attribute. Goffman (1963) believes that over time, through exposure to a range of social interactions, the individual learns to manage situations more aptly. One strategy that may be employed is to associate more with other people who are sympathetic such as those who share the same stigma, which, for example, is evident in the plethora of support groups and self-help clubs. Another source of sympathetic people would be those who, though lacking the stigmatising attribute, have the kind of intimate knowledge of it that is born out of their close association with it through someone with whom they share an important relationship. This was the case for the adoptive mother of Nkosi Johnson who became an AIDS activist as a result of her association with Nkosi who was infected with the virus (Fox, 2002).

“Stigma consciousness” as defined by Pinel (1999) demonstrates the powerful force of stereotyping in relation to the stereotyped person's own expectation of being stigmatised if certain attributes apply. This results in their acceptance of the lower status conferred upon them and consequent diminished opportunities. This may lead to lowered expectations of their own abilities or life chances and highlights the self-sustaining aspect of the processes of labelling, stereotyping and discrimination. As a result it is less likely for the person to seek to challenge structural discrimination, perhaps preferring to hide or deny the stigmatised attribute, where possible.

4.2.4 Stigma acquisition

Goffman (1963) differentiates between various patterns of stigma acquisition depending on the age at which a person acquires a stigma. When it occurs later in life, the individual may feel that an association with a group from whom he or she may have always felt different. However, post-stigma acquaintances will automatically place the person in the stigmatised group and even pre-stigma acquaintances may begin to treat him or her differently. As a result of the ambivalence that the newly stigmatised individual feels about being associated with this new group there may result in a reluctance to be aligned with it even though the support that membership can bestow is sorely needed.

Gilmore and Somerville (1994) suggest that when faced with a frightening or potentially deadly situation, the natural reaction of people is to attempt to escape from it, to control it, to deny it, or displace the fear it engenders so as to lessen the danger it elicits. Through the creation of a them and us situation, ‘disidentification’ occurs, as a result of which the other group (them) is guilty and thus deserving of this threat. Identifying HIV/AIDS with already marginalised groups or persons facilitates this process of separation. In the next step, the them group is depersonalised and seen as less that human. For the AIDS-sufferer the knowledge that they are, "going to die anyway," facilitates the depersonalisation of the individual (Gilmore & Somerville 1994, p. 134). The twin internal processes of disidentification and depersonalisation provide security in the knowledge that oneself is different from the group who has the disease. Stigmatisation, by contrast, is both an internal and an external process. The function of stigma is to isolate those carrying the stigma so that a denial of the individual's own risk and vulnerability can be maintained. This process involves disidentification and depersonalization in that undesirable attributes are used to designate scapegoats so that the discrimination that occurs appears both justifiable and correct.

Tewksbury and McGaughey (1997) suggest that in order for an attribute to become a stigma there is a difference between the expectation of what a person should be and what the person actually is. Goffman (1963) has described this as the dichotomy between the individual's actual social identity and the virtual one. This implies that where a person is known by virtue of the stigma, he or she is thereby discredited, even before actually meeting with that person. Moreover, as the determinants for stigmatisation are socially determined, the stigmatised person also tends to submit to their discrimination through a sense of shame which underscores the concept of spoiled identity by its implication that there is a concurrent spoiled self-identity. (Haour-Knipe, 1993). According to Goffman (1963) this discreditation or spoiled identity places limitations on the way the stigmatised person can present himself or herself, as may be the case of an ex-convict trying to find honest work.

Where the stigma is not known or immediately apparent, the threat of its becoming known is a source of considerable tension as it would lead to being discredited. The issue for such a person is whether or not to reveal or display the stigma or information about it (Goffman, 1963). ‘Passing’ where the individual with a stigmatising attribute behaves as though they have no connection to it, may be a way to resolve this tension. To pass, however, means to be living in a state of anxiety about the possible unwanted revelation of the secret and consequently may lead to a state of intense and perpetual vigilance, watching others and self, in order to be avoid unwittingly unveiling the secret. A further source of tension for the passer arises in situations where others denigrate the stigmatised group giving rise to a sense of disloyalty and self-hatred. (Goffman, 1963).

A concept related to passing is that of ‘covering’ where although the individual is known to possess the stigma, he or she will strive to minimise the implication of it in order to allow normal social interaction to proceed as though it were not significant (Goffman, 1963). Covering is governed by the desire to fit the social conventions or rules of etiquette and reducing the opportunity for socially awkward occasions. It has the benefit of easing the situation for the other person or persons involved in the interaction. An example of this is where the stigmatising condition is known to a friend or family member, yet this information is not disclosed to a third party if doing so were to make the social situation uncomfortable. Covering can also take the form of reducing visible indicators of the condition so that the information does not make itself obvious. In the case of someone with AIDS, this could apply to not talking about frequent visits to doctors.

4.3 Stigma and disclosure

Powell-Cope and Brown (1992) have researched the disclosure dilemma that faces the AIDS caregiver. Revelation may result in negative consequences such as shame and isolation, but secrecy also has negative consequences as the AIDS caregiver is exposed to comments or ridiculing about AIDS that may arise out of ignorance of the disease. Thus where an AIDS caregiver chooses to pass as though they had no personal connection to the illness, it is necessary for them to deceive others in order to protect both themselves and the person with AIDS. In these cases care needs to be taken to safeguard, and if necessary withhold, the information that a family member has AIDS. In addition, other deceptive strategies are used such as making excuses, lying, circumlocution, equivocation, avoiding specific social situations which might put them at risk of being questioned or even moving to a different neighbourhood. Ultimately the effect of these secretive endeavours may itself result in social isolation as the strain of being dishonest gives rise to considerable emotional distress as well as exhaustion from the effort of having to remember what has and has not been revealed or said in past encounters. Another ongoing difficulty is having to think up believable and coherent excuses to cover up the effects of the illness or frequent visits to doctors.

Factors that influence the decision to disclose include a previous openness about factors associated with HIV/AIDS such as lifestyle, and the previous level of community involvement, such as involvement in a gay community (Powell-Cope & Brown, 1992). In their research, it was found that most participants did tend to disclose information rather than maintain secrecy, but this was managed gradually through a series of stages. Initially the presence of a sick person would be revealed, later the seriousness and deadly nature of the illness would be addressed and finally the actual diagnosis would be made known. Frequently, it is the physical deterioration of the person with AIDS that influences the rate of this progression as the AIDS-caregiver requires more support and assistance. At this point the benefits of disclosure may include greater job flexibility and recognition, especially of their efforts in caring for the person with AIDS. The sense of identification with a community that shares values and experiences, is also a valuable benefit of disclosing as it can confer on caregivers a sense of belonging.

Goffman suggests another possible strategy in respect of disclosure where the secretly stigmatised or discreditable person takes the initiative to make known his or her stigmatised status thereby accepting a discredited social and personal position. Methods of disclosure may include the wearing of highly visible stigma symbols. The use of a red ribbon to indicate support of AIDS awareness would be an example of such an action. In order not to be offensive, the person with AIDS or who is closely connected with someone with AIDS, may choose to reveal information by means of intentional 'slips' or by presenting the information in a way that demonstrates an assumption that the person receiving the information will not react negatively. Goffman (1963) suggests that voluntary disclosure tends to indicate a mature phase in the moral career of the stigmatised individual which is indicative of adjustment.

For the idealistic, there is a sense that maintaining secrecy around the illness serves to support the stigmatisation both of the illness and the situations associated with it, so that they may feel morally obliged to disclose. Those who choose disclosure from the outset may resist the AIDS stigma by becoming social activists in order to effect change on the status of the illness and those who are connected to it. This could entail becoming a member of organisations or disseminating correct information about the disease in order to reduce levels of ignorance and dispel myths. Such activism provides an ameliorated sense of self to counteract the spoiled identity conferred by the disease. Through the belief in their own capacity to change public attitudes, there is a sense of being able to generate greater compassion from their social context (Powell-Cope & Brown, 1992).

In America the opposing values of public participation and the right to privacy pose particular difficulties for AIDS family caregivers who do wish to disclose so as to protect the person with AIDS as well as themselves from the negative consequences of disclosure. Powell-Cope and Brown (1992) have found that the AIDS family caregiver suffers considerable suffering which results from the fear of the negative judgement and shame which disclosure could bring about. This is more marked if those same fears are applicable to the lifestyle of the person with AIDS.

Although the focus so far has been on the disempowering aspects of disclosure, Travers and Bennett (1996) view disclosure as a sphere for empowerment for women depending on the reason for the choices made. Providing that the person has power over disclosure, and that the outcome is not discriminatory, then such control is empowering. This is not the case where fear of rejection or other consequences results in a lack of disclosure that leads the infected person to avoid appropriate medical attention.

4.4 Enacted stigma

Biller and Rice (1990) have observed that even though it may be recognised that the sanctioning of people infected with HIV/AIDS does not justify the limitation of the human rights of these individuals, by 1990, 104 countries had passed HIV-related legislation some of which does serve to place restrictions on them. Examples of legislation that has been passed include the mandatory screening of certain groups, the criminalisation of the transmission of the disease or restrictions on movement or bars on admission to certain professions. This has exacerbated the existing stigma associated with the disease. While the focus appears to have been on protecting the uninfected (the innocent) from the possibility of infection by the infected (the guilty), little attention was given in the initial stages of the epidemic to addressing the needs of groups that are at risk for contracting the disease, groups who are already vulnerable to infection through lack of access to housing, regular income, health or education.

Another area where discrimination is encountered is in the workplace where fellow-workers fear infection. Although the risk of disease transmission in the workplace is minimal, people infected or suspected of being infected with HIV/AIDS have been ostracised or tormented by their colleagues. The supposed risk of infection has been given as the reason for non-employment of a work applicant, or termination of employment for those already employed. Pre-employment screening may be used to identify seropositive persons, such as has been the case the South African mines (Parker, 1991).

The principle of autonomy as a first-order human right which is embedded in the South African constitution, implies that the HIV-infected person has a right to confidentiality and disclosure. However, as described by Botes and Otto (2003), these rights may become problematic for health professionals who need to impart sufficient information in order to enable the patient to make an autonomous decision. In part, this difficulty may arise from the patient’s own pre-existing, and erroneous, knowledge of the illness. Even if adequately informed, the patient could make decisions that are contrary to the best interests of others whom the patient knows, or even the patient him- or herself. For instance, a married person may be unwilling to use a condom as this would reveal to the spouse that he or she has been unfaithful in the context of the marital relationship. In this case the decision not to disclose his or her HIV status could be deleterious to the health of others and it is this which poses an ethical dilemma for health-workers. A further difficulty can arise where choices regarding behaviour arise from values and beliefs sited in cultural discourses. In South Africa, for instance, the power of deciding on when sex takes place and condom use tends to rest with the male partner in the relationship.

4.4.1 Scapegoating

Gilmore and Somerville, (1994) have researched the effects of scapegoating and the consequent desire to effect punishment on those who bring disgrace to their community. Scapegoating has been blamed for much of the negative action directed to people with HIV/AIDS. There have also been reports from many countries (both First and Third world) of violence, including murder towards homosexuals, sex workers, street children and those infected with AIDS. The need to generate income and the lack of opportunities to do so in the formal sector, may compel the members of already-marginalised groups to seek to earn money through involvement with sex-work (Malcolm et al., 1998). It has been observed (Alubo Zwandor, Jolayemi & Omudu, 2002; Malcolm et al., 1998) that, increasingly so, AIDS in Africa is becoming linked primarily to women through the belief that it is a ‘woman's disease’ and that women are the principal vectors for the spread of the disease.

Researchers in Nigeria have found that once a person is identified as being an AIDS sufferer there is a, "transition from the realm of the living to the dead and the beginning of isolation and other indications of rejection and separation in the community" (Alubo et al., 2002, p. 117). They are treated as though they are absent, and speculation is voiced in front of them regarding the possible duration of their life. Even family members may avoid providing the customary care that is normally accorded to sick individual in this society. There is a sense that, in the absence of a possible cure, isolation of the infected individual will hasten their death, so that both the burden of caring for the sick person and the chance of transmitting the illness will be minimised. With regard to courtesy stigma, the whole family carries the shame of the illness and may be labelled an AIDS family. For the children of the AIDS sufferer, this shame may be severe enough to hamper future relationships and curtail marriage opportunities. Even the funeral rites of the AIDS victim differ from usual custom. The usual 7-14 day period of mourning is not observed and mourners disperse rapidly after the funeral. In one community suggestions were made that AIDS-infected individuals should be killed. As Rando (1984), has observed, the absence of certain elements of funerary rituals or customary memorial rites, can significantly complicate the bereavement experience as the opportunity for the expression of memories, affect and social support is diminished.

North and Rothenberg (1999) have found that in South Africa women are disadvantaged economically, culturally and socially. Barolsky, (2003) suggests that although the extended family in the South African context can provide the resources and support necessary for the survival of the family, the effects of power structures within this system can be deleterious especially for women as they may be perceived as the original source of illness (North & Rothenberg, 1999). It is such power structures, sited in gender, which bring about lesser access to economic resources. Within such a system, women are seen as the source of illness and shame, so that the wife of the person living with AIDS is contaminated with the stigma of the illness and ostracised by the in-laws who attribute to her the blame for the illness or death of her spouse. If it is considered that women carry a disproportionately large portion of the burden of child-rearing and maintaining the family and that their social status is less than that of men, then it can be seen that the effects of such ostracism will have a broad societal impact.

4.4.2 Stigma, social death and physical death

Kalish (1981) posits the idea of social death. There are two possible aspects to the concept of social death. The first concerns the concept as it is applied to the person's own self identity, the second concerns that as it is applied to the way others view a person. In the case of the latter, a person may be perceived for practical purposes as already non-existent from a social point of view, such as would happen where a person is cut off from the social mainstream by senility or terminal illness. This may be predicated by an inability to fulfil previously held social roles and interact as a part of society. The former refers to the case where the person accepts this view so that in their self-estimation they believe themselves to be as good as dead. Kalish suggests that there is a relationship between social and physical death. Where a person has undergone a social death there is a tendency for them to be isolated from others in their social circle from whom they previously derived support and perhaps also sustenance. The stress and depression of this situation may lead to a sense of hopelessness that Kalish terms psychological death. Psychological death is the discontinuation of the awareness of self and of the surrounding environment. It can be accelerated by a hostile environment and results in a shortened life span either as a consequence of poor self-care or active intent.

Pugh (1995) notes that various studies have shown an increased suicide risk for people with AIDS. Suicidal ideation tends to peak at the time of diagnosis, and towards the end stages of the illness. In the case of the person with AIDS, the question arises as to whether this could be considered a justifiable suicide considering the physical and psychological pain of living, coupled with a lack of hope for a possible recovery. Other motivating factors for the person contemplating suicide may be a desire to spare loved ones any further pain, or lack of economic or other resources in caring for the sick person. In this case death may be construed as deliverance. For caretakers too, death might seem welcome release and this knowledge may contribute to the decision (Kalish, 1981). In this respect Pugh suggests that suicide may appear to be a type of self-administered euthanasia. However, where good hospice care and palliative medication is available, such as in Holland, the requests for euthanasia have declined. Where negative attitudes prevail towards AIDS sufferers by health professionals, the impact on the wish for suicide could be significant.

Once the person who is dying, irrespective of the reasons for the prognosis, the effect of this label can be marked. According to Kalish (1981) those who are not yet dying have a tendency to relinquish those who are dying, perhaps in order to reduce their sense of anxiety around death-related situations. As a result dying persons receive fewer visits from friends and family once they have been so-categorised. Medical personnel too, may reduce their attention, believing they cannot influence the outcome of the situation. Furthermore the stigma of dying can transform the person into a 'nonperson' to medical staff and even friends and family. This is a way of ensuring an us and them situation for those who do not fall into this category. Hence the depersonalisation of the dying person means that others will not immediately have to face their own mortality.

In the context of HIV/AIDS in South Africa, Barolsky (2003) reflects on the isolation of the person who is ill. The fear of incurring social stigmatisation and ostracism means that the cause of the illness, and even the ill person is hidden from others. This may take the form of denying the presence of the person in the home which is a form of social death. Further depersonalisation of the person with AIDS may occur when they are confined to a room outside of the main dwelling. This may be motivated by the practicalities of needing to safeguard other family members from the possibility of infection in environments which are very impoverished and which lack even the most basic sanitation. However, it may be accompanied by a rejection of the sick person so that although they are physically still alive, they are no longer considered a member of the family. Such silence and denial also result in reduced access to medical help (so as not to give away the secret) and thus hastening the death. Women who become ill, who may be viewed by their in-laws as those who have brought the disease onto the family, may be sent away from the community, to die away from the community so as not to reveal the shame of the family. In the following excerpt, Barolsky (2003, p. 55) vividly describes the process of social death which clearly shows how it is a clear precursor for physical death. Where both parents are ill there is often, "a slow isolation, almost a type of insubstantiation, as the family continues, phantom-like, hidden from the 'public' purview, removed from the skein of social networks. As parents sicken, the whole family often gradually withdraws from the community, the neighbourhood and even relatives, retreating decisively from public spaces. When parents do die, death merely formalises a social absence already long established, sometimes not even particularly noted in its conclusion at death."

4.5 Felt stigma

Janoff-Bulman (1992) has highlighted the value and importance to the trauma survivor of social support as it facilitates the conceptual reconstruction of the shattered assumptive world of the individual. However, the social responses that many survivors receive, do not reach this ideal. Firstly, those who have not undergone a traumatic event, may find it difficult to comprehend how the fundamental assumptions of the bereaved may differ. The bereaved may no longer view the world as benevolent and meaningful or themselves as worthy, competent people who have control over what happens to them, and who do not feel vulnerable and exposed. Secondly, simply being aware that survivors see the world as malevolent and meaningless makes others afraid of the ontological insecurity that this stance implies, thus producing such a sense of threat to their inner world, that they would prefer to avoid them. A further strategy in this regard is victim-blaming which fits the assumption that only people who are reprehensible in some way deserve misfortune of such magnitude. A particularly toxic aspect of victim-blaming is that certain behaviours are judged as potentially lethal or hazardous only after the event even if they were considered neutral before the event thus seemingly warranting opprobrium. Hence the victim is construed to have conspired, albeit in ignorance, in some way in the misfortune that has befallen them (Lerner, 1980). Through the (unwitting) violation of the way that things ought to be, the bereaved person carries a social stigma which marks them as tainted or flawed. More simply, knowing a person who has experienced extreme events acts as a powerful and constant reminder of the fragility of human existence, both as it applies to self and also as it applies to loved ones. Typical responses can include rejection, hostility or ambivalence. Inevitably the experience of the individual is one of felt shame.

Another aspect of victim-blaming occurs in the case of vertical transmission where the child is infected by the mother during the pregnancy, so that the mother is seen as the one responsible for the child's infection. Health workers may prefer to deal directly with the grandmother believing the mother to be unfit. This situation serves to increase the mother's feelings of guilt. The grief felt by parents, who may themselves be infected, may be severe, especially so for mothers who grieve more intensely than fathers (Sherr, 1995). This adds to the shame she might feel for the lifestyle that caused her to become infected in the first place, and may contribute to the feeling that she is undeserving of help and assistance and so voluntarily cut herself off from sources of support. This may result in increased financial hardship at a time when the need for better nutrition is paramount. The mother may also feel a sense of impotent anger where the virus was contracted as a result of heterosexual activity because the unequal and lesser status of women in South Africa may make it difficult for her to ensure that her partner uses a condom if he does not wish to do so. Inaccessibility to jobs as a result of inferior education, historically-determined social inequalities and the low status of women, may make prostitution one of the few or only avenues open for self-support. Societal attitudes which encourage men to have a variety of partners would also aggravate the situation, particularly as women are more susceptible to becoming infected through vaginal intercourse (Del C Alemán, Kloser, Kreibick, Steiner, & Boyd-Franklin, 1995).

The experience of felt shame for having HIV/AIDS, and the lack of trust that confidentiality will not be maintained thus exposing their HIV status, means that either diagnosis or treatment through public channels may be avoided. The fear of public knowledge is so strong that even in countries where the human rights of people with AIDS is safeguarded through legislation, legal action to enforce their rights may not be sought as it would publicise their status. According to Malcolm et al., (1998) there is considerable anxiety around how, when and to whom to reveal the information about their condition so that in a society where there is much enacted stigma in the form of discrimination, affected individuals may isolate themselves, or even hasten their death through suicide. The anxiety about who to tell does not exclude those nearest and dearest as fear of rejection by family members or loved ones can result in people denying their illness at a time in their lives when they need their help and care most.

The experience of felt stigma for AIDS victims in South Africa may be aggravated by the historically influenced conditions with regards to a post-Apartheid society. In South Africa in the late 1980s, the then Minister of Foreign Affairs, Pik Botha equated the diseae to a new form of attack by terrorists (Sontag, 1991). The initial response of the black community to government-instigated AIDS-prevention programs was underpinned with a great deal of suspicion arising from a deep-seated mistrust of racially White institutions that were historically associated with racist and discriminatory practices. As a result medical assistance may be avoided, in order to avoid getting the diagnosis which is so feared. To make matters worse, while for other population groups, the isolation that they may seek after an HIV/AIDS diagnosis may be curtailed or ameliorated by seeing a therapist, therapy is viewed negatively by many members of the Black community. This is particularly sad in view of the breakdown of traditional community support structures as a result of urbanisation and of the historical realities of Apartheid which contributed to this.

4.6 Stigma and illness

Sontag (1991) notes that tuberculosis in the nineteenth century, cancer in the earlier part of the twentieth century, and HIV/AIDS more recently have each evoked similar responses. Not only were these diseases, in their time, held to be a death sentence, but they were also perceived as shameful and obscene, so that to suffer from them was to break a taboo. Tuberculosis was a frightening and contagious condition which imbued its victims with a 'taint' and revealed something unpleasant about the sufferer. When writing of cancer in 1978 Sontag reflects that being diagnosed with cancer was a “scandal” that could jeopardise the life chances of the patient and that the United States passed a law in 1966 where disclosing treatment for cancer could be considered an invasion of personal privacy.

Other plagues have often been considered as being retributive in character, striking either a community or an individual. Diseases such as syphilis were understood to be a punishment for immoral or wicked behaviour. In this view there are echoes of pre-modern conceptions of illness where it is perceived to result from supernatural punishment or as a result of demonic possession. In these cases the failing need not be a personal one, but could also be collective or inherited from one's ancestors. In the Middle Ages the person suffering from leprosy was the personification of corruption and decay. Although in the nineteenth century the concept of disease as fitting the character of the sufferer was replaced by the notion that disease is an expression of character, Sontag (1991) argues that this viewpoint was no less moralistic and punitive. No longer is it the behaviour that brings about the punishment of illness as in syphilis, but the flaw rests within the individual so that the person with cancer is one of life's losers with a cancer-prone personality.

According to Sontag (1991) diseases which have a significant social impact through the number of people who are affected by them, which are incurable and which have unclear origins tend to be imbued with meaning. It is almost as if there is a social need to have one disease, identified with evil, which can be blamed on its sufferers. The widespread nature of such illnesses, the mystery surrounding them and the fact that they will cause death, brings about their association with those things of life that provoke the most dread such as disfigurement, decay, contamination, weakness, isolation and death itself. Subsequently the name of the disease itself becomes a metaphor for all these descriptions. This was the origin of words such as pestilent, from plague (la peste) meaning not only deadly but also injurious to morals. From there it is extended to apply to those people who are contaminated, immoral or who are different, perhaps by virtue of being foreign. The arrival of HIV/AIDS displaced cancer as the stigmatising illness of the day and the potential of HIV/AIDS to confer a spoiled identity is greater by far.

Other attributes of illnesses which are considered plagues are that they are repulsive, retributive and invasive and also that they originate from elsewhere. For instance, syphilis in England was the “French pox”, to the French it was the “morbus Germanicus”, to the Florentines the “Naples sickness” and to the Japanese it was the “Chinese disease”. This serves to underscore the us/them dichotomy. By extension then the non-us become a potential source for contamination. With regard to AIDS, the provenance of the disease is believed, by those of the First World nations, to be Africa, but to many in Africa it is believed to have been engineered in the United States. In earlier times, outbreaks of illnesses of which were considered plague-like were accompanied by the perpetration of acts of violence on those perceived as being foreigners, such as the Jews in Europe. Once the plague has passed, the need for such scapegoats diminishes (Sontag, 1991).

Strong (1990) suggests that there is an “epidemic psychology” where the boundaries of the good or normal can only be defined through the bad or abnormal. The first aspect of this would be an epidemic of fear of the disease and the consequent possibility of death from the disease. Secondly, there is an epidemic of suspicion where others are looked upon as possible vectors of the disease. Finally, there is an epidemic of stigmatisation directed at those suffering from the disease and the groups of people suspected of being carriers of the disease. This then lays the groundwork for the segregation and possibly also the abuse of those so stigmatised. According to Strong plagues are thus social crises which are likely to engender new outbreaks of stigmatisation stemming precisely from the inherent threat posed by the plague to shatter the existing beliefs and dearly held world-views about life, death and morality. Geis, Fuller and Rush (1986) note that to be touched by AIDS is to provoke fear of contamination even simply by knowing the affected person, thus calling for the total removal of such persons from society through isolation or ostracism.

4.7 Stigma and death

In his study of Western attitudes to death from the Middle Ages to the present, Ariès (in Corr, 1979a, p. 28) observed that between the twelfth and fifteenth centuries, "death became the occasion when man was most able to reach an awareness of himself." However, by the mid-nineteenth and twentieth centuries a feeling of distaste had developed regarding death, with a sense of it as shameful. Gorer (1965), an anthropologist, has argued that in Western societies there has been a shift in prudery where, in contrast with earlier times, copulation has ceased to be an unmentionable topic but death has become the ultimate obscenity instead. He has termed death the “new pornography”. As a result, the image of death is almost erased subconsciously from the lived experience of people and it is imbued with a feeling of unreality so that death is perceived to happen to others, to the sick or to the elderly. Becker (1973) has argued that this kind of denial of the personal possibility of death is the result of repression. Death as extinction of consciousness is so intolerable that it cannot be looked at in detail, for to do so would result in a kind of insanity. However, he contends that, to behave as though it does not apply to oneself is also a kind of insanity. According to Kalish (1981), much of human behaviour appears to suggest that humans live as though the possibility of death, while applying to every other person, does not apply to them. This constitutes a type of denial of death and people often express disbelief that it could happen to them or their loved ones, such as after an experience which has brought them close to death.

Moller (2000) notes how difficult it is to even use words such as “dying”, “death” and “dead” in polite social intercourse. The number and variety of euphemisms used instead gives credence to this assertion. The purpose of these terms is to minimise the vulgarity inherent in using blunter terms. A second strategy in removing death from social reality, is the way that death has become ‘sanitised’. People die in hospital, at a remove from day-to-day living, while corpses are quickly removed by the undertakers. The ideas of someone dying at home or of a corpse remaining there until the burial, have morbid connotations. So-called objective reporting by the media of events which result in death helps to distance the reader from the emotionality of such events, reducing them to statistical abstractions. In recent history, two events where emotionality appeared to be almost encouraged by the press are the death of Princess Diana in 1997 and the events of September 11, 2001 where more than three thousand people died. It is to be wondered whether these responses signal attitudinal change or whether perhaps the reaction to them was evidence of a different significance.

If, as Frankl (1964) has argued, the value of suffering lies in finding life's meaning from it, Moller argues that the denial of suffering and death is tantamount to the obliteration of the possibility for establishing such meaning. Stigmatising death, or illness that leads to death, facilitates denial of death as a possible personal outcome by those not directly affected by it through the division into us (people who don't die) and them (people who do). However, this kind of stigmatisation means that others feel themselves to be personally unaffected and so may remain uninvolved to the extent that they do not offer the help and support that could lessen the suffering of those who are dying or who are connected to the dying. Indeed by their very lack of involvement and by the continued victim blaming that accompanies stigmatisation they can increase that suffering of the affected individual.

When analysing the length and severity of suffering associated with bereavement, Doka and Jendreski (1986, p. 155) have speculated that “suffering shared is suffering diminished”. It would appear then that stigma can deprive the bereaved person the sharing of their experience so that the pain of bereavement is not diminished. This also applies to the clergy, whose effectiveness in comforting the bereaved person depends on the extent to which they are able to empathize.

In Africa the customs surrounding the mourning rites and burials are also being strained as a result of the greatly increased number of deaths (Seeley & Kajura, 1995). Traditionally members of the community would contribute materially to the funeral costs, in the knowledge that this would be reciprocated in their own time of need. Multiple losses have increased this burden at a time when the economic viability of communities is already strained as a result of the loss of those individuals who most contribute to the economic viability of the community. Traditional expectations of mourning rites and burials therefore tend to be reduced for AIDS victims and in addition there are few acts of communal grieving as would normally happen after a natural disaster. This situation adds to the stigma of AIDS, and compounds the difficulty experienced by the mourner, as even the memory of the AIDS victim is tainted. Not even in death are they honoured, as AIDS seemingly has the capacity to nullify any earlier life achievements.

4.8 Stigma and HIV/AIDS

Herek (1999) contends that where HIV/AIDS is concerned, there are a number of specific elements that evoke stigma. Firstly, becoming infected with HIV/AIDS is perceived as being the result of the sufferer's behaviour and where this behaviour provokes social condemnation, the person with AIDS evokes anger and moral condemnation rather than pity. Secondly, the illness is perceived to be fatal. Thirdly, the transmittable nature of the illness and misperceptions of how it is transmitted and the extent to which it is contagious. Finally, the incidence of repellent or ugly physical symptoms, especially in the advanced stages of the illness also contributes to the stigma (Herek, 1999). The physical disfiguration has been likened by Walter Burrell, an author, to the scarlet letter worn by the adulterous in the eponymous book as, "a blazing visual condemnation for all the world to see so they can pass judgement" (Lester, 2001, p. 48). Murphy (1986), in attempting to identify those who reject, isolate, harangue and ostracise homosexuals, observes that they are frequently drawn from the ranks of those who would ordinarily provide support to those who suffer, who are ill or who are dying. They include parents, siblings, friends, religious ministers, employers and fellow-employees.

Boyd-Franklin, Steiner and Boland (1995b) have examined the impact of an AIDS diagnosis on the integrity of the family. In order to determine the source of infection, other family members may be required to undergo testing, and it is possible that others will prove to be affected, thus complicating the situation. Denial is often the initial response permitting the family to continue their daily routine, but at other times may result in a desire to leave the situation, either physically or by means of substance abuse. Anger and even rage, are also common responses and may be directed at self, fate or displaced on society and the medical profession. Anger turned on self may manifest as depression, anxiety, regression, isolation and dependency.

Some of the stigmatising aspects of the illness include the effects it has on the physical appearance and the cognitive functioning of the sufferer, which amplify the blemished imaged which accrues to the person with AIDS. Worden (1991) describes the progressive physical and mental deterioration which transforms healthy young sufferers into travesties of their former selves. This too, serves to isolate the person with AIDS, whose condition may be seen as shocking and horrifying. Neurological complications can result in behavioural changes ranging from the subtle to the severe. In addition, Dane and Saylor (Walker et al., 1996) note that the perception of HIV/AIDS as an incurable illness which inevitably results in the death of the infected individual, combined with unrealistic fears of contagion, also contribute to social stigma.

There is some irony in the fact that AIDS has emerged at a point in medical history where humanity seems to have power over its well-being through having conquered many of the infectious diseases as well as through the development of improved treatment for chronic illness. Throughout history stigma has attached to epidemic illness and AIDS indeed has the image of a modern plague. Geis et al. (1986) suggest that the stigma attaching to AIDS has the emotional impact of a latter-day leprosy invoking the dread of disfigurement and death.

The words and metaphors used since the beginning of the epidemic tend to underscore society's understanding of AIDS as a latter-day plague (Sontag, 1991). The most feared diseases which have this status such as leprosy and syphilis, are not only fatal but transform the body into something repulsive. Malcolm et al. (1998) recount images of AIDS as the Grim Reaper, as punishment for immorality, as a judgement on the bad, as crime or war (with the consequent dichotomy between the innocent and guilty), as a horror and as a shame. Markers for the carriers of this shame can be physical characteristics, such as wasting, weight-loss or disfigurement (such as that from Kaposi's sarcoma), or can be membership of a group which has been conferred 'courtesy stigma' such as migrants, homosexuals, prostitutes, intravenous drug users or even closeness to such people through friendship or family ties.

Malcolm et al., (1998) concur that an epidemic of fear, stigmatisation has accompanied the HIV pandemic since it was first identified two decades ago. Fear of the disease, coupled with denial and a lack of real knowledge about the nature of the illness and the way it is transmitted, has had implications for the HIV-infected individual or group at all social levels of interaction from government to individual and has resulted in their scapegoating and isolation. The degree of stigmatisation provides an important reason that explains why information or counselling about the disease may be avoided as that too may be seen as conferring the stigma of AIDS to the person seeking it. Medical diagnosis may also be avoided in an effort to avoid the move from felt to enacted stigma and this compounds the problems that may be experienced with accessing adequate care as the infected person seeks assistance from alternative heath providers such as faith-healers or traditional healers. Fear of experiencing enacted stigma, or experiencing discriminatory behaviour or responses also restricts the infected person from making his illness known to others. As symptoms become more difficult to conceal, the sense of fear and anxiety of enacted stigma tends to increase.

Bate (2000) suggests that there are four myths surrounding HIV/AIDS which communicate certain beliefs about the illness to those who believe in the myth. The identification of these myths is valuable, as myths are symbolic narratives reflecting fundamental culturally-based facts. Through their identification, the truth of these myths can be re-evaluated, and this facilitates change. Firstly, the myth of margins refers to the process where those who do not follow the prevailing societal norm such as the American dream are marginalised. These people, as mentioned before, are unlikely to participate in the rewards promised by the myth, and as a result may suffer misfortune because they are seen as too morally degenerate and weak to live a normal life. In a similar way, Africans are considered by the myth of Western civilisation to be less civilised and hence prone to contract the illness as they do not behave in a sexually and socially mature way. Secondly, there is the myth, originating in a variety of religious traditions, of sin and evil. Within the Christian tradition, immoral sexual behaviour is understood as a sin against God which, being evil deserves evil. HIV/AIDS is thus a punishment for theose who are immoral. In African traditional cultures immoral behaviour is seen as endangering the life of the community through the destruction of relationships, including those with the ancestors. Thirdly, the myth of social disgrace conveys that it is shameful to have HIV/AIDS, or to die from it. This powerful narrative prompts individuals to delay seeking diagnosis and treatment, and families to conceal the facts of the illness, or even abandon the sick relative. Finally there is the myth of incurability. While death is the inevitable end-point of the illness, medical advances have transformed it to a chronic condition, which can be managed for a long time. The medical model, concerning itself as it does with physical healing however, is not concerned with the deeper human process of healing which can only be achieved by the transformation of the human perception from illness to wellness. Wellness and illness in this sense can be understood within the broader context of the individual's community. In this respect, the individual who is HIV positive may be judged to be sick (and doomed to die) by the community. Conversely, there is scope for healing, even if not in the medical sense, in the cultural understanding of the community through their affirmation of the person with HIV. Despondency thus transforms to well-being and hope.

The retributive aspect is underlined by moral crusaders and groups who attribute the disease to moral bankruptcy and other degenerate practices. Some clerics too, for example in South America, have added to this view of AIDS as God's punishment. Another group who have added to this chorus are xenophobic and racist political figures, such as Jean-Marie Le Pen who has called for the isolation of those who have the virus (Malcolm et al. 1998). Another common response is shame and guilt especially if the transmission to the child is a vertical one as parents reflect on their own lives. Health workers may aggravate this through the tendency to blame parents especially where parents are drug abusers. Acquisition of the virus by the mother by means of heterosexual contact may raise questions about the marital fidelity of one or both spouse placing further stress on the relationship between spouses. In an attempt to cope with social AIDS phobia which may arouse fears of rejection by the community, the family may select to live in a conspiracy of silence. As a result the family may withdraw and become socially isolated so that access to their usual support systems is severely impacted. This is associated with higher risk for depression, suicide and poor compliance with the prescribed medical regimen (Boyd-Franklin et al., 1995c). The socially prescribed gender roles in the South African extended family place the caregiving role squarely on the shoulders of women. Blame for illness is assigned to women, while men tend to deny the presence of illness in themselves. Thus women as caregivers may become involved in maintaining complex webs of silence where knowledge of illness is not imparted even between siblings, and consequently the possibility for providing support, comfort and compassion for one another is stifled (Barolsky, 2003).

Although much has been made of the role of lack of empowerment in women, as a contributor to their difficulties with regard to HIV/AIDS, Sherr (1996) argues that this belief may contribute to the perpetuation of the difficulties it attempts to account for. Therefore she recommends that gender analysis would be more useful in constructing a map of the dynamics of the infection as regards gender. While men are more likely to abandon their partner should she become infected, the reverse does not hold true for women with infected partners and this is accounted for by commitment. Men are less likely than women to disclose their status to their partners and this reflects differences in honesty. Disregard for women and irresponsibility causes men to be less concerned about infecting their partners than the converse. These arguments tend to support the commonly-expressed belief of women that they are more likely to be rejected (and hence abandoned) following on disclosure of a positive HIV status.

In reflecting on the chronic nature of HIV/AIDS Boyd-Franklin et al. (1995c) have commented on the responsibility and stress that caring for an infected child places on the family and how the function of it begins to revolve around the needs imposed by the illness. Aggravating the situation may be the concurrent illness of one or both parents. Where the parents have died, the caretaking function and parenting role may fall upon grandparents, who are themselves grieving for the loss of their child at a stage in life when their physical and emotional resources may be declining. For some grandparents however this is an opportunity for a 'second chance' at parenting, giving the opportunity to redeem what they now believe was an earlier failure at parenting.

Grawitsky (2002) differentiates between different levels of discriminatory behaviour which results from the stigma that attaches to the illness and which is thus enacted stigma. The individual category applies to discrimination in the sphere of personal relationships and includes harassment, disclosure to others and the spreading of rumours. It can lead to disruptions in relationship. Structural discrimination refers to the ways in which it is built into societal structures, such as gender-based power imbalances especially as regards the rights of women to negotiate safer sexual practices. Beliefs that identify women as vectors for illness, as well as different standards for behaviour for males and females, result in different attributions of responsibility for the behaviour which leads to infection. This can result in violence or rejection of the woman who discloses her positive HIV-status (North & Rothenberg, 1999). Where discrimination occurs in specific institution such as the labour market or the insurance industry, it is termed institutional discrimination.

With regard to the latter, in South Africa the Constitution protects the right to privacy, and discrimination on the basis of HIV status is unlawful. However Grawitsky (2002) has found that discrimination following disclosure continues to occur in the workplace, and this leads to fear of disclosure on the part of those who have witnessed this so that unaccounted for absences may lead to disciplinary action against the person living with AIDS.

4.8.1 Instrumental stigma versus symbolic stigma

Herek (1999) distinguishes between instrumental stigma and symbolic stigma. The contagious nature of the illness, its fatal outcome and the unalterable degenerative and disfiguring elements that mark the progress of the illness evoke instrumental stigma. Instrumental stigma is generally associated with fatal and contagious illnesses that evoke fear and apprehension. Symbolic stigma, by comparison, refers to the stigma which attaches to HIV/AIDS specifically whereby the disease has become a means for expressing specific attitudes to, often already stigmatised, groups of people seen to be at risk for contracting the disease. In this respect symbolic HIV/AIDS stigma tends to vary in accordance with the specific experience of a particular population in respect of the epidemic. Pryor et al. (1999) concur that the image of HIV/AIDS (and consequently the stigma that attaches to it) differs according to the culture so that the collective representation of the disease is not a uniform one throughout the world. In Western industrialised countries the ratio of infected men to women is about 16:1 and results primarily from homosexual intercourse or illegal intravenous drug use, so that the stigma attaching to these groups is also associated with the illness. On the other hand, the ratio of infection between the genders in sub-Saharan Africa is approximately 1:1, with transmission of the disease resulting primarily from heterosexual contact. In Africa therefore, HIV is associated with migrant labourers and those who break sexual taboos. Moreover the opportunistic diseases which afflict people with AIDS tend to be different in Africa where the wasting associated with the progress of the disease is called the slim disease with causality attributed to the power of witches. The stigma which attaches to HIV/AIDS therefore depends a great deal on the unique cultural and societal milieu of the infected person. According to Seeley and Kajura (1995) the stigma associated with AIDS in

Uganda means that both people with AIDS and their families are seen as wrong-doers. In some cases this leads to family members or spouses being disowned, perhaps because by not doing so they may be perceived by others as also being infected.

Various studies have shown that the associative network of concepts connected to HIV stigma includes illness, moral taint and misfortune (Pryor et al., 1996; Tewksbury & Mcgaughey, 1996). For some parents, learning of the diagnosis leads to a knowledge, or exposure, of the lifestyle of their child, which may be especially intolerable to them and may lead to a break in the relationship between them (Campbell, 1999; Springer & Lease, 2000). This is exacerbated where the child has contracted the illness as a result of homosexual contact, drug abuse, promiscuous behaviour or prostitution, as there may be exposure to moral condemnation by society, church and even the media. Moffatt (1986) describes the experience of shame as a "What-will people-think syndrome" so that the climate of understanding and support that the mourner seeks during their grief process may be denied to them, even to the extent that mourners may themselves be reluctant to ask for the support of others.

4.8.2 The social contamination reaction

According to Haour-Knipe (1993, p. 27), "AIDS, more than any other modern disease, has focussed attention on relationships between individuals and communities, on personal moral responsibility, on discrimination, and on stigma." Pryor et al. (1999) term the response to someone or something that is stigmatised as a 'social contamination reaction.' This concept echoes that of courtesy stigma as postulated by Goffman (1969). Stigmatisation of an individual or group ensures that individual or group is segregated from mainstream society, regardless of whether the stigma thus attributed is accepted by the individual or group so targeted. Through the exclusion of members who do not conform to normative social behaviours, societal norms can be maintained.

Sontag (1991) concurs that to contract HIV/AIDS is to be shown up as a member of a risk group such as homosexuals, prostitutes or drug users, which already have pariah status in society. To disclose a positive HIV/AIDS status means disclosing elements about the self to family, work colleagues, friends and neighbours and so risk the possible consequence of harassment and isolation. It is easy to socially construct this illness as a punishment for deviant or licentious behaviour. Barolsky (2003) concurs that where rejection and exclusion of infected people is the means chosen to reduce the threat to cohesion in an already fragile social system, then there is a possibility, "that HIV/AIDS could lead to the resurgence and reaffirmation of conventional hierarchies as a putative barrier against disease" (2003, p. 20).

Testing positive means that the person has tested positive for antibodies to the illness and does not mean that he or she is ill, or will be so in the near future. However, testing positive is equated with receiving a death sentence. In contrast to cancer diagnoses, which in the past tended to be concealed by doctors and family from the patient, in the case of HIV/AIDS it is the patient who conceals the knowledge from family, friends and colleagues. Sontag surmises that this is because HIV/AIDS has the capacity to confer a new, tainted identity on the person, turning him or her into the kind of person who gets the disease, that is, one of *them* as opposed to the *us* who do not.

Medical health professionals or government health departments may also be affected by the stigmatised nature of illness so that the provision of adequate health care may be hampered both by denial of the prevalence of the disease as well as by a lack of willingness to treat those who have the disease (Malcolm et al., 1998; Powell-Cope & Brown, 1992). As recently as 2002, there was still a fierce debate in South Africa regarding the use of anti-retrovirals. On the death of one of its fiercest critics, Presidential spokesman Parks Mankahlana, the African National Congress (ANC) initially did not disclose the cause of his death although it was reported that he had died in the shadow of rumours that he had suffered from AIDS. Gevisser (2000), in an editorial commented that, “whether or not he had the virus, he was a victim of the stigma and silence and denial that surrounds this syndrome and that leads to gossip campaigns and rumours [that are] often malicious and destructive”. Later the ANC released a statement decrying his treatment, “Parks Mankahlana died, vanquished by the anti-retroviral drugs he was wrongly persuaded to consume” (Kindra, 2002). Finally, anti-retroviral treatment was rolled out in Gauteng in April 2004, following the lead of the Western Cape. So great was the demand that booking times are backed up for months (Keeton, 2004). Yet even so, people, especially in the workplace, are still reluctant to submit to Voluntary Counselling and Testing, and stigma and fear are at the root of this reluctance (Lake, 2004).

The position of migrant workers and other immigrants is rendered especially tenuous at times of illnesses with a plague-like status such as HIV/AIDS. As was elucidated earlier, such illnesses are perceived to arrive from outside of the country, so that immigrants or migrant workers are seen to be vectors for the disease. In India, government's Council for Medical Research called AIDS a foreign disease and suggested that Indians should not participate in sexual contacts with foreigners and such reactions have been common throughout the world. The fear of unstoppable migration to First World nations from those in the Third World brings up fears of uncontrollable contamination so that it is seen as a threat to an entire way of life and of civilisation itself.

Research by Nzioka (2000) on the social meaning of death from HIV/AIDS in Kenya has found that to be infected by HIV equates to death, and because AIDS acts as a metaphor for moral and physical contamination, HIV infection confers on the individual a spoiled image and identity. In Tanzania, as noted by Kilonzo and Hogan (1999), the epidemic is linked with irrational fear, stigmatisation, blaming and witch-hunting. As a consequence therefore, the stigma that attaches to being infected with the illness is transmitted to caregivers, partners or family members who experience shame, embarrassment, guilt and anger. There is also fear that the negative affect attaching to the stigma will be attached to them, so there is a tendency to keep the cause of the illness secret.

In the South African context, one of the responses of the Government to the challenge posed by the epidemic is the Vice-President’s call for “moral regeneration” (Zuma, 2002). Although the invitation to a re-affirmation of African identity and value systems is significant, it may exacerbate the stigmatisation which surrounds the epidemic by creating yet another them category: marriage and family values as identifiers of the morally regenerate as opposed to those who refuse to answer the call to moral regeneration and who are thus themselves morally degenerate. Hence, as Barolsky (2003, p. 22) suggests, "under the guise of morality, it has been, and still is, possible to oppress others and to stigmatise those living with HIV and AIDS and their family."

The role of poverty is significant in the African context particularly (Green, 1996). World-wide there is a high correlation between prevalence of infection and poverty reflected in the higher incidence of the disease in poor countries, or people from a lower socio-economic group in more affluent countries. Hence rates of infection may reflect the relative poverty of women. This relative poverty may put women more at risk for infection through participation in sex-work as a means for economic survival, and this participation further increases the possibility for stigmatisation of those infected by the virus.

Powell-Cope and Brown (1992) have found that the stigma of being associated with HIV/AIDS results in rejection, loss of friends and harassment. Although less frequent, there are also reports of threat to housing and employment opportunities. The effect of these consequences of the stigmatised reactions can be deleterious to the self-esteem both of the person with AIDS, as well as their caregivers. Various studies have noted how those who affiliate with the stigmatised are also affected by the stigma as part of the social contamination reaction effect (Pryor, et al., 1999). Herek (1999) has found that people who associate themselves with AIDS sufferers also face ostracism as a result of courtesy stigma. Despite extensive public education there is still a great deal of stigma that attaches world-wide to HIV/AIDS. For instance, in an extreme exemplar of a community seeking to exclude the taint of AIDS in South Africa an HIV positive volunteer, Gugu Dlamini, was beaten to death by neighbours who accused her of bringing shame to their community by talking publicly of the disease (Dussault, 1999). In South Africa, death due to an AIDS-related illness has carried significant stigma to the extent that even in the case of prominent people the media have been criticised for revealing that the cause of death is AIDS-related. When a prominent member of the ANC, Peter Mokaba, died in 2002, newspapers noted that, "there was no official statement from his family, the ANC, the government or parliament about the cause of his death" (A leader, 2002). Moreover in an obituary on his life, the Sunday Times (Barron, 2002) commented that "[Mokaba] continued to deny the existence of HIV/AIDS (which is widely believed to have killed him)." Similarly in Mali foreign reports that the death of an official was due to AIDS led to anger and condemnation of the reports, which were seen as wrong to bring shame to the name of a important person (Henderson, 2001). More recently however, the death from AIDS of Prince Nelisuzulu Benedict Buthelezi, 53, son of Mangosuthu Buthelezi, a prominent IFP politician, may herald a change in direction and in stark contrast to President Thabo Mbeki’s quiet policy approach to the epidemic. His forthright approach may astound many as South African leaders do not have a record of speaking publicly about HIV/AIDS despite its high mortality. He has also been critical of the ruling party’s inaction, pointing out that the epidemic needs the government to respond in a way that is pro-active and vigorous. “Speaking to thousands of people at the funeral … Buthelezi tried to reduce the stigma surrounding the terminal disease, "I reach out to all the other people who died of HIV/AIDS. My son did... He died of

HIV/AIDS".” (Kalideen, 2004). "I feel the pain of any father and mother across our land at this tragic hour of history. I feel the pain for the many children of Africa who are now dying an untimely and terrible death. I am in mourning. We are a nation which ought to be in mourning." (Arendse, 2004). He hopes that by publicizing how it affects people in all socio-economic group it will remove the stigma associated with the illness. A short few months after the death of his son, Buthelezi announced that the death of his daughter was also as a result of an AIDS-related illness. At the funeral Buthelezi made a plea for those in positions of responsibility to, “open their hearts to stem a disease that was unmercifully mowing down many of our people” (Ntshingila, 2004, p. 1).

Maintaining secrecy can complicate the relationship between the sufferer and caregivers or family members adding tension at a time when emotional and physical resources are already strained (Walker et al., 1996). Powell-Cope and Brown (1992) have also found that AIDS within the family of origin can give rise to differences among family members around various issues such as the continued acceptance or rejection of the person with AIDS. These differences tend to split the family into various groupings such as between siblings, between parents and siblings and between spouses, and conflict is common among these factions. Hence stress resulting from this conflict can add to the stress of caring for the person with AIDS.

Barolsky (2003) notes that in South Africa, the extent of stigmatisation associated with HIV/AIDS can be deduced from the fact that even in extremis, sufferers have preferred not to disclose their HIV status to other family members to the extent that documentation regarding their diagnosis is concealed. As a result, families attribute the person's ill-health solely to the opportunistic infection that manifests itself without reference to HIV/AIDS. As the disease is attributed to women, men tend to deny the possibility (and the reality) of their infection. This means that medical help is not appropriately called for, so that once the disease manifests, death tends to follow swiftly. Green (1996) suggests that it has been reported that often women are more likely to be judged as promiscuous or reprehensible in their behaviour. The discourse of HIV as it is applied to women often refers to women affected by the virus as ‘rampant’, ‘promiscuous’ and ‘evil’ (Sherr,1996). As a result of this stigmatisation, apart from the physiological consequences, for women there are a number of psychological sequelae, and it can be surmised that the effects of stigmatisation thus accrue to women connected with the virus even where not infected. Thus disclosure may be even more difficult if there is fear of rejection and abandonment. Therapy for HIV/AIDS is also seen as very public and this may make it difficult for those who are afraid to disclose their status (Boyd-Franklin, Del C. Alemán, Jean-Gilles & Lewis, 1995a). For instance, attending such a clinic in South Africa requires taking a full day off work. Mariette Botes, a doctor working at a state hospital in Pretoria, was quoted in May 2004 as saying, "patients are flocking here and we are extremely full" and the report goes on to say that the clinics are congested to the point that it is difficult to move. For many sufferers rejection by the family manifests itself as isolation where their status as a fallen family member is constantly confirmed. Sufferers may also be confined to a shack outside the family dwelling, perhaps to safeguard other family members from the possibility of infection in situations where sanitation within the dwelling is difficult. Barolsky (2003) suggests that there has been a reduction of stigmatisation within the family nucleus itself so that the rejection that the sufferer anticipates from other family member does not materialise. However, this response appears for the present to be restricted to within the family who continue to anticipate rejection from the community. The need to maintain secrecy may mean that family members of afflicted people may avoid accessing organisations which are known to provide support for HIV/AIDS. A more extreme form of maintaining secrecy occurs where the sick family member is concealed within the family home and his or her presence is denied to non-family members (Barolsky, 2003).

In contrast Green (1996) suggests that it is not so much a case that stigma diminishes emotional support from family and friends, but rather the newness of AIDS. Being a relatively new disease and one which affects relatively young people means that not many people have experience of people with AIDS or young people suffering from chronic illness. As a result of this, people have relatively little knowledge about how to provide helpful support even though they wish to do so. This means that some reactions to disclosure may appear inappropriate as well as unhelpful. Instances quoted include a range of responses such as being treated as an invalid to denial. People who are HIV-positive may thus find greater support and fellowship from others who are so infected, but over time this may become a stressor as these newly-gained friendships are decimated through death from AIDS-related illnesses. In a more positive vein however, sufferers felt that disclosure, if followed by a positive response, leads to relationships that are closer and more supportive.

Green (1996) has identified a number of responses from people who are HIV-positive. Social withdrawal is a common response by those who are diagnosed as being HIV positive and among those who feel ill or who believe that they present the appearance of being ill. While rejection from close social contact is uncommon, rejection was commonly experienced from those who are not close. This rejection can be overt and cruel.

4.8.3 Grieving a stigmatised death

According to Rando (1986) social support can facilitate the anticipatory grief process and yet this is precisely what secretiveness denies them. Anticipatory grief is defined by Rando (1988, p. 72) as, "an anticipated loss of body functioning, loss through death of a loved one or object, and/or the anticipated loss of one's own life and/or functioning." Cho and Cassidy (1994) note that stigmatisation has an impact on anticipatory grief, as stigma is experienced from the time of diagnosis and increases as the illness progresses to AIDS. This is discernible in the gradual, though not subtle, diminution of social support networks through loss of friendships or other significant relationships. These losses contribute to the mounting number of losses experienced both by the AIDS sufferer as well as those closely related to him or her. Where the loss cannot be openly acknowledged or publicly mourned, it has been termed a disenfranchised loss (Doka & Jendreski, 1986; Martin & Doka, 2000) as the experience of loss is not socially validated or supported due to social constraints. Examples of such losses often involve non-traditional relationships or lifestyles, such as extramarital or homosexual relationships as they are often shrouded in secrecy. Secrecy may also be a factor where the cause of death is AIDS-related.

The lack of traditional sources of support at a social level makes disenfranchised loss particularly difficult for the bereaved. In Africa, many communities now lack the human and material resources to bury their dead according to culturally prescribed mourning rituals, which historically allowed community members to grieve their losses deeply and meaningfully (Kilonzo & Hogan, 1999). This is also the case in South Africa where, as Barolsky (2003) cites, it is no longer possible for people to attend funerals as was traditionally the case. Death has become the new unmentionable plague, accompanied by all the taboos which have attached to stigmatised illnesses in the past. Hence many of the AIDS-related deaths are marked by a certain silence, notable at many level of socio-political life, which itself speaks loudly of the disgrace of the epidemic, and how large the threat that it poses to society.

According to Robinson (2002), there is a paucity of research in the area of adult sibling loss where the cause of death is AIDS-related. (This situation appears to be even more marked in the case of bereavement of parents where the cause of death of their offspring is AIDS-related.) In a study to examine the responses among adults after a sibling's death from AIDS it was observed that the level of grief was of an intensity comparable to that of death of a spouse, parent or child. During the period of intense grief, the bereaved family members are repeatedly faced with questions regarding the death of their loved one, and its cause. In order to assess the effect of the experience of stigma for these bereaved siblings, participants in the study were asked to describe the nature of the disclosure regarding the illness. A variety of disclosure styles was discerned. Purposeful disclosers sought opportunities to tell others about the cause of death seeing this as a means of raising public consciousness regarding the illness. In contrast to this, the participants in the category “If asked I tell” did not actively seek to publicise the cause of death, but responded truthfully when questioned. Their responses were not emotionally charged, reflecting their belief that they had nothing to hide or protect. Selective disclosers were influenced by a sense of self-preservation in that the decision whether or not to disclose was determined by how they believed the information would be perceived. Protective disclosure was also variable but depended on how they believed their deceased sibling would be perceived. Restricted disclosers generally avoided revealing the cause of death, attributing it to other illnesses such as cancer. However, this pattern of disclosure appears to result in a high degree of emotional discomfort in the form of guilt, both when disguising the cause of death and when betraying the family by revealing it. For these participants the principal reason for the deceptive behaviour was a strong fear of the AIDS stigma which created a family secret. Avoidant disclosers avoid people who might want to know the cause of death, or respond to queries by saying that the loss is too painful to discuss except with those with whom they share the most intimate relationships (Robinson, 2002).

What is most significant perhaps in the study was that while all participants told of their sibling's demise to at least some people, almost no one told everyone that their sibling had died from AIDS. Even for those people who are willing to disclose the cause of death of their sibling, there are people to whom they would not wish to disclose and for all so bereaved, an element of planning what to reveal and how to do so is evident (Robinson, 2002). Although this research was carried out on the group of siblings bereaved as a result of an AIDS-related illness, it may be surmised that the parent who is similarly bereaved may face similar dilemmas. It is possible therefore, that some of these findings would have relevance also for parents whose child died as a result of this stigmatised illness.

Findings from studies where parental bereavement results from the murder of their child may also have relevance as regards parents whose children have died as a result of AIDS, as there may be certain parallel experiences because stigma plays in both types of bereavement. In a study which examines the difficulties that are experienced in finding meaning by bereaved parents whose child was murdered, Riches and Dawson (1998) firstly note that where the cause of death of the child produces a sense of stigma, it hampers the bereaved parents' social interactions. This is partly as a result of the reticence which the parents so bereaved develop to the demands to reveal details of the death to friends and others. In the case where murder is the cause of death for the child of the bereaved parent, the lifestyle of the child might be judged by others to have increased the victim's chances of being murdered. While this type of judgement may be more indicative of the unspoken, inherent fear of random violence that people have generally, it transmits itself in a condemnatory way where blame for the event is attributed to the victim and it is this which may account for the bereaved parent's reticence in discussing the event. Bereaved parents may also experience a sense of guilt so that the parents' identities are spoiled both through the notoriety of the death, as well as by the judgements that they are subjected to as a result of their child's lifestyle. This means that they become socially isolated to an extent so that contacts with others that might enable them to rationalise their loss are not available to them (Riches & Dawson, 1998). AIDS as a cause of death also brings judgements about the lifestyle of the child especially regarding the known means of transmission of the disease.

Secondly, there may be an experience of social isolation, partly resulting from the shame which attaches to the kind of death. The experience of isolation from usual support networks including family, friends, and religious organisations was also found by Geis et al. (1986) in a study of lovers of AIDS victims. This means that although this group is confronted with the same problems of loss and grief that afflict any bereaved population, they lack many of the traditional support systems that help most people deal with grief, and this makes resolution more difficult for this group than might be expected. Sherr (1995) also comments on how the bereaved in the case of AIDS has to face not only the burden of loss but also that of stigma. The stigma attaching to AIDS may cause the bereaved to isolate themselves so as not to publicise the cause of death, and this cuts them off from help, support and other resources which normally help the bereaved to cope with their loss. In research, Sherr (1995) has found that the grief reaction for those who were caretakers of people with AIDS and those who lack emotional and concrete social support is indeed more severe and prolonged than is normally to be expected.

As Klass (1988) describes, shared social bonds with other similarly bereaved parents has an important role to play in providing solace and resolution for bereaved parents especially in the creation of an inner representation of the child which, he postulates, is necessary for successful grief resolution. Braun and Berg (1994) in their examination of meaning reconstruction after parental bereavement have also linked successful grief resolution to social factors such as the extent of social support available to the bereaved parents. A number of researchers (Bowlby, 1969; Boyd-Franklin et al., 1995c; Klass, 2001; Marrone, 1999; Parkes, 1972; Richard & Dawson, 1996; Rosenblatt, 2000) have highlighted the importance to bereaved parents of spiritual or religious support. Where however, HIV/AIDS is seen as divine and just retribution for a sinful lifestyle, this avenue for support may also be limited for the person who has AIDS or who has been so bereaved. AIDS sufferers themselves may believe that they are not entitled to compassionate responses either from the community or even from God, who does not appear willing to produce a healing miracle (Murphy, 1986).

One of the factors identified by Kalish (1981) as contributing to a bereavement that is difficult to resolve has a bearing for bereaved parents whose child has died as a result of an AIDS-related illness. The AIDS sufferer may be viewed as being responsible for contracting the disease either through self-neglect or carelessness, so that once death occurs, the responsibility for it rests with him or her. It may be postulated that this contributes somewhat to the stigma attaching to dying from AIDS and may echo some of the stigma that attaches to bereaved parents whose children have died as a result of suicide. In a study replicating the original research done by Kalish, Lester (1993), confirmed that people dying from suicide were the recipients of more prejudice than either religious and ethnic groups. The study also confirmed that the dying (in this case from cancer) were also similarly subject to prejudice in an earlier era.

The taboos associated with dying have also been researched by Posner (1963) who noted that deeply ingrained cultural taboos served to isolate the dying person from society. These taboos extend to those associated with the dying person, who are in a sense 'guilty by association' and so also 'contaminated' with the same stigma. (This illustrates how Goffman's 'courtesy stigma' can attach to those in close relationship with the stigmatised person.) Hence death has become the new unmentionable plague, accompanied by all the taboos which have attached to stigmatised illnesses in the past. Hence many of the AIDS-related deaths are marked by a certain silence, notable at many level of socio-political life, which itself speaks loudly of the disgrace of the epidemic, and how large the threat that it poses to firstly families and then society as a whole.

Despite the taboos and stigma, there is evidence that an increasing number of families and communities are opting for 'open' burials where the cause of death is disclosed. On these occasions the element of celebrating the life of the deceased becomes an opportunity for education and affirmation about living with HIV/AIDS thus clearing the path for other infected people for whom the fears of rejection around disclosure may be eased (Barolsky, 2003). This inspires a tentative optimism that society may come to "reassert the vigour and power of life" (Barolsky, 2003, p. 68) thus transforming a message of hopelessness into one of hopefulness for both people living with AIDS and those affected by it.

4.9 Conclusion

This chapter has explored the issue of stigma and the process of stigmatisation. Various aspects of the stigmatisation process were reviewed, including the consciousness and acquisition of stigma, structural discrimination, and issues surrounding disclosure. Felt and enacted stigma were examined, as well as issues of stigmatisation surrounding illness and death in general. Finally, the focus fell on how stigma attaches to HIV/AIDS, to those who are infected and through the conferring of courtesy stigma and a social contamination reaction to those individuals who are associated with the HIV infected person or AIDS sufferer. It is conjectured that as a result of both felt and enacted stigma the grief process of the parents whose child has died as a result of an AIDS-related illness is likely to be complicated. Chapter 5, which follows, will discuss the paradigmatic framework of the study and the research methodology which is employed.

Chapter 5

5. Research approach: A phenomenological investigation

This chapter departs from the literature review presented in Chapters 2, 3 and 4 and explores the paradigmatic orientation of this research. The chapter begins with an exposition of phenomenology as a research approach and fundamental aspects of the phenomenological enquiry. The following section consists of an outline of the development of phenomenology from its inception to the current time, and an overview of some of the ideas that have had an influence upon its evolution. The research procedure is elucidated in the final section, from an outline of the aims of this study to a review of the ethical considerations.

The present study aims to ascertain the nature of the personal experience of meaning making which is subjective and idiosyncratic in nature, resulting from the person's experience of the world. More specifically, the aim is to achieve an understanding of the lived experience and consequent meaning-making of the participants whose children have died either as a result of cancer, which is currently a non-stigmatised long-term illness, or of AIDS, which is currently a stigmatised long-term illness in South Africa.Thus the focus will be on the world of ordinary lived experienced as it is interpreted in ordinary language, in order to produce an understanding of the participants' experience. Hence it is intended that the study shall be sited within a phenomenological framework.

5.1 Explication of selection of the methodology

This section attempts to provide a brief outline for the rationale which was employed in selecting the methodological framework for the present study.

Van Vuuren (1999, p.1) asserts that,

> "Natural science psychologies have been unable to account for human freedom and the meaningfulness of human experience… Quantitative, mechanistic and computer models of human nature, at best, record various regularities of behaviour and make predictions and, at worst, violate our forms of self-understanding."

Furthermore, he asserts that the pathway to understanding meaning is through perception, cognition and language rather than through science. Kvale (1996) agrees that in order to comprehend life as it is experienced by people, it is important to hear how they present it and talk about it, which occurs in conversation. The research interview is a professional conversation, “whose purpose is to obtain descriptions of the life world of the interviewee with respect to interpreting the meaning of the described phenomena" (Kvale, 1996, pp. 5-6). Hence the focus of research, as seen from a phenomenological point of view, is the understanding of the lived experience of the person in a way that makes known the world of the person. As a result of this focus, the departure point for phenomenological research, as elucidated by Husserl (McIntosh, 1997), is the pure lifeworld of the person devoid of theoretical interpretation. The philosophical antecedents of phenomenological research and hermeneutics are ever at the core of the endeavour and cannot be separated from it.

According to Husserl (McIntosh, 1997) phenomenological psychology is rigorous in character and it is thus capable of drawing factual conclusions which have validity. Van Manen (1990, p. 12) concurs that phenomenology can be regarded as a scientific endeavour in the sense that it is systematic, explicit and self-critical. However, it is a human science as opposed to a natural science because of its intersubjective focus. It is always concerned with structures of meaning as they relate to the lived human world in order to understand, "what it means to be in the world as a man, a woman, a child, taking into account the socio-cultural and the historical traditions that have given meaning to our ways of being in the world." As a result of this, phenomenological research does not aim to provide empirical generalisations, or identify immutable laws and causal relationships.

According to Moustakas (1994), phenomenology focusses on the way things appear regardless of causality and or explanation. It seeks to provide descriptions which reflect as closely as possible the nature of the experience. Meanings arise from this understanding and consequently phenomenology is rooted in questions that give direction to the search for meaning. Van Manen (1990) clarifies that hermeneutic phenomenological research can be understood on a cognitive and conceptual level, which is on an objective level, as well as a on a subjective level. As was mentioned above, at the heart of hermeneutic phenomenological research is a naïf study of the lived experience as if there is an attempt to ‘enter into’ the experience in the sense of having lived it. According to Kvale (1996), the apparent simplicity of using interviews (as the medium for conducting research) is illusory, as such an investigation requires a high degree of craftsmanship and skill. As the procedure is less clearly structured than in quantitative research, the researcher needs almost to navigate through the interview, making decisions, from moment to moment as the need arises, to the extent that such a process is almost an art-form. Kvale (1996) likens this to the an Odyssean voyage, which requires avoiding the Charybdis of being lured away from the focus of the research by exciting and interesting side-issues, while simultaneously also not falling into the Scylla of immunity to the human propensity to discover significant correlations between seemingly trivial incidents.

In addition to the above requirements, in phenomenology, the concepts of primary interrelatedness, interaction with all levels of being, and participation in the world-creation, are all metaphors which are adopted by the process and which result in experience (Wilkinson, 1998). As a result of this, as Van Manen (1990, p. 13) observes, “phenomenological research is a poetising activity.” As in poetry, it does not seek to provide a conclusion because the work is that in its entirety. As in poetry there is an attempt to capture the essence of an experience in lyrical form. It is not about the world, rather it is the world (as it is experienced) in spoken form.

Kvale (1996) explicates the process of hermeneutic understanding demonstrating how it involves a circular process between the parts and the whole, where each level is re-interpreted in the light of that which has already emerged in a spiral of ever-increasing understanding. Each interpretation in this cycle is a refinement on the previous one, giving rise to a more complex understanding of the phenomenon. This cycle of interpretation ends where an inner unity of the text is achieved and the various themes 'hang together' coherently. This also implies that the interpretation of each part can be understood in terms of the overall meaning of the text and that the text has a certain autonomy and can be understood in and of itself.

5.1.1 Phenomenology as a research method

According to Giorgi (1979), phenomenological analysis imposes certain specifications on the field of psychology, especially as regards the development of theory within this field. The first is its concern with the discovery and description of the “proto-psychological as it presents itself in the lifeworld” (p. 76). This implies the centrality of description as the foundation for transformation into legitimate scientific data, upon which prescription or prediction may be based. Secondly, it is necessary to ensure that the psychological phenomena which originate in the lifeworld are transformed into genuine psychological phenomena. A criticism that Giorgi has in respect of psychology, is that descriptions used in psychology are often sited in other disciplines such as physiology or sociology. Thirdly, scientific conceptualisation should be the result of a proposition obtained by induction, rather than as a result of a rigid adherence to form. The importance of this attempt to move from content-based descriptive material to rigorous results that are generalisable, would provide a sound theoretical basis. Valle, King and Halling (1989) concur that description can substitute for experimental method, provided that the method is equally disciplined. The appropriate origin of data is to be found within the structure of experience rooted in the foundations of the discipline which for the human sciences is the individual. This should yield knowledge about psychological meaning. Thus, from initial descriptions of experience, the researcher seeks to develop a more general description of the phenomenological structure and this has been termed, "empirical phenomenological analysis" (Giorgi, 1980). According to Giorgi (1980), the integration of phenomenology with experimental psychology is not intrinsically impossible. However, the integration of a psychology which is concerned with the study of consciousness, and that which is concerned with the study of behaviour requires a true synthesis beginning with all the theoretical constructs of the structure of the lived experience of the human being sited in the world. This does not mean a separation of the experience of the person from the lived world and then an attempted integration it in a way which does not fully describe the manner in which the experience is lived. Phenomenology offers a way to reconcile the objective and subjective elements of experience through the understanding of the intentional quality of perception.

A specific challenge for phenomenological research is that its value tends to be assessed in terms of a quantitative scientific paradigm based on a positivist approach which assumes a nomothetic position. In contrast to this qualitative research, which subsumes phenomenological enquiry, is idiographic and interpretative. Giorgi (1980) has presented a representative list of requirements which could transform phenomenology into a more rigorous science. The relationship between the experimental situation and the lived-world situation must be articulated clearly and precisely. There is an onus on the researcher to ensure that the experimental situation is accurately representative of the observed phenomenon as it is experienced by the participants. Experimental situations must use correct psychological descriptions. Where the phenomena under observation are non-objects, it is not possible to use traditional scientific terminology, which serves to quantify the experiential-behavioural relations of the individual within the world. There needs to be a move towards an understanding that defined variables do not occur in isolation from their interactions and Giorgi (1980) suggests that a structural approach could be helpful in this regard.

5.1.2 Focus of the research

Consciousness is the focal point of phenomenology in that phenomenology seeks to understand all that presents itself to consciousness, irrespective of its being real, as in the sense of an object, or subjective, as in the sense of feeling. The world can only be experienced through consciousness in the moment-to-moment flow by which we become aware of the world. Phenomenological research seeks to identify the being-ness, or essence, of an object or an experience, without which the object or experience would not be. For example, in attempting to determine the essence of a table, the question would be whether it would be possible to eliminate the legs and still consider it a table. When the focus is on an experience, there is an attempt to define those characteristics which constitute it, in other words, the structure and meaning of the experience, so that this is clear even for those who have not undergone the experience. A further characteristic of phenomenological research, is that the meanings which it seeks to uncover are those as lived by the person, and not those as defined by society or culture. However, it does seek to express those structures of meaning, be they cultural, social or historical, as they are experienced in the person's life, and which though not overtly expressed, are inherent to the experience. Furthermore Cohen, Kahn and Steeves (2000a) stress that the research design needs to match the question asked. It is important to differentiate between the concreteness of things, and their phenomena which is the lived experience of them.

5.1.3 The role of the researcher

In a phenomenological investigation the researcher becomes a part of the process through his or her personal connection with the phenomenon. Van Manen (1990) emphasises the importance of the attitude of the researcher. Not only is the focus of the research the natural lifeworld, but also the attitude of the researcher should be similarly natural and unadulterated. Through the authentic desire to fully understand the other's lifeworld, the researcher is changed because such depth of understanding inspires a sense of compassion and caring. This is in stark contrast to methods which bring about fragmentation through their atomistic goal of identifying constituent elements. Smith , Flowers and Osborn (1997) also support the argument that access to the personal world of the participant is dependent on the researcher's own concepts which facilitate his or her understanding of the world and hence the participant's lifeworld.

As a result of this orientation which is based in reflection and resonance, Van Manen (2002a) emphasises that phenomenological writing should have its starting point in awe or in a state of wonderment, born out of a receptive passivity. For the person who who reads such writing it should equally invoke a questioning sense of wonderment. This attitude of wonderment invites the reader to enter into the interpretive world summoned by the text, and to make it personal, so that the reader is enriched by it. It is obvious therefore, that, "no interpretation is ever complete, no explication of meaning is ever final, no insight is beyond challenge" (Van Manen, 2002b, p. 237).

The style of observation of the phenomenological researcher needs to be considered and it also needs to be respectful of the humanity that is being revealed at every turn in the research. This, "caring attunement," should be evident and manifest at all stages of the project (Van Manen, 1990). Smith et al. (1997) also emphasise the need for such an attitude, as in doing this kind of work leads participants to disclose a great deal of themselves. An attitude of attentiveness and respect for the dignity of the participants is therefore crucially important. This may be assisted by encouraging the participant to ask questions which the researcher has an obligation to answer openly after the research is completed.

Romanoff (2001, p. 254) notes that post-modern consciousness has highlighted the therapeutic value that subsists in the telling of the story. This is particularly the case in situations involving personal loss of loved ones. The narrative aspect of research, "can and does have a therapeutic impact. In research on bereavement, the narrative process offers opportunity for both continuity and change [because] death stories are reiterated to affirm their central meaning in the life course of the bereaved person." This serves to emphasise the need for a, “caring attunement” (p. 254). It is likely that only through the endowment of the interview with such a dimension, that it can be a positive experience for the interviewee. As Kvale (1996) suggests an interview can provide for the interviewee a rare opportunity to be heard by someone who displays an intense interest to his or her spoken contribution. Such caring attunement also presupposes that the researcher has been sufficiently immersed in the topic of the interview to enable a nuanced understanding of the participant's conversation. However it is essential that a certain “conscious naïvetè” be maintained where it is the participant's knowledge that is called forth. This requires a certain balancing act, emphasising the complexity that underlies such an interview (Kvale, 1996). Other roles are also assigned to the interviewer. One such is to maintain a focus on the identified themes, even though the content is not specified or directed by the researcher. Another is to clarify ambiguities that may present themselves so as to describe as clearly as possible the experience being reflected, notwithstanding the fact that, at times ambiguity is itself an accurate representation of the experience (Kvale, 1996).

5.1.4 Fundamentals of the phenomenological enquiry

Van Manen (1990) distinguishes between methodology and method. Whereas methodology is born out of the philosophical fundamentals which serve to underpin it, the method is more concerned with carrying out research in a way that is an expression of these fundamentals. As he states, "the procedures and techniques [that are used in phenomenological research] need to be conceived within the general orientation that characterises the present methodology" (Van Manen, 1990, p. 29). In order to fulfil these requirements, he has identified some elements which are, of necessity, used in interactive relationship within the committed framework of the tenets of phenomenological enquiry.

5.1.4.1 The nature of lived experience

"Lived experience is the starting point and end point of phenomenological research" (Van Manen, 1990, p. 35). The lived experience is, by definition, central to the endeavour of phenomenological enquiry, with its goal of transforming the experience into a written record of the essence of the experience. It is the very process of reflecting on an experience that gives it meaning as patterns and themes are distilled through the various interpretative acts involving memory, so creating an interwoven structure of connected experiences. Thus the significance for the person undergoing the experience emerges from the reflective process, be it in conversation, thought or fantasy.

At all stages of phenomenological research, the nature of the experience will guide the investigation, as questions will seek to answer the question of what the experience is really like and what about it renders it significant. This is made possible by the researcher's open and interested attitude, which gives rise to such questioning. This is in contrast to the type of research where the question is formulated as a null hypothesis and which can be carried out in disinterested and objective fashion.

In an attempt to define lived experience, Dilthey (Van Manen, 1990) suggests that it is that experience which presents itself in *raw* form to the person's consciousness, and it does so devoid of pre-conception, evaluation or even the awareness of consciousness of the experience. It is often the case that, when approaching a phenomenon, this endeavour poses great difficulty because of the metaphoric origins of the spoken language, which is used to express the meaning of an experience. This places in question precisely how it may be possible to bracket an experience, when pre-conceptions or information about the phenomenon creep in on the back of the very language that is used to explicate the phenomenon. Kvale (1996) emphasises that rather than entailing an absence of pre-conceptions, such bracketing entails a critical scrutiny of the researcher's own pre-conceptions. Steeves (2000a) notes that even sharing a language may not ensure that the meaning underlying the used language is the same for all participants. Thus language reveals a specialised understanding of a particular group of people in the way that such a group shares certain rules and traditions about how something is spoken about. Such specialised understanding may even transcend broad sociological groupings of class, race or locality. The goal for the researcher is to understand these underlying rules and traditions so that the participant's interpretations that are based on them can also be understood in their uniqueness.

This makes clear the necessity for understanding the meanings pre-associated with the language used. In the field of parental bereavement for instance, commonly used metaphors include those of bereavement as a stage-defined process, bereavement as pathology and bereavement as loss. Each of these metaphors elicits more than the bereavement thus amplifying and expanding on the meaning of the experience in a particular direction. Other metaphors used to explain the grief process are: “draining”, “emptiness and holes” and “part of me died”. Talk about dying is often also expressed in metaphor and death can be seen as a battle, struggle or resistance against something harmful (Rosenblatt, 2000, p. 59). However, as Rosenblatt points out, while these metaphors reveal something of the experience, they also obscure something else of the experience and this also provides avenues for further exploration.

5.1.4.2 Investigation of the lived experience

In phenomenological research the function of data gathering is the collection of the raw and unadulterated descriptions of the experience which is being investigated. (Polkinghorne, 1989). It is assumed that there is a string of interlinked connections between the person's world and experiences, their feelings and the way in which these are spoken or written about. There is also an assumption that there is a realm of human experience and consciousness that can be revealed through understanding how meaning is configured within that consciousness.

According to Polkinghorne (1989) it is possible for researchers to utilise three sources to generate descriptions of an experience: the researcher's personal understanding of the experience; the shared understanding of other participants in response to interview questions; and depicted symbols and representations which are to be found outside of the framework of the research environment. These include novelists, poets and artists among others. Sometimes reference is made in the interview to specific forms of literature or other art forms (such as song) that are meaningful for the participants in that they have affected his or her experience in as significant way. Kahn (2000a) suggests that it would be useful for the researcher to study such sources so as to gain increased understanding.

The beginning point of the research is the description of the lived experience which provides the data upon which the research is based. This enables the researcher to gain enlightening orientation to the phenomenon in question. Recognition of the over-arching themes of the experience can assist in the transition of understanding the experience as the personal account of one person, to the understanding of the experience as a human experience possible for any person. The reason for seeking the descriptions that others can provide about an experience is to allow for the researcher's own experience to be enlarged by this. Thus it is a way of remaining true to the primary function of phenomenological research of understanding the nature of the phenomenon as a human experience.

Van Manen (1990) suggests that there are certain requirements for the description of the lived experience to serve as raw data. The experience is described subjectively in a naïf and natural way, avoiding generalisations, statements of causality or interpretation. The focus is on trying to capture a sense of the how the event stands out. There is moreover an attempt to recapture the feelings that were experienced in a way that is straightforward in the linguistic sense.

The interview, as a means for gathering data, may assist in this process of exploration and description of the experience especially as it may become the means for enlarging the meaning of it within the context of the interviewer-interviewee relationship. However, Van Manen (1990) cautions against entering into such a situation without thorough preparation. The goal is for the production of concrete experience, that are richly descriptive so that the description will be sufficiently illuminating in itself, thus avoiding the need for speculation. Clarity of purpose on the part of the interviewer will also be of assistance on those occasions when the interviewee's focus is somewhat diluted in digression.

The professional interview in the context of research is set apart from others by its defined focus. In contrast to spontaneous conversation the flow of information tends to be uni-directional with clearly defined and unequal ranking between interviewer and interviewee in terms of power (Kvale, 1996).

5.1.4.3 Reflection of essential themes

While people tend to reflect easily and spontaneously on the meaning of events, the determination and clarification of such meaning is more difficult and require for the meaning structure of the lived experience to be made clear. This is made difficult because meaning has multiple levels and dimensions which are interrelated. The process of examining the themes that are central to the evolving account is used to uncover this multi-layered meaning structure. For instance, when accounts of the loss of a child are gathered, it may be possible to discern certain themes such those as of powerlessness, burden, or emptiness (Neimeyer, 2001c). A theme can be recognised as the point of an anecdote, which however does not fully capture it as it describes only a certain facet of it. Themes are indicative of the desire and ability to create meaning from experience. As such, they demonstrate the capacity for insight and interpretation that gives a sense of structure to the feelings underlying the experience.

Van Manen (1990) suggests three approaches that can be utilised in revealing themes. The first, which is termed the wholistic or sententious approach, is the attempt to articulate a phrase that embraces the whole. The second is the selective or highlighting approach attempts to identify a specific phrase or phrases which can reveal something of the essence of the phenomenon. Thirdly the detailed, or line-by-line approach, seeks to establish the meaning in each sentence or segment. Irrespective of the approach used however, is the necessity to distinguish between those themes that are essential, and those that are supplementary to the essence of the phenomenon, without which the phenomenon would not be.

5.1.4.4 Writing up the research

Van Manen (1990, p. 116) explains the importance of anecdote as, "a methodological device in human science to make comprehensible some notion that easily eludes us." The context is an important aspect of the anecdote, so that the words and language used to recount it express both social and personal aspects of the lived experience. An anecdote engages the attention of the listener in a way that invites reflection of the meaning of the story both for the teller and the listener through the way in which it connects with the listener's own experience. Through writing the anecdote, a form of reflection is called for, and it is this that evokes a form of consciousness that enables or facilitates phenomenological enquiry. As Van Manen (1990, p. 129) avers, “to write is to exercise self-consciousness.” Writing changes the ephemeral nature of thought, making visible that which is invisible, and through this objectification permits a different level of reflective dialogue to occur. Thus, in the act of writing, the author brings into being the self. At the same time, writing also converts the experience to the abstract and makes it an intellectual exercise. However, the narrative power of the story can also be more emotionally stirring than the lived experience, and serves as a reminder of the paradoxical nature of writing because, as a creative activity, it makes the experience more concrete than it would be if it were only an oral activity.

5.1.5 Issues of validity and reliability

According to Kvale (1996) hermeneutical modes of understanding allow for multiple interpretations all of which are themselves valid. For instance the questions that the reader addresses to the text as well as the reader's openness to the questions that the text invokes will help to determine the meanings that can be elucidated. The text can also be interpreted at different levels which produces a variety of meanings. Interpretations may also be considered valid in terms of the community that validates them. For instance, if the context of interpretation is self-understanding then it is the person who validates it. For critical common-sense understanding it would be the wider community, who would wish to validate it and would thus exceed the individual's self-understanding, while theoretical understanding is validated by the research community, once again extending the reach of understanding. Thus the search for the actual meaning takes relational and contextual aspects into account and this has a bearing on issues relating to validity. Aspects that are considered necessary for establishing validity include the soundness of the theoretical presuppositions and the logic underlying the questions generated therefrom, as well as the adequacy of design and methods for the purpose of the study. With respect to interviewing, the questions posed should be directed towards revealing meaning and checking information and this concern must be evident at all stages of the research process

Within the context of phenomenological research, validity and reliability are considered to be a conclusion that has power to persuade the reader of its own conviction. In order to do so the inferences used in the transformation of raw data and the synthesis into a general structural description must be clear, logical and well-supported. According to Polkinghorne (1989) it is necessary that the following concerns be addressed:

- The researcher or interviewer should not have influenced the participants' descriptions in a way that the reflection of the participant's actual experience is altered.
- The transcription should be an accurate reflection of the interview.
- The researcher should identify all possible alternative conclusions and demonstrate the superiority of the selected conclusion.
- The general structural description needs to maintain its relationship to the original reflection of the experience.
- The general structural description must be generalisable.

In summary, the philosophy underlying hermeneutic phenomenological research makes it particularly apt for the study of the meaning of an experience such as parental bereavement. It enables the researcher to describe in depth an experience which is sited in consciousness, rather than study behaviour, emotions or thoughts in a way that is theoretical. It is a contention of this research, that such knowledge will best be able to inform suitable therapeutic modalities in the field of parental bereavement as a result of an HIV/AIDS-related illness.

5.2 An overview of the development of phenomenology

The following section explores the development of phenomenology from its origins to the present. It seeks to reveal the relationship of phenomenology to existentialism and hence to psychology. This section is structured according to various luminaries, with the precepts which they have proposed.

5.2.1 Definition and introduction of phenomenology

From an etymological perspective, phenomenology has its roots in two Greek words, *phainomenon* and *logos*. Phainomenon or phenomenon is everything that manifests itself, whatever its form, and whether it is accessible though the senses or in other ways. Hence it refers to the general property of something and to the various ways in which something can appear. Logos signifies the giving of an account. The current definition of phenomenology is that it is the study of lived phenomena as they are experienced by human beings. This reflects a change from the original definition, as conceived of by Husserl who defined phenomenology as the study of the structure of conscious experiences of human beings (Sokolowski, 2000).

Phenomenology, as a movement, arose in Europe, first in German and then French philosophy, in the early twentieth century where it quickly rose to prominence eventually typifying the course of European philosophy in this period. While the 19th century was dominated by the scientific ideal in the guise of positivism, the “critique of knowledge” introduced by Kant led through historicism to an anarchistic relativism (Vander Hoeven, 1964). This critique was a watershed that marked the beginning of a change which invoked within the humanist movement a critical self-reflection and forced it to re-examine its own foundations. The dualism between the autonomy of the conscious mind and the rational domination of reality manifests as a tension where the meaning function of rational distinction constantly threatens the autonomous nature of the conscious in which is the launching pad of reason.

5.2.2 Phenomenology at its inception

According to Kockelmans (1967), the definition of phenomenology has appeared elusive, difficult and undefinable from its inception. The aim of phenomenology is a method to let everything appear in a clear way and as it is manifest (Kockelmans, 1965). In his book *Phenomenology of Mind*, Hegel explored phenomenal knowing and considered knowledge as it appears to consciousness. The goal was to attain absolute knowledge through transcending phenomenal knowing. In inaugurating phenomenology, Husserl saw it as a move for philosophy away from abstraction in metaphysical realms and returning to concrete living experience (Moran, 2000). Later however, there was disagreement between Heidegger and Husserl regarding its meaning and definition. As Vander Hoeven (1964, p16) has remarked, "under the banner of phenomenology sails a rather heterogenous company." Perhaps, as he suggests, this very vagueness and elusiveness is a reflection of the character of the time in which it is manifest, thus capturing the essence of its nature.

5.2.3 From Descartes to Husserl

The legacy of the mind/body and human being/world duality first posited by Descartes (1595-1650) continues to this day, particularly in the natural sciences. Positivism sought to provide freedom from the yoke of traditional beliefs and practices, and replace these with the hope that all human problems could be solved through unbiased understanding and application of the one correct method. The goal of scientific objectivity was the elimination of subjective elements and in a sense this included the elimination of the human being in a non-human universe. For a science to be empirical when engaging in a particular study, it should follow specific rules in the formulation of the basic concepts. Hypotheses must be formulated and tested according to prescribed criteria. Hypotheses must then be explained according to laws and these explanations must be verified. The knowledge produced by these methods excludes the observer as it attempts to overcome personal perspective and personal bias through objectivity. This makes such knowledge theoretical. In addition, knowledge is represented as fact, so that it is formal. This aspect is combined with the functional one in order to describe the relationships between elements. Such quantitative materalism, which arises from one element of Descartes' dualism, the res extensa (that which is tangible and measurable), found its ultimate expression in the natural sciences through its attempt to transform all knowledge into mathematical relationships and constructs. Hence the categorisation of information and its numerical descriptions, renders this kind of knowledge quantitative (Polkinghorne, 1983). Positivism sought, by these means, to reveal the underlying laws of the universe, and its components. The other element of the duality, the res cogito was concerned with the human mind or soul. Freud's intrapsychic personality theory and the reductionist effort to identify the elements underlying human behaviour, was an attempt to adhere to these principles. The basic elements of life and death could then be transmuted into a physiological framework. This has moderated the insightful awareness of the reality of the individual's inner life to some extent (Kruger, 1979).

While the scientific approach helped to free science from historical prejudice, it also excluded the relationship between science and man, and contributed to a dehumanised notion of humanity (Kruger, 1979). Seen from this perspective, metaphysical ideas were considered incorrect and as holding back progress. In reaction to the de-humanising aspect of this approach, the anti-positivist movement was launched by Dilthey (1833-1911). While believing that the positivist position could contribute to knowledge by adherence to a rigorous scientific approach, he could not agree that this could be correctly applied to the study of human phenomena. He saw that positivism was limited in this application, as it would yield explanatory models that are too limited to account for the spectrum of human life and the social and historical realities pertaining to it. Hence he proposed that in order to study human life it is necessary to study the experience and behaviour of human beings empirically (Polkinghorne, 1983).

Dilthey also rejected the empirical view of experience as based only in sensations and impressions, which he believed could not capture the fullness of the human experience. He asserted that at the basis of knowledge there is experience rather than sensate response. Basing his conviction on the guidelines proposed in 1819 by Schleirmacher, Dilthey proposed that the general system of interpretation consisted of psychological as well as grammatical interpretation. Central to psychological interpretation is the need to consider the totality of thought of the author, not merely the text produced by the author. However, as a "stubborn empiricist," Dilthey proposed the use of the discipline of hermeneutics to provide the framework for gaining access to a true understanding of the meaning of human actions and linguistic expression (Polkinghorne, 1983, p. 222). It was his hope that by producing as objective a knowledge as that produced by the physical sciences, a certainty of outcome would emerge to form the basis for political and social resolutions. It was necessary therefore to abandon introspection as a suitable device for producing understanding as personal bias will cloud any knowledge derived from it. It was his belief that understanding can yield valid and genuine knowledge of the human realm through an objectivity of approximation where degrees of truth move successively closer to a certainty of understanding (Polkinghorne, 1983).

Wundt (1832-1920), also in contrast to positivist philosophy, was primarily concerned with the subjective elements of experience, and emphasised the role of apperception, which he understood to be the act of transforming the awareness received from the senses to a perceptive experience. Experience is therefore not a passive participation in a stream of events, but rather involves the person who is actively and creatively involved in the production of it. Nonetheless, Wundt believed that the appropriate method for the investigation of these processes remained experimentation, which should be directed towards the psychological investigation of immediate experiences, thought processes and the historical development of the emotional sphere (Polkinghorne, 1983).

The breadth of human experience, as the focus of psychological enquiry, was also proposed by Brentano (1838-1917). In order to understand lived experience, the researcher should take cognisance not only of perceptions, but also of judgements and value-systems. In the spirit of the era, he initially shared positivist aspirations regarding the use of scientific methods of inquiry, but called attention to metaphysical issues as the focus of inquiry. In order to identify the basic elements that constitute experience, Brentano attempted to establish descriptive categories and a system of classification of sensations, feelings and judgements that could form the basis for a study of causal relationships (Polkinghorne, 1983). This inquiry made him aware of the inadequacy of methods derived from the physical sciences, because they required conscious experience of the experience as it occurs, thus going against the positivitic precepts against subjectivity. Mental phenomena can be differentiated from purely physical phenomena by their characteristic of intentionality by which mental phenomena in consciousness can refer to the physical phenomenon. This redefined the focus of psychology as separate from positivistic goals of reducing experience to the physical phenomenon. The mental phenomenon comprises strata from the representational to the judgemental (where the object can be accepted or otherwise) and the emotive, where they are endowed with feelings. Another concept that Brentano stressed was the role played by time in experience and particularly the difference in the way present time is experienced, as compared to past and future time. He believed that these differences arise from the way the phenomenon is represented mentally, excluding the judgemental stratum. Past and future can only appear indirectly as part of present time and are thus not independent of it. More than any other, Husserl was influenced by Brentano's work, especially the a priori science of the acts and contents of consciousness (Moran, 2000).

5.2.4 Husserl's contribution

The prevailing dominance of positivism of the era within which Husserl began his career, directed the focus of attention, within the social sciences, to an attempt to understand the motivation of subjective activity so as to ground it in scientific verifiability. The premise of the natural scientific method within the social sciences, after Kant, asserted that the human being (preferably termed the subject) is an integral component which cannot be omitted when attempting to understand the act of the human being. Each fact is only a fact insofar as it is so perceived and interpreted. The goal of positivism was to incorporate these subjective factors into an absolute or objective form which was more acceptable to the scientific method.

Vander Hoeven (1964) recounts how the reductionist effort to define the ‘building blocks’ of behaviour resulted in the psychologism of the 19th century whereby the subjective character of human acts was subjugated into elements which are able to give rise to complexes of representations out of which the whole can be constructed Eventually this gave rise to a “disastrous scepticism, [where the] logical norms of human thought-activity were directly endangered," through being subsumed into a so-called factuality of relative stability and convenience (Vander Hoeven, 1964, p. 20). The realisation that there is no way of dealing with knowledge which surpasses this reductionist approach reveals that, rather than it being a scientifically verifiable reality, it is, at best, verisimilitude.

Husserl criticised psychologism on the grounds that by allowing a presupposed view of reality to determine the phenomena to be studied, impaired the ability to clearly understand these phenomena (Bruzina, 1970). He maintained that a positivist approach would, of necessity, fail to achieve the desired scientific goal of universal validity if a sceptical convenience led to an understanding of the human act-experience as a construction from standard recurring components without any real meaning, and so he saw phenomenology as a radical break from psychologism.

Husserl turned his focus on the need for a more in-depth understanding of the human act-experience which would be based on a more nuanced and accurate description of it (Vander Hoeven, 1964). At the same time, Husserl, with a background in mathematics, was greatly optimistic about science and positivism, believing that logic and exactness of method should firmly and solidly underpin any endeavour within this field. Moreover, the objectivity of logic must be founded in the fundamental epistemological distinction between the real and the ideal, the ideal being that which is conceived in terms of thought. Hence all viewpoints generated in consciousness must be studied in the absence of presuppositions. In order to eliminate this type of presupposition it is important to recognise that the study of general meanings or essences (or eides) is a valid undertaking. Equally, in order to examine this material, it is valid to use a mode of consciousness which concerns itself with the object, and this Husserl termed intuition (Bruzina, 1970). It is possible therefore to deduce the general meaning of an object through a process of essential intuition because the meaning of an object is relatively invariant. Thus the aim of phenomenology is the elucidation of essential structures using grounds and method.

5.2.4.1 Eidetic reduction

The technique of eidetic reduction is used to ascertain the essential nature (eidos) of a concrete act and its components through analysing its various possibilities (and impossibilities). By freely, but systematically, considering the various configurations of characteristics of an object in the imaginative sphere, the elements necessary for understanding the essential nature of the object become evident, thus revealing a field of pure phenomenon. According to Levinas (1967), essence exists in the conceptual idea of an object or the object as it is. Hence, in establishing the essence of an object, it is necessary to analyse what constituents are used to define an object, and how their presence, or lack of such presence, would confirm or invalidate the essence if the object. For instance, a table can still be a table whether it has a round or square top, or whether the top is of wood or glass, but is it still a table if it has no table-top? In other words, it is possible that the table-top constitutes a vital element of the essence of table.

Levinas (1967) refers to the ideality characteristic of the essence where this does not arise from the object as an extension, but is rather its way of constituting itself in the consciousness. Hence ideality characterises how an object is, or it very Being-ness and it is thus not possible to distinguish between that which is perceived and imagined and any distinction between them results from the temporal nature of some objects. Eidetic intuition therefore is, "that mode of life in which the object intended by it, is not only 'meant' but also primordially given" (Levinas, 1967, p. 87). It differs then from perception by means of the senses where the aim is the categorical identification of a formal object, such as recognising an object as a ‘table’. The act of ideation, on the other hand, leads to the intuition of material essence. This transcends the formal object so that the existence of it is not necessary for eidetic knowing even though there is an implied relationship between the object and the intuition of the essence. Furthermore, although eidetic knowledge implies precision as regards nature of being or essence, it also implies a certain vagueness or fuzziness. For instance, thinking of the essence of table could produce many objects the size of which differs, or the material of construction and so on. Areas of study which are particularly suited to eidetic sciences include those that the natural sciences find themselves unsuited to studying. Time, consciousness and thinking cannot be defined geometrically but are accessible to study in their idealised form as essences. This imprecision of essence is, in part, indicative of the same characteristic in perception which also has an element of imprecision (Levinas, 1967).

For each essence, different levels of clarity are possible, so that degrees of this quality exist on a continuum from absolute clarity to its opposite of obscurity where understanding is beyond the reach of consciousness (Husserl, 1967). Even where obscurity reigns, it is still possible to bring clarity through the reach of the imagination. For instance, models or analogies can be used, which, while not being the object under scrutiny, assist with the understanding of its nature. This process facilitates the, "rigorous conceptual precision of the generic essence of perception" (Husserl, 1967, p. 116).

The position of a priori knowledge presents a complicating dimension to the question as it evolves from an inductive thought process, based on previous experience of the object, but which may not represent the essence of an object. Returning to the example of the table, a priori knowledge may lead to the understanding that tables are made of wood. Yet, if it is made of a different substance, it can still be a table, so it can be understood that the material of its construction does not constitute essence. This argument formed the basis of one of Husserl's criticisms of psychologism as he believed that psychologism failed to recognise the part that the a priori plays in understanding the nature of being (Levinas, 1967).

A distinction is also made between dependent (concrete) and independent (abstract) content. For instance, a table is an independent content as it is sufficient on its own. It is possible to have an intutition which is a vision of the object and so imagine it. However it is imagined, the object itself will continue to be as it is. Dependent contents, by contrast, need to be related to other objects such as would be 'big' or 'black'. Ultimately then this depends upon knowledge of the kind or class such as 'size' or 'colour'. In both these instances the goal of eidetic knowledge is the determination of the very condition of existence of an object, the absence of which would make it non-existent. It can thus be seen why the discipline defining the determinants of existence are termed ontologies, as they are relate to the metaphysical concerns regarding the very nature of being (Levinas, 1967).

5.2.4.2 Phenomenological reduction

In addition to eidetic reduction, phenomenological reduction can be understood as consisting firstly of the “bracketing of being”. Secondly, it is the reduction of the cultural world to that of the immediate experience of the individual, and thirdly, it comprises the transcendental reduction of the phenomenal worldly 'I' to transcendental subjectivity (Kockelmans, 1967). According to Husserl, the transcendental-phenomenological reduction is an essential component of phenomenology, and any approach cannot be so termed without this component.

Phenomenological reduction enables access to pure understanding, that is an essential intuitive grasping of the object, in the original form in which it exists in consciousness. This differentiates it from the natural attitude which is the successive identification and recognition of objects or ideas as they present themselves to the person. To understand consciousness, it is necessary to distinguish between consciousness, and that of which the individual is conscious, by examining how each act is connected to the object to which it relates. Study of essence, will, of necessity, return to an intentional analysis of the different modes of consciousness in which the particular being is constituted as that particular being. Each object and its every element has a parallel in the constituting act of consciousness in which it is defined as itself. This is because ideas and values have relevance only insofar as they have a mind directed towards them.

The implication of this for consciousness, is that an object cannot be seen as existing inside consciousness, but rather that consciousness is a pure field of lived experience containing various objects as appearings-in-the-field. An object is thus a phenomenon, or, something that appears, in a field characterised by the polarisation between subject and object. The nature of the object itself can be real or illusory and its value is not as a thing but as a phenomenon within consciousness, which presents itself as something existing elsewhere, whether in reality or not.

5.2.4.3 The structure of perceptual experience

From a phenomenological point of view, the perception of a phenomenon is based upon that which ‘stands out’ from its background so that it is possible to distinguish between the focal point and the ground. The focal point cannot however be separated from the ground, but is rather where the ground resolves itself at that particular moment, so that the entire ground is a field of potentiality. The focal point can only have meaning insofar as it is a part of the ground. This field of potentialities, where many focal points are possible, is the “external horizon” of the perceptual meaning (Bruzina, 1970).

Apart from the context of external potentialities around the focal point, it is possible to consider the interior potentiality of the focal point. Each object has a noematic meaning which comprises a cohering series of meanings, which encompasses the totality of possible meanings and includes the ones antecedent to the current one, as well as those that will succeed it in an historical sense. There is therefore a sense of contuinuity inherent in each appearance so that each one has noematic sense. It is this set of meanings which are already foreshadowed (retentions) and foreshadow those yet to be (protentions) which is termed the “inner horizon” of the perceptual objective within an act of perceptual consciousness (Bruzina, 1970).

The world becomes perceptible in a phenomenological sense as a result of this inherent structure as regards historicity and horizon. Within this framework there exists a possible harmony or disharmony, compatibility or incompatibility, so that the structure of perceptual experience proceeds in an overall frame. The world then is an all-inclusive field of as-yet-undefined appearances in the perceptual plane which advance in temporal succession (Bruzina, 1970).

Another aspect of the structure of perceptual experience is that of active and passive genesis for constructing strata of meaning. Meanings tend to have other coherent meanings associated with them which make up a meaning complex. Although there are certain aspects of objects that are undefined, there is not a universe of possibilities because only certain meanings could be held to be typical. For instance, a pen is typically not vegetable.

According to Husserl the development of these meaning complexes is termed “constitution by passive genesis” and it forms the foundation for the activity of higher levels of consciousness where constitution is the development of meaning (Bruzina, 1970, p. 75). In contrast to this, “active genesis” is the constitution of new objects based on the precepts of existing objects that have already been constituted through passive genesis.

5.2.4.3.1 Temporality

The issue of temporality is an important one when considering perceptual structure as each objective has an intrinsic time horizon which permits people to view it in a way that makes sense. Where time is conceived of as flowing in a direction, that which has been as well as that which will be is also part of the present. Thus successive appearances flow into one other in sequential order which has at its core compatibility and harmony. For example, when eating a banana, the entire banana is in the past, while the eaten banana is in the future. Continuity thus makes sense as a continuity of a particular meaning so that eating a banana would not be part of a sequence of drinking milk. Coherence is the result of anticipation being confirmed and where the present acts a bridge between past and future. Where something anticipated does not appear, this would be meaningful too, as a shift from the expected flow. Bruzina (1970) sums it up by remarking that, “perception takes place within the indefinite totality of all horizontal progression, within a single all-embracing horizon-condition for all experience” (p. 73). This implies that the world is an open-ended field of potentialities succeeding one another in temporal progression. It does not, however also imply an empty field but rather one that has full meaning-complexes (objects) each with a spectrum of temporally implied sequences attaching to them.

5.2.4.3.2 Intersubjectivity

If phenomenology is concerned with understanding how the ego constitutes itself, then the question of other egos also arises because life is experienced in a communal sense and so is shared with others who also participate within that community. Sharing in that community means that objects, language and meanings pertaining to that community are also shared. Thus there is not only is the awareness of the person regarding the object that presents itself, but there is also an awareness that the object also presents itself as that object for others.

The capacity for empathy arises from this intersubjective nature of experience because through observation of the other’s reaction, gives the person an awareness of the other person’s experience of it. This then is a way for the person to have access to another’s experience as a perception of a raw event in much the way a memory is related to a natural event. Husserl uses the terms “vergegenwärtigung” (a representation) and “gegenwärtigung” (a presencing) to differentiate between the two kinds of experiencing. Thus the other’s experience provides for the person its own kind of experience in a secondary, non-immediate way. In the Fifth Cartesian Meditation Husserl expanded on this issue, defining the difficulty not so much as the trying to understand the other, but rather understanding how the other is constituted in own consciousness. While the other is a part of the person’s consciousness, it is not so in the way that objects are because the other’s being can only be construed through indications external to the person, knowing however that the other, as expressed in their physical self, is an indication of the consciousness of the other. As described by Moran (2000, p. 177), “the other then is a phenomenological modification of myself, for Husserl, grasped only ‘within my ownness’”. In this sense it acts rather as an analogy so that “when I experience another person, I ‘apperceive’ them as having the kind of experiences I would have if was over there” (Moran, 2000, p. 177).

5.2.4.3.3 Bodiliness

The view of the human body as primarily an organism has been the central crusade in the drive to understand its mechanical and functional underpinnings. Francis Crick, one of the scientists who first discovered the structure of DNA, in a recent work entitled, *The astonishing hypothesis* (Crick, 1994) contends that ultimately consciousness will be understood to be the outcome of neurological activity and nothing else. A similar view is held by Cotterill, who suggests, "that in spite of its relative complexity, the human brain exists solely for the processing of sensory information and the production of an appropriate response. The suitability of the latter is evaluated on the basis of past experience, and there are indications that the making of decisions actually precedes conscious experience" (Cotterill, 1989, p. 285).

From the phenomenological perspective however, this ‘objectification’ of the physical constitution of the body is not sufficient to produce an understanding of the body as the medium of ‘experiencing’ of the individual, through which all phenomena present themselves. All aspects of bodiliness contribute to the way the individual's experience is constituted. "The body is not simply a thing in itself but a way in which we exist for ourselves" (Schrader, 1967, p. 42). Hence, what is more important than the senses themselves, and how they function, is how experience can present itself as a result of the way the sense functions in the individual. The same would apply to left- or right-handedness, posture, bipedality and all other aspects of the human function. According to Kruger (1979) while human beings share much that is constitutive of the physical nature of the body with animals, to understand the fullness of the human being the function of parts of the human body must be based on an understanding of the whole.

5.2.4.3.4 Spatiality

The ubiquitous positivist interpretation of space as a purely measurable phenomenon is perfectly suited to empirical methods which can describe it in terms of dimensions such as length, breadth or depth, or characteristics such as temperature, humidity, emptiness and so on. However, these measurements do not necessarily assist in the description of spatial elements of a phenomenon in the lived experience of the individual even though consciousness is so conditioned by this physical understanding of space that it may be difficult to think of it differently. According to Kruger (1979, p. 48), “there is an intimate interlocking between man's bodiliness and his spatiality.” The individual's experience of space is that he or she is always at the centre of it, so that adverbs relating to space or distance may be expressed in relation to that individual.

Different spaces have different meanings so that an understanding of ‘home’, ‘church’ or even official institutional premises would arise from the personal experience of the individual. At a different level it may be seen how the different understandings of these buildings, according to the prevailing historical thought or geographical location, are transformed architecturally into constructions that may have different appearances. However different they may appear, the spatial experience of them nonetheless remains that of home, church or official institutional premises so that what is central to the experience of the structure is the relationship of the individual to it and how it presents itself to the individual (Kruger, 1979).

5.2.4.4 The life-world

Husserl's reproach of the scientific objectivity which had resulted in the de-humanisation of the world, was offset by the challenge of reintroducing the life-world as a legitimate source of knowledge about human beings. The life-world from the positivist perspective, was the source of inaccuracy resulting from subjectivity, but for Husserl, by overlooking the connections and relationships that exist between the person and their context, results in the eclipsing of the basic ‘truths’ pertaining to the life-world and which science glosses over as a pre-given. Such truths, such as, “I am a person” or, “I live in the world,” are the source of meaning for the person, so that their removal from legitimate scientific activity by objectification, removes the meaning from science itself (Pivčevič, 1970).

Apart from transcendental subjectivity (consciousness as a phenomenal field), Husserl's aim is to show that both logical meaning and perceptual meaning originate equally from the subjective field. This subjective field, as a source and originator of meaning, is termed the “life-world” by Husserl which is the world as the universal ground of experience. Study of the life-world must, of necessity, include the field of perceptual experience because it underlies and accompanies all awareness of the world for the person who is in the world. Hence the ground for any constituting activity where meanings are developed and rendered by themes, and which exists prior to this activity, is the life-world. The life-world is pregiven, and this is where human beings live and carry out activities of judging and understanding. First through passive genesis, at a foundation level and then by active genesis at a higher level, meanings are thematized so that the world is understood as the matrix for the perceptual experiences which are encountered. The result of this activity is the production of generalities which are however not yet pure idealisations. Idealisations are necessary aids for interpreting the world and result in scientific laws such as those governing time, mathematics, causality and the perception that the world is determined of and in itself (Bruzina, 1970). The fast pace of progress in the scientific arena and the modern idealisations arising from them, have inspired a false sense of human self-sufficiency which led to their disconnection from their point of origin. Meaning however can only arise within that connection and relationship so the crisis which has resulted from the disconnection is a crisis of meaning. Such idealisations are not the world however, and so to experience the original world it is necessary to abandon these disconnected idealisations which arise out of the scientific method. It is important to do so because while these idealisations construct a better understanding of nature, they tend to conceal the world as it relates to the person.

Husserl proposes that in order to uncover the basis of knowledge requires a return to the life-world and a phenomenological investigation of structure of the life-world itself. The means for achieving this requires ‘bracketing’ which can be defined as a neutral stance of the suspension of the functioning of existential beliefs in order to see unadulterated consciousness. Bracketing, in its form as a suspension, is termed ‘epoché’, while bracketing as the means to disclose pure phenomena is ‘transcendental reduction’ (Bruzina, 1970).

That which is suspended in epoché is all judgement about the spatio-temporal being of things which are assumed to exist in the world. It entails a major modification of normal perception which assumes an objective world as existing and in which the individual lives. To understand how the world is brought into being for each and by each individual requires that all assumptions regarding the world be put aside or bracketed. This does not mean that the existence of the world or the assumptions about it are denied, but as these assumptions or laws arise from the natural sciences, logic and mathematics, it means that these are severed from the phenomenological enquiry. Their tenets and propositions then are not used as foundations to elucidate on the world. According to Husserl once these empirical assumptions are bracketed the epoché yields a concept of consciousness within a self-contained realm of being which cannot causally influence or be influenced by anything else. As a result, consciousness can be a realm of absolute being which does not depend for its existence on anything outside of itself (Pivčevič, 1970).

If it were possible to identify the original life-world, it would not include the precepts of scientific thought as the experience of the life-world is itself the necessary foundation for these precepts. Thus there is a kind of folding-in on self, where the life-world has historicity through which it acquires the meaning of the existence of the world. At all time the life-world is pre-given. The original foundations of experience give rise to the ideas that are used to interpret and systematise the life-world. This process is central to formal processes of knowing (Farber, 1967).

The difficulty faced by Husserl was how to reconstitute reality as a transcendental system when the standpoint of the philosopher is ‘natural’ and thus non-philosophical. He attempted to resolve this through the concept of the ‘transcendental Ego’ a position which can be attained by reflecting on the person's own awareness of his or her own phenomenologically contained essence. The Ego invests the being of the world with existential validity, and this in turn yields a sense of own meaning and validates the person's own existence. The transcendental Ego is not an extension of the Ego but rather something inextricably correlated to the world. However, having reached this position, with its pivotal requirement for the bracketing of empirical considerations, it is perplexing to conceive of the possibility of an empirical ego and its world. (Pivčevič, 1970). However, the issue of the transcendental Ego was to remain problematic both for Husserl and for those who followed.

5.2.4.5 The concept of intentionality

In the attempt to differentiate between physical and mental phenomena, Brentano posited “intentional inexistence” as a characteristic of physical phenomena in which every such phenomenon contains within itself something as an object. The use of the word 'inexistence' serves to clarify the position of the object as something that may, or may not, exist outside of the mental realm. Intentionality, as defined by Sokolowski (2000), refers to the fact that every act and every experience is something that the person is conscious of, or experiencing of, so that every act of consciousness or experience is an intention that has an object correlated to it.

The use of the word intentional reveals the relationship between the mental phenomenon and the object, so that, for example, “in love something is loved, in hate something is hated, in desire, something is desired” (Pivčevič, 1970, p. 46). Thus to love, hate or desire something is described as intentional because it does not require the existence of that which is loved, hated or desired. In addition to the above, mental phenomena can only be perceived in inner consciousness through a process of inner perception. For instance, while a colour is a physical phenomenon, seeing the colour is a mental one which is not part of the external phenomenon. Thus, as human beings, we become aware of something by reaching out from mental models we have constructed and this has been termed an egocentric phenomenon which implies that all that any one person can be sure of is one’s own conscious existence and the states of consciousness pertaining to it (Sokolowski, 2000). This applies particularly to the emotions which are themselves mental phenomena which can be directed at another object (Pivčevič, 1970).

An initial attraction to the concept of intentionality as posited by Brentano, led Husserl to recognise the human act as an intentional one which is characterised by meaning something. As he described it, "the universal fundamental property of consciousness, [is] to be consciousness of something" (Bruzina, 1970, p. 58). Subsequently however, Husserl's standpoint on intentionality diverged significantly from Brentano as he was not interested in the classification of mental phenomena. His interest lay in the establishment of how intentionality is able to explicate the noetic, or purely intellectual, conditions of objective truth (Pivčevič, 1970). A second formulation, according to Husserl, that attaches to intentionality is, “ego cogito cogitatum,” which originated in the famous Cartesian conclusion of “cogito ergo sum”. This encapsulates Husserl's concept that each conscious process (cogito) has a particular meaning as well as bearing in itself that which is particularly meant (cogitatum) (Bruzina, 1970). The concept of intentionality is central to the idea of meaning, but is not a matter of linguistic significance. Whilst the natural and material reality of something can be understood in terms of objective measurement and thus reflects on one kind of reality, this understanding is not relevant when considering real existence which is embedded in the meaning attributed to it (Vander Hoeven, 1964). Intentionality can thus be understood as an element of consciousness which points to that which is not of itself in an effort to form meaning. Consciousness, and thinking, determines the nature of the object to which meaning is attached. Hence analysis is the attempt to understand the process of how meaning is created in the conscious mind through the very act of being conscious. Vander Hoeven (1964, p. 25) suggests that, "the meaning-content is immanent to the intentional act itself and that the units of meaning are nothing but the ideally grasped moments of these acts." Husserl does not however abandon the requirement, inherent in the scientific method, for stringent and rigorous analysis. The goal is to elucidate those elements of laws that make up the laws in order to clarify those connections within an experience that reveal elemental meaning.

At the core of Husserl's philosophy lay an understanding that consciousness can only be determined in relation to the existence of an object because intention is necessary in order to translate consciousness to an act. Thus an act implies also the presence of the object which is then, in part, determined by the act subsuming the object. It can be surmised therefore, that to arrive at the original object it is necessary to proceed via the act. The complexity of humans results in a complex layering of meaning so that total meaning must be grasped through the analysis of its various layers and constituents, each of which has its own meaning (Kockelmans, 1967).

How objects may exist for consciousness is a problem because they are constantly under flux as they undergo temporal variations from moment to moment, which arises from the egocentric predicament. Thus an epistemological dilemma arises as to whether objects have a reality in and of themselves, or whether they exist as illusory projections of the subjective mind. According to Gurwitsch (1968), Husserl's theory of intentionality is the only one that resolves this difficulty. Husserl differentiates between the real object and the noema. A perceived object is different from a real object in that it is an intellectual abstraction albeit of a real object. How the object is perceived is as the perceiving subject is aware of the real object and his or her awareness of the object. This is termed a noema, with the act in question being a noesis. An object has a multiplicity of perceptions through which it manifests itself, and through a synthesis of identification of a series of different perceptions of the same object (noemata) is constituted within the consciousness of the perceiving subject as one real object rather than multiple objects. However the noema is not the same as the act, in that it does not exist within consciousness in the same way that the act does, and is therefore an idea which bears similarity to a meaning or signification in the sphere of sense. Noemata correspond not only to objects but for every mental or emotional act as well. Husserl's noesis-noema thesis is thus a description of the mental state through which an object is experienced. This may be explained more simply as the dichotomy that exists between the world that exists in the individual consciousness and that which human beings have in common (Sokolowski, 2000).

A further aspect to be considered is the effect of the passage of time. An object presents itself to perception in the present, but may have connections to past perceptions of the same object in memory (retentions), as well as having certain expectations of future perception (protentions). The identity of the noema is thus distinct from the various perceptions in which it is represented, yet being consistent with all of them. An understanding of the temporal nature of consciousness is thus central to the capacity to make a noema explicit. The passage of time transforms each successive present moment, with its accompanying perceptions, into a stream of past events. The moment which is presently current does not disappear once it is no longer present, but is retained in short-term memory as that which has recently been present. A further transformation enables it to pass from this state into longer-term memory where it is added to the stream of consciousness which is thus subject to constant revision. It is possible only to recognise the unity of an enduring act if temporality is recognised so that for identity to be established there must be a connection to temporality, so that one noema may have numerous acts to which it corresponds (Gurwitsch, 1968).

According to Gurwitsch (1968), this sheds light on what is meant by the term intentionality and it clarifies the phrase “consciousness of something” so that intentionality can be understood as the objectifying function of consciousness. All organization of intentionality depends on the correlation that exists between the noema and the object or act. Identity itself takes on meaning in the relation it has to this multiplicity of acts within a temporal frame.

5.2.4.6 Meaning and language

An expression is rendered significant through the intentional aim of the conscious act. Two levels can be distinguished with regard to phenomena pertaining to language. The first is the word as a phenomenon discernible in speaking, listening or writing. An example of this is the word ‘cow’ which in itself is a collection of letters. The second is discerning how the object is intended through that particular meaning by the intentional act which confers meaning on an object. At this level ‘cow’ may mean, amongst other things, a herbivorous quadruped. While these levels are merged inextricably into a single entity, the meaning of the expression is only constituted in the second level so that the first level becomes merely incidental. The purpose of the expression is the communication of such meaning to another thus enabling the sharing of meaning (Bruzina, 1970).

Signs can be used as a mark to indicate something in which case it relates to an object or state of affairs. While each sign is a sign of something, meaning does not attach to all signs. In some cases, the link between object and sign can be the result of convention or of the causal relationship that exists between them. Signs can also be used as expressions and in this event are a part of written or spoken language and are used as communication tools so that the meaning associated with them can be transmitted. This communication can take place not only between the individual and another, or others, but also with self. Intentionality therefore serves to create the distinction between signs and expressions. An expression, even if it does not refer to actual objects, is brought to life by a meaning-giving act. In order to fulfil this expression, it must find a conceptual or perceptual image which enables its cognitive fulfilment either wholly, or in part, in what is a meaning-fulfilling act (Pivčevič, 1970).

5.2.5 The transition to existential phenomenology

The next section outlines the links between phenomenology and existentialism, and subsequently to psychology.

5.2.6 An overview of the three phases of phenomenology

The development of phenomenology occurred in three separate phases. The preparatory phase included Franz Brentano (1838-1917) and Carl Stumpf (1848-1936). The middle phase was dominated by German influence represented by Edmund Husserl (1859-1938) and his personal assistants, Edith Stein, Eugen Fink, Ludwig Landgrebe and Martin Heidegger (1889-1976), who developed philosophical hermeneutics together with Hans-Georg Gadamer. Other prominent names from this period are are those of Husserl's students, Roman Ingarden, Hedwig Conrad-Martius, Marvin Farber, Dorion Cains, Alfred Schütz, Aron Gurwitsch, Max Scheler and Karl Jaspers. Thus as Moran (2000, p. xiv) has commented in the preface to his work, "phenomenology as a historical movement is exemplified by a range of extraordinarily diverse thinkers." Phenomenology held sway in France subsequent to the outbreak of the Second World War where Heidegger's work was acclaimed as the appropriate methodological approach for achieving the goals of existential philosophy which sought to understand the human condition as it manifests itself in everyday, lived situations.

Although existential philosophical thought preceded phenomenology, there was eventually a merging of the two philosophies and the third phase was characterised by the joining of Husserl's precepts to those of existentialism. Heidegger does not identify himself as either an existentialist or phenomenologist, nonetheless, in his work the dual streams of phenomenology and existentialism join, resulting in the severance of the anti-scientific basis of the latter and the enrichment of the former through the incorporation of existential themes.

Influential figures of the third phase of phenomenological philosophy include Gabriel Marcel (1889-1973), Maurice Merleau-Ponty (1908-1961), Jean-Paul Sartre (1905-1980), Simone de Beauvoir, Michel Henry and Emmanuel Levinas (Jones, 2001; Moran, 2000; Sokolowsky, 2000). Leading proponents of existentialism in this period include Søren Kierkegaard (1813-1855), Friederich Nietzsche (1844-1900), Feodor Dostoevski (1821-1881) and Albert Camus (1913-1960). The merging of existential and phenomenological philosophical thought can be seen as the attempt to understand the lived experience of human existence free from presupposition. The psychological discipline arising from this philosophy seeks to, "explicate the essence, structure or form of both human experience and human behavior as revealed through essentially descriptive techniques including disciplined reflection" (Valle & King, 1978, p. 7). Some of the principal proponents of psychotherapy who were adherents of existential-phenomenological philosphy were Frankl, May, Perls and Binswanger.

5.2.7 Heidegger

Heidegger's Being and Time published in 1927 signalled a significant change of direction from Husserl. For Husserl the epoché or transcendental phenomenological reduction by the bracketing of being underpins phenomenology as a rigorous science. Heidegger, on the other hand, rejects this precept arguing that it negates the authentic philosophical attitude (Kockelmans, 1965). While Husserl admitted that in considering the reality of being it is necessary to keep the conundrum of the subject-object-correlation, Heidegger undertook to question the meaning of the Being as such. Not only can it be surmised that everything is, be it an object or person, but that Being itself is the essence of a being (Vander Hoeven, 1964). From the perspective where the human being is both the questioner and the focus of the question, the legitimate phenomena for study are those that elucidate the existence of being, the nature of being or the be-ing (Kruger, 1979). Of all beings, the human being is the only being who is, and also has a relationship to self, and the purpose of phenomenology is to reveal the essential aspect of being that may not be overtly manifest (Kockelmans, 1965).

5.2.7.1 Dasein

In the quest for understanding of the meaning of Being, the centrality of the Being who asks the question is crucial as the only being who is capable of making this enquiry. Furthermore, the way that the being, as the one who solicits the answer, understands Being, is also of critical importance. The being that is able to so question the nature existence is the human being (and only the **human** being), and so only through thorough investigation into the "Dasein" of the person, is insight into the nature of being made possible. This then forms the basis of such an investigation to provide the foundation for a genuine ontology.

The term Dasein is literally translated as to-be-there or being there/here. Dasein is used to indicate the out-standingness of a being and its openness through which a being be revealed. Dasein cannot be fixed in any one place, but is always beyond it and outstanding in the sense of ex from the Latin out and sistere to stand so that it can be termed existential (Vander Hoeven, 1964). Heidegger rejects Husserl's method because it cannot fully penetrate the essential meaning of Dasein leading as it does to ideation (Kockelmans, 1967).

The existential analysis of the human Dasein has an ontological goal and thus serves as the foundation for the understanding of the meaning of being. According to Heidegger, "the essence of Dasein lies in its existence" (Kockelmans, 1965, p. 142). From the range of possibilities for being that are open to a person, the person is able to freely select those options that will enable the being of the person that is most proper for him or her. Thus Dasein, in its totality of the range of all possible ways of being, is always greater than it already manifests itself, and it is the person that determines his or her own being, so that Dasein is always a self-determination which is responsible for its own being. Existence then is the relationship of Dasein to itself and its own being as the power to be or exist. Dasein is the openness of the person to the fundamental openness of Being itself.

5.2.7.2 Being-in-the-world, ontological anxiety and throwness

Just as the concept of Dasein is conceptually in a different league from being as Ego, so "being-in-the-world" requires a different understanding of the world, not only as the physical site of other things, but rather as that which is inhabited by human beings, the site of their being-ness. The human being inhabiting the world does not come to do so by objective understanding of the world followed by a decision as to how to inhabit it, but rather through the continual co-evolution of the relationship between the world and the person within the world. Heidegger saw this as a central precept for overcoming the subject-object dichotomy inherent in Husserl's philosophy. Things-that-are in the world can only manifest themselves through their making themselves present for a human being through an invitational aspect which requests being taken into the presence of the person. The person makes these things immanent in his or her consciousness, irrespective of whether they become apparent through the senses or through an experience such as dreaming. Hence, it follows that those things-that-are-in-the-world exist very specifically for each human being to whom they become apparent. At the death of that human being, the specific existence of that thing-that-is-in-the-world can no longer continue as it differs for each human being. Thus the world cannot be defined independently to the person as Dasein, just as Dasein cannot be defined independently of the world (Kruger, 1979).

There are three main aspects to being-in-the-world through which consciousness becomes manifest and which are constitutive of the being. The first, known as the 'umwelt', refers to the physical world of the individual and the individual's subjective awareness of it through the perception of the environment. The 'mitwelt' is the second such aspect and is concerned with the social world that the individual shares with others and through which the individual forms an awareness of others through perception and experience. This aspect is essential to the development of the person as a human being as it evolves in synchrony with others.

Finally, the ‘eigenwelt’ is concerned with the internal processes and self-dialogue of the individual through which understanding is constructed (Kruger, 1979). When these three aspects are taken into account, it becomes obvious that the individual can only be understood when considered in context because this is where values exist that are significant for the individual. Binswanger subsequently introduced the concept of ‘throwness’ which postulates that while the modes of being-in-the-world form a basis for perceiving and experiencing the world for the person, and hence the creation meaning, human beings also as ‘thrown’ into a world that is already charged with meaning. Thus at the heart of being-in-the-world is prior existence, so that the human being is constantly coming-to-existence where there is not limitless choice about existence. It is through such throwness that the person learns to understand how he or she is differentiated from the world and others who equally exist in it (Maddi, 1972).

For Heidegger, consciousness is formed by the lived human experience within a context of the passage of time, so that it can only be understood through the being-in-the-world rather than as a pure category in itself. Time as a measured, scientific concept resides in the human being, so that time exists in the person (Kruger, 1979). The temporal dimension of the Dasein is sited in its being-historicity and there is a tension between past and future which the present cannot resolve. The past is a fact by virtue of the presence of the person and is thus part of it.

The life-history, and the siting of the being within such history, means that the person’s existence is that of time as it has been lived, and as it will be lived. As such the existential significance of time presents itself as an ontological assumption where death, as part of the future, is always included within the life-history. Even the avoidance of the matter of death is embedded in the possibility of death, so that it is ever-present as the final horizon of Dasein. Death forms a part of existence and the human Dasein is thus a being-unto-death (Kruger, 1979). Human identity can only be understood through historicity because the constancy of an existence is maintained in spite of changes from moment-to-moment or year-to-year. The past is always in the present, and from that dimension the Dasein is infused by a state of non-being which gives rise to anxiety. Existence derives from ex (out) and sistere, (standing) so that ex-sistence implies that Dasein lives in the realm of as-yet-to-be possibility thus recreating itself over and over again. These decisions constitute the possible authenticity of the individual who is oscillating between past and future (Polkinghorne, 1983).

The future is also a source of anxiety and of non-being in the form of the threat of death (Vander Hoeven, 1964). Reflecting on the difference between fear and anxiety or dread, Heidegger states that fear is always related to something within the being-in-the-world. No-thing is not nothingness but depends on its not being some-thing in order to be so defined. Hence no-thing itself is only possible as a part of the world as such and that which Dasein dreads then is also the being-in-the-world itself. In contrast to the reaction where fear is involved, dread or anxiety results in the loss of the meaning of everything. The no-thing manifest in the phenomenon of dread is as real as the some-things of the world and in addition has the capacity to nullify the beings of the world. In addition, the no-thing emerges of the very scope of possibilities that constitute the being-in-the-world and cannot be defined as dread of something. The Dasein in which no-thing reveals itself thus becomes the point at which the study of the no-thing is begun. Its very being as no-thing gives rise to the very being of the possibility of being. It is through the recognition that there is not nothing then that gives existence to being. No-thing may give rise to dread but dread is constituted by Being, so that, as Heidegger concludes, "man is man because he knows that he is called by the voice of Being, by Being that originally in dread became disclosed to him as 'no-thing'" (Kockelmans, 1965, p. 158).

Buber, writing I and Thou just ten years after the publication of Heidegger's Being and Time, seeks to understand how the individual experiences his or her world in relation to other beings and objects. While experiences bring the world to the person, the world itself is experienced by the person as consisting of *It* and *I* , or *You* and *I.* In these relationships however, the realm of You is different from the realm of It in that, "whoever says You does not have something [an object]; he has nothing. But he stands in relation" (Buber, 1970, p. 55). Thus he distinguishes between the possible type of relationship between It and You where the It can be possessed but not so the other person. The only way of experiencing the other is in relationship, which is made possible at the very outset by the realisation of the distance or otherness of the other from the self. In this relationship discovering the other is forming both self and other into a new structure of I and Thou which is based on reciprocity. Through discovering the You the person becomes an I so that, "all actual life is encounter" (Buber, 1970, p. 62).

The I and Thou relationship is also illustrated in the individual's search for a spiritual connection because, “spirit is not in the I but between I and You … Man lives in the spirit when he is able to respond to his You. He is able to do that when he enters into this relation with his whole being” (Buber, 1970, p. 89). Hence this requires that the individual stand in relation to the eternal You. The stronger the individual's relationship with the eternal You, the stronger the relationship can be of the I. The greater and richer the relationships that the individual forges, the greater and richer is the I. As the merged reality of I and You is experienced in its fullness, the constituting elements of this greater whole tend to retreat into the background. There is a such a sense of immersion in this greater whole that it reveals how at its core the universe and self are one, the whole of each including the whole of the other in reciprocal fashion. While each contains the other, each has its own being, so that this containment in more of an embrace rather than an annulment. Knowing of this reciprocal containment means that the person's existence can only be given meaning through the relationship with the eternal You, and ultimately through the actualisation of the eternal You within the bounds of each person's possibility (Buber, 1970).

In this reciprocal embrace also lies the power to overcome the dread of the alienation between the world and self, through understanding how in the relationship the universe itself can be comprehended. It is the knowledge that the I is contained within the world, so that the world cannot harm the I, that allows the person to rise above anxiety. The means for achieving this is dialogue, rooted in language, so that the primal deed is language, “and there is, in eternity, the word”. There is a uniqueness to this dialogue which results in an individual sense of meaning which is unique to the individual and to his or her existence, so that meaning is not universally valid but lived idiosyncratically by each person within the context of the relationship (Buber, 1970, p. 143).

5.2.8 The existentialist contribution

Apart from phenomenology, existentialism is the other main pillar of existential phenomenology. One of the original sources of the philosophy of existence could possibly be found in Hegel's first work, *The phenomenology of spirit* which for the first time considered self-consciousness in the attempt to understand the human experience which prior to this had been the realm of the arts and religion (Ricoeur, 1967). However, while Hegel's interest in allowing the experience to appear and speak for itself provides a foretaste of Husserl's work, the promotion of the negative experiences of disappearance and contradiction serve to alienate it from phenomenology through the introduction of logic.

While Husserl as founder of phenomenology is no existentialist, Kierkegaard, as the founder of existentialism is no phenomenologist. However, a common starting point for both is their rejection of the reductionist principles of natural science as it is applied to the human being (Kruger, 1979). The focus of concern for existentialism is human existence. According to Schrader (1967), prior to Kierkegaard, the term “existence” had been used to refer to things in general, but after Kierkegaard its meaning narrowed to signify human existence as opposed to that of other beings. This is not to renounce fixed essences, however, Kierkegaard's insistence on the understanding of the uniqueness of human experience diminished the possibility of a generalised knowledge which is applicable to all, as was the positivist goal of the formulation of immutable laws. This narrowed meaning brings attention not only to the existence of the human being but also to the way in which the human being manifests within the world. In light of this, Heidegger's original definition of Dasein as, “that being which I am” becomes clearer as it highlights the cultural and historical context of exististence, which exitentialism has espoused. Thus exististalism has striven, "to illume those everyday activities and concerns which characterize man's temporal existence" (Schrader, 1967, p. 3). Included in the, “everyday activities and concerns” of existence are the phenomena of dread, anxiety and alienation which are commonly associated with existentialism. This concept is central to the necessity for a dialectical balancing of the disquilibrium which is brought about through these ‘negative’ elements. It is also an essential element of the self as spirit as well as at a broader level of human culture where a parallel integrative process also results in balance and re-balance. Thus for Kierkegaard, dread and anxiety are normal responses to the uncertainty of the freedom which underlies the human condition even if these states bring about the despair that is a ‘de-spiriting’ of the human being (Schrader, 1967).

The two currents of human existence are comprised, according to Kierkegaard, of actuality and of possibility. For the human being there is thus a continuous challenge to merge and separate these streams into making that which is idealised into reality and by taking reality and transforming it into possibility. However, as Kaufmann (1970, p. 9) remarks, human beings, “prefer to forget how many possibilities are open to them … a wealth of possibilities breeds dread.” It is precisely within the equilibrium of the moment that lie the seeds of disequilibrium in an ongoing cycle. Complete equilibrium in itself brings no joy. It is rather the ongoing struggle to balance the tension and stress of the human existence that brings about a sense of the value of the existence. In contrast to this, it is the quest for pleasure as an end in itself that leads to a sense of emptiness of existence, or nihilism. For the human being therefore, transcendence of the despair of human existence occurs through the imagination which gives access to the world of possibility. The imagination is sited within the person's consciousness of the world and self so that the person is able to choose from the bounds of his or her own possibilities the unique and individual meaning of life. Thus, for existentialists, the quest has been to describe the meaning structures of the lived existence of the individual (Schrader, 1967).

5.2.8.1 Sartre

Contributors to Sartre's philosophy were existential ideology, phenomenology (itself influenced by existential philosophy), especially the ontological aspects as expounded by Heidegger and encompassing aspects of Marxism, and Freud's ideas of psycholanalysis (Jones, 2001). Existentialism, as a term, dates to 1944 when Sartre applied the word retroactively to his own writings and those of his predecessors (Polkinghorne, 1983). Sartre was greatly influenced by Heidegger in that he strives to present a phenomenological ontology that takes both existentialism and historicism into account. However Sartre's existentialism can be termed the existentialism of consciousness and Sartre's psychology encompassed many construals of human existence (Vander Hoeven, 1964). This understanding embraces a consciousness which is reflexive and is also pre-reflexive through the self-awareness characteristic of consciousness. Through the individual's conscious reflection, a person becomes aware of his or her experiences and consciousness itself, so that consciousness could be understood as being-in-action (Spiegelberg, 1965).

The ontological element of Sartre's work results from Sartre conceptualisation of being which is a totality concerned with living in the world. Being is manifested in all human activity even when such activity is seemingly insignificant. Meaning itself derives from action and the exercising of responsibility. Existence itself is contained in all behaviour so that each action is revelatory of the being of the person. Being-for-itself can be understood as human insight (Jones, 2001).

There appears to be concordance between Husserl and Sartre in Sartre's seeming acceptance of intentionality as being consciousness directed towards something. For Sartre however freedom is intrinsic to humanity which can therefore make choices concerning life and assume responsibility for these choices. Sartre's departure from phenomenology is marked by his disagreement over the existence of a transcendental ego that manifests itself in consciousness (Jones, 2001). For Husserl consciousness is directed always to an object, and hence directional. Questions regarding the nature of the object in respect of reality are set aside in order to describe it. Acts are intended and have associated phenomena and reality is thus the correlate of intentional acts. It is not that the ego constructs its world, but rather that it arises as a consequence of experience. Consciousness then brings the person into contact with reality. As the ego is not originally in consciousness, consciousness then is revealing as a no-thing-ness which is realized in its intentional activity. According to Sartre the ego is for consciousness, rather than residing in consciousness, and is a spontaneous activity concerned with self-transcendence. Consciousness moves towards the outside of itself, in a sense existing only in that movement, and having no other content is nothing but the outside of itself. So is Husserl's emphasis on the noematic aspect of phenomena changed into a philosophy of nihility. For Sartre, it is the intentional nature of consciousness that makes it an existential theory (Natanson, 1967).

In a comparison of some of the core tenets underlying phenomenology and existentialism the following differences can be specified:

- The objectives of existentialism fall outside of the scientific paradigm, even though it is not opposed to scientific or systematic systems. Phenomenology is a rigorous science aiming at freedom from preconception and seeking absolute certainty for its foundations.
- The appropriate focus of existentialism is human existence and human reality. The appropriate focus for phenomenology is the study of the essences of consciousness.
- In existentialism, existence itself is sited within the world and consciousness is part of this existence, even while it reflects upon it. In phenomenology the life-world provides the context within which intuitive reflection and the accurate description of phenomena unalloyed by oversimplification and presupposition can occur.
- While existentialism encompasses many methods, the method in phenomenology is specified. The hermeneutic method, as a means of interpretation, transcends the phenomenological description of phenomena to produce phenomenological

existentialism. The concepts of phenomenological reduction and transcendental subjectivity are rejected.

- The goal for existentialism is the 'authentic existence'. The goal for phenomenology is the scrutiny and substantiation of beliefs by means of intuitive verification (Spiegelberg, 1965).

From the above it would appear that some of the differences between phenomenology and existentialism are irreconcilable. Spiegelberg (1965) however, argues that in principle the two philosophies are compatible. While phenomenology attempted to use positivist methods to ensure validity, it accepted insights based on non-theoretical and emotive experience. Spiegelberg also insists that to argue that phenomenology brackets questions of existence is incorrec,t and that there is no attempt to eliminate the phenomenon of human existence. What distinguishes the two is that the approach in phenomenology is one of detachment, while the approach in existentialism is one of engagement.

5.2.8.2 Marcel

Marcel also strongly opposed any reductionist type of philosophy regarding the nature of human existence. His use of the term existence as a, "movement out from" echoes Heidegger's concept of ex-sistence, and for Marcel existence offers the possibility for the means to being through transcendence of the self (Ballard, 1967, p. 214). This transcendence can be grasped in the shift of the self towards self-expression in a process founded in sensation and mediated by language. Information about the environment enters the awareness of the individual through sensation, although, "sensation cannot be regarded as a message, nor the body as an instrument" (Ballard, 1967, p. 216). It can be understood rather as the capacity of the senses to perceive the nature of the object as that nature makes itself known, such as for instance the redness of red. This perception is however not an end as the body is not an instrument to that end. Instead the body is the self in bodily form, and is inseparably a part of the bond between the individual and the world that he or she inhabits, and it is through this bodiliness that the world can exist.

In addition to the sense of self as body, self-knowledge it attained in the relationships that the individual has with others, and specifically those that are characterised by a bond of love which facilitates this intersubjective unity. Buber (1970, p. 53) too notes how different the world is for human beings once there is a shift to the intersubjective mode of being because, "the I of the basic word I-You is different from that in the basic word I-It." The linguistic elements serve to emphasise the way in which the concepts of You and It are bound up in the concept of I. To recognise the other, as distinct from self, it is essential to acknowledge the selfness of the self.

Marcel believes that it is love which enables the transcendence of relationship to the I-thou relationship where both parties become an inseparable element of "we are". Within this type of relationship, there is a mutuality which results in a "fertile indistinction of persons," permitting the person to attain knowledge of self through unity with another (Ballard, 1967, p. 145). Therefore, if the sense of self requires the union with another, then even subjectivity is an aspect of intersubjectivity which is, "directed toward participation in being" and is hence transcendent. Transcendence is meant to emphasise the harmony of wholeness as conceived by the core of religious beliefs where God is understood as the unifying force from which all else emerges. The Thou that God is understood to be, unlike other human beings, is absolute in its being so that through spiritual union with this being, the individual is able to attain the highest fulfillment of self. Also implied in this concept is the inappropriateness of attempts to objectify the human being or to remove the sense of the 'holy' from him or her. Thus for Marcel transcendence is an essential ontological component, and satisfaction of human need is dependent upon the person's capacity to express this noumenous aspect of his or her being (Ballard, 1970).

5.2.8.3 Merleau-Ponty

Merleau-Ponty (1967) gives much credit to Hegel for his determining influence on philosophy in the preceding century (Kockelmans, 1967). However, the principal interest for Merleau-Ponty is the exposition of the phenomenal field, the inspiration for which was born from the work of Husserl. As did Sartre, Merleau-Ponty (1967) gave due importance to reflection, but also added to the field of phenomenology by including a phenomenology of perception as it is the consciousness of perception which makes it possible for the individual to exist in his or her world. This alters the direction of focus from understanding perception as the way in which the world is perceived, to the world of the individual being that which is perceived. It is thus consciousness itself which makes the world possible for the individual and hence reality for the individual depends upon consciousness (Spiegelberg, 1965). Hence for Merleau-Ponty the understanding of the lived world (or Lebenswelt) takes on renewed significance. To return to the phenomena themselves, Merleau-Ponty has demonstrated that to remove the role of consciousness from the attempt to understand behaviour is not possible, and results in conjecture which serves only to distance the individual from the lived experience (Merleau-Ponty, 1967). Thus he demonstrates the central role that subjectivity and reflection play, even from the standpoint of understanding behaviour and perception objectively. It is clear from this, that the person's experience of the world is animated by the body as it experiences being-in-the-world. By suspending the beliefs that are connected to perceptions and thereby rediscovering the body's experience, the true nature of the relationship of consciousness to reality will be revealed (Carr, 1967).

Merleau-Ponty rejected the empiricist position where perceptual consciousness is understood in terms of the interaction of physical functions as the primary originators of sense data. The intellectualist position is also seen as unacceptable, as it advances the notion of perception as an act by the perceiver where meaning is conferred on the object. Accordingly, the phenomenon of perception allows that an event is not random but rather existing in a field of potentiality, and furthermore that the meaning of an event is not fixed either be by reason of causality or by the endowment of meaning. Hence the phenomenon of perception acts as a ground or as the medium within which meaning is proposed or imagined, is worked with, and is accepted (Kwant, 1967). Merleau-Ponty termed this field a stratum of “operating intentionality”, and its revelation circumvents the question of objectivity as it is pre-objective and pre-personal (Bruzina, 1970). In this respect it can be understood as being elemental in nature, and of providing a foundation for the very being of the person from which the genesis of meaning occurs. Intrinsically then, phenomenology is explicitly philosophical, and more precisely concerned with being and knowing, so that it is principally metaphysical in nature. This represents one sphere of departure from Husserl, as Husserl's representation of being is sited in rational subjectivity, whereas for Merleau-Ponty it is existential. A question posed by Merleau-Ponty with regard to the essential insights and focus of phenomenology as posited by Husserl, concerns the origin of the activity of consciousness so that the ultimate matrix or ground does not end at the life-world but needs to be considered from an ontological basis. There is no attempt to describe human consciousness in terms of its constituting aspects, but rather the person is seen as being within the matrix of temporality and horizontality, which is described as the être-au-monde (which in its literal sense is being-in-the-world) so that this is where meaning both arises and is made explicit.

In addition, this also represents a departure from the Cartesian mind-body dichotomy. From the perspective of Merleau-Ponty being is neither pure object (body) or pure consciousness (mind) but instead both are one single phenomenon because it is impossible to know the body in any way other than existing within it. Similarly the perceiving person is not a pure thinker. It is out of this phenomenon, this third order of being, that the mind/body conceptions arise which can be called existence (or être-au-monde). Each different order of being, the physical, the vital and the human interact with the environment in distinct ways. The interaction between the world and physical is reflexive in nature, much like a stimulus triggering a response. The vital order acts instinctively in order to understand the environment as it relates to the person who is in it. The human order however, emphasises consciousness primarily as the experiencing of the world by being in it, which is a bodily perception and out of which arises meaning production and evolution. It is within this that consciousness is able to recognise itself and the person as a being.

Another area where Merleau-Ponty rejects empiricist and intellectual viewpoints is in relation to linguistic expression. The former seeks to understand speech in terms of the physiological and neurological function resulting in the association of a word with another stimulus, which can be recalled for later use. The latter would conceptualise it in terms of its use as a tool for the revelation of the objective world in order to communicate pure ideas or thought as meaning units. Seen from these perspectives, words are the outcome of a natural human capacity for abstraction where an arbitrary sign, such as a word, can be used to represent something else, and where there are conventions governing the usage of such signs so that it can be used between different persons. According to Merleau-Ponty these stances reduce meaning to either mere vocalisation or reduce it to its external association with an object through its correspondence to it. Speaking is more than the external expression of an internally expressed, if silent, thought. Rather, Merleau-Ponty sees the act of speaking as the vector for the development and assertion of meaning. Speech and thought are not separate, although they are concurrent, but are rather a single phenomenon during which the as-yet unrecognised and unexpressed meaning from the field of potential of all possible meanings is synthesised. The uncertainty existing up to that time, is resolved into meaning at the moment of utterance. Thus spoken words do not arise from thoughts but are the thoughts and speaking achieves these thoughts, so that, "the name for objects does not come after recognition, but is the recognition itself." (Bruzina, 1970, p. 108).

Linguistic expression, by means of speech, is the process by which the significance of the one's existence becomes known and explicit. This heralds a new type of subjectivity where this significance is at the basis of reflection, and by extension, of thought itself. The intention precedes speech and by speaking the intention to express a particular meaning must be fitted into an already existing system of speech, which is language. Art too can be equally considered as expressive in function as it reflects something of the lived world of the individual, by capturing a meaning in some physical form. It differs from language as an expressive medium in that the language is a system in itself so that it is in certain ways its own being existing prior to the verbalised thought, unlike the artistic production. Where language is linked to a different object than it usually signifies, such as in the use of metaphor, it becomes a creative expression. The influence of the French linguist, Saussure, highlighted this concept of language as its own being which transcends the connection between the object and word as equivalent meaning. However accurate, any linguistic description of an object or event can be only one of an infinite set of such descriptions. (Carr, 1967). Moreover, according to Merleau-Ponty, expression, as an act of bringing a significative intention to life, can never, in and of itself, be sufficient because the significative intention is always greater than that which can be captured in speech. Over time, more verbalisations may arise from this greater matrix, as the individual seeks to refine meaning so as to render more explicit that which it signifies (Bruzina, 1970).

Language as a generator or transmitter of meaning, is at the core of communication between persons. Through linguistic expression an understanding emerges between individuals which represents a synthesis of meanings. At the level of a broader community common meanings acquire the status of truth in which is embedded the historicity of the community. This historicity is implicit in the lived world of the individual as a culture imbued with a multiplicity of these truths to which the individual contributes (Carr, 1967).

In an attempt to reconcile the positions of the existentialist and the linguistic analyst in respect of their stance towards the revelation of meaning, Schrader (1967) notes that each position could mutually benefit the other: existential philosophy is, “analytically clumsy,” and will therefore not succeed in its objective to describe the meaning structures of human existence. Yet, “if being and existence can be disclosed only through the medium of language, language must show a level of meaning which it cannot express” (Schrader, 1967, p. 44).

Moran (2000) observes that although Merleau-Ponty's work was some of the most outstanding of the 20th Century, his work has attracted less attention than other, perhaps more flamboyant, philosophers such as Sartre, Levinas or Derrida. Yet each of them have acknowledged the contribution he made to their own work. Currently there is something of a revival of interest in his work especially as regards issues relating to an analytic philosophy of mind and the rejection of mind-body dualism. Hence his influence can be felt in psycho-therapeutic approaches such as those of Edward Casey and Oliver Sack.

5.2.9 Phenomenology and hermeneutics

An overview of the existestial contribution of various philosophers now gives way to an attempt to understand the influence of hermeneneutics on phenomenology.

5.2.9.1 A comparison between phenomenology and hermeneutics

The origin of the term hermeneutics, as an activity of text interpretation, dates back to antiquity, although the use of the term itself is more recent. It was spurred on by the desire to achieve a fuller understanding of the texts of classical texts and especially of biblical texts. Hermeneutic procedures were used to span the chasm of culture, language and time which separated those wishing to interpret the text from the authors of the texts. This occurred in parallel to the interpretation of texts in the legal realm where the meaning of the law had to be understood in order to ensure a valid juridical outcome (Polkinghorne, 1983).

Phenomenology and hermeneutics share some significant philosophical origins but diverge in certain areas. While the focus in both disciplines is on developing a clear understanding and description of human experience through rigorous procedures, hermeneutics focuses on text interpretation through analysing the structure of implicit meanings with a text or other record of human behaviour. A difficulty in hermeneutics could be that intended meanings could be misinterpreted if non-verbal communications or factors are not included (Braud & Anderson, 1994).

5.2.9.2 Phenomenology as hermeneutics

Dilthey expanded the sense of hermeneutics as a discipline for discerning the author's meaning into a discipline for the human and social sciences. In taking on a hermeneutic stance the pretence of an acosmic, ahistorical and asocial consciousness must be abandoned as one where the philosopher confronts his or her own existence and the ontological meaning of it (Kockelmans, 1967). This made possible the transition from the understanding of texts to understanding in general, so that hermeneutic awareness reveals the meaning of human expression, regardless of its form.

If the object of the human sciences is meaningfully oriented behaviour, then the meaning of human actions must be investigated. To know the meaning of an action or of a linguistic expression requires a different perception from that which derives from sensory modalities. This type of perception may be called understanding (Polkinghorne, 1983). Polkinghorne (1983) distinguishes between understanding which refers to the general process of comprehension of physical or mathematical relationships, and understanding which has a far narrower definition. Understanding, in this sense, refers to the comprehension of meaning and this is on a different plane from understanding in the more general sense in that it is out of the reach of a purely logical analysis. It is neither purely deductive nor inductive reasoning, but is rather an ongoing process operating at several levels simultaneously. It cannot therefore be analysed piecemeal, or broken down to its constituent elements.

Gaining access to this realm poses great difficulties for the researcher because once a researcher has grasped a meaning it must be translated into a form of data which is in a valid representation for research to proceed. Hermeneutics is the discipline that regulates the act of meaning comprehension and is concerned with the correct understanding or interpretation. A system of rules governs the process of interpretation so that arbitrary or subjective understandings do not taint the validity of the interpretation.

For Heidegger, hermeneutics became more than the method for providing an objective understanding of the meaning of human expression, but rather became the method whereby understanding provides the means to access the very basis of human existence. Truth is not objectively constructed, but rather occurs within the medium of the individual's engagement with his or her world. It is precisely the belief that true and objective knowledge is possible that leads to error because there is no absolute truth. This was in direct opposition to the belief expounded by Dilthey and Husserl that an objective truth could be obtained by the use of an objective methodology. Consequently Heidegger saw the as appropriate function of hermeneutics the exploration of how the understanding underlying the social meanings contained in language, come into being. In terms of this insight historical and interactive aspects are an integral aspect of human understanding cannot be (Polkinghorne, 1983).

Gadamer, in his 1960 work titled *Truth and Method,* elaborated on the concept that the human understanding of texts and other objects of hermeneutical cannot escape the historically conditioned character of understanding. This nullifies the possibility of a value-free and objective approach to understanding. While methods and systems can be useful in helping the researcher achieve a higher level of understanding than would otherwise be possible, the intrinsic limitations of such methods must be recognised and borne in mind. When a text is approached by someone seeking to interpret it, the interpreter's own life-world inevitably intrudes as expectations, beliefs, values and concepts, so that what emerges is an amalgam of the life-world of both author and interpreter an idea which he termed, “fusion of horizons”. The concept of the hermeneutic circle illustrates this point as the interpreter begins an interpretation with certain expectations which changes as a result of these expectations not being fully met. The revised expectation is then subject to the repetition of this process so that the dialectical nature of the process is central to the meaning apprehension. The lack of certainty so engendered, and the fear that these views would reduce hermeneutics to a, “standardless morass of relativity” have sparked off many debates including those of Betti and Hirsch (Polkinghorne, 1983, p. 229).

Ricoeur, however, sought to re-affirm the position of hermeneutics as the appropriate methodology for the social and human sciences. Drawing from, and incorporating the contributions of behavioural and social sciences, as well as recognising the cultural and psychic constituents of human expression, he has succeeded in presenting a unified position with regard to understanding meaningful human action (Polkinghorne, 1983).

For Ricoeur, the will and body of a person are inextricably linked. Thus in order to understand the unity underlying existence, it is possible to begin with researching human action. His awareness of the role of the unconscious as a motivation for behaviour, means that the researcher cannot assume that he or she can be fully cognisant of the meaning of his or her action. To study meaningful action it is necessary for it to be objectified in a way that does not remove from it its meaningful properties. The consequences of actions cannot always be foreseen, but the residues from such actions be can be seen as the evidence of such action and traced to reveal the patterns of actions. As the consequences of actions are unpredictable, the causal link between intention and consequence may not be clear. It is not possible therefore to determine the right understanding of an action by identifying the intention which the author is presumed to have had. Rather, agreement about interpretation can only follow on a process of contention even though there is always scope for further argumentation, hence interpretation is required to understand the meaning of human action (Polkinghorne, 1983).

To understand meaning however, it is necessary to take into account the social context. A structural investigation can provide information about the broader system which is the context of a single event, thus facilitating and enhancing interpretation. These concepts have provided impetus for the movement from philosophic exploration of the hermeneutic approach as represented by Ricoeur to methodological specification as has appeared in the work of Geertz and Kockelmans. Kockelmans has specified the tenets which would be necessary to ensure the intersubjective validity of an interpretation. Firstly, the object is autonomous and of itself and preconceived schemes cannot be used to explain it. Secondly, the interpretation itself must be reasonable. It must also be human in that there must be an effort to uncover the profound aspects of meaning. Thirdly, to uncover the profound aspects of meaning, the historical contributors as well as the possible future developments must be delineated. Fourthly, the most important precept is that of the hermeneutic circle which allows for an indefinite process of successive approximations. While finality in this respect may never be reached, it is possible to come to an adequate and satisfactory interpretation. Finally, the meaning of the object in the present situation must be demonstrated. This requires fusion of the researcher's situation and the phenomenon under study (Polkinghorne, 1983).

To sum up, the task of hermeneutics is to reduce the imprecision and complexity of general meaning as it appears, to a more precise and clear piece of information. Hermeneutic systems are therefore descriptive and attempt to clarify the nature of the human experience. Although such information may have precision and be clear, it is nonetheless open to further interpretation, so that complete intersubjective agreement is not possible. Thus, hermeneutic knowing is multivariate. The holistic aspect is also stressed as data can only be understood as being a part of the whole, just as the whole is constituted of its parts. The process of knowing in a hermeneutic sense is not assured by precise measurement, but requires insight in order to discern the patterns that are revealed. While insight is supported by evidence, the evidence is undefined and what definition exists comes from its role as supportive evidence. Absolute knowledge is not possible for this reason, and also because many systems interact to produce human experience, and one of these is the system of the interpreter. Prediction too is impossible because different interpretations would lead to different predictions. The self-defining nature of human beings also militates against it so that it is easier to follow and understand in retrospect (Polkinghorne, 1983).

This confirms the position of the hermeneutic system as one that is situated in the naturalistic paradigm. Reality is multiple, constructed and holistic rather than single, tangible and fragmentable. The relationship of the interpreter and interpreted is interactive and inseparable rather than independent. Hermeneutic systems do not consider it possible to make generalisations that are time- and context-free, but rather offer idiographic statements. Distinguishing cause from effect is not possible because all constituent parts are in a state of mutual and simultaneous influence which again differs from the positivist position where real causes can be identified. Finally, all inquiry in a naturalist paradigm is value-bound, unlike that in the positivist paradigm which is presumed to be value-free (Braud & Anderson, 1994).

In attempting to compare naturalistic approaches to the human sciences and those which are phenomenological or hermeneutic in nature it can be noted that the objectifications inherent in the naturalistic method have a depersonalizing effect. The living content of experience, so central to human life, is abstracted away. On the other hand, phenomenology and hermeneutics cannot attain the level of a science dealing with the lives of persons or groups, because they cannot ground their conclusions in solid empirical evidence about the actual course of events. Husserl attempted to resolve this difficulty by suggesting that the method employed should be grounded in the natural attitude which enables empirical evidence about processes which transcend the awareness of the participants to be considered. A more complete understanding of the meaning of the act requires that these facts be temporarily abstracted away via the adoption of a phenomenological or hermeneutical mode of inquiry. It is the combination of the two modes, Husserl argued, that can yield a soundly based empirical science of persons and personal formations (Levinas, 1967).

Sokolowski (2000) suggests that a survey of phenomenology also requires a mention of deconstruction because Derrida’s first writings were construals of some of Husserl’s works.

According to Moran (2000), Derrida belongs to the second generation of French phenomenologists after the transformation wrought by Levinas, Ricoeur, Berger and Merleau-Ponty. Deconstruction also draws from the writings of Hegel, Heidegger, Sartre and Lacan as well as Nietzsche and Freud. He was also influenced by structuralism as espoused by de Saussure and Lévi-Strauss. Although deconstruction originally provided a correction to traditional approaches which had by then developed into a fixed ideology, since then it has been incorporated into the larger political ideological framework within which it has continued to develop.

Although Derrida's approach is both exciting and challenging, Moran (2000) asserts that his claims about language and meanings have met with a variety of responses, ranging from the very negative to the most positive. He portrays himself as going beyond philosophy, but this route has been through the phenomenology which Derrida wants to liberate from its attachments, so in a sense deconstructing phenomenology itself. According to Moran, the goal of deconstruction is to free Western philosophy of its logocentrism and metaphysics of presence, which he views as attempts to subjugate the field of being and meaning to a framework of logic in order to serve the ends of the will to (especially male) power. He rejects the notion that a sign is able to represent its meaning, and that reality can be accessed through language. An example which has been seized on by followers of deconstruction is to view all binary oppositions such as falsity/truth, as instances of logocentrism, where one opposite is good and the other bad. Rather than attempting to reject all oppositions, Derrida wished to initiate a discourse about the re-valuing of such oppositions and thus to use critique as a means to understanding how language both presents and obscures the world. He also rejects the notion of deconstruction as a philosophical method, but rather as the unravelling of meaning, "taking apart the text to show that its supposed argument or thesis actually turns against itself owing to the impossibility of meanings being present in their essence. Every speech act contains, as it were, the seed of its own negation. This is an essentially Hegelian insight which Derrida interprets in a new manner" (Moran, 2000, pp. 450-451). With regard to a rejection of the metaphysics of presence, Derrida was highly influenced by what he perceived to be contradiction in Husserl's approach to phenomenology with its anti-metaphysical and presuppositionless stance which is however rendered hollow by its dependence on those metaphysical assumptions necessitated by an adherence to rigorous science.

The ambiguity and vagueness of Derrida’s work make evident his claims, which are not claims according to him, that meaning has no original source or complete meaning and that meanings change and split on a continuous basis. His vagueness makes Derrida’s work particularly elusive when attempting interpretations, but as Moran (2000, p. 474) concludes, “his rejection of the metaphysics of presence and of the belief in meanings as ideal unities leads him to move beyond the tradition of Husserlian phenomenology.”

5.2.10 Phenomenology in the postmodern context

According to Sokolowski (2000) modern philosophy is comprised of two elements which are political philosophy and epistemology. Modernity sought to ensure a rational basis both for political society and scientific thought and this was a change from pre-modern thought which understood reason as finding its perfection in the manifestion of things, in the triumph of objectivity and the attainment of truth (Sokolowski, p. 202). While phenomenology, unlike other philosophical movements, is almost entirely devoid of any political contribution, it has contributed significantly to epistemology and method through the possible reconciliation between the pre-modern and modern tension regarding the role of reason. Phenomenology thus offers a means to restore the role of the human being: knowledge arises from the person who recognises his or her own selfhood and who therefore can own what he or she avers. Yet the primacy of truth is maintained through the way in which the mind is geared towards giving witness to the way things manifest, and by validating how it sets about achieving this truth.

If phenomenology sees human reason as ordered towards truth, then this indicates the way forward for a contribution to political philosophy. With regard to political rule for instance, phenomenology asserts the need for a recognition of human nature and the necessity to subjugate political rule to that nature. Hence any political reality must be in accordance with a view of human beings as agents of truth and not merely an execution of systems of ruling such as laws or authorities. This makes necessary a reincorporation of those civic values which were considered paramount in pre-modern society, namely education, family stability and social order. Such a system would treat people as citizens who are educated and responsible agents of truths. Phenomenology is suited to restoring this understanding of the value of the person as a citizen and such a political contribution would be important, because at the heart of phenomenology is the understanding of the centrality of the lived world of the individual.

> "The positivist conception of science has its roots in a definition of knowledge which holds that only those things of which we are absolutely certain can be counted as knowledge. If a claim to knowledge fails the test of certain truth it cannot be included in the body of scientifically approved statements because human beings cannot stand outside their language systems and cultures to obtain an absolute viewpoint" (Polkinghorne, 1983, p. 1).

This points to an understanding that all knowledge is a conditional knowledge, constructed within conceptual systems, so that knowledge is a communal achievement and is relative to time and place (Polkinghorne, 1983). Phenomenology as a source of knowledge today is cramped by archaic language that is difficult to understand. Some of the terminology used originated in the German language, and its translation into English is inaccessible and fails to capture the simplicity of its essence. Thus, as recommended by Sokolowski (2000) a more accessible language would clarify its endeavours. Finally, the lack of political philosophy has provided a constraint for the continuation of phenomenology in current thinking and rectification of this would be valuable.

Phenomenology still continues as a tradition in philosophy, though with less influence than it held a century ago when it attracted a wide array of influential thinkers. Scholarly work still continues in this philosophical tradition with numerous publications especially in Louvain and Cologne. Husserl's important contribution still suggests a route, "to philosophical realism and ontology that could replace the primacy of epistemology" (Sokolwski, p. 226) which has not yet been fully explored.

The following section presents the research problem, general and specific aims of the study and provides a description of the research procedure including the selection of participants, data collection and analysis of the data.

5.3 The research problem and the aims of the study

As was revealed by the statistics quoted in Chapter 1, the extent of the HIV/AIDS epidemic in South Africa is such that it will impact on a large percentage of its citizens, especially those in the young-adult age group. It may thus be surmised that as a result of increasing mortality, both their children and parents will be left bereaved.

5.3.1 General aims

This research seeks to enhance the construction of theory, to generate knowledge and greater insight into the field of psychology, in the areas of meaning-making around parental bereavement, and more specifically, where the cause of death for the offspring of the bereaved parent is an AIDS-related illness. The extent of the AIDS pandemic in South Africa is such that many parents are likely to face the loss of their adult children. As was described in Section 1.2 in Chapter 1, research in the field thus far appears to have focussed on the impact of such bereavement on the surviving partner, the offspring of those who die, or the caregiver. One area which has not been greatly explored is that of the impact of the epidemic on the parents of those persons who have died as a result of an AIDS-related illness and so this remains an area which requires attention. This research will attempt to explore the individual meanings and experiences of parental loss of an adult child, following on a long-term illness, specifically HIV/AIDS. The study also seeks to explore the links between existing literature and this research, and reveal inadequacies in such literature. Finally, it aspires to generate topics that may spark future research, as well as to provide some guidelines for therapeutic intervention for bereaved parents.

5.3.2 Specific Aims

This research interviewed on an individual basis six parents who have lost an adult offspring. The cause of death for the adult child of three of the participants was cancer, a non-stigmatised long-term illness, and for the children of three of the participant was an AIDS-related illness, which is currently a stigmatised long-term illness. The interviews were recorded, transcribed and analysed within a phenomenological framework and an attempt was made to understand more fully the lived experience of the participants of the study. The focus of the study was to explore and understand how the parents of the child, that has died in the ways described, make sense or meaning from the event.

5.4 Research procedure

The following section delineates the selection of participants, data collection and the analysis of the data.

5.4.1 Selection of participants

Firstly, the criteria which govern the selection of participants in phenomenological research are explored, followed by the description of the criteria which determined selection of participants in this study.

5.4.1.1 Selection of participants in phenomenological research

According to Steeves (2000b, p. 50), "random sampling is not in keeping with the hermeneutic phenomenological method." Instead, it is suggested that purposive sampling be used because the aim of the research is to gain in-depth information of the specific life experiences of the participants. Another reason for purposive sampling, is that participants are not regarded purely as the possessors of particular variables, such as age or gender as this would tend to oversimplify the complexity of the human experience in terms of variables. The aim is rather to view participants as people who are able to offer a richly-textured description of their lived experience. During the process of research, researcher and participant enter into a kind of partnership where both strive to establish a common understanding of the experience. It is necessary therefore, that the participants should have an adequate linguistic command. This is in order to be able to express their experience to the extent required to reflect the in-depth nature of their experience and to facilitate a shared understanding of it. It is also necessary that the participants should have both the knowledge of their felt feelings including the accompanying physical states, as well as the ability to express them without inhibition. (Polkinghorne, 1989).

5.4.1.2 Criteria for selection of participants in the study

In this study, the depth of the experience is of paramount interest, and so it is proposed to limit the sample to six participants. Participants were chosen with the intention to act as informants who are able to give rich and abundant descriptions of their experience. All participants have experienced the loss of adult offspring as a result of a long-term illness. The children of three of the participants have died as a result of an AIDS-related illness, which is currently stigmatised in South Africa, and the children of three participants have died as a result of cancer, which is not currently stigmatised in South Africa.

From the literature review, it would appear that the initial period (lasting perhaps a period of some months) following the loss of the child is characterised by shock and denial. Consequently for all participants the loss had occurred a minimum of six months prior to the participants participating in the study. Participants' ages ranged between 45 and 65 years. This was partly due to the age of the children who were adults at the time of their death. A further requirement, was the participant's ability to express him- or herself competently in English, as the study requires information which is richly-textured in order to convey the particpant's experience of the lived world.

The participants are members of the Johannesburg Chapter of The Compassionate Friends (TCF) and parishioners of a Catholic Church south of Johannesburg. Once these participants were contacted and briefed on the aims, nature and scope of the research, their consent to participate in the research was obtained. This was done both for ethical considerations, as well as to reduce anxiety or misconceptions, for instance with regard to issues of confidentiality. According to Giorgi (1975), it is important that participants should not be made cognisant of the researcher's own ideas or biases.

5.4.2 Data collection

While life is lived and experienced in the present moment, the study of the lived experience can only occur retrospectively through the use of memory and language. A fundamental tenet of hermeneutic phenomenology is that people seek to create meaning of their experience from the response sited within human consciousness. Data collection is thus concerned with building a script with multiple strata, each of which is an accretion of the different facets of the meaning of this response. The script is derived from interviews which provide narrative accounts of the experience. As noted by Kahn (2000a, p. 59), this script, being removed in time from the experience, will also be, "symbolic and distanced from the experiences of interest in order to allow hermeneutic interpretation."

Questions need to be sited in the felt experience rather than in intellectual abstractions of the experience and seek to encourage the reciprocal exchange of information. Kahn (2000a) cautions against asking specific or closed questions which require explanations or opinions as answers. These aims may be achieved by asking questions that will elicit narrative responses. During the course of individually conducted interviews, participants were asked to describe their personal grief experience with regard to their subjective experience of the meaning-making process. An introductory question was used at the beginning of the interview to act as an ice-breaker and to promote the flow of descriptions. Such a question was directed at finding out something of the situation leading to the loss of the child such as, "Can you tell me about your son/daughter who died?” The questions in this study focussed on asking what it is about the parent's particular bereavement experience that makes that experience significant for him or her. The interviews were semi-structured with some open-ended questions posed to all participants in order to elicit an evaluation of their experience of meaning-making following upon their loss of a child. Questions sought to direct the focus of the participant to discuss how this event has impacted on their lives. Probing questions elicit richer and more complex elaborations to the issues being presented and to obtain clarification about certain issues, so that some questions would be directed towards this end. Kvale (1996) suggests that such leading questions may enhance the reliability of the interview through the greater clarity that they produce. Subsequently the participant determined the direction of the interview in order for the interviewer not to impose on the participants' experiences. The following questions were considered:

- What meaning the participant made of the prospective death in the period prior to the death of his or her offspring.
- How the participant experienced the type of death that led to the loss of their offspring.
- How the participant's sense and understanding of how their world, and their life in the world, has changed since the event.

The recording of expressions or gestures which would not be captured in the recording process on audiotape were noted as were intonations or alterations in emphasis or volume.

In addition to the data which is embedded in the interview, Kahn (2000a) recommends that it is helpful to record fieldnotes as soon as possible after the interview. This immediacy is important to capture the detail before the researcher's own internal process of sense construction can begin, as this will result in a change in focus or a loss of detail. The data from self-reflection is used to highlight the position of the researcher so as not to impress the researcher's own expectations onto the study. Fieldnotes are used to record details that do not emerge in the spoken or textual interchange, such as body language, dress or demeanour of the participant or environmental distractions. They can also record any information that becomes available outside of the interview and this forms the basis for additional data. Finally, they can provide memory triggers and, as such, remain available for later review.

The fieldnotes which were recorded as an adjunct to the interviewing process, formed the basis for the personal researcher reflection which is presented in Chapter 8. As such they provided a valuable opportunity for self-reflection and therefore assisted in development of the interpretive process by giving form to the nascent and tentative understanding of the researcher.

Recordings were made of the interviews with the consent of the participants. These recordings were then transcribed. Steeves (2000a) stresses the importance of being aware of silences, as these form an integral part of the interview. The quality of recording is therefore important and is aided by a good tape recorder and a quiet context. According to Kvale (1996), some criteria for determining the quality of the interview are that it should provide spontaneous, rich and relevant answers with little researcher input. Ideally the interview should be largely interpreted through the course of the interview, and such interpretations substantiated during such time. The interview should be self-sufficient as regards providing an adequate description and interpretation of the experience.

5.4.3 Method and Analysis

> “The goal of the analysis is a thick description that accurately captures and communicates the meaning of the lived experience for the informants whose experience is being studied. A thick description is one that captures the experience from the perspective of the informant in its fullest and richest complexity” (Cohen, Kahn & Steeves, 2000b).

Thus, it could be said that data analysis begins at the stage of data collection, as emergent understandings are recorded in written form, and refined as more information becomes available. This process can be seen in terms of a circular process with the writing itself being an integral aspect of the research. "Phenomenological research is the search for those processes of consciousness that give the objects that appear in awareness meaning, clarity, and discrimination" (Polkinghorne, 1989, p. 51) and according to Merleau-Ponty (Segal, 1999) should reflect the essence of the experience. The process of grappling with the essential structure of the experience has been variously termed bracketing, explication, reduction or thematisation (Polkinghorne, 1989) and these produce descriptions that transcend the specific experiences of the participants.

5.4.4 Steps in the analysis

The analysis of the written material proceeds through a series of steps which systematise the process. However, these are more in the nature of guidelines, and a plan evolves as the study unfolds, in terms of what data is necessary to produce the required understanding of the phenomenon (Kvale, 1996). The general guidelines for the process are the following:

Step 1: The researcher reads through the all the transcripts in order to get a sense of the contents. (The transcript is termed the protocol). Cohen et al. (2000b, p. 76) term this phase one of, “immersing oneself in the data”, the aim of which is to provide an overview or gestalt of the whole, which will assist in the orientation of the researcher and guidance as to how to proceed further with the research process.

Step 2: After an additional reading, the transcript is broken down into units that express a self-contained meaning in a psychological sense. As this process requires that the researcher use his or her own judgement in order to estimate where meaning transitions occur in the text, it is necessary that caution be exercised to ensure that the researcher's own theoretical stance does not taint the experiences reported by the participant. Bracketing will facilitate this process, as the researcher is able to shelve preconceived ideas about the phenomenon for the time being. Resultant meaning units should therefore be a reflection of the coherent elements that naturally occur in the text (Polkinghorne, 1989). In this phase, it is important to identify the essential data from the interviews (Cohen et al., 2000b). This includes a process like editing where digressions, pauses, or 'conversational lubricants' can be removed in order to reveal the actual content free of such embellishment.

Step 3: In this step the meaning units are expressed in the researcher's own language. For instance, a description in the original transcript could read, “I was ready to explode” and the meaning identified could be expressed as, “a feeling of great anger”. These linguistic transformations result in a clarification and reduction of the content permitting the researcher to view the phenomenon in a fresh way. It is a way of making explicit the psychological sense that is implicit in the data, retaining, all the while, the link to the original data. By focussing intent awareness on the experience of the participant, insight can be gained into that experience (Polkinghorne, 1989).

Step 4: In this step a second transformation occurs through interrogation of the meaning unit in terms of the topic of study. For instance, the question of the study e.g. “what is the meaning of grief?” is applied to the first transformation which was a feeling of great anger. The transformation of the meaning unit is made necessary because the pure descriptions supplied by participants are raw in terms of psychological constructs. The aspects related to the topic of study are thus extracted and reformulated in terms of the psychological perspective. The reformulation needs to maintain the original sense, and the transformed meaning needs to be publicly verifiable so that if the transformation were to be carried out by a different researcher the results would be similar. Those meaning units that are not intrinsic to the experience being studied are then removed (Polkinghorne, 1989). A particular theme may also be constituted of a number of sub-themes, and their identification will assist in clarifying the shadings of meaning.

Step 5: At this stage, all the meaning units remaining will be connected both to each other as well as to the protocol as a whole, and the researcher synthesizes and unites the sense of these meaning units into a coherent descriptive statement of essential and non-redundant psychological meanings (Polkinghorne, 1989). It will be necessary to apply this descriptive statement to other randomly selected protocols in order to ensure that all necessary elements inherent in the experience are included, and that those elements that are included are applicable to all protocols.

Step 6: The hypothetical description at the general level of the protocol consists of those elements that transcend specific situations. It will be considered a valid identification of the experience, and such validity will endure until new cases can be shown that do not correspond to the hypothetical description.

Van Manen (1990) stresses the importance in the hermeneutic process for writing and re-writing to occur concurrently with all the stages enumerated here. It is through this circular and reflective process that the coherent image of the whole can emerge. Through the process of reduction as described above, there is inevitably interpretation. The hermeneutic circle refers to the process where the global meaning of the text both shapes and determines the meaning of discrete parts of the text. This process is a continuous one, repeated until a valid and unitary meaning is forged which has internal validity. During the analysis process, the researcher will identify themes common to those participants whose child has died as a result of cancer, and themes common to those participants whose child has died as a result of an AIDS-related illness. These themes will be broadly categorised. This process will aid in the conceptual clarification of the phenomenon, and where necessary will be subcategorised. These interwoven participant themes will facilitate the identification of patterns that give rise to hypotheses. This facilitates understanding of relationships between concepts which allows for a comparative process. Through a process of transformation, the researcher will transform naïve expressions from the participants' descriptions into statements using psychological terms. The validity of such transformations can be tested through re-examination of the original expression. Finally, synthesis entails assimilation and integration of those meaning elements into a unitary and coherent description of the phenomenon under investigation. The ethical considerations underpinning this investigation are addressed in the following section.

5.4.5 Ethical considerations

Kvale (1996, p. 109), introducing a review of ethical issues in interview inquiries, remarks that, "an interview inquiry is a moral enterprise: the personal interaction in the interview affects the interviewee, and the knowledge produced by the interview affects our understanding of the human situation." This serves to highlight the crucial and central importance of seriously considering the ethical implications of research so that the choices that are made regarding the design and method of the inquiry are informed by these considerations.

The following guidelines have been followed in the current research:

- The purpose of the study should provide to the participants some improvement of the human situation under study. To this end, in their role as co-researchers, participants were informed of the study through full disclosure of the aims, nature and requirements of the research project. Each participant only participated in the study after such informed consent.
- Information about the aims and nature of the study was provided in response to participants' questions.
- The consequences of the interview interaction such as stress or distress has been considered. Participants have been offered support through the possibility of a debriefing session, or referral if so desired. This was a particularly significant issue in this research as the subject matter occasionally caused distress to some participants.
- It was made clear to participants that there was no obligation to participate, and that they were free to terminate their participation if they so required.
- Confidentiality has been assured through anonymity. Information that is potentially revelatory has been removed or disguised to ensure the anonymity of the participant.
- Results are to be communicated to those participants who would like to receive it in the form of feedback according to their preferences.
- In addition to the above, Cohen (2000) suggests that it is important for the researcher to have someone of complete trust in order to be able to debrief and this recommendation was adhered to.

- The transcription process is faithful to the oral statements and it is the responsibility of the researcher to report knowledge that is verified in a way that does not diminish confidentiality for the participants.

5.5 Conclusion

This chapter has attempted to provide an overview of the use of a phenomenological framework as a research approach. To this end the development of phenomenology was traced to clarify the concepts underlying its use in research. The operational aspect of using a phenomenological framework was delineated, with a particular focus on the methodological assumptions, as well as the validity and reliability of such research. The research problem and the general and specific aims of the study are stated within the context of the chosen framework. The research procedure was specified, as regards the selection of participants, the collection and analysis of data, and ethical considerations. Chapter 6, which follows, presents an interwoven analysis of themes, firstly of the parents whose adult child died as a result of a non-stigmatised illness, cancer, and secondly, of the parents whose adult child died as a result of an AIDS-related illness, which is currently stigmatised in South Africa.

Chapter 6

6. Analysis and discussion of the experiences of participants

In this chapter the participants are introduced and there is an attempt to explore and analyse the main themes and experiences of bereavement for parents after the death of an adult child. There is an interwoven analysis of the themes of parents whose child has died as a result of cancer, and one of the themes of parents whose adult child has died as a result of an AIDS-related illness in order to attempt to understand the phenomenon which is under investigation. A later section explores areas of commonality and difference between them. The transcripts of the individual interviews are to be found in the appendices to the study. The lines of the appendices are numbered for ease of references. Where a quotation is used from the transcript it is referenced by the participant's initial, followed by the line reference.

6.1 Introduction

The goal of phenomenological research is to "search for those processes of consciousness that give the objects that appear in awareness meaning, clarity, and discrimination" (Polkinghorne, 1989, p.51). Thus the process of thematisation which follows seeks to attain this end by producing descriptions that transcend the specific experiences as given in the interview. The identification of meaning units becomes a reflection of the coherent elements that naturally occur in the text and through their unification permit the emergence of a lucid descriptive statement of essential and non-redundant psychological meanings pertaining to the phenomenon as experienced by the participant.

6.2 Parental bereavement through cancer

The adult children of the three participants Vasalisa, Kevin and Ella, have died as a result of cancer. A short introduction for each participant is given, as well as the researcher's impression of each participant. The information for this section is composed from the fieldnotes of each meeting which documented elements which are not captured on the audiotape. The transcripts for Vasalisa, Kevin and Ella are to be found, respectively, in Appendices A, B and C.

6.2.1 Introduction to Vasalisa

Vasalisa is a married woman in her late sixties who is retired from work. She is a grandmother and is close to her daughters and their children. Both of Vasalisa's sons have died. In the interview she focussed on the loss of her son who died as a result of cancer eight years ago at the age of 38. Another son died two years before and as a result she has no surviving male offspring. At the time of his death, her son was married with a daughter who is now in the last year of schooling. She still maintains contact with her daughter-in-law and granddaughter, although they do not see each other often as they live in another town.

6.2.2 Researcher's impression of Vasalisa

On my arrival, Vasalisa came to greet me and let me in at the external gate to her yard. Remembering our telephonic conversation, where the purpose of the research had been explained to her, she began to talk almost immediately, even before we had entered, about the events leading up to the death of her son. It also transpired during this time that she had lost another son, two months previously to the cancer diagnosis of her second son. Her son died 8 years before this interview took place. Her eagerness to talk about the event made it appear almost as though she had been rehearsing what she would tell me and almost as though this was a welcome opportunity. Subsequent to the interview, she appeared loath to bring the visit to an end and some time was spent in the garden, looking at the gardenias mentioned in the interview. Her demeanour throughout the interview was calm and rational. Only at one point, when remembering the scattering of her son's ashes on Table Mountain did her demeanour change, in that her speech became extremely slow, almost laboured.

6.2.3 Introduction to Kevin

Kevin is in his forties and is the married father of two daughters, one of whom died a few years ago a short three months after being diagnosed as having cancer. His daughter was 18 at the time of her death and had just completed Matric. Since the death of his daughter, he has been involved with TCF, and gave a talk to members of the organisations at one of their monthly meetings recently. The talk centred on his experiences with phenomena which have enabled him to take a broader view of life and death. The talk was well received, with numerous requests from members for copies of recordings of the talk. While for some the talk expressed a shared interest in the possibility of understanding life as transcending a mortal existence, for some it offered a sense of hopefulness.

6.2.4 Researcher's impression of Kevin

Kevin expressed an eager willingness to see me and also wished for me to read the e-mail correspondence that was sent to friends and family during the course of his daughter's illness. Kevin was eager to speak about events that have followed on his daughter's death which have inspired hope in him and the week prior to seeing me he had given a talk about these experiences death to members of TCF who were similarly enthused. This is understandable, as his enthusiasm and conviction are inspiring, eliciting a matching response. His style of speaking was eloquent and assured which added authority to what he has to say. At no point did he become visibly distressed, although he did pause when discussing the actual death of his daughter. On the whole however, he spoke fluently and without evident emotion.

6.2.5 Introduction to Ella

Ella is the mother of three adult children. As is the case for Vasalisa, she and her husband are also both retired. Ella's daughter died in 2002 after having cancer for seven years. Although the initial diagnosis was that the brain tumour was benign, it appears that this changed over the course of time. Ella and her family spent some years living in Israel, before returning to South Africa with her two sons. Her daughter married in Israel, so contact with her was generally telephonic in nature. During the course of her daughter's illness, Ella and her husband went to stay with the family in Israel, in order to take care of their grandchildren while their mother was receiving treatment for her condition. Ella still maintains a close relationship with her daughter's three children who are now young adults and who have also visited her in South Africa. Since the death of her daughter, her relationship with one of her daughters-in-law has become strained, and Ella attributes this directly to adjustment difficulties for all parties as a result of the loss.

6.2.6 Researcher's impression of Ella

Although Ella initially agreed to participate in the research, she subsequently contacted me to verify the nature of my connection with TCF, after which she confirmed our appointment. After the interview, she explained that if I had not been a bereaved parent she would not have been prepared to see me. She also expressed a sense of satisfaction to be able to have done so as she feels there is not often opportunity to do this in the normal course of events. Ella spoke in a very even tone throughout the interview with few breaks especially during the first half of it.

6.3 Analysis of themes of participants whose children have died as a result of cancer

This section presents an interwoven phenomenological analysis of themes of the life world of the three participants whose adult children have died from cancer, which is currently not a stigmatised cause of death in South Africa. Where direct quotations are taken from the transcripts, these will be referenced by the initial of their name, followed by the line in which the quotation appears. The initials for Vasalisa, Kevin and Ella are V, K and E respectively.

6.3.1 Temporality

In recounting events as they occurred, time appears an element that is used to define the progression of events. A number of sub-themes emerged, and these include a focus on the chronology of event, with a measuring of time, how the experience is embedded in time, and how time brought change to the person who is ill.

6.3.1.1 The chronology of events

The chronology of events appears to constitute an important aspect of the narrative and is linked to a changing sense of being, the culmination of which is the current state. The temporal aspect is incorporated and reflected right at the outset when Vasalisa remarks the speed of the change as being a, *" short time"* (V l. 4), and yet, that once such change has occurred, it cannot be reversed, so that even a lifetime may be insufficient to understand its enormity. Later she remarks, *"the minutes while he's still living "* (V l. 116), as though measuring out his very existence.

Kevin opens his interview recounting the chronological order of events when his daughter was diagnosed. Each day stands out almost in a catalogue, *"that was on the Monday. So on Tuesday we went to see the doctor; Wednesday they did the biopsy; Thursday we got the results back; Friday she was in Pretoria, at the Sisters of Mercy, and she started … and she went onto a drip, a cortisone drip, and that Monday she started her first chemo"* (K l. 8-12). Later on, there was a, *"next round of chemo, and we're now heading towards Christmas, so she took the second lot of chemo"* (K l. 96-97). As does Vasalisa, Kevin also remarks on the same inexorable process of deterioration. Initially, his daughter, *"moved into [her parents'] bedroom"* (K l. 94), but after being re-admitted to hospital, she *"went down from then on"* (K l. 141-142).

6.3.1.2 The temporal nature of the experience

Ella remarks that, *"it started off for us one day"* (E l. 4), which indicates a sense almost as though a timer has been initiated. She also reflects how, *"initially [she] was quite optimistic"* (E l. 74). The period of seven years between the diagnosis and her daughter's death, is marked by those periods of time where Ella goes to take care of her daughter's children in Jerusalem while her daughter is undergoing treatment:

- *"We stayed with the children for six weeks"* (E l. 37-38)
- *"We again stayed with the children"* (E l. 80).

It is evident, that the end point of the process that was initiated with the beginning of the illness is the death itself with the attendant funeral, so that events are measured in relation to it,

- *"Six months before she died"* (E l. 65-66)
- *"One more thing that struck me after the funeral"* (E. l. 392-393).

The temporal nature of the experience as a progression of events through time, is also a characteristic of time subsequent to the death. It is clear that for Vasalisa there is a clear and present knowledge of the time that has elapsed since the death, almost as though an internal clock is ticking: *"It's eight years since he died, eight years"* (V l. 440-441). The following excerpt depicts this passage as being delineated almost in stages of two years:

> *"The first about two years I never even went out to a restaurant. I went to Cape Town about two years after and everybody was still crying, and I said, "this is no good, I want to go home." It took about another two years, until I can say, I can go and work"* (V l. 394-400).

The temporal aspect also emerges when she discusses how the family has evolved, when speaking of her grandchildren, *"there is four children now"* (V l. 515). Also her phrase when referring to her son's, *" little girl, she's not a little girl, she's in Standard Ten this year"* (V l. 424), seems to indicate how the time when the death occurred is compared to the present. There is a strong sense of progression which culminates in the present awareness that, *"I haven't been up Table Mountain since [the death] and I actually want to go"* (V l. 416). This last quotation shows how the temporal progression provides a certain unifying element to the experience, which reveals it to be a flowing stream of consciousness which is being continually revised in terms of current experience.

6.3.1.3 Observing the changes wrought by the illness

A different aspect of temporality is reflected in how time is apportioned between the week she would spend with her son and the three months between visits. The time when she is with her son is governed by a need to, *"handle [her]self very well,"* (V l. 34) even though it appears to cost her a great deal, something which is revealed in the need for recuperation on her return home. This was predicated principally by the belief that time was limited and that she, *"knew he didn't have much time. I didn't say it in so many words and maybe even my brain didn't acknowledge it quite like that, but something inside me knew it"* (V l. 92-94). She also comments that she "*was geared*" (V l. 80) for staying a week, though not longer. Going back home she would, *"lead my own little life"* (V l. 89) and the use of the word 'little' is interesting. It suggests that perhaps the life she led in Cape Town was by implication 'big' and this perhaps gives insight as to its limitation in terms of length of time as well as the need for recuperation. The sense of time running out, her son's life elapsing, seems to have been a strong motivation driving her to return:

- *"Until I felt I have to go again"* (V l. 90)
- *"I knew he didn't have much time"* (V l. 92)
- *"Something inside me knew [time was running out]"* (V l. 94).

At the news of her son's illness Vasalisa expresses how difficult it was to reconcile the change to the image she had of her son as, *"a healthy, healthy, living person"* (V l. 20). Watching the progression of the illness heralds a succession of changes to her son as, *"he went, all the stages, he went down, they all went down"* (V l. 97) in an inexorable process of deterioration as *"it was going slowly down"* (V l. 128). Eventually the physical dictates of the illness are such that her son reverts to the kind of dependency he had displayed in his infancy so that she remarks that, "*it was like having my baby back"* (V l. 74).

Ella also finds that the illness changes her daughter, both physically and behaviourally. She describes her daughter as being *"terribly, terribly thin"* (E l. 89) and she is warned that, *"there would be some kind of personality change, she was never going to be the same person"* (E l. 81-82). During those periods when her daughter is better,

- *"She was her old self again"* (E l. 85)
- *"She behaved normally"* (E l. 89-90)

During the time that Kevin's daughter is hospitalised she loses her capacity for self-sustenance and she is, *"linked up to machines and drips and whatever"* (K l. 131). She also appears to diminish in size, *"she was never a big girl"*, but now becomes even smaller and thinner (K l. 132). The treatment also deprives her of the capacity to ward off infection, hence her isolation in, "*her own separate little room"*, so that there is an incremental removal of her from the mainstream of life (K l. 171). Kevin focusses on providing a fairly detailed description of the business side of nursing the cancer patient which gives an indication of how removed this experience is from daily living. It is almost as though they have entered a separate world, populated by different people, the ill and those concerned with their care. The language spoken is perfused with medical terminology, some of which Kevin uses with an almost casual familiarity, such as his use of the word "*chemo*". Eventually there is the final move to Hospice which is, *"a sort of transit point"*, between life and death and the learning in that world is to distinguish those whose death is more or less imminent (K l. 238-239):

- *"You get a sense, you get a feeling 'this one's not going to last'"* (K l. 239)
- *"We looked at other people as well who were dying"* (K l. 237-238)

Hence there is a progressive aspect to the experience with change as the marker which defines this passage. Up until the time of his illness, the sequence in Vasalisa's son's life had been from non-existence (before conception) to dependent existence (as a child) and later on to an independent adult existence. This sequence now appears to have reversed which perhaps accounts for the sense of dislocation evident where she says of the process that, *"it didn't feel possible. Well it did and it didn't"* (K l. 30).

6.3.2 Disbelief, denial and dissociation

For each of the participants there is an attempt to accept what has occurred but accepting it in its entirety is very difficult, as it nullifies the possibility of hope, and even when there is acceptance there may still be hope for extra-ordinary intervention or salvation. It is also difficult for participants to explain how in understanding, it was not understanding, or in knowing, there was not knowing, and how reality is somehow not reality.

The first reaction that Vasalisa describes on receiving the news is one of disbelief:

- *"At first I wasn't quite sure I heard right"* (V l. 17)
- (On hearing the diagnosis) *"So I said, no, I don't think so"* (V l. 19)
- *"I don't think I ever really accepted it"* (V l. 24)

- *"I don't think it ever went in"* (V l. 44).

These excerpts indicate how difficult it was for Vasalisa to fully comprehend the significance of the diagnosis, and the predicted finality of the outcome of the disease. It seems almost a though there are two types of knowledge which she does not connect. In the first instance, she is aware of people who have died of cancer and knows that her son too is suffering from a mortal illness and she comments that, *"I know he was dying"* (V l. 41). In the second instance, this knowledge seems somehow separate from the reality of the dying process. Although it was spoken about, with *"talk about funerals,"* and the fact that, *"all knew,"* about the imminent death yet, *"nobody actually used the word 'dying'."* V l. 44-49). It was as if the two types of knowledge were held separate in her mind:

- *"We were just looking after a dying person."* (V l. 50)
- *"Maybe even my brain didn't acknowledge it quite like that, but something inside me knew it."* (V l. 93-94)

She believes that even though all the signs of the progression of the illness were indicative of the imminent death of her son,

- "*The understanding, the perfect understanding of it wasn't there."* (V l. 212-213)
- *"I thought … he has to die … but the other part of you says no, illogically"* (V l. 225-228).

Perhaps the reason Vasalisa uses the word 'illogically' is because, in retrospect, she finds it difficult to explain how she could have failed to fully understand when all the facts were there for her to see, and yet, as she recounts it, it's almost as though she is trying to make sense of it still. Her narrative is paused and she reflects, struggling for words:

> "*I don't think I ever really accepted it until I … I…(thinking) even when he couldn't move any more, when he was a skeleton, I couldn't er…(long pause)"* (V l. 23-26).

Just how strange this lack of understanding is to her, is captured in the doubly bestowed escalation implied in the words, 'even when'. It is as if she is saying that these *should* have been sufficient cues, but somehow were not. This lack of understanding, tantamount to a denial or distortion of self-evident happenings, is explained as a necessary process as, *"your brain just tells you to take it easy"* (V l. 55). Later in the interview she reflects that she believes that she, *"was two parts for those whole two years."* (V l. 216). She also comments that in retrospect it felt as though her, *"whole body had shut down."* (V l. 107-108). It might be surmised that this is what is required for the person's very survival as later she describes herself as not being *"quite normal anymore"* (V l. 136) at the time that his death was imminent or her experience at the scattering of the ashes as being one of falling apart (V l. 296). However, during her son's illness she felt she had to *"handle [her]self very well"* (V l. 34), if only to take care of him. She would return home to recuperate and allow herself to shed the tears that she believed would spoil their time together. *"I could cry here (at home) but … we always had a beautiful time down there"* (V l. 217-218). It is clear that the experience appears to permeate every aspect of her body. Perhaps the most significant aspect of this is how she links the event when her arm was cut by the broken glass with the actual death of her son through a juxtaposition of the two events in terms of time and narrative (V l. 134-146).

When Ella's son telephones her to give her the news that her daughter has died, for Ella there is an enormous sense that it cannot be real,

- *"I just couldn't believe it, this is not happening to me, it's not something I want to hear; it's not something I can comprehend or understand. Because there's no pain, it's somebody else that they're talking about"* (E l. 329-332).
- *"And I just sat there absolutely still, I just couldn't believe my ears, … it just was like, … this wasn't happening to me"* (E l. 105-106).

The lack of appropriate emotional response is almost puzzling to her, and this is perhaps the reason why she comments on her repetition of the fact, almost as though through re-iteration it could feel more real:

- *"I just kept on repeating to myself"* (E l. 328)
- *"I remember sitting there in front of the person who was doing my nails and saying, 'My daughter just died.' And she got up and put her arms around me."* (E l. 326-328)

The last excerpt stresses how strange her reaction at the time seems to be now as she reflects back on it, and how the import of her words seemed more clear to her companion, who reacted in a way to offer comfort and solace. The protective function of such a sense of unreality and of the accompanying disbelief is made apparent when Ella remarks, that *"there's no pain"* something which she expects should accompany such an event (E l. 331). There is also a sense of dissociation that flows from this, because if one does not experience pain on hearing such news, it could be that, *"it's somebody else that they're talking about"*, not oneself in one's own body (E l. 332). Even two years later, there is a sense of disbelief about her daughter's death, so that, *"on the few occasions when somebody does phone and* *the voices you hear sound like her aren't hers, … it's a terrible shock. …The voice sounds like hers, so was it all a bad dream, a nightmare or was it reality"* (E l. 336-342). Prior to her daughter's death, Ella had become used to her daughter not being a part of her daily life primarily because of the distance which separated them as she lives in South Africa and her daughter was in Israel. As a result, special occasions and anniversaries stand out, because there would naturally have been some contact between them on those occasions:

> *"In a way it's like she's still living there, but when you phone or if it's her birthday, she's never on the phone*" (E l. 335-336).

It is as though one part of her knows her daughter is dead, but another significant part of her cannot fully feel it, as occurred when she first received news of the death. For that part of her, her daughter is still alive, still able to speak and so she still expects to hear that voice.

On getting the diagnosis of his daughter's illness Kevin experienced a dream-like quality which caused him to question its reality. To him it felt, *"like it was a dream. Is this … is this real?"* (K l. 24). He describes the undiluted bluntness of the surgeon's diagnosis, and twice using the term, *"reality check"* (K l. 18 and l. 22). Perhaps it is this which contributes to the sense of fatalism which enables him to see the outcome almost as predestined.

- *"What's the point in trying to fight it, if it's an inevitable thing"* (K l. 42-43)
- *"That was the writing that was on the wall"* (K l. 50)
- *"How do we work our lives towards this inevitability that we can't do anything about?"* (K l. 51-52)
- *"I don't react against things that I know are unchangeable"* (K l. 53)
- *"If she's going to die, she's going to die"* (K l. 54-55)
- *"Certain things you can change, certain things you can't"* (K l. 82-82).

It seems as though the period from the diagnosis until after the death is characterised by a sense of disembodiment: hearing the diagnosis feels, *"like it was a dream"* (K l. 24); during her admission to hospital he was on *"autopilot"* (K l. 166); the time immediately following on the death is, *"that stage when you don't know what you should be thinking or feeling or whatever"* (K l. 412-413). Receiving assured news of such finality and certainty appears to have a galvanising effect on Kevin and his wife, causing them to ask, *"so what do we do now? … So what do we do between now and that period, or that eventuality to give her and us as much of each other as possible?"* (K l. 50-56). It seems important to them to allow his daughter to choose what she would like to do, and in fact allowing her this wish is a good feeling for him:

- *"I mean we weren't going to break any rules or do crazy things, but if there were things she wanted to do then we tried to accommodate that as much as possible"* (K l. 73-75).
- "*She wanted to do that and we had to allow it"* (K l. 80)

Hope appears to make it easier to sustain or re-ignite denial. It is as though there is such a longing to have grounds for hope, even though this co-exists with the hard reality and perhaps it is this process that fuels the cyclical movements between denial and despair. For Kevin there was a short period of partial remission and this was reflected in a sense of, *"feeling helluva good, [but] the surgeon has said two months"* (K l. 112-114), so that there is the sense of an ever-present clock ticking down. For a while it appeared perhaps to have stopped, and this gave rise to a surprising but hopeful questioning, *"not quite knowing what's going on ahead"* (K l. 114) with the tentative, unuttered, *"dream for some kind of miracle, which we always hoped for"* (K l. 49-50). The questioning however resolves itself and there is a renewed sense of inevitability, "*then you can kind of see the writing on the wall"* (K l. 120-121).

It seems that for Ella it is as though the initial diagnosis of the cancer as benign facilitated an understanding of the illness that did not necessitate having to see it as fatal. For instance, when asked whether she was concerned about the possibility of death she answers:

> *"No, because I never knew it was malignant"* (E l. 470).

There appears to have been a lengthy period during which time Ella was able to keep anxiety about the illness at bay, through belief in the possibility of a cure:

> *"Initially I was quite optimistic about it, because I felt that, at the time that they had done the radiation and they'd given her medication, they felt she'd be alright for the next few years, and I thought that with science, and technology developing as fast as it is, I didn't see the worry, because I felt … that something would come up. There would be an answer, there would be a cure. I never, in my wildest dreams, thought that this would happen"* (E l. 174-180).

She also seems to not believe that her daughter would die rather holding on to the thought that, *"they said that she could live with this"* (E l. 25), so that she remarks,

- *"We'd never thought this was going to happen"* (E l. 136)
- *"We were quite hopeful that this would work out"* (E l. 41)

Even after her daughter had intensive treatment that left her debilitated, Ella says that she and her husband, *"were quite happy to leave her because [they] really thought she was on the road to recovery"* (E l. 95-96). Ella describes how thoughts of a different outcome would intrude. For instance, when contemplating the possible consequences of the tumour for her daughter's mental function she explains how she would suppress them knowing that death was the only other alternative, which at this point could not be entertained:

> *"Then I'd immediately push that thought out of my mind and think what was the other alternative"* (E l. 184-185).

However, in retrospect, there is a suspicion that her daughter and her family perhaps did have other information about the illness and its implications that had not been communicated to her. Perhaps the Afrikaans word of encouragement that the doctor uttered to her daughter is an indication of the seriousness of the situation:

> "S*he spoke to the doctor and he said to her, they were talking in Hebrew and he said to her, 'Vasbyt'"* (E l. 241-242).

There are still no answers to these questions, but the wondering continues to this day:

- *"I don't know at what stage they knew that it was malignant"* (E l. 471)
- *"We could only … understand what she and her husband were telling us. Whether they kept the truth from us, we really don't know to this day"* (E l. 63-65).
- *"I get the feeling that because we're so far away that she didn't want to really really tell us the truth, because afterwards my son-in-law said something to the effect that at first they thought it was benign, but that it had become malignant. So I don't know at what stage they knew that it was malignant"* (E l. 245-249).

There are also indications that in spite of what she believed, the anxiety spawned by the illness was never entirely quiescent so that it was a pervasive sense of it:

- *"It was always there at the back of your mind"* (E l. 261)
- *"It was a worrying time"* (E l. 262-263)
- *"You're anxious about it"* (E l. 264).

Having this constant sense of anxiety and concern is not pleasant and this is made clear by her desire to, *"somehow try to push it away"* (E l. 261-262). The ability to push it away makes the shock of the death itself very great. Another occasion where Ella experiences shock is at the funeral. In part this is because, *"it's completely different"* (E l. 302) from that which she is accustomed to and as she remarks, *"it's just not what you're used to"* (E l. 296). Thus she is not prepared for the different custom. However, the greatest source of shock is seeing her daughter being placed in the tomb, as it seems impossible that she should be dead:

> *"I stood there like in a trance …I couldn't believe that this was happening. This was my child, she shouldn't have been there. She should have been at home with her family, and… living her life"* (E l. 306-310).

Yet again there is a sense of dissociation, or as she describes it, a trance-like state. Once more there is a sense of disbelief which makes it hard to believe that which she is witnessing, also because the unfolding events don't appear to make sense because they contradict all that should be occurring. Her daughter should be alive and tending to her responsibilities: she should not be dead and being buried.

6.3.3 Signs and portents

Signs appear to be an important element of the experience both prior and also subsequent to the death of their children. These include events of an ordinary nature which seem inexplicable, and extra-ordinary events. For those participants who have experienced such events, they are occasions which are pondered on very deeply

There are a number of events which Vasalisa finds very 'strange' (V l. 165 and l. 179). It seems that these events obtrude from the ground of experiences at the time of her son's death. The first is her accident with the broken glass, which was very out of character as it resulted from careless disposal of the glass. What makes the timing of it strange and significant is that it occurred at about the time that her son was dying. Although she is not able to explain the events, she attributes them to being in a state which was different from the usual: *"I wasn't …quite normal any more… I was in such a state. But don't ask me why"* (V l. 136-7. Another strange event is the decision her husband made to return home, which was contrary to his customary behaviour, thus enabling him to supply emergency care to prevent her dying from this wound. She wonders whether her son had some agency in the decision her husband made. Finally, the extraordinary behaviour of her son's cat at the time of his dying she also defines as 'odd' (V l. 26). It seems that her dilemma lies in trying to reconcile logic with the strangeness of events and perhaps this is where it remains a struggle for her to make meaning of the signs which she experienced as significant. It is almost as though a strong sense of rationality militates against the making of meaning, because making sense does not lie in the realm of everyday reality, but requires appeal to connections between people that is outside of this reality:

> *"There's a lot of things we … don't understand. I mean all these signs, but how do we understand signs, but I think we were crazy, I think that's what we were"* (V l. 269-272).

There are various references which highlight this,

- "*I wasn't … quite normal any more … but don't ask me why. It wasn't a logical thing"* (V l. 136-138).
- "*The other part of you of course says no, illogically"* (V l. 225)
- "*And there is no logic, there is no logic"* (V l. 582)
- "*I can't change the world, I mean logically, I can't do that"* (V l. 611)
- "*With the logic I had, I could tell you, yes, I saw it. But it's the understanding, the perfect understanding of it wasn't there"* (V l. 211-213).
- "*There is no logic, there is no logic coming in"* (V l. 582).

It is also interesting that the specific words used to refer to these states or conclusions that she believes are irrational or illogical include, 'not normal', 'crazy' and 'stupid'. Perhaps the last statement quoted in the preceding paragraph illustrates how difficult understanding becomes for her when it is not linked to logic. It also appears that she links these signs with spirituality so that her strong position and preference with regard to spirituality may account for her resistance against finding meaning in the signs, *"My son wasn't very spiritual, I'm not, how, what kind of sign could there be*" (V l. 203-204).

In contrast to Vasalisa, Kevin appears to relish recounting events which are inexplicable in the usual course of existence. For instance he tells an anecdote of an event that occurred as his daughter was unconscious. He had stepped out onto a balcony to take a breather, a balcony which is higher than the surrounding topography, also because the Hospice is atop a hill. It is there that a parakeet with clipped wings comes to him. That this is highly significant is clear from his preface to the anecdote, *"talking about the bird, I do need to tell you this"* (K l. 678). As was the case for Vasalisa's signs there is an element about this event that transcends rationality, and he asks, *"Please tell me how a bird that can't fly, flutters down from a tree and lands on the balcony?"* (K l. 683-684). In contrast to Vasalisa, Kevin does appeal to a realm beyond human existence, and believes that it is related to the spirit leaving her body. Since the death of his daughter there have been other signs that have made an impression on Kevin:

- *"[My wife] smells her perfume, every now and then, that [my daughter] loved* (K l. 414)
- After the death of his daughter, his wife, *"was dozing in [my daughter's] room, and she was lying with her hands open and she was waking up, and she felt these hands in hers and this presence in the room, saying, 'It's OK'"* (K l. 417-419)
- *"I was just lying there with my eyes closed, and it was clouds of white, black and grey spots, whatever, in front of my … in front of me, forming into her face. But peaceful, beautiful, smiling, happy, contented, all the right things, all the right things"* (K l. 425-428).

Although he sees these events as signs, Kevin also acknowledges that others may interpret them differently. For instance, the coincidental conversation about life after life a scant three months before his daughter fell ill it felt, *"almost as though something was getting us ready for what was going to happen … and that's open to debate and interpretation of course"* (K l. 488-490). He knows that his conviction of seeing his daughter's face on the anniversary of her birthday is something that could be *"debate[d]…for hours"* (K l. 432). He is also uncertain about why he perceives these signs:

> *"I don't know if I'm particularly susceptible to anything that's paranormal. Maybe I am and I don't realise it, or there's signs that I miss, or whatever - I don't know"* (K l. 438-441).

However, it seems to him that losing a child makes a parent more eager to hear about such experiences,

> *"In my presentation, [to TCF] when I discussed the paranormal, everyone was nodding … And they want to talk about it, and maybe they don't know quite how to express it but everybody loves to know that there's some kind of reinforcement that I'm not weird, and, you know, I don't believe that it is weird"* (K l. 661-665).

Certainly Vasalisa also expressed a fear of being judged 'crazy' and 'stupid' if she were to publicise how she interprets events that seem 'odd' to her. Kevin explains that it seems to him that, *"can talk to people easier if they've been through a similar situation. Unless you've been there, you don't understand"* (K l. 566-567). This is because the realm for such understanding is based not so much in the rational but rather in the realm of faith as Kevin remarks, *"none of us is ever going to know if what I say is junk or not. I believe that it's not"*

(K l. 560-561). People lacking this belief would therefore tend to dismiss such interpretations as he makes: *"I also know that there are people that you can speak to that haven't been through it, who will listen, but there are others who don't want to listen* (K l. 567-569).

Unlike Vasalisa and Kevin who have experienced things which seem significant though inexplicable, Ella has not done so. However, she has a strong belief in a spiritual reality that enables her to account for the seeming senselessness of death and this brings her comfort:

> *"I've studied, the path of spirituality for a long time …I haven't seen anything physically that substantiates it, but it's just a feeling of comfort that I get from that belief"* (E l. 438-442).

In this she does echo the sentiments of Vasalisa and Kevin who both realised that comfort lay in a realm which is only accessible by faith. For Vasalisa and Kevin the signs they have borne witness to are highly significant in attesting to the veracity of that which they wish to believe. For Ella, the veracity of her beliefs is founded on her earlier studies, in terms of which, *"everything happens for a reason, and that it's ordained before … a person is born, your life and how you go, what you're going to be in life …The soul chooses its parents, the life they're going to lead before … it comes down to earth."* (E l. 426-431).

6.3.4 Doing it their own way

Participants appear to experience some pressure from other people around them to grieve in a particular way and this becomes a cause for concern for them. For instance, as was noted earlier, participants have both a subjective and an objective sense that they are abnormal in some way. The numerous references to feeling crazy, are also reflected in the reactions of others to them, who may be dismissive of the meaning they attribute to their experiences or who may avoid the subject altogether. Initially participants may try to comply in order not to lose social approbation. However, later on, perhaps as these strategies fail to produce the desired results, there is a search for a more idiosyncratic approach.

The well-meaning suggestions proffered by others for alleviating the pain of the experience are not always helpful. Vasalisa's family grew concerned after some time had passed and they saw that it was almost as though she was not fully present any more. She remembers: *"but they said, "You wouldn't talk, you weren't laughing, you weren't … outgoing. You were … not there." And I did everything but I wasn't quite there"* (V l. 453-455). They encouraged her to attend TCF but for Vasalisa, *“it eventually became too much”* (V l. 464) hearing about the pain of other bereaved parents and she found that, *“it just didn’t go with me. And I slowly just broke away and I thought I’d just have to do it by my own way”* (V l. 478-479). Doing it her own way included spending time with a friend who had also lost her son, giving each other mutual support. It also means that she gives herself permission to withdraw. The importance of these periods is that they help her, *“to get in touch”* (V l. 510) with the deceased. It also means spending time with memories, *“I've got photos of my kid … and I take my albums out from time to time. That's a bit heavy, that’s a bit of a cry time. But it's a happy time as well because there's lots of beautiful memories”* (V l. 568-571). This is seen as a necessary process because as Vasalisa remarks it is important to maintain the balance between putting on a socially acceptable front and spending time mourning. She says, *“you’ve got to make your little world still liveable because I’m still here, and my children are still here and my husband … and sometimes you have to put yourself a bit in the background for them because [they] will get very easily upset when I’m upset”* (V l. 544-549).

In contrast to Vasalisa’s experience, it seems that Kevin received feedback which indicated to him that he was not grieving in a socially understood way because, *“everybody kept on saying 'aren't you feeling sad; aren't you missing [your daughter]?'”* (K l. 596-597). This becomes a matter of concern for him so that eventually he sees a psychiatrist who classifies his style of grieving as, *“atypical but not abnormal”* (K l. 601). He understands this to be a sanction and as a result becomes more comfortable with his type of response and says: *“OK, this is the way that I am”* (K l. 602). Doing it his own way for Kevin means, *“the acceptance of what has happened”* (K l. 595) and the acceptance of a greater reality of existence which encompasses death:

> *“I really do believe that [she] is in a better place. I really do believe that we're all going to go to that better place. I also believe that maybe we will see [her] when we go to that better place. Maybe we won't, but that doesn't matter”* (K l. 604-607).

Acceptance for Kevin means he can, *“feel a calmness and a comfort”* (K l. 611-612) even though this does not obviate the pain of the loss, which can be severe, *“usually at two o'clock in the morning”* (K l. 603-604).

6.3.5 “Good things in the bad things”

One of the strategies that participants use to try to reduce the pain attaching to the loss is to find elements of their experience which have a positive slant. Such elements perhaps made it possible to survive the experience while it was occurring. They also appear to bring a measure of meaning and of comfort which is important in fuelling the hope that they will be able to continue to exist after such a loss.

There is a certain discomfort for Vasalisa in attempting to juxtapose the signs she finds significant, with a more rational type of understanding. This creates a certain dilemma which she has not entirely resolved, so that on the one hand, there is the sign, yet on the other, she attempts to resist any explanation which cannot be sited in the rational and logical, *“what kind of sign could there be between the one* [her son’s dying] *and the other broken blooming glass”* (V l. 204). Vasalisa’s language is the strongest she has used in the interview, with a use of an expletive, when recounting the frustration she experienced at the time of the death of her son. As she remarks, *“he wanted me there and I couldn’t get there. I mean, it’s Cape Town, Cape Town for God’s sake”* (V l. 160-162). The signs she has described take on their greatest significance in this regard and she describes them as, *“good things in all the bad things”* (V l. 182). This interpretation is made possible by understanding the signs as providing evidence of her son desire and ability to communicate with her: *“They were signs which he most probably would have wanted me to know”* (V l. 183-184), and it is perhaps in this that there is an element of resolution.

Kevin tries to see death in a more neutral way which is neither good nor bad, but rather part of natural living where, *“people live and die all the time … and people die in different fashions”* (K l. 162-164). However, it is the nature of events associated with the dying process that endow it with a certain value, and he appears unwavering in his striving to make the experience as good as possible for his daughter. This means ensuring that those who are entrusted with caring for his daughter, do it with passion:

- *“The staff were wonderful as well”* (K l. 167-168)
- *“The people there are absolutely stunning- those women are superb”* (K l. 150-151).
- “*[Her uncle] came along and massaged her and they were wonderful as well*” (K l. 189-190).

Another element which is seen as important for him, is the quality of interaction: *"the most important thing was that we communicated - all of us. All the time"* (K l. 176-177) which he repeats to emphasise how they, *"communicated all the time"* (K l. 190-191). This would be an important issue because without communication, the strategy of ensuring as good an experience as possible, could not be implemented or evaluated. This element of evaluation is one that appears constantly when describing the last three weeks of his daughter's life:

- *"I think that we did the right thing, in that we involved family, friends, the boyfriend"* (K l. 193-194).
- *"So I think there was a certain comfort for us, in that we were doing the right thing"* (K l. 199-200)
- *"That we were doing the right things for the right reasons"* (K l. 201-202)
- *"Every night we'd sit out here, … and we'd go through what we were doing. Are we doing the right thing, could we do more, should we be doing this or whatever"* (K l. 202-205)

Something of this same spirit also prevails once it is known that death is imminent and Kevin then sees his mission as one to give his daughter, *"time to sort out any unfinished business and she had to be conscious enough to be able to do that. So if there was anything that she wanted to say, or whatever, she had to have the chance to clear her slate on this level, on this plane, this existence, whatever. She had to be able to do that"* (K l. 259-263). Once again she is asked what she would wish and it becomes a undertaking for him to ensure she will be able to see her old friend before her death. The opportunity to achieve these ends, to fulfil her dying wishes, the chance to say goodbye and the option to participate in the nursing of and caring for her until her death, is something for which Kevin is grateful:

> "W*e've been fortunate in what happened to us. When you think of people … imagine losing someone suddenly, now you see them, now you don't: No time for unfinished business, no time to say goodbye"* (K l. 442-446).

He also confirms that this sense of gratitude persists in spite of *"all the suffering and the rest, the chemicals, the morphine and whatever it took to take care of her"* (K l. 447-448). Ella too feels an immense sense of gratitude for the support shown her in Israel by some old friends who understood the intense alienation they were experiencing which she described as an 'ordeal' (E l. 282).

- *"The one friend of ours who lives there … And they came very often to visit us during those seven days"* (E l. 393-399)

- *“So if those friends of ours hadn’t been there we would have gone out of our minds. So to have had that support, you know people speaking to us in a language that we understand”* (E l. 286-289)
- *The people we knew from when we’d lived there …were there for us. They came and spoke to us, because it’s a time during that week, when people don’t leave you alone. They’re there for you, and the food never stopped coming”* (E l. 151-156).

6.3.6 Relating to the person, dying and deceased

Once the patient enters the final stage of the illness, much is required in terms of care-giving and nursing. There is also a need to accept the changed status of the person from well to sick, from living to dying and from independent to dependent. This is not purely a physical endeavour but also occupies the mind of the parent. However, after the death, and especially after the business of the funeral, the extreme activity around the patient ceases. From a perspective of mental activity though, the deceased is still a focus of attention for the bereaved parent perhaps more so because there is more time.

For Vasalisa this is evidenced in the need to care for her son, by being with him, by not crying, by ensuring that their time together is untainted by unpleasantness or disagreement. Perhaps this is because knowledge of the impending death heightens the sense of the preciousness of this fading life, so that there is a sense of *“grudg[ing] every minute you’re not with them”* (V l. 115). In addition to the dilemma which is posed by the juxtaposition of her son as a healthy person and as a person with cancer, it appears almost incomprehensible that he, now living, could become dead. Death appears to transform those people whom she has known for many years so that they become inaccessible, *"they're dead, they're gone”* (V l. 12). Insofar as her son is concerned, it appears impossible to reconcile these images:

- *"I know he was dying …but I don’t think it ever went in"* (V l. 41 and l. 44).
- *"If someone is dead, that’s one thing, but as long as they’re still alive you care for them"* (V l. 87).
- *“The minutes while he’s still living – you don’t think dying yet. It’s still living"* (V l. 116).

These dilemmas highlight the intersubjective nature of existence. While Vasalisa's son exists in the sense of an objective reality, he also exists as an image of that reality in Vasalisa's consciousness. The degree of change to the objective reality creates a discrepancy of such significant magnitude with the subjective reality to the extent that it is impossible to reconcile them. Ella refers to her daughter before the illness as, *"her old self"* (E l. 85). There is a similar sense when Kevin uses the terminology *"to lose her"* (K l. 293) when anticipating his daughter's death. It appears that death will put her out of his reach and make her ever more inaccessible to him in this existence. Vasalisa feels that as a result of these events she herself has changed and that the way she would have behaved before her child's illness is altered:

- *"But if it's your child you do watch"* (V l. 114)
- *"I wasn't ...quite normal any more"* (V l. 135)
- *"I'm not quite that person: I can cry yes. But actually falling apart …(stops talking)"* (V l. 295)

In contrast to all that has changed both internally and externally, Vasalisa believes that henceforth there are some areas that will not change, *"I don't think it will ever change, I don't think it can change."* (Interviewer) *What can't change?* (Vasalisa) *The way I feel, still that loss"* (V l. 553-l. 556). In part, it is impossible for it to change, "y*ou can do it on the odd day, but you can't do it in general, … you can't"* (V l. 565). Partly, this is also because she does not wish it to change because it is in some way a means to maintain a connection to her son. Although remembering causes pain (and she believes will always do so), the life they shared deserves to be remembered, "*we lived a whole life, a lifetime together, why shouldn't they deserve a tear?"* (V l. 363). Somehow the sadness she experiences is something that she believes is due to him, perhaps almost as a tribute to the affection which they shared. Moreover, if this is the price of the only connection she is able to effect with her son, then so be it.

For Kevin too there is an attempt to provide good care but additionally, especially at the outset, there is an attempt to overcome the illness and all family members are recruited towards this end, including his daughter. He asks that she, *"draw on all the reserves that you have in order to fight this thing … be positive"* (K l. 185-187). His daughter responded in a way that he considered, *"very brave. She fought right until the very end but she was very positive"* (K l. 100-101) and, *"[She] refused (with emphasis) to believe that she was not going to beat this thing. Which was superb*" (K l. 178-179). Hence he did not disclose to her the seriousness of her illness but is heartened by her being, *"a wonderful patient"* (K l. 180). There is almost a feeling of wonderment and perhaps also gratitude in him when he says, *"yet she was still so noble, and gracious, throughout the entire process, and I think that was* *amazing"* (K l. 198-199). Perhaps gratitude arises from her co-operation which has enabled him to salvage something positive in the suffering enabling him to reach out to similarly afflicted families, *"and comfort them, if it was comfort. I don't know if it helped or not. But it was also kind of fulfilling for us, and I think it helped us cope with our situation"* (K l. 240-243). As was the case for Vasalisa, there is a sense of wanting to share each waking moment with her, and as Kevin recounts, *"we lived [at Hospice]: I used to sleep in the car, [her mother] used to sleep on the floor or on a Lazyboy thing in the room. Then we'd get up in the morning and sort of freshen up and go back again. We just lived there"* (K l. 232-237).

The situation was different in the case of Ella whose daughter lived for seven years after the onset of her illness. Yet in their case too, there was a strong need to be with her or at least to hear how she was progressing, even though the distance between them made this impossible:

- *"It was very difficult, because we couldn't phone in every day to find out how she was, and on the other hand, … so you've got your life here, but it was always there at the back of your mind"* (E l. 259-l. 261).
- *"You can't constantly be on the phone to them all day. You've got to let them get on with life, the job of living as well"* (E l. 265-266).

During these years Ella and her husband made trips to Israel at the times when her daughter was undergoing radium treatment or had operations. Unlike the case for Vasalisa and Kevin, where it was to be with their child, Ella undertook to care for her grandchildren:

- *"We stayed with the children for six weeks"* (E l. 37-38)
- *"We again stayed with the children"* (E l. 80).

However, unlike Vasalisa and Kevin, Ella felt that they were, *"the outsiders, because [they] weren't there every day to see her and to help her through it"* (E l. 212-214). In fact, when her daughter was hospitalised, it was her son-in-law who was at her daughter's bedside, where, *"he slept in the chair next to her bed and never left her"* (E l. 79-80).

Witnessing the extent of the suffering leads to the realisation that such a state is incompatible with living and that death is preferable to a continuation of suffering. Vasalisa remarks that she came to see that, *"he has to die, he can't live like that"* (V l. 222) and *"I didn't want to hold on any more when I last saw him …because it really too bad"* (V l. 228-9). This was even though this was in direct contrast to her wishes and wanting him to live. Similarly

Kevin finds that eventually once, *“they'd taken all the drips out, all the drains, they were giving her morphine, and her body was just shutting down”* (K l. 255-257). As it became evident that death must be imminent and that *“there comes a time when the hospice staff, talk to the patient and say, 'you are going to die.' And I looked at [my daughter], and I said, 'This is not going to take long' ”* (K l. 247-249). This then was the moment to tell that she was dying, *“So there comes a time when you have to talk about it”* (K l. 263-264). True to form form, *“she still didn't want to believe it. She said, 'Bugger you, I'm going to carry on fighting'”,* (K l. 266-267) but somehow she knows that this is the end and expresses her final desire to be with her childhood friend. For Kevin, this becomes the last thing he can do for his daughter together with the attempt to, *“take away her fear of dying; dying was not going to be a terrifying experience, but was going to be a pleasurable, an unbelievable pleasurable experience,”* (K l. 278-280). Thinking that the friend might not arrive in time increases his sense of urgency and fills him with dread:

- *“I was terrified that [she] was going to die before [her friend] got there”* (K l. 286-287)
- *“We were terrified we were going to lose her*” (K l. 291-292)
- *“I was terrified we were going to lose her before [her friend] actually arrived”* (K l. 292-293)

In the period while they are waiting for the friend to arrive, it is almost as though he himself is on that journey, willing his daughter to be survive just a little longer. He acts as a cheerleader or coach on each step of her friend’s journey: *“[She]’s jumping on the plane now, … she's on the way from Brisbane to Sidney. Now she's on the flight from Sidney … she's probably flying over India now”* (K l. 289-291*).* Achieving this end fills him with a sense of achievement, relief and delight, so much so it is difficult for him to express how much so in words:

- *“We managed to get [her friend] here. [She] arrived on the Monday or the Tuesday, [my daughter] died on the Thursday, and I was very pleased that we were able to do that* (K l. 281-283)
- *“[She] was weak, she was emaciated, whatever, but she was still… when she saw [her friend], her thin arms just came out and grabbed [her]. I mean it was … it was … it was very much …us”* (K l. 283-286).
- *“Anyway, it happened, so that was great, it was really great”* (K l. 294-295)

As regards the second of his self-appointed tasks, to remove the fear of dying, he recalls,

> “*I hugged her and I said, ‘… don't be afraid …because what you're going on now is going to be the most wonderful experience you've ever felt in your entire existence. So it's time to go now. We've said our goodbyes, we've finished all that, and we're finished with you on this earth. And now you must go”* (K l. 302-309).

It was clear to him that death is preferable to continued suffering because by now, *“she was battling to breathe, there was the pain, the morphine”* (K l. 316). At this point he desperately wishes to *“let it be over”* and for the *“pain and misery”* (K l. 326) to end and he takes on the role of the intermediary asking for intercessions that she should die:

- *“My mom is a very religious woman, and I said, 'Tell [her] she must go”*’(K l. 320-321).
- *“I said, [to the school chaplain] 'Please tell her to go, please release her, whatever it is, it's finished now”* (K l. 325-326).

For Ella too there is a realisation that life under certain circumstances imposes suffering that is too great to be borne. When she remembers the suffering undergone by a friend with a brain tumour and its effects on her loved ones, she decides that she doesn’t, *“really want for her and her family to suffer through”* such physical and mental deterioration (E l. 183). This came after a visit where her daughter was coping in certain respects but not in others:

- *“We then went over to visit and we got quite a shock, because she’d lost an enormous amount of weight”* (E l. 57-58)
- *“She went for another MRI scan, and they found that this growth had grown”* (E l. 69-70)
- *“When I saw that … she was fine to a certain extent but there were lots of things where she wasn’t fine, and I thought to myself, “Gee, what kind of quality of life is this young woman going to have?” You know I’ve heard of people who have had brain tumours who have become vegetables, and she wouldn’t have wanted that. So on the one hand, you know, the loss is absolutely tremendous, but on the other hand nobody knows how she would have been if she had lived. You know, if this thing had carried on growing the way it was which it would have done inevitably have done at some stage”* (E l. 107-116).

However, after an operation to remove part of the tumour that was affecting her ability to speak, it appears to Ella that:

- *“She was her old self again”* (E l. 85)
- *“She behaved normally as she got stronger”* (E l. 89-90)

In respect to her behaviour though, there is a change, especially as regards her, *"mannerisms. She had become a little emphatic about things that she wanted done maybe that way … and her family were finding it hard to deal with it, and it was obviously the personality change that she was already undergoing"* (E l. 204-208). This change required a corresponding change in Ella's behaviour to her daughter:

> *"We didn't argue with her: if she said white's white it's white"* (E l. 211-212).

As in the earlier transcripts of Vasalisa and Kevin, there appears to be accommodation of the whims of the patient:

> *"What was the point of making a big argument about something … if she wants it done that way, do it that way. We were only there for a short time, for three weeks or something"* (E l. 211-219)

Vasalisa highlights she has a good understanding that her son is dead and remarks that she knows that he cannot be physically close to her. The inaccessibility of the deceased can be painful and make the yearning to hear or see them more acute, *"it's just sad that they're not there now to share maybe a phone call or a visit"* (V l. 571-572). Even if the deceased should appear in dreams, she is clear that she doesn't *"feel they're beings here"* (V l. 597). However, the deceased can still be present in memory, so that even if it evokes feelings of sadness. She notes that, *"it's a happy time as well, because there's lots of beautiful memories, so why would I wish this away … I don't"* (V l. 569-571). Her final comment that, "*I'm not that spiritual, that I feel my children that much, but I always think about them, when nobody is bugging me. My thoughts can travel easily here, without hampering it with people or things"*, (V l. 638-640) emphasises how much she values the opportunity of spending time where she is able to be with her children in her thoughts, to the extent that she will create that space to do so.

For Kevin there is a clear differentiation between a body with soul and one without and there are numerous references that highlight this distinction:

- *"Then she closed her eyes, and that's when I think her spirit, soul whatever left her* (K l. 320-321)
- *"But she wasn't there. There was no consciousness or whatever"* (K l. 333-334)
- *The essence has gone …This is the rest that's just lying here shutting down* (K l. 321-322)

- *"This soul this … whatever had gone. And this is just a body shutting down"* (K l. 337-338).

When saying his daughter died, Kevin uses pithy language, in contrast to his style which is rather more circumlocutory, and it seems as though the very style mirrors the finality of the event:

- *"At quarter to ten she died, she took her last breath and that was it"* (K l. 340-341)
- *"Then she died. (Pause) And that was that."* (K l. 154-155)
- *"She died at about a quarter to ten in the evening"* (K l. 295)
- *"She died on a Thursday"* (K l. 249)

In spite of the clear understanding that the deceased no longer share a physical way of being, Vasalisa believes that there is some other way of maintaining contact. She attributes significance to her husband's coming home when she had her accident by linking it to her dying son, *"they were signs which he most probably would have wanted me to know … and somehow must have transferred from him, or from me, to my husband"* (V l. 183-187). Hence communication is possible even beyond the spoken medium and the appropriate realm for this kind of communication is more spiritual, so much so that she feels he somehow made a connection with her and her husband:

> *"I'm not a very spiritual person, but I'm sure he wanted me there and I couldn't get there"* (V l. 149-151),

The sense of continued communication is also strongly portrayed in Kevin's interview, and in fact he sees it as a communication born of a continuing relationship which death has altered but not annulled. At the moment of her death he kisses her and explains that if he'd ever done so before, *"she'd look and say, 'Dad' so [he] leant down and … kissed her and …thought, 'hah! Got you!' … [Y]ou need to have that kind of relationship, if you believe that there's a hereafter and if you believe that there's any kind of communication. … it needs to be a normal relationship"* (K l. 345-350). A year later he reports appealing to his daughter, calling her by name and saying:

> *"'Here's somebody who is coming. Please be there and help her. So it's that kind of relationship*" (K l. 357-359).

On her birthday he appears to become aware of seeing her face and takes great comfort from the understanding that *"she'd actually made the effort to let [him] know, 'hey, I'm OK'"* (K l.

433-434). Yet even in the evanescent perfection of this pellucid moment he rues its fleeting ephemeral nature:

> *"You want to hold onto this thing for as long as possible. It came, it sat and I don't even know how long it was, I mean I think I was just totally wrapped up in this experience and then it went"* (K l. 428-431).

This tantalising glimpse is all-absorbing and goes beyond time and space, so that he is totally lost to everything but the experience in which he is immersed. However the experience serves to draw attention to the fact that the relationship is different from the way it used to be, and can never be that same way again. He longs to be with her again, and remarks somewhat wistfully:

> *"I want, I'd love to consciously converse with her, but I know that I can't"* (K l. 452-453).

Her death has put her out of reach as far as human contact is concerned:

- *"When I talk to her it's a one-sided conversation"* (K l. 449)
- *"I'm not expecting answers. I'm not expecting to communicate with her"* (K l. 450-451).

Ella also does not believe that it is possible for her to communicate with her daughter, so that connection with her has been severed, but there are other connections which survive and persist:

> *"There will always be a connection with her husband and her children, whom we are in constant contact with … although they're far away, we still have … that connection with them"* (E l. 363-367).

Her daughter remains accessible to her in the sphere of imagination through thinking about her, and then she is imagined as a whole person, living an existence that appears distinctly human in nature:

> *"I imagine that she's still her quiet self, overlooking what's going on, and perhaps getting pleasure out of things that her children accomplish"* (E l. 448-450).

Not only is her daughter accessible to Ella in her thoughts but Ella feels her still to be her child and by virtue of this still part of her. A history such as they shared must persist:

> *"She's your child. Whether she's still living or she's dead, she's still your child. She's part of you. You know, you have her, nurture her, bring her up, she was part of everyday life, and even though she was living overseas, she's still part of your everyday life"* (E l. 413-416).

6.3.7 Rites and rituals

In planning the funeral, it appears a matter of some importance to parents that their dying child should have their wishes met, even where these wishes are not stated explicitly. This becomes clear in the desire of those who survive to find ways to carry out these rituals that are appropriate to the nature of the bereaved.

For instance Vasalisa engaged with her son over this topic. Even though he appeared to think it unimportant, she said to him that it did matter to her, so that he did choose a reading, and *"this was enough"* (V l. 286). Although she does not elaborate on the funeral, scattering the ashes was an intensely significant experience, perhaps because it took on the aspect of, *"the finishing"* (V l. 310) thus acting as a marker. It also stands out in Vasalisa's mind, *"as the worst day of my life, and that is a long life"* (V l. 302). All descriptions of the day point to the unparalleled difficulty of it,

- *That day was an awful day, an awful day …it was really an awful day"* (V l. 305-306)
- *"It hurt"* (V l. 365)
- *"I wouldn't wish it on my worst enemy. It was a bad day. It was really bad"* (V l. 367-368)
- *"It was really terrible"* (V l. 340)

Kevin also does not describe the funeral, but the description of the events immediately following upon her death have a strongly ritual element to them:

> "*So we kicked everybody else out and [her mother, her sister], the school chaplain and I had time with [her]. We said prayers, then everyone else came in, said more prayers, I mean, I closed her eyes, … pulled the sheet up and sorted it out a little bit … so I leant down and I kissed her"* (K l. 341-344).

A year later there is another ritual event, he and his wife,*"went back on the anniversary of her death and we took flowers to the Hospice people and the oncologist and so on"* (K l. 354-355). No doubt there are others, but it does appear to be important that significant dates are honoured and marked.

Ella gave more time to discussing the funeral and funerary rites than did the other participants. In contrast to the others, considerable detail is provided, both to the days preceding the funeral and to the funeral itself. She explains about the custom how, *"in the*

Jewish religion … you're in mourning for seven days" (E l. 149-150). She also expresses surprise at the size of the funeral and how she "c*ouldn't believe it, that there could be so many people that were there for [them]* (E l. 148-149). The funeral was large and attended by, *"half the town, school friends, teachers, their children's teachers, neighbours, children of their neighbours, places where they lived"* (E l. 145-147). Yet while the support was good, it was also very hard being foreign, not being well-versed in the language and customs. This is possibly because it was so unlike what she was accustomed to that the burial itself came as a shock.

- *"The one thing that is a shocker … they don't bury in a coffin, unless you're a soldier, and when I saw this body that was covered in a velvet cloth, just in a shroud"* (E l. 289-295).
- *"The grave, it's … built up at the sides with bricks and then they put the body in. They almost entomb it because they have … two lintels on the side, like … on a pre-cast wall and then they lay the sheet across it on top and then they put the soil on top of that"* (E l. 302-306).

Another difficult situation was the wording of the inscription of the tombstone:

> *"When they discussed the tombstone, we weren't included. My son-in-law didn't want anything in English"* (E l. 311-312).

6.3.8 Innerscape and outerscape: bodiliness and spatiality

Participants refer to the relationship to the physical self as a way to describe various experiences related to the death of their children. On other occasions, the inner self finds expression in the way that events appear to mirror the internal state.

The scattering of the ashes is one such occasion for Vasalisa. She describes an impression of things not making sense and remarks, *"when I looked I … thought, how can people walk around like this?"* (V l. 334). Another remark about her physical response to this is described as and "*fall[ing] apart"* (V l. 295). During the course of the illness Vasalisa portrays herself variously as being different from her usual self, the most evocative of which is her feeling of being divided into, *"two parts for those whole two years"* (V l. 216). Kevin defines this period as one of *"running on autopilot"* (K l. 166) which seems to indicate that although a part of him was functioning as usual, another part of him was not fully present.

It seems that Vasalisa links the accident with the glass to being *"in such a state"* (V l. 137) ascribing it to how, *"something tumbled inside"* (V l. 205) at about the time her son was dying, with her wishing to be near to him, yet perhaps fearing how she would react were she to be there, although this is not expressed directly. The site of the injury is described as, *"all loose and hanging"* (V l. 188), the loss of blood nearly led to her own death and has resulted in scarring. It is almost as though the lacerating experience of her body expressed the lacerating experience of the loss of her son and her sense of being torn apart, something she is not able to put into words. The periods of withdrawal are motivated by pain which is not sited in the physical body. Vasalisa attempts to draw this distinction by remarking that at those times she is not sick, nor is she in *"actual pain"* (V 501-507) although she does experience pain.

The physical environment is also a focus of attention, and appears to mirror some of the internal process. On the chosen day for the scattering of her son's ashes it, *"was the most terrible weather in Cape Town"* (V l. 292). When they finally get there it is still an, *"awful day, an awful day … really an awful day"* (V l. 305) in spite of beautiful weather. In language redolent of the emotions she is experiencing, Vasalisa comments that she thought, *"Table Mountain … was splitting up, exploding, doing its own thing"* (V l. 327-329) and that there was a "*total flooding of Table Mountain*" (V l. 338). Vasalisa also clearly divides spaces into those suitable for crying or showing emotion such as her own home, of which she says, *"in my own four walls I can let myself go"* (V l. 352-353). Other spaces are those which must be protected from the outside world in order for them to remain sacrosanct in the knowledge that they will provide the wellspring of memories. Since the death, at significant times, such as anniversaries, she withdraws from the world to review those memories. It is clear that creating an appropriate environment at these times is very important to her:

- "*Then I go to bed. When it was hot in summer I didn't put the electric blanket on, but now I put the electric blanket on top of me. I will drink, but I will not eat and I can do that quite happily for three days."* (V l. 494-496)
- "*My bedroom has got things as well, but far less. And it is as if I need, I don't want to see all these things … it's too busy"* (V l. 523-525)
- "*Sometimes, I take a little object away …or when I have a bunch of flowers, … I take them to the bedroom. Some kind of flower. Like the gardenias. I've got one*

> *beautiful one here, I will cut that off with me to the bedroom, and a candle*" (V l. 527-532).

In connection with his daughter's dying, Kevin understands that his daughter has gone when, *"her spirit, soul, whatever left her"* (l. 311). This is repeated as though to underscore its importance:

- *"We saw her spirit go, we saw her spirit leave her body. We believe we saw her spirit leave her body"* (K l. 210-211)
- *"The spirit leaving her body"* (K l. 508-509)

Once this has occurred it is simply, *"her body … just shutting down"* (K l. 256). "*The essence has gone. This is the rest that's just lying here shutting down"* (K l. 321-3220 and what is left is a mere *"shell"* (K l. 318). During the time when his daughter is a patient at the Hospice, Kevin's world shrinks to that within those confines, so that both he and his wife are *"just living there"* (K l. 236). Even before that when she was in ICU, *"she had her own separate little room*"(K l. 172) and hence the world appears to come there, from medical personnel to the school chaplain; *"there were a lot of people that came to see her"* (K l. 195) including her oldest friend from New Zealand. At times it appears necessary to leave the room, sometimes for a cigarette (K l. 174 and l. 223) or to go out onto the balcony, so that he can get a bird's eye view as it is a high point topographically speaking. It is interesting how metaphorical this seems to be, because this does in fact appear to be his process in dealing with the loss of his daughter, to step out of the pain and take a broader view of life, where existence can continue beyond the life of the body.

The sense of being different and foreign at the funeral is just another in a succession of experiences which gave Ella the message of being alien:

> *"Although we all are Jews, it's a different culture and … customs are so different,* (E l. 289-290)

Thus it felt like a culture shock:

> *"My son-in-law and his family, they understand English, but they don't want to talk it. …We would all go there and for ten minutes it's all [chit-chat] and then it was like we weren't there. Just sit in the corner and behave yourselves like good children. And it became an ordeal because you couldn't understand what was happening"* (E l. 276-283).

This sense of being foreign and out of place, which is something related to the physical reality, is perhaps most evident at the burial when it seems inconceivable that the shroud-wrapped body and her daughter are one and the same. Although Ella describes the grave as being *"completely different"* (E l. 302), she herself feels as though she is also completely different from her usual self and describes herself as if feeling in a trance. Hence the foreignness she experiences as being Jewish but different, mirrors her sense of being herself, but different.

Interestingly when trying to reconcile the disappointment of her son-in-law's decision not to use English in the inscription on the tombstone, she comments that she and her family,

> *"know in our heart of hearts what's there and if it's in English or in Hebrew we know what's there and what it means to us"* (E l. 314-315).

It is as if it has become clear to her that no matter what language is used, it cannot be deleted when it concerns a language written in the heart for this is where meaning resides.

6.3.9 The illness itself: Cancer

Each participant has particular conceptions of cancer which pre-date their personal encounters with the illness. Common elements referred to are its reputation which provokes dread, the metaphorical language used to describe it, and the traumatising aspect of witnessing the suffering caused by it and the treatment of it. This section explores three sub-themes in this regard. The first is the view of cancer as an illness that evokes dread because of its frequent association with death and the second the view of cancer as an illness that causes suffering. The third explores the metaphors which participants used when referring to the illness.

6.3.9.1 A dread-provoking illness

Vasalisa thinks firstly about the ubiquity of cancer, so that, *"you hear about cancer every day. Lots of people"* (V l. 8-9) are affected by it. Secondly, she understands it to be an illness which leads to death. Those people she has known who suffered from cancer, *"are dead;* (with emphasis) *they're gone"* (V l. 12). Somehow there is an unuttered belief that cancer only affects certain types of people, in this case those who are not healthy. What makes it so difficult to relate to the knowledge that her son has cancer, is that he is not like those people:

> *"Why would he have cancer? I mean, he was such a healthy* (with emphasis) *healthy, living person"* (V l. 19-20).

Part of the urgent need to see him after the diagnosis, was perhaps to verify this fact, or confirm it for herself, and she recalls how she said, with great firmness and determination:

"I said, 'I'm going down'" (V l. 21).

6.3.9.2 Treatment and suffering

In contrast to Vasalisa and Kevin, Ella initially believed her daughter's tumour to be benign. Although management of the tumour made it necessary for her daughter to take substantial quantities of medication, Ella and her family, *"were quite hopeful that this would work out"* (E l. 41). Hence for Ella, cancer is divided into two categories one of which can be lived with, and the other which is fatal. Her daughter's cancer while it was still benign can be described as a *"condition"* (E l. 54) that can be managed. On the other hand, malignant cancer can cause devastating loss and suffering:

- *"Cancer … causes so much misery and suffering"* (E l. 465-466)
- *"I've heard of people who have had brain tumours who have become vegetables"* (E l. 110-110)
- *"A friend of ours who had died from a brain tumour, and I saw how she'd deteriorated, until she was a vegetable"* (E l. 181-182).

Yet, as Ella makes clear, the distinction between benign and malignant tumours is not as clear-cut as it might seem because, as she remarks, "*with any tumour, there is always the thought that it could be malignant",* (E l. 252-253) with all that this implies. Hence, cancer, may always be viewed as a potential harbinger of death so that it is linked to thoughts that, *"this person is not going to make it"* (E l. 467).

Kevin also appears to believe that cancer can deprive the sufferer of dignity. Hence where the dying patient is able to retain some form of dignity, it can lessen the pain of the experience. For instance he describes the death of a friend, which, *"fortunately, …was also comparatively dignified"* (K l. 373). He describes the nursing of cancer patients as being, *"unpleasant sort of work"* (K l. 179) comprising *"all kinds of gory details, but,"* he hastens to add that his daughter, *" was not gory, she was very dignified throughout"* (K l. 313-314). Eventually, as life seeps away, all that remains is the, *"battle to breathe that was so sad, … undignified, and there's no quality, dignity"* (K l. 336-338). For Ella too, it appears important to her that her daughter's death not be difficult or unpleasant and hopes that her daughter, *"had quite a peaceful death"* (E l. 187) especially after, *"her body had suffered so much already"* (E l. 197).

6.3.9.3 Illness metaphors

Kevin's first encounter with the cancer is through the surgeon, who says to him, *"well, we opened her up, and I looked at the stuff and I didn't even need to send it to pathology. I just knew that's what the situation was"* (K l. 45-47). This appears to be compelling testimony for Kevin since the surgeon has, in a sense, seen the cancer face to face. Kevin's language when talking of the cancer is almost one of personifying it, almost like a wily enemy with a battle plan:

- *"It's a cunning disease"* (K l. 124)
- *"It had struck again"* (K l. 124-125)
- *"It's a cunning disease, it's an insidious disease"* (K l. 186-187).

The response to the disease is also portrayed in terms of the language of battle with terminology which is distinctly martial. The strategy for fighting the disease takes on a flavour of a battle-plan against an identified enemy:

- *"She fought"* (K l. 16)
- *"Some things that you can fight for"* (K l. 30)
- *"What's the point in trying to fight it, if it's an inevitable thing"* (K l. 43-44)
- *"I'm going to carry on fighting"* (K l. 267)
- *"It's bad, and you've got a hell of a fight on your hands"* (K l. 64)
- *"We're going to have to draw on all the reserves, that you have in order to fight this thing"* (K l. 185-186)

People who have cancer arrive at the ICU and may die from treatment, and Kevin comments that *"ICU is not the greatest of places to be and there were other people in there, one dying of cancer who reacted badly to the chemo - he, in fact, died. It's a place where people die"* (K l. 138-140). It is evident then that cancer may necessitate sometimes aggressive treatment and that it can be fatal. Kevin terms his experience of watching his daughter die an *"ordeal"*.

6.3.10 Change and transformation: the world since the loss

All participants concur that the world has changed for them, both externally and internally, in ways that can be seen by others.

6.3.10.1 A different world, a changed family

Vasalisa opens the interview with a very poignant and wistful phrase *"the lovely family I had"*, which implies how it has changed. This is confirmed when she remarks that, *"life* *changes so dramatically"* (V l. 3) as a result of the loss of her children. Later, she remarks that her *"world will never be the same"* and, *"how it changed… in so many … in so many ways"* (V l. 383-393). It is difficult for the participants to put into words how their world has changed. Vasalisa explains that, *"it's not that easy to explain really"* (V l. 387-388) and Kevin remarks that he is, *"not a hundred percent sure of what it is"* (K l. 574). Kevin believes that he has *"changed at work, [and] …at home"* (K l. 585-586) and that his "*perception of the outside world is different,"* even though, *"the outside world ain't changed"* (K l. 633-634). The change is attributed directly to the experience of losing his daughter explaining that as a result of it he *"learnt a whole lot of lessons*" (K l. 634).

For Vasalisa the change is characterised by an isolating differentiation. Initially this translated into a wish to avoid social events. The memories associated with the deceased trigger feelings of intense emotion, so that it is easier to not expose oneself in public places. For instance, Vasalisa mentions how songs can do this, or seeing people who look like the deceased, and this in particular gives her, *"an odd shock"* (V l. 578). She reflects how she is now able to venture farther than before, but some places would continue to be difficult.

The changed family profile is also a source of pain. The loss of an only son or daughter, or only child, changes the parent in a public as well as in a private way, *"I only had two sons. I still have girls"* (V l. 392). This issue is also a source of pain for Ella who recounts two occasions which sparked intense sorrow. Both occasions concerned observing a father with his daughter, which reminded her how she had been used to seeing this kind of interaction between her own husband and daughter. Such a sight will never occur again, and others cannot understand the depth of sorrow elicited by such a small, everyday event:

- "*My husband can never do that, … people will look at it from a different point of view, they won't see it with your feelings or things like that"* (E l. 400-403)
- "*That again hit home because it could have been like that once but not any more"* (E l. 408-409)

6.3.10.2 Effect on personal philosophy

Even prior to the interview, Kevin made it very clear that the loss of his daughter has changed him and his family. In the interview he reflects on this:

> *"It made me, like I said at the very beginning, we're very different people"* (K l. 530-531).

Since the death of his daughter, he has found it important and comforting to seek confirmation of his long-standing beliefs, "*that life persists and that we … are an embodiment of God*" (K l. 516-517). His daughter's death has transformed this belief into a deep conviction, and he speaks about this in a way that almost resembles a personal Credo:

> *"The thread that I've adopted …that ultimately it reinforces everything that we experienced … her dying, the spirit leaving her body, the fact that it's gone to a better place, that there's no such thing as a Hell, I don't believe that there's such a place as Hell"* (K l. 506-510).

The implications arising from these beliefs help him to see that, "*there are just certain functions that you have to perform here,*" and one of these is, *"to be very enlightened people"* (K l. 519-520). Hence it highlights the importance he places on taking a more philosophical approach to life. He describes two dimensions to the change he has experienced. The most obvious is to do with how his, *"approach to things has changed."* He believes he has become, *"a more compassionate person, a more patient person, … a more understanding person [and] more caring"* (K l. 583-590). But he believes these to be outward manifestations of an inner change, and this refers back to his personal conviction of a, "*supreme love [that] makes what we're going through here irrelevant*" (K l. 609-610). Having such beliefs helps him to, *"feel a calmness and a comfort"* (K l. 611-612). Perhaps the caring and compassion, which he terms outward manifestations of the inner transformation, are also directed towards himself. He contrasts his current decision-making style to his earlier one and sees how he can, *"make a decision (snaps fingers) like that and just believe intuitively that it is the right decision"* (K l. 618-619).

Although Vasalisa made reference to the change in the way that others saw her, Kevin places greater emphasis on how he sees others differently. He:

> *"would rather spend time talking about this, than sitting at some tea party, making social chit-chat. I ain't got time for that. I ain't got time for that. To me it doesn't achieve anything"* (K l. 547-550).

However it is probable, that seen from the perspectives of others in his social circle, he would be seen as having changed. It appears that he also selects people with whom he will share meaningful discussions and perhaps others may perceive him as isolating himself to some extent: *"I can talk to people easier if they've been through a similar situation. Unless you've been there, you don't understand … I also know that there are people that you can* *speak to that haven't been through it, who will listen, but there are others who don't want to listen and it's up to us to suss that out"* (K l. 565-570).

6.3.10.3 Searching, maybe to find

There is a strong sense of searching, though not necessarily with success. Initially there is searching for the dead child:

- *"I would look, I would actually look for him"* (V l. 396)
- *"The feeling [of] looking for [him] or his ghost or something"* (V l. 531)
- *"I saw one who looked like my … son …I look for it. I do"* (V l. 580-582)

There is also a more vague search, perhaps for a place where one can be comfortable. Vasalisa explains that there was a sense of the searching, of, *"looking for something"* (V l. 409) until eventually she, *"found it within [herself] and within [her] family"* (V l. 414).

For Kevin, there is a lesser sense of searching, and this arises out of his conviction that with, *"the spirit leaving her body, [and] the fact that it's gone to a better place"* (K l. 520). As a result of such conviction, the grief, sadness and missing is less than it might be. It seems as though the nature of the searching has changed for Vasalisa and has led her to reconsider more spiritual aspects of life even though she has frequently stated her rejection of such beliefs:

- *"I'm not a very spiritual person"* (V l. 149)
- *"I'm not very spiritual"* (V l. 576).
- *"I was upset that [the church] couldn't give me more* (V l. 407).

Yet later she comments that when she withdrawal from the world in order to reflect on her dead children, it is *"not physical. It's more spiritual, if I can use that word – I do seldom but sometimes it fits"* (V l. 541-542).

6.3.10.4 New values for life

Another area of change that Vasalisa reflects on, is that of values. It has become of paramount importance since the loss of her son to her to see that peace is maintained, especially within her family. This is understood in the context of the unpredictability and uncertainty of life:

> *"This fighting, … did they think five minutes before that they would lose that person in the family. They didn't. Or they wouldn't have the fight still"* (V l. 619-622).

Another effect of this same feeling of unpredictability is to inspire a certain urgency, so as to prevent possible future regret, and so she remarks, *"when somebody dies you sit there … saying, 'if I would have done' 'if'. They're useless. They don't mean anything. Do it now"* (V l. 623-625). The scope for reaching out is her *"surrounding world"* (V l. 612), by which she means the sphere of her family and close friends.

Kevin also reports a change in respect to values. Rather than a complete change however, there is more of an accentuation of previously held values, as though their importance is better understood. Meaningfulness is of core importance: he uses his strongest language when repudiating the facile nature of social intercourse,

> *"Don't take me to a party and talk shit, I don't want to talk shit"* (K l. 536-537).

Meaningfulness is related to the capacity to help those who participate in its evolution:

> *"If that's helping my development, and your development and helping us achieve what it is that we are hoping to achieve, then it's far more meaningful for me"* (K l. 554-556).

Helping others in altruistic fashion is also seen as fulfilling and meaningful. In the Hospice he talked to other families to, "*comfort them… it was also kind of fulfilling"* (K l. 241-243). Similarly, he has been involved at TCF and if there, "*are one or two people that it helps, then it is worthwhile"* (K l. 246). Another value which has been reinforced for him is sincerity, which once again appears to refer to the need for being real or to have meaning:

> *"I don't have time for things that I don't believe are sincere"* (K l. 544-545).

It is almost as though he measures the value of an action:

- "*What's the point"* (K l. 643)
- "*Who's gaining?'* (K l. 644)
- "*What's the point in being spiteful?"* (K l. 644-645)
- "*What is the consequence?"* (K l. 648-649)
- *"Is it going to benefit somebody else?"* (K l. 654)

This applies even to everyday irritating situations such as exchanges with errant taxi drivers, because any action is seen as part of a greater existence, to which he has a responsibility in terms of his spiritual growth and development. Kevin appears to establish the legitimacy surrounding the significance he attributes to signs as testament to a continued existence. An example of this is a situation with a non-functioning clock he inherited from his grandfather, which inexplicably began to work again at a significant moment. He also recounts a conversation about life after life which he believes was fortuitous for him:

> *"About three months before [she] was diagnosed, we were sitting with some friends, and …the conversation actually turned, to life after life, whatever. And … we started off discussing those books, and then this guy gave us these other books to read, … it was like something was preparing us"* (K l. 485-488).

Although this type of thinking was not new to him, this conversation sparked a renewed interest in the possibilities it revealed, and this was helpful for him. Another past event is also viewed as significant in preparing him for his daughter's death, and that was his involvement with a friend who reported:

> *" 'I keep on seeing my mum and dad and they're calling me', and I said, 'They're waiting to help you over - go!'"* (K l. 376-383).

Hence when his daughter reported seeing somebody it enabled him to derive enormous comfort from the belief that *"there was someone"* (K l. 403) to ease her departure from this earthly existence and so he is able to urge her to leave, saying:

> *"That person's here to help you, and you must go"* (K l. 405-406).

This enormous sense of comfort can be better understood when it is taken into account that he is aware that, *"She didn't want to die… she still had some things that she wanted to do"* (K l. 391-392). This then may counterbalance his inability to accommodate her wish for continuing life. Perhaps there is also a sense for him that she will be appropriately taken care of by a, *"presence … to help [her] on that journey"* to a place where he cannot yet follow (K l. 402). Finally, when he is taking a break on the balcony outside her room, *"the highest part anywhere around, … there were trees above … that's all, on the balcony … and this bird flutters down"* (K l. 679-681). For him it is almost as though this is a confirmation of his preference for needing to take a bird's eye view on the nature of existence and reality. Returning then to the conjectured sense of disembodiment that Kevin may have experienced, it is possible that it for Kevin it should more aptly be termed a state of being dis-spirited. The bird in some way is able to serve for him as a metaphor for the free flight of the spirit of his daughter, then lying unconscious in the final hours of her life. Thus for him, viewing life as surpassing the earthly span, and understanding that people, *"are a manifestation of God"* is a way to restore the spirit into his being (K l. 518). The value of signs subsequent to her death reinforce these beliefs as does reading into this topic, and discussing it with others, especially people who have been similarly sensitised.

For Ella it appears that, *"life is definitely not the same"* (E l. 384) and this sentiment is re-iterated word for word, *"life is definitely not the same"* (E l. 392). This is the case even though it seems difficult to truly accept that her daughter has died. The factor which has mostly contributed to this is the fact that her daughter lived in another country since her marriage. This makes the death difficult to comprehend because for many years she had been accustomed to only having periodic contact with her daughter, both in person and over the telephone. Although she is able to make theoretical sense of the loss from a spiritual perspective, *"from the physical and everyday point of view, it's hard to… accept"* (E l. 432-433).

It appears important to Ella to express her gratitude to these people who showed support at a time when she was experiencing intense isolation in her sorrow and let them know how important their contribution was:

- *"Today when I say to these friends from the Moshav, 'You actually can't believe what you did for us', they don't see it as having done something more than special for us"* (E l. 156-158)
- *"To have all these people coming who understood our culture … and their being there for us it was just so comforting. Just wonderful"* (E l. 263-365).

Ella also has a strong sense of faith and a belief of her daughter's continuation in another form of existence and this provides a form of inspiration for her which guides her own behaviour:

> *"She never spoke about other people and sometimes when I find myself doing that, I try not to do it … I often think, well, she didn't, she would just keep quiet about it, she wouldn't make an issue of it"* (E l. 453-456).

She also has a strong conviction, that her daughter wouldn't like to be forgotten. This has become a source of difficulty in the relationship with her daughter-in-law, whom she believes does not approve of such an endeavour:

> *"We often talk about her. I never feel that I can't talk about her and if it makes other people uncomfortable, well, tough on them because she was part of our lives and just because she's not here, it doesn't mean to say we don't think about her"* (E l. 369-372).

This relationship has also been strained by another change which has occurred since the death of her daughter. She finds that she has become more concerned and over-protective about her surviving children as she realises how much her own existence is entwined with theirs;

> *"You can never let go of a child no matter what their age. They're always there, part of you"* (E l. 388-389).

Acknowledging this over-protectiveness is perhaps a realisation of the fear that underlies the possibility of losing another child, something that the loss of her daughter has made to seem more real.

This section has presented an interwoven phenomenological analysis of themes of the life world of the three participants whose children have died from cancer. The following section presents a similar analysis of themes of the life world of the three participants whose children have died as a result of an AIDS-related illness.

6.4 Parental bereavement as a result of an AIDS-related illness

The adult children of the three participants Selinah, Rosemary and Lorraine, have died as a result of an AIDS-related illness which is currently a stigmatised cause of death in South Africa. A short introduction to these participants is provided as well as the researcher's impression of the participants. The transcripts for these participants is respectively, in Appendices D, E and F. The information for this section is composed from the fieldnotes of each meeting which documented elements which are not captured on the audiotape.

6.4.1 Introduction to Selinah

Selinah is a single mother of an adult daughter who died as the result of an AIDS-related illness in 2002. Selinah's only child lived in a rural area with Selinah's mother. During this time Selinah lived in Johannesburg where she has been working as the domestic worker of the same family for ten years. Selinah's parents died in the last few years, and her mother died about a year before her daughter. Selinah found the death of her parents distressing, and continues to miss them. Her daughter came to Johannesburg in order to seek treatment for an ongoing and lengthy illness, and it was here that she and her mother learnt of her condition. At the time of diagnosis, the illness was already in an advanced stage and her daughter came to stay with her in order to receive care and nursing until the day before her death, when she was taken to a Hospice. A mainstay of Selinah's life is her religion, as was also the case for her daughter while she was still alive.

6.4.2 Researcher's impression of Selinah

Selinah appeared calm and composed when I arrived, but talking about some of the events relating to her daughter's death were highly distressing for her, and consequently for me, as I felt responsible for having elicited this reaction and helpless in the face of her suffering. The pace was greatly slowed at this point and elements of the interview are inaudible as she had placed her head on her arms which were resting on the table in front of her. However, as the interview progressed she regained her composure and this continued until the end of the interview.

6.4.3 Introduction to Rosemary

Rosemary is the widowed single mother of six children. She is a seamstress and lives in modest circumstances. Her eldest son died as a result of homicide some years before her daughter contracted HIV. Since her daughter's death in 1999, she has been taking care of her daughter's son who is now 14. Her hope for him is that he might become a doctor or another professional and she has been putting money aside in order to enable him to attend university once he leaves school. Earlier this year she discovered that she is also HIV-positive which she believes she contracted in the period when she was nursing her daughter, prior to her death. Another son is also HIV-positive. Rosemary is a devout church member and attends services at her local Catholic church daily.

6.4.4 Researcher's impression of Rosemary

Rosemary was eager to see me, and began to talk about her losses immediately on meeting me. Her style was very forceful and she presented as very determined and in control of her emotions at all times during the interview. It was difficult to pose questions as she would interrupt almost as soon as I had begun talking. About half-way through the interview her pace slowed somewhat, even though she continued to return to the proselytising stance which appeared the most comfortable one for her. At all times during the interview she maintained a forceful and unemotional presence.

6.4.5 Introduction to Lorraine

Lorraine is the retired and mother of two children. Her daughter emigrated to another continent where she now lives with her husband and young children. She discovered her son had contracted HIV approximately eight years ago. He subsequently died as a result of an AIDS-related illness in 2002. Six months after his death her partner also died after suffering a heart attack and colon cancer in quick succession. Her life has changed dramatically since these deaths, and she now lives on her own in a new residence. For some months now she has been unwell, with numerous lung infections and depression. She contacted TCF for the first time in mid-2004, on recommendation from her physician.

6.4.6 Researcher's impression of Lorraine

At the time of our meeting, Lorraine was not well, having just overcome a bout of illness, something that has plagued her since the deaths of her son, two years earlier, and her partner, six months after that. She also misses her daughter very much as she is in another country, with her husband and children. She appeared quite frail, with a nervous edginess. For most of the time she spoke almost without interruption so that it was often difficult to break into the narrative. Although she spoke of her distress she did not show evidence of this during the course of the interview.

6.5 Analysis of themes of participants whose children have died as a result of AIDS

This section presents an interwoven phenomenological analysis of themes of the life world of the three participants whose children have died from AIDS, which is currently a stigmatised cause of death in South Africa. Where direct quotations are taken from the transcripts, these will be referenced by the initial of their name, followed by the line in which the quotation appears. The initials for Selinah, Rosemary and Lorraine are S, R and L respectively.

6.5.1 The chronology of the events

Many of the events that are narrated are sited in time, both as a specific time, and more generally in a way that indicates the passage of time, and how events changed with its passage. Hence the passage of time acts as a punctuation mark in a stream of events:

- *"He came home and that was at the end of 2001"* (L l. 32-34)
- *"Day and night"* (S l. 58)
- *"In '99 – I can say that this child knew from '96 and then in '98 … it was now … AIDS… I looked after her the whole '99, not the whole '99 actually… until July '99 ..and then she passed on the 11th of July"* (R l. 1-16)
- *"I don't know what is my future, I don't see my future …All this horrible stuff happens to me. Starting with losing my parents, and losing my only child"* (S l. 152-158)

- *"I didn't go to church for a year … one Sunday I just … decided to go to church and since then I've been going"* (S l. 176-186).

6.5.2 Reaction to the news

Themes of disbelief or lack of understanding, denial or the lack of it, are touched on by all participants. Denial can also be seen as a wish to not give up hope for oneself, or for one's child. Some participants hasten to assure that there was immediate acceptance which may be indicative of how this was a choice to be made. Another common aspect for participants is that of dissociation, disembodiment and dislocation.

At the outset, the constant illnesses of her daughter are a source of concern for Selinah and occupy much of her mental time as she attempts to understand their cause:

- "*I didn't think of…*" (S l. 21-23)
- *"[I] thought maybe it's just something."* (S l. 22-23)
- *"I couldn't figure out …"* (S l. 23)
- *"I couldn't understand what was wrong with her"* (S l. 26)
- *"I couldn't understand"* (S l. 39-40)

Selinah concludes the paragraph starting at line 21, with the pithy phrase, *"I don't know"* almost as though to indicate how, in retrospect, she finds it difficult to understand how it came to pass that she had not been able to deduce the cause of the illnesses. The closely repeated avowals are almost a reflection of the process that it appears she underwent at the time in her mind in trying to make sense of that which was happening, repeatedly searching for a satisfactory and reasonable explanation that could account for the events. However it seems that there was a disinclination to consider all possible reasons, and this is possibly why she was unable to formulate an answer which would bring the questioning to an end. This comes to an end once the cause of the illnesses is established as understanding finally becomes possible:

> *"I couldn't understand, until I knew what was wrong with her"* (S l. 39-40).

Even though Selinah had not been able to account for her daughter's persistent illness consciously, the implications were clear enough to arouse great anxiety:

> *"Every time she phones me she says she's sick, and it was hard. Yeah, it was very hard"* (S l. 29-30).

Initially there appear to have been cycles characterised by illness followed by a restoration to health and this seems to be reflected in Selinah as she cycles between concern and hope.

During this time she is able to manage the anxiety aroused by the concern for her daughter’s well being. She explains how:

- *“Maybe I thought she was fine now*” (S l. 38)
- *“I thought maybe it would just go away”* (S l. 21-22)

This hope is rendered vain each time her daughter’s health relapses, especially once the illness becomes chronic in nature,

- *“Then she started to get this sick, complaining, … every time”* (S l. 39)
- *“She start to complain that she always feels sick, complaining stomach, headache, stomach, every time”* (S l. 7-8).

This theme is repeated a little later as she describes how her daughter, *“was always sick”* (S l. 26-27). The use of the words ‘every time’ and ‘always’ is interesting and appears to indicate that at this stage of the illness there was no longer any respite. On each occasion when speaking to her daughter, there is none of the longed for improvement. Moreover the persistence of the illness forces itself into her consciousness to such an extent that she herself becomes ill herself thinking about it:

> *“I began to get sick myself because I was always so worried and … and I was always crying. I couldn’t do anything, I was just crying. I couldn’t talk to another person without crying”* (S l. 29-34).

As she describes it here, her anxiety and concern is all pervasive, filling her entire being, so that even in her social interactions she is unable to distance herself from the sense of doom that hangs over her.

In contrast to Selinah, Rosemary does not describe a sense of denial or disbelief on receiving the news of her daughter’s illness:

- *“The minute I get the news I accepted it there and then”* (R l. 37-38)
- *“So I accepted death, the way it comes”* (R l. 41-42)

In spite of this, it is evident that there AIDS-related symptoms were manifesting themselves, and Rosemary comments that her daughter, *“became sick: she was thin, and coughing and all that”* (R l. 6-7). However, it appears that she did not think about the possibility of AIDS. Unlike Selinah, she does not relate any concern for the illness and yet it was the severity of symptoms that spurred her daughter to disclose her status to her mother, as she required nursing. In addition, it seems that during her daughter’s illness she did try to give advice to her daughter to stop her health from deteriorating although this was spurned:

> *"I said to her, "Leave your drinking, leave your smoking." Now she stopped smoking, but she took time to stop drinking. Now that cold builds in the lungs and causes pneumonia"* (R l. 80-83).

Understanding the possible outcomes of certain behaviours increases Rosemary's sense of helplessness because even this could not avert the final outcome:

- *"If I say something, they must listen. I said, don't go that way. Please listen. Now these children don't want to listen to us"* (R l. 197-198)
- *"I told her, "You know what, you're going to die a lonely death, because I won't be there. And it happened that way. I felt very guilty"* (R l. 181-182)
- *"How could I say a thing like that, when it happened exactly as I've said it. It's not nice. It is my child. It happened the way I've told it"* (R l. 187-189)
- *"I said to him, "you know what, one day, I'll be sitting here, and they'll come and call me to come and pick up your body." And it happened that way. They called me … and I found my child. I don't like it"* (R l. 192-195)

It is possible that the acceptance that she finally displays, is a kind of resignation in the face of unstoppable events and the ineffectiveness of her attempts to forestall them. If this is the case, it represents a choice, where the only alternative is destructive self-blame, a choice she cannot afford to make when she has a grandson to raise:

> *"Then it comes into your mind to kill yourself. If you give in to it, you'll do it"* (R l. 255-256).

Lorraine also does not recount any sense of or disbelief in receiving the news that her son is HIV-positive. Rather, for Lorraine the news comes as a painful shock, so much so that she wishes to inform her daughter who is in the United States:

> *"I burst out crying and I said … we'd better phone [my daughter]"* (L l. 355-356).

Yet, even before the news of the diagnosis, Lorraine recalls how in retrospect there her son suffered a bout of coughing that was so severe that it caused her considerable distress:

> *"We were in Cologne, and he started to cough, and I thought I was going to have a heart attack"* (L l. 371-372).

Rosemary's reaction to the news is one of pain,

- *"I was hurt. But I didn't want to show her because I was going to weaken her. I just looked at the other side, and my heart was aching.'"* (R l. 9-12)

- *"I felt tears in my eyes and I didn't want her to see that I'm really hurt and I'm going to cry, so I turned my face away"* (R l. 50-51).

However, it seems to her that at this time it is important to shield her daughter from the full impact of her own pain, so that she turns away, in order to hide the inevitable tears that would betray its presence. When asked to explain about the nature of the hurt, it seems to Rosemary that, *"it's a wound that's so sore, … it's … unexplainable … it takes years to heal"* (R l. 55-58). So it can be understood that this kind of pain is so great in intensity and duration that it is beyond the power of speech to explain. For her the pain is exacerbated by the experience of loneliness, serving as a reminder of the lack of family to buffer it for her,

- *"There's nobody for me"* (R l. 96)
- *"I was very, very lonely, seeing that I've got little family"* (R l. 101).

The severity of loneliness can be surmised from the threat she made to her daughter as the ultimate sanction, to encourage a change of behaviour: *"you're going to die a lonely death"* (R l. 181). For herself too, knowing that she is alone poses a great threat to the possibility of survival, so that, having no others to turn to, she asks that, *"God give [her] the strength"* to face this adversity (R l. 11).

Selinah describes very clearly the sense of dissociation she experiences on receiving the news of the diagnosis:

> *"I don't know how to say this. At that moment I feel like I'm living in another … I am in somebody else's body or mind or something. I couldn't … ja … I, I, I couldn't feel myself, I don't know how to say it"* (S l. 43-45).

Interestingly, this excerpt is both prefaced and closed by a phrase indicating her inability to express herself in this matter. This is possibly an indication of just how alien such feelings are to her and that if they are so out-of-the-ordinary this means that others too would not understand this sense of dislocation and disembodiment. Lorraine also describes the sense of the unreality of life and of disembodiment since her son's death, and how hard it is to believe that her life has changed so much or that her son is no longer alive:

> *"Everything just seems so unreal … that I'm just going from the one day to the other, but everything … it's like I'm not in my body … everything just seems all … I still just imagine that I'm working … that I'm going to fetch him to take him out"* (L l. 534-537).

Selinah attempts to explain that it was not solely that she no longer felt herself, but also that nothing else felt as it should:

> *"So it was like it's the end of everything"* (S l. 47).

There is such implied doom or catastrophic presentiment in this awareness, that it makes this experience truly, *"horrible. It was really very, very horrible"* (S l. 49-50). A little later she repeats, *"it felt like it was the end of everything"* (S l. 66). In order to elucidate the meaning of the phrase, Selinah explains how her very being is threatened with extinction as a result of this catastrophe:

> *"Maybe … I'm going to die with her, because she was everything to me, all my hopes: she was my life" … so to find out that she's got that disease everything just cut off my life"* (S l. 67-70).

6.5.3 The illness itself: AIDS

Each of these three participants devotes considerable space to describing the horror of AIDS-related symptoms and their effect on the children. Another aspect is on the changes that the illness brings to the lives of those so afflicted. There is a traumatising aspect to the witnessing and to the sense of helplessness that it engenders. This section will explore three sub-themes that emerged. The first presents how AIDS tends to polarise experiences so that they tend to be viewed as opposites, such as being ill as opposed to being well. The second sub-theme is the impact of AIDS on the lived experience of the participants and how it has led to a changed existence. Finally, the experience of being present to the reality of the illness unfolding in one's child, is explored.

6.5.3.1 Dichotomies: Illness vs health; HIV vs AIDS

Lorraine explains that at the outset she did not know the, *"difference between being HIV positive and having AIDS"* (L l. 254-255):

> *"At that stage … I really didn't understand"* (L l. 356-357).

As it does become more clear, she is able to accustom herself to the idea, especially as her son remains relatively well, which was the case for about perhaps 6 years,:

> *"It was on my mind, but I was OK because I could see that he was … all right"* (L l. 367-368).

Having AIDS however, is very different from being HIV-positive and Lorraine makes numerous references to the horrifying nature of the illness, which eventually results in a broad range of ailments such as TB, pneumonia, abscesses in the eyes, bed sores, candida, a variety of infections, pericarditis, depression, neuropathy, wasting and debility:

> *"The suffering is absolutely horrific, horrific. Some illnesses you can control, but with AIDS it attacks every single part of your body. If you scratch yourself, it becomes a major issue. He got a bedsore… it doesn't heal, never"* (L l. 386-390).

AIDS takes away her son's ability to walk and care for himself, and he has to leave his home so that he will be nursed and cared for:

- "*Before he came to stay with me he had a flat in Killarney, a beautiful flat"* (L l. 89-90)
- "*I brought him home and he really wasn't well"* (L l. 60).
- *"This boy, he was so full of life, and vital and to look at what he turned into* (L l. 241)
- "*But he was, you know, in a lot of pain …and in hospital and out of hospital"* (L l. 6-7)
- "*He couldn't even sit still for more than 10 minutes maybe, and then he had to go and lie down"* (L l. 130-133)

To an extent Lorraine finds that there are similarities between HIV/AIDS and cancer, in the traumatising experience of watching the gruelling procedures these patients undergo and the suffering they cause, as well as the fatal outcome of both. But somehow AIDS is worse:

> *"It was just different from other illnesses. Well, God forbid, that you've got cancer, of course that's you know, something different, but ahh, this AIDS!"* (L l. 425-427).

Rosemary also begins by differentiating between HIV and AIDS commenting that being, *"HIV-positive it's not as bad as AIDS. The full-blown AIDS that's when it hurts"* because AIDS is *"bad"* (R l. 298-300). Rosemary also differentiates between a person with HIV/AIDS and one without, which, by implication defines HIV/AIDS as causing its bearer to be sullied or unclean.

> "*You can be HIV-positive, you can be clean"* (R l. 40)

Selinah describes two states of being, where one is healthy and she considers it normal, and this is in contrast to being sick:

- "*When she was not sick, when she was normal"* (S l. 3-4)
- "*She was living …a normal life until she was older"* (S l. 6-7).

Lorraine too refers to how different her son was when well, before he fell ill:

- "*Here's a picture of him … this, this is exactly how when he was well. He loved life, and he knew how to live"* (L l. 328-331)

- *"When he was well, he was the most incredible child. He had a heart of gold and … his friends idolised him. He had a sense of humour!"* (L l. 272-275).

6.5.3.2 A changed existence

Being well gives a person access to an independent and happy life, which is what Selinah considers normal. Such a world is characterised by, *"no crying, just think normally and laugh … be happy"* (S l. 134). Some similar thinking can also be found in Rosemary's interview where she remarks that, *"an ordinary person"*, is someone who does not have AIDS (R l. 299). Being ill on the other hand, initiates the person into a world which is diametrically opposed to this, one that lacks independence, requiring dependence on the care and assistance from others, even for the most basic physiological functions:

- *"They don't like to eat, they can't wash themselves, they can hardly go to the toilet, just stay in bed all the time"* (R l. 300-302).
- *"He couldn't even bath himself"* (L l. 6-7).
- *"[He] wasn't allowed to drive towards the end"* (L l. 130).
- *"He couldn't eat, and couldn't swallow"* (L l. 29-29)
- *"She used to come to the hospital and feed [him] when he was so ill … because he couldn't feed himself"* (L l. 281-283)
- *"His clothes were just falling off him"* (L l. 133)
- *"How hard it was for him to go for a walk, I mean he'd take two steps, and say, 'I have to go to go back'"* (L l. 264-266)
- *"It was an absolute ordeal for [him] to sit in the car for the journey"* (L l .422-423)

Even things of lesser importance, but which indicate the ability to enjoy life and have fun are no longer possible, so that her son is transformed from one who was the life and soul of the party to one who can no longer even participate in those activities:

> *"[He] used to love spicy foods and he couldn't tolerate it – he just couldn't. And the one New Year …they took him [to a party]. At nine o'clock I see he's back …and he says, 'I'm so tired, I just couldn't sit there any more.' This from a person that used to go to bed at three or four o'clock in the morning!"* (L l. 413-419).

With each successive bout of illness, the cycle of dependency on someone who can take care of the AIDS patient, is repeated:

- *So I looked after her … in and out of hospital, then she'd go to work, then for a week or two she'd be back in hospital. It went on and on until July '99* (R l. 12-15)

- "*Whenever she's staying by me, then she's really sick. When she gets better, she goes back to work*" (R l. 283-284)
- "*In hospital and out of hospital, and on drips and God alone knows what, and … the doctor said he'd try to set up everything at home*" (L l. 7-10)
- "*When he'd started to go down,… he was …in every hospital*" (L l. 362-363)
- "*So many things happened to him, I can't remember all of them*" (L l. 370-372).

In common with other fatal illnesses, AIDS has the capacity to deprive a person of someone who is beloved, and it is this loss which creates the pain she has experienced, because, "*if someone can't get better, then it's very sad*" (S l. 332).

During the period when Selinah was attempting to understand her daughter's illness she, "*couldn't understand, until [she] knew what was wrong with her*" and the process of identification required medical expertise (S l. 39-40). This made it necessary for her daughter to leave her home and independent existence. Selinah describes how in order to identify her illness they, "*brought her from home to here …That's when [she] found out that she's …very sick, and then she stays there*" (S l. 7-13). Thus AIDS is the "*horrible disease*" (S l. 214) that changes her daughter's life with consequent impact on her own life. Perhaps part of the reason that she did not consider AIDS as a possible cause of the illness can also be related to the newness of the disease, because as Selinah notes, she and her generation, "*didn't grow up with AIDS and stuff*" (S l. 333-334). Hence it is possible that until such time as it became personal it was very feasible not to consider it as the likely causative agent in her daughter's illness almost as though it was neither truly real nor applicable in her case.

6.5.3.3 Watching the suffering with horror

The sense of **helplessness**, and of being unable to help or ameliorate the symptoms of the disease makes it very difficult for those who are taking care of AIDS patients:

- "*[It] will make you sad seeing somebody lying there, if there is not anything the doctors can do about it, so I think it hurts*" (S l. 334-336)
- "*If someone can't get better, then it's very sad*" (S l. 332)

Rosemary also expresses similar sentiments:

- "*It hurts to see your child withering away. Looking at her every day until she becomes so small. It hurts*" (R l. 137-138)

- “*The experience that I found out from her sickness … with blown-up AIDS. You cannot touch her. Each and every place is sore. You take her into the bath. I couldn’t wash her, eina eina, everything I had to do. It’s really not easy when it comes to the last. It’s not a nice thing. It’s not a nice thing”* (R l. 262-266)
- “*There isn’t a thing that is not sore. Whatever you touch it’s eina, eina”* (R l. 272-273)
- “*The full-blown AIDS that’s when it hurts”* (R l. 298)
- “*Shrunken, full of pain”* (R. l. 312)
- “*It’s very painful, it’s very painful. And others are so thin”* (R l. 315-316)
- *“She had … bedsores”* (R l. 318)
- “*They’ve got sores all over the body*” (R l. 321)

Similarly watching the suffering of a beloved child without being able to offer lasting help is very painful for Lorraine:

- “*It was dreadful to watch him suffer the way he was suffering”* (L l. 2-3)
- “*I used to sit and watch that he couldn’t eat, it was just too terrible. And he used to gag ... but what could I do, it’s just one of those things. It can’t be helped’* (L l. 407-410)
- “*The suffering is absolutely horrific, horrific”* (L l. 386-387)
- “*He got an abscess in that eye, which had to be lanced. He never murmured! … I don’t know how I sat there”* (L l. 53-55).
- “*He really suffered, … the nerve-endings in his feet had gone and … that’s very painful”* (L l. 35-137)

For Lorraine to be aware of the extent of her son’s desperation is a further cause of anguish, as she knew, *“that he wasn’t going to get better”* (L l. 242-244):

- “*It was terrible, it was just too awful, it was heartbreaking to hear, ‘I pray so hard every night just to get better’. Awful to hear that”* (L l. 248-249).
- “*The only thing he used to say was, ‘I wish I could get better, Mom, that’s all. I pray so hard every night’. It’s very upsetting to hear that”* (L l. 55-57)
- “*[He] tried to commit suicide, twice. The first time …he went up to the ledge [of a building] …and the next time he tried to do it was he took an overdose of [a] painkiller”* (L l. 94-99)

The suffering in the terminal stage of HIV/AIDS makes it heart-rending for each of these participants to watch, irrespective of whether one is attached to the person who is undergoing this suffering, and this would be the case regardless of the illness, be it AIDS or any other:

- *"Even an ordinary person looking at that person, if you're somebody who's got feelings, you do feel sorry for them"* (R l. 298-299)
- *"[It] will make you sad seeing somebody lying there"* (S l. 334)
- *"I used to stay there maybe 10 or 15 minutes, and then I'd come home, and say, 'I can't bear to see this. I just can't'" (*L l. 446-448).

6.5.4 Disclosure

Disclosure is an issue requiring decision-making, both as regards the person who has HIV/AIDS as well as for family members to the world. For two of the participants there is some reticence in disclosing the cause of death at the beginning of the interview, and this may reflect a general habit of reticence, and of wanting to feel more certain of the reaction before such a revelation. Unlike some other illnesses, once a person is suffering from AIDS, it may be difficult to avoid disclosure as it is the illness itself that alters the appearance of the bearer, so that others will know. By the time these interviews took place, each participant had already chosen disclosure of the cause of death of their offspring so that some of the difficulties that they may have experienced in this regard are no longer an issue for them. The difficulties experienced in obtaining participants may also indicate how parents are generally loath to disclose a death from AIDS.

As far as Selinah is concerned, she believes that AIDS differs from other fatal illnesses only insofar as, *"it's a new thing"* (S l. 333). However, she refers thinking of AIDS at the time of diagnosis as, *"that disease"* (S l. 70) without identifying it. When referring to AIDS for the first time, Rosemary also struggles with it, *it was now ehm what's the name? ehm…AIDS"* (R l. 5-6). Later she refers to AIDS, calling it, *"this thing that's so incurable"* (R l. 65-66). The first time that Selinah mentions the name of the disease is in response to the question, "*What effect do you think the kind of illness has: Do you think it might be better or worse than any other kind of illness?"* (S l. 332-333).

For Selinah, it seems as though her daughter was as unaware of the possibility of HIV, so that, *"when [they] found out the doctor said it's a very, very, very late stage"* (S l. 63-64). In the case of Rosemary's daughter, however, her, *"child knew from '96 that she's HIV – but she didn't tell"* (R l. 2-3) until her symptoms made it such that she required nursing. As the illness became, *"AIDS … she became sick: she was thin, and coughing"* (R l. 6). The reason for her initial reticence was that, *"at that time it was a very big secret, she was so shy in telling people in case nobody would look at her"* (R l. 3-4). Thus it appears that the fear of social rejection was a factor in not disclosing her status. It also seems that, *"in those years, [people living with HIV/AIDS] were very secretive"* (R l. 347). Rosemary believes that the reason for this, was the beliefs that attached to the illness:

- *"They emphasised entirely on sleeping around"* (l. 351-352)
- *"If they tell, then [others will] know, I've been sleeping there, I've been sleeping there and I've been sleeping there"* (R l. 354-355)

More recently, she believes this appears to have changed, with greater emphasis placed on alternate possibilities for contracting the virus, which do not imply immoral behaviour:

"But now you get it through needles, you get it from many things" (R l. 355-356).

She believes that HIV can be contracted by mothers in caring for their offspring or by performing some humanitarian act of helping someone who has been injured. Thus a person can be at risk merely through fulfilling a maternal role or demonstrating compassion for the suffering of others:

- *"I was doing her washing, even underwear. So really, it is easy to pick it up but it didn't even cross my mind, I only told myself it's my child, I cannot turn my back away from her, who must do it if I can't as a mother"?* (R l. 30-33)
- *"This old lady … was looking after the [grand]child, the child had sores, she was washing those sores … Today she's dead. We do contract it from our children"* (R l. 338-341)
- *"If you are bleeding, I've got to help you, get a tissue and hold it"* (R l. 341-342)
- *"You jump straight in to help, not knowing that person's status, that's how this things are caused, accidents"* (R l. 358-360)

Being able to publicise those alternative means of transmission, Rosemary is able to disclose both her own HIV-positive status and the cause of death of her daughter, so that, *"now it's in the open"* (R l. 367), even though she acknowledges that, *"there are still those that are still keeping it a secret"* (R l. 370-371). Proliferating such beliefs is possibly protective in that it removes the stigma. Rosemary believes that openness has a number of advantages. Firstly, it enables those in contact with infected body fluids to protect themselves, and secondly, it means that others will be careful in not offending those who have HIV/AIDS in careless ways through lack of sensitivity:

- *"There are still those that are still keeping it a secret"* (R l. 371-372)
- *"Let it be out in the open, and then a lot of people will know how to help you, how can they approach you, what can they do when it comes to your … maybe help or something"* (R l. 378-380)

It seems to Rosemary therefore, that disclosure benefits both the person who is living with HIV/AIDS as well as those who are not. In contrast to Rosemary and Selinah, Lorraine's experience is somewhat different because she was told shortly after her son found out the diagnosis:

> *"I think I knew as soon as he found out, he came to tell me"* (L l. 382).

Even so, there was a short period where her son did not disclose the information of his diagnosis, possibly for fear of upsetting his mother, and so equivocated regarding the reason for his hospitalisation:

> *"He was scared to tell me at that stage he didn't tell me. He said the doctor told him he'd got malaria, which … but the doctor told [him that he was HIV-positive]* (L l. 373-375).

Bearing in mind how the infection was transmitted, it is also possible that her son had been aware of the possibility of HIV infection for a period of time prior to any symptoms, but may have avoided confirmation out of fear. It could be conjectured that the relatively early disclosure in his case may be attributed to a variety of factors: better information and understanding regarding the possibility of infection (especially as he was told of it); better access to medical resources as a result of better economic circumstances; and less fear of rejection. Nowhere in the interview does Lorraine make direct reference to stigmatised aspects either of his sexual orientation or to those pertaining to HIV/AIDS. With regard to his friends, she reports how:

- *"They were marvellous to him. His friends were wonderful to him"* (L l. 480)
- *"Just because he'd come out of hospital, we gave him a birthday party at home. And all his friends came, and I mean they absolutely idolised [him]. Really all his friends, he was very, very loved"* (L l. 483-485)
- *"She's a divine girl … she used to come to the hospital and feed [him] when he was so ill … like the time when he had pneumonia … because he couldn't feed himself"* (L l. 279-283).

An issue which relates to disclosure, is that of having a visible sign of the infection, as this may obviate the possibility of hiding the illness. A difficulty which Rosemary well-understands that afflicts the person who is HIV-positive, is the subjective sense that one's status is visible to the casual observer: *"You see somebody looking at you maybe for a time. It's as if that somebody sees through you what is your status"* (R l. 117-120). Although Rosemary is aware that this is not the case, saying:

> *"The thing is they don't. It's in your head. They don't see what it is …as long as you take care of yourself"* (R l. 127-128).

Without adequate self-care one's status will become more transparent, as the person develops visible eruptions and loses weight. This awareness is evident when she discusses her daughter's symptoms as compared to others who are living with AIDS:

> *"Others are so thin … Mine wasn't like that. She was all right. She wasn't thin to that extent that everybody could see and the others they do get sores, even if they're dead. Now she had nothing really, all she had was bedsores … others, they've got sores all over the body"* (R l. 317-322).

Thus the person living with AIDS may be seen as carrying the visible signs of the illness, and this may be why Rosemary has a view of HIV/AIDS as a latter-day plague:

> *"I told myself the end of the world it's near… some other times it was floods, that's not nice; fire, that's not nice; (chuckles) I think this is better. But now I think it's a [plague] really"* (R l. 325-328)

In this respect then, it may be thought that HIV/AIDS takes on a sense of Divine retribution in the same way that earlier calamities did. Hence the questioning that occurs in those affected by HIV/AIDS makes sense, as they try to understand the cause of their punishment. As Rosemary comments regarding her reaction to her own HIV-positive status, *"you keep on questioning yourself why, why me, how did it happen?"* (R l. 117).

6.5.5 Relating to the person, dying and deceased

For the adult child who has been leading an independent life, being ill with AIDS means that they become dependent once more on their parents, and this is the case for the offspring of all three participants, who move in with their parents in order to be cared for and nursed. Thus this requires adjustments in the roles of each person as they try to accommodate changed and changing circumstances with changed understanding of self. Three sub-themes are explored in this section. The first, is the experience of extreme hopelessness which is a response to the progression of the illness. The second, is a look at the experience of caretaking of the person with AIDS, and the third explores how the death occurred for the children of the participants.

6.5.5.1 Frail hope against hopelessness

Once it was established that Selinah's daughter was suffering from AIDS, and also at, *"a very, very, very late stage"* (S l. 64) of the disease meant that her daughter *"needed help"* (S l. 245) which necessitated a move to her mother's room to be there, *"day and night"* (S l. 246). Although Selinah could understand the inevitability of death, this understanding is still subject to a hopeful questioning, that Selinah knows is unrealistic. For instance, she explains how she hoped,

> *"that maybe she's gonna live maybe for me, for a long time. I don't know how, but since she was my only child"* (S l. 73-74).

It's almost as though Selinah wants to believe that by her daughter desiring it, it could be possible to stave off death even though it is an inevitable outcome in every other case. In a different vein, Lorraine expresses a not-dissimilar idea, that the terminally ill child tries to live in order not to increase the parent's sorrow. This is evident in how her son would try to accommodate her wishes with regard to looking after himself or taking medication:

> *"No matter how he felt, if I wanted him to do anything, he'd do it. He said, 'I'll do anything just as long as my mother's happy'"* (L l. 262-264).

It is also possible that Selinah's daughter's wish to be taken to Hospice was motivated by a desire to spare her mother the pain of watching her die:

> *"She asked if I could organise for Hospice to come and pick her up … and then I asked her to stay overnight, and she said, no … go back home and have a good rest. And she didn't make it through the night. I think she knew, because she said to me, 'No'"* (S l. 316-323)

This mirrors to an extent the parent's desire to fulfil the wishes of the child:

> *"When he was so ill, I coped with it, you know, it was because I wanted to make him as happy as I possibly could, to make him as comfortable as I could"* (L l. 4-6)

Yet, whatever hopes survive, they are undermined by the self-evident progressive nature of the illness, which erodes at this hope, rendering it forlorn:

- *"She was getting very thin"* (S l. 244-245)
- *"I can see all the changes"* (S l. 246)
- *"I see the changes in her body, I can see the changes, she was getting thinner, and thinner, and thinner and thinner"* (S l. 260-261)

- *"She stopped eating, stopped drinking"* (S l. 262)
- *"She was not drinking, just lying there"* (S l. 267)

These symptoms become markers for the harsh reality that, *"there's nothing more that could be done"* (S l. 262-263). This then is the demise of the last remaining shreds of hope:

- *"She can't eat anymore, she can't drink water, she just lies there, there's no hope (very faint). You know when somebody is sick and they're still eating, maybe you just hope"* (S l. 263-265*)*.
- *"You could see it was coming closer"* (S l. 258)

Lorraine makes a similar prognostication when she says they were, *"fighting a losing battle here"* (L l. 78-79). For Selinah, existence becomes a succession of terror-filled events as she lives in momentary expectation of her child's death. Even going shopping is fraught with the anxiety of what might await on her return:

- *"Sometimes when I have to go out of my room and when I have to go back, I got so scared to go into my room, I thought maybe when I get in there, I will find her lying in there"* (S l. 248-251)
- *"Living that life every day. When I have to go to the shops every day, and when I come back, and open that gate, I get so frightened, if I have to go into my room"* (S l. 252-255)

At the point where Selinah realises the inevitability of the illness' progression, her daughter begins to leave instructions to her about disposing of her personal effects and about her wishes regarding the burial. Although it can be surmised that this was intensely hard for Selinah, it also led to the realisation that her daughter, *"was not scared anymore"* (S l. 276-277) and this is experienced as a relief for Selinah for whom the constant fear was a daily 'via dolorosa'. It is at this time when it is almost as though their roles switch:

> *"She's the one who almost comfort me, instead that I am the one that has to comfort her, and then she was the one that say something to make me feel better, when she see that I'm crying"* (S l. 280-283).

6.5.5.2 Taking care of the ill

Thinking back to the time when her daughter was terminally ill and living with her, Selinah recalls that this was a very hard period in her life, so hard in fact that she remarks that:

> *"Some I can remember, some I can't because it was so hard"* (S l. 121-122).

Prior to this point, Selinah's role was very clearly the one to care both for her daughter's physical needs and emotional needs. This is described as an unrelenting and hard period in her life governed by the requirements of the sick person who can no longer be self-sufficient as regards daily care. It was also a very sad period, when it is hard for her not to cry. She would like to tell her daughter of her great love for her, yet finds it impossible almost as though the illness has taken away her power of speech:

> *"I couldn't say it, I will just think for myself. I think maybe if… I can tell her how much I love her, and whatever to tell make her feel better, but I couldn't say it"* (S l. 106-108).

She finally discovers she can sing to her daughter:

> *"I will sit there and try and sing. When I was singing to her, I never cry. I know I can sing without crying until I finish singing"* (S l. 119-121).

In this singing she transmits both her love for her daughter, and by remembering for her daughter the love that she feels for God, also reminds her of the love that God has for her, a love which had been expressed in the religious songs in the church where they had worshipped. Perhaps the motivation for this was to prepare her daughter for the journey to God, and so partially accounts for the sense of relief she felt once it seemed to her that her daughter had lost her fear of dying. This also perhaps explains why she found it difficult to tell her of her own love because that would merely serve to keep her daughter on earth where she was bound to continue suffering. Hence the singing became a way to offer her release from her earthly ties and obligations, an act that is redolent of her ultimate self-sacrifice. Yet she feels certain that although she was not able to communicate her love for her daughter in words, her daughter did know it:

> *"I knew that I loved her, and she knew that. I couldn't tell her, all I can do it there is only one thing … I can sing for her, that was what I was doing. Only just sit there and sing for her"* (S l. 110-113)

Rosemary does not elaborate at length on the relationship she had with her daughter, but it appears that at times it was strained:

> *"She was a very cheeky somebody. Whenever she's back on her feet, (laughing) then she's got some cheeky words for me"* (R l. 178-180).

Yet in the telling of this she is moved to laughter, which might indicate a lack of rancour. For all participants their inability to ease the obvious suffering is particularly awful:

- *"There isn't a thing that is not sore. Whatever you touch it's eina, eina"* (R l. 273-274)

- *"I couldn't watch. I used to stay there maybe 10 or 15 minutes, and then I'd come home, and say, I can't bear to see this. I just can't"* (L l. 446-448)
- *"It was so hard, when you've got a sick person, day and night … so I don't know how did I survive that I'm still asking myself, up until today"* (S l. 122-124).

Perhaps however the real strain of the nursing is the way in which the illness caused pain that could not be eased, whatever Rosemary did to try to nurse her, and ease her suffering:

> *"I couldn't wash her, eina eina, everything I had to do. It's really not easy when it comes to the last. It's not a nice thing. It's not a nice thing"* (R l. 265-267)

Perhaps in light of this, the forgetfulness she experienced at the time that her daughter was dying, was a necessary break from the helplessness of not being able to relieve her daughter's suffering:

> *"That Sunday, something just made me forget it. I didn't even think about her that day"* (R l. 141-143).

It is the forgetting however that has caused her such anxiety as she judges herself as having evaded her maternal duties of taking care of her child:

- *"And that's when they need their own, not a stranger. But now strangers are doing that"* (R l. 267-268)
- *"If I was turning my back away, who do I expect will come and do that for her?"* (R l. 278-279)
- *"It was my wish to be with her at the last, but she had to go to the hospital. I wanted to stand by her, up to the last"* (R l. 276-277)

Knowing she has been absent during this vitally important time, she is desperate to know about her daughter's last moments during which it appears her daughter, *"tried to run away"* (R l. 149-150). Rosemary also regrets having missed that last opportunity for communication, at a time when her daughter knew she was dying, because some people have, *"got something to say before they leave this world"* (R l. 174-175). Now, it is her son that she continues to care for, *"he was 9, now he's 14, staying with me. Her son."*

6.5.5.3 The final departure

Eventually there comes a time when it is evident that death is near, and there is an episode where it appears to those keeping vigil as though Selinah's daughter has died:

- *She was gone for a little while, maybe ten or fifteen minutes. She was just gone (S* l. 308-309)

- *We thought she was dead, and then she came back"* (S l. 312).

This is understood, especially by her daughter, as a sign of impending death and so she requests to go to Hospice where she dies during the night. Although Selinah accompanies her to the Hospice in the ambulance, it is as though the final stage must be travelled alone by her daughter. Once again there is a sense that she takes over a role of parental protector, requesting Selinah to leave almost as though if she had not done so it would have been harder for her to die:

> *"I think she knew because she said to me, no. I wanted to stay with her for the night, and she said go home and have a nice good rest"* (S l. 320-322).

Neither Selinah nor Rosemary were present when their daughters died, Selinah at her daughter's request and Rosemary because she was not seeing her daughter. The situation as regards the death of Lorraine's son is unclear because she skims over the death itself, moving from his being in a coma, to a brief, and singular mention of the funeral:

> *"He was in a coma, and they were giving him physio. I said, 'What are actually doing, what are you trying to achieve? It's awful because [my daughter] wasn't here, she'd just had a baby, so she couldn't come out for the funeral"* (L l. 452-455).

In common with the Selinah and Rosemary, Lorraine found the last days of her son's life very difficult,

> *"I keep thinking of going to the hospital, and he used to be lying on his side, and I'd kiss the back of his head, and I couldn't … I couldn't watch. I used to stay there maybe 10 or 15 minutes, and then I'd come home, and say, I can't bear to see this. I just can't. When he was in hospital and he could talk and he knew I was there, you know, I'd stay and I'd talk to him, but this, I … I could not"* (L l. 444-450).

6.5.6 Doing it their own way

When faced with such an experience as the loss of a child to such a horrific illness, each parent faces the threat of annihilation, and a fear of not being able to survive something of such magnitude. For each of them, a way needs to be found that will enable them to survive, firstly the period when their child is ill and later in extremis, and secondly, how to survive after the death of their child.

Rosemary imagines the pain as a long-lasting wound, *"a wound that's so sore … it takes you years to heal* (R l. 55-58). It is also deleterious to health because Rosemary believes that:

> *"It can kill you! It can cause a stroke or it can cause a heart attack because there's not a single day that your heart is free. You are mourning day in and day out. It's not healthy. It's very unhealthy"* (R l. 232-234).

In order to support her contention she quotes cautionary tales of others who have succumbed to the pain and how it has affected them negatively:

- "*The people are worrying a lot … and it makes them sick and sicker by the day. … if you cannot be happy you can't be healthy*" (R l. 129-132)
- "*One woman … when [her] child was buried, she was also dead … It's because she became so weak. She couldn't take it*" (R l. 203-208)
- "*If you give in to it. Sometimes you are so hurt. Then it comes into your mind to kill yourself. If you give in to it, you'll do it. Shake it man, shake it*" (R l. 255-257)

In the face of such intense suffering each participant struggles to find a way to survive the crushing pain that results from remembering. Small wonder then that Rosemary chooses not to deliberate on these thoughts and she makes several references to how she does not, "*dwell in it*" (R l. 225-228). The consequences of such thoughts can be fatal, causing illness or the desire for the obliteration of self. Rosemary has used a variety of strategies successfully in order to survive this life-threatening pain. In the first place she avoids reflecting on the events that have such personally destructive potential, through the hurt they have caused:

- "*But I don't dwell in it. I don't dwell in it. I get hurt, and in 2 or 3 days I say, if I'm going to hang my head in sorrow, how am I going to pick up myself*" (l. 227-229)
- "*Don't linger on it*" (R l. 109-110)
- "*I don't dwell on it … if it's your time to die, you die*" (R l. 38-41)
- "*There's not a single day that I think about my son having that or myself. There is not a single day. It's only when I maybe was speaking, then it comes by the way*" (R l. 113-115)

Rosemary uses this strategy for many of life's difficulties, be it on contemplating her own death, to coping with a child in jail by avoiding, *"sit[ting] and worry[ing] … every day"* (R l. 166). When her daughter was ill she also, *"never sat and … worr[ied] about her sickness"* (R l. 77-78). It is as though to dwell on it for more than a couple of days will make it harder to escape the clutches of possible paralysing despair. Although she believes it is important to do this, it is difficult, but she believes that perseverance will eventually succeed:

> *"If you keep [on], continue with it, you forget. That's how I pulled through"* (R l. 92-93).

A second strategy that Rosemary uses, is to avoid being alone particularly in the early stages of loss, and to be involved in activities especially with others:

- *"Don't be alone when it's still fresh, try to mix, keep yourself busy, meet people"* (R l. 73-74)
- *"I kept myself busy, I joined the prayer groups. I was busy"*(R l. 77).

Importantly, in a world where one has no agency or influence the course of events, accepting that which occurs, is vital and a cornerstone for survival, and both Lorraine and Rosemary make reference to this when they discuss how they were obliged to accept such difficult news:

- *"Well then I just accepted it. There's nothing I can do. I can cry, I can run away, I can hang myself, it's there"* (R l. 21-24).
- *"I had to accept it, what could I do?"* (L l. 343-344).

In any event, life itself is uncertain and even prone to ending without warning:

- *"If it's your time to die, you die. We all have to die. So I accepted death, the way it comes: you can be killed, it can be a car accident"* (R l. 41-43)
- *"So I've accepted it… there's nothing you can do. You can cry, you climb in a tree, you can do everything …We've got to accept these things"* (R l. 208-213)
- *"The minute I get the news I accepted it there and then"* (R l. 37-38)
- *"So I accepted death, the way it comes"* (R l. 41-42)
- *"Well then I just accepted it. There's nothing I can do"* (R l. 2 2-23)
- *'Once you have been tested and they gave you the positive way, accept it there and then. It's hard to accept it"* (R l. 108-109)
- *"Just try to accept it and take it as it comes"* (R l. 110-111)
- *"I accept all these things"* (R l. 227).

As Rosemary comments in line 109, her strategies for overcoming hurt and grief are not easy to carry out without Divine assistance. Thus for Rosemary, her greatest strength is to place her trust in God. Through faith it is possible to conquer the seemingly unending and life-threatening pain of loss:

- *"I overcame the hurt through prayers"* (R l. 16-17)
- *"If you give it to the Lord, and you pray over this [the wound] … eventually it comes down"* (R l. 58-60).

According to Rosemary another benefit is the strength of God as the only way to counterbalance the weakness attaching to the human condition, and withstand the tough challenges of life:

- *"My heart was aching. I said, "God give me the strength, as you did with the first one"* (R l. 11-12)
- *"The only thing that gives us strength is prayers. God gave me strength until now* (R l. 17-18)
- *"God is our strength. Without God you become so weak"* (R l. 203)
- *"We've got to … live in that Jesus faith - prayers are very strong."* (R l. 64-67)
- *"It's for you to stand firm with God by your side"* (R l. 139).

It is reassuring for Rosemary that in contrast to other aspects of life, "*God doesn't hurt you"* (l. 243) even though He has limitless strength. It is clear that such strength is related to God's omnipotence, the power to change all things even those which are beyond human agency such as HIV/AIDS:

- "*We've got to … live in that Jesus faith - prayers are very strong. Even this thing that is so uncurable if God wants to cure it, it's just a word, and then everybody's cured"* (R l. 64-67)
- "*If I can't trust God, I can trust in nobody. I just have to trust in God that He will give my doctor the strength to heal me, then I'll be healed"* (R l. 69-71).

Estelle also tries not to ponder too much on events and it would appear that her coping style in her life is to try to be positive, even to the extent of encouraging others to follow the same strategy. For instance, when her partner, *"knew he had cancer, he used to go to the computer every day and look at the all the things about cancer. And I used to say to him, 'Please don't do it, what are you torturing yourself for, just leave it, you will get better, you will see"* (L l. 314-317). Similarly with her son:

- "*He said to me, 'I wonder where I'll be this time next year?' and I said, 'They are bringing out new drugs every single day, and I'm sure they'll bring out something that'll help you, and you'll get better'"* (L l. 244-247).
- "*I used to try to be positive you know like when he was having a treatment, or in depression, then he'd say, 'Am I ever going to feel all right?' and I'd say 'The medication takes time to work, I know that it's hard, but just be patient. You'll see, one day you'll just get up and say, 'Oh I can't believe it, I feel great today'"* (L l. 298-303).

Perhaps it seemed to Lorraine that by imparting a hope for improvement, and through encouraging them to persevere, she could increase their chances for attaining a happier state, which was important because her own happiness was linked to that of her loved ones:

- *"When he was so ill, I coped with it, you know, it was because I wanted to make him as happy as I possibly could, to make him as comfortable as I could"* (L l. 4-6)
- *"He was running around… and I was happy and he was happy"* (L l. 118-120)
- *"I knew I had to be strong for him … I cried to [my husband] but I never, ever cried to [my son] because I just didn't want to upset him, and I knew I had to be strong for him"* (L l. 290-296)
- *"I did cry, but never to [my son], never to [my son]"* (L l. 298).

Finally, when her son is in a coma, and her daughter writes a moving letter to her son, she does cry:

> *"I just couldn't help crying, and it was the most beautiful letter"* (L l. 325-327).

Since the death of her son, she attempts to cope by keeping busy or distracted:

> *"I go to the gym, and I've always got something to do, I like to be home in the afternoons, because I love reading so … I always see that I've got something to read, and if there's something nice to watch on the TV, I'll watch it, and I don't mind being on my own"* (L l. 548-552).

However, even with the best of intentions, at times her strategy is invalidated by her inability to adhere to it, both because she is driven to seek out memories, and also because of external reminders. On one occasion she sought medical assistance to help her to avoid this type of thinking which is so upsetting to her:

- *"On Friday, I was devastated, because … it was his birthday, and I've [kept] all the insertions in the paper, all the cards people sent, and I said to myself, 'Don't look at it,' and I looked, and I said, 'Leave it.' No but I had to take it out, so that set me off, and then some people phoned, and it upset me terribly"* (L l. 82-86)
- *"I was under [the psychiatrist] already but I could see that I just wasn't coping … I went into … hospital and he changed all my medication … because … he said, 'I don't want you thinking about anything.' So they sedate you … to make you comfortable so that you sleep and all that sort of thing* (L l. 520-528).

6.5.7 The grief landscape

There is a relationship between internal feelings of despair, and physical health. Many of the images that the participants conjure up to convey their experience, refer to desolation, emptiness and devastation. The common expression of being sick with worry is one such case where outside events are transmuted to an internal state for Selinah. When hearing about her daughter's illness that was becoming chronic Selinah remarks that:

> *"I began to get sick myself"* (S l. 31).

The identification of the illness brings with it a sense for Selinah of feeling disembodied, of no longer being herself, so that she felt as though she was, *"living in another … in somebody else's body or mind or something"* (S l. 43-44). Her own body is emptied of that which or who she is, and seems, *"empty, [and] feeling … emptiness"* (S l. 140-141). The nature of this emptiness is almost that of an infinite void and it seems to her that, *"there is nothing that can fill that space"* (S l. 83-84). Being in such a state means that, *"day and night you're just sitting there and staring"* (S l. 58). Normal bodily functions too seem to be suspended and, *"you can't sleep, you can't eat"*, (S l. 123-124) so that Selinah still does not understand how it was possible to survive such a state.

There is also a great sense of nothingness when Lorraine makes the following comment:

> *"Then they were both gone, and I was like standing there, with nothing, with absolutely nothing"* (L l. 503-504).

She also describes how when her partner died, *"it was like jumping from the fire into the frying-pan, or vice-versa"* (L l. 180-181). The error may be appropriate because there was perhaps a sense of being consumed by the event, much as fire consumes, leaving behind charred devastation and wasted ground without any sign of life,

> *"I've never ever ever known such pain, even now. Like I mean, on Friday, I was devastated'* (L l. 81-82).

The repetition of the words, "never, ever, ever", emphasises its unchangeable quality, so that the facile specious clichés used by people to comfort her cannot even begin to impact on her belief of the permanence of this state:

> *"They say you get over it, but you don't. And sometimes it gets worse than others"* (L l. 455-456).

This innerscape of desolation and devastation mirrors the outerscape of Lorraine's current life, which was made evident to her on her return after a lengthy visit to her daughter on another continent:

> *"I came home and there was nothing. I just … I arrived home all on my own to this empty cluster house. I had to put down my bag, get dressed and go out to buy food. You know what I felt like!"* (L l. 517-520).

For Lorraine the pivotal part played by her son, whom she idolised makes her feel that it that nothing in this landscape could provide sustenance for her. She remembers her appealing to her doctor with the words:

> *"I feel as though I'm going to fall to pieces"* (L l. 517-522)

This phrase is reminiscent of one in the 1921 poem The Second Coming by W. B. Yeats, "things fall apart, the centre cannot hold". In response to this her psychiatrist decides she should be admitted into hospital where, for a while, she is nurtured and cared for:

> *"It was like a holiday. It was the best place to be …they sedate you … make you comfortable"* (L l. 525-528).

The intensity of the fear when Selinah's daughter's death was imminent seems to consume her entire being so that she is no longer in control of its basic functions. She comments that she, *"was so scared … so scared, [she] was just shaking"* (S l. 247-248). This fear also feels to her like a weighty burden, so that once her daughter has died she felt, *"like something was lifted off [her] shoulders"* (S l. 294-295). During this period time it seems as the world itself has ceased and feels, *"like it's the end of everything"* (S l. 47) and yet she feels she has been forced to *"stay behind"* (S l. 159) in this post-apocalyptic world. No wonder then it seems a punishment.

The words 'for ever' appear only three times in Selinah's transcript: the first two instances are in conjunction with the expressed apprehension for the duration of the pain of the loss. The use of 'for ever' here signifying her assertion that her daughter's presence will be henceforth always at hand by thinking of her, provides for Selinah a way to out of the difficulty posed by the possibility of an ever-present pain. Thus the 'for ever' of the pain may be counterbalanced by the 'for ever' of a continued presence of her daughter. If such pain would make continued life unbearable and intolerable, then it would necessitate the identification of some means to make it more tolerable. Certainly, for Selinah, feeling her daughter is in close proximity is what has enabled her to enjoy attending church once more and as she has asserted with unadulterated simplicity which makes the conviction of it seeming almost an act of faith:

> *"I enjoy the service"* (S l. 203).

In this sense, her ability to change the 'innerscape' enables her to cope with the 'outerscape' and this is important insofar as she has a sense of being obliged to remain within these confines. It also provides for her an answer, albeit obliquely, to the rhetorical question posed earlier in the interview, when she asked:

> *"Why do I have to go through all this horrible stuff and then stay to live"* (S l. 166-167).

If her earlier experience was of an emptiness which nothing can fill, thinking of her daughter, in the way described in the excerpt above, has the power to fill some of that void because Selinah has discovered that by turning her thoughts to her daughter, she is able to summon her presence. However, it cannot be concluded that this is a panacea because as Selinah describes it, this is not always a route to feeling happy:

> *"Sometimes I think about her … and then I laugh about it …and then sometimes I'm feeling sad and I just cry"* (S l. 359-365).

The hope that she has is that one day she will be able to think about her daughter in a way that will not evoke sorrow and, *"that maybe some day maybe [she] will just think of [her] without crying, just think about happy times"* (S l. 132-133).

6.5.8 The role of God

The participants each refer to their relationship with God in their interviews, though for each the nature of this relationship is very different. It is also different for each of them at different times with the current state showing evidence of having changed from an earlier state. This section contains four sub-themes. The changing nature of this relationship is explored as are issues regarding attempts to reconcile retribution and forgiveness, goodness in the face of death as well as those of suffering and healing. An area which all three participants spoke of is how they saw AIDS as a test imposed by God.

6.5.8.1 The changing relationship with God

Selinah describes how she initially felt angry with God:

- *"To tell you the truth, I was angry with Him*" (S 1. 72)
- *"I was angry, I was very very angry. I was very angry"* (S l. 174)
- *"I was very angry, asking myself what have I done, so bad, that God have to punish me"* (S l. 178-179)
- *"I was very angry with God at that time"* (S l. 180).

As a result of this anger she stopped attending church services for a year, until, without any discernible reason, she remembers that:

> *"One Sunday I just get up in the morning, and decided to go to church and since then I've been going to church"* (S l. 184-186).

Initially, being at Church was very hard, bringing her face to face with, *"all those memories"* which the singing and the sermon would evoke (S l. 193). She describes that first occasion as one that was painful for her:

> *"I cry and I cry almost the whole service. I couldn't hold myself"* (S l. 198).

This was so great that she, *"couldn't hear even the Bible, or the minister"* (S l. 204). However, since then she persisted and there has been an enormous change:

> *"But I think it get better, because the following week I went back to church again. So since then I've been going to church. I'm not crying any more at church. I used to cry every Sunday I used to go to church but now it's better because I'm not doing that any more"* (S l. 199-203).

She finishes this excerpt by stating with great simplicity:

> *"I listen to what they say and I enjoy the service"* (S l. 202-203).

6.5.8.2 Reconciling retribution and forgiveness

During the time when her daughter was ill, Selinah seems to have wondered whether it possible that AIDS is a kind of retribution from God. Yet, reasoning that her daughter has not deserved such retribution, causes her to wonder whether this retribution could in fact directed at herself for past misdeeds:

- *"I thought at that time that maybe God is punishing me. Yes, because that was [her] first boyfriend and her last boyfriend. Because she was a very open child. She was very open and I couldn't understand. I still don't. That's why I thought maybe it was a punishment. Maybe I did something wrong before God, so maybe He's punishing me for that, like that, so"* (S l. 234-239).
- *"What have I done, so bad, that God have to punish me in that way"* (S l. 176-177)
- *"I remember asking what have I done that God have to punish me"* (S l. 178-179).

6.5.8.3 Reconciling Divine goodness and evil death

If *"God doesn't hurt"* people, it appears difficult to understand how death and suffering can be permitted (R l. 243). Rosemary resolves this dilemma through a split whereby she suggests that, *"death really is devil's work"* and, *"evil … a lot of evil"* (R l. 245-259) especially if it results from criminal activity. Death is also evil in that it causes people to act in ways that are contrary to nature, such as a mother that can kill her child. It is therefore important that death should be resisted, especially the impulse to suicide:

> *"It comes into your mind to kill yourself. If you give in to it, you'll do it. Shake it man, shake it. The Bible tells us not to take our own life"* (R l. 255-257).

At the time that Selinah hears of the diagnosis, and the advanced stage of the illness, it seems to her that her daughter will somehow be able to circumvent death because of the special circumstances which surround Selinah's life. She has already suffered loss (that of her parents) and more importantly her daughter is her only child. However, as events progress it becomes clear that even in her case, AIDS will make no exception. Thus the period leading up to the death, and after the loss of her daughter is marked by a great sense of anger towards God. There appears to have been a wish to make sense of what was happening and to understand it, yet it all seemed to her, *"to be very confusing"* (S l. 231). Uppermost in her mind was the quandary as to God's motivation for causing her daughter to suffer from the illness. If her daughter, *"loved God [and] loved church very much"*, and also lived a moral life because, *"her first boyfriend … was the last one"*, then she surmises that it may be that God sent this as a demonstration to the world that anyone can be infected with AIDS (S l. 212-224):

> *"Maybe it's just that horrible disease will have to come to her so you can't say this one can't get this, it's too good to get that"* (S l. 214-215).

It appears almost inconceivable that her daughter could have done anything to have deserved such retribution, however she is certain that whatever wrong she committed it is not beyond God's mercy:

> *" Maybe she did wrong, I don't know, but I think probably God will forgive her, if she did wrong"* (S l. 218-219).

Not finding explanation leads Selinah to assume a measure of guilt, that it is she whom God wishes to punish because what she is experiencing watching her daughter suffering and dying feels like the most extreme form of punishment:

> *"That's why I thought at that time that maybe God is punishing me … that's why I thought maybe it was a punishment. Maybe I did something wrong before God, so maybe He's punishing me for that"* (S l. 234-239).

Yet after all this cogitation it remains incomprehensible, and it seems to Selinah that God has sent such affliction without just cause. It is this that possibly fuelled the anger that she experienced initially:

> *"I didn't go to church for a year, I was very angry, asking myself what have I done, so bad, that God have to punish me in that way…I remember asking what have I done that God have to punish me, that I have to struggle with all this bad, everybody's dying …I was very angry with God at that time"* (S l. 176-180).

Since the death of her daughter, Selinah also continues to wonder about the issue of Divine punishment:

- *"I don't know, if maybe she did wrong, I don't know, but I think probably God will forgive her, if she did wrong, I don't know. I'm not sure."* (S l. 217-219)
- *"Maybe. Maybe. I don't know. I'm not wondering too much about that because I don't understand this stuff, because N she had her first boyfriend and it was the last one. So I don't understand this stuff. You see. So that's why I say, if she did wrong, ja because I'm not sure, I don't know, you know."* (S l. 222-226)

It seems then that this is perhaps an issue that she has debated with herself, and perhaps still does deliberate on internally. She frequently refers to her uncertainty through the use of the word 'maybe' and by intimating she does not know, and is unsure. It seems to be very confusing to her and she sums it up by saying that with, *"something like this, I don't get the right answer"* (S l. 230-231). Rosemary too has given this matter some thought even though she's aware that it is of necessity speculative in nature:

> *"Let it be out in the open, and then a lot of people will know how to help you, how can they approach you, what can they do when it comes to your … maybe help or something"* (R l. 415-417)

However, it appears that she would like to hope that her daughter has been forgiven, if for nothing more than *"God's mercy"* (R l. 407):

> *"Maybe she's with God, because she did get a priest to pray for everything before she goes. They called in a priest, and then I think God forgives us. We can be all a sinner but once you turn to Him, He doesn't say wait for the years that you've been sinning, He forgives you there and then, you've only to beg, really, really meaning it. So in that hour, there's no more thinking back, if you really give yourself wholeheartedly to Jesus, he forgives you"* (R l. 407-414)

Hence Rosemary believes that it is possible that her daughter has been absolved, and in this state therefore any judgements regarding any actions or behaviour are irrelevant, and thus she concludes, "s*o she's forgiven*", and this is important as it influences the future of her daughter's soul (R l. 414).

During the time when he was very ill and suffering, Lorraine's son would pray to feel better:

> *"He used to say was, 'I wish I could get better, Mom, that's all. I pray so hard every night'"* (L l. 55-56)

In spite of this, no improvement in his health materialised. Lorraine makes no reference to how she construed this event, praying for help without any apparent response. However, it seems that for Lorraine now that there is no clarity about whether God even exists, perhaps because it seems to her inconceivable that the God she had believed in, could not have responded. Hence this puts in doubt the whole faith structure, and shows that it is based on no tangible evidence which no one on earth has access to. Consequently she wonders about the nature of an after-life:

> *"Where's he gone … How can anybody know? Nobody can know. Maybe there is such a thing as heaven, with God sitting there. But I don't know that. Maybe it's like when a dog dies, the dog's dead and where's the dog going? You know, they say your soul goes, I don't know that. I don't know enough about these things. I know you can't ask questions, because where are you going to get an answer from"* (L l. 612-618)

Finally, she concludes that she, *"can't ask why, can't ask questions"*, perhaps because there either are no answers to be received, or perhaps because the only answers that present themselves are unacceptable to her (L l. 587-588). This would be maddening indeed, and Lorraine refers to her use of medication at the time she refers to questioning which may indicate how persistent and useless this process has been, so that she prefers to lessen its impact so that she is able to cope:

> *"There's just some days when I just go absolutely hysterical – but I think also the change of the medication has helped"* (L l. 593-595).

How then to reconcile the fact that an omnipotent God has the power to bring about healing, and yet does not necessarily choose to do so? For Rosemary it appears that she achieves this reconciliation by understanding healing differently. Even when one is not cured from HIV/AIDS it is possible to attain healing in other spheres of one's life:

- *"I didn't expect I'll be healed by now, the way I was sick in November, but here am I, back again, healthy, happy"* (R l. 72-73)

- *"Even if you are so sick, once you give yourself unto the Lord, you become healed"* (R l. 156-157)
- *"People can see you are sick, but inside I can say you are free. You are free, you feel happy"* (R 1. 56-158)

The pain of loss and bereavement can similarly be healed through faith and Rosemary believes that:

> *"if you're not going to live through that wound through prayers, it takes you years to heal, but if you give it to the Lord, and you pray over this it becomes … eventually it comes down"* (R l. 57-60).

Rosemary believes that the healing that faith brings is partially dependent on that specific ability it confers to reconcile diametrically opposed characteristics such as being happy in the midst of sorrow as was evident in the penultimate extract. She sees sorrow as bringing about illness, taking up much mental energy, *"because there's not a single day that your heart is free. You are mourning day in and day out. It's not healthy. It's very unhealthy"* (R l. 232-234).

6.5.8.4 AIDS as a test

All three participants refer to the experience of losing a child to AIDS as a test imposed on them by God:

- *"So I stood up to that test up to now"* (R l. 33-34)
- *"Maybe God, he knows maybe something prepared for me maybe He's testing me with all this stuff"* (S l. 208-209)
- *"I probably said why has God done this to me, and then I think, maybe he's testing me for something"* (L l. 590-591).

Following this line of thought, Lorraine eventually comes to the conclusion that if being tested is a Divine plan to produce greater resilience and strength, then it is spurious and contemptible in light of the experiences that she has undergone, and those that she still suffers:

> *"They say you get stronger when something like this happens. You know that's just a lot of bullshit. You don't get stronger"* (L l. 591-593).

6.5.9 Powerlessness

As stated earlier, witnessing the suffering of the person who is dying from an AIDS-related illness elicits a sense of helplessness. In addition to this, a number of situations cause the various participants to feel a sense of being powerless in the face of events although for each of them the event that provokes such a reaction is different.

For Selinah the feeling of helplessness and powerlessness gives rise to a resigned sense of forced inactivity:

> *"There is nothing you can do to help that person, …Day and night you're just sitting there and staring …There is nothing you can do"* (S l. 52-59).

The malevolent intention of the person who infected Lorraine's son is one instance that provokes a sense of powerlessness for her:

- *"He was actually murdered because he met somebody and they had sex and afterwards the person told him that he was HIV-positive"* (L l. 344-345)
- *"My ex-husband said that if he ever saw him, he would kill him. I … I just … I said, 'You know P, from what you're telling me, it's like he signed your death warrant.'"* (L l. 430-432).

Selinah feels angry, wondering whether her daughter was callously used to give an object lesson, almost a pawn in a cosmic game-plan:

> *"Maybe it's just that horrible disease will have to come to her so you can't say this one can't get this, it's too good to get that"* (S l. 214-215).

A prevalent theme in Rosemary's narrative that appears and re-appears, is the sense of life as bringing unpredictable events. A person has no agency, especially the power to stop them:

- *"What can you do?"* (R l. 28)
- *"There's nothing I can do. I can cry, I can run away, I can hang myself, it's there"* (R l. 21-24)

In any event, life itself is uncertain and prone to unexpected ending:

- *"This life is very short. There's car high-jacking, there's rape, there's so lot of things that happen to people*" (R l. 399-401)
- *"If it's your time to die, you die"* (R l. 41)
- *"I don't know when, how long [my life will be] …my time only God knows it. I may think that I've still got three years, and maybe I've got three days"* (R l. 391-395)
- *"I said, "Ag, to hell with this whole thing. What can you do?"* (R l. 27-28).

Rosemary refers obliquely to receiving the news of the deaths of her son and daughter, highlighting how powerless she is to change this fact, wish it though she may:

- *"I can now get a phone call "your son is dead". I get hurt at that time and then I speak to myself, "There's nothing you can do. You can cry, you climb in a tree, you can do everything. He is gone"* (R l. 209-211)
- *"It can be tomorrow, tomorrow I can get a call, she didn't make it, she died last night. My time only God knows it"* (R l. 392-393)

Death is thus an ever-presenting reality existing as a possibility that waits to impose its grim reality on the lives of those who are at risk for death simply by virtue of mortal humanity. It could strike oneself, or one's nearest and dearest at any time and it is impossible to prevail against it. The lack of agency is made clear to Rosemary at all different aspects of life and this makes it difficult for her and other mothers in particular to keep their children safe, which produces a feeling of powerlessness in averting even those problems which they can foresee:

> *"Especially ask mothers, with our children roaming the streets … Even this thing that is so uncurable"* (R l. 64-66)

For Rosemary the lack of information regarding possible means of transmission has contributed to her becoming infected is a result of negligence by those in authority:

> *"We don't know anything. But if they have told you why, use gloves … Then you know how to prevent yourself from getting it"* (R l. 342-344).

However, even when adequate information is available, such as that regarding nutritional guidelines for health maintenance, this may become further sources of frustration if limited resources make adherence to such guideline impossible:

- *"Try to do whatever they tell you to do: eat healthy and all that. We don't all have those monies to eat what they want us to eat"* (R l. 111-113)
- *"Not taking care of yourself, and not having the necessary funds to buy what you need, and then you become weaker and weaker, by the day because there are tablets that you can get, but only when you've got money*" (R l. 308-311).

There is an unwitting cruelty that arises when one has such limited recourse and access to resources as a result of living in straitened economic circumstances in a similarly challenged community where simple survival consumes much of one's reserves. The unconscious irony when she comment on her daughter's dying days makes this even more affecting, *"now she had nothing really, all she had was bedsores. I don't know how long did she lay in the hospital, to have that. But she was cured by the time she was dying* (R l. 319-322). It is possibly for this reason that on a number of occasions Rosemary remarks on being weak:

- “*We are still weak, very weak”* (R l. 259-260)
- “*Without God you become so weak”* (R l. 203)

To escalate the situation, even in the case where medical assistance is given it appears to take away something else so that longer life is only bought at the cost of greater suffering and indignity;

- “*They can keep you to live longer. But … if these things can keep you living longer, why at the end must you suffer like that. Shrunken, full of pain … why must they suffer? If they’ve got something that can prolong their life - OK death doesn’t say your life has been prolonged - but let them die peacefully, not in pain like that”* (R l. 314-316)
- “*Others, they’ve got sores all over the body. Why must people suffer like that, what have we done?”* (R l. 322-323)

For Lorraine whose son could afford better medical care, the initial stage of the illness seemed manageable:

- “*In the beginning he was OK. He was on anti-retrovirals and all that. He used to go on holiday and he seemed to be fine”* (L l. 348-349)
- “*In the beginning, you know, I took it as a sort of another illness, but when he’d started to go down, … he was sort of in every hospital”* (L l. 361-364).

Later however, even the medical establishment and the entire pharmacopoeia available to it does not appear to have given the desired relief nor, does it seem to her, is the level of medical expertise all that competent:

- “*He got candida … It was just too dreadful and at first the stuff that he took for it, it did help [but] then he got immune to it”* (L l. 19-23)
- “*There was a drug they put him on, for that condition, which has got terrible side effects. It’s a drip but it’s awful”* (L l. 29-31)
- “*They tried to prevent the infection from going into the other eye, of course then he would have been blind, and in the end they said, ‘It’s going into the other eye’”* (L l. 57-59)
- “*He started to have blood transfusions … which didn’t make him feel better”* (L l. 350-353)
- “*The HIV doctor that was looking after him was a disgrace*” (L l. 35-36)

- *(The HIV doctor) gave a drip for an ulcer, which he never had at all …on the Tuesday he said to [my son], ‘No you can go home, you’re fine”, which he wasn’t …his behaviour was disgusting”* (L l. 43-48).

6.5.10 On being alone

Although Lorraine recounts, *“in the beginning everybody comes”*, (L l. 80) the sense of being alone after the death of her son and of her partner in short succession, made it feel for her as though it would be impossible to continue living with the degree of suffering that she experienced. The frantic and busy schedule which is governed by caring for the ill, transmutes with suddenness and finality into an empty loneliness, without purpose, which seems to have little reason for living:

- *“Even though [he] was so sick, he was with me, and [my husband] was with me, I had them both around all the time. Then they were both gone, and I was like standing there, with nothing, with absolutely nothing. And I, you know, it was just too awful”* (L l. 502-505)
- *“I wonder how I survived afterwards, because I felt so alone, because you are alone. At the end of the day you’re on your own”* (L l. 462-463).

The loneliness that Lorraine refers to, is not purely a lack of people. She claims that she does have a, *“support system in [her] brother and [nephew],* (L l. 646-647). She also has, *“one friend … that was [her son’s] friend, and … an Italian friend”* (L l. 490-493). There is a sense of disappointment for Lorraine in that these people are not able to give her what she needs, and however much she understands how difficult it is for them to fulfil her expectations, the disappointment remains:

> *“I’ve got a support system … but … it’s not emotional enough for me because if I give I want to give with everything that I’ve got and well. I don’t blame them for it. You know everyone reacts differently to everything, everyone’s different. But you do expect certain things from certain people. You do”* (L l. 644-651).

Her daughter, who perhaps would give her the sort of support she seeks is far away and Lorraine says with remarkable simplicity, *“I miss [her] you know”* (L l. 646). However, her domestic worker goes far beyond the bounds of duty and, *“is just absolutely incredible... I was sick the one time and she heard me coughing, and she came to see if I was all right*” (L l. 469-474). In spite of this, part of the loneliness arises from the fact that there is no one in her immediate circle who can share in the experience she has been through because:

"They have never in their wildest dreams know what a mother feels when they've lost a child. There is … nobody can understand it" (L l. 657-659).

If people who knew her son cannot support her, new people, who have not known, nor ever will know him, will perhaps not be able to do so either, and perhaps this is why she does not feel ready to seek new friendships yet. Hence it is less a lack of available people, but rather the lack of understanding that causes her to feel that she is alone in a world full of people. So severe was the effect of this, that she describes it as a sense of threatened disintegration of her being, so that she requested assistance from her psychiatrist, by explaining to him:

"I'm just not coping. I feel as though I'm going to fall to pieces." (L l. 523-524).

Lorraine feels this being alone most on weekends and when she is ill:

- *"I was sick on Sunday, but I just forced myself to get up and I had a cup of tea or something, I had to get up and do it on my own and that's when it hits you"* (L l. 581-583).
- *"You know what it's like to lie here and get sick on your own? And on Sunday … I couldn't have spoken to anyone, but …what will happen if I faint, what will happen - I could have a heart attack, and I'm just here all on my own"* (L l. 464-469).
- *"I got so sick, and I came home and I actually couldn't believe it. My house was empty"* (L l. 512-513)
- *"I came home and there was nothing"* (L l. 517).

The sense of being alone and unsupported means that for Rosemary there is no buffer to shield her and lend her the strength to cope with the constant challenges that life throws at her:

- *"There's nobody for me except God. You can have families and everything; what they do is say "shame, shame". It doesn't help us"* (R l. 96-98)
- *"I'm alone, I'm on my own, I must stand up and see my face"* (R l. 229-230)
- *"I was very, very lonely, seeing that I've got little family. It's only myself and my children, and my Church – those I know at church like priests. When it comes to family, I don't have family"* (R l. 101-103)

Being unsupported by other people puts her at particular risk for intrusive thoughts about her children who have died, or about other misfortunes that she has suffered:

"When you're alone and then you find yourself thinking about them" (R l. 19-20).

6.5.11 The pain of the loss

The pain of the loss is referred to on various occasions, and although it is not described, the magnitude of it needs to be inferred by the enormity of the occasion which prompts it. Other ways to infer its magnitude are from repeating the fact of it, or from the effects that it has on the life of the person.

In attempting to explain how much her daughter meant to her, Selinah makes clear how her very existence is bound up with her daughter's:

> *"I never had other children, so that's why I say, she was my life*" (S l. 77-78).

She speaks very lyrically in order to convey how for her, her daughter represented both the beginning and the end, in fact everything because,

> *"She was my only child, she was my firstborn and my lastborn"* (S l. 76).

As a result of her daughter representing so much for her, Selinah explains how this impacted on her life on a moment-to-moment basis:

> *"Everything I do, I do for her, everything I think, I think for her, so maybe it was that. She was my life"* (S l. 77-79).

Since the death of her daughter, Selinah wonders how she will be able to sustain a loss of such magnitude, because if her daughter comprised such an enormous part of her, her loss similarly deprives her of a part of herself:

> *"So I didn't know if I will make it without her, how my life is going to be without her, … (pause) (inaudible) my life feels empty …I can say that it's … it's empty … I can feel that something is missing, … and … there is nothing that can fill that space, it's empty right now"* (S l. 80-84).

In this excerpt Selinah uses the word 'empty' three times. She also uses it a little later when she remarks,

> *"I'm feeling empty, I'm feeling this emptiness"* (S l. 140-141).

The use of the word empty appears to convey a sense of the hollowness of her life and how it is now an unfilled vessel, disembowelled and eviscerated, and as she remarks, *"everything just cut off my life"* (S l. 70). It is almost as though she is questioning whether it is possible for life to hold any meaning now, in contrast to the meaning it held before her daughter's death. This is so devastating that to dwell in this state is unbearable:

> *"I'm still getting so sad sometimes, when I'm just sitting alone and thinking about her, I can't take it"* (S l. 88-89).

The part immediately following this in the interview is inaudible because she became very distressed at this point. It was evident that she did enter this state at just this time, and even just to witness such depth of sorrow was highly distressing. No wonder then that Selinah says:

- *"Maybe I'm just going … I'm going to die with her"* (S l. 67).
- *"So I didn't know if I will make it without her, how my life is going to be without her"* (S l. 80-81)
- *"I think I will just die after she die because I think maybe, in my mind, that I'm not going to make it"* (S l. 127-128)
- *"I just know I'm still here … but I don't see what I live for"* (S l. 151-152)
- *"I don't know what is my future, I don't see my future"* (S l. 152-153)
- *"Why do I have to go through all this horrible stuff and then stay to live"* (S l. 166-167)
- *"Everything … I loved, it's gone … and then I'm living for what? I don't know"* (S l. 150-151)
- *"So I don't know how did I survive that I'm still asking myself, up until today"* (S l. 123-124).

Lorraine echoes some of the sentiments expressed by Selinah, in particular the penultimate and last excerpts above which are uncannily alike the two which follow:

- *"You've just got to try, but then I say to myself, what have I got to try for, for what, for who, what am I trying for? [My daughter]'s not here. Can't ask why, can't ask questions"* (L l. 585-588)
- *"I wonder how I survived afterwards, because I felt so alone, because you are alone"* (L l. 463-464).

In her interview Lorraine also refers to the centrality of her son in her life and says, *"I idolised him, I absolutely idolised him"* (L l. 272) and how, *"he really was, he was a very very special son"* (L l. 286). The intensity of the pain she experienced at his dying, cannot be compared to any other she has ever known and she remarks that she has, *"never ever ever known such pain"* (L l. 81). Since losing him, memories trigger an awful sense of engulfment no matter what one is doing at the time:

> *"It's the most awful, awful feeling. Like if I start thinking about certain things"* (L l. 87-89).

As Lorraine has remarked in this last excerpt, remembering can be intensely painful, so that not remembering may offer some protection from this pain appears to threaten survival. However, it may also reflect something of the unrelieved sameness of that period where personal interests and needs come second to those of the patient, because as Selinah remarks, *"when you've got a sick person, day and night, you can't sleep, you can't eat"* (S l. 122-123). It seems as though life itself becomes dissociated from its normal course, narrowed down to a repetition of basic essential tasks, bounded by the confines of the sick-room. Lorraine also describes how life becomes limited to the needs of the person who is terminally ill:

> *"When [my son] was so sick…I was with [him] all the time. I never even had time to be friends with anyone … I just never had time, because whatever time I had I'd go to [him] …It was nothing to even think about"* (L l. 488-498).

Even when she was not physically with him, her thoughts would be with him:

> *"I would never leave him … even if I had staff. If I did go, [my husband] and I would go to an early show, and then come back. I wouldn't go for dinner afterwards. In the mornings I tried to take him out, to take him for coffee, whatever, and I didn't leave him. In the afternoons I had to go to work, I used to phone him to say hello, I used to ask him, 'what are you doing?' and I just wouldn't leave him"* (L l. 266-267).

Death represents for Selinah the last refuge she can seek to leave this anguish which cannot be borne. The use of the word 'make' is interesting when Selinah says, *"I didn't know if I will make it"* (S l. 80) and *"I think maybe… I'm not going to make it"* (S l. 126-127). Although she applies it in the sense of survival, it also has alternative meanings or connotations: to create, build, construct, craft and formulate. Thus it seems that for Selinah life does not happen to one, so much as it is created on a moment-to-moment basis in the actual living of it.

Rosemary often refers to the pain which she is subjected to as causing her hurt, in fact she uses the word hurt or hurts in relationship to herself 12 times:
I was hurt (l. 9); *I'm really hurt and I'm going to cry* (l. 51); *you are hurt inside* (l. 117); *it hurts to see your child withering away* (l. 137-138); *it hurts* (l. 138); *it hurt* (l. 171); *I get hurt* (l. 209); *I do get hurt* (l. 227); *I get hurt* (l. 228); *sometimes you are so hurt* (l. 255); *that's when it hurts* (l. 299-300); *it hurts you* (l. 375). Although there is little variation or detail in the description of the hurt, the frequency of its expression makes the message difficult to

miss. It is also possible to understand the depth of the pain of loss by its surmised or potential effects. Being hurt, is accompanied by more rumination which is also painful and it appears that this is more severe in the initial period following on the loss: *"when you're alone … you find yourself thinking about them, but it's not like when … those years when it was still fresh"* (R l. 18-20). Such contemplation is so painful that, *"each and every three or five minutes you cry"* (R l. 129). Questioning is also a painful component of the grief: *"because you are hurt inside. You keep on questioning yourself why, why me, how did it happen?"* (R l. 117-118) and, *"you question yourself"* (R l. 148). Where one is powerless to alter the course of events, then worrying about possible outcomes is pointless and worse, it could be injurious to one's well-being, threatening one's continued existence, *"if we are going to worry ourselves day and night … you are going to die"* (R l. 42-45). One strategy for dealing with such powerlessness over events is magical thinking, replaying what has happened in different scenarios, and for Rosemary this time was characterised by, *"keeping on telling [her]self 'if only'"* (R l. 172-173). An example of this is wishing she had been present when her daughter died: *"if I knew and I was here I would have kept her there, kept her there, to pray"* (R l. 150-151). It feels to Rosemary that 'if only' she had heard her daughter's last words then she could have been comforted, yet this option is not available to her since her daughter is no longer alive. Finally, a component of grief that adds to the hurt and pain is a sense of guilt:

> *"I had that sense of guilt"* (R l. 178)

This sense of guilt arose both from that which she had done and that which she had failed to do:

- *"I told her, "You know what, you're going to die a lonely death, because I won't be there. And it happened that way. I felt very guilty*" (R l. 181-182)
- *"I say, "jinna, how could I say a thing like that, when it happened exactly as I've said it. It's not nice. It is my child. It happened the way I've told it"* (R l. 187-188)
- *"I said to him, "you know what, one day, I'll be sitting here, and they'll come and call me to come and pick up your body." And it happened that way … I don't like it"* (R l. 192-195).
- *"The Thursday when they started phoning me my phone was off …I felt very guilty"* (R l. 183-188)
- *"The week that she passed away … that Sunday, something just made me forget it. I didn't even think about her that day"* (R 1. 40-142)

- *"By the time I come there, she'd just passed away"* (R l. 146)
- *"I didn't even go, I didn't go"* (R l. 288-289) (to the hospital when her daughter was dying.

Adding to the sense of guilt is a regret that she was not able, through her own decision, to minister to her daughter in the last moments of her life, which she sees is the job for a mother to do rather than stranger, well-meaning though they may be. In this it is possible that there is a sense of failure as a mother, coupled with self-condemnation: *"It was my wish to be with her at the last, but she had to go to the hospital. I wanted to stand by her, up to the last, really that was my wish. If I was turning my back away, who do I expect will come and do that for her?"* (R l. 276-279). It appears that she wishes to forget about her true motivation, which she now judges to be unworthy, because she initially attributes her absence to unfortunate circumstance. Shortly thereafter she takes responsibility for it, castigating herself, *"no man, stop lying"* (R l. 288) blaming her anger instead: *"I was cross with her and … I didn't even go, I didn't go, to be honest"* (R l. 288-290).

6.5.12 Rites and rituals

There does not appear to be much discussion in the interviews as regards rites and rituals. For one participant disagreement around the burial, has given rise to dissension in the family, and for another, this focus was more on the business of the arrangements pertaining to it. This lack of focus on funerary rites in part may reflect a numb exhaustion which was the prevailing experience once the suffering of the now deceased is finally at an end.

The important issue for Selinah as regards funerary rituals is that if possible these should have accommodated her daughter's last wishes. Some of those wishes she has been able to fulfil and these relate to the disposal of her daughter's personal belongings in a way which is contrary to cultural norms:

> *"She said to me, 'don't give anybody my clothes. Those you don't want, you must just burn them,' that's what she told me. She said I must burn them"* (S l. 273-275).

Her daughter also expressed a wish to be buried at home:

> *"She asked me if I will have enough money to take her body home"* (S l. 275-276).

However, Selinah was not able to fulfil her daughter's wishes in this respect, as a result of economic constraints, and subsequent to the interview explained how this has become a source of conflict within her extended family as such a burial is important as regards cultural norms. For Rosemary much of that which needed to be done at the time of death, appears to have been business related, the closing off of accounts, dealing with the mortuary and funeral home. She closes off that paragraph by stating:

> *"I do get hurt, like anybody. But I don't dwell in it. I don't dwell in it. I get hurt, and in 2 or 3 days I say, if I'm going to hang my head in sorrow, how am I going to pick up myself. I'm alone, I'm on my own, I must stand up and see my face"* (R l. 227-230).

Thus it may be that by avoiding reflection on the more personal experience of the funeral procedures is a way to cope with the pain of the loss and survive. Although Rosemary does not discuss in any detail the funereal procedures, she does place great emphasis on the fact that her daughter did receive the last rites while in hospital. It is this which enables her to hope for eternal redemption for her children who have died:

> *"I think God forgives us. We can be all a sinner but once you turn to Him, He doesn't say wait for the years that you've been sinning, He forgives you there and then, you've only to beg, really, really meaning it"* (R l. 409-412).

Perhaps her devotion and acceptance are ways for her to demonstrate the sincerity of her belief. The possibility of God's mercy and of absolution appears an important component which helps Rosemary diminish the sense of guilt and self-blame, particularly with regard to her absence at the time of her daughter's death:

- *"I even had to come and confess because I so much wanted to be there but unfortunately I couldn't be there. I even confessed"* (R l. 171-172)
- *"After confessing it … after a while it went away"* (R l. 175-176)

God's mercy and absolution also facilitates the hope that her daughter will not be judged harshly by God, especially as Rosemary believes that the hospital, *"called in a priest"* (R l. 408-409) to administer the last rites to her daughter.

Lorraine also does not discuss the funeral although she does remark that:

> *"It was awful because [my daughter] wasn't here, she'd just had a baby, so she couldn't come out for the funeral, it was … they say you get over it, but you don't. And sometimes it gets worse than others"* (L l. 453-456).

As has occurred on other occasions, she does not find the right words to fully describe the awfulness of it and the anticipated lack of cessation of her pain. The only relief to be found in the experience may be in the shadings of it, where some days will be more or less awful than others.

6.5.13 Change and transformation: the world since the loss

That the world is a very different place since the death of their children is expressed variously by all participants. Such change requires significant accommodation of sufficient magnitude so as to permeate to the very core of their being. Perhaps such enormity of change is never fully wrought, but remains in the process of attainment, which is done more or less successfully at different times. A number of sub-themes were identified and are expanded on in this section. Hope in a better future appears an important component that enables participants to continue with their lives in face of pain which is sometimes intolerable. Such hope may also arise from a conviction that the relationship with their deceased child may be able to continue, although much altered. Finding ways to counter feelings of vulnerability and powerlessness in the face of an uncaring universe, that can foist suffering on one with no warning appears an important component in learning to negotiate the world again. Finally, things to be grateful for also represents a choice in striving for a life which is less painful.

6.5.13.1 Hoping for a restoration of hope for living

Selinah reports her daughter's death very simply with the words, *"that night she died"* but the simplicity does not in any way imply that it is not significant (S l. 325). It is an event that will henceforth become a part of her, almost etched into her, regardless of volition:

> *"I don't know. I don't think it's something you can forget. I don't know, maybe I'm wrong, but I don't think it's something you can just forget"* (S l. 325-327).

It could be construed then that part of her dilemma since her daughter's death is that it appears an insoluble conundrum to her how she will be able to craft her life henceforth, from day to day, without the foundation stone that her daughter provided in terms of life's meaning. At present, however, how this situation will resolve itself is unclear to Selinah:

- *"Maybe I'm going to feel this way for ever, or maybe it will get better and better, I don't know"* (S l. 86-87).
- *"So I don't know how, with pain like that how long does it take to end. Or maybe it's for ever, I'm not sure"* (S l. 128-130).
- *"I don't know what is my future, I don't see my future"* (S l. 152-153).

She reflects that she continues to have hope for a cessation of pain so that it will not be the 'for ever' that she refers (S l. 86 and l. 130). This is perhaps the only thing that enables her to continue:

> *"Sometimes I have that hope that maybe some day maybe I will just think of [her] without crying, just think about happy times, and then no crying, just think normally and laugh about it be happy, maybe, I don't know, I'm not sure*" (S l. 132-135).

This hope which appears is almost forlorn and has a now-you-see-it-now-you-don't character:

> *"Maybe I do have hope for tomorrow, sometimes I don't"* (S l. 141-142).

Lorraine also expresses a hope for the future, and this is expressed as a supplication to God:

> *"When I get into bed at night, I just pray just to be well and healthy, just to ask for a little bit of inner peace just to be happy"* (L l. 618-620).

This is in spite of what she said earlier,

> *"Maybe there is such a thing as heaven, with God sitting there, you know. But I don't know that"* (L l. 613-614).

Perhaps she is motivated by a desire to believe that there is a God who will somehow be able to ease her way, or may there is a fear that if there is a God it is best to appease Him, so as to ward off further misfortune.

Initially Selinah was very angry and ceased attending church for a year. However, this anger has now changed and she no longer feels this way:

- *"Maybe God, He knows maybe something prepared for me … now I'm not angry at God anymore"* (S l. 208-210).
- *"I think maybe He has a reason why he make me stay behind…maybe, I thought sometimes, maybe God does have a reason to make me stay behind, so He's the only one who knows why. I don't because I don't see it"* (S l. 156-160).

Being able to believe that even her suffering can be a part of God's plan, even though it remains beyond her understanding, has been helpful and it has enabled her to return to regular worship at church. This is something which she is able to enjoy, even though life remains barren of those things that bring her joy:

> *"Life right now is not that nice or happy …because everything I … loved, it's gone"* (S l. 146-150).

It seems that the element that differentiates this time from the time immediately following on the loss, is that there is a hope that she will feel better in the future even though the present remains bleak for much of the time:

- *"Sometimes I have that hope that maybe some day maybe I will just think of N without crying, just think about happy times, and then no crying, just think normally and laugh about it be happy"* (S l. 132-134).
- *"I think that I am still feeling the same. I'm feeling empty, I'm feeling this emptiness … maybe I do have hope for tomorrow, sometimes I don't"* (S l. 140-142).

Even hope seems to flicker in and out of existence, and perhaps it would be more accurate to say that she hopes that there may be a more consistent hope in the future. When she is able to connect with the sense of hope she is able to think differently about the future:

> *"I think it will go easier and easier, but how, and when and how long it's going to take, that's the thing I don't know but I believe it will go away*" (S l. 343-344).

6.5.13.2 Forging a new relationship with the deceased

The factor which appears to be at the basis of nascent hope for participants, is the belief that their deceased children will always be accessible in thought and in mind. Since the death of her daughter, it seems to Selinah that her daughter is still a part of her, accessible to her in her mind, by thinking about her. This is quite a contrast to the experience at the time of diagnosis when she felt her mind was in somebody else's body. It is also in contrast to the emptiness experienced then as her previously emptied self is filled with the memories her daughter's being:

> *"No matter she's gone she will be a part of my life for ever because she won't … nothing will just wipe her out of my mind. So she will be still there … thinking about her that's how she become a part of my life every time … the time I'm thinking about her then she's there"* (S l. 348-353).

Although for now this is something of a mixed blessing, the hope that she expressed regarding her desire to be able to think of her daughter without sadness appears a strong motivating factor:

> *"Sometimes … I think about her …and then I laugh about it sometimes. It makes me feel happy. Sometimes I will just laugh at myself and laugh harder, sometimes you know, like she's here, ja. Talking to her, remembering what she's saying that time to me or doing something funny and then we laugh about it. Ja, sometimes it go like that and then sometimes then I'm feeling sad and I just cry"* (S l. 358-365).

Lorraine also refers to such imaginary encounters, almost a type of magical thinking, where her son is still alive and where together they relive some beautiful moments which they have shared in the past:

- "*I still just imagine that I'm working … that I'm going to fetch him to take him out. Sometimes I'd make arrangements to meet him and he'd come with a gift for me, but not just anything*" (L l. 536-539).
- "*[My son] always was always interested in how I looked. You know if I buy something, I say to myself, I wonder if [he] would like this, I wonder if he'd like the way I've done the flat*" (L l. 456-459).

6.5.13.3 Existential fear arising from vulnerability and impotence

Knowing how life can change, with horrific consequences, provokes in Lorraine a sense of anxiety and an existential insecurity also for her own well-being which manifests in her anxiety about her illnesses and her being alone, and this is felt most acutely on weekends:

- "*I get very nervous, you know, that maybe I won't get to [my brother], or that I won't see [my daughter] again*" (*L* 545-547)
- "*I hate the weekends; I hate the weekends… during the week … I've always got something to do … and I don't mind being on my own … but the weekends are horrible, absolutely horrible*" (L l. 547-553).

Since the death of her son Lorraine has been ill with numerous lung infections:

> *"I'm very worried about my lungs at the moment. I really am because I keep thinking, 'Is it getting worse, is it getting worse?' because every single month … I've been on an antibiotic"* (L l. 574-577).

Being ill, somehow causes her to identify with her son's suffering, almost as though she can now understand it more clearly:

> *I used, for [my son], just to say, 'Just feel better.' I mean, when I was sick on the weekend, I always think, if I feel like that, how on God's earth, did [he] manage? How!* (L l. 440-442).

Faith in God helps to bring a sense of control into a life which appears essentially not open to Rosemary's control, including one's own mortality:

- "*You are prepared for anything that can happen to you then, and that's how we've got to leave this world*" (R l. 158-159)
- "*There's so lot of things that happen to people so really we must just live for God*" (R l. 399-401)

- *"It's there, it's there. Nobody can change it, nobody can take it away, except God"* (R l. 79-80)
- *"My time only God knows it"* (R l. 394)
- *"There's so lot of things that happen to people so really we must just live for God"* (R l. 401-402)

The briefness of life and the certainty of its ending coupled with lack of knowledge of the timing of its end makes it imperative for her to *"be happy in those few days"* (R l. 392) and, *"forget about things of this world"* (R l. 402) before death comes. She makes clear that her way of coping has been something which she has chosen in order to survive both the loss of her children and her own illness:

- *"It is a choice. Give it to Jesus"* (R l. 236)
- *"So live in that positive way, then you can survive"* (R l. 45-46).

Making such a choice is a decision which does make it possible to live in spite of all that has occurred, and it is possibly for this reason that she believes that: *"to me it's been hard and it's easy"* (R l. 36) even though as she averred, *"it's been a hard road"* (R l. 36). Another important aspect for Rosemary is to turn her focus on others, partly in order to forget and not ponder on the tragic events in her life, but also in an altruistic sense to help others: *"that little time you've got, make something of it. Help somebody if you can, whatever you can do with it"* (R l. 423-424). In this it is possible for her to *"make [her]self happy"* (R l. 419).

6.5.13.4 Being thankful for small mercies

For Rosemary much of the focus of life now is on acceptance of the reality of death. Understanding that it is possible for it to occur at any moment makes it easier to accept the transience of those things that attach to human life, so that, *"when that blow comes … it doesn't hurt as that person that doesn't really, really know that this thing can happen"* (R l. 397-399). Thus it becomes necessary to, *"forget about things of this world, spend [time] with your God"* (R l. 402-403). A further consequence of such an understanding necessitates a certain gratitude for any blessings of life, thus thanking God,

- *"Make a break and say thank you God"* (R l. 404)
- *"Say thank you God, I've seen the day; Thank you God I've got a piece of bread, thank you"* (R l. 88-89).

Having known such significant loss, Rosemary finds it easy to be grateful for small things and also to not become upset with certain life events, so that there is a new kind of perspective for that which is and which is not important. For instance Rosemary suggests:

> "*My child can go to jail, once the sentence is finished …I forgot. I'm not going to sit and worry about him every day. He wanted that life, he's got it. All I know is, he's alive, and that's it … That's how I take life* " (R l. 165-167).

If the world for the parent who has lost a child is divided by this event into the world before and the world after, the world of acquaintances is also divided into two for Lorraine, those who knew her son, such as those friends of his that "idolised him" and those who never did know him, such as her domestic worker of whom she remarks, *"she didn't know [him]*" (L l .469-474). Lorraine also expresses a thankfulness for the unexpected kindness and compassion of people, especially those who have no obligation to help her, such as her domestic worker who spent some nights with her when she moved home, and a neighbour, who took her to hospital when she returned to an empty flat and felt so unutterably alone:

> *"My neighbour, she took me into hospital, they have been to me unbelievable. I've never met people like that"* (L l. 530-531).

Being happy becomes a central tenet in the ability to maintain one's health and Rosemary remarks that *"if you cannot be happy you can't be healthy"* (R l. 131-134). The success of this outlook could be evaluated in the way faith helped her after her son's death;

> *"I had to go and pick up his body … and bury him. But through prayers, really I went through it …I think people thought, but this woman it's happiness"* (R l. 200-203).

Faith has also enabled her to overcome the tension which results when a person with HIV is not able to comply with medically-prescribed guidelines for maintaining health, thereby achieving the calm she believes is necessary for health:

> *"We don't all have those monies to eat what they want us to eat, but try just to … calm, stay calm"* (R l. 112-113)

A further difficulty that Rosemary has overcome through faith is the sense of being alone and unsupported because God is a constant presence and accessible through prayer at any time. Providing that her thoughts are focussed on God, God is available to bring comfort and succour to any difficulty or problem of life that she brings to Him:

- *"There's nobody for me except God. You can have families and everything; what they do is say "shame, shame". It doesn't help us. Let us pray, let us pray for this problem, ask God to take you through this, and He'll take you through"* (R l. 96-99)
- *"The main important thing in the life of today is God. Take God in your life, let Him be your sleeping, your waking up. When you wake up… Just say thank you God, I've seen the day; Thank you God I've got a piece of bread; thank you – things like that, as we are now speaking now. You can just sit on yourself and speak to Him. Speak to Him and say, "It's like this, it's like this. Please God help me through this. I've got a problem like this and this. Help me through it. It doesn't go the same day, but if you keep, continue with it you forget. That's how I pulled through"* (R l. 84-93)
- *"Give it to Jesus … Each and every step you make, He's there with you. Don't wait to go into church, or go into your room. He's sitting here with you, he's sitting right here"* (R l. 236-238)

6.5.14 Relating to others

Lorraine has come to the conclusion that however concerned people are at the outset, later this changes, perhaps once people, *"think they've done their share"* (L l. 560):

- *"I've got a nephew that was absolutely incredible to [my son] … and then in the beginning … he used to phone me every day, 'We'll look after you', but now it's a different story. A different story"* (L l. 554-558)
- *"She often says, 'I'll speak to you and make arrangements,' but she doesn't phone. In the end you feel that, you know, 'I'm not going to phone either.'"* (L l. 568-570)

Her evident distress and continuing sorrow, means that others are driven to give her advice which is impossible for her to follow given the experience she is in:

> *"I was talking to him on the phone and I was crying, and he said, 'You know, you must try and pull yourself together'. I said, 'Don't tell me that, you get inside my body and tell me if you can pull yourself together!' And I said, 'I'm going, and I'll speak to you tomorrow.' Because, really, that's just the worst thing you can say, take control, or … they've got no right to do that because they have never in their wildest dreams know what a mother feels when they've lost a child. There is … nobody can understand it"* (L l. 652-659).

There are attempts by people to comfort her, *"they say you get over it, but you don't. And sometimes it gets worse than others"* (L l. 455-456). Others make well-meaning suggestions of how she could help herself, such as returning to work:

> *"I don't want to work … because I've worked enough! I don't feel like working. I'm quite happy to be here. Like my sister-in-law once said to me, 'You know, you've got to try and you've got to try and meet some other ladies of your age or ..'. I said to her, 'I'll do it when I'm ready"* (L l. 622-625).

The support she is looking for needs to allow her space for the release of emotionality, something her daughter understands, but not her brother:

> *"The first time I went to … I was crying there every single night and she said to me, 'It doesn't matter, mom, you know, you have to cry, it's normal. '"* (L l. 505-507).

This causes her to explore her options, such as that of moving to her daughter who is in another country:

> *"But I don't think that would have been a good idea … I don't think it would have been fair to her, I mean she's got a husband and children"* (L l. 571-573).

More recently she has visited TCF where she was encouraged to take things at her own pace:

> *"'If you don't feel like coming to the meeting, don't come…You must do what you want'"* (L l. 629-632).

She has found this encouraging and it leads her to conclude:

> *"If I make friends fine and good, and I know, there may be certain things that I have to do on my own"* (L l. 622-632).

6.6 Conclusion

Van Manen (1990) has emphasised how phenomenological research is totally sited in the lived experience of the phenomenon. By the act of reflecting on an experience that is presented from memory gives it meaning through the identification of various patterns and themes. Reflection on these themes allows an immersion by proxy in the experience as lived by the participant so that it acquires an immediacy not easily achieved in other ways. The layers of meaning revealed in the process have made possible a rich and complex understanding of the phenomenon through the linked connections that expose how meaning is configured within consciousness.

This chapter introduced the participants to the reader, together with some comments on the researcher's impression in their regard. It also presented an interwoven analysis of those participants whose children died as a result of cancer, a long-term illness which is currently not stigmatised in South Africa, and a similar analysis of those participants whose children died as a result of AIDS, which is currently stigmatised in South Africa. The following chapter firstly presents a discussion of elements from interviews which relate to the literature review, and secondly attempts to compare areas of commonality and divergence between participants whose children have died from cancer and those who have died as a result of AIDS.

Chapter 7

7. Discussion and integration of results

The previous chapter presented interwoven analyses of those participants whose children died as a result of cancer, a long-term illness which is currently not stigmatised in South Africa, and of those participants whose children died as a result of AIDS, which is currently stigmatised in South Africa through analysis of themes that have emerged from studying the transcripts of the interviews. It also introduced the participants and presented the researcher's impression of them.

This chapter is comprised of two sections. The first of these is an examination of the interviews in an attempt to understand how the various phenomena relating to parental bereavement were reflected by participants in the interviews. The second of these, attempts to compare areas of commonality and divergence between participants whose children have died from cancer and those who have died as a result of AIDS so as to present an integrated delineation of themes.

7.1 Comparison of themes in the interviews with the literature

The following section examines how various elements described in literature were reflected in the interviews.

7.1.1 The sequelae of grief

At the outset, participants were asked to reflect on, and describe, how they experienced the period of time leading up to the death of their child, and at this point the main focus for most was the period leading up to the diagnosis. This is described in a narrative way, as a sequence of historically-sited events and occurrences. For Kevin and Ella, there is considerable emphasis on the medical aspect of the process, but for others such as Vasalisa and Selinah there is less emphasis on this aspect. Rosemary does not dwell on it at all. It is interesting to reflect that although it is possible that participants experienced a range of somatic and emotional symptoms as described in the literature, they do not refer to them. It is likely that these were experienced however, and in fact are referred to in a tangential manner. For instance, Vasalisa describes **social withdrawal** as posited by Worden (1988) when enumerating the behavioural sequelae of grief, which is characterised by a loss of interest in activities and others:

- *"Somebody said to me a while ago, "Are you still crying, don't you get over it?" It's not a matter of getting over it, and then why shouldn't I cry. They are my kids …we lived a whole life, a lifetime together, why shouldn't they deserve a tear? The people they think you can put it on the side and say that's where it can stay. You can do it on the odd day, but you can't do it in general"* (V l. 560-566).
- *"But it's a happy time as well because there's lots of beautiful memories, so why would I wish this away, why would I want to wish it away - I don't. It's just sad that they're not there now to share maybe a phone call or a visit"* (V l. 569-573)

However, this social withdrawal appears less important to Vasalisa in itself, but is rather an outcome of a different way of experiencing the world as an opportunity for a reconnection with her sons who are no longer a part of her day-to-day existence. In this respect it is for her an addition to her quality of life rather than a reduction. This appears to corroborate the findings of Klass (1997) that parents do not forget the child who died, nor do they wish to do so. Although these memories are painful, they comfort by maintaining the parent's connection to the child. At the same time however, it is a cause for concern for others, such as her daughters, who see the behaviour without understanding the meaning it holds for her. It is possible then that this is the reason why other symptoms are not described by participants although if outside observers were to discuss their observations they would interpret behaviours following the bereavement which differ from those prior to the bereavement as signs of continued distress and hence a cause for concern. This also supports Klass' assertion (1988) that the symptoms as observed in the literature did not help to explain the long term changes to the self that manifest in the bereaved.

The impact of the stress resulting from grief may have a negative **impact on health** (Parkes, 1972). Stroebe, Stroebe and Domittner (1988) confirm that the risk of illness is significantly raised especially during periods of active mourning, which includes anniversaries of the death or birthdays of the deceased. This appears to be the case for Lorraine who suffered a lung infection during such an anniversary:

> "*I'm very worried about my lungs at the moment … because every single month since I've been back from [my daughter] I've been on an antibiotic"* (L l. 574-578).

Another behaviour that is referred to in the literature is **searching**. This was most evident in Vasalisa's interview when she remarks,

> *"You still have people looking like they did and it gives you an odd shock … [her daughter] saw a guy and from the side he looked just like [my son]. I saw another one who looked like my other son. And I said I don't go and look for it, but I do sometimes: I look for it. I do"* (V l. 577-578)

Kevin's searching has a different flavour, it appears to be more of a keeping a watch for significant signs that let him know his daughter is fine wherever she may be:

> *"[My wife] smells her perfume, every now and then, that [she] loved …[My wife] was dozing in [her] room, and she was lying with her hands open and she was waking up, and she felt these hands in hers and this presence in the room, saying, 'It's OK.' The clearest one for me … I was just lying there with my eyes closed, and it was clouds of white, black and grey spots, whatever, in front of my … in front of me, forming into [her] face. I drew enormous comfort from that. She'd actually made the effort to let me know, 'hey, I'm OK'"* (K l. 412-433).

Some references are made to **questioning** behaviour, although for many there are no answers. Where there is a strong philosophical framework, it appears that it is possible to reconcile the lack of answers with the idea that although none appear available, there are some available in terms of a larger, more encompassing framework, which does not necessarily make sense in terms of earthly living. However, where there is none, or where it cannot accommodate this process it leads to a sense of the futility of the endeavour:

- *"[God]'s the only one who knows why. I don't because I don't see it …show me why, why do I have to go through all this horrible stuff and then stay to live"* (S l. 159-167)
- *"Can't ask why, can't ask questions"* (L l. 587-588)
- *"I would love to have the ultimate knowing"* (K l. 557)
- *'You keep on questioning yourself why, why me, how did it happen?"* (R l. 117-118)

Magical thinking is described by Parkes (1972) as an intensely painful phase, characterised by 'if only'. The pain of Rosemary's experience of missing her daughter's dying words can only be guessed at:

> *"I so much wanted to be there but unfortunately I couldn't be there. I even confessed. It took some months, keeping on telling myself 'if only'"* (R l. 171-173).

7.1.2 Anticipatory grief

The period prior to the death of the child bears certain similarities for all participants. There is the time prior to diagnosis, when the child is ill and is showing severe enough symptoms to warrant medical intervention. There is often concern at this point, and also anxiety, especially in the case of Selinah. For some participants, this is not such a clear issue as their child is not geographically close, and so this phase of medical exploration is carried out without their being aware of it. This is followed by the diagnosis and a period of treatment, nursing and care-giving. During this time a major readjustment is required of the parent, especially in terms of the cognitive schema, where their image of their child needs to be modified from healthy to ill. The diagnosis itself is difficult to take in at first, and most participants describe at some length the **sense of disbelief and unreality** that accompanies the news. When discussing this sense, most find it difficult to explain directly the experience and possibly this is because it is unlike others in their lives. There is also a belief that it is hard to understand this, unless one has experienced it. This is less the case for Ella, who at the outset is told that her daughter's tumour is benign, and for Rosemary, who does not dwell on it, not during the interview, and reportedly not when she hears the news, and thus appears to actively choose **avoidance** of cogitation as a coping strategy. During this time there is still hope for participants that the dreaded outcome will be stayed in some way, even when the initial information is very clear. It is as though there is such a longing to have grounds for **hope**, even though this co-exists with the hard reality and perhaps it is this process that fuels the cyclical movements between **denial and despair**, that characterise this period of time. Worden (1988) has also commented on these cycles, but suggested that awareness of the impending demise facilitates an acceptance of it, even though this acceptance alternates with denial.

- *"I can say that maybe she's gonna live maybe for me, for a long time. I don't know how, but since she was my only child"* (S l. 72-74)
- *"Some kind of miracle, which we always hoped for"* (K 49-50)
- *"Maybe I thought she was fine now*" (S 1 l. 38)
- *"I thought maybe it would just go away"* (S 1 l. 21-22)
- *"We were quite hopeful that this would work out"* (E l. 41)
- *"With science, and technology …I felt … that something would come up. There would be an answer, there would be a cure"* (E l. 177-179)

- *"They are bringing out new drugs every single day, and I'm sure they'll bring out something that'll help you, and you'll get better'"*(L l. 246-247)

The first of these excerpts, by Selinah, demonstrates a kind of **bargaining** as well: how not having other children would somehow preclude her from the expected outcome of the illness. The last statements speak about how there was hope that the treatment would succeed, or that it would buy sufficient time for advances in medical sciences to provide a cure. Other statements however are indicative of the doubt that would have countered the hope so that in retrospect there was always the awareness that this was more serious or that the full truth was withheld to protect either patient or parent:

- *"She spoke to the doctor and he said to her, they were talking in Hebrew and he said to her, "Vasbyt" … But I get the feeling that because we're so far away that she didn't want to really really tell us the truth"* (E l. 241-246)
- *"His HIV doctor … I don't know if he was trying to comfort me, but … he'd say, '[He] will be fine', and I said to him one day, 'Doctor is [my son] dying?' and he said, 'Nooo, don't be silly!' at the same time when [another doctor] told me that [he] was in the last stages of AIDS"* (L l. 258-262).

According to Parkes (1972), the first task of mourning is to accept the reality of the loss and he views denial as a protective mechanism to buffer the person from the full impact of the pain that a reality-based understanding would elicit. Shapiro (1994) describes this as an initial **sense of unreality** followed later by a **sense of divided consciousness**, attributing this to a refusal to believe the news of the death on one level, though understanding about it on another and this does appear to fit the descriptions provided by participants.

- *"At first I wasn't quite sure I heard right"* (V l. 17)
- (On hearing the diagnosis) *"So I said, no, I don't think so"* (V l. 19)
- *"Like it was a dream. Is this … is this real?"* (K l. 24)
- *"I just couldn't believe it, this is not happening to me, it's not something I want to hear; it's not something I can comprehend or understand. Because there's no pain, it's somebody else that they're talking about"* (E l. 329-332)
- *"And I just sat there absolutely still, I just couldn't believe my ears, … it just was like, … this wasn't happening to me"* (E l. 105-106)
- *"I couldn't understand what was wrong with her"* (S 1 l. 26)

- *"Maybe even my brain didn't acknowledge it quite like that, but something inside me knew it."* (V l. 93-94)
- *"The understanding, the perfect understanding of it wasn't there."* (V l. 212-213).
- *"I thought … he has to die … but the other part of you says no, illogically"* (V l. 225-228).

Selective forgetting is one characteristic of this and this was clearly demonstrated in Rosemary's interview when she forgot about the situation regarding her daughter while she was involved at the anniversary party. As she remembers, *"something just made me forget"* (R l. 141). Hence it appears that this type of response can also be a part of anticipatory mourning as a generic response to having to cope with the trauma of seeing someone suffering and the irreversible reality of the anticipated event.

For those parents who are involved in the nursing or care-giving this is a difficult period, as it is physically, mentally and emotionally demanding. There is also the hard reality of observing the deterioration of health of their child, with the awareness of what this signals. The following excerpts tell of the enormity of the task in hand, when a parent is involved in caring for a dying child:

- *"When you've got a sick person, day and night, you can't sleep, you can't eat, (long pause) so I don't know how did I survive that"* (S l. 122-124)
- *"We read very little during the ordeal, obviously, we were exhausted"* (K l. 500-501)
- *"The experience that I found out from her sickness, when that time now comes, I found with blown-up AIDS. You cannot touch her. Each and every place is sore. … eina eina, everything I had to do. It's really not easy when it comes to the last. It's not a nice thing. It's not a nice thing"* (R l. 263-267)
- *"We spent a lot of time …we lived there: I used to sleep in the car, G used to sleep on the floor or on a Lazyboy thing in the room. Then we'd get up in the morning and sort of freshen up and go back again. We just lived there"* (K l. 233-237)
- *"I couldn't stay much longer than a week. I had to come back and recuperate and go down then again"* (V l. 32-33)
- *"She was getting very thin and needed help, so she was here with me day and night, and I can see all the changes"* (S l. 224-246)
- *"It was dreadful to watch him suffer the way he was suffering"* (L l. 2-3)

- *"I used to stay there maybe 10 or 15 minutes, and then I'd come home, and say, 'I can't bear to see this. I just can't'"* (L l. 446-448).

Not only is it physically draining, but the anxiety is also terrible in its intensity, watching and waiting, continually expecting the worst:

- *"Sometimes I get so scared, I don't know how I got through it, I really don't. Sometimes I was so scared, I feel so scared, I was just shaking like that. Sometimes when I have to go out of my room and when I have to go back, I got so scared to go into my room, I thought maybe when I get in there, I will find her lying in there"* (S l. 246-251)
- "*When I come back, and open that gate, I get so frightened … that is the thing that is very hard … that you could see it was coming closer"* (S l. 253-258)
- *"I looked at [my daughter] and I said, 'This is not going to take long.' She died on a Thursday"* (K l. 248-249)
- *"We're fighting a losing battle here"* (L l. 78-79)

The process was different in Ella's case, as the geographical distance between her and her daughter obviated the possibility of closer contact. When her daughter required assistance, it was in the form of caring for her daughter's children while she was undergoing treatment elsewhere. For her the news of her daughter's death produced a similar sense of disbelief as was evidenced by Vasalisa when she heard the news that her son had cancer. Thus this appears to support the opinion expressed by Worden (1988) that anticipatory grief can facilitate an acceptance of the death and this appears to be the case even if its precise timing is not known or immediately expected (as was the case for Rosemary).

7.1.3 Denial

According to Kalish (1981), much of human behaviour appears to suggest that human beings live as though the possibility of death, while applying to every other person, does not apply to them. This constitutes a type of denial of death and people often express disbelief that it could happen to them or their loved ones, such as after an experience which has brought them close to death. Most of the participants make reference to the disbelief that they experienced on first hearing about the diagnosis:

- *"At first I wasn't quite sure I heard right"* (V l. 17)
- *"I don't think it ever went in"* (V l. 44).
- *"We'd never thought this was going to happen"* (E l. 136)

- *"I couldn't understand what was wrong with her"* (S l l. 26).

The descriptions provided by Kevin and Ella make clear that there is a sense of unreality to the experience, although for Ella this disbelief occurred on hearing the news of the death of her daughter, as she had not up until then believed that her daughter would die from the illness:

- *"I just couldn't believe my ears, … it just was like, … this wasn't happening to me"* (R l. 105-106)
- *"I just couldn't believe it, this is not happening to me, it's not something I want to hear; it's not something I can comprehend or understand. Because there's no pain, it's somebody else that they're talking about"* (R l. 329-332)
- *"Like it was a dream. Is this … is this real?"* (K l. 24).
- *"That stage when you don't know what you should be thinking or feeling or whatever"* (K l. 415-416)
- *"At that moment I feel like I'm living in another … I am in somebody else's body or mind or something. I couldn't … feel myself, I don't know how to say it"* (S l. 43-45)

According to Braun and Berg (1994) events that reveal to the person their inability to influence the outcome of events tend to contribute to loss of hope for the future, a sense of powerlessness, loss of personal control and loss of purpose in living also contribute to the sense of disorientation as it undermines the entire collection of assumptions about life. The event which can create such dread-filled dislocation and disembodiment is severe enough to threaten personal survival because the extent of discontinuity with the loss of a child brings about a sense of personal annihilation. Hence, it is possible that the sense of dissociation, of not feeling as though one is part of oneself is a way to create a sufficient measure of distance from the awfulness of the situation in order to be able to survive. Without skilful language to distance and sanitise the experience the reader/listener is left with the raw, unadulterated pain of the experience which is so relentless, one does not know how to survive.

In contrast to other participants, Rosemary does not describe a sense of denial or disbelief on receiving the news of her daughter's illness:

"The minute I get the news I accepted it there and then" (R l. 37-38).

Yet acceptance in this sense may simply be the other side of the coin to denial, so that the fact that it is mentioned at all in this context seems to indicate some underlying vacillation about it which has not been disclosed since then. A similar process may have occurred for Vasalisa, who says about her response to the news of the diagnosis, *"So I said, no, I don't think so"* (V l. 19), and then a few moments later she concludes that, *"I don't think I ever really accepted it"* (V l. 24). Both of these parents had previously lost another child, and it is possible that this had an impact on this process: For Rosemary there was the knowledge born from bitter experience that children can die, but for Vasalisa it may have seemed inconceivable that losing a child could happen to her twice in such a short time when many parents do not lose any children.

7.1.4 Acute mourning

Parkes (1972) contends that the **second task of mourning** is to experience the emotional and behavioural pain of loss because its avoidance or suppression will result in a drawn out process of bereavement. However this ventilation of feeling or emotion may not always serve to reduce pain. Bonanno (1999a) has found evidentiary support that the expression of negative feelings such as anger may alienate others and the support that they could offer. He asserts that it is this support that enables the griever to cope more successfully with the pain of the loss so that a measure of dissociation and emotional self-deception may be helpful. In the interviews it appears that there is merit to both arguments. For instance, Kevin and Rosemary have focussed their efforts on the transcendent elements of their loss, and have become involved in activities that have an altruistic motive. They find that this process lends a sense of purpose to their lives, which makes the pain of the loss more tolerable. Yet Vasalisa, Lorraine and Ella expressed a need to mourn their losses in ways that are appropriate to them. It is true that such a process does not always meet with social approbation; in Ella's case, this is creating a serious rift with her daughter-in-law and in Vasalisa's case, although there has not been alienation from her daughters, they have expressed concern for what they judge an abnormally long period of withdrawal. For Lorraine, it appears that the concern of her brother and his wife lead them to giving advice which is unacceptable to her:

- *"We've had such problems with my daughter-in-law. She can't give us the time to mourn and do the things that we need to do… maybe mourn her so that we can, … close, get on with our lives and know that we have done our mourning and that there's no more that we can do"* (E l. 342-353)

- *“Apparently I didn’t manage because the kids said to me …“You wouldn’t talk, you weren’t laughing, you weren’t … outgoing. You were … you were not there. And I did everything but I wasn’t quite … there”* (V l. 451-455)
- *“I thought I’d just have to do it by my own way”* (V l. 479-480)
- *“Then I go to bed. When it was hot in summer I didn’t put electric blanket on but now I put the electric blanket on top of me. I will drink but I will not eat and I can do that quite happily for three days. My husband is very unhappy when I do that”* (V l. 494-497)
- *My sister-in-law once said to me, ‘You know, you’ve got to try and you’ve got to try and meet some other ladies of your age or ..’. I said to her, ‘I’ll do it when I’m ready*’” (L l. 624-626)

However, for these participants, even though they understand that these times are sad and give rise to experiences which could be seen as morbid or even pathological by others, the benefits are sufficiently strong to outweigh the emotional costs so that they will make specific plans to carry out such activities. Thus while Bonanno (1999b) uses a reduction of grief symptomatology as a yardstick for recovery, it may be that the so-called grief symptomatology has other benefits for the bereaved person which are less tangible but may yet be subjectively perceived as necessary.

7.1.4.1 Intensity of the loss

Schwab (1990) has commented on the intensity of loss experienced by parents who have lost a child, noting that many initially report that they believe they would not be able to survive such a loss. Braun and Berg (1994) comment on how the child’s life is pivotal to the parent's sense of meaning and purpose in life, their experience of self and their vision of the future. With regard to this, Selinah describes her emotions very movingly:

> *“It felt like it was the end of everything. Maybe I’m just going … to die with her, because she was everything to me, all my hopes: she was my life …she was just my hopes … she was my life … Everything I do, I do for her, everything I think, I think for her… She was my life, everything just shut down, so I didn’t know if I will make it without her, how my life is going to be without her, so… (pause) (inaudible) my life feels empty … it’s empty … I can feel that something is missing, you know, and I … there is nothing that can fill that space, it’s empty right now”* (S l. 66-84).

In saying this, Selinah unknowingly echoes an assertion made by Arnold and Gemma (1994, p.9), "the loss of a child is a loss like none other", because it, "signifies the loss of the future, of hopes and dreams, of new strength and of perfection".

7.1.5 Psychosocial factors and their effect on grief

Rando (1984) has focussed on the nature of the relationship with the deceased prior to the loss, noting that the amount of 'unfinished business' in the relationship between the child and the parent which are the issues that were never addressed or settled during the lifetime of the child can have an effect on the grief reaction. This is evident for Rosemary whose remarks prior to the death of her children return to haunt her after their deaths:

> *"I had that sense of guilt … She was a very cheeky somebody … and then the last week that made me feel guilty, I told her, "You know what, you're going to die a lonely death, because I won't be there. And it happened that way. I felt very guilty … I felt very guilty. I wasn't happy at all. I say, "jinna, how could I say a thing like that, when it happened exactly as I've said it. It's not nice. It is my child. It happened the way I've told it. Even one day this one, [my son] … I said to him, "you know what, one day, I'll be sitting here, and they'll come and call me to come and pick up your body." And it happened that way … I don't like it."* (R l. 177-195).

7.1.5.1 Coping strategies

Moos & Schaefer (1986) believes that during a crisis it is important to find a way to maintain a satisfactory self-image. This 'identity crisis' may require a shift in behaviour or values and part of this process may explain the shift that is evidenced as Rosemary first attempts to avoid revealing how she did not see her daughter in the last few days prior to her death, and then reveals her lack of honesty:

- *"If I knew and I was here I would have kept her there"* (R l. 150-151).
- *"When it comes to the last… they need their own, not a stranger"* (R l. 266-268)
- *"I wanted to stand by her, up to the last, really that was my wish"* (R l. 277-278)
- *"No man, stop lying … I was cross with her and I told her she would die a lonely death. And it happened. I didn't even go [to the hospital], I didn't go, to be honest"* (R l. 288-290)

The helplessness and frustration engendered by wishing to do something to alleviate suffering but not being able to makes this a very difficult time for parents who witness the suffering:

- "*You're living with a sick person, and you don't know what to do. There is nothing you can do to help that person …It's very hard*" (S l. 51-53).
- "*He was so full of life, and vital and to look at what he turned into, for me was the most horrific thing and in the back of my mind, I probably knew that he wasn't going to get better*" (L l. 244-245).

Each parent appears to find their own means to resolve this dilemma:

- "*All I can do it there is only one thing … I can sing for her, that was what I was doing. Only just sit there and sing for her*" (S l. 111-113)
- "*I had two big concerns, the one …to get [her friend] here, I think that was the biggest thing that [my daughter] wanted. The second was to take away her fear of dying*" (K l. 276-309)
- "*I wanted to make him as happy as I possibly could, to make him as comfortable as I could*" (L l. 4-6)
- "*He said, 'I want you to cook [for] me…You cook me that and that and that'*" (V l. 66-69)
- "*If she wants it done that way, do it that way*" (E l. 218).

7.1.5.2 Relationship to the deceased and personal factors

Kander (1990) has considered the importance of the unique constellation of characteristics pertaining to a specific child and how these can make certain aspects of the grief more difficult. Death of an only child equates to loss of the parent's role as parent, and this is clearly reflected in Selinah's poignant excerpt quoted above. Role or gender-identification may establish a particular bond between child and parent, making the loss of the child a central loss. In addition, being a particular gender holds specific meaning for the parent, and dictates certain aspects of the relationship that they share. The loss of an only son or daughter can also result in a particular sense of loss. This is evident in Vasalisa's interview, where she refers to the loss of her sons, and in Ella's interview, where she refers to the loss of her only daughter. In describing how large an impact the loss of her sons has had, Vasalisa remarks,

> "*My world will never be the same …With two of my sons gone. I only had the two sons. I still have girls*" (V l. 388-392):

The underlying sentiment is very similar for Ella, as she recalls:

> *"Life is definitely not the same … the one friend of ours … was sitting with his arm around his daughter … my husband can never do that… Another good friend of ours whose daughter made her party for her sixteenth birthday … And that again hit home because it could have been like that once but not any more"* (E l. 391-409).

Kander (1990) has also observed that the death of an adult child severs a long-established relationship with many degrees of interconnectedness even though some appropriate separateness had been achieved prior to the death as a result of the child's independence. This is particularly noticeable in the case of Vasalisa whose son was himself a father and living in Cape Town, and that of Ella, whose married daughter was living in Israel and had three children. For these two participants, as well as for Rosemary, there is an ongoing interconnectedness through the relationships they continue to share with their grandchildren.

Doka and Martin (2000) have described strategies which they consider are employed by the male griever in coping with the emotional pain of loss. It appears that in certain respects this is the case for Kevin. For instance the shelving of thoughts and feelings and the private ventilation of feelings in order to meet expectation of the masculine role, is revealed in the following statement:

- *"I've had my moments, usually at two o'clock in the morning"* (K l. 602)
- *"I'm trying to put it as clinically as possible without too much emotion"* (K l. 577-578)

He also expresses his grief externally by active means and by 'doing':

> *"If we go to a meeting, let's sort it out and let's move on because there are other things to do. Because at the end of the day it might free me up to do other things, a Compassionate Friends presentation for example. I don't have time for things unless they're sincere. It's cut to the chase you know. I looked forward to this afternoon because we're exploring things that are of mutual interest. I would rather spend time talking about this, than … making social chit-chat … To me it doesn't achieve anything. Nobody's helping anybody else … And if that's helping my development, and your development and helping us achieve what it is that we are hoping to achieve, then it's far more meaningful for me"* (K l. 538-555).

Finally his feelings tend to be expressed indirectly and sometimes with humour such as when he describes the moments directly following his daughter's death:

> *"I closed her eyes, … pulled the sheet up and sorted it out a little bit … And then … then I thought … now what's the relationship that I had with this person? (pause) If I ever kissed her she's look and say, 'Dad' so I leant down and I kissed her and I thought, 'Hah! Got you!'"* (K l. 343-347).

However, it could be said that Rosemary shares some of these characteristics in her style of grieving which is more distinctly instrumental with little description of emotions and feelings, tending rather to describe certain experiences as ones that hurt. She also chooses to vent feelings privately preferring to shelve them:

- *"I felt tears in my eyes and I didn't want her to see that I'm really hurt and I'm going to cry, so I turned my face away"* (R l. 50-51).
- *"There comes a time when you're alone and then you find yourself thinking about them"* (R l. 19-20).

She describes this as a preference for avoiding cogitating on these thoughts on three occasions believing that it, *"can cause a stroke or it can cause a heart attack because there's not a single day that your heart is free. You are mourning day in and day out. It's not healthy. It's very unhealthy"* (R l. 232-234). She believes that, although, *"it doesn't go the same day, … if you keep, continue with it, you forget"* (R l. 92-93). She also expresses a preference for being active:

- *"I kept myself busy, I joined the prayer groups. I was busy. I've never sat and … worry about her sickness. No. I've never made it a worry in my life"* (R l. 77-79)
- *"I really keep myself busy. You won't find me at home so much … that little time you've got make something of it, help somebody if you can, whatever you can do with it"* (R l. 421-424).

Rather than displaying a fear of death, in particular her own, she refers to this in a humorous way:

> *"I told myself the end of the world it's near. But now, is this the way we are going to leave this world? This is the question I ask myself. Because some other times it was floods, that's not nice, fire, that's not nice (chuckles) I think [AIDS] is better"* (R l. 325-328).

Brubaker (1985) has suggested that the reason that men preponderantly use instrumental styles of coping is related to gender role expectations which define the expression of grief. Riches and Dawson (1996) have observed that for masculine-style grievers, the need to reject help in order to be seen as strong and as a survivor, fits with a society that values stoicism and strength in males. It is possible however, that in reviewing the grieving style that Rosemary has chosen, that gender is not the only defining factor in this respect. This is not to say that the grief is felt less powerfully than those who express their emotions, and this was alluded to by both Rosemary and Kevin who referred to those quiet times when they feel it most intensely. Rosemary, as a single mother, has had to take on the responsibility for raising her daughter's son and so has a strong need to be and be seen as strong and as a survivor. Moreover, it is evident from the interview, that Rosemary does not have an extended family to rely on, as she makes several references to her being alone. Thus it would appear that the availability for help is centred around her religious activities. As Bonanno (1999a) has found, minimising negative emotion can foster connection to important others and garner support from them and it is possible that for Rosemary this is a way of accessing the only kind of help that is available to her, which is through her church. As Martin and Doka (2000) have found, the most predictive factors for positive bereavement outcome are positive self-esteem and personal competencies in managing the tasks of daily living, and for both Rosemary and Kevin this is the recompense for their forbearance and displayed strength.

7.1.5.3 Regulation of emotion

As was theorised by Moos & Schaefer (1986) in coping with crisis it is necessary to respond to the requirements of the situation, and to maintain sufficient social support. It is also necessary to regulate emotions, especially such as guilt, self-blame and a sense of failure. For both Kevin and Rosemary, it has been possible to achieve all of these through establishing a meaning framework that can accommodate all of these, for Kevin in a philosophical way and for Rosemary in a religious way. While their respective crises exponentially increased the need for a response from them, both before and since the death, their respective belief systems have facilitated a reduction of responsibility for those things over which they have no agency and thus confer on them a sense of being able to cope with those responsibilities over which they do have a sense of control.

7.1.6 The impact of grief on meaning frameworks

Berger and Luckmann (1967) argue that experiences are interpreted in terms of an objective reality and become meaningful for the individual when they are perceived as making sense in terms of that objective reality. For the participants, the illness and death of their children serves to some extent to invalidate the meaning structure that has been put in place to justify their experience of reality as it cannot accommodate this event. In this regard the sense of dislocation which was described can be understood as reflecting an inner reality whereby their previously held understanding of the world is no longer a useful framework. Loss of such a framework or paradigm, can, as Janoff-Bulman (1992) has argued, cause a shattering of assumptions that the world is benevolent and meaningful and that the self is worthy. The initial sense of disbelief and of denial is evidence of the way in which things do not appear to make sense. Participants describe this as feeling as though they were in a dream, or in a state of unreality. Antonovsky (1979) has also reflected on the importance of the sense of comprehensibility in experiencing the world as coherent and meaningful. This may account for the intensive questioning that takes place as the person tries to make sense in some way, or to perceive the underlying logic which is believed must be there, and an example of this is Vasalisa's comment on hearing news of her son's diagnosis:

> *"Why would he have cancer? I mean, he was such a healthy (with emphasis) healthy, living person. Why should he have cancer?"* (V l. 19-21).

Braun and Berg (1994) suggest that the nature of life beliefs includes a sense of the goodness of life including immunity to tragedy and the last excerpt is illustrative of this. Yet often the questioning does not lead to any answers leaving a feeling of uselessness so that one, *"can't ask why, can't ask questions"* (L l. 587-588)

Moos & Schaefer (1986) suggests there is a need to accept the loss intellectually, and also to explain it, as the first step in managing a crisis. Even though certain elements make sense, others do not. For instance, Rosemary is able to accept that death must occur as a consequence of human mortality but agonises over the suffering that she has witnessed:

> *"Why at the end must you suffer like that. Shrunken, full of pain. This is my question, why must they suffer? … Why must people suffer like that, what have we done?"* (R l. 313-323).

Cognitive conservatism is the tendency to perceive and interpret new information in the light of what is already known in a way that makes sense in terms of their personal 'paradigm'. Hence it is easier to reinforce pre-existing beliefs than it is to change them so that the process is self-confirming and self-perpetuating (Janoff-Bulman, 1992). This process is evident in Ella's interview when she recalls how she was able to avoid believing the possibility that her daughter's illness could be fatal:

> *"I was quite optimistic about it, because I felt that, at the time that they had done the radiation and they'd given her medication, they felt she'd be alright for the next few years, and I thought that with science, and technology developing as fast as it is, I didn't see the worry, because I felt that they … that something would come up. There would be an answer, there would be a cure. I never, in my wildest dreams, thought that this would happen"* (E l. 174-180).

Similarly, Vasalisa struggles to understand how her healthy son could have cancer and Ella to accept that it could be malignant:

- "*Why would he have cancer? I mean, he was such a healthy (with emphasis) healthy, living person. Why should he have cancer? … I don't think I ever really accepted it until I … I…(Thinking) even when he couldn't move any more, when he was a skeleton"* (V l. 19-26)
- *"A friend of ours …had died from a brain tumour, and … she'd deteriorated, until she was a vegetable, I didn't really want for her and her family to suffer through but then I'd immediately push that thought out of my mind and think what was the other alternative"* (E l. 181-185).

In both of these excerpts it is evident that it is very hard to let go of the pre-existing conceptualisations. Selinah's excerpt also shows something of how difficult this is, revealing how she would question the reason for the persisting illness trying to attribute it to anything, though not to AIDS:

> *"I didn't think of … [AIDS] I thought maybe it would just go away like she was a ill child since she was a baby and thought maybe it's just something … I couldn't figure out … I couldn't understand what was wrong with her, she was always sick …she was not getting better"* (S l. 19-30).

As was noted by Janoff-Bulman, it easier to reinforce pre-existing beliefs than it is to change them, but they are remarkably resistant to change even in the face of inconsistent evidence or lack of substantiation. There is a preference for people to change elements of the paradigm in a way that does not signify a significant departure from the main elements of it but can rather be accommodated, but the news that the participants receive regarding their children cannot be fitted in although there is an extended effort to do so. It is this inability that shakes the stability of the internal world, filling the person with a pervasive sense of anxiety and dread, which is well demonstrated in the preceding excerpt. Vasalisa also makes oblique reference to how hard this process is when she recounts how she would go to visit her son:

> *"I couldn't stay much longer than a week. I had to come back and recuperate and go down then again"* (V l. 32-33).

Moos and Schaefer (1986) have observed that an important element in managing a crisis is the ability to preserve a reasonable emotional balance by managing upsetting feelings aroused by the situation and Vasalisa is able to do this through regulating the length of the visits to her son because she remarks,

> *"In that week I think I handled myself very well"* (V l. 33-34).

Lorraine also believes that she managed better during her son's illness than later, principally because she wanted to ease his suffering:

- *"When he was so ill, I coped with it"* (L l. 4).
- *"I never, ever cried to P because I just didn't want to upset him, and I knew I had to be strong for him"* (L l. 290-296)

Such regulation would increase the sense of manageability, posited by Antonovsky (1979), as the ability to balance strain avoiding both overload and underload.

If the world is benevolent and the self is worthy, then in a meaningful world, harm and suffering will not happen. However, where death and suffering do occur, it threatens the implicit, though spurious, security which is offered by such beliefs. The sight of the suffering of the children of the participants obliterates the sense of the world as benevolent:

- *"It's a cunning disease, it's an insidious disease"* (K l. 186-187)
- *"It's really not easy when it comes to the last. It's not a nice thing. It's not a nice thing"* (R l. 266-267)
- *"It's a really, really evil sickness this one"* (R l. 303)
- *"Death is the devil's work, but now there comes a time that God also gives way. God doesn't hurt you, and he's not a jealousy God, but seeing that death is there, we've got to go somehow, but death really is devil's work"* (R l. 242-245)
- *"All this horrible stuff happens to me"* (S l. 156-157)
- *"The end of the world it's near … Because some other times it was floods, that's not nice, fire, that's not nice ... But now I think it's a [plague]"* (R l. 325-328)
- *"He had a friend … and he was crying … and he said, 'This is all wrong. I wouldn't even let my dog die like that.'"* (V l. 337-340).

It seems then that not only is the world not benevolent, but holds within it elements of direst malevolence and even evil. The sense of the self as worthy also can no longer remain unchallenged for some of the participants:

- "*I was very angry, asking myself what have I done, so bad, that God have to punish me in that way*" (S l. 176-177)
- "*I thought maybe it was a punishment. Maybe I did something wrong before God, so maybe He's punishing me for that*" (S l. 237-239)
- "*Why must people suffer like that, what have we done?*" (R l. 322-323).

According to Janoff-Bulman (1992), the early response of self-blame, whether behavioural or characteriological, is an attempt to re-establish a sense of meaning and non-randomness in the world through a belief in control that could have been exerted that could have averted the event. This process appears to support McIlwraith (1998) who suggests that feelings of guilt may be related to a belief that as the parents are responsible for having brought the child into the world, they should be able to ensure the survival of the child. This inability may result in feelings of failure for the parent. When a child dies, idealistic assumptions about motherhood may rapidly turn to self-blame and feelings of failure. Mothers, under these circumstances, are likely to feel marginalised by failing to live up to the benchmark family ideal where they are principally responsible for child outcomes (Farnsworth & Allen, 1996) and this is reflected particularly in the way Rosemary feels sad at missing her daughter's last days in hospital:

> *"I wanted to stand by her, up to the last, really that was my wish. If I was turning my back away, who do I expect will come and do that for her?"* (R l. 277-279)

Selinah's dilemma, in being unable to do or say something to improve the situation is also an expression of this:

> "*You don't know what you are doing right, or what is wrong … what to say to her, to .. make her feel better, I think maybe if … I can tell her how much I love her, and whatever to tell make her feel better, but I couldn't say it*" (S l. 95-98).

The Leiden Bereavement Study (Cleiren, 1991) indicates that those parents who lose an only child suffer more guilt than those who have surviving children and in Selinah's case this may be seen in the characteriological self-blame where Selinah wonders whether she is responsible for her daughter's illness:

- "*Maybe I did something wrong before God, so maybe He's punishing me for that, like that*" (S l. 238-239).

- *"Asking what have I done that God have to punish me"* (S l. 178-179).

According to Janoff-Bulman (1992) such self-blame is linked to depression and certainly this was very evident in Selinah's case where she sees no reason for her continued existence:

"I'm living for what? I don't know" (S l. 151)

In contrast, Rosemary's self-blame is more with regard to her behaviour, and hence is not expressed in such terms. Her ability to avoid characteriological self-blame enables her to believe that she has done something which in retrospect is ill-judged, and which has unpleasant effects. Hence her confession can be effective in reducing guilt by absolving a particular action because it is not her very being that is at fault:

> *"I had to come and confess, I felt very guilty. I wasn't happy at all. … How could I say a thing like that…?' It's not nice"* (R l. 186-188).

The sense of the world as safe and under control may be illusory, but provides a context for a sense of optimism about life. However, the losses which have been suffered by the participants nullify such optimism, and the new world seems meaningless, leaving those within it open to suffering on a purely random basis. Attig (2001) concurs, and extends this to describing the experience of loss as "soul pain" (p.37) resulting in a loss of the meaning that provided spiritual sustenance and a sense of being rooted in the world. The challenge then for bereaved parents is how to re-create a sense of the meaningfulness of the world which can contain the enormity of the events that they have undergone. This is captured by Vasalisa when she describes, with great difficulty and many pauses, her impression that the physical world itself is disintegrating and flooding as she herself is doing:

- "*This was really … I thought this was … is … I thought Table Mountain … was actually … I don't know, splitting up, exploding and doing its own thing, and it was the most beautiful day – everything. You know Cape Town when it's beautiful … when I looked I … I thought, how can people walk around like this? … and the crying, it wasn't just crying, it was a total … flooding …of…Table Mountain"* (V l. 327-340).
- "*I told myself the end of the world it's near"* (R l. 325).

Similarly Lorraine describes the feelings that are triggered by thinking of past events:

- "*It's like a tidal wave, it just like comes over you. It's the most awful, awful feeling"* (L l. 87-88)
- "*I feel as though I'm going to fall to pieces"* (L l. 523-524).

Successful resolution through the reconstruction of a new assumptive world then would be characterised by its ability to restore hope in a world which may be unpredictable and only subject to very limited control. Hope at this point is unlike that in the early stages, where it stokes the belief that perhaps the dreaded event will be averted, and this sense is captured by Selinah:

- *"I have that hope that maybe some day maybe I will just think of [my daughter] without crying, just think about happy times and then no crying, just think normally and laugh about it, be happy"* (S l. 132-135)
- *"Maybe I do have hope for tomorrow, sometimes I don't"* (S l. 141-142)
- *"I believe it will go away – just to think about it and not feel bad or sad"* (S l. 344-345)
- *"If [God] tells me. Then my life will be better'* (S l. 167-168).

Lorraine too, prays that there will be a time when her pain will ease:

- *"When I get into bed at night, I just pray just to be well and healthy, just to ask for a little bit of inner peace just to be happy"* (L l. 619-621).

An outcome of this at the Erikson's adulthood stage of Generativity is to resolve the issue of trust as it impacts on the ability to love oneself and others (Erikson, 1997). For, if the pre-existing worldview predicates deservingness as a criterion for a meaningful and controllable world, then to suffer personal trauma would indicate a lack of personal worthiness. Hence love, both of self and of others who are equally subject to the vagaries of fate, is the successful outcome of this developmental crisis with altruism as its visible indicator. A number of participants did focus on this issue when asked to elaborate on how their view of the world has changed since the loss:

- *"I'm willing to help anything. I was a community dingus ... that little time you've got make something of it, help somebody if you can"* (R l. 419-424)
- *"Is it going to benefit somebody else, and if it does, I'm not going to know about it … I would like to know … that it's done some form of good, … I feel good about doing this, because it can help somebody else"* (K l. 651-655).

7.1.7 Altruistic orientation after the experience of grief

Rando (1983) found that the most effective styles in terms of coping were active and externally directed styles that comprised altruism and this altruistic orientation and motivation was clearly expressed by both Rosemary and Kevin.

- *"My approach to things has changed. More caring. The compassion and caring is perhaps an outward manifestation of the change"* (K l. 589-590)
- *"If I have one or two people that it helps, then it was worthwhile"* (K l. 246)

For Vasalisa and Ella there does not appear to be an equivalent desire to help others, but both express a wish for their immediate environment to be more peaceable in its relations among people:

- *"Don't fight. Don't fight. The world - I can't change the world, I mean logically, I can't do that - but my surrounding world"* (V l. 610-612)
- *"She never spoke about other people and sometimes when I find myself doing that, I try not to do it"* (E l. 453-454)
- *"I was always aware of a closeness with my children, but I think it's more, and I think it spreads out to other people"* (V l. 606-608).

7.1.8 The emergence of existential concerns

The death of someone very close, means that death becomes more of a personal reality and this is especially so in the case of Rosemary who is HIV-positive:

- *"Before I've experienced [the death of my children] I knew one thing that I've got to die one day, but I really didn't know … But now today, there I know exactly that my days have been numbered. I don't know when, how long, … My time only God knows it. I may think that I've still got three years, and maybe I've got three days…This life is very short"* (R l. 388-400)
- *"If it's your time to die, you die. We all have to die. So I accepted death"* (R l. 41-42).

Knowing how possible it is to die causes Lorraine to fear for the frailty of human life, both hers and her daughter's:

- *"I get very nervous …that maybe I won't get to [my daughter], or that I won't see [her] again"* (L 545-547).

For some of the participants it appears that in addition to accepting death, it is seen as a release from earthly suffering, and a desirable condition:

"I really do believe that we're all going to go to that better place" (K l. 603-604).

It seems impossible to want to live after losing one's child, yet death does not come and life seems so difficult that it is hard to understand why it is that it should persist:

- *"Maybe I'm just going … to die with her"* (S l. 67)
- *"You are so hurt. Then it comes into your mind to kill yourself"* (R l. 255-256).

- *"Maybe God does have a reason to make me stay behind, so He's the only one who knows why. I don't because I don't see it"* (S l. 158-160)
- *"I don't see what I live for. I don't know what is my future, I don't see my future"* (S l. 152-153)
- *"You've just got to try, but then I say to myself, what have I got to try for, for what, for who, what am I trying for? [My daughter]'s not here. Can't ask why, can't ask questions"*(L l. 585-588).

7.1.9 Renegotiating relationships after bereavement

Although it is not clearly stated, it seems that there is a sense that discussing death is not socially acceptable and this process might be underlying the difficulties that both Ella and Vasalisa have experienced as regards their needs for mourning their loved ones:

- *"We've had such problems with my daughter-in-law. She can't give us the time to mourn and do the things that we need to do* (E l. 342-344)
- *"I go to bed … for three days. My husband is very unhappy when I do that"* (V l. 484-497)

These excerpts are also illustrative of Attig's (2001) assertion that the bereaved person needs to learn how to relate to others in different ways and this process may be difficult resulting in tension between fulfilling a personal desire for mourning in a way that may not be considered as healthy by others, and the wish to maintain sufficiently functional relationships which enable the bereaved to continue on a daily basis. Moos & Schaefer (1979) also finds that the ability to sustain relationships with family members, and others can be of assistance in resolving the crisis and its aftermath. Vasalisa expresses this dilemma when she remarks:

> *"Somehow, you know, you've got to make your little world still liveable because I'm still here, and my children are still here and my husband is still here and other family members are still here. And … sometimes you have to put yourself a bit in the background ... for them, because my girls will get very easily upset when I'm upset and so you always try not to be upset when they're there"* (V l. 545-551).

Another relationship that must be renegotiated is that between parent and child (Attig, 2001). Although reciprocity as it happened before the death is no longer a possibility, there remains for some parents a sense of the support of their child. Part of this relearning includes finding a way to cope with those days, anniversaries, which have assumed a particular significance in respect to their deceased.

- *"I have my days when I cry quicker than other days, but you see it comes now from days for dates. My son one died on the 3rd of August and [the other] died on the 16th of February … I don't want to talk then, I want to just be me"* (V l. 487-493)
- *I happened to be flying from London to New York on [her] birthday, the 8th of August. Fortunately I had 3 seats and I was just lying … on the seats. I guess I was conscious of the fact that it was her birthday … I was just lying there with my eyes closed, and it was clouds of white, black and grey spots, whatever, in front of my … in front of me, forming into [my daughter]'s face* (K l. 419-426)
- *"We went back on the anniversary of her death and we took flowers to the Hospice people and the oncologist"* (K l. 355-356)
- *"On Friday … it was his birthday, and I've got a (inaudible) there of all the insertions in the paper, all the cards people sent, and I said to myself, 'Don't look at it,' and I looked, and I said, 'Leave it,' no but I had to take it out"* (L l. 82-85)

Renegotiating the relationship with self means that the parent needs to find ways to accommodate the new information about the self that was not necessary prior to the event.

The final aspect of the process of relearning the world is the "reweaving [of] lasting love into life's fabric" through which the deceased are given new presence in the life of survivors (Attig, 2001, p.51). As excerpts show, there appears support for Attig's conclusion that this process requires more than a purely cognitive response:

- *"I think she will be for the rest of my life because she was my child. So no matter she's gone, but I think she will be a part of my life for ever because … nothing will just wipe her out of my mind. So she will be still there … thinking about her that's how she become a part of my life every time … the time I'm thinking about her then she's there"* (S l. 348-353)
- *"Sometimes I will just laugh at myself and laugh harder, sometimes you know, like she's here ... Talking to her, remembering what she's saying that time to me or doing something funny and then we laugh about it"* (S l. 361-365)
- *She is here. She's around. Of that I'm one hundred percent convinced and there've been instances that have proven that to us"* (K l. 363-365)
- *"I still just imagine … that I'm going to fetch him to take him out"* (L l. 536).
- *"I say to myself, I wonder if [he] would like this, I wonder if he'd like the way I've done the flat"* (L l. 456-459).

- *"Life has to go on, but she'll always be a part of it"* (E l. 353-354).

7.1.10 Finding meaning versus constructing meaning

Frankl (1964a) sees a need for meaning which must be 'satisfied', something that is discovered and not created by the individual. He believes that meaning in life can be found through love and through suffering. While love can be sought, suffering cannot, and this is the reason that he contends meaning is discovered, because once suffering occurs it opens the door to understanding and compassion. He contends that being brought face-to-face with an immutable reality motivates the individual to seek for life's meaning with transformed resolve. Kevin expressed this dilemma well when he says:

> *"We went through a situation that we didn't ask for. I think that we've all learnt some enormously valuable lessons"* (K l. 632-633).

However, according to Neimeyer (2000), the process of meaning-making is nonetheless highly personal and idiosyncratic. In contrast to Frankl's (1964a) belief that meaning must be discovered, there is no global 'meaning' that the bereaved person must find, but rather a process of creating or constructing a significant new understanding. Wheeler (2001) has identified some common areas of meaning-making as being altruistically motivated, valuing life, accepting that which cannot be changed, valuing the spiritual above the materialistic, and finding new religious-spiritual beliefs. Some bereaved parents find meaning from personal growth, such as feeling better about oneself, becoming a better person, and pursuing further education.

- *"[We] are more aware of things than we were before. I think we're more appreciative of the good things in the world …I think that we tend to look more towards the positive than the negative"* (K l. 635-638).
- *"Is it going to benefit somebody else"* (K l. 651)
- *"What's the point in being spiteful"* (K l. 641-642)
- *"I feel I've got a lot more solid and comfortable base"* (K l. 619-620)
- *"I've become a more compassionate person, a more patient person, I believe I've become a more understanding person …My approach to things has changed. More caring. The compassion and caring is perhaps an outward manifestation of the change"* (K l. 582-590).

For some parents, learning of the diagnosis leads to a knowledge, or exposure, of the lifestyle of their child, which may be especially intolerable to them (Kander, 1990) as it exposes them to what Moffatt (1986) describes as the experience of shame and the "What-will people-think? syndrome". This is evident in Rosemary's explanation as to why people would prefer to not reveal their positive HIV status:

> *"They emphasised entirely on sleeping around …if [people with HIV] tell, then [others]'ll know, I've been sleeping there, I've been sleeping there and I've been sleeping there"* (R l. 351-355)

This sense of shame may have some roots in the Just World theory (Lerner, 1980) which leads people to wonder why HIV happens to some people rather than others, and how their behaviour may bring it upon then as some form of retribution, and this has been something that has occupied Selinah's thoughts as she attempts to counter possible accusations of promiscuity:

> *"Maybe she did wrong, I don't know … I don't understand this stuff, because she had her first boyfriend and it was the last one"* (S l. 218-224).

Some parents seek comfort in recounting or enumerating how things could have been worse, or how the child is now free of a worse fate such as prolonged suffering. Searching for positive meanings is part of a process of reinvestment in life, not through negating the enormity of the loss, but by finding something in it that was not negative. Allied to this, is identifying the good that has come from the death, which is a legacy of their child (Rosenblatt, 2000):

- *"If those friends of ours hadn't been there we would have gone out of our minds. So to have had that support, you know people speaking to us in a language that we understand"* (E l. 286-289)
- *"You just couldn't believe it, that there could be so many people that were there for us … They're there for you, and the food never stopped coming… I say to these friends from the Moshav, 'You actually can't believe what you did for us'"* (E l. 147-156)
- *"The staff at [the] Clinic when she was in intensive care, were wonderful"* (K l. 167-168)
- *"She was a wonderful patient"* (K l. 180)
- *"[My brother-in-law] …they were wonderful as well"* (K l. 189-190)
- *"She was still so noble, and gracious, throughout the entire process, and I think that was amazing"* (K l. 198-199)

- "*We've been fortunate in what happened to us. When you think of people who've just, when I went to that sibling's event for that presentation, imagine losing someone suddenly, now you see them, now you don't. No time for unfinished business, no time to say goodbye"* (K l. 441-445)
- "*This guy gave us these other books to read … spiritual-type stuff … it was like something was preparing us … for what was going to happen … we were fortunate"* (K l. 485-491)
- "*So I must live each and every day, counting my blessings"* (R l. 391-392)
- "*If I look at other people in other situations, we had friends, family, school, the support base that we had was absolutely amazing"* (K l. 492-493)
- "*My neighbour, she took me into hospital, they have been to me unbelievable. I've never met people like that"* (L l. 530-531)
- "*To me they are good things in all the bad things. I mean if your child dies it's always a bad thing, but I think they were good things. They were signs which he most probably would have wanted me to know*" (V l. 181-184)
- *"I hear families fighting, which luckily we didn't have it, that's one thing I don't even have to be sorry about, … We didn't have anything to make up"* (V l. 601-604).

Religious or spiritual beliefs can provide higher-order cognitive schemas of universal truths and values that provide shelter from chaos and the need to make sense of an essentially senseless event (Tedeschi & Calhoun, 1995). This is especially helpful where God is seen as benign as it can be used to minimize the crushing aspects of an event, by incorporating them into something larger. In the excerpts that follow the participants appear to derive comfort from the belief that although what has happened here is unbearable, this mortal life is a part of a larger existence which is only accessible through faith, and that within that larger existence there what has occurred can make sense:

- "*Pick any religion in the world. Pick any kind of spiritual, psychic or whatever kind of interpretation, there's a common thread that runs through all… that life persists and that we … an embodiment of God. God, supreme being, whatever …and there are just certain functions that you have to perform here and … [my daughter] had done what she needed to do. Cool. Cool, she's done and it's over"* (K l. 511-521)

- *"If you really give yourself wholeheartedly to Jesus, he forgives you … We'll only experience that when it comes to us. Then we'll know exactly what's going on. Right now we're just guessing"* (E l. 412-417)
- *"God doesn't hurt you, and he's not a jealousy God … but death really is devil's work"* (R l. 243-245)
- *"I look at it from, say a spiritual point of view, I believe that everything happens for a reason, and that it's ordained before…a person is born, your life and how you go, what you're going to be in life, what stresses and strains, that you know, to me is a very big comfort … the soul chooses its parents, the life they're going to lead before they … before it comes down to earth … I haven't seen anything physically that substantiates it, but it's just a feeling of comfort that I get from that belief"* (E l. 425-442)
- *"I just know I'm still here, and God wants me to be here … I think maybe he has a reason why he make me stay behind … maybe God does have a reason to make me stay behind, so He's the only one who knows why. I don't because I don't see it"* (S l. 151-160)

This would appear to corroborate findings of Davis and Nolen-Hoeksema (2001) indicating how religious or spiritual beliefs facilitate the process of meaning-making even though this does not put an end to the process of searching or the sorrow.

- *"My life right now is not that nice or happy, …because everything I loved, it's gone. Then I'm living for what? I don't know. I just know I'm still here, and God wants me to be here, but I don't see what I live for"* (S l. 146-150)
- *"So [my belief], to me is a very big comfort. But from the physical and everyday point of view, it's hard to…accept"* (E l. 431-433)
- *"I've had my moments, usually at two o'clock in the morning, but I really do believe that [she] is in a better place"* (K l. 602-603).

These excerpts also substantiate Golsworthy and Coyle's (1999) contention while spirituality or religion may assist the bereaved person in living with the loss it does not reduce the experience of grief. For each of these participants, their faith and beliefs were in place prior to the death of their children and could be made to accommodate the event, even though it may be difficult in the short term, such as Selinah, who felt punished by God, and also angry:

> *"I didn't go to church for a year, I was very angry, asking myself what have I done, so bad, that God have to punish me in that way…I was very angry with God at that time"* (S l. 176-180).

It appears difficult for Selinah to reconcile the losses of her loved ones with her faith, but it seems that gradually it is changing and that attending Church is now a comfort to her,

> *"I think it get better, because the following week I went back to church again … I enjoy the service"* (S l. 199-203)

Williams and Gamino (1998) have commented on how negativity or anger toward a higher power may indicate the mourner's inability to derive a sense of meaning from of the death. However, finding meaning from the death, helps to mitigate some of the sense of anger and is thus able to lessen the severity of the grief response and it appears that for Selinah the meaning is in the sphere of accepting that some does exist to God, even if she cannot as yet know of it. Golsworthy and Coyle (1999) have found that for some their experience of bereavement appeared to shake their faith, leading to questioning and doubt:

- *"I probably said why has God done this to me, and then I think, maybe he's testing me for something, … because they say you get stronger when something like this happens. You know that's just a lot of bullshit. You don't get stronger"* (L l. 590-593).
- *"Maybe there is such a thing as heaven, with God sitting there, you know. But I don't know that. Maybe it's like when a dog dies, the dog's dead and where's the dog going? You know, they say your soul goes, I don't know that. I don't know enough about these things. I know you can't ask questions, because where are you going to get an answer from. That I know"* (L l. 613-618).

However they also suggest that there is a link between personal support and feeling spiritually supported with God being seen as instrumental in the provision of the support. This is most evident when Rosemary says:

> *"Give it to Jesus. He'll take it through with you. Each and every step you make, He's there with you"* (R l. 236-237).

In contrast, Davis and Nolen-Hoeksema (2001) also found that people who are unable to make sense of their loss within six months of the loss, appear to be unable to make sense of it later. In Vasalisa's case this does appear to be so, possibly because, as she comments numerous times, she did not have a religious faith or spiritual framework prior to the loss:

- *"We're not very religious"* V l. 274)

- *“I'm not very spiritual”* (V l. 576)
- *“I'm not that spiritual*” (V l. 638)

It seems that she believes that a religious framework might be helpful for some but not for her, even though she did attempt this:

- *“I don’t know if it’s easier if people are religious, I think, maybe it helps, I don’t know, for some maybe”* (V l. 282-284)
- “*I get out of church and all I want to do is cry … I was actually upset, I was upset that they couldn’t give me more”* (V l. 402-406)

In the following interchange between Vasalisa (V) and the interviewer (I), she makes clear that she still has not made the sort of meaning she would have liked to have done:

(Vasalisa) *I was looking for something.*

(Interviewer) *And they couldn’t give it to you?*

(Vasalisa) *No.*

(Interviewer) *Did you ever find what you were looking for?*

(Vasalisa) *No.*

(Interviewer) *Still not?*

(Vasalisa) *No.*

In her interview Vasalisa uses the words such as ‘logic’ and ‘illogical’ six times when trying to resolve the discrepancies which arise for her as she attempts to make sense of the events that have happened, and more especially those signs which appear to her to be most significant. Events that cannot be fitted into her rational framework are described as ‘odd’ and she ponders over them trying to understand:

- “*What kind of sign could there be between the one and the other?”* (V l. 203-204)
- “*There’s a lot of things we don’t understand. I mean all these signs, but how do we understand signs, but I think we were crazy, I think that’s what we were, and I would say that he,* ***he*** *wanted me down there*” (V l. 269-272)

In certain respects, there are similarities between the strength of her commitment and Rosemary’s, although in Rosemary’s case her strong commitment is in a direction diametrically opposed to Vasalisa’s. There is also similarity between them as both have lost two children, and in addition Vasalisa also lost her father as a young child. The enormity of the losses they each have suffered may cause them to wish to distance themselves from these devastating losses either, in Rosemary’s case, through faith, or in Vasalisa’s case, through a belief in logic and reason, without faith. Whereas Rosemary accepts a pre-digested meaning framework from her religious convictions, for Vasalisa, it appears that a strong sense of rationality militates against the making of meaning coupled as it is with a strong commitment to not having a spiritual framework. It is for this reason perhaps that Vasalisa believes she will never achieve an understanding, because it necessitates the kind of higher-order cognitive schema termed a quantum leap:

- *"There's a lot of things we don't understand. I mean all these signs, but how do we understand signs"* (V l. 269-270)
- *"I don't think a lifetime is long enough to actually understand why"* (V l. 4-5).

According to Rosenblatt (2000) the challenge that death poses to religious belief may be resolved in a variety of ways. For Kevin at the outset, and for Selinah later, it is resolved by not seeing God as responsible for the death, and believing that the child is with God. For Rosemary it is more of not seeing God as responsible for the death, but believing that God chose not to intervene and the sense that only a belief in the existence of God makes the loss bearable. For most of the participants, but especially for Kevin, there is an understanding of the death as part of God's plan, with the child's task on earth was completed. For none of the participants is there a loss of belief in God, as a result of the event. For Vasalisa there is a rejection of religious language, and death is seen as an arbitrary event, a belief that preceded the death of her sons. According to Marrone (1999) loss of a child initiates a process of psychological and spiritual transformation and from the interviews it does appear that for all participants there has been a process of reviewing their beliefs in the light of the loss. Marrone suggests that this process may facilitated by hope for **reunion**, where the parent hopes to be reunited with their child in an after-life;

> *"I really do believe that [she] is in a better place … I also believe that maybe we will see [her] when we go to that better place"* (K l. 603-605).

Reverence, where the child's death is deemed to serve a higher, perhaps inspiring altruistic social service; and **retribution**, where the child's death is viewed as punishment for the sins of the parent thus validating the sense of guilt which is commonly experienced are both evidenced in Selinah's narrative:

- *"Maybe it's just that horrible disease will have to come to her so you can't say this one can't get this, it's too good to get that"* (S l. 214-215) (reverence)
- *"Maybe I did something wrong before God, so maybe He's punishing me for that"* (S l. 238-239) (retribution)

7.1.11 The continued presence of the child in the parent’s life

Rosenblatt (2000) has observed the continued presence of the child in the parent's life in the narratives of bereaved parents. This is achieved through keeping reminders of the child, creating reminders, memories and memorials which are symbols honouring the life of the child.

- *“I mean, I've got photos of my kids …I've got some in the bedroom and some in the study and I take my albums out from time to time”* (V l. 568-573)
- *“I’ve got … all the insertions in the paper, all the cards people sent”* (L l. 83-84)

Continued interaction of parent and child is also evident in other ways. Klass (2001) has enumerated some, quite diverse, sometimes involving feelings and a sense of presence, or having mental conversations with the deceased:

- *“I said [to my daughter], “Here's somebody who is coming. Please be there and help her.” So it's that kind of relationship I don't know if she listens or not, I don't know if she reacts or not. But I don't care actually. You know. She is here. She's around. Of that I'm one hundred percent convinced and there've been instances that have proven that to us”* (K l. 359-365)
- *Sometimes I’m thinking about her when she does something silly or something jokes, or sometimes I … I think about her when she’s singing or doing something, and then I laugh about it* (S l. 358-360)
- *“I drew enormous comfort from [the experience of her presence]. She'd actually made the effort to let me know, “Hey, I'm OK”* (K l. 432-433)
- “*We often talk about her … she was part of our lives and just because she’s not here, it doesn’t mean to say we don’t think about her”* (E l. 369-372)
- *“Life has to go on, but she’ll always be a part of it”* (E l. 353-354)
- *“I'm not that spiritual, that I feel my children that much, but I always think about them”* (V l. 638-639)
- *“You can never let go of a child no matter what their age. They’re always there, part of you”* (E l. 388-389)

In response to a question regarding whether Ella still has a relationship to her daughter, she responds:

“Yes, because I don’t think that she’d like to be forgotten about” (E l. 375)

Klass has also observed that parents keep track of the child's timeline as a way of remaining connected to their child as a way of remaining connected to their child, even though this may set off recurrent bouts of grief as new losses are encountered:

- "*We went back on the anniversary of her death and we took flowers*" (K l. 355)
- "*She was 30 when she died. She's now, let's see, she was, she would be 36 on the 9th of this month*" (R l. 294-295)
- *"It's eight years since he died, eight years"* (V l. 440-441)
- "*But you know, it's five years gone now, five years ago. On the 9th of this month she made five years*" (R l. 290-292)
- *"My son one died on the 3rd of August and the other died on the 16th of February. So these are not good days"* (V l. 489-490)
- *"We went to see my daughter-in-law and my granddaughter and that helps, and their little girl. She's not a little girl, she's in Standard Ten this year"* (V l. 423-425)
- *"So there is four children now, so they become more and more, and there's a lot of birthdays during the year. As I said, my few days I take to my bed, nobody says anything. I think they all know"*

The last excerpt (and to an extent the penultimate one) have a particular unvoiced poignancy: Vasalisa's sons will never again have a birthday, and are not able to see the growing up of the children of the family.

Even after the child has died, there are connections to others to whom they were connected and this gives hope for the future:

- *"There will always be a connection with her husband and her children"* (E l. 363)
- "*I've got her boy, he was 7, now he's 12, staying with me. Her son*" (R l. 225).

In contrast to this, for Selinah, this is not the case because her daughter was her only child:

"I don't know what is my future, I don't see my future" (S l. 152-153).

Golsworthy and Coyle (1999) focus on hope as a significant component of religion imbuing a sense of purpose to the loss. Through providing hope for continued existence, it allows for hope for meeting the deceased again in the next world is and the continuing communication with the child means that the child is still alive somewhere and there is therefore a hope for being reunited with their child in heaven. From the interviews and excerpts quoted above, this is clearly the case as the religious or spiritual framework is able to hold out such anticipation for a happier existence for all participants barring Vasalisa and perhaps Lorraine, although it is though she is trying to keep her options open as she still prays. In addition to hope for reunion with lost loved ones, religion also appears to hold out the hope for forgiveness and the expiation of sins through faith in a forgiving God. This was a focus for both Rosemary and Selinah. It also provides a route for expiation for the guilt experienced by parents with both Rosemary and Vasalisa, who are Catholic, seeking confession:

- *"After [my son] died … I went to confession"* (V l. 447-448)
- *"I even had to come and confess because I so much wanted to be there but unfortunately I couldn't be there. I even confessed … and then after a while it went away"* (R l. 171-176).

Faith in God's compassion also provides hope for redemption for anyone, no matter what went before, almost as an eternal wiping the slate clean:

> *"I don't want to be the judge there but, the way they've told me in hospital, maybe it's God's mercy. Maybe she's with God, because she did get a priest to pray for everything before she goes. They called in a priest, and then I think God forgives us. We can be all a sinner but once you turn to Him, He doesn't say wait for the years that you've been sinning, He forgives you there and then, you've only to beg, really, really meaning it"* (R l. 406-412)

An aspect of religion which may be helpful in a tangential way, is one highlighted by Rosemary for whom the Church provides a supportive social context:

> *"I was very, very lonely, seeing that I've got little family. It's only myself and my children, and my Church – those I know at church like priests"* (R l. 101-103).

Another aspect of mourning that is facilitated by religion, is the funerary rite. According to Fulton (1979), the funeral acknowledges the existence of the deceased. Seeing that the loss is also mourned by others in the community has a positive effect on the bereaved person:

> *"Half the town, schoolfriends, teachers, their children's teachers, neighbours, children of their neighbours, places where they" lived. You know, you just couldn't believe it, that there could be so many people that were there for us"* (E l. 145-149)

Aspects of the ceremony such as the sharing of food (*"the food never stopped coming"*, R l. 153) and social exchanges increase the bereaved person's sense of communal participation. This is clearly indicated in Ella's interview as she discusses this in some detail. Although she is Jewish, specific traditions are different in Israel, so that this experience was a very difficult one for her, describing it as shocking several times, 'horrific' (l. 162) and 'very painful' (l. 306-307);

> *"Customs are so different, …, and … the one thing that is a shocker… [was] when I saw this body that was covered in a velvet cloth, just in a shroud it was… such a culture shock"* (E l. 290-295).

As a result of this, many of the rites and rituals attaching to death were not able to deliver the comfort that she would have normally expected and only serve to increase a sense of non-belonging and alienation. Even the tombstone is inscribed in a foreign language:

> *"When they discussed the tombstone, we weren't included. My son-in-law didn't want anything in English"* (E l. 311-313).

There are also more private rituals that participants refer to which appear to hold great subjective significance which is of a spiritual nature:

- *"We kicked everybody else out and [my wife, my other daughter], the school chaplain and I had time with [the deceased]. We said prayers, then everyone else came in, said more prayers"* (K l. 342-344)
- *"His birthday is on the 6th of July. We decided we take his ashes up on Table Mountain on his birthday"* (V l. 289-290).

7.1.12 Issues relating to stigma and the stigmatisation of HIV/AIDS

Walker, Pomeroy, McNeil and Franklin (1996) have described how the social stigma that attaches to HIV/AIDS is transferred to the person who is diagnosed as being HIV-positive or having AIDS. This shame is partly why Rosemary's daughter was not willing to disclose her HIV status:

> *"In '99 – I can say that this child knew from '96 that she's HIV – but she didn't tell anybody. At that time it was a very big secret, she was so shy in telling people in case nobody would look at her"* (R l. 3-4)

There are other references to the stigma attaching to a positive HIV status:

- *"If I can say I'm positive, people will think I've been sleeping around. It's not because of sleeping around*" (R l. 332-334)
- *"In those years they were very secretive … because they emphasised entirely on sleeping around"* (R l. 347-352)

A visible sign means that the stigmatised attribute itself can be seen irrespective of whether or not the information has been disseminated officially (Goffman, 1963) and the physical symptoms of person who has AIDS can bring this information into the open. The aspect of the illness which is visible is mentioned by both Rosemary and Selinah:

- *"They've got sores all over the body"* (R l. 322)
- *"Shrunken, full of pain"* (R l. 313)
- *"It's very painful … And others are so thin. Why. Mine wasn't like that. She was all right. She wasn't thin to that extent that everybody could see and the others they do get sores"* (R l. 316-319)
- "*I can see the changes, she was getting thinner, and thinner, and thinner and thinner*" (S l. 260-261)

For both Rosemary and Selinah, it appears that they are very aware of the public understanding that AIDS results from immoral behaviour:

- "*[She] she had her first boyfriend and it was the last one. So I don't understand this stuff … So that's why I say, if she did wrong … because I'm not sure"* (S l. 223-225)
- "*Because I couldn't understand, I still don't understand that's why I say I don't know, that's why I thought at that time that maybe God is punishing me. Yes because that was [my daughter]'s first boyfriend and her last boyfriend. Because she was a very open child*" (S l. 233-236)
- *"If I can say I'm positive, people will think I've been sleeping around"* (R l. 333-334).
- *"You can have families and everything; what they do is say 'shame, shame'"* (R l. 96-98).

(The last excerpt is somewhat out of context because the idiosyncratic use of the word 'shame' is a South African cliché. However, it is interesting in this context because of the ability of a stigmatised illness to elicit a sense of shame).

For both Rosemary and Selinah it would appear that some of the content of their interviews reveals that they have been impacted by the stigma of the illness as defined by Herek (1999) who contends that where HIV/AIDS is concerned, there are a number of specific elements that evoke stigma. These include the perception that contracting HIV/AIDS is the result of the immoral; the illness is perceived to be fatal; the transmittable nature of the illness; repellent or ugly physical symptoms. Green (1996) and Sherr (1996) have noted that often women are more likely to be judged as promiscuous, reprehensible or evil. Apart from the earlier quotations, the following excerpts also demonstrate that at some level both Rosemary and Selinah have understood AIDS as resulting from immorality is revealed in their expressed desire for Divine absolution for their daughters. Rosemary additionally believes in the need for contrition and repentance, as well as change of lifestyle:

- *"I would have kept her there, kept her there, to pray now your way, give yourself over, forget about the things now, give yourself over to the Lord"* (R l. 50-153)
- *"Now this is time to turn back to Jesus. Leave your drinking, leave your smoking"* (R l. 81-82).

While Selinah calls AIDS, *"that disease"* (S l. 70), Rosemary implies that it confers a tainted image, *"you can be HIV-positive, you can be clean"* (R l. 40-41).

7.1.12.1 Felt stigma

The stigmatised person is generally well aware of the attributes associated with a particular stereotype and consequently may develop a sensitivity to it that can make social interaction a minefield for the stigmatised individual, particularly so where the stigma is visually evident, and as Rosemary points out, stress exacerbates the illness:

> *"It's as if that somebody sees through you what is your status. It's not like that, it's in your mind …The thing is they don't. It's in your head. They don't see what it is. As long as you take care of yourself. You know, you are happy, you don't sit like this, each and every three or five minutes you cry over this. The people are worrying a lot about this, and it makes them sick and sicker by the day. There's this thing – if you cannot be happy you can't be healthy"* (R l. 119-132)

The role of poverty too is significant in the African context particularly (Green, 1996). Worldwide there is a high correlation between prevalence of infection and poverty reflected in the higher incidence of the disease in poor countries, or people from a lower socio-economic group in more affluent countries. In her interview Rosemary reflects on the further dilemma that once infected, not being able to take care of oneself can make the illness more deadly. Thus in higher socio-economic groups, there may be a perception of lower prevalence of the infection as infected people remain well and socially active to an extent that their status is not obvious. However, for people with fewer resources there may be a faster progression to AIDS and death. Rosemary finds this aspect of not being able to comply with medical recommendations very frustrating:

- *"Not taking care of yourself, and not having the necessary funds to buy what you need, and then you become weaker and weaker, by the day because there are tablets that you can get, but only when you've got money"* (R l. 308-311)
- *"Once you have been tested and they gave you the positive way, accept it there and then. It's hard to accept it … Try to do whatever they tell you to do: eat healthy and all that. We don't all have those monies to eat what they want us to eat, but try just to … calm, stay calm"* (R l. 108-113).

In spite of being able to afford better medical care, the care of the AIDS-infected person is still problematic, and suffering cannot be taken away from Lorraine's son:

- *"When he'd started to go down, … he was in every hospital"* (L l. 362-363)
- *"So many things happened to him, I can't remember all of them"* (L l. 370-372).
- *"The suffering is absolutely horrific, horrific"* (L l. 386-387)

Not being able to take necessary care of oneself may mean that even if the desire of the person who has HIV is to avoid disclosure, this ultimately depends on self-care and this is a further frustration.

> *"They don't [guess a person's HIV status] … as long as you take care of yourself … The people are worrying a lot … and it makes them sick and sicker by the day … if you cannot be happy you can't be healthy"* (R l. 127-132)

7.1.12.2 Issues of disclosure

Powell-Cope and Brown (1992) have researched the disclosure dilemma because revelation may result in negative consequences such as shame and isolation, but secrecy also has negative consequences as the person is exposed to comments about AIDS that may arise out of ignorance of the disease or even ridiculing the condition. Goffman, (1963) believes that where others denigrate the stigmatised group it may give rise to a sense of disloyalty and self-hatred and this is something of which Rosemary shows high awareness of both of these aspects:

> *"It is much better not to be kept a secret … there are still those that are still keeping it a secret, but it is their choice that they choose to keep it that way. But I say if it's in the open, each and every person that approaches you, knows exactly how to approach you. Because now, you can come here, sitting like that. I don't know your status, and if I say why … you're sitting like that, like a person who's got AIDS, and it hurts you, because you know exactly your status. I don't know, and you don't even tell me, that you shouldn't say that because you're like this. Now you're going to hate that person, and*

start feeling sorry for yourself. Let it be out in the open, and then a lot of people will know how to help you, how can they approach you, what can they do when it comes to your … maybe help or something" (R l. 369-380).

In contrast Green (1996) suggests that it is not so much a case that stigma diminishes emotional support from family and friends, but rather the newness of the illness, something which is mentioned by Selinah:

"AIDS … it's a new thing … we didn't grow up with AIDS" (S l. 333-334).

Although it is not part of the interview, after the interview Selinah claimed that she was not personally ashamed that her daughter had died as a result of an AIDS-related illness, and during the interview, when asked whether AIDS was different from other illness, she replied:

"I don't think so because anybody who loves anybody to see them getting sick…it can be any illness in the world, if someone can't get better, then it's very sad" (S l. 330-332).

Lorraine also believes that what differentiates AIDS from other illnesses is the suffering, which she tends to equate to that of cancer, and does not mention the stigmatising aspects of the illness:

"[AIDS] was just different from other illnesses. Well, God forbid, that you've got cancer, … that's …, something different, but ahh, this AIDS!" (L l. 425-427).

Perhaps the fact that Selinah, and perhaps also her daughter, did not identify the illness until it was too late to change its course may be attributed to Selinah's lack of knowledge about the illness:

"When we found out … it's a very, very, very late stage" (S l. 63-64).

However as Barolsky (2003) has found, in South Africa, sufferers prefer not to disclose their HIV status to other family members so that once the disease manifests, death tends to follow swiftly and in this respect the situation for the daughters of Selinah and Rosemary was unlike that of Lorraine's son, who disclosed his HIV status 8 years prior to his death. In many cases where the cause of death is AIDS-related the bereaved may isolate themselves so as not to publicise the cause of death, and this cuts them off from help, support and other resources which normally help the bereaved to cope with their loss but this has not been the case for these participants who participated because they have disclosed. In this respect there appears to be a correlation between the willingness of Lorraine, Selinah and Rosemary to participate in the study, and their willingness to make the cause of death public knowledge.

7.1.13 The view of HIV/AIDS as a latter-day plague

In common with other plagues AIDS is considered as being repulsive, invasive and retributive in character, striking as a punishment for personal or communal immorality or licentiousness (Sontag, 1991). The pre-modern conception of illness which is seen as supernatural punishment:

- *"Why must people suffer like that, what have we done? … I told myself the end of the world it's near. But now, is this the way we are going to leave this world? … Because some other times it was floods … fire… But now I think it's a [plague] really"* (R l. 322-328).
- *"What have I done, so bad, that God have to punish me in that way?"* (S l. 177).

Selinah remembers how her daughter gave her directions which are contrary to the culturally-prescribed custom of distributing her clothes after an appropriate period of time. Historically, clothes were burnt in the case of leprosy, at one stage a stigmatised plague-like illness (Sontag, 1991):

> *"She said to me 'Don't give anybody my clothes. Those you don't want, you must just burn them,' that's what she told me. She said I must burn them"* (S l. 273-275).

Rosemary's distinction that, *"you can be HIV-positive, you can be clean"* (R l. 40) also appears to hark back to biblical times when lepers were obliged to be separate from the community and to announce their presence as unclean.

Barolsky (2003) notes that in the South African extended family, the care-giving role falls to women, which is the case for all three participants, although in Lorraine's care there was more assistance in the form of nursing staff and greater access to medical facilities. Barolsky also suggests that in traditional culture blame for illness is assigned to women and it is interesting how, in Selinah's case she does appear to consider taking on the blame for her daughter's illness.

7.1.14 The trauma of witnessing the suffering of the person with AIDS

According to Hyer and Brandsma (1999), and Neimeyer (2001b) traumatic losses, which include deaths resulting from disfiguring deaths or deaths at an inappropriate life-stage, are characterised by cycles where survivors are subject to traumatic memories and the attempted avoidance of such memories. The progressive physical and mental deterioration of the AIDS sufferer is painful to observe to the extent that caregivers may wish for their suffering to cease (Worden, 1991).

- "*It was so hard, when you've got a sick person, day and night, you can't sleep, you can't eat, so I don't know how did I survive that*" (S l. 122-124)
- "*She was getting very thin and needed help, so she was here with me day and night, and I can see all the changes, and sometimes I get so scared, I don't know how I got through it, I really don't*" (S l. 244-251)
- "*[It] make[s] you sad seeing somebody lying there, if there is not anything the doctors can do about it*" (S l. 335-336)
- "*Why at the end must you suffer like that. Shrunken, full of pain. It's very painful, it's very painful. And others are so thin. Why. Mine wasn't like that. She was all right. She wasn't thin to that extent that everybody could see and the others they do get sores*" (R l. 313-319)
- "*He used to be lying on his side, and I'd kiss the back of his head, and I couldn't, I used to say to [my husband], I couldn't watch. I used to stay there maybe 10 or 15 minutes, and then I'd come home, and say, I can't bear to see this. I just can't*" (L l. 445-448).

Watching such suffering is extremely hard for Rosemary and Selinah, and perhaps it is no coincidence that neither of them was able to be present in the dying moments of their daughters, something that Rosemary bitterly regrets because of the preceding ill-humour between them. This supports the contention by Tedeschi and Calhoun (1995) that traumatic deaths cause the most distressing psychic pain because of the difficulties in integrating the change to internal meaning structures especially where the self-theory is insufficient to contain such change.

Barolsky (2003) has established that where there are orphans after an AIDS-related death, the caretaking function and parenting role may fall upon grandparents. This is the case for Rosemary who is now raising her daughter's son, now 12 years old. The interview does not reflect how much is invested in the hope for this grandson to do well at school and become a professional (for which she means a medical doctor), as this emerged during further conversation during leave-taking. It may be conjectured that the very instrumental style of her grieving is dedicated to this end. Hence, as Barolsky has observed, raising a grandchild may be viewed as an opportunity for a 'second chance' to redeem what they now believe was an earlier failure at parenting.

7.2 Comparison of themes occurring in the interviews

This section seeks to compare to what degree there is concordance in the themes identified from those parents who have lost a child as a result of cancer, a long-term illness not currently stigmatised in South Africa, and AIDS which is stigmatised.

Experiences of dissociation, disembodiment and dislocation are common to most of the participants irrespective of whether the illness concerned is cancer or HIV/AIDS even though it may occur at different times for them, which is not necessarily when they first get the news of the illness. It appears difficult for participants to explain this sense, and they rely on analogies or the use of, “as if”. There are references to not being in one’s body, of things having a dream-like quality and of seeming unreal. Part of the difficulty arises from juxtaposing the enormity of the event, with a reaction that is not in keeping with this magnitude. It is also difficult for participants to understand how the world outside does not mirror the internal one so that one’s sense of being split apart should be reflected in a splitting of the landscape. This interlocking of bodiliness and spatiality lends a very specific and individual flavour to the experience. This is indicative of how the sense of self is utterly transmogrified by the event so that the once-familiar world they occupied is now utterly foreign as indeed is their sense of who they are.

Another common theme is the sense of the power of the event to bring about a disintegration of the sense of self of the person and participants used expressions such as feeling as though they were falling to pieces, being flooded and not being able to survive. Thus the event which can create such dread-filled dislocation and disembodiment is felt as being severe enough to threaten personal survival, the coming to an end of one’s very self through death, either voluntarily or involuntarily. Hence, it is possible that the sense of dissociation, of not feeling as though one is part of oneself is a way to create a sufficient measure of distance from the awfulness of the situation in order to be able to survive, at least until other mechanisms are in place. Denial at this point is a form of rejection of the information and serves a similar end, by deferring having to accommodate this change, in order to cope with the requirements of daily living that are more urgent. In no case was there much detail about the dying process itself, and in some cases it was glossed over entirely. Where it is reflected on it tends to be done with great simplicity as a pithy statement of fact. Perhaps this also serves to illustrate to what degree the behaviour of the bereaved is automatic at that stage, without a strong sense of actually being present.

For all participants there is a sense of standing back with amazement when reflecting on how they managed to cope particularly during the period of illness prior to the death of their children. This appears almost as a type of dissociation in itself, where at times the person engages a coping persona, while at other times another persona is evident, one that is more concerned with the immediacy of the event, and a ventilation of emotions appropriate to the event.

The focus on the chronology of events is interesting and common to all of the interviews. Such an approach lends coherence to the narrative, which is greater than the enumerated events. Instead it presents to the listener a flowing sense of the experience as it moves forward in time. Consciousness of the event, embedded as it is in this temporal reality, also moves in tandem with events. Thus as events change with time, so does the consciousness, almost by implication. For instance, in the nursery rhyme, Solomon Grundy, the narrative cycles through an entire existence captured in fast-forward motion. Though the words are minimal an entire life is lived flashing through a shared awareness of these various experiences: Solomon Grundy, born on a Monday, christened on Tuesday, married on Wednesday, took ill on a Thursday, worse on Friday, died on Saturday, buried on Sunday. This is the end of Solomon Grundy. This was evidenced most clearly in Kevin's interview.

Another area where participants devoted a substantial portion of the interview is on the experience of being with their dying child. Even where the diagnosis has been understood, and there is evidence of the effects of the illness, there are periods characterised by hope. This hope may be aroused by temporary or partial remissions during which time the patient seems somewhat better. However, the inevitable relapses give rise to despair, of almost having to receive the news afresh.

In attempting to understand how the illness affects the relationship between parent and progeny, it is evident how much of the parent's sense of self is bound up in their child because the sense of self is experienced in a communal sense. Moreover, the objective existence of the child is matched by an equivalent subjective existence within the parent so that a change to the one necessitates a change to the core components of this existence. The prior communal understandings of living, worthiness and dying are transformed by the son or daughter who moves from one state into another so that the experience of the one puts the person in touch with that experience in a secondary way thorough being with the one who is undergoing it. Thus for parents the confrontation with death is not purely something they witness, but rather it enters their consciousness in an intersubjective way where there is a "dying to" something for them as well. This occurrence finds expression in different ways for different participants, such as trying to understand the nature of death as something that is contained within a more complex understanding of life, or by feeling as though it is the end of existence, or by becoming more intensely aware of one's own mortality.

As participants reveal the lived experience of their world, it becomes obvious that this event is cataclysmic to them insofar as it catapults them into an alien landscape, devoid of all those once-familiar route-markers which made it possible to traverse. The old world is all around, and the person lives within its confines, subject to its regulations, but it can never again be accessed, never again be one's own, rather as though one has stepped through a one-way mirror. The old meaning structure is no longer valid, nothing appears familiar, and even visiting oncecomforting old haunts or hearing a familiar song is fraught with memories which threaten one's survival, creating intense anxiety and dread, or as Attig (2001) has termed it, soul pain. That which once was sustaining is found to be empty of nourishment. How then to survive becomes an issue which is answered with difficulty. Negotiating a new route through this landscape represents an enormous effort and once any is established, it represents a significant achievement perhaps a kind of *bit map*, which lends some degree of comprehensibility that aids in maintaining a sense of self in the face of threatened disintegration. It is perhaps for this reason that such emphasis is placed by participants on recounting how certain decisions have been taken to do things which they wish to do. The value of these idiosyncratic resolutions is not so much that they represent a final solution or even an adequate one, but rather that they enable the bereaved person to form one small new familiar map in this untested terrain. In this respect the value of retiring to one's bedroom for a few days, or of avoiding dwelling on certain thoughts, or rejecting well-meaning but useless suggestions, become small lifelines. Exerting a small measure of control in small areas external to one may help to establish a sense of agency which combats the helplessness and powerless that characterises their position and which is an illustration of throwness as described by Binswanger (Maddi, 1972).

It appears to the participants that the world is divided into those who have lost a child and those who have not done so. The experience of it makes clear to the bereaved that not only is their world changed by this experience, but so are they, in a way which no other experience in their lives has been able to do. Thus they believe that it is not possible for someone who has not experienced such a loss to fully understand the impact that it has. This experience is so defining, and has such a capacity to change the person so bereaved that it makes them feel alone in a world full of people, and the sense of being alone, set apart or different was marked in all of the interviews. There are also references to how they see that others judge their behaviour to be aberrant, or even crazy. For the bereaved person, now living behind the one-way mirror, it is possible to understand how others view them better than its converse, they themselves lived there before, and there is a realisation that to know or see what has occurred, is not the same as living through the experience. A tension develops between fulfilling a personal desire for mourning in a way that may not be considered as healthy by others, and the wish to maintain sufficiently functional relationships which enable the bereaved to continue living in this new existence.

There are areas of commonality in the way cancer and HIV/AIDS are perceived by all participants. Both are seen as fatal illnesses, which can result in such suffering for the patient that it is painful for anyone who witnesses it. Another commonality is the change that the illness brings to the relationship between parent and child, and how the concept of the both parent and child is altered by the experience. However for the participants whose adult children have died as a result of HIV/AIDS, the response seems to be more intense with more references to the traumatising effect of it, so that even memories of the illness are extremely painful and attempts are made to consciously avoid them. There are numerous references to the suffering that AIDS causes and the sense of powerlessness caused by the inability to alleviate the suffering of the patient. There is also a difference in the metaphors that are applied to the two illnesses: as regards those which are applied to cancer, these are often of a combative or martial nature, but those applied to HIV/AIDS refer to it as a plague and attribute to it an evil nature.

A noteworthy divergence occurs between the participants as regards the issue of retribution and punishment, which does not appear at all for those parents whose children died from cancer, but which is addressed at some length by two of the parents whose children died as a result of an AIDS-related illness. In addition to questioning whether their child could have been infected as a result for wrong-doing, there is also a question of whether their child could have become ill as a result of any parental wrong-doing and this does appear to place a particular burden of sorrow on the grieving parent. Another divergence is how each participant whose child had died from AIDS spoke of the illness as a 'test', perhaps of Divine provenance, while no participants whose child died of cancer mentioned this aspect.

Finding participants whose children have died as a result of cancer was a straight-forward task, but an finding participants whose children have died as a result of AIDS-related illness proved to be a difficult task. Of the numerous members of TCF, only two in Gauteng gave this as a cause of death and this is significant in itself as epidemiological statistics indicate that an AIDS-related cause of death is the most prevalent in the young adults age group. Requests were also made to Hospice through a social worker, but no one volunteered their participation.

It seems that being able to appeal to prospective participants on the basis of shared membership of TCF was the most effective means for recruitment of participants, whereas when the request came from a third party it was not successful. The three participants who agreed to participate and whose adult children died as a result of AIDS, did not appear to exhibit any overt sense of shame of the cause of death. They indicated that the significant issue as regards AIDS is that it has been the cause of death of their children. In spite of this, for two of the participants, there was a difficulty in enunciating the name of the illness, and one of them expressed very clearly the sense of felt stigma, describing an internal dialogue where she argues with herself to counter the impression that others are able to perceive a person's HIV-status simply by looking at them.

It appears that whatever the cause of death of their son or daughter, that those parents who participated in this study, share a number of similarities regarding changed understanding of their world, both in relation to others and to themselves and this necessitates a re-understanding of their world, and the forging of new meaning structures that can accommodate the loss. It would also appear that the traumatising aspects of witnessing a painful disfiguring death, coupled with fears of retribution and punishment tends to increase the severity of the process. The process of forging such new meaning structures tends to be idiosyncratic for each participant and is often orientated around negotiating daily challenges such as keeping traumatising memories from becoming overwhelming.

In conclusion, this chapter has attempted to demonstrate how the literature which has accounted for the various phenomena relating to parental bereavement was reflected by participants in the interviews. There was also an attempt to compare areas of commonality and divergence between participants whose children have died from cancer and those who have died as a result of AIDS so as to present an integrated delineation of themes. From the copious quantities of data as presented in the previous chapter, phenomenological methodology enabled a unified and rich understanding of the experience under investigation which reflects the complex and nuanced phenomenon which underlies it.

Chapter 8

8. Personal reflection, evaluation, recommendations and conclusion

This final chapter presents a reflection of the experience of the researcher and recommendations for therapeutic practice which arise from the conclusions as presented in the preceding chapter. There is an evaluation as regards the strengths and limitations of the study and recommendations for future research. The unique contribution of the study to the field of psychology is also addressed.

8.1 A personal reflection on the experience as researcher

The process of bracketing, which is essential in phenomenological research, can be facilitated by keeping a journal of the process where the researcher's personal shifts can be recorded as they occur. Of particular interest are those issues that are taken for granted as these are revealing of the in-built societal discourses. It is thus necessary for the researcher to pay attention to how and when these understandings emerge so as to be able to test them. All of this is essential in developing a self-reflexive stance by which the researcher is able to demonstrate an awareness of his or her own role as participant in the research process. It is this self-reflexive stance that contributes to the rigorous nature of phenomenological research. The contents for the section that follows were derived from such a journal of the research process.

Having worked in the field of parental bereavement as a volunteer counsellor for about 8 years, during which I have seen perhaps over 100 parents, I did not feel daunted by the idea of interviewing bereaved parents as it seemed to me that I had an understanding of the difficulties that such work would entail. Meeting bereaved parents as a counsellor, necessitates that they share their experience, often the most difficult and painful of their lives, and this was also the requirement in the context of research. On my first interview however, I discovered that interviewing parents in the role of researcher is very different from being with them in the role as counsellor and also-bereaved parent. During the counselling of bereaved parents, feelings of helplessness, panic, fear and intense sorrow are frequently experienced for both client and counsellor, but the process is conducive to their expression and subsequent containment. As an interviewer however, this process is not available to one, so that it seemed that by asking for this experience to be laid out to view was both intrusive and hurtful with no opportunity for relieving the painful feelings it brought up. For instance, during one of the interviews, the participant became very distressed and as she cried, put her head on her arms which were resting on the table and said very softly that she could no longer take it. The sense of helplessness that this engendered in me was so unbearable that it fuelled a strong desire to leave, as it seemed to me that I could not, would not, take it. On the whole however, the composure of participants was at odds with the content of their narratives, and the enormity of it became more obvious through its analysis.

There was also a difference between listening to stories of bereavement and transcribing them. When listening to someone telling a story of their lives, or their children's lives, the actual time that one is confronted with a particular comment as a listener, tends to pass quickly as the speaking moves on, somewhat relentlessly, perhaps rather like a flowing river. In the process of transcribing the interviews however, I would listen and re-listen to the tape, replaying a particular phrase as often as needed to capture the spoken word to transmute it into written speech. Somehow the significance and full implication of the words would be boosted, with the enormity of particular phrases echoing again and again, each time increasing in its affecting power, so that there came a time, in each interview, where I had to break, in order for me to regain composure. For instance, during the interview Kevin appeared composed and coping and as a result of this, it was possible for me to minimise some of the impact of the story of his daughter while listening to it. However in the interview he recounts how, when his daughter was dying, he urged her on, telling her, that the time had come for her to go. The hearing and re-hearing of this aroused an intense sorrow which could no longer be hidden in the 'business' of the story as I entered that world, for an instant, to realise what it must take to get to that point with one's own child. At that moment the pain seemed almost unbearable.

During the interviews an image that would flash in my mind was a scene from the film Beetlejuice (Burton, 1988) where the protagonist, played by Geena Davis, has died unbeknownst to her. She finds herself in her own house, which, while familiar in every respect, is at the same time strangely odd. She steps out of the back door for an instant, whereupon the house disappears and she is cast into a boundless, featureless infinity of yellow sand. To complicate matters a large worm-like creature appears threatening to swallow her up. Thus as the participants shared accounts of their worlds with me the intense sense of dislocation became very tangible. Reflecting on these experiences put me in touch with the difficulties inherent in being with a person suffering intense pain. If the capacity for empathy arises from the observation of the other's response that gives the person an awareness of their experience of it, then the listener has access to another's experience as a perception of a raw event in much the way a memory is related to a natural event. As described by Moran (2000, p.177), "the other then is a phenomenological modification of myself, … grasped only 'within my ownness'". In this sense it acts rather as an analogy so that, "when I experience another person, I *apperceive* them as having the kind of experiences I would have if was over there" (Moran, 2000, p.177). Thus the difficulty for the listener is less a problem of lack of understanding, but of too much understanding of the situation. The human vulnerability revealed in the suffering of others, and the seeming inability to contain it within oneself, provokes a desire to soothe the pain of it for the sufferer (and consequently for the self) by reducing or by escaping it. This indeed appears at the heart of many of the social difficulties that the bereaved parent experiences. While others are sympathetic to the plight of the bereaved parent, their felt inability coupled with the extreme discomfort that such contact engenders is manifested in many of the reactions that bereaved parents find distressing. These include avoiding the bereaved or offering well-meaning but sometimes spectacularly insensitive comments, and these situations are common themes in bereavement counselling. In light of this, it is interesting that of the thousands of articles which have been written on the subject of bereavement, that this aspect has not been researched.

The reaction of others in the social group becomes clear to the bereaved parents and there were various references to this in the interviews, so that over time they learn to present two different façades. One is the coping self, which is presented to the world in general, and which enables the person to manage their day-to-day existence both at work and from a social perspective. It seems that bereaved parents thus become adept at sensing how they need to present to others so that the façade presented is more a function of the ability of the person receiving it than a representation of the experience of the bereaved parent. The other façade surfaces only when they believe that it will be accepted. This might explain the sense I experienced that my status as bereaved parent gave me legitimacy in the eyes of the participants as someone whom they believed would 'understand'. Introducing myself as a member of The Compassionate Friends (TCF) made my status as bereaved parent overt because all members of the organisation are bereaved parents. Most of them referred to this when greeting me, and Kevin defined bereaved parents as members of a ‘band’ of people who are distinct from the general population. Furthermore, he inferred that my status qualified me for an equivalent membership which would make me eligible for understanding the significance he had attributed to the events which he had experienced. Further support for this idea was provided when Ella she confided that she had initially felt hesitant about participating in the research until my status was confirmed to her.

Seeing bereaved parents in their coping mode provides a comfort to the people around them because it fosters the hope in others that it is possible to survive such a loss that has the ability to arouse such a sense of personal vulnerability and existential anxiety. For the bereaved parent however, it appears that there is also a strong need to express the grieving aspect as well. It is almost as though a strong sense of rationality militates against the making of meaning. Events stand out for the participants in a way that needs to be recognised, and yet the significance of these events is not accessible for understanding in the normal way. This may go some way to explaining why for bereaved parents there is a sense of understanding the world differently which non-bereaved parents cannot easily do. So in a sense if these are to be understood, there has to be a stepping out of the accepted and acceptable stream of social thinking and this occurs in the periods of active grieving. Thus the value for parents of such endeavour may be that it assists in the process of meaning-making.

8.2 Implications for therapeutic practice

It would appear from the above that even in therapeutic practice, the bereaved person will only present their grieving façade if he or she believes that the therapist will be able to manage its presence. The presence of the client in the therapeutic situation in and of itself may indicate that he or she is at a particular nexus in their process which is negatively impacting on their ability to manage the requirements of daily living. In this respect, enhancement of coping behaviours is important to ease the sense of being stuck and refresh hope. However if the therapist signals that this is all that is under review, the client will not move out of this sphere and it may appear to the therapist that the therapeutic objective has been achieved.

Venturing into the realm of the aspect which may be actively grieving does have benefits however, as has been noted in the interviews and these benefits are in regard to making new life meaning from the experience. Much of the meaning that is created, may appear less than comprehensive and may attach to seemingly unimportant events. For instance, for Lorraine, having her neighbour 'see' her state and evidence this in spoken speech, appears very significant. As is the case in this example, it also tends to be idiosyncratic. Perhaps it was significant for Lorraine as it gave hope that that her suffering is witnessed and hence real.

Staying with the vivid image of a desert landscape, which the interviewing process evoked for me, and using it as an analogy, it is possible that this could proffer some possible ideas for therapeutic intervention with bereaved parents. When cast in such a featureless, boundless environment, the sense of dislocation is unbearable and puts survival into question. There are no markers, or familiar sights that give a clue to a way out or a way back. For the person in such a situation, making one place stand out, by planting a marker, would provide a little area of familiarity, a new reference point. If another is created, and then another, even if a little way apart, this begins to provide a small, now newly-familiar route, so that eventually whole areas are mapped providing an oasis where resources can be gathered for survival even though the greater landscape is still alien. Finally these markers can be linked by string to begin to provide some boundaries and form to the boundless and formless vastness. Like the Odyssey of ancient myth it behoves the therapist to navigate between the Scylla of personal threat and annihilation and the Charybdis of imposing meaning as pre-digested salvation. Unlike common misconceptions of meaning as an all-encompassing framework of spiritual significance, from the interviews it is evident that the meaning that emerges for most participants is limited in scope and immediate value, and often seems frail or mundane. Creation of meaning is laborious and takes time to mature and evolve. That is not to say that lesser meaning is worthless, but rather is sufficient to enable the getting up in the morning to face a new day in spite of the pain carried within. Ultimately its value will be perceived in the image that is created after a considerable period of time, because up until such time, only small elements will be visible. Once it does emerge however it becomes a guiding force that can lead to transformation. To summarise, some elements that might be beneficial in grief work would include:

8.2.1 To accept the invitation

This refers to accepting the client's invitation to follow them into the world of that part of themselves which is grieving. This is done in the knowledge and assurance that the aspect of the client that enables them to cope with the needs of life is competent and able to still continue with its task. This also implies that should the client signal a need to manifest denial, this is considered part of the mechanism for self-protection.

8.2.2 To witness

This refers to the viewing the world as it is now for the client. The story of the loss may be a starting point, but as the narrative develops the difference between the world as it was, and the world as it is now, tends to emerge. The purpose of this is to bear witness to the client that this new world is as visible and real to the therapist, who is a third party, as it is to the client.

8.2.3 To validate

This refers to reflecting back to the client that the world does indeed look different and a return to life as it was before the loss may never happen. Those elements that stand out for the client become markers. The purpose of validation is to certify the efforts made by the client in attempting to create new small areas of familiarity in a vastness of uncertainty.

8.2.4 To accompany

This refers to continuing the above process with the client, bearing in mind that the small areas mentioned are often revealed in the catalogue of experiences arising from the minutiae of daily living such as shopping or driving. An expectation for particular forms of meaning to emerge would become in itself a 'tyranny of meaning-making'. The focus at all times should be on a participative accompaniment of the client on the journey that he or she is undertaking.

8.2.5 To encourage linkages

This refers to the process of continuous review of the landscape, where individual small areas of familiarity are linked by themes and united in a conceptual sense. It requires that the therapist take a bird's eye view so that more than just the immediate environment is in sight. The therapist may act as an external aide-mémoire offering confirmation to the client of how far he or she has come.

8.2.6 To offer hope

This refers to a hope for a life which has a semblance of control and familiarity. Control arises from being able to reflect on how through one's agency the landscape has altered a little. It is also helpful to occasionally refer back to the landscape as it was at the outset, and how it is now mapped out with various reference points, even if much of it remains unmapped.

It is hoped that these guidelines will offer assistance for the therapist who accompanies the client through a journey through the landscape of their grief in order to identify new meaning structures that can accommodate the enormity of their unique lived experience.

To conclude, Eliot well captures the sense of this journey in the words of a poem:

In the dark time of the year. Between melting and freezing
The soul's sap quivers. There is no earth smell,
Or smell of living thing.
…
If you came this way,
Taking any route, starting from anywhere,
At any time or at any season,
It would always be the same: you would have to put off
Sense and notion. You are not here to verify,
Instruct yourself, or inform curiosity
Or carry report.
…
And what the dead had no speech for, when living,
They can tell you, being dead: the communication
Of the dead is tongued with fire beyond the language of the living.

T.S. Eliot
Little Gidding, 1942.

Since time immemorial humanity has been confronted with loss, and the loss of a child is the perhaps the darkest time of life, when the soul's sap quivers. Such an experience is beyond time and space, a desert of the soul. However they present, the processes which follow appear in many ways to be inexorable. The process requires the mobilisation of all personal resources, and then should these prove insufficient, the creation some new ones.

Even though it is possible to survive such bleakness, the process of such survival challenges the bereaved person and requires of them to transcend despondency and trust that the soul's sap will indeed rise once more.

8.3 The unique contribution of the study

This phenomenological enquiry of the lived experience of parental bereavement, especially that which follows on the death of an adult child as a result of AIDS which is currently a stigmatised illness in South Africa, has yielded some pertinent insights into the phenomenon. In particular, the felt experience of the retributive aspects of the illness were in contrast to those of parents who have also suffered the loss of an adult child as a result of cancer, a long-term illness which is not currently stigmatised in South Africa.

Furthermore, the study revealed some of the dynamics involved in the reconstruction of meaning structures that underpin an understanding of the world for the bereaved parent, regardless of whether the cause of death was stigmatised or not. It would appear that bereaved parents tend to regulate shifts between coping and active grieving. While active grieving may be emotionally challenging, its value may lie in its capacity to enhance the process of meaning-making.

The research also suggests that the effect on those who have a tangential connection to the grief through contact with the bereaved parent is significant enough to desire them to wish to modify such experience. The effect of this also plays a role in how the bereaved parent feels obliged to present him- or herself to the world.

8.4 Recommendations and implications for future research

As was noted in Section 8.1, an area which has been identified as a result of this study is the paucity of research as to the effect on others of being with a bereaved parent. In a country with a high prevalence of HIV/AIDS infection, the number of bereaved parents will undoubtedly increase and so research in this field would offer some useful and pertinent insights, especially if it is considered that recent research, such as that by Bonanno (1999) confirms the importance of social support for the bereaved.

8.5 Strengths of the study

The following strengths of the study have been identified which point towards the validity, value and pertinence of the study:

- The phenomenological framework of the study generated a description which transcends the listing of attributes, and adds a complex and textured quality to the understanding of the phenomenon of parental bereavement, especially in the context of HIV/AIDS.
- The use of participant quotations from the raw data has added to the validity of the study and reduced possible researcher bias.
- A comparison of the research findings with previous research findings from the extant body of literature, furnished many correlates that consolidate the findings of the present study.
- Finally, the commonalities which emerged despite the diversity of participants, and hence of those variables attaching to the participants, serve to demonstrate the ubiquity of the experience as observed in the research.

8.6 Limitations of the study

The following limitations are found to apply to the current study:

As phenomenological research is qualitative, focussing rather on attaining a depth of understanding as regards the phenomenon, the number of participants is necessarily limited. However such a sample size cannot be held to be representative of the lived experience of parental bereavement, either as a result of a stigmatised or non-stigmatised death of adult offspring in South Africa. The limited sample of six participants, while yielding some fundamental insights, is thus insufficient to draw conclusions regarding correlations or causality between variables. The use of quantitative research would be able to clarify some of these providing information that complements that which results from qualitative research such as this study.

Although the study set out to explore the possible role of a stigmatised illness as the cause of death for the progeny of the bereaved parents, it was only possible to access those parents who have elected to disclose this fact. Hence, those parents who most fear the possible consequences arising from such disclosure were unwilling to participate in the study, so that the central issue may not have been addressed.

The subjective aspect of the interpretive process means that the data could have yielded different results if it had been analysed by a different researcher. The bias of the researcher may have introduced bias in the analysis of the data relying as it did on interpretive processes. To reduce such bias the following strategies were followed:

- The researcher strove to bracket personal presuppositions.
- Validation of themes identified in the analytic process was achieved though direct quotations from the raw data.
- Transcriptions of interviews were faithful to the material recorded.
- The researcher compiled field notes and kept a journal.
- The literature was studied extensively, and where possible was utilised to qualify and support the findings of the study.

8.7 Conclusion

In conclusion, it is observed that the experience of parental loss may be renderend differently where the cause of death of offspring is AIDS which is a stigmatised, and stigmatising, illness. In particular, the traumatising aspects of witnessing a painful disfiguring death, coupled with fears of retribution and punishment tends to increase the severity of the process. However, it is also observed that there are more commonalities than divergences regarding the phenomenon of parental bereavement especially in regard to transformation in the understanding of the world, both in relation to others and to the bereaved person himself or herself, which necessitates the forging of new meaning structures that can accommodate the loss. Such new meaning structures tend to be idiosyncratic and their value can only be fully comprehended through an understanding of how they facilitate the construction of such new meaning structures. The phenomenological framework for the research yielded rich descriptions that bore faithful testimony to the complexity of the phenomenon.

References

A leader who still had much to offer. (2002, June 10). *The Star,* p. 1.

Alubo, O., Zwandor, A., Jolayemi, T. & Omudu, E. (2002). Acceptance and stigmatisation of PLWA in Nigeria. *AIDS care. 14(1),* 117-126.

Antonovsky, A. (1979). *Health, stress and coping.* San Francisco: Jossey-Bass

Arbuckle, N.W. & de Vries, B. (1995). The long-term effect of later life spousal and parental bereavement on personal functioning. *The Gerontologist, 35(5),* 637-647.

Arendse, I. (2004, 2 May). AIDS killed my son – Buthelezi. Retrieved June 24, 2004 from the World Wide Web: http://news24.co.za

Arnold, J.H. & Gemma, P.B. (1994). *A child dies. A portrait of family grief.* Philadelphia: The Charles Press Publishers.

Attenborough, R. (Producer and director), & Eastman, B. (Producer). (1993). *Shadowlands* [Film]. New York: Savoy Pictures.

Attig, T. (2000). Anticipatory mourning and the transition to loving in absence. In T.A. Rando (Ed.). *Clinical dimensions of anticipatory mourning: Theory and practice in working with the dying, the loved ones, and their caregivers,* (pp. 115-133). Champaign: Research Press.

Attig, T. (2001). Relearning the world: making and finding meanings. In R.A. Neimeyer (Ed.). *Meaning reconstruction and the experience of loss*, (pp. 33-53). Washington, DC: American Psychological Association.

Bailey, B.J. & Gregg, C.H. (1986). Grief, pathological grief and rehabilitation counseling. *Journal of Applied Rehabilitation Counseling, 17 (4),* 19-23.

Bailley, S.E., Kral, M.J. & Dunham, K. (1999). Survivors of suicide do grieve differently: Empirical support for a common sense proposition. *Suicide and Life-Threatening Behavior. 29(3),* 256-271.

Ballard, E.G. (1967). Gabriel Marcel: The mystery of being. In G.A. Schrader, Jr. (Ed.) *Existential philosophers: Kierkegaard to Merleau-Ponty,* (pp. 209-260). New York: McGraw-Hill Book Co.

Balk, D.E. (1999). Bereavement and spiritual change. *Death Studies, 23(6),* 485-484.

Barolsky, V. (2003). *(Over) extended: AIDS review 2003.* Pretoria: University of Pretoria

Barron, C. (2002, June 16). Peter Mokaba: Obituary. *The Sunday Times,* p. 17.

Barroso, J. & Powell-Cope, G. (2002) Metasynthesis of Qualitative Research on living with HIV infection. *Qualitative Health Research*, *10* (3), 340-354.

Bate, S.C. (2000). Good news in a world of AIDS. *Trefoil, 67 (264),* 39-49.

Baures, M. M. (1996). Letting go of bitterness and hate. *Journal of Humanistic Psychology, 36(1),* 75-90.

Becker E. (1973). *The denial of death.* New York: Free Press.

Bengel, J., Strittmatter, R. & Willmann, H. (1999). *What keeps people healthy? The current state of discussion and the relevance of Antonovsky's Salutogenic Model of health.* Cologne Federal Centre for Health Education.

Benoliel, J. Q. (1979). Dying in an institution. In H. Wass (Ed.). *Dying: facing the facts,* (pp. 136-157). Washington: Hemisphere Publishing Corporation.

Berger, P. L. & Luckmann, T. (1967). *Social Construction of Reality, a Treatise in the Sociology of Knowledge.* London: Penguin.

Biller, R. & Rice, S. (1990). Experiencing multiple loss of persons with AIDS: Grief and bereavement issues. *Heath and Social Work, 15(1),* 283-290.

Bonanno, G. A. (1999a). Factors associated with effective loss accommodation. In C.R. Figley (Ed.). *Traumatology of grieving: conceptual, theoretical and treatment foundations* (pp. 37-51). Philadelphia: Brunner/Mazel.

Bonanno, G. A. (1999b). Emotional dissociation, self-deception, and adaptation to loss. In C.R. Figley (Ed.). *Traumatology of grieving: conceptual, theoretical and treatment foundations,* (pp. 89-105). Philadelphia: Brunner/Mazel.

Bonanno, G. A. & Kaltman, S. (1999). Toward an integrative perspective on bereavement. *Psychological Bulletin, 12(6),* 760-776.

Bonanno, G. A., Keltner, D., Holen, A. & Horowitz, M. J. (1995). When avoiding unpleasant emotion might not be such a bad thing: Verbal-autonomic response dissociation and midlife conjugal bereavement. *Journal of Personality and Social Psychology, 46,* 977-989.

Boston, S. & Tresize, R. (1988). *Merely mortal : coping with dying, death and bereavement.* London: Methuen in association with Channel Four Television.

Botes, A. & Otto, M. (2003). Ethical dilemmas related to the HIV-positive person in the workplace. *Nursing Ethics 10 (3),* 281-294.

Bowen, M. (1978). *Family therapy in clinical practice.* New York: Aronson.

Bower, J.E., Kemeny, M.E., Taylor, S.E. & Fahey, J.L. (1998). Cognitive processing, discovery of meaning, CD4 decline, and AIDS-related mortality among bereaved HIV-Seropositive men. *Journal of Counselling and Clinical Psychology, 66(6),* 979-986.

Bowlby, J. (1969). *Attachment and loss: Sadness and depression* (Vol 3). New York: Basic Books.

Bowlby, J. & Parkes, C. M. (1972). Loss and Recovery. *Journal of Social Issues, 44* (3), 37-52.

Boyd-Franklin, N., Del C. Alemán, J., Jean-Gilles, M. M. & Lewis S. Y. (1995a). Cultural sensitivity and competence. In N. Boyd-Franklin, G.L. Steiner, & M.G. Boland (Eds.). *Children, families and HIV/AIDS. Psychosocial and therapeutic issues*, (pp. 53-77). New York: The Guilford Press.

Boyd-Franklin, N., Drelich, E. W. & Schwolsky-Fitch, E. (1995b). Death and dying/ Bereavement and mourning. In N. Boyd-Franklin, G. L. Steiner, & M.G. Boland (Eds.). *Children, families and HIV/AIDS. Psychosocial and therapeutic issues,* (pp. 179-198). New York: The Guilford Press.

Boyd-Franklin, N., Steiner, G. L. & Boland, M. G. (1995c) Rationale and overview of the book. In N. Boyd-Franklin, G.L. Steiner, & M. G. Boland (Eds.). *Children, families and HIV/AIDS. Psychosocial and therapeutic issues* (pp. 3-16). New York: The Guilford Press.

Boyle, F. M., Vance, J. C., Najman, J. M. & Thearle, M. J. (1996). The mental health impact of stillbirth, neonatal death or SIDS: prevalence and patterns of distress among mothers. *Social Science and Medicine, 43(8),* 1273-1282.

Braud, W. & Anderson, R. (1994). Conventional and expanded views of research. In W. Braud & R. Anderson (Eds.) *Transpersonal research methods for the social sciences: Honoring human experience* (pp. 3-26). Thousand Oaks, California: Sage Publications.

Braun, M. J. & Berg, D. H. (1994). Meaning reconstruction in the experience of parental bereavement. *Death Studies, 18,* 105-129.

Brody, J. E. (2003, January 27). Often time beats therapy for treating grief. *The New York Times,* Section F, p. 7.

Brotherson, S. E. (2000). Parental accounts of a child's death: Influences on parental identity and behaviour. *Dissertation Abstracts International. Section A: Humanities and Social Sciences, 61,* 781.

Brubaker, E. (1985). Older parents' reactions to the death of adult children: implications for practice. *Journal of gerontological social work, 9 (1),* 35-48.

Bruzina, R. (1970). *Logos and Eidos: The concepts in phenomenology.* Paris: Mouton.

Bruner, J. (1990). *Acts of meaning.* Massachusetts: Harvard University Press.

Buber, M. (1970). *I and thou*. Edinburgh: T. & T. Clark.

Burton, T. (Director), Bender, M. & Hashimoto, R. (Producers). (1988). Beetlejuice [Film]. U.S.A.: Geffen Pictures.

Calhoun, L. G. & Tedeschi, R. G. (1990). Positive aspects of critical life problems: Recollections of grief. *Omega, 20,* 265-272.

Calhoun, L. G. & Tedeschi, R. G. (2001). Posttraumatic growth: The positive lessons of loss. In R. A. Neimeyer (Ed.). *Meaning reconstruction and the experience of loss*, (pp. 157-172). Washington, DC: American Psychological Association.

Campbell, T. (1999). AIDS-Related death: a review of how bereaved gay men are affected. *Counselling Psychology Quarterly, 12(3),* 245-253.

Capps, L. & Bonanno, G. A. (2000). Narrating Bereavement: Thematic and Grammatical Predictors of Adjustment to Loss. *Discourse Processes, 30(1),* 1-26.

Carlisle, C. (2000). The search for meaning in HIV and Aids: The carers' experience. *Qualitative Health Research, 10(6)*, 750-766.

Carr, D. (1967). Incarnate consciousness. In G. A. Schrader, Jr. (Ed.) *Existential philosophers: Kierkegaard to Merleau-Ponty,* (pp. 360-430). New York: McGraw-Hill Book Company.

Carr-Gregg, M. & Lennox, N. (1993). Perinatal death and the grief of a father. *Australian Family Physician, 22 (7),* 1187-1189.

Cashdan, S. (1988). *Object relations therapy. Using the relationship.* New York: W.W. Norton & Company.

Catalan, J. (1995). Psychiatric problems associated with grief. In L. Sherr (Ed.). *Grief and AIDS,* (pp. 59-72). West Sussex, England: John Wiley & Sons.

Cheadle, J. C. (1998). *A cybernetic approach to grief: an application of the cybernertic paradigm in the field of parental loss of a child.* University of South Africa: Unpublished Master's dissertation.

Cho, C. & Cassidy, D. F. (1994). Parallel processes for workers and their clients in chronic bereavement resulting from HIV. *Death Studies, 18,* 275-292.

Cleiren, M. (1991). *Adaptation after bereavement: A comparative study of the aftermath of death from suicide, traffic accident and illness for next of kin*. Leiden: DSWO Press.

Cohen, Z. M. (2000). Ethical issues and ethical approval. In Z.M. Cohen, D.L. Kahn, & R.H. Steeves, R.H. *Hermeneutic phenomenological research: A practical guide for nurse researchers,* (pp. 37-44). California: Sage Publications Inc.

Cohen, M., Kahn, D. L. & Steeves, R. H. (2000a). *Hermeneutic phenomenological research: A practical guide for nurse researchers.* California: Sage Publications Inc.

Cohen, M., Kahn, D.L. & Steeves, R. H. (2000b). How to analyze the data. In Z.M. Cohen, D.L. Kahn, & R.H. Steeves, R.H. *Hermeneutic phenomenological research: A practical guide for nurse researchers,* (pp. 71-83). California: Sage Publications Inc.

Corr, C. A. (1979a). Reconstructing the changing face of death. In H. Wass (Ed.). *Dying: Facing the facts* (pp. 5-43). United States of America: Hemisphere Publishing Corporation.

Corr, C. A. (1979b). Living with the changing face of death. In H. Wass (Ed.). *Dying: Facing the facts,* (pp. 44-75). United States of America: Hemisphere Publishing Corporation.

Cotterill, R. (1989). *No ghost in the machine*. London: William Heinemann Ltd.

Crick, F. (1994). *The astonishing hypothesis. The scientific search for the soul.* London: Simon and Schuster.

Crossley, M. L. (2000a). Narrative psychology, trauma and the study of self/identity. *Theory and Psychology, 10(4),* 527-546.

Crossley, M. L. (2000b). *Introducing narrative psychology. Self, trauma and the construction of meaning.* Buckingham: Open University Press.

Davidson, G. W. (1979). Hospice care for the dying. In H. Wass (Ed.). *Dying: facing the facts,* (pp. 158-181). Washington: Hemisphere Publishing Corporation.

Davis, C. G. (2001). The tormented and the transformed: understanding responses to loss and trauma. In R. A. Neimeyer (Ed.). *Meaning reconstruction and the experience of loss,* (pp.137-155). Washington, DC: American Psychological Association.

Davis, C. G., Nolen-Hoeksema, S. (2001). Loss and meaning: How do people make sense of loss? *American-Behavioral Scientist. 44(5),* 726-741.

Davis, C. G., Wortman, C. B., Lehman, D. R. & Silver, R. C. (2000) Searching for meaning in loss: Are clinical assumptions correct? *Death Studies, 24(6),* 497-541.

Del C Alemán, J., Kloser, P., Kreibick, T., Steiner, G. L. & Boyd-Franklin, N. (1995). Women and HIV/AIDS. In N. Boyd-Franklin, G. L. Steiner, & M. G. Boland (Eds.). *Children, families and HIV/AIDS. Psychosocial and therapeutic issues.* (pp. 90-111). New York: The Guilford Press.

Ditchik, F. (1991). The reactions of husbands and wives to the death of their child and its effect on their marital relationship. *DSW, 27(3).*

Doka, K. J. & Jendreski, M. (1986). Spiritual support for the suffering: Clergy attitudes towards bereavement. In R. DeBellis, E. Marcus, A. H. Kutscher, C. Smith Torres, V. Barrett, & M. Siegel (Eds.) *Suffering: Psychological and social aspects in loss, grief and care,* (pp. 155-160). New York: The Haworth Press.

Dussault, J. (1999). The stigma of AIDS. *Unesco Courier, 52(10),* 35-37.

Edmonds, S. & Hooker, K. (1992). Perceived changes in life meaning following bereavement. *Omega, 25(4),* 307-318.

Erikson, E. H. (1997). *The life-cycle completed.* W.W. Norton & Co. Inc. New York.

Fabry, J. (1967). If Freud could talk with Frankl. In F. Crous, A.A. Havenga Coetzer & G. Van Den Heever (Eds.). *On the way to meaning. Essays in remembrance of Viktor Frankl,* (pp. 49-56). Goodwood: National Commercial Printers.

Farber, M. (1967). *Phenomenology and existence: Toward a philosophy within nature.* New York: Harper Torchbooks.

Farnsworth, E. B. & Allen, K. R. (1996). Mothers' bereavement. *Family relations, 45*(4), 360-367.

Figley, C. R. (1995). *Compassion fatigue: coping with secondary PTSD among those who treat the traumatized.* New York: Brunner/Mazel.

Figley, C. R. (1999). *Traumatology of grieving: conceptual, theoretical and treatment foundations*. Philadelphia: Brunner/Mazel.

Finan, E. (2002, April 29). Is art just skin deep? *Time Magazine,* p. 54.

Fox, J. (2002). *Nkosi's Story*. Parkview: The life story project: Spearhead.

Frankl, V. E. (1964a). *Man's search for meaning: an introduction to logotherapy.* London: Hodder & Stoughton.

Frankl, V. E. (1964b). *The will to meaning: Foundations and applications to Logotherapy.* London: Hodder & Stoughton.

Frankl, V. E. (1967). *Psychotherapy and existentialism.* New York: New American Library.

Freud, S. (1984). Mourning and melancholia. In A. Richards (Ed.). *On Metapsychology,* (pp. 245-268). London: Penguin Books. (Original work published 1917).

Fulton, R. (1979). Death and the funeral in contemporary society. In H. Wass (Ed.). *Dying: facing the facts,* (pp. 236-255). Washington: Hemisphere Publishing Corporation.

Galloway, M. C. (2001). Medical Research Council report on prevalence of HIV/AIDS in South Africa. Retrieved June 01, 2002 from the World Wide Web: http://mrc.ac.za.

Geis, S., Fuller, R. & Rush, J. (1986). Lovers of AIDS victims: Psychosocial stresses and counseling needs. *Death Studies, 10(1),* 43-53.

Gergen, K. J. (1982). *Toward transformation in social knowledge* New York*:* Springer-Verlag.

Gevisser, M. (2000, October 29). Parks deserved a better ending. *Sunday Times*. Retrieved August 30, 2004 from the WorldWide Web: http://www.sundaytimes.co.za.

Gibran, K. (1973). *The Prophet.* London: Heinemann.

Gilbert, K. R. (1996) "We've had the same loss, why don't we have the same grief?" Loss and differential grief in families. *Death Studies, 20,* 269-283.

Gilmore, N., & Somerville, M. (1994). Stigmatization, Scapegoating and Discrimination in Sexually Transmitted Diseases: Overcoming 'Them' and 'Us.' *Social Science and Medicine 39,* 1339-1358.

Giorgi, A. (1975). Convergence and divergence of qualitative and quantitative methods in psychology. In A. Giorgi, C. T. Fischer, & E. L. Murray (Eds.). *Duquesne studies in phenomenological psychology:* Volume 2, (pp. 82-103). U.S.A.: Dusquesne Univesity Press.

Giorgi, A. (1979). Phenomenology and psychological theory. In A. Giorgi, R. Knowles & D. L. Smith (Eds.) *Duquesne studies in phenomenological psychology*. Volume 3, (pp. 60-80). U.S.A.: Dusquesne Univesity Press.

Giorgi, A. (1980). Toward a phenomenologically based research in psychology. *Journal of phenomenological psychology, 1(1),* 75-98.

Goalder, J. S. (1983). Morbid Grief Reaction: A social systems perspective. *Professional Psychology: Research and Practice. 16(6),* 833-842.

Goffman, E. (1963). *Stigma: Notes on the management of a spoiled identity.* New York: Simon & Schuster.

Goldblum, P. B., Erickson, S. (2000). *Working with AIDS Bereavement: A Comprehensive Approach for Mental Health Providers. UCSF AIDS Health Project: Monograph series number three.* San Francisco: University of California.

Golsworthy, R. & Coyle, A. (1999). Spiritual beliefs and the search for meaning among older adults following partner loss. *Mortality, 4(1)*, 21-41.

Gorer, G. (1965). *Death, grief and mourning in contemporary Britain*. London: Cresset Press.

Grawitsky, R. (2002). HIV/AIDS in the workplace: Whose responsibility is it? *South African Labour Bulletin, 26 (1)*, 72-74.

Green, G. (1996). Stigma and social relationships people with HIV: Does gender make a difference? In L. Sherr, C. Hankins & L. Bennett (Eds.). *AIDS as a gender issue: Psychosocial perspectives,* (pp. 46-63). London: Taylor & Francis.

Gurwitsch, A. (1968). Intentionality of consciousness. In M. Farber (Ed.). *Philosophical essays in memory of Edmund Husserl,* (pp. 65-83). New York: Greenwood Press Publishers.

Hafen, B. Q., Karren, K. J., Frandsen K. J. & Smith, N. L. (1996). *Mind/body health: The effects of attitudes, emotions and relationships.* Boston: Allyn and Bacon.

Hagemeister, A. K. & Rosenblatt, P. C. (1997). Grief and the sexual relationship of couples who have experienced a child's death. *Death Studies, 21(3),* 231-253.

Hagman, G. (2001). Beyond decathexis: toward a new psychoanalytic understanding and treatment of mourning. In R.A. Neimeyer (Ed.). *Meaning reconstruction and the experience of loss*, (pp. 13-31). Washington, DC: American Psychological Association.

Haour-Knipe, M. (1993). AIDS prevention, stigma and migrant status. *Innovation: The European Journal of Social Sciences, 6 (1),* 21-38.

Harvey, J. H. (2001). The psychology of loss as a lens to a positive psychology. *American Behavioral Scientist, 44 (5),* 838-854.

Harvey, J. H., & Miller, E. D. (Eds.). (2000). *Loss and trauma: General and close Relationship Perspective*s. Philadelphia: Brunner-Routledge.

Havenga Coetzer, P. (1997). Victor Frankl the man. In F. Crous, A. A. Havenga Coetzer & G. Van Den Heever (Eds.). *On the way to meaning. Essays in remembrance of Viktor Frankl,* (pp. 11-18). Goodwood: National Commercial Printers.

Heidegger, M. (1962). *Being and time.* Oxford: Blackwell.

Heidegger, M. (1967). Phenomenology and fundamental ontology. In J.J. Kockelmans (Ed). *The philosophy of Edmund Husserl and its interpretation,* (pp. 294-312). Garden City: New York. Doubleday & Company.

Henderson, C. W. (2001, July 23). In Africa, stigma blocks treatment -even talk- of AIDS. *AIDS weekly,* p. 17.

Herek, G. M. (1999). AIDS and stigma. *American Behavioral Scientist, 42,* 1106-1127.

Hicks, M. A. (1995). Shattered dreams: Ministering to parents after the loss of a child. *Journal of Family Ministry. 9 (1),* 26-36.

Hodgkinson, P. E. (1982). Abnormal grief - The problem of therapy. *British Journal of Medical Psychology. 55,* 29-34

Holmes, T. H. & Rahe R. H. (1967). The social readjustment rating scale. *Journal of Psychosomatic Research, 11(2)* 213-218.

Husserl, E. (1967). On eidetic reduction. In J.J. Kockelmans (Ed). *The philosophy of Edmund Husserl and its interpretation* (pp. 104-117). Garden City: New York. Doubleday & Company.

Hyer, L. & Brandsma, J. M. (1999). The treatment of PTSD through grief work and forgiveness. In C.R. Figley (Ed.). *Traumatology of grieving: conceptual, theoretical and treatment foundations,* (pp. 131-148). Philadelphia: Brunner/Mazel.

Jacob, S. R. & Scandrett-Hibdon, S. (1994). Mothers grieving the death of a child. Case reports of maternal grief. *Nurse Practitioner, 19(7),* 60-65.

Jackson, E. N. (1979). Bereavement and grief. In H. Wass (Ed.). *Dying: Facing the facts* (pp. 256-281). United States of America: Hemisphere Publishing Corporation.

Jaffe, D. T. (1985). Self-renewal: Personal transformation following extreme trauma. *Journal of Humanistic Psychology, 25(4),* 99-124.

Janoff-Bulman, R. (1985). The aftermath of victimization: Rebuilding shattered assumptions. In C. Figley (Ed.), *Trauma and its wake,* (pp. 15-35). New York: Brunner/Mazel.

Janoff-Bulman, R. (1992). *Shattered assumptions: towards a new psychology of trauma.* New York: Free Press.

Janoff-Bulman, R. & Berger, A.R. (2000). The other side of trauma: towards a psychology of appreciation. In J.H. Harvey & E.D. Miller (Eds.). *Loss and trauma: General and close Relationship Perspectives,* (pp. 29-44). Philadelphia: Brunner-Routledge.

Janoff-Bulman, R. & Frantz, C. M. (1997). The impact of trauma on meaning: from meaningless world to meaningful life. In M. Power and C. Brewin (Eds.). The *transformation of meaning in psychological therapies. Integrating theory and practice,* (pp. 91-106). Chichester: John Wiley and Sons.

Jiong, L., Precht, D. H., Mortensen, P. B., & Olsen, J. (2003). Mortality in parents after death of a child in Denmark: a nationwide follow-up study. *Lancet*, *361,* (9355), 363-368.

Johnson, S. (1984). Sexual intimacy and replacement children after the death of a child. *Omega, 15,* 109-118.

Jones, A. (2001). Absurdity and being-in-itself. The third phase of phenomenology: Jean-Paul Sartre and existential psychoanalysis. *Journal of psychiatric & mental health nursing, 8(4),* 367-373.

Jung, C. G. (Ed.). (1964). *Man and his symbols.* Aldus Books: London.

Kahn, D. L. (2000a). How to conduct research. In Z. M. Cohen, D. L. Kahn, & R. H. Steeves. *Hermeneutic phenomenological research: A practical guide for nurse researchers,* (pp. 57-70). California: Sage Publications Inc.

Kahn, D. L. (2000b). Reducing bias. In Z. M. Cohen, D. L. Kahn, & R. H. Steeves.*Hermeneutic phenomenological research: A practical guide for nurse researchers,* (pp. 85-92). California: Sage Publications Inc.

Kalideen, N. (2004, May 3). Buthelezi praised for AIDS revelation. *The Star*, p. 3.

Kalish, R. A. (1981). *Death, grief and caring relationships.* Monterey, CA: Brooks/Cole.

Kander, J. (1990). *So will I comfort you…* Cape Town: Lux Verbi.

Katz, H. (1999). *Mind, Body and social components in disease progression and resistance: A study of people diagnosed as HIV positive*. Unpublished Social Work Thesis. University of the Witwatersrand.

Kaufmann, W. (1970). I and you: a prologue. In M. Buber. *I and thou*. Edinburgh: T. & T. Clark.

Keeton, C. (2004, May 23). Finally a glimmer of hope for the hopeless. *Sunday Times,* p. 20.

Kelley, P. (1997). *Companion to grief: Finding consolation when someone you love has died.* United States of America: Simon and Schuster Inc.

Kessler, B. G. (1987). Bereavement and personal growth. *Journal of Humanistic Psychology, 27(2),* 228-247.

Kilonzo, G. P. & Hogan, N. M. (1999). Traditional mourning practices are abridged in response to the AIDS epidemic: Implications for mental health*. Transcultural Psychiatry*. *36 (3)*, 259-283.

Kindra, J. (2002, March 22). HIV/Aids drugs killed Parks, says ANC. *Mail & Guardian.* Retrieved August 30, 2004 from the World Wide Web: http://www.aegis.com/news.

Kiser, L. J., Ostoja, E. & Pruitt, D. B. (1998). Dealing with stress and trauma in families. *Child and adolescent psychiatric clinics of North America, 7(1),* 87-103.

Klass, D. (1988). *Parental grief: Solace and resolution.* New York: Springer Publishing Company.

Klass, D. (1993). The inner representation of the dead child and the worldviews of bereaved parents. *Omega, 26(4),* 255-272.

Klass, D. (1997). The deceased child in the psychic and social worlds of bereaved parents during the resolution of their grief. *Death Studies, 21,* 147-175.

Kleber, R. J.& Brom, D. (1992). *Coping with trauma: Theory, prevention and treatment.* Amsterdam: Swets and Zeitlinger Publishers.

Kockelmans, J. J. (1965). *Martin Heidegger: A first introduction to his philosophy.* Pittsburgh, Pa.: Duquesne University Press.

Kockelmans, J. J. (1967) (Ed). *The philosophy of Edmund Husserl and its interpretation.* Garden City: New York. Doubleday & Company.

Kruger, D. (1979). *An introduction to phenomenological psychology.* Cape Town: Juta & Company, Ltd

Kübler-Ross, E. (1974). *On death and dying.* New York: Macmillan.

Kushner, H. S. (1981). *When bad things happen to good people.* New York: Avon.

Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing.* Thousand Oaks California: Sage.

Kwant, R. C. (1967). Merleau-Ponty and Phenomenology. In J. J. Kockelmans (Ed). *The philosophy of Edmund Husserl and its interpretation,* (pp. 375-392). Garden City: New York. Doubleday & Company.

Lake, H. (2003). It's time to ACT. *Perspective: African Journal on HIV/AIDS, (6),* 17-20.

Lang, A., Gottlieb, L. N. & Amsel, R. (1996). Predictors of husbands' and wives' grief reactions following infant death: the role of marital intimacy. *Death studies 20(1),* 33-57.

Leahy, J. M. (1992). A comparison of depression in women bereaved of a spouse, child or a parent. *Omega: Journal of death and dying, 26(3),* 207-217.

Lerner, M. J. (1980). *The belief in a just world: A fundamental delusion.* New York: Plenum.

Lerner, M. J. & Simmons, C. (1966). Observer's reaction to the "innocent victims": Compassion or rejection? *Journal of personality and social psychology, 4,* 203-210.

Lester, D. (1993). The stigma against dying and suicidal patients. A replication of Richard Kalish's study twenty-five years later. *Omega: Journal of death and dying. 26(1),* 71-74.

Lester, T. (2001). The literature of AIDS. *Black issues book review, 3(40),* 48-52.

Levinas, E. (1967). Intuition of essences. In J.J. Kockelmans (Ed). *The philosophy of Edmund Husserl and its interpretation,* (pp. 83-104). Garden City: New York. Doubleday & Company.

Lewis, C. S. (1978). *A grief observed.* London: Faber and Faber.

Liiceanu, A. (2000). Parallel selves as the end of grief work. In J.H. Harvey & E.D. Miller (Eds.). *Loss and trauma. General and close relationship perspectives* (pp. 112-127). Philadelphia: Brunner-Routledge.

Lindemann, E. (1944). Symptomatology and management of acute grief. *American Journal of Psychiatry, 101,* 141-148.

Link, B. G. & Phelan, J. C. (2001). Conceptualising stigma. *Annual Reviews: Sociology. 27,* 363-385.

Littlewood, J. L. (1991). Gender differences in parental coping following their child's death. *British Journal of Guidance and Counselling, 19(2),* 139-148.

Maddi, S. R. (1989). *Personality theories: A comparative analysis.* Pacific Grove: Brooks/Cole.

Malacrida, C. (1998). *Mourning the dreams: How parents create meaning from miscarriage, stillbirth and early infant death.* Canada: Qual Institute Press.

Malcolm, A., Aggleton, P., Bronfman, M., Galvão, J., Mane, P. & Verrall, J. (1998). HIV-related stigmatization and discrimination: its forms and contexts. *Critical public health, 8(4),* 347-371.

Mantala-Bozos, K. I. (2003). The Role of Religion and Culture on Bereavement: The example of the Orthodox Christian tradition. *The Journal of Critical Psychology, Counselling and Psychotherapy, 3 (2),* 1-18.

Marrone, R. (1999). Dying, mourning and spirituality: A psychological perspective. *Death Studies, 23(6),* 495-520.

Martin, T. L. & Doka, K. J. (2000). *Men don't cry … women do: Transcending gender stereotypes of grief.* Philadelphia : George H. Buchanan.

Martinson, I., Papadatou, D., Pask, E. & Stevens, M. (1998). Experiences of mothers in five countries whose child died of cancer. *Cancer nursing, 21(5),* 301-311.

Mawson, D., Marks, I. M., Ramm, L. & Stern, R. S. (1981). Guided Mourning for morbid grief: a controlled study. *British Journal of Psychiatry. 138,* 185-193.

McAdams, D. P., Diamond, A., de St. Aubin, E. & Mansfield, E. (1997). Stories of commitment: The psychosocial Construction of generative lives. *Journal of Personality and Social Psychology, 72(3),* 678-694.

McBroom, P. (1997). Smile though your heart is breaking. Retrieved March 28, 2004 from the World Wide Web: htttp://www.berkeley.edu/news/berkeleyan.

McIlwraith, H. (1998). *Coping with bereavement.* Oxford: OneWorld Publications.

McIntosh, D. (1997). Husserl, Weber, Freud, and the method of the human science. *Philosophy of the social sciences, 27(3),* 324-254.

McIntosh, D. N., Silver, R. C. & Wortman, C. B. (1993). Religion's role in adjustment to a negative life event: coping with the loss of a child. *Journal of personality and social psychology, 65(4),* 812-821.

Merleau-Ponty, M. (1967). What is phenomenology? In J. J. Kockelmans (Ed). *The philosophy of Edmund Husserl and its interpretation,* (pp. 356-374). Garden City: New York. Doubleday & Company.

Middleton, W., Raphael, B., Burnett, P. and Martinek, N. (1998). A longitudinal study comparing bereavement phenomena in recently bereaved spouses, adult children and parents. *Australian and New Zealand Journal of Psychiatry, 32(2),* 235-241.

Miles, M. S. & Brown Crandall, E. K. (1986). The search for meaning and its potential for affecting growth in bereaved parents. In R. H.Moos, (Ed.). *Coping with life crises - an integrated approach,* (pp.235-243). New York: Plenum Press.

Miles, M. S. & Demi, A. S. (1991). A comparison of guilt in bereaved parents whose children died by suicide, accident or chronic disease. *Omega: Journal of death and dying, 24(3),* 203-215.

Moffatt, B. C. (1986). *When someone you love has AIDS.* New York: NAL Penguin Inc.

Mohanty, J. N. (1969). *Edmund Husserl's theory of meaning.* The Hague: Martinus Nijhoff.

Moller, D. W. (1990). *On death without dignity: The human impact of technological dying.* New York: Baywood Publishing Co.

Moos, R. H. & Schaefer, J. A. (1986). Life transitions and crises: A conceptual overview. In R. H.Moos, (Ed.). *Coping with life crises - an integrated approach,* (pp.3-28). New York: Plenum Press.

Moran, D. (2000). *Introduction to phenomenology.* London: Routledge.

Moriarty, H. J., Carrol R. & Cotroneo, M. (1996). Differences in bereavement reactions within couples following death of a child. *Research in Nursing & Health, 19(6),* 461-469.

Moustakas, C. (1994). *Phenomenological research methods.* Thousand Oaks California: Sage.

Murphy, P. (1986). Experiences in a hospice: The AIDS patient. In R. DeBellis, E. Marcus, A.H. Kutscher, C. Smith Torres, V. Barrett, & M. Siegel. (Eds.) *Suffering: Psychological and social aspects in loss, grief and care,* (pp. 87-92). New York: The Haworth Press.

Murphy, S. A. (1997). A bereavement intervention for parents following the sudden, violent deaths of their 12-28 year-old children: description and applications to clinical practice. *Canadian Journal of Nursing Research, 29(4),* 51-72.

Nadeau, J. W. (2001). Family construction of meaning. In R.A. Neimeyer (Ed.). *Meaning reconstruction and the experience of loss*, (pp. 95-111). Washington, DC: American Psychological Association.

Najman, J. M, Vance, J. C., Boyle, F., Embleton, G., Foster, B. and Thearle, J. (1993). The impact of a child death on marital adjustment. *Social science and medicine, 37(8),* 1005-1010.

Natanson, M. (1967). Phenomenology and existentialism: Husserl and Sartre on intentionality. In J.J. Kockelmans (Ed). *The philosophy of Edmund Husserl and its interpretation,* (pp.338-348).Garden City: New York. Doubleday & Company.

Neimeyer, R. A. (1998). *Lessons of loss. A guide to coping*. New York: McGrawHill.

Neimeyer, R. A. (1999). Narrative Strategies in grief therapy. *Journal of Constructivist Psychology, 12,* 65-85.

Neimeyer, R. A. (2000). Searching for the meaning of meaning: grief therapy and the process of reconstruction. *Death Studies, 24(6),* 541-558.

Neimeyer, R. A. (Ed.). (2001a). *Meaning reconstruction and the experience of loss*. Washington, DC: American Psychological Association.

Neimeyer, R. A. (2001b). Traumatic loss and the reconstruction of meaning. *Innovations in End-of-Life Care*, 3(6). Retrieved March 30, 2003 from the World Wide Web: http://www.edc.org/lastacts.

Neimeyer, R. A. (2001c). The language of loss. In R. A. Neimeyer (Ed.). *Meaning reconstruction and the experience of loss,* (pp. 261-310). Washington, DC: American Psychological Association.

Neimeyer, R. A. & Levitt, H. M. (2000). What's narrative got to do with it: Construction and coherence in accounts of loss. In J. H. Harvey & E. D. Miller (Eds.). *Loss and trauma. General and close relationship perspectives,* (pp. 401-412). Philadelphia: Brunner-Routledge.

Neugarten, B. L. (Ed.). (1968). *Middle age and ageing.* Chicago: University of Chicago Press.

Nichols, M. (Producer), Bosanquet, S & Haley, M. (Directors) (2001). *Wit* [Film]. United States: Avenue Pictures Productions.

Nolen-Hoeksema, S., McBride, A., & Larson, J. (1997). Rumination and psychological distress among bereaved partners. *Journal of Personality and Social Psychology, 72,* 857-862.

North, R. L. & Rothenberg, K. H. (1999). Partner notification and the threat of domestic violence against women with HIV infection. *New England Journal of Medicine, 329(16),* 1194-1196.

Ntshingila, F. (2004, August 8). Now Buthelezi's daughter dies of AIDS. *The Sunday Times*, p. 1.

Nzioka, C. (2000). The social meanings of death from HIV/AIDS: An African interpretive view. *Culture, Health and Sexuality. 2(1),* 1-14.

Oliver, R. C. & Fallat, M. E. (1995). Traumatic childhood death: how well do parents cope? *Journal of Trauma, 39(2),* 307-308.

Palmer, D. D. (1996). *Kierkegaard for beginners.* New York: Writers and Readers Publishing Co.

Parker, M. (1991). South Africa - undermined by AIDS. *South, 123,* 17-18.

Parkes, C. M. (1972). *Bereavement: Studies of grief in adult life.* New York: Basic Books.

Parkes, C. M. (1988). Bereavement as a psychosocial transition: processes of adaptation to change. *Journal of Social Issues, 44(3),* 53-65.

Pennebaker, J. W., Hughes, C. F. & O'Heeron, R. C. (1986). Confronting a traumatic event: Toward an understanding of inhibition and disease. *Journal of abnormal psychology, 95,* 274-81.

Pinel, E. C. (1999). Stigma consciousness: the psychological legacy of social stereotypes. *Journal of personality and social psychology. 76,* 114-128.

Pivčevič, E. (1970). *Husserl and phenomenology.* London: Hutchinson University Library.

Polatinsky, S. & Esprey, Y. (2000). An assessment of gender differences in the perception of benefit resulting from the loss of a child. *Journal of traumatic stress, 13(4),* 709-718.

Polkinghorne, D. (1983). *Methodology for the human sciences: Systems of inquiry.* New York: State University of New York Press.

Polkinghorne, D. (1988). *Narrative knowing and the human sciences.* Albany: Suny Press.

Polkinghorne, D. E. (1989). Phenomenological research methods. In R.S. Valle & S. Halling (Eds.). *Existential-phenomenological Perspectives in Psychology: Exploring the Breadth of human experience* (pp. 41-60). New York: Plenum.

Ponzetti, J. J. (1992). Bereaved families: a comparison of parents' and grandparents' reactions to the death of a child. *Omega: Journal of death and dying, 25(1),* 63-71.

Posner, J. (1976). Death as a courtesy stigma. *Essence, 1(1),* 39-50.

Powell-Cope, G. M. & Brown, M. A. (1992). Going public as an AIDS family caregiver. *Social Science Medicine, 34(5),* 571-580.

Pryor, J. B., Reeder G. D. & Landau, S. (1999). A social-psychological analysis of HIV-related stigma. *American Behavioral Scientist, 42,* 1193-1212.

Pugh, K. (1995). Suicide in patients with HIV infection and AIDS. In L. Sherr (Ed.). *Grief and AIDS,* (pp. 29-44). West Sussex, England: John Wiley & Sons.

Ramsey, J. L. & Blieszner, R. (2000). Transcending a lifetime of losses. The importance of spirituality in old age. In J. H. Harvey & E. D. Miller (Eds.). *Loss and trauma. General and close relationship perspectives,* (pp. 225-236). Philadelphia: Brunner-Routledge.

Rando, T. A. (1983). An investigation of grief and adaptation in parents whose children have died from cancer. *Journal of Pediatric Psychology, 8(1),* 3-20.

Rando, T. A. (1984). *Grief, dying and death. Clinical interventions for caregivers.* Champaign, Illinois: Lexington Books.

Rando, T. A. (1985). Bereaved parents: particular difficulties, unique factors, and treatment issues. *Social Work, 30(1)*, 19-23.

Rando, T. A. (Ed.). (1986). *Parental loss of a child.* Champaign, Illinois: Lexington Books.

Rando, T. A. (1988). *How to go on living when someone you love dies.* Champaign, Illinois: Lexington Books.

Rando, T. A. (1993). *Treatment of complicated mourning.* Champaign, Illinois: Lexington Books.

Raphael, B. (1983). *The anatomy of bereavement.* New York: Basic Books.

Raphael, B. & Dobson, M. (2000). Bereavement. In J. H. Harvey & E. D. Miller (Eds.). *Loss and trauma: General and close Relationship Perspectives,* (pp. 45-85). Philadelphia: Brunner-Routledge.

Redding, R. A. (1979). Physiology of dying. In H. Wass (Ed.). *Dying: facing the facts,* (pp. 76-107). Washington: Hemisphere Publishing Corporation.

Riches, G. & Dawson, P. (1996). Communities of feeling. The culture of bereaved parents. *Mortality, 1(2).* 143-162.

Riches, G. & Dawson, P. (1998). Spoiled memories: Problems of grief resolution in families bereaved through murder. *Mortality, 3(2),* 143-160.

Ricoeur, P. (1967). *Husserl. An analysis of his phenomenology.* Evanston: Northwestern University Press.

Roberts, P., Bruce, J., Izarraz, L. & Soni, R. (2000). “A little sad, a lot stronger”. The impact of web memorialization on bereaved parents and others. *Gerontologist, 40 (1),* 153.

Robinson, L. A. (2002). Disclosure after a sibling's death from AIDS. *Community health, 25 (1),* 22-31.

Romanoff, B. D. (2001). Research as therapy. In R. A. Neimeyer (Ed.). *Meaning reconstruction and the experience of loss,* (pp. 245-255). Washington, DC: American Psychological Association.

Rosenblatt, P. C. (2000). *Parent grief. Narratives of loss and relationship.* Philadelphia: Brunner/Mazel.

Rowe, D. (1991). *The courage to live. Discovering meaning in a world of uncertainty.* London: HarperCollins Publishers.

Rubin, S. S. (1981). A two-track model of bereavement: Theory and research. *American Journal of Orthopsychiatry. 51,* 101-109.

Rubin, S. S. (1985). The resolution of bereavement: a clinical focus on the relationship to the deceased. *Psychotherapy, 22 (2),* 231-235.

Rubin, S. S. (1999). The Two-Track Model of bereavement: overview, retrospect, and prospect. *Death Studies, 23(8),* 681-715.

Russel, G. (2002). Good grief. Retrieved March 28, 2004 from the World Wide Web: http://www.Memphis edu.makegift.html.

Sanders, C. M. (1988). Risk factors in bereavement outcome. *Journal of Social Issues, 44(3),* 97-111.

Satel, S. (1999, April23). An overabundance of counselling? *New York Times*. Retrieved March 28, 2004 from the World Wide Web: http://www.sallysatelmd.com/html/a-nytimes4.html

Schrader, G. A. (Jr.) (1967). Resurgent humanism. In G. A. Schrader (Jr.) (Ed.). *Existential philosophers: Kierkegaard to Merleau-Ponty,* (pp. 1-44). New York: McGraw-Hill Book Company.

Shuchter, S. R., & Zisook, S. (1993) The course of normal grief. In M. S. Stroebe, W. Stroebe & R. O. Hansson (Eds.). *Handbook of bereavement: theory, research and intervention*, (pp. 23-43). Cambridge: Cambridge University Press.

Schwab, R. (1990). Paternal and maternal coping with the death of a child. *Death studies, 14,* 407-422.

Schwab, R. (1992). Effects of a child's death on the marital relationship: a preliminary study. *Death Studies, 16,* 141-154.

Schwab, R. (1996). Gender differences in parental grief. *Death Studies, 20(2),* 103-113.

Schwartzberg, S. S. & Janoff-Bulman, R. (1991). Grief and search for meaning: Exploring the assumptive worlds of bereaved college students. *Journal of Social and Clinical Psychology, 10,* 270-288.

Seeley, J. & Kajura, E. B. (1995). Grief and the community. In L. Sherr (Ed.). *Grief and AIDS,* (pp. 73-86). West Sussex, England: John Wiley & Sons.

Segal, A. M. (1999). *Architectural metaphor in psychotherapy: a phenomenal study.* Rand Afrikaans University: Unpublished Doctoral Thesis.

Séguin, M., Lesage, A. & Kiely, M. C. (1995). Parental bereavement after suicide and accident: A comparative study. *Suicide and life-threatening behavior, 25(4),* 489-498.

Shakespeare, W. (1964). *Macbeth.* Bristol: Western Printing Services Ltd.

Shanefield, S. B., Benjamin, A. J. & Swain, B. J. (1984). Parents' reactions to death of an adult child from cancer. *American Journal of Psychiatry, 131(9),* 1092-1094.

Shapiro, E. R. (1994). *Grief as a family process: a developmental approach to clinical practice.* New York: Guilford.

Sherr, L. (Ed.). (1995). *Grief and AIDS.* West Sussex, England: John Wiley & Sons.

Sherr, L. (1996). Gender, psychology and HIV infection. In L. Sherr, C. Hankins & L. Bennett (Eds.). *AIDS as a gender issue: psychosocial perspectives,* (pp. 16-45). London: Taylor & Francis.

Simpson, M. A. (1979). Social and psychological aspects of dying. In H. Wass (Ed.). *Dying: facing the facts,* (pp. 108-136). Washington: Hemisphere Publishing Corporation.

Singh, B. & Raphael, B. (1981). Postdisaster morbidity of the bereaved. *The Journal of Nervous and Mental disease, 169(4),* 203-212.

Smith, J. A., Flowers, P. & Osborn, M. (1997). Interpretive phenomenological analysis. In L. Yardley (Ed.). *Material discourses of health and illness,* (pp. 68-91). London: Routledge.

Sokolowski, R. (2000). *Introduction to phenomenology.* Cambridge: Cambridge University Press.

Sontag, S. (1991). *AIDS and its metaphors.* London: Penguin.

Sormanti, M., & August, J. (1997). Parental Bereavement: Spiritual connections with deceased children. *American Journal of Orthopsychiatry, 67(3),* 460-469.

Soul City. (2004). *HIV and AIDS: Prevention, care and treatment.* Johannesburg: Jacana Media.

Spence, D. (1984). *Narrative truth and historical truth: Meaning and interpretation in psychoanalysis.* New York: Norton.

Spiegelberg, H. (1965). *The phenomenological movement: A historical introduction.* Netherlands: Martinus Nijhoff.

Spratt, M. L. & Denney, D. R. (1991). Immune variables, depression, and plasma cortisol over time in suddenly bereaved parents. *Journal of neuropsychiatry and clinical neurosciences, 3(3),* 299-306.

Springer, C. A. & Lease, S. H. (2000). The Impact of Multiple AIDS-Related Bereavement in the Gay Male Population. *Journal of Counseling & Development, 78 (3),* 297-305.

Stamm, B. H. (1999). Conceptualising death and trauma: a preliminary endeavour. In C. R. Figley (Ed.). *Traumatology of grieving: conceptual, theoretical and treatment foundations,* (pp. 3-17). Philadelphia: Brunner/Mazel.

Steeves, R. H. (2000a). How to start fieldwork. In Z. M. Cohen, D. L. Kahn, & R. H. Steeves, R. H. (Eds.). *Hermeneutic phenomenological research: A practical guide for nurse researchers,* (pp. 25-35). California: Sage Publications Inc.

Steeves, R. H. (2000b). Sampling. In Z. M. Cohen, D. L. Kahn, & R. H. Steeves, R.H. *Hermeneutic phenomenological research: A practical guide for nurse researchers,* (pp. 37-56). California: Sage Publications Inc.

Stroebe, M. S. (2001). Bereavement research and theory: Retrospective and prospective. *American Behavioral Scientist, 44 (5),* 854-866.

Stroebe, M. S., & Stroebe, W. (1991). Does `grief work' work? *Journal of Consulting and Clinical Psychology*, *59*, 477-482.

Stroebe, M. S., & Stroebe, W. (1992). Coping with bereavement: A review of the grief work hypotheses. *Omega: Journal of Death and Dying*, *26*, 19-42.

Stroebe, W., Stroebe, M. S. & Domittener G. (1988). Individual and situational differences in recovery from bereavement: A risk group identified. *Journal of Social Issues, 14* (3), 143-158.

Stroebe, M. S., Stroebe, W. & Hansson, R. O. (1993) *Handbook of bereavement: theory, research and intervention*. Cambridge: Cambridge University Press.

Stroebe, M. S., Van Den Bout, J. & Schut, H. (1994). Myths and misconceptions about bereavement: The opening of a debate. *Omega, 29(3),* 187-203.

Strong, P. (1990). Epidemic Psychology: A Model. *Sociology of Health and Illness 12(3),* 249-59.

Talbot, K. (1996). Transcending a devastating loss: the life attitude of mothers who have experienced the death of their only children. *Hospice Journal, 11(4),* 67-82.

Tatelbaum, J. (1983). *The courage to grieve.* London: Random House, UK, Ltd.

Tedeschi, R. G. & Calhoun, L. G. (1995). *Trauma and transformation: Growing in the aftermath of suffering.* USA: Sage Publications.

Tewksbury, R. & Mcgaughey, D. (1997). Stigmatization of persons with HIV disease: Perceptions, management, and consequences of Aids. *Sociological Spectrum, 17 (1*), 49-71.

Travers, M. & Bennett, L. (1996). AIDS, women and power. In L. Sherr, C. Hankins & L. Bennett (Eds.). *AIDS as a gender issue: psychosocial perspectives,* (pp. 64-77). London: Taylor & Francis.

Trolley, B. C. (1993). Kaleidoscope of aid for parents whose child died by suicidal and sudden, non-suicidal means. *Omega: Journal of death and dying, 27(3),* 239-250.

Ulmer, A., Range, L. M. & Smith, P. C. (1991). Purpose in life: A moderator of recovery from bereavement. *Omega, 23(4),* 279-289.

Updegraff, J. A. & Taylor, S. E. (2000) From vulnerability to growth: Positive and negative effects of stressful life events. In J. H. Harvey & E. D. Miller (Eds.). *Loss and trauma: General and close Relationship Perspectives,* (pp. 3-28). Philadelphia: Brunner-Routledge.

Valle, R. S. & King, M. (1978). *Existential-phenomenological alternatives for psychology.* New York: Oxford University Press.

Valle, R. S., King, M. & Halling, S. (1989). An introduction to existential phenomenological thought in psychology. In R. S.Valle & S. Halling (Eds.). *Existential-phenomenological perspectives in psychology: Exploring the breadth of human experience.* New York: Oxford University Press.

Vance, J. C., Najman, J. M., Thearle, M. J., Embelton, G., Foster, W. J. & Boyle, F. M. (1995). Psychological changes in parents eight months after the loss of an infant from stillbirth, neonatal death or sudden infant death syndrome - a longitudinal study. *Pediatrics, 96(5),* 933-938.

Vander Hoeven, J. (1964). *The rise and development of the phenomenological movement.* Hamilton: Canada. Guardian Publishing Company Ltd.

Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy.* London: The State University of New York.

Van Manen, M. (2002a). Writing phenomenology. In M. Van Manen (Ed.). *Writing in the dark: Phenomenological studies in interpretive inquiry,* (pp. 1-8). Canada: The Althouse Press.

Van Manen, M. (2002b). Writing in the dark. In M. Van Manen (Ed.). *Writing in the dark: Phenomenological studies in interpretive inquiry,* (pp. 237-252). Canada: The Althouse Press.

Van Setten, H. (1999). Album angels: Parent-child relations as reflected in 19th-century photos, made after the death of a child. *Journal of psychohistory, 26(4), 819-834.*

Van Vuuren, R. (1999). *An existential-phenomenological view of the nature and scope of psychology as a human science*. St. Augustine College of South Africa, Johannesburg. Colloquium: RAU.

Walker, R. J., Pomeroy, E. C., McNeil, J. S. & Franklin, C. (1996). Anticipatory grief and AIDS. Strategies for intervening with caregivers. *Health & Social Work, 21(1),* 49-57.

Warnock, M. (1970). *Existentialism.* London: Oxford University Press.

Watson, J. A. (1986). Suffering and the quest for meaning. In R. DeBellis, E.Marcus, A. H. Kutscher, C. Smith Torres, V. Barrett & M. E. Siegel (Eds.). *Suffering. Psychological and social aspects in loss, grief and care* (pp. 175-188). New York: The Haworth Press.

Weiss, R. S. (1988). Loss and Recovery. *Journal of Social Issues, 44(3),* 37-52.

Wheeler, I. (2001). Parental bereavement: the crisis of meaning. *Death Studies, 25(1),* 51-67.

Wiener, L. S. (1998). Telephone support groups for HIV-positive mothers whose children have died of AIDS. *Social Work, 43(3),* 279-285.

Williams, A. M. & Gamino, L. A. (1998). A content and comparative analysis of loss in adaptive and maladaptive grievers. *Journal of Personal and Interpersonal Loss, 3(4),* 349-369.

Wilkinson, H. (1998). Phenomenological causality: and why we avoid examining the nature of causality in psychotherapy: a dialogue. *International Journal of Psychotherapy, 3(2),* (147-165).

Worden, W. J. (1988). *Grief counselling & grief therapy.* London: Tavistock Publications Ltd.

Wortman, C. B., & Silver, R. C. (1989). The myths of coping with loss. *Journal of Consulting and Clinical Psychology, 57*, 347-357.

Wright, D. L. (1992). When parents grieve: an undiagnosable pain. *Journal of humanistic education and development, 30(3),* 100-110.

Yalom, I. D. (1980). *Existential psychotherapy.* New York: Basic Books.

Yalom, I. D. & Lieberman, M. A. (1991). Bereavement and heightened existential awareness. *Psychiatry, 54,* 334-345.

Yorkstone, P. (1981). Bereavement. *The British Medical Journal, 282.*

Ziel, S. (2001). Black South Africans do live in Nuclear Family Households. *Society in Transition, 33(1).*

Zisook, S. & DeVaul, R. (1985). Unresolved grief. *The American Journal of Psychoanalysis, 45(4),* 370-379.

Zisook, S. & Schuster, S. R., Irwin, M., Darko, D. F., Sledge, P. & Rosovsky, K. (1994). Bereavement, depression and immune function. *Psychiatric Research, 52, 1-10.*

Zinner, E. S. (2000). Being a man about it: The marginalization of men in grief. *Illness, Crisis & Loss, 8,(2),* 181-188.

Zuma, J. (18 April 2002). Opening Address at the launch of the Moral Regeneration Movement at the Summit held at Waterkloof Air Force Base.