

Outcomes and Coping Following Parental Bereavement

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Abstract

Background

This thesis addresses the topic of parental bereavement, using a multi-method approach. It aims to add to knowledge about the phenomenon of parental bereavement, outcomes for bereaved parents following the loss of their child, and factors associated with these outcomes.

Method

An initial literature study and qualitative investigation were carried out. Findings from these informed the choice of quantitative variables to be tested in a group of parents in early and mid-bereavement. Census records were used to provide information on long term health and social outcomes.

Results

The literature related to the parent's experience following the death of their child is limited. The qualitative study indicated a variety of factors for testing, related to the circumstances of the loss, continuing bonds with the deceased child, restoration-oriented stressors, for example, employment and relationship problems, and ruminative behaviours. In early bereavement, lower grief levels were found in people who had displayed cognitive restructuring behaviours. Grief and depression were prevalent, and were found to exist independently. Rumination was associated with grief and depression in mid-bereavement. Grief was predicted by depression and self-blame and depression was, in turn, predicted by rumination and education level. Rates of mothers returning to work following the loss of a child in the first year of life were lower than

those whose child lived. Mortality rates were up to four times higher in bereaved parents than non-bereaved comparisons, up to 35 years post-loss.

Conclusions

The loss of a child has ongoing social, emotional and health consequences for parents. Social factors are a particularly important issue, and therapeutic interventions may benefit from reducing negative aspects of coping such as rumination rather than promoting specific coping strategies. Support for bereaved parents should come from a number of sources, in order to address their complex and potentially long-term needs.

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This thesis is dedicated to the memory of Ross Munro

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Thank you for the days x

Publications Arising from this Thesis

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Table of Contents

Abstract	1
Background.....	1
Method.....	1
Results.....	1
Conclusions.....	2
Publications Arising from this Thesis	7
Chapter One - Introduction	20
1.0 Abstract.....	20
1.0.1 Background.....	20
1.0.2 Method.....	20
1.0.3 Results.....	20
1.0.4 Conclusions.....	20
1.1 Overview.....	21
1.1.1 Definition of Bereavement.....	21
1.2 Historical Perspective on Grief and Bereavement.....	21
1.2.1 Freud's Comparison of Mourning and Melancholia.....	21
1.2.2 Engel's Theory of Grief as a Disease.....	22
1.2.3 Bowlby's Attachment Perspective on Loss.....	22
1.2.4 Parkes and Weiss's Psychosocial Transitions in Bereavement.....	24
1.3 Contemporary Models of Bereavement.....	25
1.3.1 Dual Process Model of Bereavement.....	25
1.3.2 Integrative Risk Factor Framework for Coping with Bereavement.....	27
1.4 Social Theories of Bereavement.....	28
1.5 Prolonged Grief as a Distinct Diagnostic Condition.....	28
1.6 Outcomes for Bereaved Parents.....	32
1.6.1 Health Outcomes.....	32
1.6.2 Changes in Social Functioning.....	34
1.6.3 Emotional Consequences.....	35
1.7 Aims of the Thesis.....	35
1.8 Thesis Structure.....	36
Chapter Two – Literature Review of Factors Associated with Differential Outcomes of Parental Bereavement	38
2.0 Abstract.....	38
2.0.1 Background.....	38
2.0.2 Method.....	38
2.0.3 Results.....	38
2.0.4 Conclusions.....	39
2.1 Introduction.....	40
2.2 Method.....	40
2.3 Method of Analysis.....	53
2.3.1 Demographics.....	53
2.3.2 Outcome Variables.....	55
2.3.3 Predictors.....	55
2.4 Conclusion.....	57

Chapter Three – Methods	59
3.0 Abstract	59
3.0.1 Background	59
3.0.2 Method.....	59
3.0.3 Results	59
3.0.4 Conclusions	60
3.1 Introduction.....	61
3.2 Requirements for the Qualitative Method Chosen	61
3.2.1 Function of the Research	61
3.2.2 Participant Population	62
3.2.3 Timing of Research	62
3.2.4 Participant Recruitment.....	63
3.2.5 Data Collection Method	63
3.2.6 Protecting the Participants from Harm.....	64
3.2.7 Protecting the Researcher from Harm.....	64
3.2.8 Selection of Qualitative Method.....	65
3.2.9 Limitations of IPA.....	66
3.2.10 Conclusions for Choice of Qualitative Method.....	67
3.3 Quantitative self-report data	67
3.4 Cross-sectional Data Collection.....	68
3.5 Analysis of Secondary National Data Sources	68
3.6 Choice of Quantitative Self-Report Measures	69
3.6.1 Outcome Measures	69
3.6.1.1 Grief	69
3.6.1.2 Depression	70
3.6.2 Predictors.....	72
3.6.2.1 Trait Optimism/Pessimism	72
3.6.2.2 Rumination.....	72
3.6.2.3 Coping Style	73
3.6.2.4 Continuing Bonds	74

Chapter Four - Bereaved Mothers’ Continuing Bonds and Ambivalence about their Own Mortality after the Death of Their Child – An Interpretive Phenomenological Analysis	76
4.0 Abstract.....	76
4.0.1 Background	76
4.0.2 Method.....	76
4.0.3 Results	76
4.0.4 Conclusions	77
4.1 Introduction.....	78
4.1.1 Previous Studies of Bereaved Parents’ Coping	78
4.1.2 Social Issues Following Bereavement.....	80
4.1.3 Phenomenological Research.....	80
4.2 Method	81
4.2.1 Participants	81
4.2.2 Data Collection.....	83
4.2.3 Data Analysis	84
4.2.4. Impact of the Researcher on Participant Accounts	86

4.3 Results.....	87
4.3.1 Theme 1a - Continuing the Bond with the Deceased Child – The Physical Connection.....	88
4.3.2 Theme 1b - Continuing the Bond with the Deceased Child – Linking Objects.....	91
4.3.3 Theme 1c - Continuing the Bond with the Deceased Child – Symbolic Representations	92
4.3.4 Theme 2a - Ambivalence to Personal Mortality	95
4.3.5 Theme 2b– Death as a Release.....	97
4.3.6 Theme 2c - Influence of Other Children	98
4.3.7 Theme 3a - Social Changes Attributed to the Bereavement - Marital Situation.....	101
Theme 3b – Social Changes Attributed to the Bereavement - Employment Status	104
4.4 Discussion.....	106
4.4.1 Continuing Bonds.....	106
4.4.2 Coping Styles	107
4.4.3 Phenomenology of Parental Bereavement – Impact of Cause of Death	108
4.4.4 Ambivalence about Personal Mortality.....	109
4.4.4.1 Possible Sources of Support for Bereaved Parents.....	111
4.4.4.2 Suicide Risk.....	112
4.4.5 Social Changes	113
4.4.6 Methodological Considerations.....	113
4.4.7 Limitations.....	114
4.4.8 Conclusion.....	115
Chapter Five - Factors Affecting Outcomes in Parent’s Early Bereavement.....	116
5.0 Abstract.....	116
5.0.1 Background	116
5.0.2 Method.....	116
5.0.3 Results	116
5.0.4 Conclusions	116
5.1 Introduction.....	118
5.1.1 Prolonged Grief as a Distinct Diagnostic Condition.....	118
5.1.2 Rumination as an Avoidance Focussed Method of Coping	119
5.1.3 Identification of Risk Factors for Prolonged Grief in Bereaved Parents ...	119
5.1.4 The Impact of Bereaved Parents Continuing Bonds with their Lost Child	121
5.2 Method.....	122
5.2.1 Participants	122
5.2.2 Measures.....	123
5.2.2.1 Grief.....	124
5.2.2.2 Depression	124
5.2.2.3 Trait Optimism/Pessimism	124
5.2.2.4 Rumination.....	124
5.2.2.5 Coping Style	125
5.2.2.6 Continuing Bonds	125
5.2.2.7 Suicidal Ideation	125
5.2.2.8 Education	126
5.2.2.9 Cause of Death.....	126

5.2.2.10 Death anticipation	126
5.2.2.11 Linking Objects/Symbolic Representations.....	126
5.2.2.12 Relationship status	127
5.2.2.13 Employment status.....	127
5.2.2.14 Open-Ended Questions	127
5.2.2.15 Participation Experience	128
5.2.3 Participant Demographics	128
5.2.4 Procedure.....	129
5.2.5 Statistical Analyses.....	130
5.3 Results.....	131
5.3.1 Hypothesis One – Prolonged grief can be measured independently from depression.	133
5.3.2 Hypothesis Two – Increased levels of rumination will be associated with higher levels of grief or depression	135
5.3.3 Identification of the factors most closely associated with grief and depression.	135
5.3.3.1 Factors Associated with Increased Grief	135
5.3.3.1.1 Categorical Variables Associated with Grief.....	135
5.3.3.1.2 Continuous Variables Associated with Grief.....	136
5.3.3.1.3 Relative Importance of Factors Associated with Increased Grief	137
5.3.3.2 Factors Associated with Depression	139
5.3.3.2.1 Categorical Variables associated with Clinical Depression ..	139
5.3.3.2.2 Continuous Variables Associated with Depression	139
5.3.3.2.3 Relative Importance of Factors Associated with Increased Depression Scores	140
5.3.4 Association with Continuing Bonds and either Grief or Depression	142
5.3.5 Thematic Analysis of Other Relevant Information	142
5.4 Discussion.....	142
5.4.1 Prolonged Grief Independent of Depression	142
5.4.2 Rumination and Grief/Depression.....	143
5.4.3 Risk Factors for Prolonged Grief and Depression.....	143
5.4.4 Continuing Bonds and Grief.....	144
5.4.5 Research Experience	145
5.4.6 Limitations of the Study	146
5.4.7 Conclusion.....	147

Chapter Six - Factors Affecting Bereavement Outcome in Bereaved Parents Four Years Post-Loss 149

6.0 Abstract	149
6.0.1 Background	149
6.0.2 Method.....	149
6.0.3 Results	149
6.0.4 Conclusion.....	150
6.1 Introduction.....	151
6.1.1 Factors Associated with Outcomes in Mid-bereavement.....	151
6.1.2 Findings from Research in Early Bereavement.....	152
6.2 Method	154
6.2.1 Participants	154

6.2.2 Measures.....	156
6.2.2.1 Grief	156
6.2.2.2 Depression	156
6.2.2.3 Trait Optimism/Pessimism	157
6.2.2.4 Rumination.....	157
6.2.2.5 Coping Style	157
6.2.2.6 Continuing Bonds	158
6.2.2.7 Socioeconomic Status	158
6.2.2.8 Suicidal Ideation	159
6.2.2.9 Education	159
6.2.2.10 Cause of Death.....	159
6.2.2.11 Death anticipation.....	160
6.2.2.12 Linking Objects/Symbolic Representations.....	160
6.2.2.13 Relationship status	160
6.2.2.14 Employment status.....	160
6.2.3 Time 2 Questionnaire	160
6.2.4 Qualitative Data.....	161
6.2.5 Participant Demographics	162
6.2.6 Procedure.....	163
6.2.7 Statistical Analyses.....	164
6.3 Results.....	166
6.3.1 Qualitative Analysis	171
6.3.1.1 Additional Problems not Specified in Questionnaire	171
6.3.1.2 Impact of the Bereaved Parent Status of the Researcher	172
6.3.1.3 Advice for Other Bereaved Parents	172
6.3.2 Hypothesis One – Prolonged grief can be measured independently from depression at Time 1.....	174
6.3.3 Hypothesis Two – Increased levels of depressive rumination will be associated with higher levels of grief and depression at Time 1.....	175
6.3.3 Hypothesis Three – Levels of reflective rumination would be associated with higher levels of grief and depression at Time 2.	175
6.3.4 Exploratory Analysis – Identification of the factors most closely associated with grief and depression.	176
6.3.4.1 Factors Associated with Increased Grief at Time 1	176
6.3.4.1.1 Categorical Variables.....	176
6.3.4.1.2 Continuous Variables.....	177
6.3.4.2 Relative Importance of Factors Associated with Increased Grief at Time 1	178
6.3.4.2 Factors Associated with Increased Depression at Time 1	179
6.3.4.2.1 Continuous Variables.....	179
6.3.4.2.1 Categorical Variables.....	180
6.3.4.3 Relative Importance of Factors Associated with Increased Depression Scores at Time 1	180
6.3.5 Exploratory Analysis - Predicting Scores at Time 2 from Significant Time 1 Factors	182
6.3.5.1 Grief	182
6.3.5.2 Depression	183
6.4 Discussion.....	184
6.4.1 Prolonged Grief and Depression	184

6.4.2 Rumination and Depression	184
6.4.3 Factors Associated with Prolonged Grief.....	185
6.4.3.1 Depression	185
6.4.3.2 Self-blame	186
6.4.3.3 Child Living at Home	186
6.4.4.4 Frequency of Grave Visitation.....	187
6.4.4.5 Restoration-Oriented Stressors	188
6.4.5 Factors Associated with Depression.....	189
6.4.5.1 Rumination.....	189
6.4.5.2 Problems at Work	189
6.4.5.3 Education Level	190
6.4.5.4 Substance/Alcohol Use	190
6.4.6 Unexpected Findings	190
6.4.7 The Research Experience for Participants.....	191
6.4.8 Limitations of the Research.....	191
6.4.9 Conclusions	192

Chapter Seven - Mortality, Marriage and Employment Changes in Bereaved

Parents in Scotland	194
7.0 Abstract	194
7.0.1 Background	194
7.0.2 Method.....	194
7.0.3 Results	194
7.0.4 Discussion	195
7.1 Introduction.....	196
7.1.1 Marital Status	196
7.1.2 Employment Status.....	197
7.1.3 Mortality Risk.....	197
7.2 Method	199
7.2.1 Analysis	201
7.3 Results.....	202
7.3.1 Mortality Rates	203
7.3.2 Change in Marital Status	203
7.3.3 Change in Employment	204
7.4 Discussion	205
7.4.1 Limitations of the Study	207
7.4.2 Conclusions.....	208

Chapter Eight – Long-Term Mortality, Employment and Relationship Changes in Bereaved Mothers in England and Wales

8.0 Abstract	210
8.0.1 Background	210
8.0.2 Method.....	210
8.0.3 Results	210
8.0.4 Conclusions	211
8.1 Introduction.....	212
8.2 Method	214
8.2.1 Analysis	217
8.3 Results.....	217

8.3.1 Mortality Rates	218
8.3.2 Employment Status	219
8.3.3 Relationship Status	221
8.4 Discussion	224
8.4.1 Mortality	224
8.4.2 Employment.....	225
8.4.3 Relationships.....	225
8.4.4 Limitations of the Study	227
8.4.5 Conclusions.....	228
Chapter Nine – General Discussion	229
9.0 Abstract.....	229
9.0.1 Background	229
9.0.2 Method.....	229
9.0.3 Results	229
9.0.4 Conclusions	230
9.1 Introduction.....	231
9.2 What are Bereaved Parents Coping With?	231
9.2.1 Prolonged grief	231
9.2.2 Depression	232
9.2.3 Mortality	233
9.2.4 Restoration-oriented stressors	234
9.2.4.1 Difficulty Caring for Other Children	234
9.2.4.2 Employment Difficulties.....	234
9.2.4.3 Financial Difficulties	235
9.2.5 Continung Bonds	236
9.3 Cultural Considerations.....	237
9.4 Social Models of Bereavement.....	237
9.3 Limitations of the Thesis	237
9.4. Recommendations for Future Research.....	240
9.5 How do Bereaved Parents Cope with the Death of Their Child?	241
9.6 Is Time the Great Healer?	242
9.7. Conclusion – What this Thesis Adds to Knowledge about Parental Bereavement.....	243
References.....	245

Appendices

Appendix I – Proposed Diagnostic Criteria for Prolonged Grief Disorder.....	254
Appendix II – Inventory of Complicated Grief.....	256
Appendix III – Patient Health Questionnaire - 9 (PHQ-9)	258
Appendix IV – Life Orientation Test – Revised (LOT-R)	259
Appendix V – Ruminative Response Styles Questionnaire – Depressive Rumination	260
Appendix VI – Ruminative Response Styles Questionnaire – Reflective and Brooding Rumination	261
Appendix VII –Brief Cope	262
Appendix VIII - Continuing Bonds Scale	264
Appendix IX – Interview Schedule.....	265

Index of Tables

Table 2.1 – Studies Reporting Factors Associated with Grief in Parental Bereavement	43
Table 3.1 Summary table of measures used in the research	75
Table 4.1. Participant Characteristics	82
Table 5.1 – Demographics of participants who returned completed questionnaires	129
Table 5.2 – Minimum, maximum, mean, standard deviation and number of responses for continuous variables.....	132
Table 5.3 – Frequencies of positive/negative responses in categorical variables.....	133
Table 5.4 – Categorical variables univariately associated with higher grief	136
Table 5.5 – Continuous variables univariately associated with higher grief	137
Table 5.6 –Multivariate Hierarchical regression analyses testing the relative contribution of factors to total grief score	138
Table 5.7 – Categorical variables univariately associated with depression.....	139
Table 5.8 – Continuous variables univariately associated with depression.....	140
Table 5.9 –Multivariate Hierarchical regression analyses testing the relative contribution of factors to total depression score	141
Table 6.1 – Comparison of demographics for all parents potentially contactable, those actually contacted and those who returned completed questionnaires	162
Table 6.2 – Minimum, maximum, mean, standard deviation and number of responses for continuous variables at Time 1	167
Table 6.3 – Minimum, maximum, mean, standard deviation and number of responses for continuous variables at Time 2	168
Table 6.4 – Frequencies of positive/negative responses in categorical variables at Time 1	169

Table 6.5 – Frequencies of positive/negative responses in categorical variables at Time 2	170
Table 6.6 – Difference between measures at Time 1 versus Time 2	170
Table 6.7 – Frequencies of sex of child and parent, education status, socioeconomic status and frequency of grave visitation reported at Time 1	171
Table 6.8 – Other problems reported at either Time 1 or Time 2	171
Table 6.9 – Categorical variables univariately associated with likelihood of grief diagnosis at Time 1	177
Table 6.10 – Continuous variables univariately associated with higher grief at Time 1	177
Table 6.11 –Multivariate regression analysis testing the relative contribution of factors to grief score at Time 1	179
Table 6.12 – Continuous variables univariately associated with higher depression at Time 1	179
Table 6.13 – Categorical variables univariately associated with likelihood of depression diagnosis at Time 1	180
Table 6.14 – Multivariate regression analyses testing the relative contribution of factors to depression score at Time 1	181
Table 6.15 – Multivariate regression analyses testing factors which predict Time 2 grief score	182
Table 6.16 – Multivariate regression analyses testing factors which predict Time 2 Depression score	183
Table 7.1 – Group characteristics of individuals included in the analysis	202
Table 7.2 – Comparison of Mortality Rates by Group	203
Table 7.3 – Comparison of Changes in Marital Status by Group	203

Table 7.4 – Comparison of Changes in Employment by Group.....	204
Table 8.1 – Group characteristics of members of each cohort	217
Table 8.2 – Mortality of cohort members or their spouses, followed up to 2006.....	218
Table 8.3 – Mean time between event and death for deceased in individual cohorts, by bereavement status	219
Table 8.4 – Comparison of Changes in Employment by Group (71-01).....	220
Table 8.5 – Comparison of Changes in Employment by Group (81-01).....	220
Table 8.6 – Comparison of Changes in Employment by Group (91-01).....	220
Table 8.7 – Comparison of Change in Employment Status from Not Working to Working by Group (91-01)	221
Table 8.8 – Comparison of Changes in Relationship Status by Group (71-01)	222
Table 8.9 – Comparison of Changes in Relationship Status by Group (81-01)	222
Table 8.10 – Comparison of Changes in Relationship Status by Group (91-01)	222

List of Figures

Figure 1.1 – The Dual Process Model of Coping with Bereavement (Stroebe & Schut, 1999)	26
Figure 1.2 – The Integrative Risk Factor Framework (Stroebe et al., 2006).....	28
Figure 4.1. Key Recurrent Themes in Coping with the Loss of a Child	87
Figure 5.1 – Stroebe et al. Integrative Risk Factor Framework (2006)	120
Figure 5.2 - Scattergram of participants' grief and depression status	134
Figure 5.3 – Factors Univariately Associated with Grief	138
Figure 5.4 – Factors Univariately Associated with Depression.....	141
Figure 6.1 - Scattergram of participants' grief and depression status at Time 1	174
Figure 6.2 – Factors Univariately Associated with Grief at Time 1	178
Figure 6.3 – Factors Univariately Associated with Depression at Time 1	181

Chapter One - Introduction

1.0 Abstract

1.0.1 Background

The current chapter introduces the topic of parental bereavement in order to establish a rationale for the thesis.

1.0.2 Method

Key theories of bereavement are described, from a historical and contemporary perspective. The experience of parental bereavement is then considered, with specific reference to health, social and emotional outcomes.

1.0.3 Results

The Integrative Risk Factor Framework (Stroebe, Folkman, Hansson & Schut, 2006) was identified as an important theoretical model for scoping the experience of parental bereavement. In particular, the health and social functioning domains were considered as key aspects for investigation.

1.0.4 Conclusions

The aims and structure of the thesis were set out, indicating that the focus of the thesis will be on outcomes and risk factors of bereavement, and that the experience will be evaluated with separate groups of parents who are in early, mid and late bereavement.

1.1 Overview

1.1.1 Definition of Bereavement

According to Parkes and Weiss (1983), bereavement is “the most severe psychological trauma most people will encounter in the course of their lives. (p. ix). There are around half a million deaths in the United Kingdom every year (General Register Office for Scotland, 2010; National Statistics Office, 2010), and it is likely that most of those who are exposed to a bereavement will experience distress, depression and sadness as a result, at least in the immediate aftermath of the death notification (Shuchter & Zisook, 1993). The majority of people would, however, expect to recover from the loss and return to normal functioning after a period of time, but for some, this natural process is disrupted or prolonged. This failure to resolve bereavement symptoms has been of interest to generations of researchers.

1.2 Historical Perspective on Grief and Bereavement

1.2.1 Freud’s Comparison of Mourning and Melancholia

In considering the place of grief in psychopathology, Freud (1917) expressed surprise that grief had not, at that time, been considered a psychiatric condition. He believed that grief shared many common factors with other conditions considered to be pathological, particularly his “melancholia”, which we now refer to as clinical depression. The rationale Freud gives for the non-pathologising of grief is that its inception can be explained as a result of a natural process, thereby causing it to be different from depression, whose aetiology could not be explained. In considering the impact of grief on daily life, Freud described the physical debilitation that occurs as grieving individuals attempt to detach themselves from preoccupation with the memory of the

deceased. Freud believed that self-esteem was the key difference between grief and depression. Those who experience depression believe they are worthless; those who experience grief believe that life is worthless in a world without their loved one.

1.2.2 Engel's Theory of Grief as a Disease

The seminal work by Engel (1961) was the first published article to consider the potential pathological nature of grief in the light of widely-held claims to the contrary. The article argued that, since grief leaves the sufferer in an impaired state of functioning and with a clear presentation of symptoms of distress and disability, it should be categorised as a psychological disorder. Engel considered many arguments against the categorisation of grief as a disease and offered compelling suggestions in favour of the concept. For example, he considered the perspective that grief may be considered a natural phenomenon, one that an individual will recover from in time, without intervention. Engel argued that this could be said to be true of many ailments, including wounds, disease or burns, and yet an individual is not expected to bear the pain of these other ailments without analgesia or antibiotics. Why, then, should one be expected to bear the pain of grief without assistance or support? Engel called for scientific research to be carried out into the phenomenon of grief, to understand it in greater detail, thereby considering whether treatment to alleviate the symptoms of grief is possible.

1.2.3 Bowlby's Attachment Perspective on Loss

John Bowlby believed that the study of grief and mourning should be fundamental to all psychological study. His statement that “there is little doubt...that much psychiatric illness is an expression of pathological mourning” may be a strong claim, however he has provided compelling evidence for this assertion, albeit from a mainly

psychoanalytic perspective (Bowlby, 1981). The evidence he has presented suggests that, for emotional disorders such as depression and anxiety, there normally exists a precipitating event associated with a loss of some kind, and it is a disordered form of grieving that manifests itself as the emotional disorder. For other psychiatric conditions, the loss is of the subjective norms of life, and again, it is the grieving and searching for this previous normal behaviour which is the individual's, or society's, key focus in consideration of their psychiatric condition.

The theory of grieving, according to Bowlby, follows a four-phase approach. In the first few hours and days of bereavement, the individual experiences emotional numbing, unable to fully comprehend or accept the loss. At this time, severe distress and sometimes anger may be present in the bereaved. Spontaneous and uncontrollable crying is common, with the bereaved reporting the occupation of a dreamlike state, going through the motions of life, often with a sense of unreality. Following this numbing phase, a period of yearning, pining and searching for the loved one takes place. During this time, the bereaved person often thinks they see the deceased as a face in the crowd or out of the corner of their eye, in a familiar seat or place in the home. Bowlby's third phase of grief represents a time when the bereaved person experiences disorganisation and intense despair. At this time, the world appears to be a confusing place where normal rules do not apply, and the bereaved must begin to accept and normalise their experience. The final phase of grief, according to Bowlby, is a phase of reorganisation. This is the time when the bereaved must establish a "new normal" in their life, accommodating the loss of the loved one and generating an autobiographical narrative which incorporates the life and death of the deceased. Bowlby indicated that the path through these phases is unlikely to be a straightforward one, with oscillation

between phases being a common phenomenon. In order for grief to be processed and for the bereaved to come to terms with their loss, they must therefore successfully complete phase four, reorganising their life and accommodating the impact of their loss. Bowlby's belief is that unresolved grief stems from an inability to reach resolution during the searching phase and, whether consciously or unconsciously, the bereaved person is unable to establish a representation of the deceased in any form, effectively prolonging the searching phase indefinitely.

Bowlby suggested that there are two key issues to be addressed within bereavement research, namely that we gain an understating of what "normal" mourning or grief is, and that, in turn, we gain an understanding of why some people react differently to loss, resulting in an "abnormal" pattern of mourning or grief.

1.2.4 Parkes and Weiss's Psychosocial Transitions in Bereavement

The perspective of bereavement taken by Parkes and Weiss (1983) is one of a psychosocial transition. The bereaved person has experienced a rupture of their normative view of the world, resulting in a need to establish and accept a new and altered world view. This is essentially a developmental process, much as that followed when an amputee learns to walk again following removal of a limb. The bereaved person must stop attending to the wishes of their lost loved one and must, as, for example, in the case of spousal bereavement, begin to learn to think in terms of "I" rather than "we". The challenge to the assumptive world view experienced by the bereaved can be all-encompassing. New roles need to be learned to accommodate domestic tasks which were previously the domain of the deceased. Social events once experienced as a couple or as a family will now have a poignant focus, as one key

individual will be missing. Life events such as significant anniversaries will be profoundly moving, as the bereaved considers the “what if” scenario of the deceased’s potential experience of these important dates. Essentially, Parkes and Weiss are describing Bowlby’s fourth phase of grief – that of reorganisation and accommodation of the loss within everyday life. For Parkes and Weiss, healthy grief requires the loss to be assimilated and a new world view constructed in its wake.

1.3 Contemporary Models of Bereavement

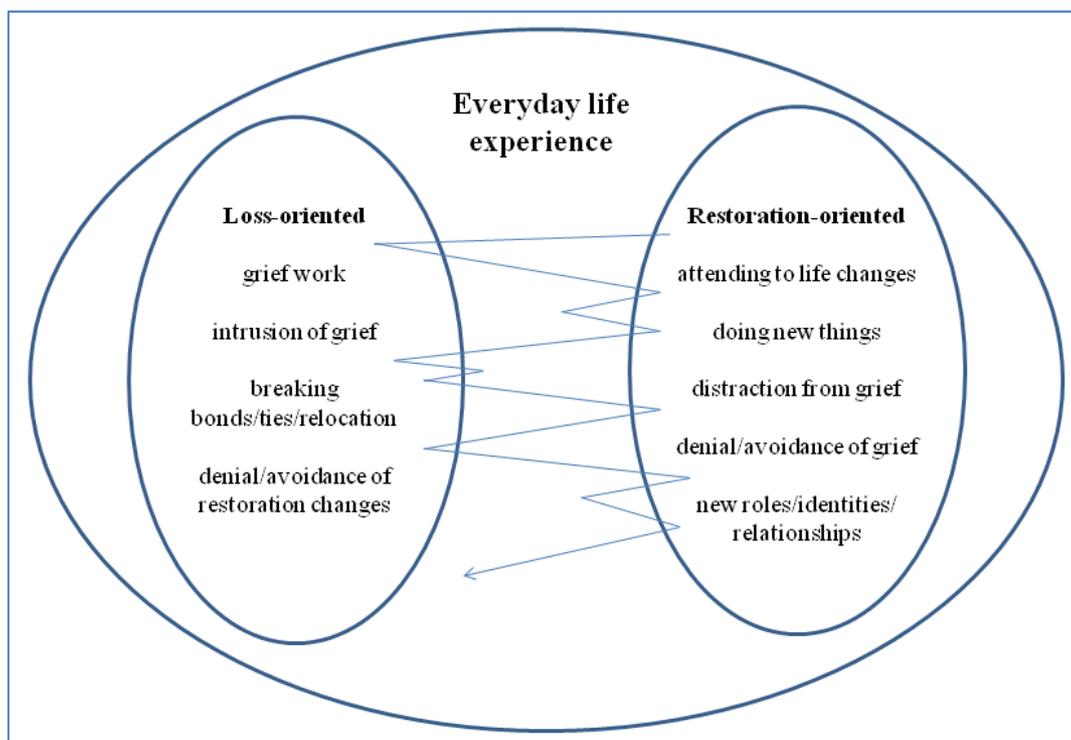
1.3.1 Dual Process Model of Bereavement

In recent years, researchers have turned their attention to consideration of the processes which influence individual outcomes within the bereaved. The Dual Process Model of coping with bereavement (Stroebe & Schut, 1999) elegantly depicts the grieving process from a cognitive perspective (see Figure 1.1). The model illustrates that coping with bereavement requires the bereaved individual to address two forms of stressors. The first, loss-oriented stressors, are those which are directly related to the death of the loved one. These would include allowing Bowlby’s first, second and third phases of grief to be experienced, moving from the period of emotional numbing, through the time of yearning, pining and searching for the loved one, to acceptance that the previous accepted norms and worldview are changed. The individual must confront their loss in a way most suitable to facilitate this process. At the same time as the loss-oriented stressors are being “worked through”, the Dual Process Model pays cognisance to the fact that changes in everyday life take place when a loved one dies. Tasks previously undertaken by the deceased spouse, for example, may now become the responsibility of the deceased, perhaps requiring new skills to be learned or knowledge to be gained. Social events and hobbies in which both parties previously took part may now require a

new partner to be found or may become inappropriate for the individual, in the absence of the lost partner. Financial changes mean that standards of living may have to change, financial support may need to be sought from other sources, and the spousal home may no longer be appropriate for the bereaved to inhabit.

The bereavement process, according to Stroebe and Schut, is one of oscillation between loss-oriented stressors and restoration-oriented stressors. Sometimes, the bereaved may be in one domain or the other, but there will also be times when neither type of stressor is being attended to. This is believed to be an adaptive process, effectively allowing the bereaved some respite from the ongoing stressors, before again attending to one or both of the processes for adjusting to bereavement.

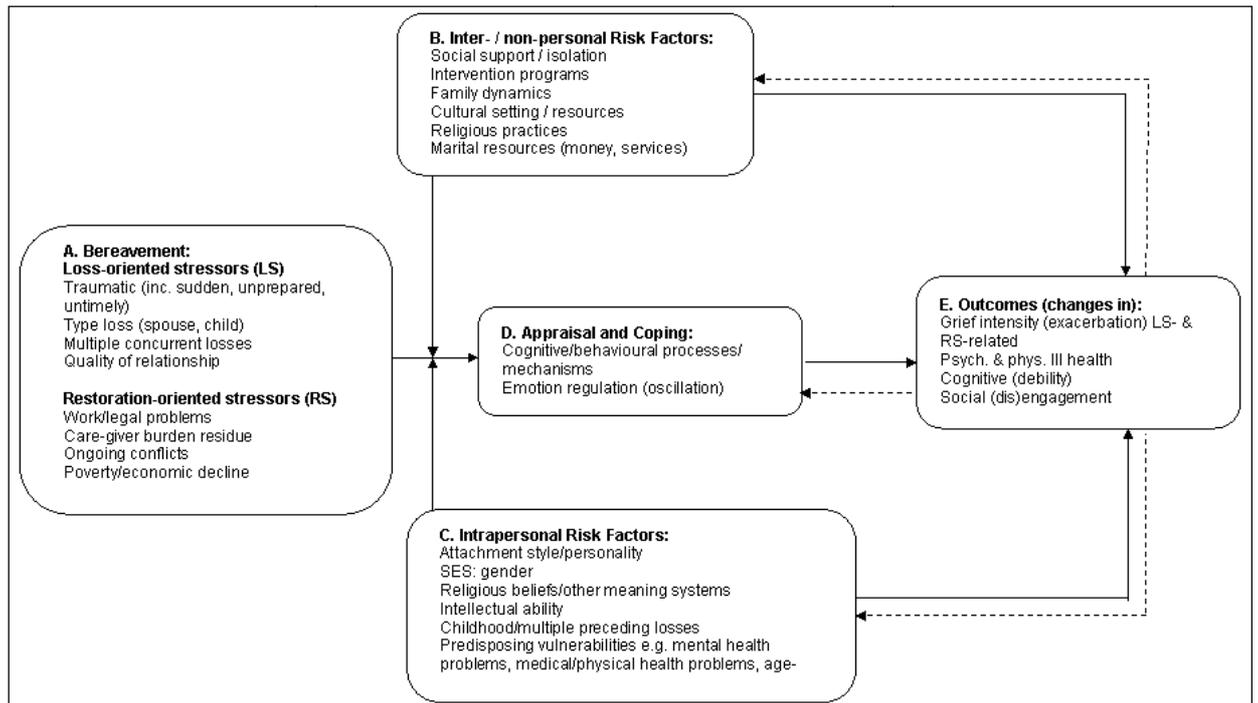
Figure 1.1 – The Dual Process Model of Coping with Bereavement (Stroebe & Schut, 1999)



1.3.2 Integrative Risk Factor Framework for Coping with Bereavement

The Integrative Risk Factor Framework (Stroebe et al., 2006) further refines the Dual Process Model, by taking account of the interaction of a number of cognitive processes which may lead to a more detailed analysis of the pathways of coping with bereavement. The Integrative Risk Factor Framework, illustrated in Figure 1.2, posits that factors within a number of individual domains interact to determine the bereaved person's outcome following their loss. The framework suggests a number of possible pathways to bereavement outcome. Presence of, and attending to, the loss- and restoration-oriented stressors provides a starting point for the bereaved individual's grieving process, and this can be affected by interpersonal factors such as level of social support and economic resources, as well as intrapersonal factors such as gender and personality factors. The progress towards coping with their bereavement is then further impacted by the appraisal and coping processes themselves, where coping styles may be important in determining bereavement outcomes. The framework suggests that all of these domains may interact to cause changes in bereavement outcomes, which may, in turn, feed back into the bereavement process, further affecting the individual domains again. The Integrative Risk Factor Framework has, for the first time, provided researchers with a theoretical approach to testing pathways of coping with bereavement. Its publication has provided a call for bereavement researchers to attempt to begin defining and testing the potential pathways which may eventually be used to predict bereavement outcomes.

Figure 1.2 – The Integrative Risk Factor Framework (Stroebe et al., 2006)



1.4 Social Theories of Bereavement

Hagman (1995) argued that most modern theories of bereavement are derived from psychoanalytical perspectives, with a specific emphasis on Freud’s “Mourning and Melancholia” work (Freud, 1917). This epistemological position, Hagman argues, has caused a fundamental bias in bereavement theories since they are based on the cultural norm of European grief in the late 19th and early 20th centuries. At this time, the fashion for mourning was for a prolonged, introspective focus on the sadness accompanying the loss, stereotypically portrayed by Queen Victoria following the death of Prince Albert. The focus, then, was on facilitating decathexis and detachment from the relationship with the deceased. The theories that have been derived from this position therefore required the bereaved person to focus on “tasks of mourning” and, specifically, to try to restrict their thoughts and memories of the decedent. The notion of keeping an ongoing relationship with the deceased was very much viewed as abnormal and the possibility

that an ongoing attachment to the lost loved one may be beneficial rather than detrimental to wellbeing was not considered in early bereavement theories.

Attig (2001) posited that the early experience of profound loss in bereavement is a manifestation of the sense of suffering one feels when faced with the knowledge that they must live their lives without the loved one they have lost. He suggested that the personal “wholeness” that exemplifies contentedness in life is due to the connections that are built with meaningful others and, when one of these connections is broken, the sense of self has to be rebuilt taking account of the, now missing, meaningful connection. This theory has echoes of Bowlby’s (1981) view that pining and yearning for the deceased is a fundamental component of bereavement. During this time, the bereaved person is effectively searching for the lost loved one, an experience which is manifested by thinking they see the face of the decedent in a crowd, or catching sight of them out of the corner of their eye. The process of grieving, according to Attig, is one in which our world is “relearned” or reconstructed incorporating the absence of the loved one, combined with a coming to terms of the pain of the loss. This can be done either by finding ways to reduce the intensity of the pain or by learning to accept it and thus the pain become habitualised. This task of reconstructing our new view of the world, according to Attig, is achieved through a process of finding or making meaning of the lost loved one’s life and death.

Meaning reconstruction is achieved when the bereaved person is able to construct a narrative which then places the lost loved one in the individual’s new assumptive world view (Neimeyer, 2001). This narrative approach is influenced strongly by theories of social constructivism (Crossley, 2000), whereby an individual’s perception of reality is

based on their own experiences and belief systems. When the bereaved person tells and retells their story, they are effectively constructing a new narrative which explains the position and importance that the lost loved one has in their lives, accepts the reality of the loss and recognises how their world has been changed as a result of the life and death of the loved one. Consequently, Neimeyer suggested that irresolution of grief is manifested as an inability to find a meaningful narrative which incorporates the impact of the decedent's life on the bereaved. In the case of parental bereavement, it may be particularly difficult to find meaning in the loss as it undermines the basic assumption that life will follow a predictable course where the young will outlive the elderly. This may explain why the loss of a child is a particularly difficult bereavement to come to terms with.

The social view of bereavement is further extended by Valentine's (2008) work reporting how the bereaved continue an interdependent relationship with their lost loved ones. The continuing bonds reported in her studies included aspects of sharing and reciprocity which indicated that this feature of bereavement was adaptive, contradicting the earlier bereavement theories which emphasised disconnection from the deceased. Participants in Valentine's study frequently reported that they felt their loved one was "looking down on them", so that the behaviour of the bereaved should, in some way, be approved of by the lost loved one. A common phenomenon reported was the perception that the bereaved person had been contacted by the decedent in some way. This could be by the feeling of a physical presence, or by visiting a special place associated with the deceased. Both of these phenomena were reported as comforting and beneficial to the decedent, indicating that continuing bonds with a lost love one may be adaptive to the bereaved person, rather than being maladaptive as was thought historically.

1.5 Prolonged Grief as a Distinct Diagnostic Condition

The concept of prolonged grief as a potential psychiatric disorder, variously referred to as prolonged grief, complicated grief, traumatic grief, abnormal grief, chronic grief and pathological grief, has received increased attention in recent years. Whilst enduring distress has been evident in psychiatric practice for many generations, the notion that an individual can be “damaged” permanently following bereavement led mental health practitioners to begin to formulate a picture of what this ongoing course of symptoms may look like (Parkes & Weiss, 1983).

A key factor exhibited by those who demonstrated ongoing distress following bereavement was that of yearning or pining for the deceased (Parkes & Weiss, 1983). Originally believed to be indicative of a form of attachment disorder, this symptom has remained a consistent component of prolonged grief, featuring in the descriptions offered by key proponents of this phenomenon (Dillen, Fontaine & Verhofstadt-Deneve, 2008; Horowitz, 2005; Prigerson, Shear, Jacobs, Reynolds, Maciejewski, et al., 1999).

Prigerson et al.’s (2009) proposed diagnostic criteria for Prolonged Grief Disorder is shown in Appendix I. The description of the disorder is under review for inclusion in DSM-V and the current status is that more input from investigators regarding the phenomena is required before a final recommendation can be made (American Psychiatric Association, 2010). The key symptoms of the proposed disorder of prolonged grief are separation distress with persistent or intense yearning for the deceased, combined with cognitive, emotional or behavioural symptoms such as avoiding reminders of the loss, difficulty with accepting the loss and feeling incomplete

without the loved one's presence. Prigerson et al. accept that the proposed diagnostic criteria have been drawn mainly from work with bereaved spouses, and that other populations may exhibit different sets of symptoms. Whilst mindful of the need to avoid pathologising a naturally occurring phenomenon, where the grief experience would be expected to follow most bereavements, many practitioners suggest that, when symptoms persist beyond six months post-loss or where they cause significant disturbance to normal functioning, diagnosis and therapeutic intervention may be recommended (Stroebe, Schut & Stroebe, 2007). Again, this time scale is recognised as being representative of spousal bereavement, and may be different for other types of losses, including the death of a child.

1.6 Outcomes for Bereaved Parents

1.6.1 Health Outcomes

A recent review of health outcomes following bereavement reported a number of well-controlled studies which reported differences between bereaved and non-bereaved populations (Stroebe et al., 2007). Mortality following bereavement, commonly referred to as “dying of a broken heart”, is a well-supported finding with many studies reporting increased mortality following the death of a spouse. Only two studies were found which reported mortality rates in bereaved parents. The first reported that bereaved parents were twice as likely to die following the death of a child compared to a set of matched controls in the general population (Agerbo, 2005). The second study showed an increased mortality rate in bereaved mothers overall, and higher mortality from unnatural causes in bereaved fathers (Li, Precht, Mortensen & Olsen, 2003). In terms of physical health, the recently bereaved were noted as having higher rates of illness, pain and medical consultation than those in mid-late bereavement, and those bereaved

generally had higher incidences of physical illness than the non-bereaved. For bereaved parents specifically, mothers were found to have a higher incidence of physical illness overall, however fathers' health deteriorated over time following the bereavement whereas mothers' health did not (Murphy, Lohan, Braun, Johnson, Cain, et al., 1999).

A number of studies out with the Stroebe et al. systematic review also showed poorer health outcomes for bereaved parents compared to non-bereaved controls. Olsen, Li & Precht (2005) found a higher incidence of first reports of Type 2 diabetes in bereaved mothers, levels of multiple sclerosis were higher after bereavement (Li, Johansen, Bronnum-Hansen, Stenager, Koch-Henriksen, et al., 2004) as were levels of myocardial infarction (Li, Hansen, Mortensen & Olsen, 2002), however incidence of cancer, (Li, Johansen, Hansen & Olsen, 2002), recovery levels from cancer, (Li, Johansen & Olsen, 2003), incidence of stroke, (Li, Johansen & Olsen, 2003), irritable bowel syndrome, (Li, Norgard, Precht & Olsen, 2004) and rheumatoid arthritis, (Li, Schiottz-Christensen & Olsen, 2005) were not found to be significantly different in bereaved and non-bereaved parents.

As well as symptoms of prolonged grief as described earlier, bereaved parents are also at higher risk of other psychological conditions. Kreichbergs, Valdimarsdottir, Onelov, Henter and Steineck (2004) found that bereaved parents whose child died of cancer had higher levels of depression and anxiety than matched non-bereaved controls. Post-traumatic stress disorder was found to be three times more likely in bereaved mothers than the general population and twice as likely in bereaved fathers compared to a normative sample (Murphy, Johnson, Chung & Beaton, 2003). Psychological distress, as manifested as suicidal ideation is reported as "common" amongst bereaved parents

(Neria, Gross, Litz, Maguen, Insel, et al., 2007), and a study comparing bereaved parents with non-bereaved parents found the bereaved group to be twice as likely to die by suicide as the comparison group (Agerbo, 2005).

1.6.2 Changes in Social Functioning

Although widely reported as problematic following the death of a child, the notion that relationship breakdown is likely or even inevitable is not supported by empirical evidence (Murphy, Johnson & Lohan, 2003b). Some studies even suggest that the loss of a child may strengthen marital bonds, leading to a more stable relationship following bereavement (Schwab, 1998). This “myth” that marital struggles are endemic in parental bereavement is, however, a common feature in the narratives of bereaved parents as they discuss the challenges they face following their loss (Stebbins & Batrouney, 2007).

The study carried out by Corden, Sloper and Sainsbury (Corden, Sainsbury & Sloper, 2002) indicated that bereaved parents who have lost a chronically ill child may face financial difficulties from a reduction in benefit income, additional expenditure for funeral costs etc. and loss of earnings whilst absent from work. This is echoed by Stebbins & Batrouney (2007) who reported bereaved parents’ loss of income and additional expenditure across a wide range of situations. In addition, they point out that three quarters of parents interviewed reported problems at work, often having to take unpaid leave and either chose, or were forced to leave work permanently. These additional restoration-oriented stressors may, in turn, impede the process of coping with parental bereavement, thus exacerbating grief symptoms.

1.6.3 Emotional Consequences

The most problematic emotions experienced following parental bereavement are guilt and anger (Rando, 1986). Whilst no study has been found which compares the prevalence of these emotions in bereaved parents to any control group, the correlation between these emotions and grief has been demonstrated. Barr and Cacciatore (2007) found guilt-proneness to be significantly associated with grief in perinatally bereaved mothers. An association between guilt and depression was also found in parents whose child died as a result of cancer (Surkan, Kreicbergs, Valdimarsdottir, Nyberg, Onelov, et al., 2006). Anger's association with bereavement outcomes is less well defined, however one study suggested it did rise in line with grief symptoms, peaking at two years post-loss (Fish, 1986).

1.7 Aims of the Thesis

Most of the bereavement literature, including the proposed diagnostic criteria for Prolonged Grief and the Integrative Risk Factors Framework, is dominated by the experience of spousal bereavement. The primary aim of this thesis, therefore, is to further scientific knowledge in the area of parental bereavement, in terms of outcomes, coping methods and risk factors for psychological distress, using the Stroebe Integrative Risk Factor Framework as a guide. In doing so, we attempt to address two key issues recommended for the study of bereavement (Bowlby, 1981). We aim to gain an understanding of what "normal" grief may be for bereaved parents, and we also begin to identify what risk factors may be associated with prolonged grief and depression, following the death of a child.

Therefore, the specific aims of the thesis are:

- (i) To investigate which aspects of coping with bereavement are viewed by bereaved parents themselves as helpful/unhelpful in the process of adjustment to their loss
- (ii) To identify what social changes bereaved parents experience following the death of a child
- (iii) To determine which factors are associated with different outcomes, using the Integrative Risk Factor Framework as a guide
- (iv) To gather evidence of outcomes, and factors associated with these outcomes, in early, mid and late parental bereavement

1.8 Thesis Structure

The literature review in Chapter two focuses on the risk factors which are identified as being associated with poorer outcomes in parental bereavement. Chapter three provides an overview of the methods used in the thesis. Specifically, this provides a summary of the approach chosen for the qualitative study, namely Interpretative Phenomenological Analysis, along with detailed information on each of the measures being used in the quantitative studies that are later described. Chapter four reports the findings of an exploratory study, which aims to identify what outcomes are noted as important by bereaved mothers, and which factors may have played a part in determining these outcomes. Chapter five aims to identify which are the key factors which are associated with differential outcomes in a group of bereaved parents in early bereavement (up to three years post-loss) and chapter six investigates which factors are key in mid-bereavement (four years post-loss). Chapter seven reports the findings of a Scottish Census study, which compares the mortality and social outcomes for bereaved parents who experience stillbirth or infant death, to a control group, up to fifteen years post-

bereavement. Chapter eight reports similar mortality and social changes in a larger group of bereaved parents in the Census records for England and Wales, up to 35 years post-bereavement. Chapter nine provides a general discussion of the findings of the thesis and indicates their implications for research and clinical practice. Strengths and limitations of the research are reviewed and suggestions are made for further research in the field of parental bereavement.

Chapter Two – Literature Review of Factors Associated with Differential Outcomes of Parental Bereavement

2.0 Abstract

2.0.1 Background

The Integrative Risk Factor Framework indicates a number of factors which may be associated with different outcomes following bereavement (Stroebe et al., 2006). Whilst a number of these variables have emerged from previously published literature on general bereavement, the factors associated with differential outcomes following parental bereavement are less clearly defined.

2.0.2 Method

A literature review was therefore conducted to identify published studies which report potential dependent and independent variables for testing bereavement outcomes in bereaved parents.

2.0.3 Results

Grief and depression emerged as the most common outcome variables in the reported literature, however the paucity of the available research and the heterogeneity of measurement instruments employed rendered selection of variables for future testing problematic.

2.0.4 Conclusions

Grief and depression have been widely used in previous research as outcome variables, but there are no clear predictors shown to be reliably associated with differential outcomes.

2.1 Introduction

The Integrative Risk Factor Framework (Stroebe et al., 2006), as described in chapter one, indicates that outcomes for the bereaved individual depend upon factors from a number of domains. Later studies in this thesis will test different aspects of the interactive framework, however testing all of the proposed factors would not be feasible within one individual research project. A review of the literature has, therefore, been carried out in order to establish which factors have been identified as important factors and/or excluded in determining outcomes for parents who experience the death of their child. There are many reported studies which examine the factors which may affect the outcome of general bereavement experiences, however very few studies consider the experience of coping with the death of a child, from the parent's perspective. To ensure that the factors for subsequent testing are relevant to the experience of parental bereavement, the literature review has been conducted within the confines of the literature pertaining specifically to parental bereavement.

2.2 Method

The three main psychological and medical databases were searched. These were Web of Science (1981 - September 2010), Medline (from 1966 - September 2010) and Psychinfo (1887 – September 2010). The searches were carried out with the following keywords:

((child* or teenage* or adolesc* or infan* or perinatal) and (death or bereave*)) and (Title = (Death* or grie* or died or dies or suicid* or murder* or accident* or homicid* or bereave* or fatal* or deceased or los* or mourn*)) or keyword = parent* bereave*).

This search yielded 10,571 results, most of which were reports of medical findings related to causes of death. These, and any articles not related to the death of a child, were excluded from the results by examination of the article title, leaving 787 articles within the area of parental bereavement.

All of the abstracts of the remaining articles were read and papers were included which fulfilled the following criteria:

- 1) Studies included data specifically relating to parental bereavement or, if other types of bereavement were included, the data relating to parental bereavement were reported separately;
- 2) Studies incorporated a specified outcome variable, and considered the impact of, or association with, differential values of predictors;
- 3) Studies did not incorporate any interventions under test, since these may have affected bereavement outcomes which occurred naturalistically;
- 4) Evaluations were made of the current status of the participants, and were not based on retrospective judgements of earlier experiences;
- 5) Studies did not include participants from areas where child mortality rates are significantly elevated, for example, sub-Saharan Africa.

Reference sections from those papers which fulfilled the above inclusion criteria were then manually checked for any further candidate articles. Any which were identified then had their abstracts scrutinised for inclusion using the criteria, as specified above. This inclusive strategy was adopted in order to minimise the possibility of overlooking any potentially relevant studies.

The search and review process yielded 21 published empirical papers which were relevant. Within the papers, variables are reported which were found to be associated with a measured outcome. These are shown below in Table 2.1.

Table 2.1 – Studies Reporting Factors Associated with Grief in Parental Bereavement

<i>Study/ Country</i>	<i>Child cause of death/ Age/Time Since Death</i>	<i>Parent Sex/Age/ Recruitment Source</i>	<i>Outcome Variables</i>	<i>Predictors+</i>	<i>Results</i>
(Anderson, Marwit, Vandenberg & Chibnall, 2005) USA	34 murder, 23 accident Mean age 20 years (SD=7) Mean TSD = 4.5 years (SD=2.7)	57 mothers Mean age 51 years (SD=9) Recruited from support groups	RGEI (Lev, Hazard Munro & McKorkle, 1993)	CISS (Endler & Parker, 1994); RCAS (Pargament, Ensing, Falgout & Olson, 1990)	Grief associated with TSD. When TSD was controlled for, emotional coping and avoidance coping were associated with grief, positive coping associated with grief when task coping was high. No correlation between grief and child's age, gender, cause of death, marital status, education.
(Bohannon, 1991) USA	“Many types” of cause of death – details not specified Range from stillbirth to adult death – details not specified Mean TSD = 1 year 8 months, range 2 months – 5 years	33 couples Fathers mean age 44 years, Mothers mean age 41 years Recruited from support groups	GEI (Jacobs, 1987)	Gender	Fathers experienced less grief than mothers

<i>Study/ Country</i>	<i>Child cause of death/ Age/Time Since Death</i>	<i>Parent Sex/Age/ Recruitment Source</i>	<i>Outcome Variables</i>	<i>Predictors+</i>	<i>Results</i>
(Downey, Silver & Wortman, 1990) USA	SIDS Mean age 81 days (SD=49 days), range 9 days – 11 months Interviews at 15-30 days post-death, 3 months and 18 months	176 mothers and 85 fathers Mean parent age 25 years (SD=5.3) Recruited from hospital records	SCL-90-R (Derogatis, Ricklels & Rock, 1976)	Specially constructed instrument measuring meaning making	At 3 months post-death mothers were more likely to blame themselves for the death than fathers and had higher ratings of distress. Parents who attributed cause to themselves were more distressed.
(Drenovsky, 1994) USA	76% sudden deaths Age not specified TSD not specified	39 couples Mean age 43 years Recruited from support groups	CES-D (Radloff, 1977)	Gender, suddenness of death, feelings of anger and retribution	Mothers were significantly more depressed than fathers, sudden death was associated with increased depression, higher TSD was associated with decreased depression, feelings of anger and retribution do not affect depression
(Engelkemeyer & Marwit, 2008) USA	41 murder; 35 accident; 35 illness Mean age 15 years (SD=7.5) TSD 1 month – 37 years, mean 7 years (SD=8)	111 BPs, gender split not given Mean age 50 years (SD=12) Recruited from support groups and medical records	PTGI (Tedeschi & Calhoun, 2004)	WAS (Janoff-Bulman, 1989) RGEI (Lev et al., 1993)	Self-worth correlated with PTG. TSD was the strongest predictor with 8% of variance in PTG. Grief in 2 nd step of regression accounted for another 4%. When WAS variables entered at step 3, grief became NS, self-worth was then significant. No difference in WAS for gender, child's age, parent's age or education

<i>Study/ Country</i>	<i>Child cause of death/ Age/Time Since Death</i>	<i>Parent Sex/Age/ Recruitment Source</i>	<i>Outcome Variables</i>	<i>Predictors+</i>	<i>Results</i>
(Feigelman, Gorman & Jordan, 2009) USA	462 suicide, 54 accident or other traumatic deaths, 24 natural causes Age range < 15 years to over 36 years, 80% of deaths occurred between the ages of 16 and 35 years TSD between < 12 months and > 10 years.	540 BPs, 85% female Age range 46-65 years Recruited from support groups	GEQ (Barrett & Scott, 1989) ICG (Prigerson, Frank, Kasl, Reynolds, Anderson, et al., 1995)Mid- Life survey (depression) development (Wethington, Kessler & Brim, 2005) Suicidal ideation question	Societal stigmatisation from specially designed scale	Stigma scale score strongest predictor of GEQ. Grief difficulties, stigma and TSD predicted depression. Depression and grief predicted SI

<i>Study/ Country</i>	<i>Child cause of death/ Age/Time Since Death</i>	<i>Parent Sex/Age/ Recruitment Source</i>	<i>Outcome Variables</i>	<i>Predictors+</i>	<i>Results</i>
(Hazzard, Weston & Gutterres, 1992) USA	Cause of death not specified Mean age 6.3 years (SD=5.9), range few months to 17 years TSD mean 24.7 months (SD=14.0), range 6 months – 50 months	26 mothers, 19 fathers Age range 25 years to over 45 years Recruited from medical records	GEI (Sanders, Mauger & Strong, 1979)	Parent questionnaire measuring demographics, premorbid factors, factors associated with death, TSD, support, subsequent stressors, attribution	Parents of boys, whose child died suddenly had higher despair, anger, guilt and depersonalisation. Social support, subsequent stressors and blaming fate were associated with higher grief.
(Ito, Tomita, Hasui, Otsuka, Katayama, et al., 2003) Japan	SIDS, neonatal death, stillbirth, encephalopathy, accident, illness Mean age 15 months (SD=19), range 0-10 years. TSD 41 months (SD=25)	106 – 28 men, 78 women Mean age 35 years (SD=6), range 24-60 years Recruited from support groups and advertising	SCID (First, Spitzer & Williams, 1999)	RSQ(Nolen- Hoeksema, Parker & Larson, 1994) Response Style Items After Loss	Ruminative coping a weak predictor of depression but not anxiety. No association between distractive coping styles and either depression or anxiety.

<i>Study/ Country</i>	<i>Child cause of death/ Age/Time Since Death</i>	<i>Parent Sex/Age/ Recruitment Source</i>	<i>Outcome Variables</i>	<i>Predictors+</i>	<i>Results</i>
(Littlefield & Silverman, 1991) Canada	43% accidents, 32% illness, 10% congenital defect, 8% suicide, 5% murder, 2% birth complications. Mean age 14 years, range 0-45 years TSD 2.2 years (SD=1.8)	148 BPs, couples Mean age 45 years, range 22-73 years Recruited from support groups	GEI (Sanders et al., 1979)	Actual and perceived cause of death, reported marital satisfaction	Mothers grieved more than fathers, healthy children were grieved for more than unhealthy children; male children were grieved for more than female children; health of child and sex of child interacted such that the pattern of grief intensity obtained
(McIntosh, Silver & Wortman, 1993) USA	SIDS TSD - 15 days post-loss, 30 days, 3 months, 18 months	124 parents, 79% mothers. Mean age 25 years (SD=5), range 15-40years Recruited from death records	Affects Balance Scale (Derogatis, 1992) SCL-90-R (Derogatis et al., 1976)	Religion, social support, cognitive processing, meaning all from interviews	At 18 months post-loss, religion, social support, meaning and cognitive processing were not associated with distress or wellbeing
(Morrow, Hoagland & Carnrike, 1981) USA	Cancer Mean age 6 years (SD=4.6), range 1-20 years TSD not specified	37 BPs, 66% female. Age range 23-58, median 37 Recruited from support groups	Psychosocial adjustment to illness scale	Social support measured by asking participants to rate the level of support offered by up to 11 sources	Younger parents had poorer psychosocial adjustment. No gender difference. No correlation between support and adjustment

<i>Study/ Country</i>	<i>Child cause of death/ Age/Time Since Death</i>	<i>Parent Sex/Age/ Recruitment Source</i>	<i>Outcome Variables</i>	<i>Predictors+</i>	<i>Results</i>
(Murphy, Johnson & Lohan, 2003a)USA	Accident, murder, suicide. Mean age 20 years, range 12-28 years TSD 6-28 weeks	173 parents, 66% mothers. Mean age 45 years (SD=6), range 32-61 years Recruited from death records	BSI (Derogatis, 1992) Traumatic Experiences Scale – created for the study	RSE (Rosenberg, 1979) COPE (Carver, Scheier & Weintraub, 1989)	At one and five years post-death, self-esteem was a significant predictor of mental distress and PTSD. After controlling for self esteem, the use of active/ affective coping strategies predicted less mental distress for fathers but not for mothers. Repressive coping strategies were significant predictors of higher PTSD symptoms for both mothers and fathers at both one and five years post-death. Active/affective coping strategies were not significant predictors of lowered PTSD symptoms for either mothers or fathers.
(Purisman & Maoz, 1977) Israel	Death in war Adults, age not stated. TSD 2-3 years	25 mothers, 22 fathers Age not stated Recruited from military records	General adjustment assessed by raters using self-report interview data	Religion, education, ethnicity, years in the country, work outside home, ritual surrounding death, marriage, social contacts	Higher education associated with better adjustment, religion and ritual poorer adjustment, being married and having good social support was associated with better outcomes. Marriage problems were evident prior to the loss

<i>Study/ Country</i>	<i>Child cause of death/ Age/Time Since Death</i>	<i>Parent Sex/Age/ Recruitment Source</i>	<i>Outcome Variables</i>	<i>Predictors+</i>	<i>Results</i>
(Robinson & Marwit, 2006) USA	59% accident, 40% murder, 1% suicide. Mean age 18 years (SD=9). TSD mean 6.9 years (SD=7.2), range 3 months – 31 years	138 bereaved mothers. Mean age 52 years (SD=12) Recruited from support groups	RGEI (Lev et al., 1993)	Neuroticism and extraversion using EPQ (Eysenck, 1975) CISS (Endler & Parker, 1994)	Grief correlated with Neuroticism, Extraversion, TSD, Emotion, task and avoidance coping. When controlling for TSD, Neuroticism and Extraversion, Emotion oriented coping had most significance
(Shanfield, Swain & Benjamin, 1986) USA	Road accidents Mean age 24.6 years (SD=5.5) TSD 26 months (SD=5)	20 mothers, 20 fathers Mean age 40.5 years (SD=8.1) Recruited from death records	BDI (Beck, Ward, Mendelson, Mock & Erbaugh, 1961) SCL90 (Derogatis, 1979) Grief, guilt, painfulness of loss and family growth from specially designed questionnaire	Demographics	Depression - Child's problems, being a mother, few previous bereavements Grief – being an older child, mutual interdependence, less involvement in family decisions, prior bereavements Guilt – ambivalent relationship with child Greatest loss – age, few prior bereavements, emotional dependency Family growth – mutual interdependence, non-ambivalence, child moving out at older age, few child problems, child being married

<i>Study/ Country</i>	<i>Child cause of death/ Age/Time Since Death</i>	<i>Parent Sex/Age/ Recruitment Source</i>	<i>Outcome Variables</i>	<i>Predictors+</i>	<i>Results</i>
(Sidmore, 1999) USA	9 accident, 2 suicide, 2 stillbirth, 5 illness, 1 other Age range 0-26 years TSD range 14-238 months	13 mothers, 6 fathers, Age range 30-65 years Recruited from support groups	GEI (Sanders, Mauger & Strong, 1985)	Demographics – sex of parent, sex of child	Mothers had greater grief than fathers, Sex of child made no difference to levels of grief
(Surkan et al., 2006) Sweden	Cancer. Child age < 25 years TSD range 4-9 years	449 BPs, 56% female. Age range and mean not stated. Recruited from death records.	Questionnaire measuring guilt	Questionnaire measuring demographics, perception of care, perception of symptom relief, perceptions of own health care needs.	Perceptions of inadequate health care, lack of access to symptom relief, lack of fulfilment of parent needs all associated with higher guilt.
(Videka-Sherman, 1982) USA	Stillbirth, sudden or anticipated deaths due to illness and violent death Child ages not detailed TSD < 18 months	391 BPs, 70% female Mean age 41 years, range 21-67 years Recruited from support groups	HSCL (Derogatis, Lipman, Rickels, Uhlenhuth & Covi, 1974)	Specially prepared instrument measuring coping, support group involvement	Preoccupation, religiousness and altruism associated with better adjustment. Escape coping NS.

<i>Study/ Country</i>	<i>Child cause of death/ Age/Time Since Death</i>	<i>Parent Sex/Age/ Recruitment Source</i>	<i>Outcome Variables</i>	<i>Predictors+</i>	<i>Results</i>
(Wijngaards de Meij, Stroebe, Schut, Stroebe, van-den-Bout, et al., 2007) Netherlands	Stillbirth or Neonatal death 16%, Illness 48%, Accident, SIDS, suicide or murder, 36%. Mean age 10years (SD=10), range up to 30 years TSD 6, 13 and 20 months post loss	219 couples Mean age 42 years (SD=9) Age range 26-68 years Recruited from obituary notice	ICG (Prigerson, Frank et al., 1995) SCL90 (Derogatis et al., 1976)	AAS (Collins & Read, 1990) Neuroticism EPQ (Eysenck & Eysenck, 1991)	Avoidant and anxious attachment and neuroticism both predicted grief and depression
(Wijngaards-de Meij, Stroebe, Stroebe, Schut, Van den Bout, et al., 2008) Netherlands	Stillbirth or Neonatal death 16%, Illness 48%, Accident, SIDS, suicide or murder, 36%. Mean age 10years (SD=10), range up to 30 years TSD 6, 13 and 20 months post loss	219 couples Mean age 42 years (SD=9) Age range 26-68 years Recruited from obituary notices	ICG (Prigerson, Maciejewski, Reynolds, Bierhals, Newsom, et al., 1995) SCL90 (Derogatis et al., 1976)		Controlling for TSD, gender of parent, age of child and unchangeable variables, taking the body home and saying farewell predicted less grief. Controlling for TSD, gender of parent, age of child and unchangeable variables, no “changeable variables” were associated with depression. Type of disposal, whether parents cared for the body and whether they were present at the time of death were not significant on either grief or depression.

<i>Study/ Country</i>	<i>Child cause of death/ Age/Time Since Death</i>	<i>Parent Sex/Age/ Recruitment Source</i>	<i>Outcome Variables</i>	<i>Predictors+</i>	<i>Results</i>
(Wijngaards-de Meij, Stroebe, Schut, Stroebe, van den Bout, et al., 2008) Netherlands	Stillbirth or Neonatal death 16%, Illness 48%, Accident, SIDS, suicide or murder, 36%. Mean age 10years (SD=10), range up to 30 years TSD 6, 13 and 20 months post loss	219 couples Mean age 42 years (SD=9) Age range 26-68 years Recruited from obituary notices	ICG (Prigerson, Maciejewski et al., 1995) SCL90 (Derogatis et al., 1976)	Dual Coping Inventory created for the study	Women had greater grief and depression than men, TSD decreased grief and depression for both genders. High loss-orientation predicted higher grief and depression, high restoration-orientation predicted lower grief and depression. High levels of restoration-orientation moderated the effects of high loss-orientation. Men had better outcomes when their partner had high restoration orientation. High levels of loss-orientation were not associated with partner or gender effects.

Notes. TSD= Time Since Death, RGEI= Revised Grief Experiences Questionnaire, CISS= Coping Inventory for Stressful Situations, RCAS= Religious Coping Activities Scale, GEI= Grief Experiences Inventory, SCL-90-R= Symptoms Checklist 90 Revised, CES-D= Centre for Epidemiological Studies Depression Scale, PTGI= Post Traumatic Growth Index, WAS= World Assumptions Scale, GEQ= Grief Experiences Questionnaire, SIDS= Sudden Infant Death Syndrome, SCID= Structured Clinical Interview for Depression, RSQ= Response Styles Questionnaire, SCL-90 Symptoms Checklist 90, RSE= Rosenberg Self-Esteem Inventory, BSI= Brief Symptoms Index, EPQ= Eysenck Personality Questionnaire, HSCL= Hopkins Symptoms Checklist, ICG= Inventory of Complicated Grief, AAS= Adult Attachment Scale.

2.3 Method of Analysis

The research papers were scrutinised from three perspectives. These were the demographics of participants and their bereavements, the predictors used and the outcome variables used. The results of these analyses are shown below.

2.3.1 Demographics

Participants in the studies were recruited from a number of sources. Nine of the studies recruited participants from support groups (Anderson et al., 2005; Bohannon, 1991; Drenovsky, 1994; Feigelman et al., 2009; Littlefield & Silverman, 1991; Morrow et al., 1981; Robinson & Marwit, 2006; Sidmore, 1999; Videka-Sherman, 1982), two recruited participants from medical records (Downey et al., 1990; Hazzard et al., 1992), one recruited from a combination of both (Engelkemeyer & Marwit, 2008) and one recruited from support groups and advertising (Ito et al., 2003). In addition, four studies recruited from death records (McIntosh et al., 1993; Murphy, Johnson & Lohan, 2003a; Shanfield et al., 1986; Surkan et al., 2006) and three found participants from the obituary notices they had published in newspapers (Wijngaards-de Meij, Stroebe, Schut et al., 2008; Wijngaards-de Meij, Stroebe, Stroebe et al., 2008; Wijngaards de-Meij et al., 2007). One study recruited parents from the military records of their children (Purisman & Maoz, 1977).

The mean age of the child who died varied across studies. Two studies concentrated on coping with the loss of an adult child (aged 18+ years) (Anderson et al., 2005; Purisman & Maoz, 1977), thirteen considered both children and adults (Bohannon, 1991; Engelkemeyer & Marwit, 2008; Feigelman et al., 2009; Littlefield & Silverman, 1991; Morrow et al., 1981; Murphy, Johnson & Lohan, 2003a; Robinson & Marwit, 2006;

Shanfield et al., 1986; Sidmore, 1999; Surkan et al., 2006; Wijngaards-de Meij, Stroebe, Schut et al., 2008; Wijngaards-de Meij, Stroebe, Stroebe et al., 2008; Wijngaards de-Meij et al., 2007) , two investigated children aged under 18 (Hazzard et al., 1992; Ito et al., 2003), two investigated infant deaths (Downey et al., 1990; McIntosh et al., 1993) and two were unspecified (Drenovsky, 1994; Videka-Sherman, 1982). The age ranges of the parents in the studies correlated with the ages of the children, as expected, with parents of infants having a lower mean age than parents of adult children.

Cause of death was very much associated with the age range of children at their time of death. Where the demographic of the deceased included adults and children, the causes of death were a mixture of illness, accident and murder. The studies concerned with infant deaths were predominately concerned with Sudden Infant Death Syndrome, neonatal death in the first few weeks of life, stillbirth or congenital illness.

The time since death also varied both within and between studies. Some studies, such as Downey et al. (1990), McIntosh (1993) and the studies from the Utrecht centre (Wijngaards de-Meij et al., 2007)) elected to focus on a narrow time frame in early bereavement, whereas the other studies had a far broader range of time since death in their participants.

For those studies where gender was described, most had more female participants than males. Only those who specifically recruited couples (Drenovsky, 1994; Littlefield & Silverman, 1991; Wijngaards-de Meij et al., 2007, 2008a and 2008b and Shanfield & Swain, 1984) had equal numbers of male and female participants.

2.3.2 Outcome Variables

The most widely reported outcome variable was grief, which was measured in nine studies. To measure grief, six studies used the Grief Experience Inventory or Revised Grief Experience Inventory, two studies used the Inventory of Complicated Grief and one study used the Grief Experiences Questionnaire. Depression was predominately measured by the original or revised Symptom Checklist-90 (n=6), with one study using the Beck Depression Inventory, one the Center for Epidemiologic Studies Depression Scale and one the Hoskins Checklist -90. One study utilised variables from the Mid-life Development Survey to establish levels of depression in participants.

Additional outcome variables in other studies were post-traumatic growth measured by the Post-Traumatic Growth Inventory and distress and wellbeing measured by the Affect Balance Scale. Other studies utilised bespoke questionnaires or interview schedules to establish potential levels of post-traumatic stress disorder, guilt, psychosocial adjustment and overall general adjustment to the loss.

2.3.3 Predictors

In the studies where participant demographics covered a wide range of time since death, the bereavement time scale appeared to mainly be negatively associated with levels of grief and/or depression (Anderson et al., 2005; Drenovsky, 1994; Engelkemeyer & Marwit, 2008; Feigelman et al., 2009; Robinson & Marwit, 2006; Wijngaards-de Meij et al., 2008b). Hazzard et al. (1992) found no association between time since death and grief symptoms.

Gender differences were reported in only some of the studies. Bohannon (1991), Drenovsky (1994), Littlefield et al. (1991), Sidmore (1999) and Wijngaards-de Meij et al. (2008b) all reported mothers experiencing higher levels of grief than fathers, yet Hazzard et al. (1992) reported no difference in grief symptoms between men and women.

Age effects are also unclear in these studies. Age of child was not related to grief in three studies (Anderson et al., 2005; Engelkemeyer and Marwit, 2008; Hazzard et al., 1992), but Shanfield and Swain (1984) found higher grief in parents who lost older children. Wijngaards-de Meij (2008a) found the association between the age of the child and grief to be curvilinear, increasing until the age of 18 years, thereafter decreasing again.

The studies which measured coping styles explicitly produced a variety of findings. In the Anderson et al. (2005) study, emotional and avoidance coping was found to be associated with higher levels of grief. This finding was supported by Robinson and Marwit (2006), who reported that emotion, task and avoidance coping were all associated with higher levels of grief. Anderson et al. also found, perhaps unexpectedly, that when task coping was high, positive coping was also associated with grief. Ito et al. (2003) found ruminative coping to be a weak predictor of depression, but that distractive/avoidance coping had no association with grief outcomes. Comparing the coping styles of mothers and fathers, Murphy et al. (2003) found that fathers' use of active or affective coping strategies predicted less distress, but this finding did not hold for mothers. Repressive coping was not associated with one sex more than the other, as it was associated with higher PTSD symptoms for both mothers and fathers. Finally,

Videka-Sherman (1982) found that preoccupation with the loss was associated with higher grief symptoms, where altruism and, to a lesser extent, religiousness, were both associated with lower grief scores.

Four studies (Anderson et al., 2005, Bohannon, 1991, McIntosh et al., 1993 and Purisman and Maoz, 1977) chose religiosity as their key predictor. Anderson et al. established that different coping strategies were associated with religious activity but that religious coping in itself was not related to different levels of grief. McIntosh et al. found no relationship between religious behaviours and outcome and Bohannon reported religious behaviours correlated with more positive outcomes for mothers, but not so strongly for fathers. In addition, Purisman and Maoz found poorer adjustment in parents with high levels of religiosity. All four studies used different methods of measuring religious behaviour, making detailed comparison of these results problematic, however it would appear that the relationship with religious activity and outcome following parental bereavement is unclear.

2.4 Conclusion

The limited and somewhat diverse research into parental bereavement does not provide clear guidance for selection of predictors and formulation of hypotheses for testing. Grief, and to some extent, depression, would appear to be emerging as the most prominent outcome measures. Time since death and gender appear to be related to different outcomes, but the relationship between the age of the child and bereavement outcomes is less clear.

In terms of coping behaviours, use of different measures of coping and religiosity make comparison across studies difficult. From what has been published to date, clear associations between different coping strategies cannot be reliably made. In the light of the limited insight that the published research offers, an exploratory study would be appropriate to further inform the choice of factors which should form the structure of quantitative testing of this phenomenon.

Chapter Three – Methods

3.0 Abstract

3.0.1 Background

The topic of coping with parental bereavement is not one which has an extensive published literature base. There is no consensus about which factors may affect bereavement outcomes, nor is there much research evidence focussing on those outcomes themselves. Given the paucity of research evidence, a multi-method approach was employed to identify and investigate risk factors for bereavement outcomes.

3.0.2 Method

The first phase of the research was qualitative in nature, to elicit information about the lived experience of parental bereavement. Using the results from this study, later quantitative methods identified which factors had the most impact on outcomes for parents, and for how long these effects could be measured. Appropriate research methods were chosen to achieve these desired research objectives. The strengths and limitations of each method were discussed.

3.0.3 Results

Interpretative Phenomenological Analysis was chosen as the qualitative research method. Self-report questionnaires completed at a single point in early bereavement and at two time points in later bereavement provided data for analysis using multivariate regression statistics to identify the key factors which affect outcomes. Use of existing national longitudinal datasets would additionally provide data identifying the long term impact of parental bereavement.

3.0.4 Conclusions

The multi-method approach would appear to be the best method in order to provide a comprehensive analysis of the experience of parental bereavement.

3.1 Introduction

Research in the topic of parental bereavement is a relatively rare activity, as was demonstrated with the literature search reported in chapter two. Research methods and knowledge about key factors of the topic have therefore not been widely reported and, as such, the research area is still very much in its infancy. To allow a project to generate reliable results, research in this area must take a “bottom up” approach, establishing the basics before more detailed investigation of factors under examination can be carried out. This thesis will, therefore, begin with a qualitative enquiry, followed by detailed quantitative testing, before concluding with analysis of long-term existing national datasets.

3.2 Requirements for the Qualitative Method Chosen

3.2.1 Function of the Research

There are several qualitative methods commonly used in psychological research, one of which must be chosen to fulfil the requirements of the research under consideration.

The method selected must answer the research question directly, which in this case was “What are the ways in which bereaved parents cope with the death of a child?” This question requires the consideration of both contextual evidence, where the participant describes what the experience of parental bereavement is like, and generative evidence, where actions, cognitive processes and beliefs are reported as factors potentially affecting the bereavement outcome (Ritchie, 2003). The proposed study does not attempt to fulfil either an explanatory role, where the participant provides data on why they have chosen a particular coping strategy, nor does it attempt to fulfil an evaluative role by establishing the adaptiveness of any given behaviours or cognitions. The method chosen must therefore be one which is both contextual and generative.

3.2.2 Participant Population

The first consideration for the research design was the population under review. The research aimed to get as close as possible to the experience of parental bereavement, thus the participants themselves should be bereaved parents. Information from professionals or family members would not be sought in this particular project.

The results of the study were expected to inform a choice of factors for later quantitative testing in a broad range of participants whose child died at any age from birth to adulthood, and where the death occurred as a result of accident or illness, suddenly or following a lengthy period of decline. From this standpoint, it is clear that a number of participants must be involved, with a corresponding breadth of bereavement experiences. An individual case study approach would not be appropriate, since the research was intended to identify common factors across the different bereavement experiences. The research method should therefore highlight commonalities across the lived experience of parental bereavement.

3.2.3 Timing of Research

The course of parental grief over time is not clearly defined in the existing literature, however researchers have found continuing grief in bereaved parents over many years, even up to 62 years from the time of the loss (Arnold, Gemma & Cushman, 2005). This suggests that coping with parental bereavement may be a lifelong challenge, therefore the time since death for participants was not a criterion for participant recruitment.

Restrictions on the time available for data collection within the context of a PhD eliminated the option of longitudinal data collection, therefore each participant would be seen only once to gather the required information.

3.2.4 Participant Recruitment

The sensitive nature of this research was a key determining factor in participant recruitment and the researchers were keen not to unwittingly intrude on people who wished their experience to remain private. Participant recruitment would therefore be through an open invitation, allowing people who wished to take part to volunteer but without causing those who did not wish to take part any guilt.

3.2.5 Data Collection Method

The decision whether to use naturally occurring data or data generated for the purposes of the research project was made on the basis of practicality. Naturally occurring data could have been gathered by observation of bereaved parents or through conversation analysis, however both of these methods would have required multiple meetings over a period of time. Support groups would have provided an intense, concise set of data relating to parents actively discussing their experience, but may have resulted in a bias of results towards that of the culture of the organisations. Meeting bereaved parents outside of this type of situation, perhaps in a domestic or social setting, would probably give rise to rich naturally occurring data (Lewis, 2003), however the time to collect these results would not have been feasible within the constraints of the PhD process. As a result, the decision was made to arrange a single meeting with individual participants where the topic of parental bereavement would be explored in depth. Again, given the sensitive and highly personal nature of the experience, individual interviews were chosen in preference to focus groups, to provide participants with the highest level of privacy possible.

3.2.6 Protecting the Participants from Harm

The qualitative research was subject to the same ethical approval guidelines as the quantitative research. The research protocol, proposed interview schedule and participant recruitment method were evaluated and approved by the Department of Psychology Ethics Committee within the University of Stirling. At the time of the interview, the researcher made clear that withdrawal of consent to continue could take place at any time without explanation. Relevant local sources of support were provided to the participant in the form of an information sheet, and some time was set aside for an informal debrief with the researcher, once the data collection had been completed.

3.2.7 Protecting the Researcher from Harm

Since the interviews with participants would take place in their own homes, a security protocol was followed to ensure that the whereabouts of the participant was known at all times during the interview process. A named employee of the Department of Psychology was identified as the key point of contact. The researcher notified this named individual with the address of the interview, the house telephone number and the start time and likely finish time. If the interview continued past the estimated finish time, the researcher would send a text message to the named individual advising that an extension would take place. Once the interview was completed, the named individual would be sent a text informing them that the researcher was no longer at the participant's house. If any of these messages failed to be sent at the agreed time, the named individual would first attempt to contact the researcher on her mobile phone. If there was no response, the researcher was to call the home number of the participant and ask to speak to the researcher. If this did not happen or there was any doubt over the safety of the researcher, the police office local to the participant's home was to be

alerted. This security protocol was followed but no escalation was invoked throughout the data collection process.

As well as physical security, the emotional wellbeing of the researcher was considered and steps were put in place to minimise any distress which may have occurred when discussing these highly emotive experiences. The first supervisor, himself a qualified and experienced clinical psychologist, could be contacted immediately after the interview if distress occurred. Some of these meetings did take place and, where appropriate, debriefing was carried out. If the researcher experienced any ongoing concerns about the interview, both supervisors prioritised their availability for discussion, debrief and consultation at any time. Alternatively, the researcher had access to the counselling services offered by the university, should she feel that these would be beneficial.

3.2.8 Selection of Qualitative Method

A short list of three potential qualitative methods was considered for the study of the phenomenon of parental bereavement. This shortlist was derived from the research experience of the supervisors and within the wider Department of Psychology as a whole. The methods considered were discourse analysis, grounded theory and Interpretative Phenomenological Analysis (IPA). There is evidence of overlap between the techniques under consideration, however there were two key reasons why IPA was selected as the method to be used. The first is that the IPA method states clearly that its aim is to look beyond the actual words spoken in an attempt to interpret meaning from what is unsaid but implied by the research participant, thus generating deeper insight into the “lived experience” under analysis (Smith & Osborn, 2004). The degree of

interpretation that IPA recommends goes beyond what would be expected with, for example, grounded theory techniques. Secondly, the aim of the research is not to identify why the participant is voicing their experience in a particular way, but rather focuses on the phenomenological description of the experience (Smith & Osborn, 2004). This research focus therefore favours IPA over discourse analysis, since IPA's primary ontological premise is phenomenological. IPA was therefore selected as the method of choice for its combination of interpretation of participant accounts and phenomenological focus.

3.2.9 Limitations of IPA

IPA is a relatively new method for conducting research, having emerged in the last ten years and still meriting new publications clarifying the research method in detail (Smith, Flowers & Larkin, 2009). The evidence of its effectiveness has therefore had limited time to become established.

In addition, this study was carried out by an inexperienced researcher new to the process of depth interviewing. Achieving high quality data collection and relevant levels of probing and reflecting is a skill in itself and one which is likely to be perfected with practice. Although the researcher had prior experience of working with bereaved parents in a peer support situation, she had no prior experience of conducting professional research interviews. A training exercise took place with the first supervisor, where a mock interview was held and feedback given on interview technique. In addition, interview transcripts were reviewed by an independent IPA expert. This type of "rehearsal" training is seen as the best possible preparation for qualitative interviewing (Banner, 2010).

3.2.10 Conclusions for Choice of Qualitative Method

The IPA technique was chosen to elicit information about the lived experience of parental bereavement. The researcher would receive a high level of support for this study, both from an emotional and health perspective, as well as from a technical research perspective.

3.3 Quantitative self-report data

Self-report data is widely used in psychological research, relying on truthful responses to questions from which conclusions may be made. However, as a data collection technique, self-report questionnaires are not without their problems. Participants may answer questions in a particular way, which they feel presents them in the most socially desirable light (van de Mortel, 2008). It is possible to estimate the degree of this bias by using an additional measure, such as the 33-item Marlowe-Crowne Social Desirability Scale (Crowne & Marlowe, 1960). This questionnaire asks a number of questions whose answers are designed to be socially desirable but, in reality, are unlikely to be true. Scoring highly on this scale indicates that the participant is attempting to present themselves in an overly positive light, and this may skew the answers they have supplied in other areas of the questionnaire. Although this type of measure is certainly useful in identifying a social desirability bias, it was not included in the present project. Lengthy questionnaires are likely to increase the demand on participants and every attempt was made to keep the load on the participants to a minimum. The questionnaires used measures which have demonstrated high levels of reliability and validity in previous research. This, therefore, facilitated collecting reliable and valid data from large numbers of participants quickly, and cost effectively.

3.4 Cross-sectional Data Collection

As was the case in the qualitative research design, the quantitative research aims to identify common features of the phenomenon of parental bereavement across a range of bereavement experiences. The experience of parental bereavement is, thankfully, a rare one, and numbers of people who experience specific types of bereavement reduce the group sizes even more. To maximise responses and subsequent power of statistical comparisons, the participant group has been kept as wide as possible. Comparison of sub-groups will take place within the research to establish whether sub-groups of participants, for example those experiencing a sudden or violent death, have higher or lower scores on outcome variables. This will then be tested in multilevel regression analyses to establish whether certain types of parental experience significantly affect the outcomes being measured. In this way, testing of the phenomenon of parental bereavement as a single phenomenon can be carried out.

3.5 Analysis of Secondary National Data Sources

Data from Scotland, England and Wales captured from the census data collected every ten years will be used to identify the long-term impact of parental bereavement. This provides a readily available source of data which are made available free of charge to researchers. High levels of user support are offered by staff from the data service organisations. There are, however, a number of limitations of the data provided. The census has changed in format over the years, and the versions of the census data capture form ask questions differently or may omit certain questions altogether. This makes comparison of changes over time complex for some variables, and detailed methods for achieving comparative results must be negotiated with the staff involved in the data extraction process. This can be done by any researcher, however a background in

database management is extremely beneficial in this negotiation process. The data capture process takes place every ten years at a fixed date. Whilst this aids data analysis in that all results are captured simultaneously, it does leave a large window for changes which may take place and then recede. For example, a person may be fully employed on each census date but may spend most of the intervening time not in employment. Their status of “employed” will not then reflect their actual status over the period since the last data was captured. Finally, the data available are restricted to those which are components of the government’s census programme. The data items relate mainly to social factors such as employment, housing occupancy and marital status, which are augmented by life event information such as deaths and marriages. This limited information does not allow for more sophisticated analyses of factors associated with changes in social status, for example, the impact of medical treatment on levels of illness or time absent from work. This type of data source is only therefore appropriate for certain types of research where the data elements captured are sufficient for the researcher’s use.

3.6 Choice of Quantitative Self-Report Measures

3.6.1 Outcome Measures

3.6.1.1 Grief

Grief was assessed using the Inventory of Complicated Grief (Prigerson, Frank et al., 1995). The questions on this 19-item scale were adapted to suit the population by changing the term “this person” to “my child who died” (see Appendix II). Example questions are therefore, “I think about my child who died so much that it’s hard for me to do the things I normally do” and “I go out of my way to avoid reminders of my child

who died”. Each response is given a score ranging from 0 to 4. Unanswered or “don’t know” responses are given scores of -3 and -4 respectively. The total score on the Inventory of Complicated Grief indicates the severity of the participant’s grief symptoms. A score of 25 or over indicates that the participant meets the proposed diagnostic criteria for prolonged grief. Scores of 24 and under were identified as not having prolonged grief. The Inventory of Complicated Grief showed good test-retest reliability with a coefficient of 0.80 and is highly reliable with Cronbach’s $\alpha > 0.90$ and concurrent validity was established with the Texas Revised Inventory of Grief and the Grief Measurement Scale ($r = 0.87, p < .001$ and $r = 0.70, p < .001$ respectively). The Inventory of Complicated Grief was chosen as the preferred grief measure since it was developed specifically to match the proposed diagnostic criteria for DSM V, for the condition of Prolonged Grief (Prigerson et al., 2009).

3.6.1.2 Depression

Depression was measured using the Patient Health Questionnaire (PHQ-9) (Kroenke, Spitzer & Williams, 2001) . This short instrument of nine questions provides an indication of probable DSM IV “caseness” for moderate to severe depression (see Appendix III). The instrument measures the current state of depressive thinking, asking how often each of the problems has been experienced in the last two weeks. Examples of the problems are “little interest or pleasure in doing things” and “poor appetite or overeating”. A score between 0 and 3 is given for each problem, depending on the frequency experienced. There is a final question in the PHQ-9 which asks, “If you have been bothered by any of these problems in the last two weeks, how difficult have these problems made it for you to do your work, take care of things at home or get along with

other people?”. This question is used in clinical practice for diagnostic purposes and its response is not required for research purposes (Kroenke et al., 2001).

There are two methods of scoring depression using this instrument. These are either with a specified algorithm or by summing the total score (Kroenke et al., 2001). The algorithm requires that, for a probable DSM IV depressive disorder to be present, either question one or two in the PHQ-9 is given an answer of “more than half the days” or “nearly every day”. In addition, if five or more items are scored as “more than half the days”, the participant is likely to meet the diagnostic criteria for major depression. If question two, three or four was answered with at least “more than half the days” and question one or two is also answered in the same way, the participant is likely to meet the diagnostic criteria for minor depression. Using the total score method, a score of more than ten indicates moderate to severe depression, whereas a score of ten or less indicates mild or no depression. The total score method has been adopted in the present study, since this has been found to be consistent with algorithm scoring in previous research (Kroenke et al., 2001) and allows for comparison between total score for depression and other continuous variables.

The PHQ-9 was chosen over other self-report measures of depression for two reasons. Firstly, the number of questions was lower than, say, Beck Depression Inventory (Beck et al., 1961) (nine compared to twenty one, respectively). Secondly, the PHQ-9 has a higher level of validity and sensitivity to symptom severity than that reported by other screening and diagnostic instruments (Bjelland, Dahl, Haug & Neckelmann, 2002).

The PHQ-9 showed good test-retest reliability with a coefficient of 0.84 and is highly reliable with Cronbach's α between 0.86 and 0.89 and its validity, compared to the Mental Health Inventory, was $r = 0.93$, $p < .001$. (Spitzer, Kroenke & Williams, 1999).

3.6.2 Predictors

3.6.2.1 Trait Optimism/Pessimism

Optimism and pessimism were measured with the Life Orientation Test (Revised) LOT-R (Scheier, Carver & Bridges, 1994) (see Appendix IV). The LOT-R comprises ten questions, three are positively worded, e.g. "In uncertain times, I usually expect the best", three are negatively worded, e.g. "If something can go wrong for me, it will" and four are fillers. Each question is scored from 0 to 4 with 0 being strongly disagree and 4 being strongly agree. The total of the positively worded items gives an optimism score and the total of the negatively worded items gives a pessimism score. The LOT-R showed good test-retest reliability with coefficients of between .56 and 0.79 up to 28 months, and is highly reliable with Cronbach's $\alpha = 0.78$ (Scheier et al., 1994). The LOT-R was chosen as the preferred measure of optimism since it has been found to reliably measure trait optimism rather than state optimism, as is the case, for example, with the Optimism/Pessimism Scale (Burke, Joyner, Czech & Wilson, 2000).

3.6.2.2 Rumination

Two versions of the 10-item Response Styles Summary were used to assess rumination. The first version focussed on rumination traits associated with depression (Treyner, Gonzales & Nolen-Hoeksema, 2003) (see Appendix V). Ten questions measuring depression-focussed rumination are included in this scale, for example, "I think about how alone I feel" and "I think about how I don't feel up to doing anything". Participants

indicate what they generally do when they are feeling low, and responses are coded from 1 (never) to 4 (always). Higher scores indicate a greater tendency towards rumination.

The second version of the Response Styles Summary incorporates questions relating to brooding and reflection (Treyner et al., 2003) (see Appendix VI). Reflective rumination is described as a means of active problem solving by attending to a matter of concern and exploring problem-solving strategies in an attempt to alleviate stress. Brooding rumination, on the other hand, is considered to be a more passive behaviour, with no desire to achieve problem resolution. The Response Styles Questionnaire showed good high levels of construct validity ($r=0.47$, $p<.01$) and was therefore selected as a short but robust means of measuring rumination (Nolen-Hoeksema et al., 1994).

3.6.2.3 Coping Style

Coping style was measured using the Brief Cope (Carver, 1997), a 28-item instrument measuring 14 types of coping (see Appendix VII). The humour scale was removed from this study to avoid potential offence in participants. The remaining scales were aggregated into four summary sub-scales following O'Connor and O'Connor (2003). Problem Focussed Coping (subscale one) was derived from the total scores from the Active Coping and Planning scales, Avoidance Focussed Coping (subscale two) was calculated from Denial and Behavioural Disengagement. Social Support (subscale three) was derived from the Seeking Instrumental Social Support and Seeking Emotional Social Support. Cognitive Restructuring (subscale four) was calculated from Positive Reinterpretation and Growth Acceptance. Self-blame, Use of Religion, Focus and Venting of Emotions and Alcohol and Substance Use did not readily lend

themselves to any of these summary scales and were therefore retained as sub-scales in their own right. Test-retest reliability and validity of the scale have been shown to be acceptable (e.g. Cronbach's $\alpha=.81$, (O'Connor & O'Connor, 2003).

The Brief Cope was also chosen since it combined a relatively low number of questions with high levels of test-retest reliability over six and eight weeks (Carver et al., 1989).

3.6.2.4 Continuing Bonds

Continuing Bonds were measured using the Continuing Bonds Scale (Field, Gal-Oz & Bonanno, 2003) (see Appendix VIII). The wording of the questions in this scale was changed from "spouse" to "child", for example, "I seek out things to remind me of my child". There are 11 questions in the scale with the participants responding on a scale from 1 (not at all true) to 5 (very true). The total score indicates the level of continuing bonds that the bereaved has with the deceased. There is no published reliability or validity data for this scale.

A synopsis for each measure followed by a summary outline is presented in Table 3.1.

Table 3.1 Summary table of measures used in the research

<i>Construct</i>	<i>Name of Measure</i>	<i>Authors</i>	<i>Year</i>	<i>Number of Items</i>	<i>Rating Scale</i>
Grief	Inventory of Complicated Grief	(Prigerson, Maciejewski et al.)	1995	19	5-point scale ranging from 1=Never to 5=Always
Depression	Patient Health Questionnaire (PHQ-9)	(Kroenke et al.)	2001	9	4-point scale ranging from 1=Not at all to 4=Nearly every day
Trait Optimism/Pessimism	Life Orientation Test (revised) LOT-R	(Scheier et al., 1994)	1994	10	5-point scale ranging from 1=Strongly disagree to 5=Strongly agree
Rumination	Response Styles Summary			10	4-point scale ranging from 1=Never to 4=Always
Coping Style	Brief COPE	(Carver)	1997	28	4-point scale ranging from 1=Not at all to 4=A lot
Continuing Bonds	Continuing Bonds Scale	(Field et al.)	2003	11	5-point scale ranging from 1=Not at all true to 5=Very true

Chapter Four - Bereaved Mothers' Continuing Bonds and Ambivalence about their Own Mortality after the Death of Their Child – An Interpretative Phenomenological Analysis

4.0 Abstract

4.0.1 Background

The main objective of this study was to identify how bereaved mothers describe their coping strategies in their own words, to inform the design of the later quantitative studies reported in chapters four and five.

4.0.2 Method

The literature on parental bereavement is sparse, and the present study aims to add to existing knowledge by eliciting the mothers' experiences covering a wide range of child ages including infants, younger children and adults. Semi-structured interviews were carried out with 13 bereaved mothers in the United Kingdom. Causes of death include accident, illness and suicide. The methodological approach was Interpretative Phenomenological Analysis (IPA).

4.0.3 Results

The interview transcripts were analysed using IPA. This chapter reports three inter-related recurrent themes related to coping: (1) Continuing the bond with the deceased child, (2) Death and suicidal ideation and (3) Social changes following the death of their child. Participants reported that the relationship with their child was continued in a variety of ways, from tending to the grave and the child's remains, through linking objects, or by establishing a symbolic representation of the child within their daily lives.

Mothers continued the bond with children, regardless of the age of the child at time of death. All mothers talked openly about their own mortality, either demonstrating ambivalence about their own death, or expressing clear suicidal ideation. Death was seen as a release from living with the pain of loss. The presence of surviving siblings appeared to moderate suicidal ideation, but some mothers expressed concerns about their ability to care adequately for other family members during times of intense grief. Finally, participants indicated changes in the dynamics of their marital relationships and difficulties within their employment environment.

4.0.4 Conclusions

The level of suicidal ideation in bereaved parents requires urgent attention. Factors which mitigate suicidal ideation must be identified. The effect of different ways of continuing bonds with the lost child must be evaluated and their adaptiveness, or otherwise, established.

4.1 Introduction

According to Miller and Rahe (1997), the death of a child is the most significant stressor a woman can experience. The devastation that occurs for a mother when her child dies is said to leave her with “an oppressive sense of failure, a loss of power and ability, and a deep sense of being violated” (Rando, 1986), p.11). In order to come to terms with this devastating loss, according to the Dual Process Model of Coping with Bereavement (Stroebe & Schut, 1999), the bereaved must address both loss-oriented stressors and restoration-oriented stressors. Loss-oriented stressors relate to the loss itself and how the bereaved individual deals with the loved one no longer being physically present in their life. Restoration-oriented stressors relate to alterations to life which occur as a result of the death e.g. concerns over siblings, changes in domestic routines and future expectations. Coping with bereavement must therefore incorporate attendance to, and resolution of, both types of stressor.

The impact of a child’s death is believed to be long-lasting and in many cases perhaps even lifelong. Rubin (1993) found functional impairment and ongoing grief for 13 years post-death. Rogers, Floyd. Seltzer, Greenberg and Hong (2008) showed higher depression and health problems in bereaved parents up to 35 years following bereavement. (Arnold et al., 2005) found that grief continued for nearly two thirds of mothers up to 62 years post-death. The impact of surviving the death of a child may, therefore, endure for the parent’s whole lifetime.

4.1.1 Previous Studies of Bereaved Parents’ Coping

Little research exists to identify how parents actually cope with the death of a child. Hoekstra-Weebers, Littlewood, Boon, Postma and Humphrey (1991) assessed the

coping styles of bereaved parents using the Utrecht Coping List and compared those who had lost younger children (aged 3-9 years) with those who had lost older children (aged 13-19 years). The parents of younger children utilised a mainly active problem solving style of coping, such as finding ways of alleviating their distress, whereas the parents of older children were found to mainly use soothing coping styles for example, looking for diversions or relaxation.

Robinson and Marwit (2006) found bereaved parents used mainly task-oriented coping strategies, measured with the Coping Inventory for Stressful Situations, whereas Videka-Sherman (1982) found parents showed high levels of preoccupation with the child by talking about them and thinking about the loss, as well as evidence of turning to religion. Murphy et al. (2003a) demonstrated changes in coping strategies over time in bereaved parents using the COPE scale. At twelve months post-loss, mothers used repressive coping such as denial and disengaging behaviours to cope with their overwhelming sense of loss and events which may trigger intrusive memories. By sixty months post-loss, the mothers had begun to rely primarily on active coping styles such as problem solving through planning and management of activities.

It appears from these studies that parents demonstrated a wide variety of coping styles depending on time since bereavement, age of child and measure used. Lack of agreement between findings may indicate that different groups of parents do, in fact, cope differently with the death of a child, or alternatively, may reflect the use of different questionnaire measures of coping with bereavement.

4.1.2 Social Issues Following Bereavement

The quantitative studies reported in chapter five and six require the identification of appropriate predictors to determine which aspects of coping with the bereavement have better outcomes than others. The literature relating to bereaved parents' outcomes is sparse, however there have been some studies considering changes in health and social status in bereaved parents. As indicated in chapter one, bereaved parents are at higher risk of both mental and physical illness following the death of a child than matched non-bereaved controls (see Murphy et al., 1999; Li et al., 2004; Li et al., 2002; Kreicbergs et al., 2004 for examples). In terms of relationship difficulties, the picture is less clear with some researchers indicating that marital difficulties are no more common in bereaved parents than matched controls (Oliver, 1999), but others reporting that divorce was more common following bereavement (Lehman & Wortman, 1987). Financial changes may also be a feature of the parental bereavement experience, since Stebbins and Batrouney (2007) reported both financial and employment difficulties following the death of a child. It is likely, therefore, that bereaved parents will experience these, and perhaps other, as yet unreported, restoration stressors, as they come to terms with the loss of their child.

4.1.3 Phenomenological Research

A phenomenological approach to research is one in which the aim of the study is to identify the essence of the "lived experience" of a group of people (Langdrige, 2007). In the case of the present study, the "lived experience" under scrutiny is that of parental bereavement. Very little published qualitative research with bereaved parents has specifically adopted a phenomenological approach to investigate the core experiences of bereaved parents. One notable exception is Woodgate (2006) who investigated

parents' transitions following the death of their child, using thematic analysis. Four key themes were found, which were:

- (1) The need to keep memories of the child alive
- (2) Desire to reinforce the parent's belief in their own parenting ability
- (3) Recognition of the importance of being present when the child died
- (4) Importance of social support from friends, family and health care professionals (the latter if the child had received medical care prior to their death).

The Woodgate study investigated the experience of how parents cope following the death of their child due to illness, however the author recommends that a similar exploration of parental bereavement including accidental death should be carried out. The aim of this qualitative study is to explore how bereaved mothers describe coping with the death of their child in their own words, and to identify which coping behaviours, both adaptive and maladaptive, are common across a diverse range of bereavement experiences. The mothers' descriptions of their own experiences will be used to identify which coping behaviours they are using.

4.2 Method

4.2.1 Participants

Interviews were conducted with 13 bereaved mothers who were recruited from The Compassionate Friends charity (n=7) and from coverage of the study in a local newspaper (n=6). The Compassionate Friends (TCF) is an international charity which offers peer support for bereaved parents. An overview of the project, detailing the nature of the study and participant's involvement in it, was presented to the Scottish TCF Management Team after which the volunteers made contact and offered to

participate. The research project was also featured in a local newspaper as a human interest story. As a result of this, the remaining participants contacted us asking to take part. No effort was made to recruit participants beyond those who volunteered directly. The sample does not represent the full diversity of the bereaved parent population, and is described as purposive rather than representative.

Participants were aged between 32 and 64 years, with a mean age of 52 years. Time since death ranged from 1-40 years with a mean of 10 years. Child ages ranged from 2 weeks to 29 years. Further details of the research participants are provided in Table 4.1 below:

Table 4.1. Participant Characteristics

<i>Pseudonym</i>	<i>Years since death</i>	<i>Source</i>	<i>Gender of child</i>	<i>Child age at time of death</i>	<i>Cause of death</i>	<i>Participant age now</i>
Kay	1	TCF	Female	29	Long term illness	58
Donna	3	PRESS	Male	17	Accident	41
Francis	3	PRESS	Male	27	Long term illness	62
Gayle	3	PRESS	Male	2	Short term illness	32
				weeks		
Helen	4	PRESS	Male	29	Accident	60
Diane	5	PRESS	Female	5	Short term illness	36
Tracey	6	TCF	Female	19	Long term illness	55
Nancy	7	TCF	Male	9	Accident	50
Rita	7	TCF	Female	22	Unascertained/SADS	62
Katherine	8	TCF	Male	19	Suicide	46
Olivia	18	PRESS	Male	22	Accident	64
Susan	25	TCF	Male	2	Short term illness	51
Violet	40	TCF	Male	3	Cot death	61
				months		

Notes. TCF = Volunteer from The Compassionate Friends, PRESS = Volunteer from press coverage.

Due to the nature of the recruitment process, all participants knew that the researcher was also a bereaved mother. One of the participants ran the local branch of TCF which

the researcher had attended in the past. None of the others had any personal relationship with the researcher.

4.2.2 Data Collection

Ethical approval for the study was obtained from the University of Stirling Psychology Department. Interviews took place in the participants' own homes and lasted between one and four hours, with a mean time of one hour and 45 minutes. No financial incentive was offered for participation in the research.

An interview schedule was prepared prior to interviews taking place (see Appendix IX). This was created and piloted with a bereaved parent out with the participant group. The data collected in the pilot interview were not included in the current study. The questions in the schedule related to the circumstances of the death, what life was like now, and strategies and behaviours for coping with the bereavement. This approach was intended to elicit an account of the experience which was most pertinent to the participant and was designed to promote an "insider's perspective" of the phenomenon (see Conrad, 1990). The interview schedule was intended to act only as an aide memoir for the interviewer, to ensure the topics of interest were covered, however participants mainly engaged in free narrative about the circumstances of the death of their child, identifying the issues that were of particular relevance to them.

The interviews were recorded digitally, and were transcribed once all were completed. During transcription, pseudonyms were allocated for the participants and also for the child, and any other names mentioned were also changed to ensure confidentiality.

4.2.3 Data Analysis

The aim of this study was to explore the experiences of the bereaved mothers in their own words and from their own personal perspective. A phenomenological approach was chosen since it acknowledges the importance of focussing on how an experience, in this case parental bereavement, appears to those who undergo it (Langdrige, 2007).

The Interpretative Phenomenological Approach is widely used in psychology as a method for eliciting information about “the lives and experiences of others” (Brocki & Wearden, 2006). Smith and Osborn (2003) recommend the approach for areas where there is little published research or where the experience is considered to be particularly complex or novel. For these reasons, Interpretative Phenomenological Analysis (IPA) was the method deemed most suitable for this study.

All transcripts were subjected to IPA (for details, see Smith et al. (2009). The first phase of the analysis highlighted key words, phrases and idiosyncratic figures of speech in general. These statements explained how the participants coped with their bereavement. Each interview was read several times to increase familiarity with the participant’s narrative. The key phrases from each participant were identified, with a conscious effort to keep the coding emergent from each individual interview.

The next stage of analysis interrogated the transcript further by making comments and suggestions or asking questions in an attempt to generate “meaning” grounded in the participant’s own words. From here, initial themes were identified. Relationships and tensions between codes were sought out and those which appeared to refer to similar issues were grouped together as themes. From this analysis, recurrent themes emerged.

Recurrent themes are those which were prevalent in more than half of the accounts. The

coding that refers to these themes was then reviewed to ensure the themes remained relevant at the broader level, without compromising the meaning or significance of the participants' comments. Any individually coded items not relevant were removed from the broader themes.

The next phase of analysis required the whole dataset to be re-read. There were two reasons for doing this. Firstly, to ensure that the broad themes were an accurate reflection of the experiences of the participants and secondly, to check whether any additional comments should be coded to the broad themes.

Having ensured that all data relating to the broad themes were identified, the broad themes themselves were revised. Firstly, the quotations from participants were reviewed with reference to the themes, to ensure that the themes reflected what the participants were saying. Secondly, all of the transcripts were re-read to ensure that the themes were accurate in relation to the global experiences of the bereaved parents. If it was felt that a mismatch was evident, the terminology, specificity and focus of the themes were revisited until the descriptive titles and the overall testimonies were congruent. This cyclical process was continued until no further clarification or refinement was found. A separate analysis was carried out by an independent researcher, who is an IPA expert, using a random subset of the transcripts. The overall themes which emerged from this independent validity check matched those of the researcher's analysis. Once this validation check was carried out, the final interpretative thematic analysis of the transcripts was considered to be complete.

4.2.4. Impact of the Researcher on Participant Accounts

Consideration of the role of the researcher is a key component of any phenomenological research (Fry, Grogan, Gough & Connor, 2008). The participants in the present study all knew that the interviewer was herself a bereaved parent. At the conclusion of the interview, all participants spontaneously made reference to the fact that the researcher had experienced a similar experience and indicated that this was a key element in their decision to take part in the research. At this time and also during the interviews, the participants indicated their belief that the researcher would have a greater understanding of their experience, having also lived with the loss of a child. This meant that some interview content was initially given with the assumption of understanding on the part of the interviewer, at which point a deliberate attempt was made to clarify and encourage verbalisation of experience in the participant's own words.

Prior to carrying out both the interviews and the analysis, the researcher had no knowledge of the academic literature on coping and parental bereavement. This "tabula rasa" approach was a conscious decision on behalf of the researcher, to minimise preconceptions from findings published in previous studies. The researcher has personal experience of the loss of a child and had attended a local branch of TCF in the past. The participants in the current research had lost their children in a variety of situations, none of which was similar to that of the researcher. In addition, any previous contact that the researcher had with bereaved parents took place in the context of support seeking during early bereavement. The researcher therefore had no knowledge of longer term coping by bereaved parents in the situations reported in the current research.

4.3 Results

Once the analysis process was complete, it became clear that three main recurrent coping themes had been uncovered, as shown in Figure 4.1.

Figure 4.1. Key Recurrent Themes in Coping with the Loss of a Child



These were:

- a) Evidence of a continuing bond with the deceased child. This appeared to occur in three ways. Firstly, where a physical connection with the child was retained, secondly, where a linking object facilitated the bond and thirdly, where a symbolic representation of the child was adopted.
- b) High levels of death and suicide ideation. The level of ambivalence to the mothers' own mortality, which was seen as a release from the continuing pain of living with bereavement. There were indications that the presence of a surviving sibling moderated the mother's suicide ideation, however there were also concerns voiced over the ability to care for these siblings.
- c) Social changes attributed to the bereavement, manifested as relationship changes, either improving or worsening, and difficulties at work.

4.3.1 Theme 1a - Continuing the Bond with the Deceased Child – The Physical Connection

Most of the participants indicated that they felt a continuing bond with the child after the death. The only participant who did not refer to any kind of ongoing connection was Gayle, whose baby died aged two weeks. The concept of continuing bonds was offered spontaneously by all the other mothers, but did not feature in Gayle's account of her current situation.

For all other participants, the connection with the child appeared to take place on a number of different levels. Some participants chose to keep a physical connection with the child. Helen, whose adult son died as a result of a car accident, expressed the need to hold onto her son's physical remains. She told how she had carried her son's ashes around in a bag, taking them out with her when she left the house. She described this behaviour as "crazy" yet she went on to say that she believed it was "logical":

"I remember passing a house and it was like two or three in the morning and it was young Viv's house and eh they were having a party and I, I thought, I'll go in cos our Luke would like to go to that party. And my friend Hazel worked with Viv and she said "You had a party" and she said "yes" and she said "Helen went past, she was going to come in" she said "she should have just come in, she would have been most welcome" and then Hazel said "but she had Luke with her" and Viv went "how, what!" and she said "she had Luke" and she went "oh no, oh no!" so what to me at that time was quite logical to someone else was "oh no".

Helen referred to Luke as being physically present during this event. She contemplates the notion that Luke wants to join the party; not that he would have liked to have done such a thing when he was alive, but that he wants to attend the current event, now.

Helen reports her friend said she had Luke “with her”, not that she carried his ashes. At this stage, Helen has held on to her son’s remains so that she has physical contact with him. She acknowledges that others found the idea abhorrent, but she maintained this physical connection as a “logical” behaviour. Helen appears to have been unable to relinquish contact with her son, maintaining her relationship with what little she had left of his physical being. This may indicate a reluctance to believe that her son has permanently gone and an inability to adapt to life without his physical presence.

This need to continue contact with the child’s remains was also evident in other mothers’ accounts of grieving. Diane, whose daughter died from complications arising from chickenpox aged 5 years, said that she still visits the grave every day. She was aware that others felt this was not a positive use of her time, but she used the physical location of the graveside to continue her relationship with her daughter:

“I’m not going there to grieve. I go there because weather comes and it gets dirty and it gets untidy and she was a neat and tidy, clean little girl who liked to be just perfect going out and that’s her little bit of the world and I like her little bit of the world to be neat and tidy and clean and it’s somewhere I can focus on, something I can still do for her”.

Diane needed to continue to care for her daughter as she had done when her child was alive. She wanted to give her daughter’s “part of the world” as much care and attention

as she could, indicating an inability to give up the maternal role. This may have been further exacerbated for Diane since she had lost her only child. The only way she could continue to be a mother, she said, was by lavishing care and attention on the grave. It was as if the grave had become a symbol of the child, one which warranted devotion and tending, just as her child had. This appeared to help her cope by allowing her to retain a maternal role in the absence of any child to nurture. Diane had lost her only child and referred to herself as a “childless mother”. The grave was a focus for her and provided a physical symbol of her ongoing love for her child.

Whilst Diane saw caring for the grave as a positive activity, she also acknowledged that there were drawbacks to this strategy. She said several times during the interview that she visited the grave every day and had not missed a day since her daughter died five years earlier. This restricted her physical activity since she could not go too far from the grave in case it meant missing a day, and she could therefore not consider working away from home or going on holiday. She demonstrated no intention of changing her behaviour and saw attending the grave daily as a permanent situation for her, saying:

“You don’t move on from your child, you take your child with you, alive or dead your child will go with you for the rest of your life”.

Diane believes that her child is part of her own self and that leaving the child behind is not possible. There is an eternal bond which will never be broken, and the child will always be a part of her. She interprets this “moving on” as severing the relationship with the child in its physical form and is adamant that she will continue to tend the grave on a daily basis. Diane can see no other way to maintain a bond with her child,

other than to continue similar behaviours to those she carried out for her daughter when she was alive. Letting go of these tasks of keeping the grave area clean and tidy would be a betrayal of her child and her method of coping is to persevere with daily grave visits.

4.3.2 Theme 1b - Continuing the Bond with the Deceased Child – Linking Objects

For other mothers, a physical symbol was sought from items around the home connected with the child. Donna, whose son died in a road accident aged eighteen, chose a specific memento given to her by her lost child:

“Mark gave me a lovely wee em like a wee basset hound dog and that goes everywhere with me. I take it on holiday with me and I take it when I go away to work, I put it on the bedside cabinet and that’s just for me, that’s like me taking him with me”

For Donna, the physical proximity of the symbol was important as, by keeping the object near her, she felt as though she was keeping her son near her. The item had been chosen by her son as special and was given to Donna by him. It therefore represented an emotional response from her son, which Donna coveted as a symbol of her son’s love for her. The connection with her son was therefore on an emotional level, unlike Helen and Diane who sought an ongoing physical connection with their child. Keeping the object physically close to her meant that the child was also close on an emotional level.

Clearly, the significance of something that had a direct association with the child was meaningful for Donna. In Violet’s case however, the lost child was a baby of just three months. In his short life, her baby had not, in her words, established a role, therefore

could not have expressed preference for any items. Violet made many references during her interview to the fact that her baby's life was seen by others as insignificant, since he had not developed sufficient presence to be remembered. She felt cheated that others had not recognised the significance of his life, and it therefore meant a great deal to her when a neighbour offered something to place in the child's coffin:

“My neighbour said I've got a wee holy thing in the house, so she went next door and brought in an Infant of Prague and it was a nice thing, so we put it in his hand”

Violet went on to say that she had bought an identical duplicate item which she kept on display in her home. This statue appeared to unite them by providing a common bond, something that both of them could hold onto. Violet believed that, wherever her baby was now, he would be close to the statue, as she was close to it in her life. The statue served as a link between them, providing what was perceived as common experience. This allowed Violet and her baby to experience a shared connection, perhaps on a spiritual level, and meant that the baby would have something to link him to Violet. Wherever he was now, he would retain something to connect him with his mother, thus ensuring that the bond continued, even after death.

4.3.3 Theme 1c - Continuing the Bond with the Deceased Child – Symbolic

Representations

Although most of the participants indicated some kind of physical item played a part in their method of keeping connected with the child, many mothers adopted symbols for their child which they appeared to have little or no control over. Some participants

spoke of naturally occurring phenomena bringing them together with their child. Olivia described a beautiful view:

“we had just gone over this causeway onto Harris and you were just beginning to see the wee bits of the beaches in the distance and we went round this corner and suddenly this bay was revealed and it was the most gorgeous colour of water and the white sand and the beautiful hills behind and I just burst into tears then. I thought about Fraser right away, as I say, anything that’s beautiful like that, it seems to make a link to him somehow, strange, whether it’s a spiritual thing I don’t know”.

Olivia’s link to her son was with the beauty of nature; an unspoiled, pure and natural view. She also indicated that beautiful classical music had the same effect. The reason for this “link” and why it had an “overwhelming” effect on her may have been because it evoked a poignant reminder for Olivia of what her son had missed out on, since she said :

“Here am I here and he’s never going to get the chance”.

The link in Olivia’s case may have been driven by guilt and sadness that her son would not be able to experience the beautiful things in life that she had.

For Susan, a symbolic representation of her son came in the form of a ladybird. She recalled a memory of her son’s delight at seeing a flock of ladybirds not long before his death. Susan said that, throughout her life, ladybirds have appeared spontaneously and unexpectedly:

“we did see them in some very, very strange places really. It was on our towel on the beach in Cyprus, a ladybird, top of the World Trade Centre there was one on my back, we saw them, one in St. Andrews it was on the window of the car as we drove up to the caravan and never, never ever left the window of the car and it was quite windy and it just stuck there the whole time. Just little things but they mean a lot to us, so ladybirds became, that was our thing”

When asked what these incidents meant, Susan said:

“oh it just means he’s ok, he’s watching us, often it means that he’s watching George (her second son), George sees that as a symbol for him as well and we have seen ladybirds at times when it would mean that, you know, like George’s maybe done something or he’s, you know, struggling with something and suddenly there’s, you know, we’ll see a ladybird at that time so it means a lot of things. It kind of brings him into us, into the family you know. Whenever there’s a ladybird around we know that everything’s OK.”

The presence of the ladybirds reunited the family since they symbolically represented the lost child. The spontaneous nature of these visitations appeared to be particularly prized by the mothers, indicating to them that the communication worked both ways and the child was in some way able to send messages or signs to them. The signs appeared to reinforce the presence of the child, with the apparent reciprocity supporting the mother’s belief that the bond was current and ongoing.

In summary, for some mothers, the need to continue a parental role with their child was seen in the importance of spending time at the grave, in some cases with daily visits. Even though this caused restrictions to their daily functioning, these were considered to be acceptable by the mothers. It could be argued that the use of symbolic representations of the child may be a more adaptive way of continuing the bond, since many symbols chosen were portable and less restrictive than the grave or memorial site. The choice of symbols also appeared more subtle and tolerable by others than, for example, a shrine of photographs, candles and so on which some mothers kept at home. Symbols which had the ability to appear unexpectedly were taken to indicate that the child has actively chosen to make the contact, which many of the mothers found brought additional comfort.

There is some evidence of change in strategies over time, with some mothers reporting spending more time at the grave or memorial site in the earlier days of bereavement, reducing their commitment to the site over time. Some mothers returned to the site more often when they felt they were experiencing additional grief or at times of specific stress such as birthdays, Christmas and the death anniversary.

4.3.4 Theme 2a - Ambivalence to Personal Mortality

All of the mothers spoke about their own death openly and all appeared to have an ambivalent attitude to their own mortality. This was expressed in two key ways. The first theme was of seeing death as a way of being with their deceased child. Donna described her thoughts about other bereaved parents who took their own life following bereavement:

“Shortly after we lost Mark I saw the article about a young lad who was at uni who had taken his own life, he couldn’t cope. Three months later there was an article in the paper about his parents. He was an only child and they took their own life, and I actually felt jealous. I actually thought, Jesus you’re lucky [cries]. What a funny thing to think, how lucky are you? Because you’re actually together.”

Death was seen as desirable, since it would reunite the mother with her child. In addition, parents also reported that they saw death as a release from the emotional pain of grief. Diane described her consideration of plans for ending her life:

“I go to (the cemetery) all the time. There’s a really bad junction coming down out of there. I could just time it and get out of there in front of a lorry and I think, no I can’t do that because I’d leave my mum and dad. Right! We’ll all go to the cemetery together, we’ll all go in the one car then we’ll all go and there, we’re all wiped out and there’s nobody left and nobody’s got upset because we’re all dead and that’s perfect”

She then attempted to explain this comment:

“If you said to a sane person I want all my family to be killed outright in a car crash, they’re going to look at you and think you’re off your head you know, but if you talk to somebody else that’s lost a child, they’ll think, “I know what you’re talking about”. Because you can understand what it’s like to leave people behind, that’s why you can’t take your own life, because you’re stuck.”

Diane is indicating that she is experiencing inner turmoil in her choice of life or death. She wishes she was dead and with her child, but recognises that she would then be causing her own parents the same tragedy as she experienced herself. Knowing the trauma this would cause exacerbates feelings of guilt, and gives her a reason for living. She considers the idea of an “accident” where all of the family would die together as a potential way of addressing both desires and later spoke about the possibility of her own early natural death and that she saw this as a beneficial alternative:

“There was a lady who used to go (to a TCF meeting) and her son was 39 and I think, why are you here? Your son still had a life and that’s dreadful, she was devastated at losing her son at 39. And her way of looking at it was she had had her son longer so it was harder for her to say goodbye whereas I didn’t have mine for very long you know. And it’s true, it’s different perspectives isn’t it. And then that lady died and I was so glad for her, so pleased for her when she died and I thought that’s it, it’s over for you.”.

4.3.5 Theme 2b– Death as a Release

Diane saw death as a release from the pain of her grief and, if occurring naturally, would alleviate any guilt at having deliberately caused distress to her parents. Her decision to choose to live is unsatisfactory for her and causes ongoing distress, but this will inevitably be resolved once her own death occurs. This feeling that death is welcome was echoed by Helen who compared her own situation to that of the researcher:

“If there’s one thing that I, I, I have over you is that I’m old and you’re not”

The Researcher then asked – “and is that better do you think, is that easier?” to which Helen replied:

“I think I don’t have to live with it as long as you, that’s what I think.”

Helen sees her age as an advantage since death should happen sooner than someone who was bereaved at a younger age. Her grief and feelings of loss had not reduced greatly in the four years since her son’s death. She had tried many routes to alleviate her suffering including counselling, religion, spiritualist encounters and support groups. None of these had made a substantial improvement in her distress and she therefore felt that she would continue to suffer at this level of severity until she died. For Helen, it appears that death, when it comes, will mean the end of her suffering, bringing peace and ending this inner turmoil.

4.3.6 Theme 2c - Influence of Other Children

The mothers spontaneously added comments about why they didn’t choose to end their life after discussing their own deaths. All of these included consideration of the impact on other family members, especially the deceased child’s siblings. Donna said:

“My whole reason for living was them, to get them through, to make sure they’re ok, to make sure they’re functioning and they’re looking forward in their life and they’re not held back in any way”

“Norman (husband) and I said early on, if we didn’t have any children, I would not be here....The boys are here so we have no choice, it’s not a choice in my mind”

The parental duty to care for their living children was more powerful than the desire for death, but the presence of these other children meant that the choice of ending their life was not possible. Donna felt her duty was to offer the best parenting to her surviving children, at the expense of alleviating her own suffering.

Despite the moderating effect that surviving siblings had on death ideation, some mothers expressed the belief that preoccupation with the lost child was far more salient than the need to care for their other children. As Francis said:

“The first few months, the difficulty was all of the, sort of mundane things, looking after the kids or whatever, when I just wanted to go and curl up and cry”.

Francis felt obliged to fulfil her parenting role, at the expense of her own need to grieve. She put her emotions on hold in order to care for the younger children. Only when she had put them to bed and had discharged her caring responsibilities did she allow her own grief to surface. She was protecting the surviving children from exposure to her own suffering whilst endeavouring to provide them with the best care she could offer, putting her own needs secondary to those of the children.

Despite their best attempts, some mothers also reported emotional absence from surviving children. Olivia reported:

“The youngest one, Jimmy, he was 15 so he didn’t have anybody. But you know that never dawned on me for a long time and a long, long time afterwards I suddenly felt an enormous guilt that I hadn’t, maybe not been able to comfort him in the way he

needed because I was so distraught myself you know. Oh dear, it's just awful, but as you know, there's just nobody out there to help you. But I think at that time I, I felt I had to cope with this myself".

This extract suggests that Olivia's grief was so great that she was unable to offer compassion and support to her surviving son. Looking back, she is now aware that his emotional needs were unmet, but her own suffering limited her ability to offer help, even to her own son. She now feels guilty at this neglect, but recognises that she had done her best at the time.

Nancy also expressed guilt and sadness at her realisation of her surviving son's emotional distress, when she was unable to support him:

*"It really struck me at one time when I was just talking with Kieran (surviving son) we were just talking about Calum and I was saying, what's it like at school and he said "I miss him at playtimes. I don't see him" and I hadn't, you know, until he said that, it really hit me. God, the kind of the daily-ness of **his** loss".*

Nancy had been unaware of the suffering of her son, and had been unable to recognise his loss as a result of the incapacitation of her grief. She expressed anguish at her inability to care for her younger child and husband:

"I just couldn't cook, I just couldn't nurture, I couldn't feed us"

Nancy felt incapacitated by her grief, unable to perform basic tasks needed for survival. The grief had consumed her completely making even daily, mundane but essential tasks impossible. Nancy said that she felt herself fortunate that a local church stepped in to provide meals for the family, helping considerably with the domestic load. At the time, she could not bring herself to care for her family, a fact that worried her greatly with hindsight. Without the support of the local community, her surviving son's suffering could have been even greater. She needed external assistance to provide for the daily needs of her family, and worried that others without such strong support may not be so lucky, resulting in concerns for the protection of surviving siblings.

In summary, thoughts of their own mortality were expressed by all of the mothers.

Death was not seen as an undesirable event, but as a means of either ending the suffering and grief or reuniting them with their deceased child. Family, especially other children, appeared to moderate the desire for death. Conversely, especially in the early days of bereavement, other children were seen as a burden, and mothers reported a lack of ability to care for them either practically or emotionally.

4.3.7 Theme 3a - Social Changes Attributed to the Bereavement - Marital Situation

Of the thirteen mothers interviewed, two reported marriage breakdown subsequent to the bereavement. Both mothers believed that their separation was linked to the death of their child, but also noted that the marriage had not been strong prior to the event. In Helen's case, the marriage breakdown happened very soon after the death of her adult child;

“everything changes doesn’t it, everything changes, so I, I left. One day I thought, I can’t stay here any more, I’m not staying here any more and that was about maybe five months, four, five months and I just walked out and just left it all.....we had never been really happy”.

Helen decided to end the marriage and leave soon after the death of her son, but she went on to explain that she had been unhappy all her married life. Her husband was the son’s stepfather and she felt he had no real understanding of the depth of her grief. Being unable to communicate with him, and not receiving the support she felt she needed, she decided to move out, setting up a home for herself and her surviving children elsewhere.

Gayle, too, indicated there were problems in her marriage prior to the death of her son, and that she believed the trauma of the death was made the separation inevitable;

“We had really struggled from when Joshua (the previous child) was born really, we were having problems, but I think Kevin, I think just finished, finished it”.

Again, Gayle’s account is one of non- and mis-communication with her husband, with both parties grieving and expressing their emotions in separate ways. Gayle felt her husband was an additional burden that she could not cope with and left the family home with her young son.

Other mothers reported struggles in the marriage, but as at the time of the interview, these did not lead to marriage breakdown. Susan spoke of how she felt she had been the stronger partner during early bereavement and how her husband needed her support:

“it was before the funeral and he was, I think he’d been out organising that in fact and he was standing in the kitchen and he was sort of giving me a cuddle and he, he literally just leaned on me I mean his whole body just completely gave over to me and I, I almost couldn’t hold him. I mean he was so heavy anyway, but it was also like he was saying, I can’t do this you know, you’re going to have to do this, and that in itself was, was very difficult. But I also thought, I can’t, I can’t do this for you, you know, there was a bit of this in me thinking, I can only handle me you know, I can’t do this for both of us”.

Having her husband rely on her heavily was an additional burden for Susan, and one she felt she was unable to carry at that time. Her husband looked to her to guide him through his grief, but with a baby to care for as well, this was a great deal for Susan to attend to. She described a distance between the two for many years, with each following their own course of recovery. Now, some 25 years later, they have achieved a state of equilibrium, with shared memories and both becoming involved in supporting other bereaved parents.

Finally, some parents indicated that their marriage was actually stronger as a result of the suffering the pair had endured together. Katherine described the support she had received from her husband as crucial to her own ability to cope, and recalled many shared coping experiences, such as choosing a memorial site together and making decisions about where to live and what type of job she should seek to acquire. As a

result of this joint grieving, she said:

“I think Alex and I are probably closer than ever...we’ve always been really close but now we do everything together we’re really, really close and it has brought us closer”.

Katherine’s marriage had survived the suicide of her son, and she believed the way both partners had supported each other through the grief had made their marriage stronger with no reports of any tension between the pair.

Theme 3b – Social Changes Attributed to the Bereavement - Employment Status

Most of the mothers were employed at the time of their bereavement, and the employers in the main appeared to provide little support to those who needed it. Helen, for example, described returning to work despite being in a state of despair in the second year of bereavement;

“About 18 months later they said they couldn’t work with me. They said I was impossible to work with. They said I was moody some days, I didn’t speak to anyone, some days I just sat at the computer and didn’t even go for breaks. That was true.”

Helen’s behaviour was typical of someone living with grief and depression, however her employer interpreted this as “moodiness” and, as a result, she lost her job.

Katherine, too, described difficulty in returning to work and performing at pre-bereavement levels;

“ I actually lost my job through Eddie dying. I was a manager at a new nursery and at first they gave me, “oh stay off as long as you need” and then it got quite nasty and they took my manager’s job off me and said “you can come back as a nursery nurse” and I said “forget it”, so we lost the house.”

The initial support offered by Katherine’s employer did not last as long as she needed to return to her usual level of functioning at work. Rather than take a lower-paid job, essentially a demotion, Katherine took the decision to leave, but this caused the family income to be seriously depleted. With only her husband’s salary to live on, the family could not sustain their level of expenditure and sold their house, moving to a much cheaper alternative. Although this caused additional difficulties for the family, they felt this was the best option in the light of increasing financial hardship.

In Olivia’s case, she returned to work very quickly after her son’s death, and recalled her distress at how she was treated by her employer;

“It (the death of her son by electrocution) happened on the Thursday, so I was off that Thursday and then I was off the following week. Now at that time you were only allowed a week’s compassionate leave so that was a week and a day that I’d had. Do you know they took that extra day off me?”

Olivia took six days off work and was only entitled to five, according to the rules of her company. She therefore lost one day’s pay as a result of her absence from work.

Although the amount was paltry, this insensitivity on the part of her employer has

caused ongoing tension for Olivia, and she felt it was indicative of society's lack of understanding of the experience of parental bereavement.

Diane's employment situation was that she worked in a local shop with her husband, but the additional strain on the relationship following her daughter's death meant this situation was untenable. Although wishing to return to normal working patterns, her husband did not allow her to recommence working;

"After she died I thought I wanted to go back to work for a little while, just to get back in, and he asked me not to come back, he said "I think this is a good time for you just to move out of the business and not come back". So that was quite, quite difficult".

Diane's marriage had been in difficulty prior to her daughter's death, but again this event seemed to precipitate additional major changes in life, as her husband felt he could no longer run his business with his wife's involvement.

4.4 Discussion

4.4.1 Continuing Bonds

Whether adaptive or not, the mothers showed a strong desire to continue bonds with their deceased children. The more socially acceptable and portable symbolic representations of the child appeared to be more adaptive than persistent attendance at the graveside or domestic shrines. It is unclear why some mothers chose one method of continuing the bond over another. Some mothers expressed a strong desire to tend the grave or display a shrine to their child in the early days of bereavement. This focus

changed over time to caring for a symbolic representation of the child, and in some cases even moved to a connection with the child via a fleeting naturally occurring event, out with their control. The reason why this transition took place in some individuals and not others was unclear. Perhaps the parents who showed persistent adherence to care-giving behaviours around the grave or memorial site have been unable to fully accept the loss. They may have been unable to reorganise their life to accommodate the change precipitated by the loss, causing an ongoing inability to work through their grief (Bowlby, 1981). Alternatively, the mothers who retained a continuing bond with the grave may have been persistent ruminators, unable to face the reality of restoration orientation and all that accepting the loss might entail (Stroebe et al., 2007). The choice of method for continuing bonds and the association between the different forms and adaptation to bereavement are important considerations for future research, since the present data do not allow conclusions regarding the adaptiveness of continuing bonds to be made.

4.4.2 Coping Styles

Previous studies such as those by Hoekstra-Weebers et al. (1991), Robinson and Warwit (2006), Videka-Sherman (1982) and Murphy, Johnson and Lohan (2003) indicated that some parents may choose active, problem solving coping styles for their bereavement. Whilst this is an encouraging sign of potentially adaptive coping, it may only address part of the bereavement process, reflecting a focus on restoration-related stressors whilst not necessarily considering the role of loss-related stressors (Stroebe & Schut, 1999). The ability to address restoration-orientated stressors may come at the expense of dealing with loss-orientated stressors. Measurement of coping which includes consideration of loss-related stressors is needed to achieve a comprehensive

understanding of coping effectiveness. This will require bereavement-specific measures to be used such as the Dual Coping Inventory (Wijngaards-de Meij et al., 2008). The use of the Dual Coping Inventory allowed Wijngaards-de Meij et al. to identify levels of loss and/or restoration orientation in bereaved parents. The ability to make a transition in choice of method of continuing a bond with the deceased child may also be related to a change from a loss to a restoration orientation. Identifying whether such a link exists would be a crucial development in research with bereaved parents, since high restoration orientation was associated with lower levels of grief and depression not only in mothers, but also had an additional positive impact on the father's coping (Wijngaards-de Meij et al., 2008).

4.4.3 Phenomenology of Parental Bereavement – Impact of Cause of Death

The findings of the present study add to those of Woodgate (2006) by comparing the experience of bereaved mothers across a wide range of causes of death. The experiences were similar for all of the participants in the group, regardless of cause of death or age of the child at the time of their death, and the participants could therefore be treated as a homogenous group. Woodgate's first theme, keeping memories of the child alive, was found in the present study, but this was extended to a relationship rather than a more passive recollection of the child. This may be purely due to methodological differences in the analysis of data, since the present study follows IPA methodology, thereby incorporating an interpretative component within the presentation of the results, whereas Woodgate chose a purely thematic analysis with less interpretation.

Woodgate's second theme, that of the need for parents to believe they had been "good" parents, was not found in the current dataset. This may be an anomaly of the particular group of participants, or perhaps may be a further methodological issue. Woodgate's

study elicited data from interviews which, in most cases, included both parents simultaneously. Perhaps the discussion about good parenting was intended to alleviate guilt for the parent, either their own or their partners. Alternatively, the participants may have taken the opportunity to support their partner's parenting efforts to the researcher. There was no evidence in the present study of parents indicating the importance of being present when the child died. Again, this may be due to the idiosyncrasies of the particular group who volunteered for the research, or may be related to a lack of focus on this topic within the interview schedule. Alternatively, since many of the causes of death were sudden and accidental in the present study, being with the child at their time of death was, for some mothers, not an option. Parents who were present at the time of death in the previous study may have found benefit in this and sought to incorporate this as a coping strategy. A further explanation may be found in the demographics of the participants, since in the Woodgate study many participants were in the first three years of bereavement. At this relatively early stage, perhaps issues around the death itself may have been more salient to the participants. Finally, the issue of social support from friends, family and health care professionals was not found to be a key theme in the current research. Although mentioned in some accounts, this did not emerge as a key recurring theme in the analysis. This again may be due to different mean time since death in the current group of mothers, since the levels of social support obtained may have declined over time since the bereavement.

4.4.4 Ambivalence about Personal Mortality

All participants, without exception, reported a strongly held belief that their death would be welcome, either to end their current suffering or as a way of reuniting them with their lost child. If the mother had other surviving children, this appeared to

moderate their death ideation. The stress of bereavement and the all-encompassing grief that is associated with the loss of their child caused them to raise concerns about a reduction in levels of care for their surviving children.

The mothers in the present study demonstrated ambivalent feelings about their own death and all reported that it was not seen as threatening or fearful in any way. These findings conflict with those of (Barr & Cacciatore, 2008) who studied fear of death in bereaved mothers and found higher levels of fear of death in the bereaved mothers compared to the general population. The reason given by Barr and Cacciatore for their findings is that the mothers' primary concern is related to their "personal extinction" (p445). By losing a child, they have reduced their reproductive success. The authors suggest this fear of their own premature death may be adaptive, since it encourages the parents to fulfil their potential in other areas of their lives to compensate. The present study finds no evidence of such fear of death or extinction, and challenges the self-actualization theory cited by Barr and Cacciatore, since the basic ability to nurture surviving siblings was clearly compromised in this group of mothers. Participants in the Barr and Cacciatore study had a slightly different demographic to the present study, with approximately three quarters of their 400 participants experiencing miscarriage, stillbirth or neonatal death. The average time since death for these participants was eight months (median value). The focus on earlier deaths and the shorter time since bereavement may have had some impact on the results, since participants may not have time to fully accept the permanence of their loss. An alternative explanation may be that of the impact of the researcher's status of bereaved parent. Throughout the interviews, all of the mothers made reference to the fact that the interviewer would understand what they were saying since she, too, had experienced the loss of a child. Most mothers also

said that they had disclosed thoughts and feelings that they had never discussed before, again due to the perceived commonality of the experience of parental bereavement. Contemplating one's own mortality and expressing thoughts of suicide ideation are issues of a most personal nature. Perhaps the relationship with the interviewer in the present study facilitated this openness in a way that would be unlikely in the absence of the shared experience (Benoit, Jansson, Millar & Phillips, 2005).

The presence of other children in the family appeared to moderate the level of suicide ideation shown by the participants. (Agerbo, 2005) found bereaved parents to be twice as likely to complete suicide as a matched control group, but found that mother's risks decreased if there were other surviving children in the family. The present study elucidates this finding, as it shows that parents are conscious of the impact their suicide may have on their own children. They may be attempting to protect their surviving children from additional grief, and in turn the presence of other children protects them from suicidal behaviour. The approach taken by Agerbo was to look at the records of people who had completed suicide and analyse the risk factors from the statistics of this group. On this basis, it is not possible to compare the suicide rate in subsections of bereaved parents. The present study indicates that parents may delay suicide plans until their surviving children reach adult age. To identify whether this delay has an impact on subsequent suicidal behaviour, the suicide rates of bereaved parents must be scrutinized in both the short and long term.

4.4.4.1 Possible Sources of Support for Bereaved Parents

The present study also raises the question of whether there may be a need for enhanced social care following parental bereavement. Specialist palliative care social workers are

now being recognised as a valuable component to social services (Sheldon, 2000) but perhaps there is also a need for a social bereavement service to help parents who experience the death of a child. The mothers who were interviewed indicated that they had sometimes received help from friends, family and the local community to feed and care for their surviving children. In many cases, however, the mothers doubted whether the level of care given to the surviving siblings was adequate. In families where both parents care for the children, the nurturing of surviving siblings may be shared and may then be adequate during the periods of increased grief and mourning. The situation where a single parent is mainly responsible for child care may be more problematic, especially if additional social support is not forthcoming.

4.4.4.2 Suicide Risk

This study has highlighted a number of areas of concern over suicidality in this vulnerable population and the consequences for other family members. Excessive mortality following bereavement is a widely reported phenomenon (O'Connor & Sheehy, 2000), and, for bereaved parents, one possible explanation is that death has occurred by suicide, and this is a concern that requires further research efforts to resolve. Suicides may be misclassified as bereaved parents may take action, for example, to cause a road traffic accident, to take their own life without appearing to be directly responsible. Actual suicide rates and risk factors for bereaved parents must be established to enable clinicians to be more aware of the potential risk of suicide. The suicide risk may be higher in earlier months, but later suicides cannot be ruled out, and should be considered again as a risk factor when the surviving siblings reach adulthood. Based on the findings in the present study, it is essential that the needs of bereaved families are carefully considered. Further research is crucial to establish whether

additional social support is needed in families who experience the death of a child, to ensure surviving siblings are not at risk of neglect or abandonment.

4.4.5 Social Changes

The mothers did not provide a clear consensus on how their marriages were affected by the bereavement. Some mothers reported a strengthening of marital bonds whilst others indicated that their marriage situation had worsened following the death of their child. Those that did report problems suggested that these were a feature of the relationship prior to the bereavement, therefore may have been an underlying issue, possibly exacerbated by the additional stress. It appeared that there were differences in how the parents coped, but in the absence of corroboration from the fathers, taking the mothers' accounts of their husbands' behaviours does not permit a reliable comparison of coping strategies. The prevalence of changes in relationship status will therefore be measured in the later quantitative studies reported in chapters five and six.

Most of the mothers reported some difficulty in reintegrating to the work environment following their loss. The frequency of reported disruption in employment merits further investigation and will also be tested quantitatively in the larger population (see chapters five and six).

4.4.6 Methodological Considerations

There are some considerations to be made regarding the methodological approach chosen. The participants all knew in advance that the interviewer was also a bereaved parent. Many made reference to this within the interview process, often asking if the researcher had similar experiences or whether the story they were telling was typical. This happened more often in interviews where the participant was not a member of

TCF, perhaps suggesting the ongoing search for normality and referencing of the experience. When participants did ask about the researcher's experience, the fact that the interview situation was intended to elicit information about their own experience was reiterated, and the opportunity to ask questions about the researcher's experience was offered during the debriefing time.

After the interview, the researcher allowed time for debriefing with the participants where a general chat about the experience took place. It is important to note that, without exception, all of the participants said they were glad they had volunteered and found the interview to be a cathartic event. Most indicated that they would only have been able to divulge such intimate details of their experience to another bereaved parent, and many said that the interview was the first time they had been able to discuss their thoughts and feelings in such depth.

4.4.7 Limitations

We acknowledge that the reported results have been gathered from interviews with mothers only. No fathers took part in the interviews, although some had initially agreed to discuss their experiences. The views of fathers on their own coping and perhaps that of the family as a whole would add to the understanding of parental bereavement. Participants in the study were volunteers who wanted to tell their story. This is unlikely to be representative of the population of bereaved mothers as a whole. Those who chose not to volunteer may have had more negative outcomes, or alternatively may feel that they want to leave their experience in the past.

4.4.8 Conclusion

The findings from the present study are important for those interested in how bereaved parents cope with the death of their child. The suicidality of bereaved parents is a significant concern and merits prioritised further investigation. Protective factors and reasons for living must be established in this vulnerable group who appear to be at suicidal risk. In addition, the frequency and potential merits or disadvantages of continuing bonds should be assessed in large scale quantitative studies, in a wider population of bereaved parents. The predictive value of continuing bonds on symptoms of grief and depression, either positive or negative, should be evaluated and, if found helpful, considered as a factor worth incorporating into bereavement support for bereaved parents. The need for support for parents who are caring for surviving siblings should be urgently addressed, since some families may be struggling to cope with the demands of caring for children whilst enduring significant grief symptoms. The care package offered to bereaved parents should therefore consider whether childcare support and relationship management services may be appropriate, in addition to the counselling and peer support services which are currently available. Bereaved parents may require a more holistic support offering, which reflects the diversity of their emotional, social and welfare needs.

Chapter Five - Factors Affecting Outcomes in Parent's Early

Bereavement

5.0 Abstract

5.0.1 Background

Very little is known about the experience of parental early bereavement in the United Kingdom. The present study aims to provide information relating to the factors associated with differential grief and depression outcomes.

5.0.2 Method

Sixty-three participants were recruited from bereavement support organisations, between 2 and 59 months post-loss, mean 30 months (SD=15). A questionnaire was completed which comprised standard instruments measuring grief, depression, coping styles, rumination, continuing bonds and optimism/pessimism as well as a number of specific bereavement-related questions.

5.0.3 Results

Grief and depression were identified as clearly separate phenomena. Rumination was associated with both increased grief and depression scores. When controlling for depression, the key factors associated with higher grief were rumination and cognitive restructuring. Continuing bonds scores were not associated with bereavement outcomes.

5.0.4 Conclusions

Prolonged grief can be identified as a distinct psychological disorder, separately from clinical depression. Rumination is an important contribution factor to both grief and

depression. Cognitive restructuring may be associated with better outcomes and could form a beneficial component of bereavement interventions.

5.1 Introduction

5.1.1 Prolonged Grief as a Distinct Diagnostic Condition

The concept of prolonged or complicated grief as a credible psychiatric disorder has received increased attention in recent years, with a set of proposed diagnostic criteria for this condition now appearing to meet DSM criteria for the definition of a psychiatric disorder (Prigerson et al., 2009). The symptoms of prolonged grief as proposed for inclusion in DSM-V and ICD-11 are; separation distress with persistent or intense yearning for the deceased combined with cognitive, emotional or behavioural symptoms such as avoiding reminders of the loss, difficulty with accepting the loss and feeling incomplete without the loved one's presence (Prigerson et al., 2009). Whilst mindful of the need to avoid pathologising a naturally occurring phenomenon, where such symptoms would be expected to occur normally after a bereavement, many practitioners suggest that when symptoms persist beyond six months post-loss, or where they cause significant disturbance to normal functioning, therapeutic intervention may be indicated (Stroebe, Schut et al., 2007).

Individuals exhibiting symptoms of Prolonged Grief Disorder (PGD) may also demonstrate the potential for other psychiatric disorders such as major depression, anxiety disorder or post-traumatic stress disorder (Stroebe, Schut et al., 2007). Previous studies have indicated that a distinction exists between depression and grief symptoms in elderly bereaved spouses, bereaved psychiatric patients (Boelen, van den Bout & de Keijsers, 2003) and a cross-section of bereaved adults (Bonanno, Neria, Mancini, Coifman, Litz, et al., 2007). As yet, no studies were found which tested the

independence of grief from depression symptoms in a cross-sectional group of bereaved parents.

5.1.2 Rumination as an Avoidance Focussed Method of Coping

Rumination in bereavement is believed to be associated with negative outcomes such as depression (Nolen-Hoeksema et al., 1994). However, the “grief work” notion, where the individual must accept the loss and accommodate the changes needed into their life, has a conceptual overlap with many aspects of rumination (Stroebe, Boelen, van den Hout, Stroebe, Salemink, et al., 2007). The key difference identified by Stroebe et al. is that rumination may in fact be an avoidant strategy rather than an active processing one. By ruminating on matters around the loss, the individual is actually attempting to deny the reality of it and cannot, therefore, process their grief and accept the bereavement.

No published literature has been found relating to the role of rumination in the specific condition of parental bereavement, however there is a clear link between depressive rumination and psychological distress (Morrison & O'Connor, 2008). The current study aims to measure the association of depressive rumination, grief and depression in bereaved parents.

5.1.3 Identification of Risk Factors for Prolonged Grief in Bereaved Parents

The recent development of the Stroebe, Folkman, Hansson & Schut (2006) Integrated Risk Factor Framework has provided a means for identifying which are the key factors that predict bereavement outcome. A summary of this model is shown in Figure 5.1. The model is derived from earlier research which looked at specific risk factors and their impact on outcomes (e.g. the Cognitive Stress Theory, (Bonanno & Kaltman, 1999) and the Dual Process Model of Coping with Bereavement, (Stroebe & Schut,

1999)). The key feature of this new model is that it recognises the importance of multiple influencing factors on bereavement outcome, such as bereavement-related factors (e.g. whether the death was sudden or anticipated), interpersonal risk factors (e.g. social support, religious activity), appraisal and coping mechanisms and intrapersonal risk factors (e.g. gender, personality). This model is untested on any group of bereaved parents and Stroebe and colleagues have highlighted that not enough is known about the relative importance of individual factors in bereavement.

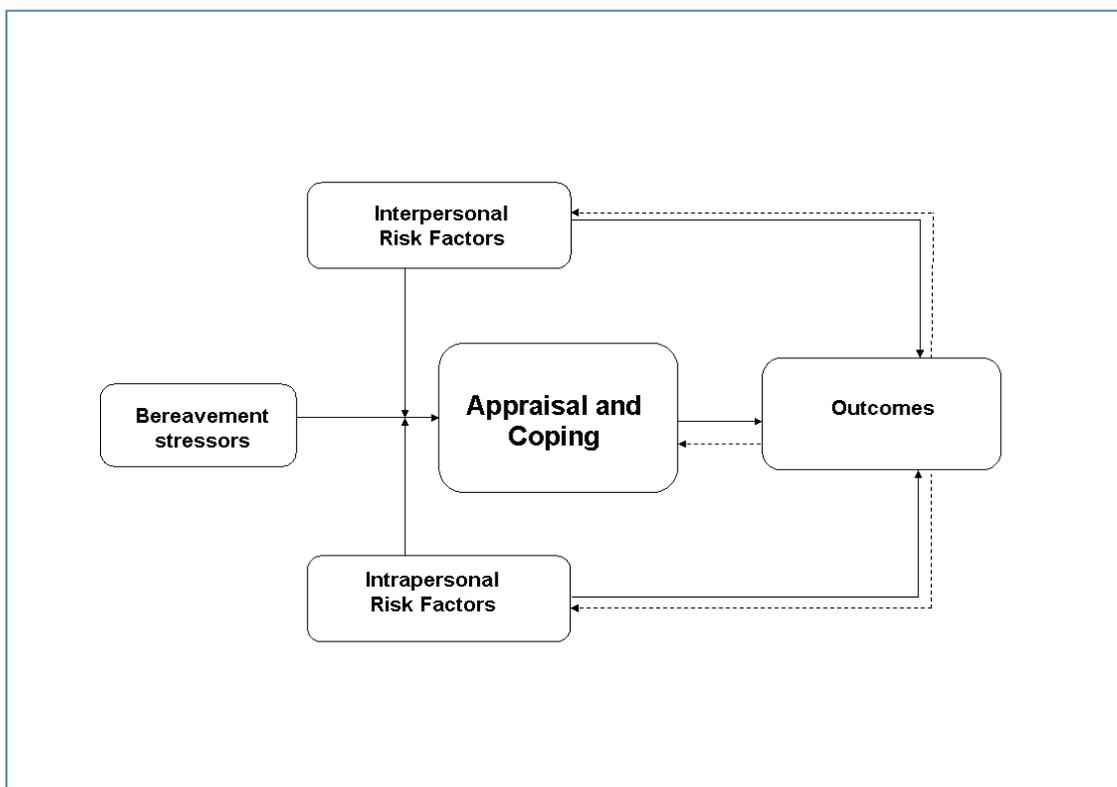


Figure 5.1 – Stroebe et al. Integrative Risk Factor Framework (2006)

A summary of the key risk factors for general bereavement indicates that the following factors are associated with poorer outcomes: greater age of the bereaved, sudden or violent deaths, lack of social support and additional domestic stressors (Sanders, 1993). The factors indicated as important by the parents interviewed for the qualitative study in chapter four were the level of continuing bonds, suicidal ideation and social changes.

These factors, and those highlighted by Sanders (1993), will be tested to establish which are most closely associated with prolonged grief and depression in a group of bereaved parents.

5.1.4 The Impact of Bereaved Parents Continuing Bonds with their Lost Child

Continuing bonds with their lost child emerged as a key theme for bereaved mothers in the qualitative investigation reported in chapter four. The mothers who were interviewed made repeated reference to the comfort they derived from their ability to maintain an ongoing relationship with the child, either through frequent grave visitation, by keeping mementoes of the child close to them or by establishing a symbolic representation of the child with which they could interact. From the general bereavement literature, however, the relative adaptiveness of continuing bonds in bereavement remains a contentious issue. An overall maladaptive association has been found between high levels of continuing bonds and prolonged grief (Field, Gao & Paderna, 2005). However, more detailed analysis suggests that continuing bonds have no association with increased grief when the individual is able to make sense of the loss and accept its ongoing permanence (Neimeyer, Baldwin & Gillies, 2006). The impact of continuing bonds in association with other factors of bereavement therefore merits more detailed investigation. The current study aims to establish the direction of any association between continuing bonds, grief and depression in bereaved parents.

The hypotheses for the current study were as follows;

- (i) Prolonged grief symptoms were present and were measurable independently from depression.

- (ii) Increased levels of rumination were associated with higher levels of grief and depression independently.

In addition, two exploratory analyses were carried out. These were

- (a) The factors most closely associated with grief and depression were identified.
- (b) The association between continuing bonds scores and grief and depression scores were examined.

5.2 Method

Ethical approval for this study was given by the ethics board of the Department of Psychology, University of Stirling.

5.2.1 Participants

Letters were sent to The Child Bereavement Charity, Child Death Helpline and The Compassionate Friends to request assistance with participant recruitment. These organisations are charities which provide support to bereaved parents within the United Kingdom. All three charities posted an invitation to participate on their web sites and The Compassionate Friends included the invitation in their quarterly newsletter, sent to people who pay an ongoing subscription to the charity.

People who expressed an interest in taking part in the study were sent information about what was involved and how the information supplied would be used. If they then agreed to take part, they could complete a questionnaire either in hard copy sent by post, or online. No reminder was sent to participants who agreed to take part but did not complete the questionnaire. Seventy two people requested a questionnaire of which, 64

were returned complete (89%). The participants were between 2 and 59 months post-loss, mean 30 months (standard deviation 15 months).

5.2.2 Measures

Data were collected using a combination of published psychological measures and questions specific to this study. Socio-demographic variables included sex and age of participant, relationship status now and at the time of bereavement, employment status now and at the time of bereavement, occupation now and at the time of bereavement, highest level of education, and age and sex of any other children in the family. Details related to the circumstances of the loss were age of child at time of death, sex of child, consideration of whether the death was sudden or anticipated, whether the child lived mostly at home at the time of their death, whether organ donation was considered and the impact of the donation decision. Information about how life has been affected post-bereavement including whether the participant has experienced problems at work, financial difficulties, difficulty caring for other children, house moves, concerns about other family members coping with the bereavement, access to grandchildren if the child was an adult with children of their own, knowledge of other bereaved parents, parent's experience of subsequent bereavements, whether the parent has a memorial site for their child and if so, how often they visit and whether the parent has a special item, object or living thing which reminds them of their child.

Published reliability and validity statistics for all measures are given in chapter three.

5.2.2.1 Grief

Grief was measured using the 19-item Inventory of Complicated Grief (Prigerson, Maciejewski et al., 1995) adapted for use by parents by referring to “my child” rather than “this person” in the question wording. The total score on the Inventory of Complicated Grief indicates the severity of the participant’s grief symptoms, with a score of 25 or over indicating that the participant meets the proposed diagnostic criteria for prolonged grief. The scale was internally consistent in the current study (Cronbach’s $\alpha = .86$).

5.2.2.2 Depression

Depression was measured using the 9-item Patient Health Questionnaire (PHQ-9) (Kroenke et al., 2001). The total score indicates the level of severity of depression, with a score of 10 or more indicating a potential diagnosis of moderate to severe depression. The scale was internally consistent in the current study (Cronbach’s $\alpha = .90$).

5.2.2.3 Trait Optimism/Pessimism

Optimism and pessimism were measured with the 10-item Life Orientation Test (Revised) LOT-R (Scheier et al., 1994) (see Appendix III). The total of the positively worded items gives an optimism score and the total of the negatively worded items gives a pessimism score. The scale was internally consistent in the current study for both optimism and pessimism (Cronbach’s $\alpha = .77$ and $.83$ respectively).

5.2.2.4 Rumination

The 10-item Response Styles Summary (Nolen-Hoeksema, 1991) was used to assess rumination where high scores indicate a greater tendency towards rumination. The scale was internally consistent in the current study (Cronbach’s $\alpha = .92$).

5.2.2.5 Coping Style

Coping style was measured using the 28-item Brief Cope (Carver, 1997), aggregating the scales into four summary sub-scales of Problem Focussed Coping, Avoidance Focussed Coping, Social Support and Cognitive Restructuring (O'Connor & O'Connor, 2003), along with the Self-blame, Use of Religion, Focus and Venting of Emotions and Alcohol and Substance Use scales. The internal consistency of the sub-scales was acceptable (Problem Focussed Coping – Cronbach's $\alpha = .75$, Avoidance Coping – Cronbach's $\alpha = .71$, Social Support – Cronbach's $\alpha = .82$ and Cognitive Reconstruction Coping – Cronbach's $\alpha = .75$). The individual scales were also internally consistent with Self-blame – Cronbach's $\alpha = .77$, Use of Religion – Cronbach's $\alpha = .79$, Focus and Venting of Emotions – Cronbach's $\alpha = .77$ and Alcohol and Substance Use – Cronbach's $\alpha = .96$.

5.2.2.6 Continuing Bonds

Continuing Bonds were measured using the 11-item Continuing Bonds Scale (Field et al., 2003), with the wording of items changed from "spouse" to "child". The total score indicates the level of continuing bonds that the bereaved has with the deceased. The scale was internally consistent in the current study (Cronbach's $\alpha = .82$).

5.2.2.7 Suicidal Ideation

To identify suicidal ideation, participants were asked three questions. The first of these was an indication of whether or not they are thinking about suicide. The second asks, "Have you ever deliberately taken an overdose (e.g. of pills or other medication) or tried to harm yourself in some other way (such as cut yourself?)", with permitted responses being "No", "Yes – once" or "Yes – more than once". The third question was,

“Have you ever seriously wanted to kill yourself when you have taken an overdose or tried to harm yourself in some other way?”. The possible answers to this question were “Yes”, “No” or “Not applicable”.

5.2.2.8 Education

Possible values for education level were secondary school only, college, undergraduate or postgraduate. These were collapsed into two categories – school or college and university (undergraduate or postgraduate).

5.2.2.9 Cause of Death

The cause of death was summarised as violent or non-violent. This was extrapolated from the cause of death which the parent supplied on the questionnaire. Violent deaths were those which occurred as a result of accident, murder or suicide in line with previous research (e.g. Neimeyer et al. (2006) (Neimeyer et al., 2006). All others were classed as non-violent deaths.

5.2.2.10 Death anticipation

Death anticipation was summarised into sudden or anticipated. Sudden deaths were described by participants as totally unexpected or expected in the hours before death. Anticipated deaths were expected for days or expected for some time.

5.2.2.11 Linking Objects/Symbolic Representations

Participants were asked if they had a special object, item or living thing that reminded them of their child. If they indicated they had such an object, they were asked whether this object helped them to cope with their loss. The options for response were “very helpful”, “usually helpful”, “neither helpful nor unhelpful”, “usually unhelpful” or “very unhelpful or upsetting”. These responses were collapsed with “very helpful” and

“usually helpful” indicating a positive effect of the symbol and other responses indicating a non-positive use of a symbol.

5.2.2.12 Relationship status

The relationship status at bereavement could be chosen from the following options – single, with partner, married, separated, divorced or widowed. These answers were summarised so that with partner or married was classified as “in a relationship.” The other answers were classified as “not in a relationship”.

5.2.2.13 Employment status

The employment status at bereavement was similarly classified. From the options, unemployed, caring for family, sick, permanently disabled, training/studying, retired, working full time and working part time, the final two were classified as “working”. All others were classified as “not working”.

5.2.2.14 Open-Ended Questions

Two questions were asked where the answer could prompt a response which required qualitative analysis. The first asked “Is there anything else you would like to tell us about your experience of coping with the loss of a child or of taking part in this research?”. This question was included for two reasons. Firstly, the questionnaire was designed with recognition of limiting the load on participants and keeping the survey as short as possible. Variables under test were chosen, but these may not have been what the participants believed to be important in their experience of coping. This question therefore acted as a means of establishing whether there were any other areas which may warrant further investigation in coping with the death of a child. The second reason for including this question was to acquire information about the experience of taking part, from the participants’ perspective. Although the consent form was completed at

the start of the study and participants were aware they could withdraw at any time, it was important to know if they had been caused distress when completing the form. This would again be useful in subsequent research projects. An additional question was asked which was intended to provide more information about the impact of the researcher's role as bereaved parent. This question was "This research project is being carried out by a researcher who has experienced the death of a child. Has this influenced your participation in this study and if so, how?" The answers to both of these questions would be subject to thematic analysis.

5.2.2.15 Participation Experience

The final question asked participants to rate the experience of taking part on a scale from 1 to 7, ranging from very negative to very positive. Again, this was intended to establish what the participant thought about their experience and would be valuable for further research.

Two versions of the final complete questionnaire were created, with the order of questions reversed for counterbalancing to minimise order effects.

5.2.3 Participant Demographics

Table 5.1 shows details of the demographics of the participants.

Table 5.1 – Demographics of participants who returned completed questionnaires

	<i>Participants (n=64)</i>
Mothers	59 (92%)
Fathers	5 (8%)
Deaths - female	23 (36%)
Deaths - male	41 (64%)
Mean parent age (SD)	48.8 years (11.7)
Mean child age (SD)	18.9 years (12.6)
Non-violent death	46 (72%)
Violent death	18 (28%)
Sudden death	50 (78%)
Death anticipated	14 (22%)
Relationship status at bereavement	52 (81%) in a relationship. 12 (19%) not in a relationship
Employment status at bereavement	43 (68%) employed, 20 (32%) not employed (n=63)
Education level	School 17 (27%), College or University 47 (73%)

The number of mothers agreeing to take part in the research far exceeded the number of fathers, which is consistent with previous research carried out with bereaved parents (e.g. (Murphy, Tapper, Johnson & Lohan, 2003; Woodgate, 2006).

5.2.4 Procedure

The University of Stirling Psychology Department ethics committee approved the project, following a pilot test of materials and processes, which also received ethical approval. The pilot exercise asked ten bereaved parents known to the researcher to review the materials which were to be sent to potential participants. Suggestions for improvements were incorporated into the final versions of the documents used in the study.

Three charities were approached for help with recruitment, who subsequently advertised the project on websites and in their newsletter. Respondents were offered the questionnaire in either a paper format or online. Participants who requested a paper

copy were sent the questionnaire along with a consent form, both of which were to be returned to the university in a reply paid envelope. Those who chose to complete the questionnaire electronically were sent a link to the online version. Prior to displaying the questionnaire, an initial screen was displayed containing a duplicate of the consent form. The questionnaire was only initiated if the participant answered positively to a question confirming they have read the consent information and were happy to proceed.

All participants were given a unique identification number. No details which would allow the participant to be identified were included in the collected data to ensure participant confidentiality.

5.2.5 Statistical Analyses

First, the number of participants who met diagnostic criteria for prolonged grief and those who met diagnostic criteria for depression were assessed using crosstabulation. A Chi-square test was not run since two of the cells contained a value of less than five (Field, 1999).

Second, the association between grief score and rumination score, then depression score and rumination score was analysed using simple linear regressions.

Third, the association between the outcome variables and the categorical predictors were considered. Univariate logistic regression analyses were carried out, testing each of the categorical outcome variables with each of the predictors. Only variables which were found to have a significant univariate association with the outcome variables were included in the next step of the analysis. Continuous variables were examined using

linear regression, to determine which were significantly associated with the measured outcomes variables. Again, only those which were found to be univariately significant were included in further analyses.

Those factors which remained were then included in multivariate regression analyses.

Depression is known to be a risk factor for prolonged grief (Stroebe, Schut & Finkenauer, 2001), therefore this was controlled for by entering depression into step one of the predictors in the grief analysis. Given the large number of potential variables, a forward entry regression method was chosen to examine the relative importance of all significant factors, as recommended by Field (2005).

5.3 Results

The means and standard deviations for all continuous variables are shown in Table 5.2.

Table 5.2 – Minimum, maximum, mean, standard deviation and number of responses for continuous variables.

	<i>Mean</i>	<i>Standard Deviation</i>	<i>Minimum</i>	<i>Maximum</i>	<i>Total n</i>
Grief score	41.6	11.5	16	66	64
Depression score	10.9	7.3	0	27	64
Optimism/pessimism score	13.5	6.1	5	49	64
Rumination score	25.5	6.4	14	40	64
Religion	4.2	1.9	2	8	63
Self-blame	4.8	1.9	2	8	62
Venting	4.5	1.9	2	8	62
Substance/Alcohol use	3.6	2.3	2	8	63
Problem focussed coping	10.2	3.3	4	16	63
Avoidance focussed coping	7.4	3.0	4	14	62
Social Support	10.0	3.0	4	16	63
Cognitive Reconstruction	9.8	3.4	4	16	62
Continuing Bonds Score	43.7	9.8	11	60	64
Time since death (months)	30	15	2	59	56
Experience of taking part	6.0	1.2	3	7	64

The frequencies of dichotomous categorical variables are shown in Table 5.3.

Table 5.3 – Frequencies of positive/negative responses in categorical variables.

	<i>Yes</i>	<i>%</i>	<i>No</i>	<i>%</i>	<i>Total n</i>
Prolonged Grief	59	92	5	8	64
Clinical Depression	30	47	34	53	64
Child lived at home at time of bereavement	34	53	27	42	61
Other children at time of bereavement	49	77	15	23	64
Know other bereaved parents	50	78	14	22	64
Problems at work	35	55	14	22	49
Financial difficulties	27	42	30	47	57
Relationship difficulties	41	64	20	31	61
Difficulty caring for other children	21	33	22	34	43
Moved house	12	19	41	64	53
Concerns about other family members coping	56	88	6	9	62
Experienced other bereavements since the death of their child	31	48	32	50	63
Visiting grave daily or weekly	28	44	32	50	60
Reported having a positive symbol	38	60	24	38	62
Reported positive impact of researcher as bereaved parent	18	33	36	67	54

There were only seven responses to the question about whether organ donation was helpful or unhelpful, therefore these data are excluded from further analysis.

5.3.1 Hypothesis One – Prolonged grief can be measured independently from depression.

The mean grief score for the group was 41.6, SD = 11.5 with a range of 16 - 66 (the maximum possible score being 76). The mean depression score was 10.9, SD = 7.3 with a range of 0-27. The maximum possible depression score is 27. Although 47 % of this group met diagnostic criteria for moderate or severe depression, 92% were likely to meet diagnostic criteria for prolonged grief.

An illustration of the number of participants meeting diagnostic criteria for prolonged grief and those likely to have moderate/severe depression is shown in figure 5.1.

Distribution of Grief and Depression Scores

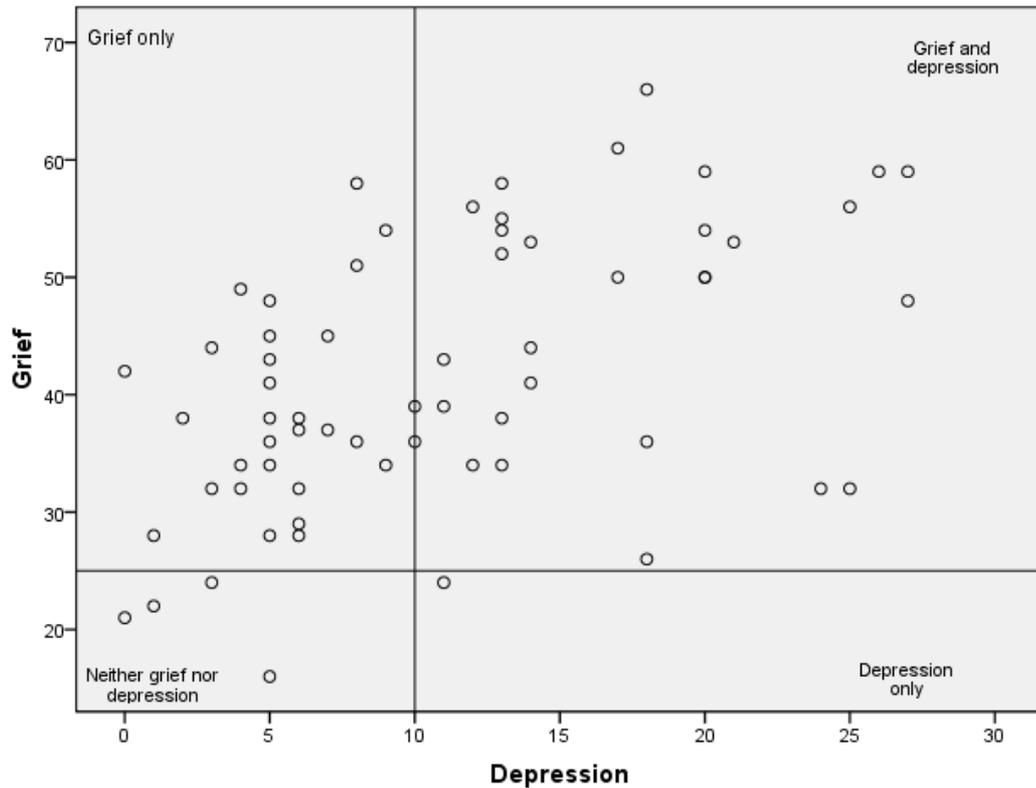


Figure 5.2 - Scattergram of participants' grief and depression status

Only one participant had depression without prolonged grief but 30 people (47%) had prolonged grief without depression. This indicates that depression and prolonged grief are separate constructs and that it is possible to meet diagnostic criteria for prolonged grief without having a likely diagnosis of depression. In this group of bereaved parents, having depression without prolonged grief was rare. The hypothesis, that bereaved parents could be diagnosed with prolonged grief independently from depression, was therefore supported.

5.3.2 Hypothesis Two – Increased levels of rumination will be associated with higher levels of grief or depression

Separate simple linear regressions were run to test the association of rumination separately with grief and depression scores. The association of rumination with grief was highly significant, $\beta = .73$, $t(63) = 8.34$, $p < .001$, and accounted for 53% of the variation in grief scores. The association of rumination with depression was also highly significant, $\beta = .75$, $t(63) = 8.82$, $p < .001$, and accounted for 56% of the variation in depression scores. The hypothesis that rumination scores are associated separately with both grief and depression was therefore supported.

5.3.3 Identification of the factors most closely associated with grief and depression

5.3.3.1 Factors Associated with Increased Grief

5.3.3.1.1 Categorical Variables Associated with Grief

Due to the large number of participants (92%) who met diagnostic criteria for prolonged grief in this sample, using grief diagnosis as a dichotomous categorical variable would be of little use. Instead, a median split was applied to the prolonged grief score. This was carried out at the median score of 43, with participants having a score of 43 or less being categorised as lower grief, and those scoring above 43 being categorised as having higher grief.

Univariate logistic regressions were carried out on all of the categorical variables, to determine which were associated with higher grief. Table 5.4 shows the categorical variables which showed a significant association.

Table 5.4 – Categorical variables univariately associated with higher grief

<i>Variable</i>	<i>B(SE)</i>	<i>Odds ratio</i>	<i>95% CI</i>	<i>p value</i>
Employment status of “working” at time of bereavement	1.50(.57)	4.46	1.46-13.65	<.01
Difficulty caring for other children	1.45(.65)	.23	.06-.84	<.05

The factors which were not significantly associated with higher grief were the participants’ own sex, relationship status at bereavement, change in relationship status, change in employment status, having other children, problems at work, financial problems, relationship problems, house move, concerns over other family members coping, other bereavements, knowing other bereaved parents, sex of child, violent death, sudden death, child living at home, frequency of grave visitation, having a helpful symbol and having considered suicide.

5.3.3.1.2 Continuous Variables Associated with Grief

Univariate linear regressions were then run to establish which continuous variables were associated with higher grief scores. Table 5.5 shows the variables which showed a significant association with grief scores.

Table 5.5 – Continuous variables univariately associated with higher grief

<i>Variable</i>	<i>t value</i>	<i>β</i>	<i>p-value</i>
Combined optimism/pessimism score	-3.58	-.41	<.001
Rumination	8.34	.73	<.001
Depression	4.72	.51	<.001
Problem-focussed coping	-2.22	-.27	<.05
Avoidance	4.84	.53	<.001
Cognitive restructuring	-4.17	-.44	<.001
Self-blame	2.39	-.47	<.001
Substance/alcohol use	2.16	.27	<.05

The following variables were not associated with higher grief – own age, number of restoration stressors, months since bereavement, child’s age, continuing bonds score, religious coping, venting and social support.

5.3.3.1.3 Relative Importance of Factors Associated with Increased Grief

Factors that were univariately significant in either the logistic regressions or the correlations were then analysed to ascertain which made the most significant contribution to explaining the variation in grief scores. The factors included in this analysis are shown in Figure 5.3.

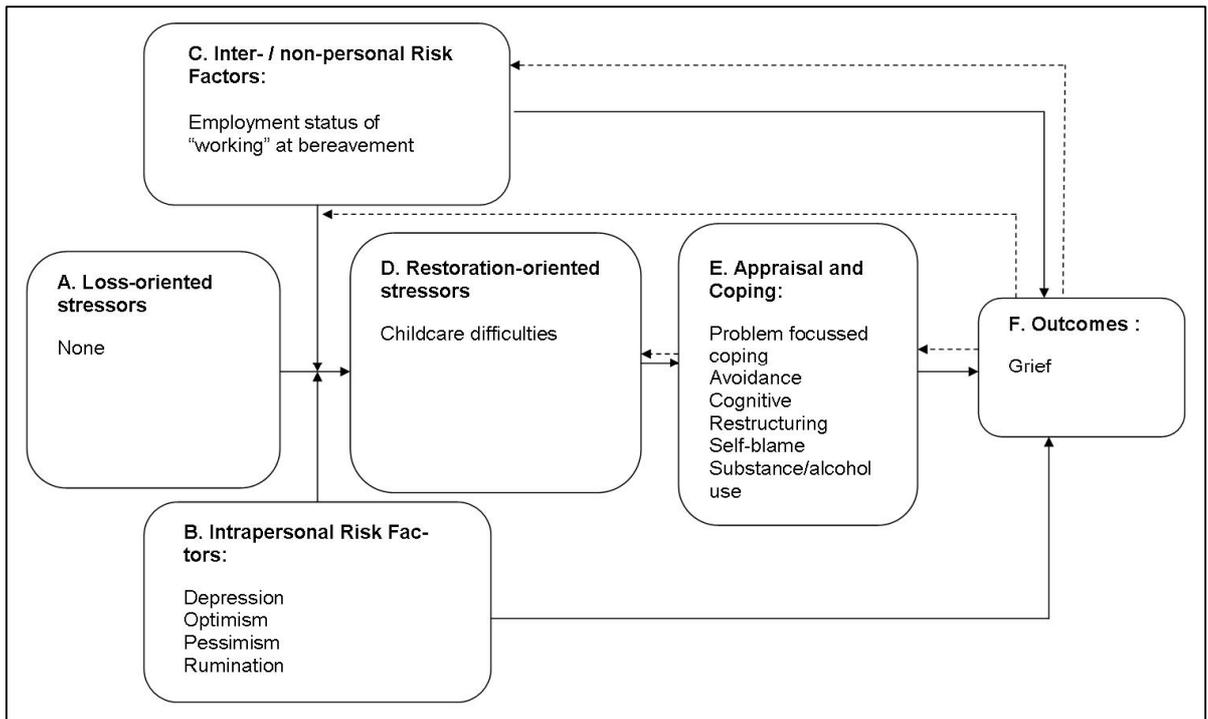


Figure 5.3 – Factors Univariately Associated with Grief

A forward-entry multiple regression analysis was conducted on the significant variables, controlling for the effect of depression by entering the depression score into step one. The analysis produced three models. The final model is shown below in table 5.6.

Table 5.6 –Multivariate Hierarchical regression analyses testing the relative contribution of factors to total grief score

	<i>Variable</i>	<i>R²</i>	<i>ΔR² for step</i>	<i>Final β</i>	<i>t</i>
Step1	Depression	.23	.23*	.78	3.51*
Step 2	Rumination	.57	.34***	1.52	5.55***
Step 3	Cognitive restructuring	.62	.05***	-.91	-2.47*

Note *p<.05, **p<.01, ***p<.001.

The model accounted for 62% of the overall variation in grief scores. Depression` accounted for 23% of the variance, rumination accounted for another 34% and cognitive restructuring accounted for another 5%.

5.3.3.2 Factors Associated with Depression

5.3.3.2.1 Categorical Variables associated with Clinical Depression

Univariate logistic regression analyses were carried out on the categorical variables, to determine which were associated with the classification of clinical levels of depression. Table 5.7 shows the categorical variables showed a significant association at $p < .05$.

Table 5.7 – Categorical variables univariately associated with depression

<i>Variable</i>	<i>B(SE)</i>	<i>Odds ratio</i>	<i>95% CI</i>	<i>p value</i>
Higher grief	1.69(.56)	5.40	1.82-16.03	<.01
Financial difficulties	1.84(.60)	.16	.05-.51	<.01

The factors which were not significantly associated with depression were own sex, relationship status at bereavement, change in relationship status, employment status at bereavement, change in employment status, having other children, problems at work, relationship problems, difficulty caring for other children, moving house, concerns over other family members coping, other bereavements, knowing other bereaved parents, sex of child, violent death, sudden death, child living at home, frequency of grave visitation, having a helpful symbol and suicidal attempts.

5.3.3.2.2 Continuous Variables Associated with Depression

A simple linear regression was run to establish which continuous variables were

univariately associated with higher depression scores. Table 5.8 shows the variables which showed a significant association at $p < .05$.

Table 5.8 – Continuous variables univariately associated with depression

<i>Variable</i>	<i>t value</i>	<i>β</i>	<i>p-value</i>
Grief	.33(.07)	.51	<.001
Time since bereavement	-.14(.06)	-.29	<.05
Combined optimism/pessimism score	-.30(.15)	-.25	<.05
Rumination	.85(.10)	.75	<.001
Alcohol/substance use	1.25(.39)	.38	<.01
Problem focussed coping	-.59(.27)	-.27	<.05
Avoidance	1.26(.28)	.51	<.001

The following variables were not associated with depression: own age, number of restoration stressors, child age, venting, religious coping, self-blame, social support and cognitive restructuring.

5.3.3.2.3 Relative Importance of Factors Associated with Increased Depression Scores

The significant factors were then analysed with a multivariate stepwise regression test to establish which made the greatest contribution to explaining the variation in depression scores. The factors included in this analysis are shown in Figure 5.4.

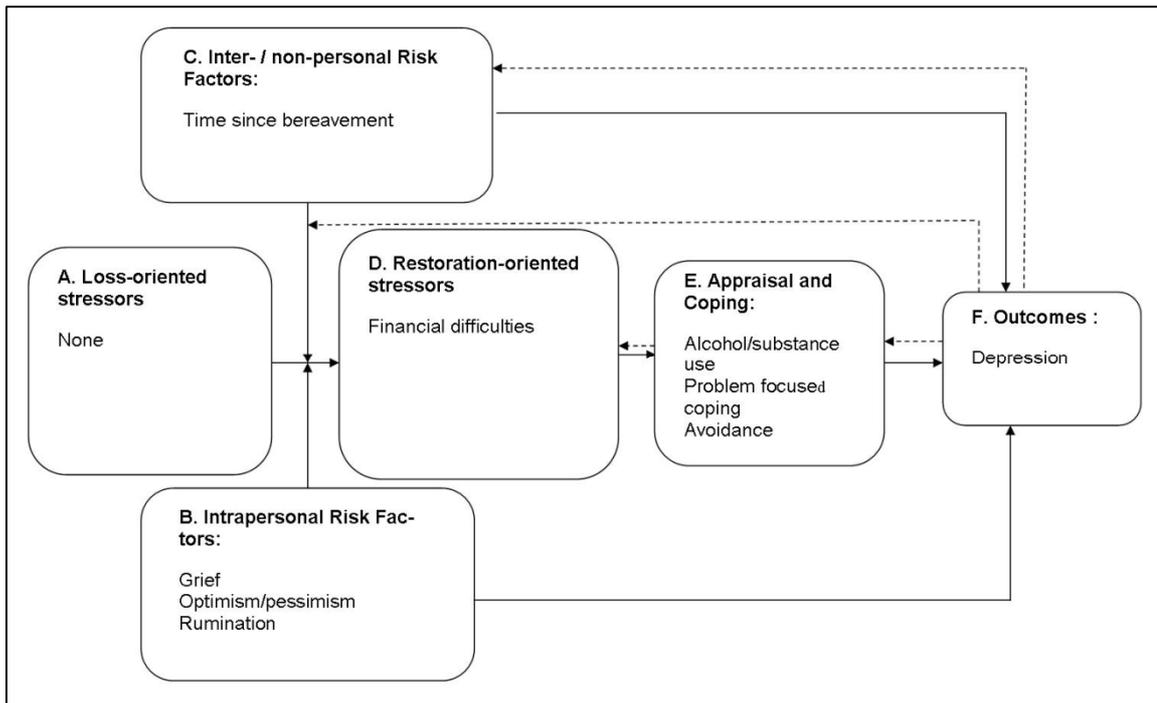


Figure 5.4 – Factors Univariately Associated with Depression

Again, the relatively large number of potential predictors indicated a forward entry regression method was appropriate (Field, 2005). The analysis produced only one model as shown in table 5.9.

Table 5.9 –Multivariate Hierarchical regression analyses testing the relative contribution of factors to total depression score

	<i>Variable</i>	<i>R²</i>	<i>ΔR² for step</i>	<i>Final β</i>	<i>t</i>
Step1	Rumination	.46	.46*	.68	6.24*

Note *p<.05, **p<.01, ***p<.001.

Rumination accounted for 46% of the variation in depression scores, $F(1,46) = 38.93$, $p < .001$, $\beta = .68$, $p < .001$.

5.3.4 Association with Continuing Bonds and either Grief or Depression

The univariate linear regressions indicated that there was no significant association between continuing bonds and either grief or depression scores.

5.3.5 Thematic Analysis of Other Relevant Information

Most of the comments made were reinforcing the answers to earlier questions, for example, indicating relationship problems or concerns over other family members coping. The most widely reported “other” concern was the impact of other people’s unhelpful reactions (n=9). In terms of comments about the actual questionnaire, one respondent found the forced choices frustrating, however another reported this was helpful as it made completing the answers easier. One participant suggested a “comments” box beside each question to enable personalised comments to be added. In addition, many positive comments were made about the experience of taking part and the feeling of doing something positive to help other bereaved parents.

5.4 Discussion

5.4.1 Prolonged Grief Independent of Depression

The results of the present study clearly indicate that depression and prolonged grief are separate constructs, with one not necessarily being a subset of the other. Almost half of the participants in the present study (47%) met diagnostic criteria for prolonged grief but not depression. Currently, in the absence of an accepted grief condition in medical terms, the suffering experienced by this group may not be recognised clinically. This may, in turn, have implications for the bereaved in terms of employment rights and insurance policies covering salaries whilst absent from work. To ensure that the distress of people experiencing prolonged grief in the absence of depression is recognised and

potentially treated, prolonged grief must be included as a recognised disorder in version five of the Diagnostic and Statistical Manual of Mental Disorders.

5.4.2 Rumination and Grief/Depression

Rumination was univariately associated with both grief and depression. Indeed, in the multivariate regression analysis, it was the only variable associated with depression and, when controlling for depression in the multivariate analysis of grief, held the strongest association with prolonged grief. This finding presents problems for those who offer therapeutic interventions with the bereaved since, as a potentially stable personality trait, the tendency to ruminate may not be easily altered. In this case, the additional risk factors univariately associated with complicated grief and bereavement, such as alcohol and substance use, a tendency for self-blame and childcare difficulties, must be addressed, if progress is to be made in alleviating symptoms of grief and depression in bereaved parents.

5.4.3 Risk Factors for Prolonged Grief and Depression

The additional factor associated with differential levels of prolonged grief, aside from depression and rumination, was cognitive restructuring. This construct refers to the individual reinterpreting the stressor in a positive light, for example, looking for something good that has come about as a result, or considering that the situation may not be as bad as it first seems. Benefit-finding, such as this, is an often unexpected finding in people who have experienced a traumatic event (Janoff-Bulman & Frantz, 1997). For the bereaved parent, this reinterpretation could mean carrying out some charity fundraising or helping other bereaved parents in a support group. Considering the experiences of others which may in some way be worse than their own

bereavement, for example, the cause of death, being able to say goodbye to the child or the child being able to end their life at home, may allow bereaved parents to re-evaluate their experience and find some positive, or perhaps more accurately less negative, aspects of their bereavement. This type of positive meaning making following bereavement has been associated with a better quality of life in parental discourses (Lichtenthal, Currier, Neimeyer & Keesee, 2010).

Engelkemeyer and Marwit (2008) (2008) found lower grief was associated with higher levels of post-traumatic growth in a group of parents bereaved up to 30 years (median time approximately 5 years) when time since death was controlled for. Posttraumatic growth increased in line with time since death in their participants. The concept of posttraumatic growth refers to the situation where an individual, when facing traumatic stress, experiences a profound change in their perception of life (Tedeschi & Calhoun, 2004). They may find a new direction for their life, spiritual strength or a changed sense of priorities as a result of their experience, thus developing a sense of recognising some good from the traumatic event which has occurred. Elgelkemeyer and Marwit found the presence of post-traumatic growth to be stronger in those who were tested at a later time since bereavement, but the present study indicates that this type of cognitive restructuring is both present and adaptive in early parental bereavement. This finding should be considered by bereavement therapists when developing interventions based on empirical evidence.

5.4.4 Continuing Bonds and Grief

The group of parents in the present study demonstrated no relationship between their level of continuing bonds and either grief or depression. An analysis of the interview

data in chapter four indicated that some forms of continuing bonds may be adaptive, such as a special linking object, whereas others, such as frequent grave visitation, may be maladaptive. The findings from the present study indicate that these behaviours were not the key determinants of differential grief or depression outcomes.

5.4.5 Research Experience

The participants in the present study rated it a positive experience, with a mean satisfaction score of 6 out of a maximum of 7. This indicates that research with bereaved parents should not be dismissed as potentially distressing and that recruiting potentially vulnerable participants may not necessarily be a barrier to future research. Indeed, other researchers have found that participating in qualitative bereavement research is seen as beneficial by those involved (Buckle, Dwyer & Jackson, 2010) and the present study suggests this finding extends to quantitative bereavement research also. Ethics committees must therefore be wary of paternalistically “protecting” bereaved people from participating in research, since, paradoxically, their informed consent to take part in studies such as the present project may actually be perceived by participants as highly valuable in their bereavement process.

Two thirds of the respondents in the present study indicated that the decision to take part was either wholly or in part influenced by the fact that the researcher was a fellow bereaved parent. Lack of prejudice when interpreting answers to questions, expertise in choosing relevant questions and level of understanding of the overall experience were cited as reasons for favouring a peer researcher. However, one third of participants said that the researcher being a bereaved parent had no impact on their decision to take part. The impact of the researcher on participant recruitment is therefore unclear.

5.4.6 Limitations of the Study

The recruitment process for this study involved support organisations advertising the study on web sites and in newsletters. The web sites, in particular, were likely to be visited by those actively seeking support. This may explain the large proportion of participants who were experiencing prolonged grief at the time. The newsletter is sent to people who had previously contacted the organisation and felt they would like to subscribe to the quarterly newsletter. These people may not actively be seeking bereavement support at the time of reading the invitation to participate. Although volunteers were asked where they saw the invitation to participate, very few indicated whether the response was due to the call on the web site or the notice in the newsletter. It is therefore not possible to identify any differences between the two recruitment methods. Replicating this research in a group of non-support seeking parents in early bereavement would identify how representative the current research is of the global population of bereaved parents.

Secondly, this group of participants was also comprised mainly of mothers. Previous research with bereaved parents has found that the majority of participants who agree to take part are mothers e.g. Murphy, Johnson and Weber, 2002; Lohan and Murphy, 2006. The perspective of fathers, and any sex differences, should be considered to establish a clear picture of parental bereavement for both parents.

Finally, the quantitative method of data collection may provide different responses to that of a qualitative approach. The questions relating to suicide in particular elicited different responses in respondents in the present study compared to that reported in chapter four. In the present study, suicidal ideation was present in less than one third of

participants (27%). In the study reported in chapter four, all of the mothers interviewed indicated that they had welcomed death or considered suicidal behaviours. One possible explanation for this could be that the impersonal nature of a questionnaire affected the likelihood of releasing such personal information. Alternatively, the participants in the interviews for the qualitative study may have been more likely to offer such information in a face to face encounter, where, by the time these issues were discussed, a relationship of trust with the researcher may have emerged. It is possible, however, that the parents who were interviewed felt obliged to say that they had wished for death when asked directly, as a means of indicating the level of the loss they have experienced. Finally, the difference in findings may be simply due to the fact that the interviewed group had a high level of death and suicide ideation, but the participants in the present study did not.

5.4.7 Conclusion

The group of bereaved parents in the present study were experiencing high levels of prolonged grief, but did not necessarily exhibit sufficient symptoms of depression to warrant a clinical diagnosis. The presence of prolonged grief as a diagnostic category condition separate to depression has been supported, and reinforces the need for a distinct new diagnostic condition to be added to DSMV. Rumination is a key factor in both prolonged grief and depression following bereavement. Due to the nature of such personality factors, therapeutic intervention for modification of ruminative behaviour may be difficult. Clinicians and therapists must be aware of the importance of this behaviour and any interventions must take cognisance of its presence. Cognitive restructuring and the ability to find benefits in the experience of parental bereavement, even in the early stages, must not be overlooked. Bereaved parents should be

encouraged to consider whether any facets of their experience did not occur in the worst possible form, and should also be assisted in their search to find any aspects of their life which have improved as a result of their living with the traumatic experience. Parents who have made attempts to find ways of coping may well find these efforts beneficial. The seeking and successful developing of strategies should be compared to the actual strategies chosen to identify whether it is the chosen activity which is important in grief processing, or the very act of considering and choosing a strategy. The role of continuing bonds in parental bereavement did not emerge from the present data. Their impact and association with grief and depression requires further analysis.

Parents in the early stage of bereavement provide an essential insight into the experience of grieving the loss of a child. The majority of participants in the current study (92%) indicated that taking part in the research was a positive experience, and researchers and ethics committees alike should not avoid including this group of people in research, for fear of distress being caused. It is imperative that bereaved parents are given a voice to allow their experiences to inform both medical and therapeutic practitioners and society as a whole, to allow this vulnerable group to receive optimum clinical and social care and support. More studies of this type with parents in early bereavement are required to establish how representative these findings are compared to the overall population of bereaved parents. Chapter six will examine if similar variables predict grief and depression later in the bereavement process.

Chapter Six - Factors Affecting Bereavement Outcome in Bereaved Parents Four Years Post-Loss

6.0 Abstract

6.0.1 Background

Grief in parental bereavement declines from the time of death until around three years, when a rise in symptoms is often experienced. Following this, bereaved parents are expected to steadily experience reduced symptoms. The experience of the loss of a child in this phase of mid-bereavement has received little attention from researchers, and requires investigation.

6.0.2 Method

A questionnaire was administered to a group of bereaved parents recruited from death records in Scotland. The questionnaire was completed by 106 participants at Time 1, mean 48 months post-loss (SD=10.9), and 81 participants completed the follow-up questionnaire at Time 2, three months later. The cause of the child's death included sudden and violent deaths as well as long term illness and stillbirths. The mean child's age at time of death was 8 years 8 months (SD=3.5 years).

6.0.3 Results

Prolonged grief and clinical depression were measured separately at Time 1. Depression-related rumination was associated with both grief and depression at Time 1. Reflective rumination was associated with grief and depression at Time 2. The factors significantly associated with grief at Time 1, in multivariate regression analyses, were depression, self-blame, the child normally living at home at the time of their death,

visiting the child's grave weekly or more frequently and the number of restoration stressors. Time 1 depression and self-blame predicted grief scores at Time 2. The factors multivariately associated with depression at Time 1 were rumination, problems at work and having a lower level of education. Time 1 rumination and level of education predicted depression at Time 2.

6.0.4 Conclusion

Those who offer support to bereaved parents must be aware that depression and grief may not necessarily co-exist in bereaved parents, and the presence or absence of each of these conditions must be evaluated and treated accordingly. In addition, the importance of social factors must not be underestimated. Bereaved parents require social and employment support through their grieving period. Therapeutic interventions must cover a variety of domains in order to address the factors which are associated with poorer outcomes in bereaved parents.

6.1 Introduction

The grief experienced by bereaved parents is thought to reduce from the time of bereavement until about three years, when an often unexpected increase in emotional distress is experienced (Rando, 1983). After this time, the parent is believed to experience an improvement in outcomes over time. By four years post-loss, the parent is therefore likely to have lived through the worst times of their loss and should be making a recovery in terms of negative symptoms. This period of mid-bereavement, from four years post-loss, is therefore of interest to researchers, since bereaved parents should then be moving towards resolution of their grief (Rando, 1983).

6.1.1 Factors Associated with Outcomes in Mid-bereavement

When measured in mid-bereavement, grief has been found to be associated with time since death (Anderson et al., 2005; Feigelman et al., 2009; Robinson & Marwit, 2006) emotional coping and avoidance coping (Anderson et al., 2005), sex of the parent, with mothers experiencing higher levels of grief than fathers (Bohannon, 1991; Littlefield & Silverman, 1991), social support and subsequent stressors (Hazzard et al., 1992). Losing a male child was linked with higher levels of depression (Hazzard et al., 1992) (Robinson & Marwit, 2006) as was the death being sudden (Hazzard et al., 1992) or the child being healthy prior to their death (Littlefield & Silverman, 1991).

Coping styles focussing on emotional expression, keeping busy and avoidance were associated with lower levels of grief (Robinson & Marwit, 2006). Finally, ruminative coping was found to be associated with higher levels of depression in a Japanese cohort (Ito et al., 2003). Although most of these factors were found to be associated with

different levels of depression or grief univariately, the relative importance of each when compared collectively in multivariate analyses has not yet been established.

6.1.2 Findings from Research in Early Bereavement

The results from chapter five indicated that grief and depression are distinct constructs in early bereavement, since prolonged grief was found independently from depression. These findings have, to date, not been tested in a group of parents in later bereavement, to establish whether the findings hold in respect of mid-bereavement.

Rumination was found to be associated with both grief and depression outcomes in early bereavement, however continuing bonds were not associated with grief or depression, despite their apparent importance highlighted in the phenomenological investigation of bereavement reported in chapter four. In the early bereavement study reported in chapter five, depressive-type rumination was found to be associated with higher levels of grief and depression. Other types of rumination, specifically reflective rumination, may not be maladaptive, and may even facilitate processing of grief and loss-related cognitions (Nolen-Hoeksema et al., 1994), however this claim has not yet been supported empirically with bereaved parents. The relationship between depressive and reflective rumination, separately, to grief and depression symptoms in mid-bereavement will be evaluated.

Continuing bonds was not found to be associated with grief or depression symptoms in early bereavement, despite its importance in the phenomenological study reported in chapter four. This may be due to factors associated with early bereavement, such as limited length of time to develop satisfactory strategies for continuing the bond with the

lost child. The relative adaptiveness of continuing bonds behaviour in mid-bereavement therefore requires investigation.

The hypotheses for the current study were as follows;

- (c) Prolonged grief is a construct independent of depression in parents in mid-bereavement at Time 1
- (d) Increased levels of depressive rumination would be associated with higher levels of grief and depression at Time 1
- (e) Increased levels of reflective rumination would be associated with higher levels of grief and depression at Time 2.

In addition, five exploratory analyses were carried out. These were :

- a) Analysis of the factors most closely associated with grief and depression at Time 1 were identified
- b) Examination of the relative importance of continuing bonds in explaining grief and depression scores at Time 1 was investigated
- c) Determination of whether grief and depression scores at Time 2, measured three months after the baseline at Time 1, could be predicted by those factors found to be most strongly associated with grief or depression at Time 1.
- d) Consideration of whether the researcher's status as bereaved parent had any bearing on the individual taking part in the research
- e) Analysis of whether participation in the research was viewed positively or negatively.

6.2 Method

Ethical approval for the study was granted by the ethics committee of the Psychology Department at the University of Stirling.

6.2.1 Participants

The General Register Office for Scotland (GROS) provided a list of death records for people who died in Scotland in 2005, aged from 0 to 30 years, and those who were stillborn. This yielded a total of 1351 records. The death registration process requires the informant to give the name of both parents of the deceased, if known. In the present sample, three deaths were recorded with no mother's name and 81 deaths were recorded with no father's name. Twenty-four parents had experienced more than one loss. From this, the number of registered bereaved parents of a child who died in Scotland in 2005 aged up to 30 years old was 2594.

Deaths recorded by a non-parent, for example, a grandparent, aunt/uncle or spouse, were excluded from the list of potential participants (parent n=444). If the registering parent supplied an address outside Scotland, they were also excluded from the list of potential participants (parent n=78). A mortality check was carried out to identify if any of the parents listed were subsequently present in the register of deaths. The name and address of each parent were used as search criteria in the death register. If a match was found, the parent had died and their records were removed from the list of potential participants. This step was intended to ensure that no letters were sent to families where the intended recipient is also deceased. Eighteen bereaved parents were found to have died following their child's death and were, therefore, removed from the database. Of these 18 deaths, 12 were from causes related to drug and alcohol use.

Finally, an address checking analysis was run on the database, using a commercial data cleansing organisation (www.data-8.co.uk). This was intended to check the database against records held of people who have moved away but left no forwarding address. This commercially-available service compares the given name and address combination against a register of “moved away” UK names and addresses. This register is generated mostly from electoral roll details, but is augmented by information from product warranty registrations, lifestyle questionnaires and magazine subscriptions. By comparing the mailing details presented against those held by commercial data cleansing organisations, it is possible to identify people who no longer live at the given address. The parent names and addresses were run through this data cleansing service and this step removed another 21 parents. The number of bereaved parents remaining in the potential participant list following all of these steps was 2033 (78% of all parents bereaved in Scotland in 2005).

Although both parents’ names may be given on the death certificate, only the address of the informant is recorded in UK death registration data. There is no indication whether the given address is correct for the non-registering parent. In the present sample, 64% of deaths following a live birth were registered by fathers and all of the stillbirths were registered by mothers. To minimise the impact of these biases of informant sex, an offer to take part was sent to both parents, at the registering parent’s address.

The letters were planned to be sent out over a two-week period and 1148 (56%) were posted as a first batch. We received 12 complaints from people we contacted, mostly relating to the use of their personal details which were not always understood to be in

the public domain. Although the number of complaints received was small (1% of the total letters sent) the level of distress that was experienced by these people was significant. Consequently, the research team took the decision not to send out any further invitations in order to avoid potentially causing distress to any other parents. Of the 1148 letters posted, 130 were returned undeliverable, therefore 1018 parents were assumed to have been contacted.

6.2.2 Measures

The study utilised the same approach as that of the early bereavement research presented in chapter five, namely a combination of published psychological measures, bereavement-specific questions and socio-demographic variables.

6.2.2.1 Grief

The 19-item Inventory of Complicated Grief was used to assess grief (Prigerson, Maciejewski et al., 1995). A score of 25 or over indicates that the participant meets the proposed diagnostic criteria for prolonged grief. The scale was internally consistent in the current study at Time 1 (Cronbach's $\alpha = .93$) and at Cronbach's $\alpha = .92$ at Time 2.

6.2.2.2 Depression

Depression was measured using the 9-item Patient Health Questionnaire (PHQ-9) (Kroenke et al., 2001) which assesses probable psychiatric caseness for moderate to severe depression. The total score is used to indicate probable caseness, with a score of 10 or above suggesting moderate to severe depression. The scale was internally consistent in the current study (Cronbach's $\alpha = .93$ at Time 1 and $.95$ at Time 2).

6.2.2.3 Trait Optimism/Pessimism

The Life Orientation Test (Revised) LOT-R measures trait optimism/pessimism (Scheier et al., 1994). The total score calculated from the 10-item measure indicates the relative strength of trait optimism or pessimism. The scale was internally consistent in the current study for both optimism and pessimism (Cronbach's $\alpha = .83$ and $.87$ respectively).

6.2.2.4 Rumination

Rumination was measured at Time 1 using the 10-item Response Styles Summary to measure depression-related rumination (Nolen-Hoeksema, 1991). Higher scores indicate a greater tendency towards the measured style of rumination. The scale was internally consistent, with Cronbach's $\alpha = .93$.

6.2.2.5 Coping Style

Coping style was measured using the Brief Cope (Carver et al., 1989), a 28-item questionnaire measuring 14 types of coping. The humour scale was removed from this study to avoid potential offence in participants. The remaining scales were aggregated into four summary sub-scales following O'Connor & O'Connor (2003). Problem Focussed Coping (subscale one) was derived from the total scores from the Active Coping and Planning scales, Avoidance Focussed Coping (subscale two) was calculated from Denial and Behavioural Disengagement. Social Support (subscale three) was derived from the Seeking Instrumental Social Support and Seeking Emotional Social Support. Cognitive Restructuring (subscale four) was calculated from Positive Reinterpretation and Growth Acceptance. Self-blame, Use of Religion, Focus and Venting of Emotions and Alcohol and Substance Use did not readily lend themselves to any of these summary scales and were therefore retained as sub-scales in their own

right. The internal consistency of the sub-scales was acceptable at Time 1 (Problem Focussed Coping – Cronbach’s $\alpha = .83$, Avoidance Coping – Cronbach’s $\alpha = .78$, Social Support – Cronbach’s $\alpha = .81$ and Cognitive Reconstruction Coping – Cronbach’s $\alpha = .74$) and at Time 2 (Problem Focussed Coping – Cronbach’s $\alpha = .69$, Avoidance Coping – Cronbach’s $\alpha = .80$, Social Support – Cronbach’s $\alpha = .70$ and Cognitive Reconstruction Coping – Cronbach’s $\alpha = .53$).

6.2.2.6 Continuing Bonds

Continuing Bonds were measured using the Continuing Bonds Scale (Field et al., 2003) (see Appendix VII). The wording of the questions in this scale was changed from “spouse” to “child”, for example, “I seek out things to remind me of my child”. There are 11 questions in the scale with the participants responding on a scale from 1 (not at all true) to 5 (very true). The total score indicates the level of continuing bonds that the bereaved has with the deceased. The scale was internally consistent in the current study (Time 1 Cronbach’s $\alpha = .83$, Time 2 Cronbach’s $\alpha = .87$).

6.2.2.7 Socioeconomic Status

Carstairs scores are used in research in Scotland to identify relative socioeconomic status (SES) as defined by a participant’s postcode (McLoone, 2004). The scores are constructed using indices of poverty including level of overcrowding in the home, male unemployment, and no car ownership, as recorded in the Census statistics published by GROS. The postcodes given by the participants were checked against the list of all postcode areas in Scotland and their corresponding Carstairs score as published by McLoone (2004). The scores were then collapsed into three categories to simplify comparisons, following Leyland, Dundas, McLoone & Boddy (2007). Those

participants with scores 1 or 2 were described as Affluent, those with scores 3, 4 or 5 were described as Intermediate, and those with score 6 or 7 were described as Deprived.

6.2.2.8 Suicidal Ideation

Participants were asked two questions to establish their level of suicidal ideation or previous self-harm attempts. The first question, “Have you ever deliberately taken an overdose (e.g. of pills or other medication) or tried to harm yourself in some other way (such as cut yourself?)”, allowed responses of No, Yes – once or Yes – more than once. The second question was, “Have you ever seriously wanted to kill yourself when you have taken an overdose or tried to harm yourself in some other way?” to which the participant could answer “Yes”, “No” or “Not applicable”.

6.2.2.9 Education

The options for education level were secondary school only, college, undergraduate or postgraduate. These were again collapsed into two categories – school or college and university (undergraduate or postgraduate), to simplify analysis.

6.2.2.10 Cause of Death

The cause of death being either violent or non-violent was derived from the underlying cause of death code supplied by GROS on the death records. Violent deaths were those which occurred as a result of accident, murder or suicide in line with previous research (e.g. Neimeter et al. (2006) and as carried out in chapter five. All others were classed as non-violent deaths.

6.2.2.11 Death anticipation

The anticipation of the death was summarised as either sudden or anticipated, where sudden deaths were totally unexpected or expected in the hours before death and anticipated deaths were expected for days or expected for some time.

6.2.2.12 Linking Objects/Symbolic Representations

If participants indicated that they had a special object, item or living thing that reminded them of their child, their response was summarised as either being a linking object, photograph, hospital memento, physical remains, symbols or other, with more than one category identified where this was indicated in the response.

6.2.2.13 Relationship status

The options for relationship status were single, with partner, married, separated, divorced or widowed. These answers were summarised so that with partner or married was classified as “in a relationship”, as in chapter five. The other answers were classified as “not in a relationship”.

6.2.2.14 Employment status

The options for employment status were unemployed, caring for family, sick, permanently disabled, training/studying, retired, working full time and working part time, the final two were classified as “working”. All others were classified as “not working”.

6.2.3 Time 2 Questionnaire

A second questionnaire was issued to participants at Time 2, three months later. This shorter questionnaire requested an update of the relationship and employment status at that time. It also included the same grief, depression, continuing bonds and coping

measures taken at Time 1, to establish which had changed over time. Rumination at Time 2 was measured using the 10-item Response Styles Summary for reflective rumination (Nolen-Hoeksema, 1991) . Higher scores again indicate a greater tendency towards the measured style of rumination. The scale was internally consistent with Cronbach's $\alpha = .72$. The data captured at Time 2 was important since this permitted the prediction of outcomes, rather than merely the association between predictors and outcomes, if sampling had taken place at only one time point.

6.2.4 Qualitative Data

At both Time 1 and Time 2, participants were asked whether they were experiencing any other stressors not listed in the questionnaire. At Time 1, they were asked if there was anything else they would like to say about the experience of parental bereavement. These questions were intended to establish whether there were any other relevant stressors which should be taken into account when considering the experience of parental bereavement. The answers to these questions were grouped into broad themes, to identify if there were any recurring themes being reported which had been missed in the quantitative measures. At Time 1, participants were asked if they had any views on taking part in the research. The reason for asking this question was to establish what the participants felt about completing the questionnaire. They were also asked whether the fact that the researcher was a bereaved parent influenced their decision to take part. At Time 2, parents were asked what the biggest challenge was that they had faced since their child died, what advice they would give to other bereaved parents and what support they feel should be offered to people in this situation. Again, answers to all of these questions were subject to thematic analysis to identify if there were any key factors which were not tested quantitatively.

Two versions of the final complete questionnaire were created, with the order of questions reversed for counterbalancing to minimise order effects.

6.2.5 Participant Demographics

Table 6.1 compares the demographics of the sample contacted and the sample completed to the total potential death registration sample supplied by GROS.

Table 6.1 – Comparison of demographics for all parents potentially contactable, those actually contacted and those who returned completed questionnaires

	<i>Potential Participants (n=2033)</i>	<i>Sample Contacted (n=1018)</i>	<i>Sample Completed (n=106)</i>
Mothers	1049 (51.6%)	524 (51.4%)	73 (68.9%)*
Fathers	984 (48.4%)	494 (48.6%)	33 (31.1%)
Affluent addresses	702 (34%)	344 (34%)	50 (48%)
Intermediate addresses	845 (42%)	409 (40%)	45 (43%)
Deprived addresses	486 (24%)	265 (26%)	9 (9%)**
Now live outside Scotland	n/a	n/a	2 (2%)
Deaths - female	516 (39.5%)	395 (41.1%)	43 (40.6%)
Deaths - male	789 (60.4%)	566 (58.9%)	63 (59.4%)
Deaths - unknown sex	2 (0.1%)	0	0
Mean child age (SD)	14.63 (11.15)	13.26 (10.98)	8.58 (10.85)
Non-violent death	978 (74.8%)	709 (73.8%)	81 (76.4%)
Violent death	329 (25.2%)	252 (26.2%)	25 (23.6%)

Note *p<.05, **p<.01

Comparisons between categorical variables in the group of potential participants, the sample who were contacted and the sample who completed questionnaires were made using Chi-square tests. There were no significant differences found in the comparison

of the potential participants and sample contacted groups. For the sample completed and sample contacted comparison, two differences were found. First, the percentage of mothers agreeing to take part in the research was higher than that of the potential population, $\chi^2(1) = 6.05$, $p=.014$. This is consistent with previous research carried out with bereaved parents (e.g. that reported in chapter five, Murphy, Tapper, Johnson & Lohan, 2003; Woodgate, 2006). Second, the number of participants in the deprived category was under-represented compared to the bereaved population, $\chi^2(2) = 10.76$, $p=.005$.

The mean age of the child at time of death was lower in the participants who completed the questionnaire compared to those who were contacted, $t(994) = 4.07$, $p < .001$. The mean age of parents who agreed to take part in the research was 42.8 years ($SD = 10.3$). Age is not available from the data supplied by GROS, therefore this cannot be compared to the potential participants or those contacted. Ninety-three participants (88%) were married or in a relationship at the time of the bereavement. Thirteen (12%) were single, separated, divorced or widowed. Within the sample, 29 (27%) were educated to high school level, 33 (31%) had attended college, 23 (22%) were university graduates and 19 (18%) had a postgraduate qualification. Two participants (2%) did not supply their level of education.

6.2.6 Procedure

GROS was approached to obtain a list of recorded deaths and their Privacy Advisory Committee considered the request. Since the records were already in the public domain, they approved the data for use in this research. The University of Stirling Psychology Department ethics committee approved the project, following a pilot test of materials

and processes, which also received ethical approval. The pilot exercise asked ten bereaved parents known to the researcher to review the materials which were to be sent to potential participants. Suggestions for improvements were incorporated into the final versions of the documents used in the study.

The first batch of participants were sent an information pack and an invitation to participate in the research. Those who agreed to take part indicated on the response form whether they would prefer to complete the questionnaire in paper format or online. Participants who requested a paper copy were sent the questionnaire along with a consent form, both of which were to be returned to the university in a reply paid envelope. Those who chose to complete the questionnaire electronically were sent a link to the online version. Prior to displaying the questionnaire, an initial screen was displayed containing a duplicate of the consent form. The questionnaire was only initiated if the participant answered positively to a question confirming they had read the consent information and were happy to proceed.

All participants were given a unique identification number which was cross-referenced to their details as supplied by GROS. No details which would allow the participant to be identified were included in the collected data to ensure participant confidentiality.

6.2.7 Statistical Analyses

First, the descriptive statistics were calculated for all variables. Any differences between Times 1 and 2 were compared using paired t-tests for continuous variables and repeated measures Chi-squares for categorical measures. Then, participants who met

diagnostic criteria for prolonged grief and those who met diagnostic criteria for depression were compared using a binomial test.

Second, the association between the rumination and grief and depression separately would be tested using univariate linear regressions.

For the exploratory analysis, logistic regression analyses were carried out, testing each of the categorical outcome variables with each of the predictors. Only variables which were found to have a significant univariate association with the dependent variable were included in the next step of the analysis. Continuous variables were examined using linear regression, to determine which were significantly associated with the outcome variables. Again, only those which were found to be significant were included in further analyses.

Those factors which remained were then included in multivariate regression analyses. Depression is known to be a risk factor for prolonged grief (Stroebe et al., 2001), therefore this was controlled for in the grief analysis by entering depression into step one of the predictive factors. Given the large number of potential predictors, a forward entry regression method was chosen to examine the relative importance of all significant factors, as recommended by Field (2005).

Finally, the factors found to be significantly associated with grief and depression at Time 1 were then tested using multivariate regression analyses to identify whether any variables predicted grief and depression scores at Time 2.

The level of significance will be set at $p < .01$ for the main analyses to include only the variables with the most highly significant associations, and $p < .05$ for post-hoc analyses throughout, to limit the number of variables included in the multivariate analyses to those likely to have the highest level of association with outcomes.

6.3 Results

Of the 1018 people contacted, 154 returned positive responses indicating they would like to take part in the research. Of these, 109 actually returned questionnaires. Three were only partly completed and were therefore excluded from analysis. Missing data were addressed using the method recommended from the WHOQOL Brief manual was used, i.e. “Where an item is missing, the mean of the other items in the domain is substituted” (p.7). Eighty one participants (76%) completed measures at both Time 1 and Time 2. There were no significant differences in participants’ sex, age, child’s sex, age, cause of death or suddenness of death between those who did/did not complete measures at Time 1 and Time 2.

For suicidal ideation, the first question asks, “Have you ever deliberately taken an overdose (e.g. of pills or other medication) or tried to harm yourself in some other way (such as cut yourself)?”. Seven people answered yes to this question. The second question for suicidal ideation is, “Have you ever seriously wanted to kill yourself when you have taken an overdose or tried to harm yourself in some other way?”. For this question, 19 people answered yes. There was clearly some confusion amongst participants on what was being asked, therefore the answers to these questions were excluded from analysis. Suicidal ideation as a dependent variable was therefore not included in the analysis.

There were only two responses to the question about whether organ donation was helpful or unhelpful with one reply to each, therefore these data are excluded from further analysis.

The means and standard deviations for all continuous variables at Time 1 are shown in Table 6.2. Time 2 results are shown in Table 6.3.

Table 6.2 – Minimum, maximum, mean, standard deviation and number of responses for continuous variables at Time 1

	<i>Mean</i>	<i>Standard Deviation</i>	<i>Minimum</i>	<i>Maximum</i>	<i>Total n</i>
Grief score	28.3	15.6	2	62	105
Depression score	6.13	6.4	0	26	104
Child age	8.6	10.8	0	30	105
Optimism/pessimism score	12.2	2.1	7	21	106
Rumination score	20.7	6.3	8	36	106
Age	42.8	10.4	22	66	101
Venting of emotions	3.6	1.5	2	8	104
Religion	3.3	1.9	2	8	104
Self-blame	4.4	2.1	2	8	106
Substance use	2.7	1.4	2	8	104
Problem focussed coping	8.4	3.4	4	16	105
Avoidance focussed coping	6.0	2.7	4	16	106
Social Support	8.1	3.0	4	16	106
Cognitive Reconstruction	10.2	3.1	4	16	106
Continuing Bonds Score	40.2	12.2	12	67	104
Time Since Death (months)	47.6	3.6	42	54	106
Perception of taking part	5.6	1.2	2	7	104

Table 6.3 – Minimum, maximum, mean, standard deviation and number of responses for continuous variables at Time 2

	<i>Mean</i>	<i>Standard Deviation</i>	<i>Minimum</i>	<i>Maximum</i>	<i>Total n</i>
Grief score	22.38	15.43	0	58	79
Depression score	5.27	6.67	0	26	81
Rumination score	19.35	7.9	10	55	78
Venting of emotions	3.56	1.87	2	8	80
Religion	2.88	1.27	2	8	80
Self-blame	4.46	2.18	2	8	80
Substance use	3.76	2.52	2	8	80
Problem focussed coping	8.54	3.89	4	18	80
Avoidance focussed coping	7.24	4.12	4	20	80
Social Support	8.07	3.05	4	18	80
Cognitive Reconstruction	9.41	3.21	4	14	80
Continuing Bonds Score	33.49	12.81	11	64	79

Depression scores did not differ between Time 1 and Time 2, however grief scores were lower at Time 2, $t(76)=3.47$, $p=.001$. The level of alcohol and substance use increased from Time 1 to Time 2, $t(79)=-4.12$, $p<.001$. Religious coping declined over time, $t(78)=3.02$, $p=.003$. Avoidance focussed coping was greater at Time 2 than Time 1, $t(79)=3.03$, $p=.003$. Cognitive reconstruction also declined over time, $t(79)=2.21$, $p=.030$. Self-blame, problem-focussed coping and social report remained stable between Times 1 and 2. Continuing bonds scores also decreased over time, $t(78)=4.77$, $p<.001$.

The frequencies of dichotomous positive/negative categorical variables at Time 1 are shown in Table 6.4.

Table 6.4 – Frequencies of positive/negative responses in categorical variables at**Time 1**

	<i>Yes</i>	<i>%</i>	<i>No</i>	<i>%</i>	<i>Total n</i>
Grief rating	57	54	48	46	105
Depression rating	28	27	77	73	105
Sudden death	86	82	19	19	105
Violent death	25	24	81	76	106
Child lived at home at time of bereavement	40	42	56	58	96
Only child at time of bereavement	39	37	66	63	105
In relationship at time of bereavement	93	88	13	12	106
Working at time of bereavement	83	78	23	22	106
Know other bereaved parents	66	63	39	37	105
Problems at work	29	33	60	67	89
Financial difficulties	22	23	73	77	95
Relationship difficulties	49	48	52	52	101
Difficulty caring for other children	23	25	70	75	93
Moved house	10	11	81	89	91
Concerns about other family members coping	71	70	30	30	101
Experienced other bereavements since the death of their child	50	47	56	53	106
Reported having a linking object with their child	66	63	39	37	105
Reported having a symbolic representation of their child	10	9	95	90	105

The frequencies of dichotomous positive/negative categorical variables at Time 2 are shown in Table 6.5.

Table 6.5 – Frequencies of positive/negative responses in categorical variables at Time 2

	<i>Yes</i>	<i>%</i>	<i>No</i>	<i>%</i>	<i>Total n</i>
Grief rating	42	52	39	48	81
Depression rating	16	20	65	80	81
Problems at work	22	32	46	68	68
Financial difficulties	17	23	57	77	74
Relationship difficulties	38	48	41	52	79
Difficulty caring for other children	15	21	57	79	72
Moved house	6	8	66	92	72
Concerns about other family members coping	52	66	27	34	79

The number of people who moved house did not change significantly between Time 1 and Time 2. All other categorical measures showed a significant decline between Times 1 and 2, as shown in Table 6.6.

Table 6.6 – Difference between measures at Time 1 versus Time 2

	χ^2	<i>p-value</i>
Grief rating	$\chi^2(1) = 19.87$	<.001
Depression rating	$\chi^2(1) = 42.29$	<.001
Problems at work	$\chi^2(3) = 21.02$	<.001
Financial difficulties	$\chi^2(3) = 33.68$	<.001
Relationship difficulties	$\chi^2(1) = 19.72$	<.001
Difficulty caring for other children	$\chi^2(2) = 16.52$	<.001
Concerns about other family members coping	$\chi^2(3) = 40.76$	<.001

Table 6.7 shows the responses to questions with categorical outcomes which were not yes/no answers, which were measured at Time 1.

Table 6.7 – Frequencies of sex of child and parent, education status, socioeconomic status and frequency of grave visitation reported at Time 1

		<i>n</i>	<i>%</i>			<i>n</i>	<i>%</i>	<i>Total n</i>
Sex of child	Male	63	59.4	Female	43	40.6		105
Sex of parent	Male	33	31.1	Female	73	68.9		106
Education status of parent	School/college	62	59.6	University	42	40.4		104
Frequency of grave visitation	Up to weekly	40	44.4	Monthly/few times per year	50	55.6		90
Socio-economic status of parent	Deprived	9	8.7					
	Intermediate	45	43.3					
	Affluent	50	48.1					

6.3.1 Qualitative Analysis

6.3.1.1 Additional Problems not Specified in Questionnaire

The answers to the “any other problems” questions which were reported by more than one participant are shown in Table 6.8.

Table 6.8 – Other problems reported at either Time 1 or Time 2

<i>Reported problem</i>	<i>n</i>
Depression	11
Problems with friends/social relationships	6
Guilt	4
Anger	4
Sleep problems	2
Anxiety	2
Legal problems	2

These low numbers suggest that there are not other problems being experienced by the group of bereaved parents which warrant further investigation. The answers to the question asking the participant if there was anything else they would like to say about their experience appeared to elicit narrative either about the lost child or about how the

parent coped. The question asking what was the biggest challenge at Time 2 elicited similar answers to the “other problems” questions answered at both time points. The analyses of these narratives did not appear to yield any examples of definite coping behaviours but were rather personal narratives indicating the individual’s feelings about their loss. Whilst potentially interesting as a source of information about the lived experience of parental bereavement, these answers did not indicate any other variables which should be included in the quantitative evaluation of the bereavement experience.

6.3.1.2 Impact of the Bereaved Parent Status of the Researcher

Thirty one participants (42%) said that the research being carried out by a fellow bereaved parent encouraged them to take part, or that they would only have taken part if this was the case. Twenty four (33%) said it made no difference. This indicates that response rates in the current study may have been higher than if participants had not been told the status of the researcher, or had believed the researcher to be a non-bereaved parent.

6.3.1.3 Advice for Other Bereaved Parents

When asked what advice they would give other bereaved parents, 37 participants (50%) said talking about the child, either to family, friends or counsellors, was helpful. The question about what help should be offered to bereaved parents reinforced this with eleven participants (15%) suggesting counselling should be offered, five (7%) suggesting talking generally and thirteen (18%) suggesting peer support groups. Two participants stated that more information would be useful for bereaved parents, one participant requested employment rights and financial support and one participant recommended altruistic charitable behaviour for bereaved parents. It appears from these

suggestions that talking to other people, either friends, family or professionals, was seen as potentially helpful for the parents questioned.

6.3.2 Hypothesis One – Prolonged grief can be measured independently from depression at Time 1

The mean depression score for the group was 6.1, SD = 6.4 with a range of 0 - 26 (the maximum possible score being 27). The mean grief score was 22.4, SD = 15.4, with a range of 2 - 62. The maximum possible grief score is 76. More than half (54%) of this group of bereaved parents probably met diagnostic criteria for prolonged grief and 27% demonstrate “caseness” for moderate or severe depression.

An illustration of the number of participants meeting diagnostic criteria for prolonged grief and those likely to have moderate/severe depression is shown in figure 6.1.

Distribution of Grief and Depression Scores – Time 1

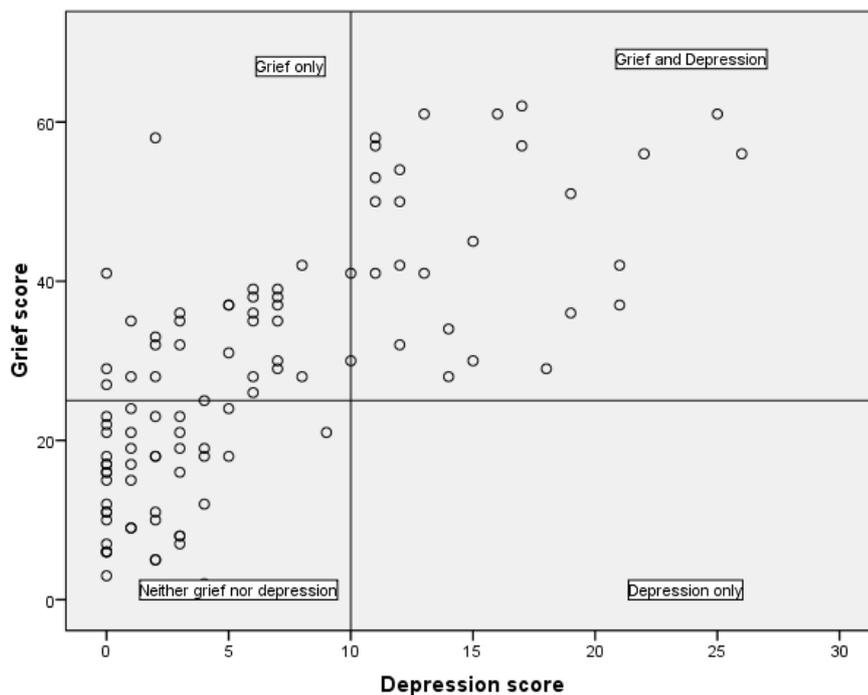


Figure 6.1 - Scattergram of participants' grief and depression status at Time 1

Over a quarter of the sample (27%) met diagnostic criteria for prolonged grief but not depression. No participants met diagnostic criteria for depression but not grief. This indicated that grief was found independent of depression, but depression was not found independent of grief. Those participants who demonstrated a likelihood of prolonged grief were not merely a subset of the depressed participants, but could be identified independently. A post-hoc binomial test confirmed the significance of the difference in depression diagnosis in the group without prolonged grief at $p < .001$. The hypothesis, that prolonged grief could be measured independently from depression, was therefore supported.

6.3.3 Hypothesis Two – Increased levels of depressive rumination will be associated with higher levels of grief and depression at Time 1

Separate simple linear regressions were run to test the association of depressive rumination with grief and depression at Time 1, univariately. The association of rumination with grief was highly significant, $\beta = .74$, $t(104) = 11.24$, $p < .001$. The association of rumination with depression was also highly significant, $\beta = .79$, $t(103) = 12.98$, $p < .001$. The hypothesis that depressive rumination scores associated with higher grief and depression scores at Time 1 was therefore supported.

6.3.3 Hypothesis Three – Levels of reflective rumination would be associated with higher levels of grief and depression at Time 2.

Separate simple linear regressions were again run to test the association of reflective rumination with grief and depression at Time 2, univariately. The association of rumination with grief was highly significant, $\beta = .46$, $t(75) = 4.46$, $p < .001$. The

association of rumination with depression was also highly significant, $\beta = .79$, $t(103) = 12.98$, $p < .001$. Post-hoc analyses considered whether this effect was related to the sex of the parent (Treyner et al., 2003). The data file was split by sex of parent and the linear regressions were run again. Both mothers and fathers demonstrated a strong association of reflective rumination with grief, fathers $\beta = .84$, $t(21) = 6.85$, $p < .001$, and for mothers, $\beta = .37$, $t(54) = 2.90$, $p = .005$. Both groups also showed a strong association of reflective rumination with depression, fathers returning $\beta = .76$, $t(22) = 5.30$, $p < .001$, and for mothers, $\beta = .40$, $t(53) = 3.11$, $p = .003$. The hypothesis that reflective rumination scores are associated with higher grief and depression scores was therefore supported.

6.3.4 Exploratory Analysis – Identification of the factors most closely associated with grief and depression.

6.3.4.1 Factors Associated with Increased Grief at Time 1

6.3.4.1.1 Categorical Variables

Univariate logistic regressions were carried out on all of the categorical variables, to determine which were associated with the likely diagnosis of prolonged grief. The factors which were associated are shown in Table 6.9.

Table 6.9 – Categorical variables univariately associated with likelihood of grief diagnosis at Time 1

<i>Variable</i>	<i>B(SE)</i>	<i>Odds ratio</i>	<i>95% CI</i>	<i>p value</i>
Financial difficulties – yes/no	2.15(.66)	.12	.03-.43	<.01
Violent or non-violent death	1.86(.59)	6.42	2.02-20.40	<.01
Relationship difficulties – yes/no	1.47(.43)	4.34	1.88-10.04	<.01
Grave visitation – up to weekly/more than weekly	1.56(.47)	.21	.08-.53	<.01
Sudden or anticipated death	1.78(.60)	.17	.05-.55	<.01
Concerns about family members coping – yes/no	1.30(.46)	3.68	1.49-9.07	<.01
Child lived mainly at home or not at home	1.22(.45)	3.40	1.42-8.17	<.01
Problems at work – yes/no	1.32(.49)	3.75	1.42-9.88	<.01

6.3.4.1.2 Continuous Variables

Univariate linear regressions were run to establish which continuous variables were associated with higher grief scores. Table 6.10 shows the factors significantly associated with higher grief scores.

Table 6.10 – Continuous variables univariately associated with higher grief at Time 1

<i>Variable</i>	<i>t</i>	<i>β</i>	<i>p-value</i>
Optimism score	-5.57	-.49	<.001
Pessimism score	6.92	.57	<.001
Rumination	11.73	.76	<.001
Depression	10.32	.72	<.001
Child age	4.69	.42	<.001
Number of restoration stressors	7.06	.58	<.001
Self-blame	10.48	.72	<.001
Venting	5.02	.45	<.001
Substance/alcohol use	2.71	.26	<.01
Avoidance	8.89	.66	<.001
Cognitive restructuring	-2.06	-.20	<.05

6.3.4.2 Relative Importance of Factors Associated with Increased Grief at Time 1

Factors that were important univariately were then analysed to ascertain which made the most significant contribution to explaining the variation in grief scores. The factors included in this analysis are shown in Figure 6.2.

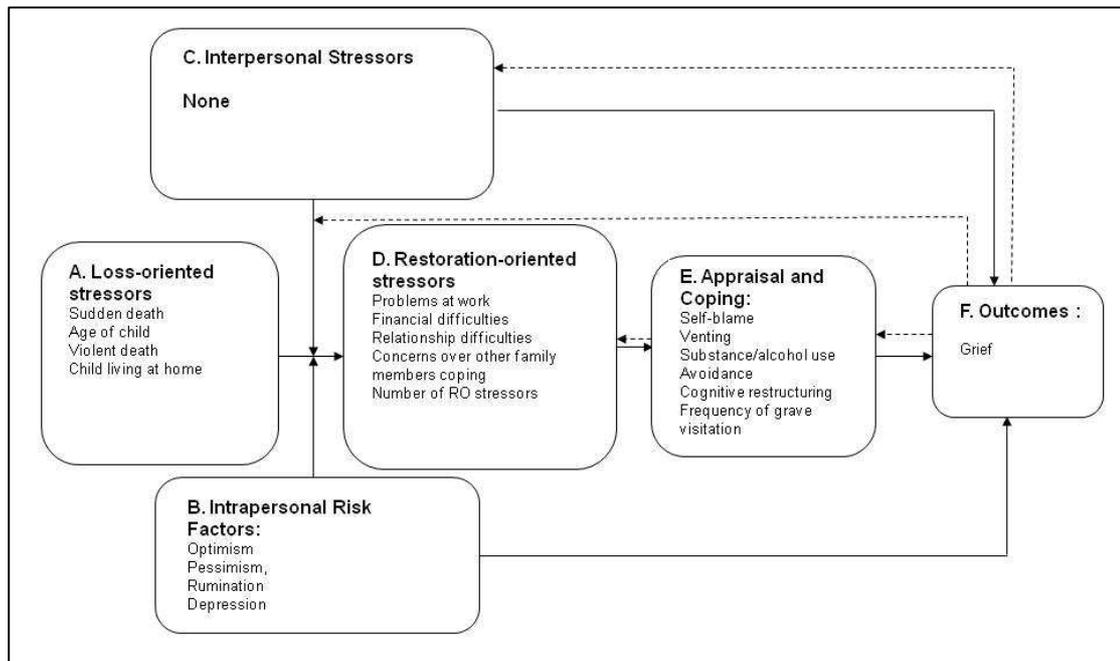


Figure 6.2 – Factors Univariately Associated with Grief at Time 1

A forward-entry multiple regression analysis was run on the significant variables, entering the depression score into step one. The analysis produced five models. The final model is shown in table 6.11.

Table 6.11 –Multivariate regression analysis testing the relative contribution of factors to grief score at Time 1

	<i>Variable</i>	<i>R²</i>	<i>ΔR² for step</i>	<i>Final β</i>	<i>t</i>
Step1	Depression	.50	.50***	.278	2.84**
Step 2	Self-blame	.65	.15***	.379	4.01***
Step 3	Child lived at home	.70	.05**	.180	2.40*
Step 4	Frequency of grave visits	.72	.02*	-.182	-2.45*
Step 5	Number of RO stressors	.74	.02*	.191	2.18*

Note *p<.05, **p<.01, ***p<.001.

The model accounted for 74% of the overall variation in grief scores, $F(5,57) = 30.34$, $p<.001$. Depression accounted for 50% of the variance in grief scores, self-blame accounted for a further 15%, the child normally living at home explained another 5%, the frequency of grave visits added another 2% to the explained variation, as did the number of restoration stressors.

6.3.4.2 Factors Associated with Increased Depression at Time 1

6.3.4.2.1 Continuous Variables

Again, linear regressions were run to identify those continuous variables which were univariately associated with higher depression scores. Table 6.12 shows the factors significantly associated with higher depression scores.

Table 6.12 – Continuous variables univariately associated with higher depression at Time 1

<i>Variable</i>	<i>t value</i>	<i>β</i>	<i>p-value</i>
Rumination	11.73	.451	<.001
Venting	5.02	-.243	<.01
Alcohol/substance use	2.71	.160	<.05
Problem focussed coping	1.79	.234	<.01

6.3.4.2.1 Categorical Variables

Logistic regressions were carried out on the categorical variables, to determine which were associated with the classification of depression. The factors which were significantly associated with depression are shown in table 6.13.

Table 6.13 – Categorical variables univariately associated with likelihood of depression diagnosis at Time 1

<i>Variable</i>	<i>B(SE)</i>	<i>Odds ratio</i>	<i>95% CI</i>	<i>p value</i>
Financial difficulties – yes/no	2.21(.55)	.11	.04-.32	<.001
Education – school/college or university	-1.63(.59)	.20	.06-.62	<.01
Grave visitation – up to weekly/more than weekly	-1.49(.52)	.22	.08-.62	<.01
Problems at work – yes/no	1.44(.54)	4.21	1.45-12.17	<.01

6.3.4.3 Relative Importance of Factors Associated with Increased Depression Scores at Time 1

The significant factors from the univariate analysis were then included in multivariate regressions test to establish which made the greatest contribution to explaining the variation in depression scores. The factors included in this analysis are shown in Figure 6.3.

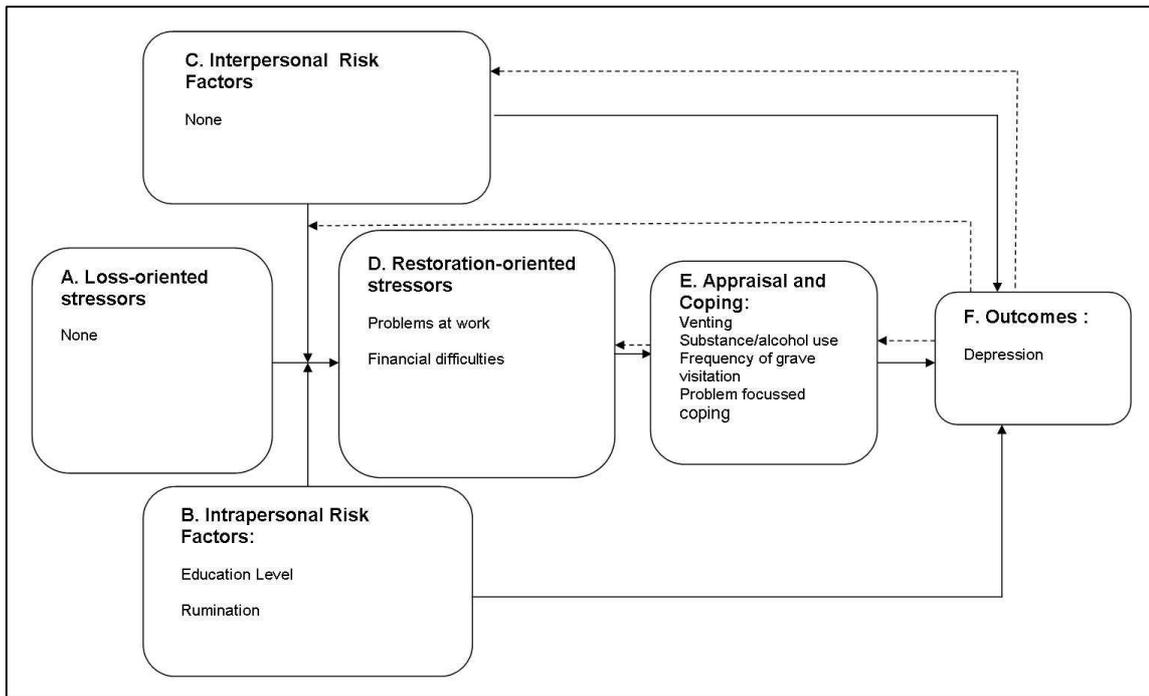


Figure 6.3 – Factors Univariately Associated with Depression at Time 1

Again, the large number of potential predictors indicated a forward entry regression method was appropriate (Field, 2005). The analysis produced three models, the final model being shown in Table 6.14.

Table 6.14 – Multivariate regression analyses testing the relative contribution of factors to depression score at Time 1

	<i>Variable</i>	<i>R²</i>	<i>ΔR² for step</i>	<i>Final β</i>	<i>t</i>
Step1	Rumination	.67	.67***	.733	10.70***
Step 2	Problems at work	.72	.05**	.230	3.43**
Step 3	Education level	.74	.02*	-.147	-2.22*

Note *p<.05, **p<.01, ***p<.001.

The final model consisted of rumination, problems at work and lower education level and explained 74% of the variation in depression scores, $F(3,66) = 58.95$, $p < .001$, $\beta = -.147$, $p = .030$.

6.3.5 Exploratory Analysis - Predicting Scores at Time 2 from Significant Time 1 Factors

6.3.5.1 Grief

The factors found to be significantly associated with higher grief scores at Time 1 were: depression score, self-blame, child living at home at the time of their death, frequency of grave visits and number of restoration oriented stressors. These were entered into a regression analysis, with Time 2 depression in step one, to control for its effects, and the remaining variables in step two, with a forward method of analysis. Grief score at Time 2 was entered as the dependent variable. The final model showed that only two variables would predict Time 2 grief; Time 2 depression and self-blame, as shown in table 6.15 below.

Table 6.15 – Multivariate regression analyses testing factors which predict Time 2 grief score

	<i>Variable</i>	<i>R²</i>	<i>ΔR² for step</i>	<i>Final β</i>	<i>t</i>
Step1	Time 2 Depression	.23	.23***	.244	1.74
Step 2	Self-blame	.34	.11**	.381	2.72**

Note * $p < .05$, ** $p < .01$, *** $p < .001$.

The final model of Time 2 depression and self-blame significantly predicted Time 2 grief, $F(2,59) = 13.54$, $p < .001$.

6.3.5.2 Depression

A similar analysis was run on the factors found to be significantly associated with higher Time 2 depression scores which were: rumination, problems at work and education level, with depression score at Time 2 as the dependent variable, using a forward entry method. The final model showed two factors predicting Time 2 depression; rumination and education level, as shown in table 6.16 below.

Table 6.16 – Multivariate regression analyses testing factors which predict Time 2 Depression score

	<i>Variable</i>	R^2	ΔR^2 for step	Final β	t
Step 1	Rumination	.36	.36***	.580	6.03***
Step 2	Education level	.41	.05*	-.224	-2.33*

Note * $p < .05$, ** $p < .01$, *** $p < .001$.

The final model was significant at $F(2,66) = 22.57$, $p < .001$.

6.4 Discussion

6.4.1 Prolonged Grief and Depression

The current study indicated that depression and prolonged grief are indeed separate constructs, since it was possible to meet diagnostic criteria for depression without grief and grief without depression, at Time 1. This result supported the findings reported in chapter five from early bereavement, and suggests that this is a finding that remains stable over time. Longitudinal studies following a cohort of bereaved parents over time would be required to further support this hypothesis, however it seems clear that the two conditions are indeed independent of each other. This finding supports the call for prolonged grief to be recognised as a distinct diagnostic condition in DSM-V (Prigerson et al., 2009).

6.4.2 Rumination and Depression

Both depressive and reflective rumination were found to be associated with grief and depression symptoms at Times 1 and 2, respectively. This finding suggests that reflective rumination may be just as maladaptive as depressive rumination. Reflective rumination was thought to be adaptive in bereavement, since it allowed the bereaved person to consider some of the issues causing them distress and either reappraise them in a less negative light or establish strategies for reduction in their symptoms by problem solving (Stroebe, Boelen et al., 2007). This did not appear to be the case in the current study, as reflective rumination was associated with both increased grief and depression scores, separately. Treynor et al. (2003) suggest that there may be a gender difference in the adaptiveness of reflective rumination in depression following bereavement. Again, this was not the case in the current study, with both mothers and fathers demonstrating an association between reflective rumination and both higher

grief and depression scores. The Stroebe et al. hypothesis about reflective rumination and grief is based mainly on the findings from Treynor et al., however the participants in that study were recruited from a random selection of households who were asked if they had experienced a significant stressor. Those participants did demonstrate that reflective rumination was not maladaptive in terms of depression symptoms, however this may not be the case when the stressor in question is bereavement generally, or perhaps parental bereavement in particular. The evidence from the current study does not support Stroebe et al.'s hypothesis that reflective rumination is adaptive in a group of bereaved people, either in terms of grief or depression symptoms.

6.4.3 Factors Associated with Prolonged Grief

The factors most strongly associated with Time 1 grief were depression, self-blame, the child normally living at home, the frequency of grave visits and the number of restoration stressors.

6.4.3.1 Depression

Depression is a widely-reported risk factor for grief (see Stroebe et al. 1996 for examples) however the present study is the first of its kind to demonstrate the importance of depression in the grief symptoms of bereaved parents. Depression was a key risk factors for grief accounting for 50% of the variation in grief scores at Time 1. This is important information for those involved in the treatment and care of bereaved parents, and treatment for depression symptoms should continue to form a key part of bereavement therapies. However, the finding that many people experiencing prolonged grief symptoms may not necessarily be depressed must not be overlooked. It is not enough to treat depression on its own – cognisance must also be given to alleviating the symptoms of grief.

6.4.3.2 Self-blame

The importance of self-blame in the prolonged grief symptoms of bereaved parents specifically has not previously been measured. Boelen, van den Bout and van den Hout (2006) reported self-blame as a key factor in depression and grief for a group of bereaved people, including bereaved parents, however the participant group also included others bereaved in different circumstance. Self-blame has been found to be associated with post-traumatic stress symptoms and depression in parents who had experienced late abortion, stillbirth or infant death (Jind, 2003), however grief was not measured. Hazzard et al.'s (1992) study demonstrated high levels of self-blame in bereaved parents although this symptom was not found to be statistically associated with higher grief scores. In the present study, self-blame accounted for 11% of grief symptoms at Time 1. The importance of self-blame was further demonstrated by these factors being the only variables which predicted levels of grief at the second point of measurement. Attending to cognitions about self-blame should therefore form an integral part of any therapeutic intervention for bereaved parents.

6.4.3.3 Child Living at Home

A further important factor in parental grief was the child normally living at home at the time of their death. This variable was originally designed to measure the significance of adult child leaving home and whether this had an impact on the parent's grief, however the situation also occurs in bereavements at other ages. Young babies who received continual care from birth may never have made the transition to leaving hospital, and many seriously ill children may have been living in hospice or hospital accommodation before the death. Additionally, babies who were stillborn would not normally have left the hospital environment. The sample therefore included children who did not normally

live at home across all age range. If the child did normally live at home prior to their death, the grief symptoms for the parent were higher. On first examination, it appears that this may be an important finding for those offering clinical care for seriously ill children or neonates since retaining the child in a hospital environment may appear to be linked to better bereavement outcomes. This assumption must be tempered, however, by the parent's desire to take the child home to die, which appears to have, mainly anecdotal, evidence of alleviating bereavement symptoms (Whittle & Cutts, 2002). The parent's and, where possible, the child's wishes about their place of death must be paramount in deciding on actions where the child's death is anticipated.

6.4.4.4 Frequency of Grave Visitation

Parents who visited their child's grave or memorial site weekly or more frequently had higher symptoms of grief at Time 1 than those who visited less frequently. A causal link was not established in the present study, therefore it is unclear whether people visit the grave frequently because they are grieving more strongly, or whether more frequent attendance to the grave exacerbates grief symptoms. No studies were found which investigated the impact of frequent grave attendance, nor were any found which unpicked the relationship between frequency of grave visitation and grief symptoms. From the phenomenological study reported in chapter four, mothers indicated that they used the graveside as a place to continue communication with their child and also as a means of maintaining their parental role of nurturing and caring for that child. Highly frequent grave visitation behaviour may therefore potentially indicate maladaptive attachment issues, or perhaps failure to accept the death.

6.4.4.5 Restoration-Oriented Stressors

Having a high number of reported stressors associated with the death of their child was found to be linked with poorer grief outcomes at Time 1. This is evidence which supports the dual processing model of bereavement, which states that outcomes for the bereaved are affected by loss-oriented stressors (features of the bereavement itself) but also restoration-oriented stressors which manifest themselves following the death. For bereaved parents, these appear to be highly significant. In particular, problems at work elicited a mean risk factor of 3.75 for grief and were also associated with higher levels of financial distress. In the UK, there are no employment rights for bereaved people and “compassionate leave” is at the discretion of the individual employer, leading to potentially highly variable support for bereaved people following their loss. Other restoration-oriented stressors which were important were financial difficulties, relationship difficulties, problems caring for other children and concerns about other family members coping. Perhaps support for bereaved parents should be extended from therapeutic intervention to the establishment of an advocacy role, similar to that carried out by palliative care social workers. An advocate working on behalf of bereaved parents could signpost potential sources of help for financial, relationship and childcare services, and may provide a valuable lifeline to parents in extreme distress. In addition, there are concerns about substance and alcohol use by parents as a coping strategy following their child’s death. In the parental mortality analysis carried out to avoid contacting bereaved parents who died following the death of their child, two-thirds of the parents who had died in the three years since their child’s death had causes of death linked to substance and alcohol use. This small sample may not be representative of the mortality of bereaved parents, and the link between child and parent mortality may have more direct causes, however the potential risk of death by substance or alcohol in

bereaved parents cannot be ignored. The issue of parental alcohol or substance use should therefore be a key consideration for anyone involved in the care and support of bereaved parents.

6.4.5 Factors Associated with Depression

The factors most closely associated with Time 1 depression were brooding rumination, problems at work and education level.

6.4.5.1 Rumination

Rumination appears to be a key factor in maladaptive coping by bereaved parents, since it is important for both grief and depression. The link between brooding rumination and depression has been strongly supported (see for example Nolen-Hoeksema et al. (1994) and its relevance in the specific experience of parental bereavement does not detract from this finding.

6.4.5.2 Problems at Work

As a specific restoration-oriented stressor, experiencing problems at work was strongly linked with higher levels of depression following the loss of a child. As stated previously, bereaved people have no specific employment rights and must rely on the generosity of their employer in being allowed leave from work to adjust to their loss. Further analysis of bereaved parents with specific reference to their experience in employment is therefore crucial to understanding and subsequently supporting people experiencing depression following bereavement. The exact nature of the problems being experienced and potential solutions for these merits detailed examination.

6.4.5.3 Education Level

The present study demonstrated a link between lower education levels and depression following bereavement. Brief literature searches found no studies reporting evidence of depression being linked to education levels, however intelligence is believed to be a protective factor for depression (Gale, Hatch, Batty & Deary, 2009). Education level was intended to provide a very crude approximation of intelligence in the current study, although inevitably there will be cases where the two are not linked. In considering the potential benefits of rumination as a type of “grief work” Stroebe et al. (2007) suggest that it may be helpful for an individual to attend to thoughts of their bereavement and loss as a means of carrying out their “grief work”. Problem-solving and cognitive reappraisal are essential, they say, in coming to terms with loss and reducing intrusive feelings of grief. The possibility that lower levels of intelligence/lower education levels impede this processing requires further investigation. This is especially true since, along with rumination, education level was one of the key factors which could predict depression scores at the second study measurement point.

6.4.5.4 Substance/Alcohol Use

Although significant only in the univariate analysis, substance and alcohol use was linked with higher levels of depression in the present study, at Time 1. This finding reiterates the importance of this coping style in bereaved parents, and further reinforces the need for advice and guidance in this area to be offered to bereaved parents.

6.4.6 Unexpected Findings

Factors which were assumed to be important in bereavement outcomes from the literature review reported in chapter four, but which were not supported in the current study, were the cause of death (violent or non-violent), the age of the child at their time

of death and whether the death was sudden or anticipated. All of these factors were important univariately which supports the findings found in the previously reported research, however when taken into account multivariately, these were not the key factors associated with either grief or depression. Only by conducting analyses where factors such as these and those from the other domains in the Integrated Risk Factor Framework are compared with each other, can the relative importance of key factors be determined.

6.4.7 The Research Experience for Participants

The participants in the current research reported the experience of taking part as mainly positive. Although there were problems with the recruitment process, these are likely to have been avoided if the invitation letter sent to the parents had explained that their information came from access to death records, which are publicly available data. The mean satisfaction scores given by participants (5.6 from a maximum of seven) showed that the experience was seen positively and this was supported by comments made which expressed comfort from doing something potentially useful for other bereaved parents.

6.4.8 Limitations of the Research

The current research, as is the case in any where volunteers are required to take part, is potentially at risk of bias due to only a subsection of those eligible to participate agreeing to proceed. This risk is tempered, however, by the coverage of participant demographics, since those who took part in the current study appeared to be representative of those in the bereaved parent population in Scotland as a whole. There was over-representation of mothers in the current study, however this is a feature of much research with bereaved parents. Additionally, those economically deprived were

also under-represented and the experience of people having low socio-economic status should be reviewed further. In the present study, there was no consideration of ethnic identity or the impact of personal cultures on the bereavement experience. This type of analysis should be carried out in an environment more culturally-diverse than that found within Scotland. Finally, the conflicting responses in the questions about suicidal ideation were disappointing, especially since the topic was covered so openly in the qualitative study reported in chapter four. Clearer and perhaps more sensitive wording of the question in future studies may elicit different results.

The present study recruited a very small sample size which, although mainly matching the spread of demographics in the population as a whole, would benefit from replication in a larger sample, to ensure that any small or moderate effect sizes were not overlooked.

6.4.9 Conclusions

High levels of depression and prolonged grief were found in this sample of parents bereaved four years previously. Grief and depression were identified separately, confirming that they are independent constructs. This supports the notion that bereaved parents are a group who require and deserve specific support to reduce their symptoms of distress following the death of their child. Within the analyses, the importance of social variables has been highlighted and in particular, the impact of problems at work on bereavement outcomes. Bereaved parents should therefore be able to access sources of support which may assist them in securing the help with employment, finance, relationships and limiting alcohol and substance use that they may need. These factors must be communicated clearly to those in bereavement support organisation to ensure

that the support offered to bereaved parents fits the precise requirements of this vulnerable group enduring the distress of the loss of their child.

Chapter Seven - Mortality, Marriage and Employment Changes in Bereaved Parents in Scotland

7.0 Abstract

7.0.1 Background

Bereaved parents are at risk of a number of negative outcomes following their loss. Suicidal ideation and alcohol/substance use are reported to be high, but it is unclear whether mortality rates are increased. The rate of marriage breakdown may be higher following the death of a child, and employment problems are likely to be found.

7.0.2 Method

A longitudinal retrospective cross-sectional design was employed comparing differences in the status of bereaved and non-bereaved parents of children born between 1991 and 2001. The data source was Scottish Census data linked to Vital Events Records up to 2006. Participants were Census sample parents and their spouses who experienced stillbirth or infant death (n=738) and those whose child lived (n=49,828).

7.0.3 Results

Up to ten years post-event (birth or death), bereaved parents had twice the mortality rate of non-bereaved parents. Divorce rates were not statistically different between the groups, however bereaved parents were significantly more likely to marry than non-bereaved parents and were significantly more likely to change employment status during the follow up period.

7.0.4 Discussion

Early childhood death is associated with highly significant mortality effects and important social changes in parents in the first ten years post-death.

7.1 Introduction

The Dual Process Model (Stroebe & Schut, 1999) suggests that the bereaved must cope with a number of restoration-oriented stressors following their loss. These stressors could be social, financial or health based, and their presence or severity may impact on the health or wellbeing outcomes for the bereaved person (Stroebe et al., 2006). The qualitative study described in chapter four indicated that the bereaved mothers had experienced a number of stressors following the death of their child. Employment problems, challenges within the marital relationship and suicidal ideation were identified as impacting on the daily experience of the parents. The potential impact of these problems indicates the need for a broader, large-scale quantitative investigation to establish the generalisability of these problems to a wider population of bereaved parents.

7.1.1 Marital Status

Marriage breakdown following the death of a child is not supported unequivocally in empirical research (Schwab, 1998), despite its prominence in the literature from support organisations such as the Child Bereavement Charity, the Stillbirth and Neonatal Death Society and The Compassionate Friends. The effect of the death of a child on the parents' marital status was reviewed and the findings were reported as inconclusive (Schwab, 1998). Indeed, a later study noted that several methodological issues such as lack of comparison groups, participant recruitment bias and low numbers of participants hindered a clear evaluation of the results (Oliver, 1999). A systematic review of over 100 studies concluded that there was insufficient unequivocal evidence to support the notion that divorce is more prevalent within bereaved parent couples than non-bereaved (Murphy et al., 2003). The Oliver review suggested that the opposite may in fact be

true, since it cites studies suggesting improvements in relationships following the death of a child. Evidence of changes in marital status following the death of a child, compared to an appropriate control group, is therefore required.

7.1.2 Employment Status

Given the literature which provides supporting evidence of multiple emotional and health issues in bereaved parents, it seems inevitable that bereaved parents who are in employment will experience some disruption in their ability to perform satisfactorily at work. Employment issues may arise due to problems with concentration and attention (Arbuckle & Devries, 1995). Comparison of bereaved parents with matched non-bereaved controls found the bereaved groups had a significantly higher level of unemployment (Lehman & Wortman, 1987). Furthermore, the bereaved parents were significantly more likely to have changed jobs in the period since their child died than the non-bereaved parents within the same time scale reflecting potential instability in employment. The number of bereaved participants was small (n=41) with a recruitment success rate of 45%. No information was available relating to the status of non-respondents so it is unclear how representative the sample under analysis might have been. The database searches carried out as described earlier did not reveal any other published research reporting on the employment status of bereaved parents. The effects of parental bereavement on employment are therefore unclear.

7.1.3 Mortality Risk

The most recent study found to evaluate mortality rates in bereaved parents was carried out in Denmark using data from national registers (Li, Precht et al., 2003). Some 21,000 bereaved parents were compared to 300,000 non-bereaved parents and the results

showed a highly significant hazards ratio of 1.43 for bereaved parents, with 95% confidence intervals between 1.24 – 1.64. Odds ratios were highest in bereaved parents whose children were aged between 10-18 years at time of death, and in deaths which occurred between 9-18 years previously. However, parents bereaved by the death of their adult children were identified and examined and no increased risk of mortality was found compared to rates from the general population in Israel (Levav, Friedlander, Kark & Peritz, 1988). The study of mortality following bereavement in a specific area of Wales showed an apparent increase in parental mortality in the first two years post-bereavement, but this was not statistically significant compared to mortality rates in the local non-bereaved population in general (Rees & Lutkins, 1967). The number of bereaved parents in the study was small at n=12. Comparisons in mortality rates of bereaved parents compared to non-bereaved parents are therefore inconsistent.

It is essential that bereaved parents and those who support them are given realistic expectations of changes they may expect to face in their lives based on methodologically sound evidence. This will enable them to enlist adequate resources to address their psychosocial transition through bereavement. To facilitate this, the present study aimed to establish what some of these expectations for life following the death of a child might be. Mortality statistics across a large scale population were compared, for the first time in Scotland, to the statistics related to bereaved parents. Divorce and marriage rates were compared across groups. Lastly, changes in employment status were examined and again, for the first time, comparisons were made of changes following either the birth or the death of a child.

The hypotheses under test are therefore that:

- a) bereaved parents will be at higher risk of mortality than non-bereaved parents
- b) divorce rates would be higher amongst bereaved than non-bereaved parents
- c) parents who have experienced the death of their child are less likely to be employed than those whose child lived.

7.2 Method

Ethical approval for the study was granted by the ethics committee of the Department of Psychology, University of Stirling.

The Longitudinal Studies Centre in Edinburgh, Scotland was contacted to obtain access to data in the Scottish Longitudinal Study database (SLS). In addition to Census data, the SLS contains linked data from Vital Events recorded at the General Register Office for Scotland, relating to births, deaths, marriages, stillbirths and divorces. The SLS contains Census data related to 5.5% of the Scottish population selected by date of birth falling on one of twenty dates spread throughout the year. This selection process is intended to provide a random sample of Census respondent data. Those Census respondents nominated for inclusion in the SLS database by virtue of their date of birth are known as SLS members. Spouses of SLS members were identified by date of birth on the child's birth certificate. The SLS members indicated their spouse's date of birth on the 2001 Census and if these matched exactly those on the birth certificate, the details given in the Census were included in the analysis as non-SLS members.

The participants' responses to the Census determine the change in marital and employment status with their status at event date taken as the "before" situation and the 2001 Census responses indicating the "after" situation. Census respondents were asked for their marital status however no options were provided on the Census to indicate cohabitation or non-marital partnerships. The available responses were (a) single (never married), (b) married (first marriage), (c) re-married, (d) divorced (decree absolute) or (e) widowed. For the 2001 Census, there was an additional option (f) separated but still legally married. Responses a, d, e and f were aggregated as not married; b and c were aggregated as married, to facilitate subsequent parsimonious analysis. The change in marriage status outcome was therefore coded as one of the following four options: continually married, continually unmarried, married to not married or not married to married.

For employment status, the available responses indicated whether the person was working (full time, part time or self employed), in training or education, about to start work, unemployed, sick or disabled and unable to work, retired, looking after home or family and other. Responses indicating full time, part time or self employed were aggregated as working; all other responses were taken to indicate not working, again to simplify results. The change in employment status outcome was therefore coded as one of the following four options: continually working, continually not working, working to not working or not working to working.

Mortality was measured using death and widowhood status of bereaved parents and their spouses. Death and widowhood status were obtained by checking the participants' details against the Vital Events death and widowhood records. These were available up

to 2006. No death or widowhood information was available for non-SLS members. The number of participants for the mortality analysis was therefore 28,928.

For 645 cases (1.3% of the total sample), marital status was not recorded or was unreliable at the time of the event. These records were excluded from the analysis, therefore the maximum number of participants in the marital status comparisons was 49,921.

A priori t-tests and Chi-square tests revealed no significant differences in employment, marital, mortality or widowhood status between the stillbirth parents and the infant mortality parents. Their data were therefore aggregated throughout the analysis process as bereaved parents. The numbers of parents experiencing infant death and stillbirth were supplied already aggregated for death and widowhood data, due to the small numbers involved in order to protect confidentiality. No individual analysis by type of bereavement was therefore possible for these measures.

7.2.1 Analysis

Chi-square tests were carried out on the data. The 2x2 analysis of mortality compares bereaved parents with non-bereaved, their status being alive or dead. The marital status comparison was initially conducted comparing the two groups of parents with a simple changed status/did not change status. Secondary Chi-squares examined the direction of the change separately. The analyses were therefore comparing the groups of parents for got married/did not get married and got divorced/did not get divorced. The same process was followed for employment data with an initial analysis of change/not change followed by an analysis of became employed and became unemployed. This facilitated

further examination of the data to establish the direction of any significant differences found for each measure.

7.3 Results

The characteristics of each participant group are shown in Table 7.1.

Table 7.1 – Group characteristics of individuals included in the analysis

	<i>Non-bereaved parents</i>	<i>Bereaved parents</i>
n (SLS members and spouses)	49,828	738
n (SLS members only)	28,928	435
Mother:father	26,208:23,620	387:351
Age in years at event date (birth/death) mean (SD)	30.6 (5.7)	29.5 (6.3)
Years since event mean (SD)	4.7 (3.0)	5.7 (2.9)

Ninety seven percent of the population reported an ethnicity status of “White”. One percent reported ethnicity as “Asian”. It was not possible to split these data by bereavement status since this would have been potentially disclosive.

Independent Chi-square tests showed the difference in sex of parent to be non-significant, The difference in age at event date as shown in table 7.1 was significant, $t(747) = 4.6, p < .001$ and the difference in number of years since event was also significant at $t(50,564) = 8.7, p < .001$. These differences are present due to the method of establishing event dates for the two groups of participants. If a parent experiences a stillbirth or infant death, this is taken as the event date, regardless of whether a subsequent birth to the parent took place. For live births, the date of the last birth was used as the event date.

7.3.1 Mortality Rates

Table 7.2 shows the mortality analysis for both groups. From event date to 2006, 482 (0.96%) of non-bereaved parents died or were widowed, compared to 15 (2.0%) of bereaved parents. A Chi-square test confirmed that the difference was significant, $\chi^2(1) = 8.62$, $p=.003$ with an odds ratio of 2.11, 95% confidence intervals between 1.27 – 3.52.

Table 7.2 – Comparison of Mortality Rates by Group

	<i>Mortality status</i>		
	Alive	Dead	Total
Bereaved	723 (97.97%)	15 (2.03%)	738
Non-Bereaved	49650 (9.04%)	482 (0.96%)	50132
Total	50373 (99.02%)	497 (0.98%)	50870

7.3.2 Change in Marital Status

The change in marital status for bereaved and non-bereaved parents is shown in Table 7.3.

Table 7.3 – Comparison of Changes in Marital Status by Group

	<i>Marital status</i>		
	Changed	Not Changed	Total
Bereaved	110 (15%)	611 (85%)	721
Non-Bereaved	5174 (10%)	44026 (90%)	49200
Total	5284 (11%)	44637 (89%)	49921

Bereaved parents were significantly more likely than non-bereaved parents to change their marital status, $\chi^2(1) = 16.87$, $p<.001$. The number of bereaved parents who got married was 52 (7.2%) and non-bereaved was 2027 (4.1%). This difference was highly significant, $\chi^2(1) = 17.02$, $p<.001$ with an odds ratio of 1.81; 95% confidence interval 1.36-2.41. The number of bereaved parents who got divorced was 58 (8%) and the

number of non-bereaved parents who got divorced was 3147 (6.4%). This difference was not statistically significant. A further Chi-square test for the bereaved group, looking at sex of parent and marital status was not significant.

7.3.3 Change in Employment

Table 7.4 shows the change in employment status for bereaved compared to non-bereaved parents.

Table 7.4 – Comparison of Changes in Employment by Group

	<i>Employment status</i>		<i>Total</i>
	<i>Changed</i>	<i>Not Changed</i>	
Bereaved	267 (37%)	471 (63%)	738
Non-Bereaved	13424 (27%)	36404 (73%)	49828
Total	13691 (27%)	36875 (73%)	50566

Bereaved parents were significantly more likely than non-bereaved parents to change their employment status, $\chi^2(1) = 31.43$, $p < .001$. The number of bereaved parents who changed employment status from not working to working was 238 (32%) and non-bereaved was 12,089 (24%). This difference was highly significant, $\chi^2(1) = 25.17$, $p < .001$ with an odds ratio of 1.49; 95% confidence interval 1.27-1.74. The number of bereaved parents who became unemployed was 29 (3.9%) and non-bereaved was 1335 (2.7%). This difference was also significant, $\chi^2(1) = 4.33$, $p = .037$ with an odds ratio of 1.49; 95% confidence interval 1.02-2.16. Comparing employment status in the bereaved group for mothers and fathers using a Chi-square test showed no significant difference for these groups.

7.4 Discussion

Following stillbirth or infant death, bereaved parents are significantly no more likely to divorce than non-bereaved parents, but are significantly more likely to become unemployed or start working. Bereaved parents are twice as likely to die as a non-bereaved control group. Clearly these additional stressors are likely to place extra strain on families who are already experiencing great psychosocial adjustments.

The higher levels of mortality in bereaved parents are of major concern. The number of deaths reported in this study is too small to permit more detailed analysis, however larger scale studies should be carried out to identify causes of death and whether there are any potential risk factors which may affect this outcome. Bereaved parents may be more likely to have completed suicide than matched non-bereaved comparisons (Li et al., 2003). Insufficient information was provided to rule out the contribution of death by suicide to the difference in mortality statistics. Alternatively, the stress of the bereavement may involve significant physiological effects, for example, suppressing the immune system (Kim & Jacobs, 1991) thereby increasing one's propensity to disease (Vedhara, Cox, Wilcock, Perks, Hunt, et al., 1999). Maladaptive coping strategies such as alcohol misuse have been reported as employed by parents experiencing stillbirth and infant death (Vance, Najman & Boyle, 1994) and this may in turn lead to higher incidence of alcohol-related illness or accidental death (Li, Smith & Baker, 1994). It is imperative that these options be further investigated in order to establish the factors leading to increased mortality in bereaved parents.

The marital status data quantify, for the first time, the changes experienced by bereaved parents compared to their non-bereaved counterparts. Although divorce rates appeared

higher in the bereaved group, this difference was non-significant suggesting that the divorce rate in parents bereaved at birth or in the child's first year of life is no higher than that of parents of living children. Although bereaved parents report struggles and challenges in their relationships (Schwab, 1998), (Oliver, 1999; Murphy et al., 2003), it appears that this may not inevitably lead to marriage breakdown in the longer term. The present study reports the actual marriage status of parents of a prospective representative sample of participants at a mean of four to five years post-event. In this particular group of bereaved parents, it appears that the divorce rate is no higher than the comparable population of non-bereaved parents, as was found in previous comparative studies (Schwab, 1998).

The statistics on marriage rates in bereaved parents have previously not been reported, but those in the present study support the notion that the death can have cohesive effects on a marriage as well as detrimental effects (Oliver, 1999). This is an important and, to date, overlooked change that may be important for bereaved parents to know about. Much of the literature around the area of parental bereavement reports only negative consequences. Only recently have issues such as posttraumatic growth begun to be assessed (Engelkemeyer & Marwit, 2008). The existence and measurement of potentially positive outcomes following parental bereavement, such as benefit finding (Holland, Currier & Neimeyer, 2006) should be considered by those involved in therapeutic interventions for bereaved parents.

The higher number of bereaved parents returning to work compared to non-bereaved parents could be explained in a number of ways. One simple explanation is that the parent returns to work since there is no childcare requirement for them to stay at home.

Alternatively, social support in the workplace may be beneficial to the bereaved parent (Kavanaugh, Trier & Korzec, 2004). Further analysis of the reasons for and consequences of returning to work after parental bereavement would provide greater insight into this finding. However, this information may again prove to be valuable to bereaved parents and those who care for them.

The higher rate of change to unemployment in bereaved parents is of concern. There appears to be no published literature which explains job loss after bereavement, however, in the phenomenological study reported in chapter four, twelve of the interviewees were employed at the time of the bereavement and eight of these reported losing their jobs soon after. Lack of understanding by employers and inability to perform at pre-bereavement levels were frequently reported. If this type of involuntary unemployment is common in bereaved parents, there may be cause for evaluation of employment rights following bereavement. There is a growing body of evidence which suggests that the concept of complicated bereavement should be acknowledged as a diagnosable and distinct medical condition (Bonanno, 2006). If the experience of bereaved parents suggests that job loss occurs as a result of their bereavement, perhaps the diagnosis of prolonged grief should be supported as a protective mechanism for bereaved people in the workplace. Further clarification of the reasons and factors associated with job loss following parental bereavement is required before such considerations can be made.

7.4.1 Limitations of the Study

The number of bereaved parents included in the study was small, but was consistent with the expected numbers within Scotland. More detailed examination of factors such

as causes of death, gender of bereaved parents and age of bereaved parents was not possible due to the restrictions placed upon the provision of potentially disclosive information supplied by the SLS. Data cannot be supplied where the numbers are small enough to potentially allow identification of individuals

The changes in relationship status were restricted to those officially married. No changes in permanent non-married relationships were measured, however this is a restriction necessitated by the questions provided in the Census data collection forms.

Finally, the sampling points in the study were restricted to the year of the event and the following Census year, 2001. No detailed analysis of changes by year was possible, due to the fixed nature of the Census sampling terms.

7.4.2 Conclusions

Retrospective sampling of participants by random cross section has shown that parents who experience stillbirth or infant death experience twice the rates of mortality and three times the unemployment rate of non-bereaved parents, but also experience higher marriage and employment rates. The negative consequences of the death of a child for parents are huge, however it is possible, in some cases, for positive changes to be experienced.

Further research examining the causes of death is necessary to allow practitioners to identify those at greatest risk of death or serious illness. Professionals involved in relationship counselling or providing information to bereaved parents should report the

positive as well as the negative outcomes. Employers must consider whether bereaved parents need additional support beyond basic compassionate leave arrangements.

Those who offer caring, supportive or therapeutic assistance to bereaved parents should take into account the needs for further adaptation beyond specifically child- or grief-related issues and should be aware of additional social needs in the first ten years following the death of the child. Most importantly, the information about potential consequences which might be anticipated by bereaved parents must be provided to assist this vulnerable group in their period of reconciliation and post-loss adjustment.

Chapter Eight – Long-Term Mortality, Employment and Relationship Changes in Bereaved Mothers in England and Wales

8.0 Abstract

8.0.1 Background

Up to ten years post-loss, mortality rates for bereaved parents were found to be double that of non-bereaved comparisons in Scotland, as were changes in employment status. No difference in divorce rates was found. In this study, the longer-term association of parental bereavement with mortality, employment and marriage changes up to 35 years post-loss was investigated.

8.0.2 Method

A longitudinal retrospective cross-sectional study was carried out using Census and Vital Event data from England and Wales from 1971 to 2006. The study reported differences between parents bereaved by stillbirth or in the child's first year of life (n=2761) compared to parents whose child was born and lived beyond the first year of life (n=120,874).

8.0.3 Results

Bereaved parents have four times the mortality risk of non-bereaved counterparts in the first ten years post-loss, reducing, but remaining statistically significant, up to thirty five years post-loss. Employment changes are more likely in the bereaved group in the first ten years only. There is no difference in divorce rates between bereaved and non-bereaved parents.

8.0.4 Conclusions

The increased mortality rate in bereaved parents requires urgent investigation as it exceeds even the risk of smoking on incidence of lung cancer. The changes in employment status suggest the impact of the death of a child on working patterns resolves after around ten years. Parental bereavement, in itself, is not associated with marriage breakdown.

8.1 Introduction

The study reported in chapter seven indicated that, at up to ten years post-loss, bereaved parents who have experienced the death of a child in the first year of life or stillbirth are more likely to become married or change their employment status, than non-bereaved counterparts. In addition, they are more likely to die themselves, or experience the death of their spouse. The data from the Scottish Centre for Longitudinal Studies reported earlier is restricted to a relatively recent time period, from 1991, therefore longer term comparisons are not possible using this dataset.

Within the limited published literature, very few researchers have attempted to consider the long-term implications for parents following the death of their child.

Some, such as Engelkemeyer and Marwit (2008), Hazzard et al. (1992) and Robinson and Marwit (2006) have considered the consequences for parents over a wide range of times since death, including longer terms of up to 31 years, but far fewer have considered outcomes for bereaved parents in a specifically longer term period.

The published papers that have reported the long-term effects of the death of a child have different definitions of what they consider to be “long term” parental bereavement. Lehman and Wortman (1987), for example, consider 4-7 years to be long term, and compared bereaved parents to bereaved spouses in this time frame. Their findings were that the levels of depression and impaired social functioning were higher in both bereaved groups compared to non-bereaved controls, and that bereaved spouses were experiencing more negative outcomes than bereaved parents. Schapp, Wolf, Bruinse, Barkhof-van de Lande and Treffers (1997) considered parents who had stillbirth and neonatal death 3-9 years previously and found that four of their 19 couples interviewed were experiencing both negative psychosocial impact and emotional consequences at

this time. Dyregrov and Dyregrov (1999) followed up parents who had experienced a sudden infant death, 12-15 years previously. Measures of psychological distress taken at this time indicated that the impact of their loss had diminished significantly over the term, and very few of the 26 parents assessed maintained a level of symptoms which indicated “caseness” for depression or anxiety at the time of assessment. Unfortunately, none of these studies considered a control group to identify whether the findings were bereavement-related and could be differentiated from the changes in a similar non-bereaved group. Lack of methodological rigour, small sample size and the absence of a control group make these findings of limited value when attempting to definitively establish the outcomes for bereaved parents in the longer term.

Earlier studies in this thesis indicate that the death of a child has a very significant impact on a parent up to six years post-loss. The SLS study reported in the previous chapter showed that employment difficulties remained up to ten years following a stillbirth or the death of an infant, and that mortality rates were also significantly higher in bereaved than non-bereaved parents. Marriage rates were higher, but divorce rates were no different to those of non-bereaved parents. Divorce rates were expected to be higher in bereaved parents than non-bereaved and perhaps the time since death being restricted to a maximum of ten years was not long enough for relationship problems to have manifested themselves in terms of legal divorce statistics.

The current study aims to consider the impact of the death of a child on bereaved parents’ mortality rates and social functioning, up to 35 years post-loss. Using a similar method to that described in the previous study, secondary analysis of census data will examine the experience of parents whose child is stillborn or dies in the first year of

life, compared to parents who have a live baby in the same time period. From this dataset, within a time frame of up to 35 years post-loss, based on the findings from the SLS study reported in the previous chapter, it was hypothesised that:

- a) Bereaved parents would have higher mortality rates than non-bereaved parents
- b) Divorce rates were higher in bereaved parents than non-bereaved parents
- c) Bereaved parents would be less likely to return to employment following the death of their child, than non-bereaved parents.

8.2 Method

Ethical approval for the study was granted by the ethics committee of the Department of Psychology, University of Stirling.

The Centre for Longitudinal Studies Information and User Support (CeLSIUS) contains census data from 1971, 1981, 1991 and 2001 censuses, for people resident in England and Wales, whose date of birth falls on one of four specified dates throughout the year. The database effectively contains data relating to around 1% of the population of England and Wales (currently around 950,000) study members. Members who were born after 1971 on one of the four dates, or who became resident in England or Wales and had a birthday on one of the key dates, joined the CeLSIUS dataset at the first available census, and members are removed from the data set on death or emigration from England and Wales.

The data available from CeLSIUS are similar to those provided by the SLS, with a few important caveats. Firstly, the data collection procedures have varied since 1971, and each census does not gather responses from individuals using the same questions and available responses over time. This makes direct comparisons over time problematic,

however CeLSIUS have developed a number of standard protocols for addressing this issue. For the purposes of the current study, the collection of marital or relationship data was particularly problematic, since each census considered different options relating to relationship status. The method adopted by the CeLSIUS technical teams amalgamates relationship status into either :

- 1) In a relationship – this covers cohabiting and married statuses
- 2) Not in a relationship – relating to single, widowed, separated or divorced
- 3) Not known – this situation would arise when the census record was completed incorrectly by the respondent.

Employment status, for the purposes of this study, was handled in the same way as the SLS dataset, with the options being:

- 1) Working – full or part time or self employed
- 2) Not working – unemployed, sick, disabled and unable to work, retired, looking after the home, family or other, in training or education
- 3) Not known – as above

Mortality and widowhood were measured by cross-referencing the CeLSIUS database with that of the Vital Events Record in the Office of National Statistics.

Employment and relationship status data are available up to the last census data collection point, in 2001. Mortality data were reviewed and added at 2006, therefore an additional five years of Vital Events is available for analysis.

Unlike the SLS dataset, records from CeLSIUS are only available for members of the cohorts, and not their spouses or partners. In addition, linking information for stillbirths

and infant deaths are only possible by cross-referencing to the Register of Births, which is available only for the child's mother. A limitation of these data is that they, therefore, relate only to the experience of the mother.

At each of the census time points, participants may return results which are incorrectly completed or unreadable. The CeLSIUS database marks these as missing data, and these records are therefore excluded for analysis at that particular census point. It is possible, therefore, that members of the CeLSIUS dataset may have their data included at one census, be excluded as missing data from the next and then reintroduced at a third time point. Taking this restriction and the methods used for data alignment over time into account, tracking individual members through each of the time points was not feasible within the restrictions of the present study. Data is therefore provided for members at their time of inception into the appropriate cohort, and at the most up to date data capture point i.e. 2001 for employment or relationship status and 2006 for mortality. No attempt has been made to track individual members over time, identifying changes that may have been recorded in the interim period.

To facilitate comparison with the SLS study reported earlier, data from parents experiencing stillbirth or infant death were aggregated, into one "bereaved parent" group for each census cohort. Again, restrictions on potentially disclosive information were adhered to, and no data were supplied which could be traced back to potentially identify individual census respondents.

8.2.1 Analysis

Chi-square tests were used to establish whether differences between groups were statistically significant. The mortality analysis was carried out using a 2x2 analysis comparing bereaved and non-bereaved parents with a status of either “alive” or “dead”. Relationship status was initially analysed using the two groups of parents and a “changed/not changed” comparison. Those cohorts who returned a statistically significant result were then subject to secondary analysis to identify in which direction the difference lay. Employment status was handled in the same manner, initially considering a “changed/not changed” comparison followed by detailed analysis of any which returned a significant association.

8.3 Results

The characteristics of each participant group are shown in Table 8.1. The table shows the maximum number of census records available. The actual number included in each individual analysis may be less than this total, due to missing data in subsequent censuses.

Table 8.1 – Group characteristics of members of each cohort

	<i>Cohort</i>	<i>Non-bereaved mothers</i>	<i>Bereaved mothers</i>
n	1971-81	36,062	1,120
n	1981-91	36,434	745
n	1991-01	30,956	481
Mean age at start of census period in years (SD)	1971-81	22.0 (5.7)	21.9 (9.0)
Mean age at start of census period in years (SD)	1981-91	22.4 (5.7)	22.5 (8.4)
Mean age at start of census period in years (SD)	1991-01	24.1 (5.2)	23.8 (8.3)

Independent t-tests showed no significant difference between the age of bereaved and non-bereaved participants in each cohort.

8.3.1 Mortality Rates

The members of each cohort were followed up at 2006, to identify how many had died or been widowed, between 1971 and 2006. Table 8.2 shows the results of this mortality analysis for the bereaved and non-bereaved mothers.

Table 8.2 – Mortality of cohort members or their spouses, followed up to 2006

<i>Cohort</i>	<i>Group</i>	<i>n alive or not widowed</i>	<i>%</i>	<i>n dead or widowed</i>	<i>%</i>	<i>Total n</i>
1971-81	Bereaved	1094	86.0	178	14.0	1272
1971-81	Non-Bereaved	35935	88.7	4589	11.3	40524
1981-91	Bereaved	777	94.0	50	6.0	827
1981-91	Non-Bereaved	38758	96.0	1623	4.0	40381
1991-01	Bereaved	622	94.0	40	6.0	662
1991-01	Non-Bereaved	39460	98.7	509	1.3	39969

For each cohort, the percentage of bereaved mothers who had died or were widowed as at 2006 was higher than the non-bereaved. A comparison was made between the bereaved and non-bereaved group for each individual cohort. These results were statistically significant for all three cohorts. For the 1971-81 cohort, the difference was $\chi^2(1) = 8.70$, $p=.003$, $n=41,796$; risk ratio = 1.24, confidence interval 1.08-1.42. For the 1981-91 cohort, the difference was $\chi^2(1) = 8.55$, $p=.003$, $n=41,208$; risk ratio = 1.50, confidence interval 1.14-1.98. and for the 1991-01 cohort, the difference was $\chi^2(1) = 11.1$, $p<.001$, $n=40,631$; risk ratio = 4.74, confidence interval 3.47-6.49.

The mean time between the event date and death was also calculated for each group in each cohort by subtracting the event (birth or death) date from the date of death. The results are shown in Table 8.3.

Table 8.3 – Mean time between event and death for deceased in individual cohorts, by bereavement status

<i>Cohort</i>	<i>Status</i>	<i>Mean time between event and death in years (SD)</i>
1971-81	Bereaved	20.9 (8.7)
1971-81	Non-Bereaved	20.2 (9.7)
1981-91	Bereaved	13.6 (10.6)
1981-91	Non-Bereaved	12.7 (8.9)
1991-01	Bereaved	4.7 (5.9)
1991-01	Non-Bereaved	5.6 (1.4)

For the 1971-81 and 1981-91 cohorts, the mean time since death is longer in the bereaved group compared to the non-bereaved group, suggesting that the bereaved parents died earlier than the non-bereaved, on average. This situation was reversed in the 1991-01 cohorts. The difference was significant for all cohorts. For the 1971-81 cohort, this was $t(41,794) = 2.54, p=.011, n=41,799$. For the 1981-91 cohort, this was $t(41,206) = 2.87, p=.011, n=41,208$. Finally, for the 1991-01 cohort, the difference was $t(40,629) = 14.54, p<.001, n=40,631$.

8.3.2 Employment Status

The employment status of cohort members was followed up to 2001. The change in employment status of bereaved compared to non-bereaved parents between 1971 and 2001 is shown in Table 8.4.

Table 8.4 – Comparison of Changes in Employment by Group (71-01)

	<i>Employment Status</i>		Total
	Changed	Not Changed	
Bereaved	424 (44%)	535 (56%)	959
Non-Bereaved	14,924 (46%)	17,211 (54%)	32,135
Total	15,348	17,746	33,094

The difference in change of employment status between groups was not significant.

The change in employment status of bereaved compared to non-bereaved parents

between 1981 and 2001 is shown in Table 8.5.

Table 8.5 – Comparison of Changes in Employment by Group (81-01)

	<i>Employment Status</i>		Total
	Changed	Not Changed	
Bereaved	277 (45%)	340 (55%)	617
Non-Bereaved	13,601 (45%)	16,593 (55%)	30,194
Total	13,878	16,933	30,811

Bereaved parents in the 1981-91 cohort had the same rate of employment change as non-bereaved parents between 1981 and 2001 than non-bereaved parents.

The change in employment status of bereaved compared to non-bereaved parents

between 1991 and 2001 is shown in Table 8.6.

Table 8.6 – Comparison of Changes in Employment by Group (91-01)

	<i>Employment Status</i>		Total
	Changed	Not Changed	
Bereaved	150 (31%)	331 (69%)	481
Non-Bereaved	11,333 (37%)	19,623 (63%)	30,956
Total	13,878	16,933	31,437

Bereaved parents in the 1991-01 cohort were less likely to change employment status between 1991 and 2001 than non-bereaved parents, $\chi^2 (1) = 6.01, p=.01, n=31,437$; risk ratio = 1.09, confidence interval 1.02-1.15. Further analysis of the change in employment status in the 1991-01 cohort was carried out, to ascertain in which direction the difference in change rates occurred. The change in status from not working to working is shown in Table 8.7.

Table 8.7 – Comparison of Change in Employment Status from Not Working to Working by Group (91-01)

	<i>Employment Status</i>		Total
	Became employed	Became unemployed or unchanged	
Bereaved	70 (15%)	411 (85%)	481
Non-Bereaved	5,795 (19%)	25,161 (81%)	30,956
Total	5,865	25,572	31,437

More non-bereaved parents became employed than bereaved parents. This difference was significant at $\chi^2 (1) = 5.42, p=.02, n=31,437$; risk ratio = 1.05, confidence interval 1.01-1.09. There was no difference between groups becoming unemployed.

8.3.3 Relationship Status

The relationship status of cohort members was also followed up to 2001. The change in relationship status of bereaved compared to non-bereaved parents between 1971 and 2001 is shown in Table 8.8.

Table 8.8 – Comparison of Changes in Relationship Status by Group (71-01)

	<i>Relationship Status</i>		
	Changed	Not Changed	Total
Bereaved	472 (49%)	487 (51%)	959
Non-Bereaved	16,417 (51%)	15,750 (49%)	32,167
Total	16,904	16,222	33,126

Bereaved parents in the 1971-81 cohort were no more likely to change relationship status between 1971 and 2001 than non-bereaved parents.

The change in relationship status of bereaved compared to non-bereaved parents between 1981 and 2001 is shown in Table 8.9.

Table 8.9 – Comparison of Changes in Relationship Status by Group (81-01)

	<i>Relationship Status</i>		
	Changed	Not Changed	Total
Bereaved	357 (54%)	305 (46%)	662
Non-Bereaved	17,255 (52%)	16,220 (48%)	33,445
Total	17,582	16,525	34,107

Bereaved parents in the 1981-91 cohort were no more likely to change relationship status between 1981 and 2001 than non-bereaved parents.

The change in relationship status of bereaved compared to non-bereaved parents between 1991 and 2001 is shown in Table 8.10.

Table 8.10 – Comparison of Changes in Relationship Status by Group (91-01)

	<i>Relationship Status</i>		
	Changed	Not Changed	Total
Bereaved	351 (63%)	206 (37%)	557
Non-Bereaved	20,978 (60%)	14,021 (40%)	35,007
Total	14,235	21,329	35,564

Bereaved parents in the 1991-01 cohort were no more likely to change relationship status between 1991 and 2001 than non-bereaved parents.

8.4 Discussion

Bereaved parents are more than four times more likely to die or become widowed in the first ten years following the experience of stillbirth or the death of their child in the first ten years of life. Up to twenty years, this risk reduces to 1.5 times that of non-bereaved parents, and up to 35 years, bereaved parents still have a higher mortality rate than those non-bereaved (1.2 times). Non-bereaved parents were more likely to become employed in the first ten years following the birth of their child, than bereaved parents were following the death of their child. There was no statistically significant difference in relationship breakdown rates between bereaved parents and non-bereaved parents at any of the comparison time points.

8.4.1 Mortality

The mortality rates of the present study support the findings from the SLS database reported earlier. As before, detailed analysis of the cause of death was not possible within the restrictions set out by CeLSIUS, however it is imperative that future research considers which parents are at risk of increased mortality and whether any of these groups may be targeted with monitoring, support or interventions to alleviate this. It may be that stillbirths and infant deaths are more prevalent in people who, themselves, suffer serious poorer health (Fretts, 2010), thus leading this group to a lower life expectancy. However, the magnitude of the risk factor identified here indicates that analysis of parents bereaved by different circumstances is also urgently required to identify whether they are also at a similar risk of premature mortality to those who experience stillbirth or infant death.

8.4.2 Employment

Non-bereaved parents took up employment more often than bereaved parents, in the first ten years following their relevant vital event (birth or death). There is no published literature relating to employment following parental bereavement, making comparisons between this and other studies impossible. The results from the present study, however, appear to be counter-intuitive since, if anything, one would assume that a parent with a small child may be less likely to return to employment than one without a small child. This result may be explained by the bereaved parent having a subsequent live birth which may, in turn, have resulted in them taking longer to return to work than the initially non-bereaved. This scenario may explain why the difference is only seen in the first ten years following the birth or death of the child. Alternatively, the bereaved parent may be experiencing employment difficulties, similar to those reported by the participants in chapters four, five and six. Further analysis of employment following parental bereavement is required to explain this difference.

8.4.3 Relationships

The present study found no difference in relationship status between the bereaved and non-bereaved groups. The similarity in relationship breakdown rates provides support for the notion that claims of higher rates of marriage breakdown following parental bereavement are not valid (Schwab, 1998). The importance of the topic in bereaved parent support networks may therefore be due to marital conflict during bereavement, but this may not necessarily lead to higher levels of marriage breakdown. Bonanno (1991) suggests that grief is higher in bereaved parents reporting marital problems, however once grief symptoms have subsided, perhaps conflict does too. Klass (1986) carried out a qualitative analysis of bereaved parents in a self-help group and found that

their relationship problems were highly complex and were often affected by factors separate from the loss. Although there may be differences between parents as they grieve for their child, perhaps this, in itself, is not a key risk factor for relationship breakdown. Further analysis of parents who divorce could identify the relative importance of features of the relationship and other risk factors, including the experience of parental bereavement.

No difference in the rate of mothers entering a relationship was found in the present sample. This could be due to the different methods of measurement used by CeLSIUS compared to the SLS, or it may be a phenomenon linked to the sex of the parent. The SLS study represented both sexes, whereas the present study considers the situation for mothers only. Post-hoc analysis of the SLS data, however, found no sex difference in any of the mortality, marriage or employment results.

With the exception of the mortality issue, one positive finding from the present study was that the impact of the death of a child does appear to reduce over time. The layman's phrase "time is a great healer" does appear to hold, at least in terms of levels of employment and longevity of relationships. Beyond the time period of up to ten years, it appeared that the impact of the death of their child was no longer statistically significant in these areas. This may suggest that, although the trauma of losing a child stays with a parent throughout their whole life (Talbot, 2002), recovery and reintegration into a potentially fulfilling life is possible, but parents should perhaps expect this to take place over a longer time frame than that suggested for other types of bereavement (Prigerson & Maciejewski, 2005).

8.4.4 Limitations of the Study

The limitations of this study are similar to those of the Scottish study presented in chapter seven. The data supplied are restricted to avoid producing potentially disclosive results. In addition, the fixed sampling time points do not permit detailed year on year analysis of changes. This means that one can say, for example, that bereaved parents may have employment difficulties in the first ten years of bereavement, however these appear to be resolved by year twenty. No more detailed analysis of the second ten year period is possible, therefore the actual time to resolve employment issues may be somewhere between eleven and twenty years.

Finally, an important limitation of this and the previous study is the restriction of identification of bereaved parents whose child is less than one year old at their time of death. More detailed record linking work could potentially link census and vital events records for parents whose child died at a more advanced age. A comparison group, in this case, would have to be drawn from demographic matching. This would mean, for each bereaved parent, a comparison group of parents of a similar age, social background, education background, marital, employment and parental status would have be drawn from census data. If it were possible to conduct this further analysis, a rich source of case-controlled information, relating to a wide range of parental experiences, would provide a definitive mapping of the impact of parental bereavement over a lengthy time frame. This information would be invaluable to those offering therapeutic interventions to bereaved parents, or indeed to bereaved parents themselves, to allow adequate support to be provided over the long-term bereavement experience.

8.4.5 Conclusions

Increased mortality rates in bereaved parents, initially up to four times those of non-bereaved parents, merit further immediate investigation. This risk factor for premature death is greater than that of the risk of smoking on the incidence of lung cancer (Doll, Gray, Hafner & Peto, 1980). Investigations into the causes of death of these parents susceptible for decreased life expectancy following parental bereavement is required to establish whether specific high risk groups can be identified, and appropriate interventions delivered. Furthermore, evaluation of the needs of bereaved parents both in the workplace and in those seeking to return to work should be carried out to identify whether changes in employment practices are required to support this vulnerable group through their life-changing event. However, it has been noted that in the medium to long term (more than ten years post-bereavement) a return to levels of employment and relationship functioning may be achievable for those parents who experience stillbirth or infant death.

Chapter Nine – General Discussion

9.0 Abstract

9.0.1 Background

The current thesis offers a wealth of novel information about the experience of parental bereavement from multiple research methods.

9.0.2 Method

The findings from research carried out within the thesis are compiled and considered from a variety of perspectives. The key messages from the research carried out are then presented.

9.0.3 Results

Bereaved parents are coping with a variety of emotional and social problems. Levels of grief and depression were high up to four years post-loss. Grief and depression were shown to be independent constructs, and individuals with a prolonged grief reaction did not necessarily also exhibit clinical depression symptoms. Ruminative coping was associated with higher grief and depression in early and mid-bereavement. Cognitive restructuring was associated with lower grief symptoms in early bereavement. Depression and self-blame could predict higher grief in mid-bereavement, and rumination and education level predicted higher depression. Bereaved parents were no more likely to divorce than non-bereaved comparisons and were less likely to return to work following stillbirth or infant death, than mothers whose child lived, within the first ten years following the birth or death. High rates of mortality, up to 35 years post-loss remain an issue of significant concern.

9.0.4 Conclusions

Although the present PhD research was time-limited and focussed on a subset of factors which may affect the parental bereavement experience, important novel findings have emerged. Depression and grief are not necessarily co-morbid diagnoses and each should be assessed and treated independently. Factors which were associated with higher grief and depression emerged more clearly than those having an association with lower grief and depression. Therapeutic interventions should perhaps focus on reducing the impact of negative behaviours rather than seeking to promoting positive behaviours. Further research is necessary to identify whether other factors may be also be important.

9.1 Introduction

The results of the studies reported in the previous chapters have provided information about the experience of parental bereavement from a number of different sources. The phenomenological study in chapter four reported findings from a group of mothers, with a variety of bereavement experiences, from early bereavement (one year) up to late bereavement (forty years). Chapter five illuminated the experience of early parental bereavement, with a sample of parents recruited from support and self-help groups across the UK. Chapter six reported bereavement experiences from a cross-section of Scottish parents, around four years post-loss. The results from chapters six and seven came from a wide selection of parents who have experienced stillbirth or infant death, up to 35 years earlier. The research population for the current thesis is, therefore, demographically diverse and claims of providing a longitudinal perspective on parental bereavement are, accordingly, inappropriate. Despite this apparent limitation of the work carried out, a rich pool of data has been accumulated, in many cases, for the first time. It is therefore appropriate that overarching conclusions about the experience of parental bereavement be drawn from the project, with the caveat of population demographics and sampling variations in mind.

9.2 What are Bereaved Parents Coping With?

9.2.1 Prolonged grief

The standard measurement instruments used in chapters five and six indicate that bereaved parents are coping with high levels of grief. A comparison of parental grief with other types of grief, for example, spousal grief, is not warranted with the current data, as no comparison groups were recruited. The advantage of producing a type of “league table” of bereavement experiences may not necessarily be helpful, therefore the

key message about grief from chapters five and six is that a large percentage of bereaved parents are likely to be experiencing symptoms of prolonged grief in early to mid-bereavement (up to four years). This, then, poses a dilemma for the proposed diagnostic criteria for prolonged grief. Prigerson et al. (2009) suggests that grief becomes a disorder when symptoms are present for more than six months. The results presented in the current thesis seem to indicate that prolonged grief is the norm for many bereaved parents, however if this extended period of grief is “normal” for parental bereavement, how can this be classified as a disorder? However, if bereaved parents are expected to experience a severe and sometimes disabling grief reaction in early to mid-bereavement, the clinical significance of this must not be overlooked. Engel’s (1961) view of grief as a disease, discussed in chapter one, indicated that, even though grief may be natural and expected, when it impairs everyday functioning for an individual, its importance must be acknowledged. The experience of grief following parental bereavement must therefore be highlighted as potentially problematic for an extended period, although further research is needed to identify a “normal” trajectory for parental grief, and to indicate when problematic grief symptoms may routinely be expected to subside.

9.2.2 Depression

Although often a feature of the parental experiences reported in chapters five and six, depression is not necessarily a feature of grief, nor is grief universally associated with depression. The data presented in chapters five and six clearly show that depression and grief are dissociable constructs, with many bereaved parents meeting presumptive diagnostic criteria for prolonged grief, in the absence of major depression. Primary care practitioners must be aware of this distinction, since treating one condition may not

necessarily alleviate symptoms of the other. For example, pharmacological treatment of depression is now widespread (National Institute for Health and Clinical Excellence, 2010) but the effectiveness of antidepressants as a treatment for grief symptoms is inconclusive (Hensley, Slonimski, Uhlenhuth & Clayton, 2009). Treating one aspect of the bereavement experience is unlikely to result in the alleviation of all the distressing symptoms. The potential for inappropriate and/or ineffective mistreatment is likely to be higher in the absence of a grief diagnosis classification. DSM-V must therefore contain a description of a grief disorder to allow bereaved people to receive treatment specifically recommended for their condition.

9.2.3 Mortality

Increased mortality following the death of a child has been discussed in a number of studies, however these have often lacked methodological rigour or appropriate comparison groups (Hendrickson, 2009). The findings from studies seven and eight show conclusively, for the first time in the UK, that bereaved parents are at a significantly higher risk of premature death compared to non-bereaved counterparts. This important finding merits further urgent investigation. The mortality search in chapter six, where death records were searched to identify any bereaved parents who had died following the loss of their child, showed that causes of death were mainly alcohol or substance-related. Whilst the possibility of a familial link of unhealthy behaviours may be one explanation, the importance of alcohol and substance use as maladaptive coping strategies following the experience of parental bereavement must not be overlooked. This is an issue that those in a position to provide front-line support to bereaved parents need to be aware of. Again, assessment, and where appropriate,

treatment for alcohol and substance use may be part of the overall care package which should be offered, where appropriate, to bereaved parents.

9.2.4 Restoration-oriented stressors

9.2.4.1 Difficulty Caring for Other Children

In early bereavement, as reported in chapter four, difficulty caring for other children was associated with higher levels of grief. No studies were found reporting difficulties or need for assistance with childcare following the loss of a child and this appears, to date, to be an unreported phenomenon. From the phenomenological results reported in chapter four, it appears that many parents are aware that they are struggling, but perhaps find it difficult to ask for help. The reasons for this require further investigation, however a possible explanation may be the link between self-blame and grief, as reported in chapter six. If parents blame themselves for their child's death, then do they perhaps question their ability to nurture and protect other children? Help-seeking behaviour may further reinforce this belief and perhaps there is a reluctance to ask for help in an attempt to bolster their perceived level of nurturing self-efficacy. This proposed explanation lacks published empirical support, however the need for, and reticence to seek, assistance with childcare following bereavement requires urgent investigation, in order to avoid the risk of child neglect and the need to invoke child protection procedures.

9.2.4.2 Employment Difficulties

Higher levels of grief in early bereavement were associated with being employed at the time of the child's death. This directly contradicts findings from other studies into spousal bereavement, where employment status is seen as a buffer, notably by

providing enhanced levels of social support and perception of self-worth (Pai & Barrett, 2007). The reason why employment is a risk factor for grief in parental bereavement is unclear, however, from the results of the phenomenological study, it appears that support from employers may often be perceived as inadequate. When a baby is born, the new parents are offered time away from work, paid in the early stages and unpaid with job protection in the later stages. Financial support is available in the form of child tax credits and the childcare element of working tax credit, if the parents are employed. The death of a child appears to have a life-long impact on parents, and yet this vulnerable group are not currently offered any form of social or employment rights. It now falls upon our society to offer the same support to parents when a child leaves this world, as when it enters.

9.2.4.3 Financial Difficulties

In early bereavement, financial difficulties were associated with higher levels of depression. Loss of income in terms of state benefits has been reported as problematic for parents experiencing the death of a child with a long term condition (Corden, Sloper & Sainsbury, 2002). In these cases, parents often do not work or work part-time and rely on social security benefits as a key source of income for the family. These payments cease on the child's death and the financial impact is often devastating. The current research extends this finding to parents who have not previously relied on income related to their child's condition. Again, the issue of employment rights may be crucial here, since many parents in the qualitative study reported that they had left their jobs due to unacceptable pressures of work following their loss. If parents are unable to work due to prolonged grief, employers may pay only a percentage of salary in the longer term, therefore reducing overall earnings. In its most basic terms, the loss of a

child means a reduction in child benefit and child tax credit, which, particularly in low income families, may mean a significant drop in income. Financial difficulties are a risk factor for poorer outcomes in spousal bereavement (Martikainen & Valkonen, 1998) and, indeed, some studies indicate the moderating effect of higher income on grief symptoms (Stroebe et al., 2006). The mechanisms causing families to experience financial distress following the loss of a child therefore merits further investigation.

9.2.5 Continuing Bonds

The results of the qualitative study reported in chapter four indicated that the mothers found a high level of comfort in continuing bonds with their lost child. Whilst no attempt was made to measure grief symptoms in this group, the mothers indicated the importance they bestowed on the presence of linking objects or symbolic representations of the child. Findings from research in non-specific bereavement contradict this idea by indicating that both feeling that the deceased was still present or providing a guiding influence, or having a specific linking object with the deceased, were both associated with higher grief and depression (Boelen, Stroebe, Schut & Zijerveld, 2006). Furthermore, the results of the studies reported in chapters five and six show no association between continuing bonds and either grief or depression. The reason for this apparent contradiction in findings is unclear. Perhaps the nature of the relationship that is lost in parental bereavement has an influence on the need and adaptiveness of continuing bonds, compared to other losses, for example, spouses, other family members or close friends. Alternatively, perhaps the different methodological approaches used in the current thesis, qualitative versus quantitative methods, prompted different results. Asking questions to attempt to elicit whether a parent had a linking object or had constructed a symbolic representation of the child, without providing

potentially leading examples was problematic. The interview situation allowed answers to be probed and may have elicited clearer accounts of the details of such continuing bonds. Given the apparently high levels of continuing bonds behaviour exhibited by bereaved parents, more detailed investigation of the relative adaptiveness of different strategies for continuing bonds merits further investigation.

9.3 Cultural Considerations

The research reported within this thesis has been carried out in the context of the 21st century culture of the United Kingdom. The results reported must therefore be considered in the context of the cultural norms of Western society. Had the research been carried out elsewhere, the results may well have been different. Some cultures, such as the Achuar in eastern Ecuador, have a tradition of completely forgetting the deceased, therefore any notion of continuing bonds in this cultural context would be considered as a bizarre behaviour (Rosenblatt, 2008). For the Merina in Madagascar, however, consideration of the needs and wishes of deceased ancestors is as much a part of daily life as the requirements of the living (Walter, 199). The importance of the cultural norms in grieving is therefore significant in any understanding of grief reactions.

9.4 Social Models of Bereavement

In early 21st century Britain, the predominant model of cultural grief is influenced by the medical model, which in turn has been derived from observed reactions to grief responses in the late 19th century (Hagman, 1995). The notion of an introspective mourner continuing bonds with a lost loved one after their death is viewed as maladaptive, and the current position in thanatology research is that resolution of grief symptoms is achieved when the mourner has “moved on” and has severed emotional ties with the lost loved one (Field, 2003). Social theories of bereavement such as

Neimeyer's (2001) and Valentine's (2008) would dispute this belief, arguing that a continuing bond with the deceased is instead an adaptive and normal response to grief. Although this thesis provides limited evidence for the adaptiveness or otherwise of the continuing bond response, its prevalence in both the qualitative and quantitative studies suggests that it is a widely-occurring phenomenon. Different forms of continuing bonds may be relatively more or less adaptive and further research into this area is needed if the social models of bereavement are to receive increased support.

Building narratives and finding meaning following the loss of a loved one was not explicitly tested in this thesis, as the research undertaken was predominately quantitative in nature and the existence of a bereavement narrative would most be addressed most appropriately with qualitative research. An interesting finding, however, was that no particular positive coping style was associated with grief or depression. The current thesis does not, therefore, answer the question of how bereaved parents cope more positively with the death of a child. Perhaps the ability to build a narrative and find meaning in the lost loved one's life may be the behaviour that is associated with the resolution of grief symptoms, and may form the basis of a positive coping strategy, to come to terms with grief.

9.5 Limitations of the Thesis

The research reported in this thesis is, by nature of the PhD process, restricted to a three year time limit. A longitudinal study of the experience of parental bereavement was therefore not feasible, however mapping the experience of parental bereavement over time would prove invaluable in establishing norms for bereaved parents, and indicating adaptive and maladaptive coping mechanisms. All of the studies which required direct

input from participants elicited a clear desire from them to participate in research of this type which helped them to contemplated their own experiences, or alternatively, to help others who will encounter parental bereavement subsequently. Researchers must therefore be encouraged and facilitated in their search for knowledge about the experience, even in the early days of bereavement, following a cohort of bereaved parents from very early to long-term bereavement. Ethics committees should not be too paternalistic in their well-intentioned attempts to protect bereaved parents from the possible distress of participating in research of this kind. Bereaved parents are perfectly capable of giving their informed consent (or not) in relation to research participation, and the vast majority of participants in this programme of research reported that they had found it a positive experience. A comprehensive long-term evaluation of the bereavement experience is essential if knowledge, support and therapeutic interventions are to be improved for this deserving group of vulnerable people.

For chapters five and six which tested the Stroebe et al. (2006) model, a pragmatic view on variables under test had to be taken. The number of individual factors to be tested was restricted by the demand participants would feel when completing an over-long questionnaire. Other aspects not tested in these studies, such as attachment style, religiosity, family dynamics and cultural background warrant further investigation. More testing of a wider variety of factors would ensure that the key predictors associated with better outcomes for bereaved parents are found.

Within chapters five and six, no specific question related to therapies which the parent may have had access to, either psychological or pharmacological. Therapeutic and drug-based efficacy testing is beyond the scope of the current research, but the efficacy

of such interventions must be tested using stringent scientific protocols. Interventions found to be beneficial can then be included as factors in subsequent multivariate testing of factors thought to impact on the parental bereavement experience.

9.6 Recommendations for Future Research

There are a number of findings reported in this thesis which merit further investigation. The increased mortality of parents following the death of their child requires urgent investigation. Detailed analysis of health records is required, considering the experiences of fathers as well as mothers, across a wide range of causes of death and ages of the child at the time of their death. Causes of death and likely risk factors must be established, and comparison with a matched group of controls would indicate how important the bereavement experience is, compared to other factors associated with mortality.

A mapping of grief, depression and restoration stressors over the life course following the loss of a child, is also urgently required. Bereaved parents need to know what to expect, as the experience is, thankfully, rare in our society, and they are unlikely to have a perception of what the experience of life following the death of a child is likely to be.

The prevalence of substance and alcohol use in bereaved parents should be identified, as many parents may choose this as a means of self-medicating for grief and depression. Appropriate support and counselling, if warranted, could be offered routinely to bereaved parents as part of an overall care package, thus avoiding any ongoing healthcare costs as a result of maladaptive coping behaviours.

The requirement for support with childcare following the death of one's child should also be investigated. If required, the routine offering of childcare support would reduce any stigma the parents may associate with help-seeking and could reduce the risk of neglect of surviving siblings.

Employment and financial issues following the death of a child require more detailed examination. Comparing the experience of parents with employers who recognise and support their needs, compared to those employers who offer only routine short-term compassionate leave arrangements would identify the impact of employment practices on parental grief. Health economic research would complement these findings to illustrate the cost to society of the loss of contribution from bereaved parents who leave or reduce their activity in the employment market.

Finally, no satisfactory conclusions have yet been reached regarding the issue of continuing bonds and parental bereavement.

9.7 How do Bereaved Parents Cope with the Death of Their Child?

One of the aims of the thesis was to identify factors associated with grief and depression, hoping that there may be some behaviours, strategies or experiences that could in some way alleviate the distress of parents who experience the death of their child. Unfortunately, only one factor which was tested quantitatively was found to be positively associated with lower grief symptoms, namely cognitive restructuring. No factors were found to be associated with lower levels of depression following bereavement. It would appear from these findings that coping with parental bereavement appears to be more about reducing negatives (such as rumination, self-

blame and alcohol/substance use) than promoting more positive behaviours. This finding could represent a limitation of the choice of variables under test, however it could also mean that the experience is not one that is necessarily “coped with”, but, as one participant in the interviews pointed out “it’s just something you learn to live with”. If this is the case, feelings of grief for a lost child may never truly be resolved, but may lie dormant and hidden away by parents. This would explain the comment from a participant who said “I’ve had forty years to recover, but if I hear a certain piece of music, I can be back at day one in a heartbeat”. Whilst the day to day impact of the death of one’s child may recede over time, perhaps the grief of losing a child doesn’t get any less; it just gets further away.

9.8 Is Time the Great Healer?

The studies reported in chapters seven and eight indicate that social changes following bereavement are higher in the first ten year period following the death of a child.

Employment and relationship changes level out after this time, and match those of non-bereaved comparisons. If returning to similar levels of functioning as non-bereaved parents represents adjustment to the loss of a child, it therefore seems that somewhere around ten years might be a reasonable time frame for a bereaved parent to expect post-loss impairments to their lives to be present. At first sight, this seems to be a daunting prospect, as a ten year recovery time may seem hard to come to terms with for the bereaved parent. Compare this, though, with the common perception that “you never get over the death of a child”. Surely an adjustment period of up to ten years is more positive message to give to an individual than the prognosis of a lifetime of prolonged misery?

9.9 Conclusion – What this Thesis Adds to Knowledge about Parental Bereavement

The studies reported in the current thesis have added to knowledge in the following ways:

- The literature related to parental bereavement is sparse and provides limited information about the phenomenon
- Some bereaved parents see continuing a bond with their lost child as important.
- Bereaved parents often have high levels of suicidal ideation
- Coping with surviving siblings, particularly in early bereavement, may be problematic for many bereaved parents
- Employers do not necessarily offer the level of support that bereaved parents need to reintegrate into the workforce
- Grief and depression are dissociable and separate constructs, and can exist independently in parental bereavement
- Rumination, both depressive and reflective, is associated with poorer outcomes following the death of a child
- Social, employment and financial issues are a feature of bereavement up to four years post-loss
- Factors associated with the death such as age of child, cause of death, suddenness and level of violence are not as strongly associated with outcomes as coping strategies and ruminative traits
- Mortality is higher in bereaved parents than non-bereaved comparisons, up to thirty five years post-loss

- Marriage breakdown is no more frequent for bereaved parents than non-bereaved
- Employment issues return to similar levels as experienced by non-bereaved parents, after around ten years

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Appendix I – Proposed Diagnostic Criteria for Prolonged Grief

Disorder

(Prigerson et al., 2009)

Category Definition

A. Event: Bereavement (loss of a significant other)

B. Separation distress: The bereaved person experiences yearning (e.g., craving, pining, or longing for the deceased; physical or emotional suffering as a result of the desired, but unfulfilled, reunion with the deceased) daily or to a disabling degree.

C. Cognitive, emotional, and behavioural symptoms: The bereaved person must have five (or more) of the following symptoms experienced daily or to a disabling degree:

1. Confusion about one's role in life or diminished sense of self (i.e., feeling that a part of oneself has died)
2. Difficulty accepting the loss
3. Avoidance of reminders of the reality of the loss
4. Inability to trust others since the loss
5. Bitterness or anger related to the loss
6. Difficulty moving on with life (e.g., making new friends, pursuing interests)
7. Numbness (absence of emotion) since the loss
8. Feeling that life is unfulfilling, empty, or meaningless since the loss
9. Feeling stunned, dazed or shocked by the loss

D. Timing: Diagnosis should not be made until at least six months have elapsed since the death.

E. Impairment: The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning (e.g., domestic responsibilities).

F. Relation to other mental disorders: The disturbance is not better accounted for by major depressive disorder, generalized anxiety disorder, or posttraumatic stress disorder.

Appendix II – Inventory of Complicated Grief

Inventory of Complicated Grief

Please circle the answer which best describes how you feel right now:

1. I think about this person so much that it's hard for me to do the things I normally do...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

2. Memories of the person who died upset me...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

3. I feel I cannot accept the death of the person who died...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

4. I feel myself longing for the person who died...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

5. I feel drawn to places and things associated with the person who died...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

6. I can't help feeling angry about his/her death...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

7. I feel disbelief over what happened...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

8. I feel stunned or dazed over what happened...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

9. Ever since she/he died it is hard for me to trust people...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

10. Ever since she/he died I feel like I have lost the ability to care about other people or I feel distant from people I care about...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

11. I have pain in the same area of my body or have some of the same symptoms as the person who died...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

12. I go out of my way to avoid reminders of the person who died...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

13. I feel that life is empty without the person who died...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

14. I hear the voice of the person who died speak to me...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

15. I see the person who died stand before me...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

16. I feel that it is unfair that I should live when this person died...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

17. I feel bitter over this person's death...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

18. I feel envious of others who have not lost someone close...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

19. I feel lonely a great deal of the time ever since she/he died...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

Appendix III – Patient Health Questionnaire - 9 (PHQ-9)

Over the last two weeks, how often have you been bothered by any of the following problems?				
	Not at all	Several days	More than half the days	Nearly every day
Little interest or pleasure in doing things?				
Feeling down, depressed, or hopeless?				
Trouble falling or staying asleep, or sleeping too much?				
Feeling tired or having little energy?				
Poor appetite or overeating?				
Feeling bad about yourself - or that you are a failure or have let yourself or your family down?				
Trouble concentrating on things, such as reading the newspaper or watching television?				
Moving or speaking so slowly that other people could have noticed? OR the opposite - being so fidgety or restless that you have been moving around a lot more than usual?				
Thoughts that you would be better off dead, or of hurting yourself in some way?				
If you have been bothered by any of these problems in the last two weeks, how difficult have these problems made it for you to do your work, take care of things at home or get along with other people? Please tick one box	Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult

Appendix IV – Life Orientation Test – Revised (LOT-R)

Please be as honest and accurate as you can throughout. Try not to let your response to one statement influence your responses to other statements.

There are no ‘correct’ or ‘incorrect’ answers. Answer according to your own feelings, rather than how you think ‘most people’ would answer.

Using the scale below, write the appropriate number beside each statement.

0 = strongly disagree

1 = disagree

2 = neutral

3 = agree

4 = strongly agree

- 1) In uncertain times, I usually expect the best
- 2) It's easy for me to relax
- 3) If something can go wrong for me it will
- 4) I'm always optimistic about my future
- 5) I enjoy my friends a lot
- 6) It's important for me to keep busy
- 7) I hardly ever expect things to go my way
- 8) I don't get upset too easily
- 9) I rarely count on good things happening to me
- 10) Overall, I expect more good things to happen to me than bad

Appendix V – Ruminative Response Styles Questionnaire – Depressive

Rumination

Please tick the box that best describes you.	Never	Sometimes	Often	Always
I think about how alone I feel				
I think about my feelings of fatigue and achiness				
I think about how hard it is to concentrate				
I think about how passive and unmotivated I feel				
I think “Why can’t I get going?”				
I think about a recent situation, wishing it had gone better				
I think about how sad I feel				
I think about all my shortcomings, failings, faults and mistakes				
I think about how I don’t feel up to doing anything				
I think “Why can’t I handle things better?”				

Appendix VI – Ruminative Response Styles Questionnaire – Reflective and Brooding Rumination

Please tick the box that best describes you.	Never	Sometimes	Often	Always
I think “what have I done to deserve this?”				
I analyse recent events and try to understand why I am depressed				
I think “Why do I always react in this way?”				
I go away by myself and think about why I feel this way				
I write down what I am thinking and analyse it				
I think about a recent situation, wishing it had gone better				
I think “Why do I have problems that other people don’t have?”				
I think “Why can’t I handle things better?”				
I analyse my personality to find out why I am depressed				
I go some place alone to think about my feelings				

Appendix VII –Brief Cope (adapted)

Original wording: These items deal with ways you've been coping with the stress in your life since you're child died. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

- 1 = I haven't been doing this at all
- 2 = I've been doing this a little bit
- 3 = I've been doing this a medium amount
- 4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things.
2. I've been concentrating my efforts on doing something about the situation I'm in.
3. I've been saying to myself "this isn't real."
4. I've been using alcohol or other drugs to make myself feel better.
5. I've been getting emotional support from others.
6. I've been giving up trying to deal with it.
7. I've been taking action to try to make the situation better.
8. I've been refusing to believe that it has happened.
9. I've been saying things to let my unpleasant feelings escape.
10. I've been getting help and advice from other people.
11. I've been using alcohol or other drugs to help me get through it.
12. I've been trying to see it in a different light, to make it seem more positive.
13. I've been criticizing myself.
14. I've been trying to come up with a strategy about what to do.
15. I've been getting comfort and understanding from someone.
16. I've been giving up the attempt to cope.
17. I've been looking for something good in what is happening.
18. I've been making jokes about it.
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
20. I've been accepting the reality of the fact that it has happened.
21. I've been expressing my negative feelings.
22. I've been trying to find comfort in my religion or spiritual beliefs.
23. I've been trying to get advice or help from other people about what to do.
24. I've been learning to live with it.
25. I've been thinking hard about what steps to take.
26. I've been blaming myself for things that happened.
27. I've been praying or meditating.
28. I've been making fun of the situation.

Scales are computed as follows (with no reversals of coding):

Self-distraction, items 1 and 19

Active coping, items 2 and 7

Denial, items 3 and 8

Substance use, items 4 and 11

Use of emotional support, items 5 and 15

Use of instrumental support, items 10 and 23

Behavioural disengagement, items 6 and 16

Venting, items 9 and 21

Positive reframing, items 12 and 17

Planning, items 14 and 25

Humour, items 18 and 28

Acceptance, items 20 and 24

Religion, items 22 and 27

Self-blame, items 13 and 26

Appendix VIII - Continuing Bonds Scale

The following items may or may not be relevant to you. If the question is not appropriate for your situation, please tick Not Applicable. Otherwise, please tick one box on each line which describes how you feel.						
	Not applicable	Not at all true	A little true	Neither true nor untrue	Somewhat true	Very true
I seek out things to remind me of my child who died						
I keep items that belonged to or were closely associated with my child as a reminder of him or her						
I like to reminisce with others about my child who died						
I have inner conversations with my child who died when I turn to him or her for comfort or advice						
Even though no longer physically present, my child who died continues to be a loving presence in my life						
I am aware of having taken on many of my child's habits, values or interests						
My child has had a positive influence on who I am today						
I attempt to carry out my child's wishes						
I have many fond memories that bring joy to me						
When making decisions, I imagine my child's viewpoint and use this as a guide in deciding what to do						
I experience my child as living on through me						

Appendix IX – Interview Schedule

Interview Introduction

We've already had a look at the participant information sheet, but I just want to recap now on some of the key points.

I'm going to talk to you today about the circumstances surrounding the death of your child. I will ask you about life as a bereaved parent, how you have coped and are coping and how relationships with others/work/social life have changed.

I realise that we are going to touch on some very emotional events and if you want to stop the interview at any time we can. You don't need to give any explanation, just say that you want to stop and we will do so.

The information you give me is completely confidential – when I write up my notes I will change the names given to keep everything anonymous. No-one but me will hear this interview.

I'm recording to allow me to concentrate fully on what you say. If you don't mind, I'd also like to take brief written notes so I can refer back to some of the things you may say at different times in the interview.

Do you have any questions at this point?

(A) What is life like for you now?

-
1. Can you tell me about what happened when your child died?
 - i. *Prompt – age, name, gender, when was the death, cause, was it anticipated, other losses, how informed*
 2. Who else is in your family?
 - i. *Prompt – other children, partner, extended family support, other strong supporters*
 3. What impact has the death of your child had on your own health?
 - i. *Prompt - grief experienced, depression, other mental health issues*
 - ii. *Prompt - new physical illnesses*
 - iii. *Prompt - time off work*
 - iv. *Prompt – financial changes*
 4. In what way have your relationships with your partner or friends changed?
 - i. *Prompt – relationship problems or improvements*
 - ii. *Prompt - interactions with other people*
 - iii. *Prompt – social life, any new hobbies (creative especially)*
 5. How much of your life is affected now by the death of your child?
 - i. *Prompt – Christmas, anniversary, holidays*
 - ii. *Prompt – do you think about what age the child would be now – transitions e.g. school, work*
 - iii. *Prompt – if younger children, how did you feel when they reached the age of the lost child*
 - iv. *Prompt – are there any triggers that make them feel worse or bring back bad memories*
 6. What is the main emotion that describes how you feel about your child's death?
 - i. *Prompt – do they feel it was avoidable in any way*
 - ii. *Prompt – does anything make this emotion worse*
 - iii. *Prompt – have they ever considered suicide*
 7. Would you say these experiences have changed over time, since the death? If so, how?
 - i. *Prompt - worse then or now*
 - ii. *Prompt – how close is life now to before the death*
-

(B) Coping with bereavement – strategies and behaviours

8. Have you been offered any help with coming to terms with your grief? Was this helpful to you?
 - i. *Prompt – counselling, medication, support groups*
 - ii. *Prompt – employer, friends*
9. How often do you think about your situation now?
 - i. *Prompt – thinking about the child*
 - ii. *Prompt – thinking about current bereaved status*
10. Do you think you have been able to come to terms with the death?
 - i. *Prompt – intrusive thoughts, dealing with emotional events e.g. Christmas*
11. What things have helped you cope with the death?
 - i. *Prompt – religion, support from others, charity work, other family members (Children)*
 - ii. *Prompt – dealing with memories, photographs, memorials, symbols*
 - iii. *Prompt – alcohol*
12. What do you do to help you get through the bad days?
13. Do you have a grave or other memorial site to your child?
 - i. *Prompt – how often do you visit*
 - ii. *Prompt – how do you feel when you visit*
 - iii. *Prompt – are you happy with the arrangements you made*
14. What would you say is the biggest challenge for you as a BP?
 - i. *Prompt – everyday things, passage of time, special events, other people, finance*
15. What advice would you give other bereaved parents about how to cope with the death of their child?
16. What do you think would be a useful support for bereaved parents?
17. Are you able to see any positive changes in your life?
 - i. *Prompt – relationships, personal growth*
18. Can you tell me if you have met other BPs since the death of your child
 - i. *Prompt – better or worse off than you, how does looking into the future make you feel, can you identify with them*
19. What do you think other people think of your life and how you are dealing with it?
 - i. *Prompt – do non-BPs understand*
 - ii. *Prompt – able to be themselves, talk about the child or their feelings*
 - iii. *Prompt – do they think others appreciate their situation fully*

Is there anything that we haven't covered that you think is important for me to know about coping with life as a bereaved parent?

Outcomes and Coping Following Parental Bereavement

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2010

Abstract

Background

This thesis addresses the topic of parental bereavement, using a multi-method approach. It aims to add to knowledge about the phenomenon of parental bereavement, outcomes for bereaved parents following the loss of their child, and factors associated with these outcomes.

Method

An initial literature study and qualitative investigation were carried out. Findings from these informed the choice of quantitative variables to be tested in a group of parents in early and mid-bereavement. Census records were used to provide information on long term health and social outcomes.

Results

The literature related to the parent's experience following the death of their child is limited. The qualitative study indicated a variety of factors for testing, related to the circumstances of the loss, continuing bonds with the deceased child, restoration-oriented stressors, for example, employment and relationship problems, and ruminative behaviours. In early bereavement, lower grief levels were found in people who had displayed cognitive restructuring behaviours. Grief and depression were prevalent, and were found to exist independently. Rumination was associated with grief and depression in mid-bereavement. Grief was predicted by depression and self-blame and depression was, in turn, predicted by rumination and education level. Rates of mothers returning to work following the loss of a child in the first year of life were lower than

those whose child lived. Mortality rates were up to four times higher in bereaved parents than non-bereaved comparisons, up to 35 years post-loss.

Conclusions

The loss of a child has ongoing social, emotional and health consequences for parents. Social factors are a particularly important issue, and therapeutic interventions may benefit from reducing negative aspects of coping such as rumination rather than promoting specific coping strategies. Support for bereaved parents should come from a number of sources, in order to address their complex and potentially long-term needs.

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Firstly, I wish to acknowledge the contribution made to this thesis by the bereaved parents who participated in the research process. I admire and greatly respect each and every individual who was able to share some of their experience with me. Their bravery and consideration for other parents who may experience the loss of a child in future, was both humbling and uplifting, and to all concerned, I offer my deepest condolences and sincerest thanks.

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The help provided by staff of the Longitudinal Studies Centre - Scotland (LSCS) is acknowledged. The LSCS is supported by the ESRC/JISC, the Scottish Funding Council, the Chief Scientist's Office and the Scottish Executive. The author alone is responsible for the interpretation of the data. Census output is Crown copyright and is reproduced with the permission of the Controller of HMSO and the Queen's Printer for Scotland.

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This thesis is dedicated to the memory of Ross Munro

5th July 1994 – 18th January 1999

Thank you for the days x

Publications Arising from this Thesis

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Harper, M., O'Connor, R & O'Carroll, R. (in preparation). Grief and Depression in Early Parental Bereavement – the Impact of Rumination and Cognitive Restructuring

Harper, M., O'Connor, R & O'Carroll, R. (in preparation). Predicting Levels of Grief and Depression in Bereaved Parents Four Years Post-loss.

Table of Contents

Abstract	1
Background.....	1
Method.....	1
Results.....	1
Conclusions.....	2
Publications Arising from this Thesis	7
Chapter One - Introduction	20
1.0 Abstract.....	20
1.0.1 Background.....	20
1.0.2 Method.....	20
1.0.3 Results.....	20
1.0.4 Conclusions.....	20
1.1 Overview.....	21
1.1.1 Definition of Bereavement.....	21
1.2 Historical Perspective on Grief and Bereavement.....	21
1.2.1 Freud's Comparison of Mourning and Melancholia.....	21
1.2.2 Engel's Theory of Grief as a Disease.....	22
1.2.3 Bowlby's Attachment Perspective on Loss.....	22
1.2.4 Parkes and Weiss's Psychosocial Transitions in Bereavement.....	24
1.3 Contemporary Models of Bereavement.....	25
1.3.1 Dual Process Model of Bereavement.....	25
1.3.2 Integrative Risk Factor Framework for Coping with Bereavement.....	27
1.4 Social Theories of Bereavement.....	28
1.5 Prolonged Grief as a Distinct Diagnostic Condition.....	28
1.6 Outcomes for Bereaved Parents.....	32
1.6.1 Health Outcomes.....	32
1.6.2 Changes in Social Functioning.....	34
1.6.3 Emotional Consequences.....	35
1.7 Aims of the Thesis.....	35
1.8 Thesis Structure.....	36
Chapter Two – Literature Review of Factors Associated with Differential Outcomes of Parental Bereavement	38
2.0 Abstract.....	38
2.0.1 Background.....	38
2.0.2 Method.....	38
2.0.3 Results.....	38
2.0.4 Conclusions.....	39
2.1 Introduction.....	40
2.2 Method.....	40
2.3 Method of Analysis.....	53
2.3.1 Demographics.....	53
2.3.2 Outcome Variables.....	55
2.3.3 Predictors.....	55
2.4 Conclusion.....	57

Chapter Three – Methods	59
3.0 Abstract	59
3.0.1 Background	59
3.0.2 Method.....	59
3.0.3 Results	59
3.0.4 Conclusions	60
3.1 Introduction.....	61
3.2 Requirements for the Qualitative Method Chosen	61
3.2.1 Function of the Research	61
3.2.2 Participant Population	62
3.2.3 Timing of Research	62
3.2.4 Participant Recruitment.....	63
3.2.5 Data Collection Method	63
3.2.6 Protecting the Participants from Harm.....	64
3.2.7 Protecting the Researcher from Harm.....	64
3.2.8 Selection of Qualitative Method.....	65
3.2.9 Limitations of IPA.....	66
3.2.10 Conclusions for Choice of Qualitative Method.....	67
3.3 Quantitative self-report data	67
3.4 Cross-sectional Data Collection.....	68
3.5 Analysis of Secondary National Data Sources	68
3.6 Choice of Quantitative Self-Report Measures	69
3.6.1 Outcome Measures	69
3.6.1.1 Grief	69
3.6.1.2 Depression	70
3.6.2 Predictors.....	72
3.6.2.1 Trait Optimism/Pessimism	72
3.6.2.2 Rumination.....	72
3.6.2.3 Coping Style	73
3.6.2.4 Continuing Bonds	74
Chapter Four - Bereaved Mothers’ Continuing Bonds and Ambivalence about their Own Mortality after the Death of Their Child – An Interpretive Phenomenological Analysis	76
4.0 Abstract.....	76
4.0.1 Background	76
4.0.2 Method.....	76
4.0.3 Results	76
4.0.4 Conclusions	77
4.1 Introduction.....	78
4.1.1 Previous Studies of Bereaved Parents’ Coping	78
4.1.2 Social Issues Following Bereavement.....	80
4.1.3 Phenomenological Research.....	80
4.2 Method	81
4.2.1 Participants	81
4.2.2 Data Collection.....	83
4.2.3 Data Analysis	84
4.2.4. Impact of the Researcher on Participant Accounts	86

4.3 Results.....	87
4.3.1 Theme 1a - Continuing the Bond with the Deceased Child – The Physical Connection.....	88
4.3.2 Theme 1b - Continuing the Bond with the Deceased Child – Linking Objects.....	91
4.3.3 Theme 1c - Continuing the Bond with the Deceased Child – Symbolic Representations	92
4.3.4 Theme 2a - Ambivalence to Personal Mortality	95
4.3.5 Theme 2b– Death as a Release.....	97
4.3.6 Theme 2c - Influence of Other Children	98
4.3.7 Theme 3a - Social Changes Attributed to the Bereavement - Marital Situation.....	101
Theme 3b – Social Changes Attributed to the Bereavement - Employment Status	104
4.4 Discussion.....	106
4.4.1 Continuing Bonds.....	106
4.4.2 Coping Styles	107
4.4.3 Phenomenology of Parental Bereavement – Impact of Cause of Death	108
4.4.4 Ambivalence about Personal Mortality.....	109
4.4.4.1 Possible Sources of Support for Bereaved Parents.....	111
4.4.4.2 Suicide Risk.....	112
4.4.5 Social Changes	113
4.4.6 Methodological Considerations.....	113
4.4.7 Limitations.....	114
4.4.8 Conclusion.....	115
Chapter Five - Factors Affecting Outcomes in Parent’s Early Bereavement.....	116
5.0 Abstract.....	116
5.0.1 Background	116
5.0.2 Method.....	116
5.0.3 Results	116
5.0.4 Conclusions	116
5.1 Introduction.....	118
5.1.1 Prolonged Grief as a Distinct Diagnostic Condition.....	118
5.1.2 Rumination as an Avoidance Focussed Method of Coping	119
5.1.3 Identification of Risk Factors for Prolonged Grief in Bereaved Parents ...	119
5.1.4 The Impact of Bereaved Parents Continuing Bonds with their Lost Child	121
5.2 Method.....	122
5.2.1 Participants	122
5.2.2 Measures.....	123
5.2.2.1 Grief.....	124
5.2.2.2 Depression	124
5.2.2.3 Trait Optimism/Pessimism	124
5.2.2.4 Rumination.....	124
5.2.2.5 Coping Style	125
5.2.2.6 Continuing Bonds	125
5.2.2.7 Suicidal Ideation	125
5.2.2.8 Education	126
5.2.2.9 Cause of Death.....	126

5.2.2.10 Death anticipation	126
5.2.2.11 Linking Objects/Symbolic Representations.....	126
5.2.2.12 Relationship status	127
5.2.2.13 Employment status.....	127
5.2.2.14 Open-Ended Questions	127
5.2.2.15 Participation Experience	128
5.2.3 Participant Demographics	128
5.2.4 Procedure.....	129
5.2.5 Statistical Analyses.....	130
5.3 Results.....	131
5.3.1 Hypothesis One – Prolonged grief can be measured independently from depression.	133
5.3.2 Hypothesis Two – Increased levels of rumination will be associated with higher levels of grief or depression	135
5.3.3 Identification of the factors most closely associated with grief and depression.	135
5.3.3.1 Factors Associated with Increased Grief	135
5.3.3.1.1 Categorical Variables Associated with Grief.....	135
5.3.3.1.2 Continuous Variables Associated with Grief.....	136
5.3.3.1.3 Relative Importance of Factors Associated with Increased Grief	137
5.3.3.2 Factors Associated with Depression	139
5.3.3.2.1 Categorical Variables associated with Clinical Depression ..	139
5.3.3.2.2 Continuous Variables Associated with Depression	139
5.3.3.2.3 Relative Importance of Factors Associated with Increased Depression Scores	140
5.3.4 Association with Continuing Bonds and either Grief or Depression	142
5.3.5 Thematic Analysis of Other Relevant Information	142
5.4 Discussion.....	142
5.4.1 Prolonged Grief Independent of Depression	142
5.4.2 Rumination and Grief/Depression.....	143
5.4.3 Risk Factors for Prolonged Grief and Depression.....	143
5.4.4 Continuing Bonds and Grief.....	144
5.4.5 Research Experience	145
5.4.6 Limitations of the Study	146
5.4.7 Conclusion.....	147

Chapter Six - Factors Affecting Bereavement Outcome in Bereaved Parents Four Years Post-Loss **149**

6.0 Abstract	149
6.0.1 Background	149
6.0.2 Method.....	149
6.0.3 Results	149
6.0.4 Conclusion.....	150
6.1 Introduction.....	151
6.1.1 Factors Associated with Outcomes in Mid-bereavement.....	151
6.1.2 Findings from Research in Early Bereavement.....	152
6.2 Method	154
6.2.1 Participants	154

6.2.2 Measures.....	156
6.2.2.1 Grief	156
6.2.2.2 Depression	156
6.2.2.3 Trait Optimism/Pessimism	157
6.2.2.4 Rumination.....	157
6.2.2.5 Coping Style	157
6.2.2.6 Continuing Bonds	158
6.2.2.7 Socioeconomic Status	158
6.2.2.8 Suicidal Ideation	159
6.2.2.9 Education	159
6.2.2.10 Cause of Death.....	159
6.2.2.11 Death anticipation.....	160
6.2.2.12 Linking Objects/Symbolic Representations.....	160
6.2.2.13 Relationship status	160
6.2.2.14 Employment status.....	160
6.2.3 Time 2 Questionnaire	160
6.2.4 Qualitative Data.....	161
6.2.5 Participant Demographics	162
6.2.6 Procedure.....	163
6.2.7 Statistical Analyses.....	164
6.3 Results.....	166
6.3.1 Qualitative Analysis	171
6.3.1.1 Additional Problems not Specified in Questionnaire	171
6.3.1.2 Impact of the Bereaved Parent Status of the Researcher	172
6.3.1.3 Advice for Other Bereaved Parents	172
6.3.2 Hypothesis One – Prolonged grief can be measured independently from depression at Time 1.....	174
6.3.3 Hypothesis Two – Increased levels of depressive rumination will be associated with higher levels of grief and depression at Time 1.....	175
6.3.3 Hypothesis Three – Levels of reflective rumination would be associated with higher levels of grief and depression at Time 2.	175
6.3.4 Exploratory Analysis – Identification of the factors most closely associated with grief and depression.	176
6.3.4.1 Factors Associated with Increased Grief at Time 1	176
6.3.4.1.1 Categorical Variables.....	176
6.3.4.1.2 Continuous Variables.....	177
6.3.4.2 Relative Importance of Factors Associated with Increased Grief at Time 1	178
6.3.4.2 Factors Associated with Increased Depression at Time 1	179
6.3.4.2.1 Continuous Variables.....	179
6.3.4.2.1 Categorical Variables.....	180
6.3.4.3 Relative Importance of Factors Associated with Increased Depression Scores at Time 1	180
6.3.5 Exploratory Analysis - Predicting Scores at Time 2 from Significant Time 1 Factors	182
6.3.5.1 Grief	182
6.3.5.2 Depression	183
6.4 Discussion.....	184
6.4.1 Prolonged Grief and Depression	184

6.4.2 Rumination and Depression	184
6.4.3 Factors Associated with Prolonged Grief.....	185
6.4.3.1 Depression	185
6.4.3.2 Self-blame	186
6.4.3.3 Child Living at Home	186
6.4.4.4 Frequency of Grave Visitation.....	187
6.4.4.5 Restoration-Oriented Stressors	188
6.4.5 Factors Associated with Depression.....	189
6.4.5.1 Rumination.....	189
6.4.5.2 Problems at Work	189
6.4.5.3 Education Level	190
6.4.5.4 Substance/Alcohol Use	190
6.4.6 Unexpected Findings	190
6.4.7 The Research Experience for Participants.....	191
6.4.8 Limitations of the Research.....	191
6.4.9 Conclusions	192

Chapter Seven - Mortality, Marriage and Employment Changes in Bereaved

Parents in Scotland	194
7.0 Abstract	194
7.0.1 Background	194
7.0.2 Method.....	194
7.0.3 Results	194
7.0.4 Discussion	195
7.1 Introduction.....	196
7.1.1 Marital Status	196
7.1.2 Employment Status.....	197
7.1.3 Mortality Risk.....	197
7.2 Method	199
7.2.1 Analysis	201
7.3 Results.....	202
7.3.1 Mortality Rates	203
7.3.2 Change in Marital Status	203
7.3.3 Change in Employment	204
7.4 Discussion	205
7.4.1 Limitations of the Study	207
7.4.2 Conclusions.....	208

Chapter Eight – Long-Term Mortality, Employment and Relationship Changes in Bereaved Mothers in England and Wales

8.0 Abstract	210
8.0.1 Background	210
8.0.2 Method.....	210
8.0.3 Results	210
8.0.4 Conclusions	211
8.1 Introduction.....	212
8.2 Method	214
8.2.1 Analysis	217
8.3 Results.....	217

8.3.1 Mortality Rates	218
8.3.2 Employment Status	219
8.3.3 Relationship Status	221
8.4 Discussion	224
8.4.1 Mortality	224
8.4.2 Employment	225
8.4.3 Relationships	225
8.4.4 Limitations of the Study	227
8.4.5 Conclusions	228
Chapter Nine – General Discussion	229
9.0 Abstract	229
9.0.1 Background	229
9.0.2 Method	229
9.0.3 Results	229
9.0.4 Conclusions	230
9.1 Introduction	231
9.2 What are Bereaved Parents Coping With?	231
9.2.1 Prolonged grief	231
9.2.2 Depression	232
9.2.3 Mortality	233
9.2.4 Restoration-oriented stressors	234
9.2.4.1 Difficulty Caring for Other Children	234
9.2.4.2 Employment Difficulties	234
9.2.4.3 Financial Difficulties	235
9.2.5 Continung Bonds	236
9.3 Cultural Considerations	237
9.4 Social Models of Bereavement	237
9.3 Limitations of the Thesis	237
9.4. Recommendations for Future Research	240
9.5 How do Bereaved Parents Cope with the Death of Their Child?	241
9.6 Is Time the Great Healer?	242
9.7. Conclusion – What this Thesis Adds to Knowledge about Parental Bereavement	243
References	245

Appendices

Appendix I – Proposed Diagnostic Criteria for Prolonged Grief Disorder.....	254
Appendix II – Inventory of Complicated Grief.....	256
Appendix III – Patient Health Questionnaire - 9 (PHQ-9)	258
Appendix IV – Life Orientation Test – Revised (LOT-R)	259
Appendix V – Ruminative Response Styles Questionnaire – Depressive Rumination	260
Appendix VI – Ruminative Response Styles Questionnaire – Reflective and Brooding Rumination	261
Appendix VII –Brief Cope	262
Appendix VIII - Continuing Bonds Scale	264
Appendix IX – Interview Schedule.....	265

Index of Tables

Table 2.1 – Studies Reporting Factors Associated with Grief in Parental Bereavement	43
Table 3.1 Summary table of measures used in the research	75
Table 4.1. Participant Characteristics	82
Table 5.1 – Demographics of participants who returned completed questionnaires	129
Table 5.2 – Minimum, maximum, mean, standard deviation and number of responses for continuous variables.....	132
Table 5.3 – Frequencies of positive/negative responses in categorical variables.....	133
Table 5.4 – Categorical variables univariately associated with higher grief	136
Table 5.5 – Continuous variables univariately associated with higher grief	137
Table 5.6 –Multivariate Hierarchical regression analyses testing the relative contribution of factors to total grief score	138
Table 5.7 – Categorical variables univariately associated with depression.....	139
Table 5.8 – Continuous variables univariately associated with depression.....	140
Table 5.9 –Multivariate Hierarchical regression analyses testing the relative contribution of factors to total depression score	141
Table 6.1 – Comparison of demographics for all parents potentially contactable, those actually contacted and those who returned completed questionnaires	162
Table 6.2 – Minimum, maximum, mean, standard deviation and number of responses for continuous variables at Time 1	167
Table 6.3 – Minimum, maximum, mean, standard deviation and number of responses for continuous variables at Time 2	168
Table 6.4 – Frequencies of positive/negative responses in categorical variables at Time 1	169

Table 6.5 – Frequencies of positive/negative responses in categorical variables at Time 2	170
Table 6.6 – Difference between measures at Time 1 versus Time 2	170
Table 6.7 – Frequencies of sex of child and parent, education status, socioeconomic status and frequency of grave visitation reported at Time 1	171
Table 6.8 – Other problems reported at either Time 1 or Time 2	171
Table 6.9 – Categorical variables univariately associated with likelihood of grief diagnosis at Time 1	177
Table 6.10 – Continuous variables univariately associated with higher grief at Time 1	177
Table 6.11 –Multivariate regression analysis testing the relative contribution of factors to grief score at Time 1	179
Table 6.12 – Continuous variables univariately associated with higher depression at Time 1	179
Table 6.13 – Categorical variables univariately associated with likelihood of depression diagnosis at Time 1	180
Table 6.14 – Multivariate regression analyses testing the relative contribution of factors to depression score at Time 1	181
Table 6.15 – Multivariate regression analyses testing factors which predict Time 2 grief score	182
Table 6.16 – Multivariate regression analyses testing factors which predict Time 2 Depression score	183
Table 7.1 – Group characteristics of individuals included in the analysis	202
Table 7.2 – Comparison of Mortality Rates by Group	203
Table 7.3 – Comparison of Changes in Marital Status by Group	203

Table 7.4 – Comparison of Changes in Employment by Group.....	204
Table 8.1 – Group characteristics of members of each cohort	217
Table 8.2 – Mortality of cohort members or their spouses, followed up to 2006.....	218
Table 8.3 – Mean time between event and death for deceased in individual cohorts, by bereavement status	219
Table 8.4 – Comparison of Changes in Employment by Group (71-01).....	220
Table 8.5 – Comparison of Changes in Employment by Group (81-01).....	220
Table 8.6 – Comparison of Changes in Employment by Group (91-01).....	220
Table 8.7 – Comparison of Change in Employment Status from Not Working to Working by Group (91-01)	221
Table 8.8 – Comparison of Changes in Relationship Status by Group (71-01)	222
Table 8.9 – Comparison of Changes in Relationship Status by Group (81-01)	222
Table 8.10 – Comparison of Changes in Relationship Status by Group (91-01)	222

List of Figures

Figure 1.1 – The Dual Process Model of Coping with Bereavement (Stroebe & Schut, 1999)	26
Figure 1.2 – The Integrative Risk Factor Framework (Stroebe et al., 2006).....	28
Figure 4.1. Key Recurrent Themes in Coping with the Loss of a Child	87
Figure 5.1 – Stroebe et al. Integrative Risk Factor Framework (2006)	120
Figure 5.2 - Scattergram of participants' grief and depression status	134
Figure 5.3 – Factors Univariately Associated with Grief	138
Figure 5.4 – Factors Univariately Associated with Depression.....	141
Figure 6.1 - Scattergram of participants' grief and depression status at Time 1	174
Figure 6.2 – Factors Univariately Associated with Grief at Time 1	178
Figure 6.3 – Factors Univariately Associated with Depression at Time 1	181

Chapter One - Introduction

1.0 Abstract

1.0.1 Background

The current chapter introduces the topic of parental bereavement in order to establish a rationale for the thesis.

1.0.2 Method

Key theories of bereavement are described, from a historical and contemporary perspective. The experience of parental bereavement is then considered, with specific reference to health, social and emotional outcomes.

1.0.3 Results

The Integrative Risk Factor Framework (Stroebe, Folkman, Hansson & Schut, 2006) was identified as an important theoretical model for scoping the experience of parental bereavement. In particular, the health and social functioning domains were considered as key aspects for investigation.

1.0.4 Conclusions

The aims and structure of the thesis were set out, indicating that the focus of the thesis will be on outcomes and risk factors of bereavement, and that the experience will be evaluated with separate groups of parents who are in early, mid and late bereavement.

1.1 Overview

1.1.1 Definition of Bereavement

According to Parkes and Weiss (1983), bereavement is “the most severe psychological trauma most people will encounter in the course of their lives. (p. ix). There are around half a million deaths in the United Kingdom every year (General Register Office for Scotland, 2010; National Statistics Office, 2010), and it is likely that most of those who are exposed to a bereavement will experience distress, depression and sadness as a result, at least in the immediate aftermath of the death notification (Shuchter & Zisook, 1993). The majority of people would, however, expect to recover from the loss and return to normal functioning after a period of time, but for some, this natural process is disrupted or prolonged. This failure to resolve bereavement symptoms has been of interest to generations of researchers.

1.2 Historical Perspective on Grief and Bereavement

1.2.1 Freud’s Comparison of Mourning and Melancholia

In considering the place of grief in psychopathology, Freud (1917) expressed surprise that grief had not, at that time, been considered a psychiatric condition. He believed that grief shared many common factors with other conditions considered to be pathological, particularly his “melancholia”, which we now refer to as clinical depression. The rationale Freud gives for the non-pathologising of grief is that its inception can be explained as a result of a natural process, thereby causing it to be different from depression, whose aetiology could not be explained. In considering the impact of grief on daily life, Freud described the physical debilitation that occurs as grieving individuals attempt to detach themselves from preoccupation with the memory of the

deceased. Freud believed that self-esteem was the key difference between grief and depression. Those who experience depression believe they are worthless; those who experience grief believe that life is worthless in a world without their loved one.

1.2.2 Engel's Theory of Grief as a Disease

The seminal work by Engel (1961) was the first published article to consider the potential pathological nature of grief in the light of widely-held claims to the contrary. The article argued that, since grief leaves the sufferer in an impaired state of functioning and with a clear presentation of symptoms of distress and disability, it should be categorised as a psychological disorder. Engel considered many arguments against the categorisation of grief as a disease and offered compelling suggestions in favour of the concept. For example, he considered the perspective that grief may be considered a natural phenomenon, one that an individual will recover from in time, without intervention. Engel argued that this could be said to be true of many ailments, including wounds, disease or burns, and yet an individual is not expected to bear the pain of these other ailments without analgesia or antibiotics. Why, then, should one be expected to bear the pain of grief without assistance or support? Engel called for scientific research to be carried out into the phenomenon of grief, to understand it in greater detail, thereby considering whether treatment to alleviate the symptoms of grief is possible.

1.2.3 Bowlby's Attachment Perspective on Loss

John Bowlby believed that the study of grief and mourning should be fundamental to all psychological study. His statement that “there is little doubt...that much psychiatric illness is an expression of pathological mourning” may be a strong claim, however he has provided compelling evidence for this assertion, albeit from a mainly

psychoanalytic perspective (Bowlby, 1981). The evidence he has presented suggests that, for emotional disorders such as depression and anxiety, there normally exists a precipitating event associated with a loss of some kind, and it is a disordered form of grieving that manifests itself as the emotional disorder. For other psychiatric conditions, the loss is of the subjective norms of life, and again, it is the grieving and searching for this previous normal behaviour which is the individual's, or society's, key focus in consideration of their psychiatric condition.

The theory of grieving, according to Bowlby, follows a four-phase approach. In the first few hours and days of bereavement, the individual experiences emotional numbing, unable to fully comprehend or accept the loss. At this time, severe distress and sometimes anger may be present in the bereaved. Spontaneous and uncontrollable crying is common, with the bereaved reporting the occupation of a dreamlike state, going through the motions of life, often with a sense of unreality. Following this numbing phase, a period of yearning, pining and searching for the loved one takes place. During this time, the bereaved person often thinks they see the deceased as a face in the crowd or out of the corner of their eye, in a familiar seat or place in the home. Bowlby's third phase of grief represents a time when the bereaved person experiences disorganisation and intense despair. At this time, the world appears to be a confusing place where normal rules do not apply, and the bereaved must begin to accept and normalise their experience. The final phase of grief, according to Bowlby, is a phase of reorganisation. This is the time when the bereaved must establish a "new normal" in their life, accommodating the loss of the loved one and generating an autobiographical narrative which incorporates the life and death of the deceased. Bowlby indicated that the path through these phases is unlikely to be a straightforward one, with oscillation

between phases being a common phenomenon. In order for grief to be processed and for the bereaved to come to terms with their loss, they must therefore successfully complete phase four, reorganising their life and accommodating the impact of their loss. Bowlby's belief is that unresolved grief stems from an inability to reach resolution during the searching phase and, whether consciously or unconsciously, the bereaved person is unable to establish a representation of the deceased in any form, effectively prolonging the searching phase indefinitely.

Bowlby suggested that there are two key issues to be addressed within bereavement research, namely that we gain an understating of what "normal" mourning or grief is, and that, in turn, we gain an understanding of why some people react differently to loss, resulting in an "abnormal" pattern of mourning or grief.

1.2.4 Parkes and Weiss's Psychosocial Transitions in Bereavement

The perspective of bereavement taken by Parkes and Weiss (1983) is one of a psychosocial transition. The bereaved person has experienced a rupture of their normative view of the world, resulting in a need to establish and accept a new and altered world view. This is essentially a developmental process, much as that followed when an amputee learns to walk again following removal of a limb. The bereaved person must stop attending to the wishes of their lost loved one and must, as, for example, in the case of spousal bereavement, begin to learn to think in terms of "I" rather than "we". The challenge to the assumptive world view experienced by the bereaved can be all-encompassing. New roles need to be learned to accommodate domestic tasks which were previously the domain of the deceased. Social events once experienced as a couple or as a family will now have a poignant focus, as one key

individual will be missing. Life events such as significant anniversaries will be profoundly moving, as the bereaved considers the “what if” scenario of the deceased’s potential experience of these important dates. Essentially, Parkes and Weiss are describing Bowlby’s fourth phase of grief – that of reorganisation and accommodation of the loss within everyday life. For Parkes and Weiss, healthy grief requires the loss to be assimilated and a new world view constructed in its wake.

1.3 Contemporary Models of Bereavement

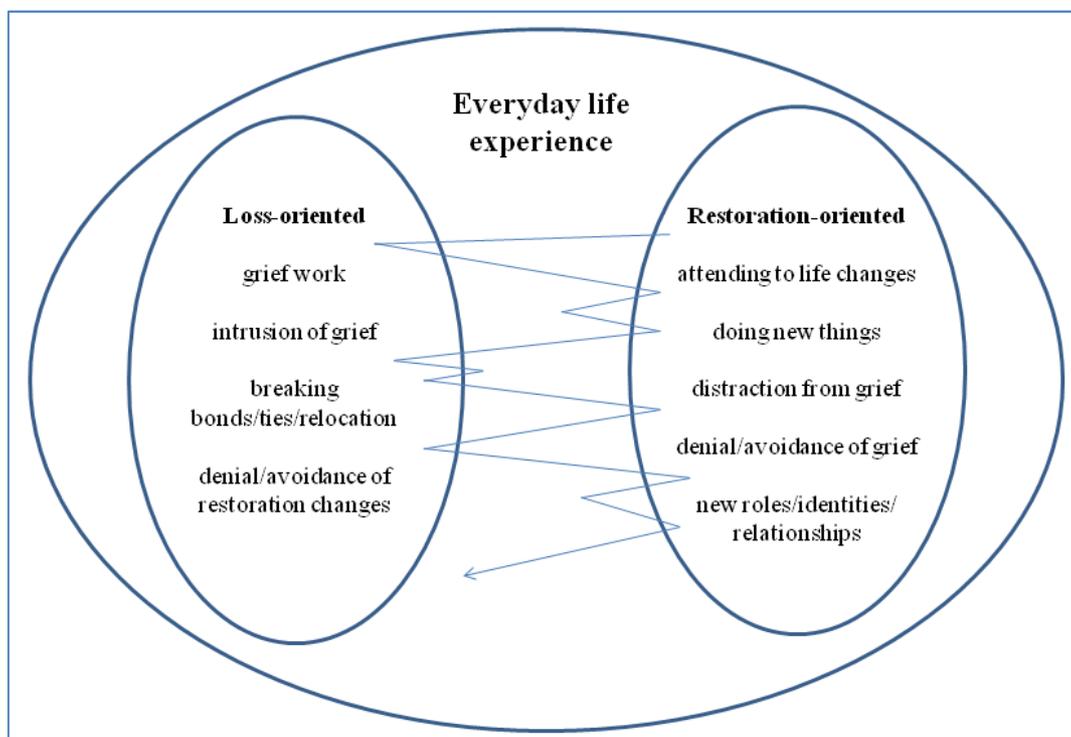
1.3.1 Dual Process Model of Bereavement

In recent years, researchers have turned their attention to consideration of the processes which influence individual outcomes within the bereaved. The Dual Process Model of coping with bereavement (Stroebe & Schut, 1999) elegantly depicts the grieving process from a cognitive perspective (see Figure 1.1). The model illustrates that coping with bereavement requires the bereaved individual to address two forms of stressors. The first, loss-oriented stressors, are those which are directly related to the death of the loved one. These would include allowing Bowlby’s first, second and third phases of grief to be experienced, moving from the period of emotional numbing, through the time of yearning, pining and searching for the loved one, to acceptance that the previous accepted norms and worldview are changed. The individual must confront their loss in a way most suitable to facilitate this process. At the same time as the loss-oriented stressors are being “worked through”, the Dual Process Model pays cognisance to the fact that changes in everyday life take place when a loved one dies. Tasks previously undertaken by the deceased spouse, for example, may now become the responsibility of the deceased, perhaps requiring new skills to be learned or knowledge to be gained. Social events and hobbies in which both parties previously took part may now require a

new partner to be found or may become inappropriate for the individual, in the absence of the lost partner. Financial changes mean that standards of living may have to change, financial support may need to be sought from other sources, and the spousal home may no longer be appropriate for the bereaved to inhabit.

The bereavement process, according to Stroebe and Schut, is one of oscillation between loss-oriented stressors and restoration-oriented stressors. Sometimes, the bereaved may be in one domain or the other, but there will also be times when neither type of stressor is being attended to. This is believed to be an adaptive process, effectively allowing the bereaved some respite from the ongoing stressors, before again attending to one or both of the processes for adjusting to bereavement.

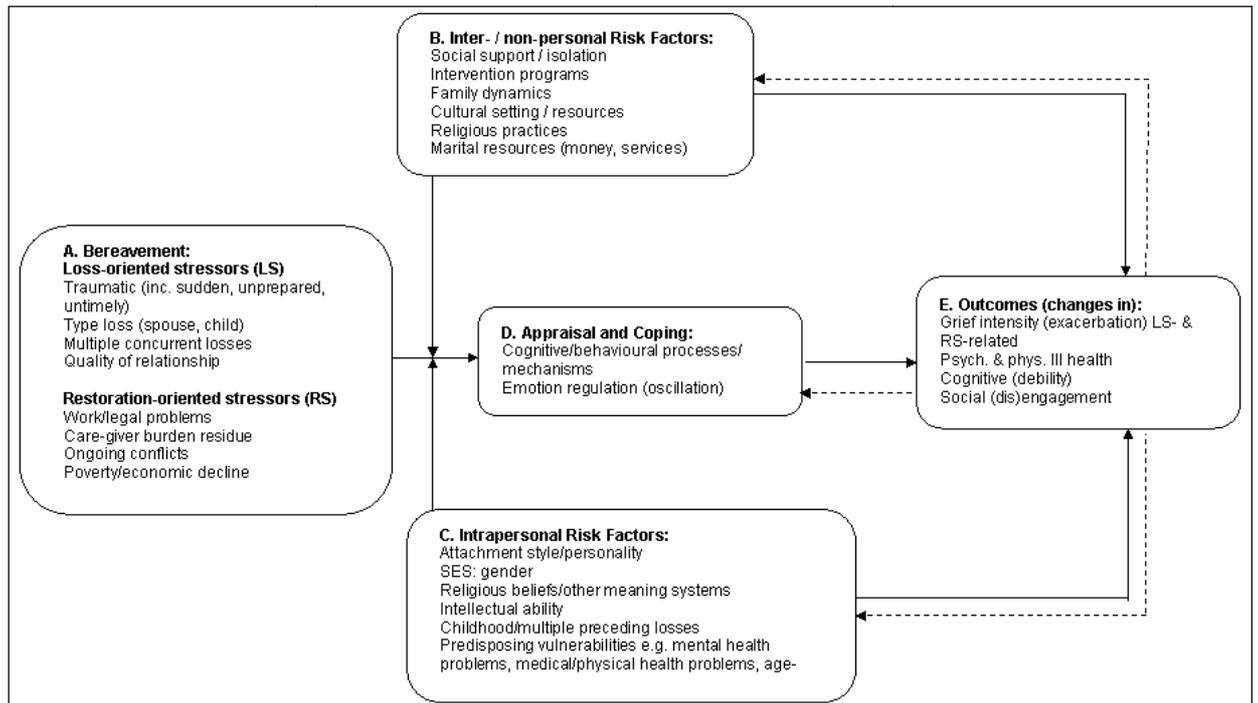
Figure 1.1 – The Dual Process Model of Coping with Bereavement (Stroebe & Schut, 1999)



1.3.2 Integrative Risk Factor Framework for Coping with Bereavement

The Integrative Risk Factor Framework (Stroebe et al., 2006) further refines the Dual Process Model, by taking account of the interaction of a number of cognitive processes which may lead to a more detailed analysis of the pathways of coping with bereavement. The Integrative Risk Factor Framework, illustrated in Figure 1.2, posits that factors within a number of individual domains interact to determine the bereaved person's outcome following their loss. The framework suggests a number of possible pathways to bereavement outcome. Presence of, and attending to, the loss- and restoration-oriented stressors provides a starting point for the bereaved individual's grieving process, and this can be affected by interpersonal factors such as level of social support and economic resources, as well as intrapersonal factors such as gender and personality factors. The progress towards coping with their bereavement is then further impacted by the appraisal and coping processes themselves, where coping styles may be important in determining bereavement outcomes. The framework suggests that all of these domains may interact to cause changes in bereavement outcomes, which may, in turn, feed back into the bereavement process, further affecting the individual domains again. The Integrative Risk Factor Framework has, for the first time, provided researchers with a theoretical approach to testing pathways of coping with bereavement. Its publication has provided a call for bereavement researchers to attempt to begin defining and testing the potential pathways which may eventually be used to predict bereavement outcomes.

Figure 1.2 – The Integrative Risk Factor Framework (Stroebe et al., 2006)



1.4 Social Theories of Bereavement

Hagman (1995) argued that most modern theories of bereavement are derived from psychoanalytical perspectives, with a specific emphasis on Freud’s “Mourning and Melancholia” work (Freud, 1917). This epistemological position, Hagman argues, has caused a fundamental bias in bereavement theories since they are based on the cultural norm of European grief in the late 19th and early 20th centuries. At this time, the fashion for mourning was for a prolonged, introspective focus on the sadness accompanying the loss, stereotypically portrayed by Queen Victoria following the death of Prince Albert. The focus, then, was on facilitating decathexis and detachment from the relationship with the deceased. The theories that have been derived from this position therefore required the bereaved person to focus on “tasks of mourning” and, specifically, to try to restrict their thoughts and memories of the decedent. The notion of keeping an ongoing relationship with the deceased was very much viewed as abnormal and the possibility

that an ongoing attachment to the lost loved one may be beneficial rather than detrimental to wellbeing was not considered in early bereavement theories.

Attig (2001) posited that the early experience of profound loss in bereavement is a manifestation of the sense of suffering one feels when faced with the knowledge that they must live their lives without the loved one they have lost. He suggested that the personal “wholeness” that exemplifies contentedness in life is due to the connections that are built with meaningful others and, when one of these connections is broken, the sense of self has to be rebuilt taking account of the, now missing, meaningful connection. This theory has echoes of Bowlby’s (1981) view that pining and yearning for the deceased is a fundamental component of bereavement. During this time, the bereaved person is effectively searching for the lost loved one, an experience which is manifested by thinking they see the face of the decedent in a crowd, or catching sight of them out of the corner of their eye. The process of grieving, according to Attig, is one in which our world is “relearned” or reconstructed incorporating the absence of the loved one, combined with a coming to terms of the pain of the loss. This can be done either by finding ways to reduce the intensity of the pain or by learning to accept it and thus the pain become habitualised. This task of reconstructing our new view of the world, according to Attig, is achieved through a process of finding or making meaning of the lost loved one’s life and death.

Meaning reconstruction is achieved when the bereaved person is able to construct a narrative which then places the lost loved one in the individual’s new assumptive world view (Neimeyer, 2001). This narrative approach is influenced strongly by theories of social constructivism (Crossley, 2000), whereby an individual’s perception of reality is

based on their own experiences and belief systems. When the bereaved person tells and retells their story, they are effectively constructing a new narrative which explains the position and importance that the lost loved one has in their lives, accepts the reality of the loss and recognises how their world has been changed as a result of the life and death of the loved one. Consequently, Neimeyer suggested that irresolution of grief is manifested as an inability to find a meaningful narrative which incorporates the impact of the decedent's life on the bereaved. In the case of parental bereavement, it may be particularly difficult to find meaning in the loss as it undermines the basic assumption that life will follow a predictable course where the young will outlive the elderly. This may explain why the loss of a child is a particularly difficult bereavement to come to terms with.

The social view of bereavement is further extended by Valentine's (2008) work reporting how the bereaved continue an interdependent relationship with their lost loved ones. The continuing bonds reported in her studies included aspects of sharing and reciprocity which indicated that this feature of bereavement was adaptive, contradicting the earlier bereavement theories which emphasised disconnection from the deceased. Participants in Valentine's study frequently reported that they felt their loved one was "looking down on them", so that the behaviour of the bereaved should, in some way, be approved of by the lost loved one. A common phenomenon reported was the perception that the bereaved person had been contacted by the decedent in some way. This could be by the feeling of a physical presence, or by visiting a special place associated with the deceased. Both of these phenomena were reported as comforting and beneficial to the decedent, indicating that continuing bonds with a lost love one may be adaptive to the bereaved person, rather than being maladaptive as was thought historically.

1.5 Prolonged Grief as a Distinct Diagnostic Condition

The concept of prolonged grief as a potential psychiatric disorder, variously referred to as prolonged grief, complicated grief, traumatic grief, abnormal grief, chronic grief and pathological grief, has received increased attention in recent years. Whilst enduring distress has been evident in psychiatric practice for many generations, the notion that an individual can be “damaged” permanently following bereavement led mental health practitioners to begin to formulate a picture of what this ongoing course of symptoms may look like (Parkes & Weiss, 1983).

A key factor exhibited by those who demonstrated ongoing distress following bereavement was that of yearning or pining for the deceased (Parkes & Weiss, 1983). Originally believed to be indicative of a form of attachment disorder, this symptom has remained a consistent component of prolonged grief, featuring in the descriptions offered by key proponents of this phenomenon (Dillen, Fontaine & Verhofstadt-Deneve, 2008; Horowitz, 2005; Prigerson, Shear, Jacobs, Reynolds, Maciejewski, et al., 1999).

Prigerson et al.’s (2009) proposed diagnostic criteria for Prolonged Grief Disorder is shown in Appendix I. The description of the disorder is under review for inclusion in DSM-V and the current status is that more input from investigators regarding the phenomena is required before a final recommendation can be made (American Psychiatric Association, 2010). The key symptoms of the proposed disorder of prolonged grief are separation distress with persistent or intense yearning for the deceased, combined with cognitive, emotional or behavioural symptoms such as avoiding reminders of the loss, difficulty with accepting the loss and feeling incomplete

without the loved one's presence. Prigerson et al. accept that the proposed diagnostic criteria have been drawn mainly from work with bereaved spouses, and that other populations may exhibit different sets of symptoms. Whilst mindful of the need to avoid pathologising a naturally occurring phenomenon, where the grief experience would be expected to follow most bereavements, many practitioners suggest that, when symptoms persist beyond six months post-loss or where they cause significant disturbance to normal functioning, diagnosis and therapeutic intervention may be recommended (Stroebe, Schut & Stroebe, 2007). Again, this time scale is recognised as being representative of spousal bereavement, and may be different for other types of losses, including the death of a child.

1.6 Outcomes for Bereaved Parents

1.6.1 Health Outcomes

A recent review of health outcomes following bereavement reported a number of well-controlled studies which reported differences between bereaved and non-bereaved populations (Stroebe et al., 2007). Mortality following bereavement, commonly referred to as “dying of a broken heart”, is a well-supported finding with many studies reporting increased mortality following the death of a spouse. Only two studies were found which reported mortality rates in bereaved parents. The first reported that bereaved parents were twice as likely to die following the death of a child compared to a set of matched controls in the general population (Agerbo, 2005). The second study showed an increased mortality rate in bereaved mothers overall, and higher mortality from unnatural causes in bereaved fathers (Li, Precht, Mortensen & Olsen, 2003). In terms of physical health, the recently bereaved were noted as having higher rates of illness, pain and medical consultation than those in mid-late bereavement, and those bereaved

generally had higher incidences of physical illness than the non-bereaved. For bereaved parents specifically, mothers were found to have a higher incidence of physical illness overall, however fathers' health deteriorated over time following the bereavement whereas mothers' health did not (Murphy, Lohan, Braun, Johnson, Cain, et al., 1999).

A number of studies out with the Stroebe et al. systematic review also showed poorer health outcomes for bereaved parents compared to non-bereaved controls. Olsen, Li & Precht (2005) found a higher incidence of first reports of Type 2 diabetes in bereaved mothers, levels of multiple sclerosis were higher after bereavement (Li, Johansen, Bronnum-Hansen, Stenager, Koch-Henriksen, et al., 2004) as were levels of myocardial infarction (Li, Hansen, Mortensen & Olsen, 2002), however incidence of cancer, (Li, Johansen, Hansen & Olsen, 2002), recovery levels from cancer, (Li, Johansen & Olsen, 2003), incidence of stroke, (Li, Johansen & Olsen, 2003), irritable bowel syndrome, (Li, Norgard, Precht & Olsen, 2004) and rheumatoid arthritis, (Li, Schiottz-Christensen & Olsen, 2005) were not found to be significantly different in bereaved and non-bereaved parents.

As well as symptoms of prolonged grief as described earlier, bereaved parents are also at higher risk of other psychological conditions. Kreichbergs, Valdimarsdottir, Onelov, Henter and Steineck (2004) found that bereaved parents whose child died of cancer had higher levels of depression and anxiety than matched non-bereaved controls. Post-traumatic stress disorder was found to be three times more likely in bereaved mothers than the general population and twice as likely in bereaved fathers compared to a normative sample (Murphy, Johnson, Chung & Beaton, 2003). Psychological distress, as manifested as suicidal ideation is reported as "common" amongst bereaved parents

(Neria, Gross, Litz, Maguen, Insel, et al., 2007), and a study comparing bereaved parents with non-bereaved parents found the bereaved group to be twice as likely to die by suicide as the comparison group (Agerbo, 2005).

1.6.2 Changes in Social Functioning

Although widely reported as problematic following the death of a child, the notion that relationship breakdown is likely or even inevitable is not supported by empirical evidence (Murphy, Johnson & Lohan, 2003b). Some studies even suggest that the loss of a child may strengthen marital bonds, leading to a more stable relationship following bereavement (Schwab, 1998). This “myth” that marital struggles are endemic in parental bereavement is, however, a common feature in the narratives of bereaved parents as they discuss the challenges they face following their loss (Stebbins & Batrouney, 2007).

The study carried out by Corden, Sloper and Sainsbury (Corden, Sainsbury & Sloper, 2002) indicated that bereaved parents who have lost a chronically ill child may face financial difficulties from a reduction in benefit income, additional expenditure for funeral costs etc. and loss of earnings whilst absent from work. This is echoed by Stebbins & Batrouney (2007) who reported bereaved parents’ loss of income and additional expenditure across a wide range of situations. In addition, they point out that three quarters of parents interviewed reported problems at work, often having to take unpaid leave and either chose, or were forced to leave work permanently. These additional restoration-oriented stressors may, in turn, impede the process of coping with parental bereavement, thus exacerbating grief symptoms.

1.6.3 Emotional Consequences

The most problematic emotions experienced following parental bereavement are guilt and anger (Rando, 1986). Whilst no study has been found which compares the prevalence of these emotions in bereaved parents to any control group, the correlation between these emotions and grief has been demonstrated. Barr and Cacciatore (2007) found guilt-proneness to be significantly associated with grief in perinatally bereaved mothers. An association between guilt and depression was also found in parents whose child died as a result of cancer (Surkan, Kreicbergs, Valdimarsdottir, Nyberg, Onelov, et al., 2006). Anger's association with bereavement outcomes is less well defined, however one study suggested it did rise in line with grief symptoms, peaking at two years post-loss (Fish, 1986).

1.7 Aims of the Thesis

Most of the bereavement literature, including the proposed diagnostic criteria for Prolonged Grief and the Integrative Risk Factors Framework, is dominated by the experience of spousal bereavement. The primary aim of this thesis, therefore, is to further scientific knowledge in the area of parental bereavement, in terms of outcomes, coping methods and risk factors for psychological distress, using the Stroebe Integrative Risk Factor Framework as a guide. In doing so, we attempt to address two key issues recommended for the study of bereavement (Bowlby, 1981). We aim to gain an understanding of what "normal" grief may be for bereaved parents, and we also begin to identify what risk factors may be associated with prolonged grief and depression, following the death of a child.

Therefore, the specific aims of the thesis are:

- (i) To investigate which aspects of coping with bereavement are viewed by bereaved parents themselves as helpful/unhelpful in the process of adjustment to their loss
- (ii) To identify what social changes bereaved parents experience following the death of a child
- (iii) To determine which factors are associated with different outcomes, using the Integrative Risk Factor Framework as a guide
- (iv) To gather evidence of outcomes, and factors associated with these outcomes, in early, mid and late parental bereavement

1.8 Thesis Structure

The literature review in Chapter two focuses on the risk factors which are identified as being associated with poorer outcomes in parental bereavement. Chapter three provides an overview of the methods used in the thesis. Specifically, this provides a summary of the approach chosen for the qualitative study, namely Interpretative Phenomenological Analysis, along with detailed information on each of the measures being used in the quantitative studies that are later described. Chapter four reports the findings of an exploratory study, which aims to identify what outcomes are noted as important by bereaved mothers, and which factors may have played a part in determining these outcomes. Chapter five aims to identify which are the key factors which are associated with differential outcomes in a group of bereaved parents in early bereavement (up to three years post-loss) and chapter six investigates which factors are key in mid-bereavement (four years post-loss). Chapter seven reports the findings of a Scottish Census study, which compares the mortality and social outcomes for bereaved parents who experience stillbirth or infant death, to a control group, up to fifteen years post-

bereavement. Chapter eight reports similar mortality and social changes in a larger group of bereaved parents in the Census records for England and Wales, up to 35 years post-bereavement. Chapter nine provides a general discussion of the findings of the thesis and indicates their implications for research and clinical practice. Strengths and limitations of the research are reviewed and suggestions are made for further research in the field of parental bereavement.

Chapter Two – Literature Review of Factors Associated with Differential Outcomes of Parental Bereavement

2.0 Abstract

2.0.1 Background

The Integrative Risk Factor Framework indicates a number of factors which may be associated with different outcomes following bereavement (Stroebe et al., 2006). Whilst a number of these variables have emerged from previously published literature on general bereavement, the factors associated with differential outcomes following parental bereavement are less clearly defined.

2.0.2 Method

A literature review was therefore conducted to identify published studies which report potential dependent and independent variables for testing bereavement outcomes in bereaved parents.

2.0.3 Results

Grief and depression emerged as the most common outcome variables in the reported literature, however the paucity of the available research and the heterogeneity of measurement instruments employed rendered selection of variables for future testing problematic.

2.0.4 Conclusions

Grief and depression have been widely used in previous research as outcome variables, but there are no clear predictors shown to be reliably associated with differential outcomes.

2.1 Introduction

The Integrative Risk Factor Framework (Stroebe et al., 2006), as described in chapter one, indicates that outcomes for the bereaved individual depend upon factors from a number of domains. Later studies in this thesis will test different aspects of the interactive framework, however testing all of the proposed factors would not be feasible within one individual research project. A review of the literature has, therefore, been carried out in order to establish which factors have been identified as important factors and/or excluded in determining outcomes for parents who experience the death of their child. There are many reported studies which examine the factors which may affect the outcome of general bereavement experiences, however very few studies consider the experience of coping with the death of a child, from the parent's perspective. To ensure that the factors for subsequent testing are relevant to the experience of parental bereavement, the literature review has been conducted within the confines of the literature pertaining specifically to parental bereavement.

2.2 Method

The three main psychological and medical databases were searched. These were Web of Science (1981 - September 2010), Medline (from 1966 - September 2010) and Psychinfo (1887 – September 2010). The searches were carried out with the following keywords:

((child* or teenage* or adolesc* or infan* or perinatal) and (death or bereave*)) and (Title = (Death* or grie* or died or dies or suicid* or murder* or accident* or homicid* or bereave* or fatal* or deceased or los* or mourn*)) or keyword = parent* bereave*).

This search yielded 10,571 results, most of which were reports of medical findings related to causes of death. These, and any articles not related to the death of a child, were excluded from the results by examination of the article title, leaving 787 articles within the area of parental bereavement.

All of the abstracts of the remaining articles were read and papers were included which fulfilled the following criteria:

- 1) Studies included data specifically relating to parental bereavement or, if other types of bereavement were included, the data relating to parental bereavement were reported separately;
- 2) Studies incorporated a specified outcome variable, and considered the impact of, or association with, differential values of predictors;
- 3) Studies did not incorporate any interventions under test, since these may have affected bereavement outcomes which occurred naturalistically;
- 4) Evaluations were made of the current status of the participants, and were not based on retrospective judgements of earlier experiences;
- 5) Studies did not include participants from areas where child mortality rates are significantly elevated, for example, sub-Saharan Africa.

Reference sections from those papers which fulfilled the above inclusion criteria were then manually checked for any further candidate articles. Any which were identified then had their abstracts scrutinised for inclusion using the criteria, as specified above. This inclusive strategy was adopted in order to minimise the possibility of overlooking any potentially relevant studies.

The search and review process yielded 21 published empirical papers which were relevant. Within the papers, variables are reported which were found to be associated with a measured outcome. These are shown below in Table 2.1.

Table 2.1 – Studies Reporting Factors Associated with Grief in Parental Bereavement

<i>Study/ Country</i>	<i>Child cause of death/ Age/Time Since Death</i>	<i>Parent Sex/Age/ Recruitment Source</i>	<i>Outcome Variables</i>	<i>Predictors+</i>	<i>Results</i>
(Anderson, Marwit, Vandenberg & Chibnall, 2005) USA	34 murder, 23 accident Mean age 20 years (SD=7) Mean TSD = 4.5 years (SD=2.7)	57 mothers Mean age 51 years (SD=9) Recruited from support groups	RGEI (Lev, Hazard Munro & McKorkle, 1993)	CISS (Endler & Parker, 1994); RCAS (Pargament, Ensing, Falgout & Olson, 1990)	Grief associated with TSD. When TSD was controlled for, emotional coping and avoidance coping were associated with grief, positive coping associated with grief when task coping was high. No correlation between grief and child's age, gender, cause of death, marital status, education.
(Bohannon, 1991) USA	“Many types” of cause of death – details not specified Range from stillbirth to adult death – details not specified Mean TSD = 1 year 8 months, range 2 months – 5 years	33 couples Fathers mean age 44 years, Mothers mean age 41 years Recruited from support groups	GEI (Jacobs, 1987)	Gender	Fathers experienced less grief than mothers

<i>Study/ Country</i>	<i>Child cause of death/ Age/Time Since Death</i>	<i>Parent Sex/Age/ Recruitment Source</i>	<i>Outcome Variables</i>	<i>Predictors+</i>	<i>Results</i>
(Downey, Silver & Wortman, 1990) USA	SIDS Mean age 81 days (SD=49 days), range 9 days – 11 months Interviews at 15-30 days post-death, 3 months and 18 months	176 mothers and 85 fathers Mean parent age 25 years (SD=5.3) Recruited from hospital records	SCL-90-R (Derogatis, Ricklels & Rock, 1976)	Specially constructed instrument measuring meaning making	At 3 months post-death mothers were more likely to blame themselves for the death than fathers and had higher ratings of distress. Parents who attributed cause to themselves were more distressed.
(Drenovsky, 1994) USA	76% sudden deaths Age not specified TSD not specified	39 couples Mean age 43 years Recruited from support groups	CES-D (Radloff, 1977)	Gender, suddenness of death, feelings of anger and retribution	Mothers were significantly more depressed than fathers, sudden death was associated with increased depression, higher TSD was associated with decreased depression, feelings of anger and retribution do not affect depression
(Engelkemeyer & Marwit, 2008) USA	41 murder; 35 accident; 35 illness Mean age 15 years (SD=7.5) TSD 1 month – 37 years, mean 7 years (SD=8)	111 BPs, gender split not given Mean age 50 years (SD=12) Recruited from support groups and medical records	PTGI (Tedeschi & Calhoun, 2004)	WAS (Janoff-Bulman, 1989) RGEI (Lev et al., 1993)	Self-worth correlated with PTG. TSD was the strongest predictor with 8% of variance in PTG. Grief in 2 nd step of regression accounted for another 4%. When WAS variables entered at step 3, grief became NS, self-worth was then significant. No difference in WAS for gender, child's age, parent's age or education

<i>Study/ Country</i>	<i>Child cause of death/ Age/Time Since Death</i>	<i>Parent Sex/Age/ Recruitment Source</i>	<i>Outcome Variables</i>	<i>Predictors+</i>	<i>Results</i>
(Feigelman, Gorman & Jordan, 2009) USA	462 suicide, 54 accident or other traumatic deaths, 24 natural causes Age range < 15 years to over 36 years, 80% of deaths occurred between the ages of 16 and 35 years TSD between < 12 months and > 10 years.	540 BPs, 85% female Age range 46-65 years Recruited from support groups	GEQ (Barrett & Scott, 1989) ICG (Prigerson, Frank, Kasl, Reynolds, Anderson, et al., 1995)Mid- Life survey (depression) development (Wethington, Kessler & Brim, 2005) Suicidal ideation question	Societal stigmatisation from specially designed scale	Stigma scale score strongest predictor of GEQ. Grief difficulties, stigma and TSD predicted depression. Depression and grief predicted SI

<i>Study/ Country</i>	<i>Child cause of death/ Age/Time Since Death</i>	<i>Parent Sex/Age/ Recruitment Source</i>	<i>Outcome Variables</i>	<i>Predictors+</i>	<i>Results</i>
(Hazzard, Weston & Gutterres, 1992) USA	Cause of death not specified Mean age 6.3 years (SD=5.9), range few months to 17 years TSD mean 24.7 months (SD=14.0), range 6 months – 50 months	26 mothers, 19 fathers Age range 25 years to over 45 years Recruited from medical records	GEI (Sanders, Mauger & Strong, 1979)	Parent questionnaire measuring demographics, premorbid factors, factors associated with death, TSD, support, subsequent stressors, attribution	Parents of boys, whose child died suddenly had higher despair, anger, guilt and depersonalisation. Social support, subsequent stressors and blaming fate were associated with higher grief.
(Ito, Tomita, Hasui, Otsuka, Katayama, et al., 2003) Japan	SIDS, neonatal death, stillbirth, encephalopathy, accident, illness Mean age 15 months (SD=19), range 0-10 years. TSD 41 months (SD=25)	106 – 28 men, 78 women Mean age 35 years (SD=6), range 24-60 years Recruited from support groups and advertising	SCID (First, Spitzer & Williams, 1999)	RSQ(Nolen- Hoeksema, Parker & Larson, 1994) Response Style Items After Loss	Ruminative coping a weak predictor of depression but not anxiety. No association between distractive coping styles and either depression or anxiety.

<i>Study/ Country</i>	<i>Child cause of death/ Age/Time Since Death</i>	<i>Parent Sex/Age/ Recruitment Source</i>	<i>Outcome Variables</i>	<i>Predictors+</i>	<i>Results</i>
(Littlefield & Silverman, 1991) Canada	43% accidents, 32% illness, 10% congenital defect, 8% suicide, 5% murder, 2% birth complications. Mean age 14 years, range 0-45 years TSD 2.2 years (SD=1.8)	148 BPs, couples Mean age 45 years, range 22-73 years Recruited from support groups	GEI (Sanders et al., 1979)	Actual and perceived cause of death, reported marital satisfaction	Mothers grieved more than fathers, healthy children were grieved for more than unhealthy children; male children were grieved for more than female children; health of child and sex of child interacted such that the pattern of grief intensity obtained
(McIntosh, Silver & Wortman, 1993) USA	SIDS TSD - 15 days post-loss, 30 days, 3 months, 18 months	124 parents, 79% mothers. Mean age 25 years (SD=5), range 15-40years Recruited from death records	Affects Balance Scale (Derogatis, 1992) SCL-90-R (Derogatis et al., 1976)	Religion, social support, cognitive processing, meaning all from interviews	At 18 months post-loss, religion, social support, meaning and cognitive processing were not associated with distress or wellbeing
(Morrow, Hoagland & Carnrike, 1981) USA	Cancer Mean age 6 years (SD=4.6), range 1-20 years TSD not specified	37 BPs, 66% female. Age range 23-58, median 37 Recruited from support groups	Psychosocial adjustment to illness scale	Social support measured by asking participants to rate the level of support offered by up to 11 sources	Younger parents had poorer psychosocial adjustment. No gender difference. No correlation between support and adjustment

<i>Study/ Country</i>	<i>Child cause of death/ Age/Time Since Death</i>	<i>Parent Sex/Age/ Recruitment Source</i>	<i>Outcome Variables</i>	<i>Predictors+</i>	<i>Results</i>
(Murphy, Johnson & Lohan, 2003a)USA	Accident, murder, suicide. Mean age 20 years, range 12-28 years TSD 6-28 weeks	173 parents, 66% mothers. Mean age 45 years (SD=6), range 32-61 years Recruited from death records	BSI (Derogatis, 1992) Traumatic Experiences Scale – created for the study	RSE (Rosenberg, 1979) COPE (Carver, Scheier & Weintraub, 1989)	At one and five years post-death, self-esteem was a significant predictor of mental distress and PTSD. After controlling for self esteem, the use of active/ affective coping strategies predicted less mental distress for fathers but not for mothers. Repressive coping strategies were significant predictors of higher PTSD symptoms for both mothers and fathers at both one and five years post-death. Active/affective coping strategies were not significant predictors of lowered PTSD symptoms for either mothers or fathers.
(Purisman & Maoz, 1977) Israel	Death in war Adults, age not stated. TSD 2-3 years	25 mothers, 22 fathers Age not stated Recruited from military records	General adjustment assessed by raters using self-report interview data	Religion, education, ethnicity, years in the country, work outside home, ritual surrounding death, marriage, social contacts	Higher education associated with better adjustment, religion and ritual poorer adjustment, being married and having good social support was associated with better outcomes. Marriage problems were evident prior to the loss

<i>Study/ Country</i>	<i>Child cause of death/ Age/Time Since Death</i>	<i>Parent Sex/Age/ Recruitment Source</i>	<i>Outcome Variables</i>	<i>Predictors+</i>	<i>Results</i>
(Robinson & Marwit, 2006) USA	59% accident, 40% murder, 1% suicide. Mean age 18 years (SD=9). TSD mean 6.9 years (SD=7.2), range 3 months – 31 years	138 bereaved mothers. Mean age 52 years (SD=12) Recruited from support groups	RGEI (Lev et al., 1993)	Neuroticism and extraversion using EPQ (Eysenck, 1975) CISS (Endler & Parker, 1994)	Grief correlated with Neuroticism, Extraversion, TSD, Emotion, task and avoidance coping. When controlling for TSD, Neuroticism and Extraversion, Emotion oriented coping had most significance
(Shanfield, Swain & Benjamin, 1986) USA	Road accidents Mean age 24.6 years (SD=5.5) TSD 26 months (SD=5)	20 mothers, 20 fathers Mean age 40.5 years (SD=8.1) Recruited from death records	BDI (Beck, Ward, Mendelson, Mock & Erbaugh, 1961) SCL90 (Derogatis, 1979) Grief, guilt, painfulness of loss and family growth from specially designed questionnaire	Demographics	Depression - Child's problems, being a mother, few previous bereavements Grief – being an older child, mutual interdependence, less involvement in family decisions, prior bereavements Guilt – ambivalent relationship with child Greatest loss – age, few prior bereavements, emotional dependency Family growth – mutual interdependence, non-ambivalence, child moving out at older age, few child problems, child being married

<i>Study/ Country</i>	<i>Child cause of death/ Age/Time Since Death</i>	<i>Parent Sex/Age/ Recruitment Source</i>	<i>Outcome Variables</i>	<i>Predictors+</i>	<i>Results</i>
(Sidmore, 1999) USA	9 accident, 2 suicide, 2 stillbirth, 5 illness, 1 other Age range 0-26 years TSD range 14-238 months	13 mothers, 6 fathers, Age range 30-65 years Recruited from support groups	GEI (Sanders, Mauger & Strong, 1985)	Demographics – sex of parent, sex of child	Mothers had greater grief than fathers, Sex of child made no difference to levels of grief
(Surkan et al., 2006) Sweden	Cancer. Child age < 25 years TSD range 4-9 years	449 BPs, 56% female. Age range and mean not stated. Recruited from death records.	Questionnaire measuring guilt	Questionnaire measuring demographics, perception of care, perception of symptom relief, perceptions of own health care needs.	Perceptions of inadequate health care, lack of access to symptom relief, lack of fulfilment of parent needs all associated with higher guilt.
(Videka-Sherman, 1982) USA	Stillbirth, sudden or anticipated deaths due to illness and violent death Child ages not detailed TSD < 18 months	391 BPs, 70% female Mean age 41 years, range 21-67 years Recruited from support groups	HSCL (Derogatis, Lipman, Rickels, Uhlenhuth & Covi, 1974)	Specially prepared instrument measuring coping, support group involvement	Preoccupation, religiousness and altruism associated with better adjustment. Escape coping NS.

<i>Study/ Country</i>	<i>Child cause of death/ Age/Time Since Death</i>	<i>Parent Sex/Age/ Recruitment Source</i>	<i>Outcome Variables</i>	<i>Predictors+</i>	<i>Results</i>
(Wijngaards de Meij, Stroebe, Schut, Stroebe, van-den-Bout, et al., 2007) Netherlands	Stillbirth or Neonatal death 16%, Illness 48%, Accident, SIDS, suicide or murder, 36%. Mean age 10years (SD=10), range up to 30 years TSD 6, 13 and 20 months post loss	219 couples Mean age 42 years (SD=9) Age range 26-68 years Recruited from obituary notice	ICG (Prigerson, Frank et al., 1995) SCL90 (Derogatis et al., 1976)	AAS (Collins & Read, 1990) Neuroticism EPQ (Eysenck & Eysenck, 1991)	Avoidant and anxious attachment and neuroticism both predicted grief and depression
(Wijngaards-de Meij, Stroebe, Stroebe, Schut, Van den Bout, et al., 2008) Netherlands	Stillbirth or Neonatal death 16%, Illness 48%, Accident, SIDS, suicide or murder, 36%. Mean age 10years (SD=10), range up to 30 years TSD 6, 13 and 20 months post loss	219 couples Mean age 42 years (SD=9) Age range 26-68 years Recruited from obituary notices	ICG (Prigerson, Maciejewski, Reynolds, Bierhals, Newsom, et al., 1995) SCL90 (Derogatis et al., 1976)		Controlling for TSD, gender of parent, age of child and unchangeable variables, taking the body home and saying farewell predicted less grief. Controlling for TSD, gender of parent, age of child and unchangeable variables, no “changeable variables” were associated with depression. Type of disposal, whether parents cared for the body and whether they were present at the time of death were not significant on either grief or depression.

<i>Study/ Country</i>	<i>Child cause of death/ Age/Time Since Death</i>	<i>Parent Sex/Age/ Recruitment Source</i>	<i>Outcome Variables</i>	<i>Predictors+</i>	<i>Results</i>
(Wijngaards-de Meij, Stroebe, Schut, Stroebe, van den Bout, et al., 2008) Netherlands	Stillbirth or Neonatal death 16%, Illness 48%, Accident, SIDS, suicide or murder, 36%. Mean age 10years (SD=10), range up to 30 years TSD 6, 13 and 20 months post loss	219 couples Mean age 42 years (SD=9) Age range 26-68 years Recruited from obituary notices	ICG (Prigerson, Maciejewski et al., 1995) SCL90 (Derogatis et al., 1976)	Dual Coping Inventory created for the study	Women had greater grief and depression than men, TSD decreased grief and depression for both genders. High loss-orientation predicted higher grief and depression, high restoration-orientation predicted lower grief and depression. High levels of restoration-orientation moderated the effects of high loss-orientation. Men had better outcomes when their partner had high restoration orientation. High levels of loss-orientation were not associated with partner or gender effects.

Notes. TSD= Time Since Death, RGEI= Revised Grief Experiences Questionnaire, CISS= Coping Inventory for Stressful Situations, RCAS= Religious Coping Activities Scale, GEI= Grief Experiences Inventory, SCL-90-R= Symptoms Checklist 90 Revised, CES-D= Centre for Epidemiological Studies Depression Scale, PTGI= Post Traumatic Growth Index, WAS= World Assumptions Scale, GEQ= Grief Experiences Questionnaire, SIDS= Sudden Infant Death Syndrome, SCID= Structured Clinical Interview for Depression, RSQ= Response Styles Questionnaire, SCL-90 Symptoms Checklist 90, RSE= Rosenberg Self-Esteem Inventory, BSI= Brief Symptoms Index, EPQ= Eysenck Personality Questionnaire, HSCL= Hopkins Symptoms Checklist, ICG= Inventory of Complicated Grief, AAS= Adult Attachment Scale.

2.3 Method of Analysis

The research papers were scrutinised from three perspectives. These were the demographics of participants and their bereavements, the predictors used and the outcome variables used. The results of these analyses are shown below.

2.3.1 Demographics

Participants in the studies were recruited from a number of sources. Nine of the studies recruited participants from support groups (Anderson et al., 2005; Bohannon, 1991; Drenovsky, 1994; Feigelman et al., 2009; Littlefield & Silverman, 1991; Morrow et al., 1981; Robinson & Marwit, 2006; Sidmore, 1999; Videka-Sherman, 1982), two recruited participants from medical records (Downey et al., 1990; Hazzard et al., 1992), one recruited from a combination of both (Engelkemeyer & Marwit, 2008) and one recruited from support groups and advertising (Ito et al., 2003). In addition, four studies recruited from death records (McIntosh et al., 1993; Murphy, Johnson & Lohan, 2003a; Shanfield et al., 1986; Surkan et al., 2006) and three found participants from the obituary notices they had published in newspapers (Wijngaards-de Meij, Stroebe, Schut et al., 2008; Wijngaards-de Meij, Stroebe, Stroebe et al., 2008; Wijngaards de-Meij et al., 2007). One study recruited parents from the military records of their children (Purisman & Maoz, 1977).

The mean age of the child who died varied across studies. Two studies concentrated on coping with the loss of an adult child (aged 18+ years) (Anderson et al., 2005; Purisman & Maoz, 1977), thirteen considered both children and adults (Bohannon, 1991; Engelkemeyer & Marwit, 2008; Feigelman et al., 2009; Littlefield & Silverman, 1991; Morrow et al., 1981; Murphy, Johnson & Lohan, 2003a; Robinson & Marwit, 2006;

Shanfield et al., 1986; Sidmore, 1999; Surkan et al., 2006; Wijngaards-de Meij, Stroebe, Schut et al., 2008; Wijngaards-de Meij, Stroebe, Stroebe et al., 2008; Wijngaards de-Meij et al., 2007) , two investigated children aged under 18 (Hazzard et al., 1992; Ito et al., 2003), two investigated infant deaths (Downey et al., 1990; McIntosh et al., 1993) and two were unspecified (Drenovsky, 1994; Videka-Sherman, 1982). The age ranges of the parents in the studies correlated with the ages of the children, as expected, with parents of infants having a lower mean age than parents of adult children.

Cause of death was very much associated with the age range of children at their time of death. Where the demographic of the deceased included adults and children, the causes of death were a mixture of illness, accident and murder. The studies concerned with infant deaths were predominately concerned with Sudden Infant Death Syndrome, neonatal death in the first few weeks of life, stillbirth or congenital illness.

The time since death also varied both within and between studies. Some studies, such as Downey et al. (1990), McIntosh (1993) and the studies from the Utrecht centre (Wijngaards de-Meij et al., 2007)) elected to focus on a narrow time frame in early bereavement, whereas the other studies had a far broader range of time since death in their participants.

For those studies where gender was described, most had more female participants than males. Only those who specifically recruited couples (Drenovsky, 1994; Littlefield & Silverman, 1991; Wijngaards-de Meij et al., 2007, 2008a and 2008b and Shanfield & Swain, 1984) had equal numbers of male and female participants.

2.3.2 Outcome Variables

The most widely reported outcome variable was grief, which was measured in nine studies. To measure grief, six studies used the Grief Experience Inventory or Revised Grief Experience Inventory, two studies used the Inventory of Complicated Grief and one study used the Grief Experiences Questionnaire. Depression was predominately measured by the original or revised Symptom Checklist-90 (n=6), with one study using the Beck Depression Inventory, one the Center for Epidemiologic Studies Depression Scale and one the Hoskins Checklist -90. One study utilised variables from the Mid-life Development Survey to establish levels of depression in participants.

Additional outcome variables in other studies were post-traumatic growth measured by the Post-Traumatic Growth Inventory and distress and wellbeing measured by the Affect Balance Scale. Other studies utilised bespoke questionnaires or interview schedules to establish potential levels of post-traumatic stress disorder, guilt, psychosocial adjustment and overall general adjustment to the loss.

2.3.3 Predictors

In the studies where participant demographics covered a wide range of time since death, the bereavement time scale appeared to mainly be negatively associated with levels of grief and/or depression (Anderson et al., 2005; Drenovsky, 1994; Engelkemeyer & Marwit, 2008; Feigelman et al., 2009; Robinson & Marwit, 2006; Wijngaards-de Meij et al., 2008b). Hazzard et al. (1992) found no association between time since death and grief symptoms.

Gender differences were reported in only some of the studies. Bohannon (1991), Drenovsky (1994), Littlefield et al. (1991), Sidmore (1999) and Wijngaards-de Meij et al. (2008b) all reported mothers experiencing higher levels of grief than fathers, yet Hazzard et al. (1992) reported no difference in grief symptoms between men and women.

Age effects are also unclear in these studies. Age of child was not related to grief in three studies (Anderson et al., 2005; Engelkemeyer and Marwit, 2008; Hazzard et al., 1992), but Shanfield and Swain (1984) found higher grief in parents who lost older children. Wijngaards-de Meij (2008a) found the association between the age of the child and grief to be curvilinear, increasing until the age of 18 years, thereafter decreasing again.

The studies which measured coping styles explicitly produced a variety of findings. In the Anderson et al. (2005) study, emotional and avoidance coping was found to be associated with higher levels of grief. This finding was supported by Robinson and Marwit (2006), who reported that emotion, task and avoidance coping were all associated with higher levels of grief. Anderson et al. also found, perhaps unexpectedly, that when task coping was high, positive coping was also associated with grief. Ito et al. (2003) found ruminative coping to be a weak predictor of depression, but that distractive/avoidance coping had no association with grief outcomes. Comparing the coping styles of mothers and fathers, Murphy et al. (2003) found that fathers' use of active or affective coping strategies predicted less distress, but this finding did not hold for mothers. Repressive coping was not associated with one sex more than the other, as it was associated with higher PTSD symptoms for both mothers and fathers. Finally,

Videka-Sherman (1982) found that preoccupation with the loss was associated with higher grief symptoms, where altruism and, to a lesser extent, religiousness, were both associated with lower grief scores.

Four studies (Anderson et al., 2005, Bohannon, 1991, McIntosh et al., 1993 and Purisman and Maoz, 1977) chose religiosity as their key predictor. Anderson et al. established that different coping strategies were associated with religious activity but that religious coping in itself was not related to different levels of grief. McIntosh et al. found no relationship between religious behaviours and outcome and Bohannon reported religious behaviours correlated with more positive outcomes for mothers, but not so strongly for fathers. In addition, Purisman and Maoz found poorer adjustment in parents with high levels of religiosity. All four studies used different methods of measuring religious behaviour, making detailed comparison of these results problematic, however it would appear that the relationship with religious activity and outcome following parental bereavement is unclear.

2.4 Conclusion

The limited and somewhat diverse research into parental bereavement does not provide clear guidance for selection of predictors and formulation of hypotheses for testing. Grief, and to some extent, depression, would appear to be emerging as the most prominent outcome measures. Time since death and gender appear to be related to different outcomes, but the relationship between the age of the child and bereavement outcomes is less clear.

In terms of coping behaviours, use of different measures of coping and religiosity make comparison across studies difficult. From what has been published to date, clear associations between different coping strategies cannot be reliably made. In the light of the limited insight that the published research offers, an exploratory study would be appropriate to further inform the choice of factors which should form the structure of quantitative testing of this phenomenon.

Chapter Three – Methods

3.0 Abstract

3.0.1 Background

The topic of coping with parental bereavement is not one which has an extensive published literature base. There is no consensus about which factors may affect bereavement outcomes, nor is there much research evidence focussing on those outcomes themselves. Given the paucity of research evidence, a multi-method approach was employed to identify and investigate risk factors for bereavement outcomes.

3.0.2 Method

The first phase of the research was qualitative in nature, to elicit information about the lived experience of parental bereavement. Using the results from this study, later quantitative methods identified which factors had the most impact on outcomes for parents, and for how long these effects could be measured. Appropriate research methods were chosen to achieve these desired research objectives. The strengths and limitations of each method were discussed.

3.0.3 Results

Interpretative Phenomenological Analysis was chosen as the qualitative research method. Self-report questionnaires completed at a single point in early bereavement and at two time points in later bereavement provided data for analysis using multivariate regression statistics to identify the key factors which affect outcomes. Use of existing national longitudinal datasets would additionally provide data identifying the long term impact of parental bereavement.

3.0.4 Conclusions

The multi-method approach would appear to be the best method in order to provide a comprehensive analysis of the experience of parental bereavement.

3.1 Introduction

Research in the topic of parental bereavement is a relatively rare activity, as was demonstrated with the literature search reported in chapter two. Research methods and knowledge about key factors of the topic have therefore not been widely reported and, as such, the research area is still very much in its infancy. To allow a project to generate reliable results, research in this area must take a “bottom up” approach, establishing the basics before more detailed investigation of factors under examination can be carried out. This thesis will, therefore, begin with a qualitative enquiry, followed by detailed quantitative testing, before concluding with analysis of long-term existing national datasets.

3.2 Requirements for the Qualitative Method Chosen

3.2.1 Function of the Research

There are several qualitative methods commonly used in psychological research, one of which must be chosen to fulfil the requirements of the research under consideration.

The method selected must answer the research question directly, which in this case was “What are the ways in which bereaved parents cope with the death of a child?” This question requires the consideration of both contextual evidence, where the participant describes what the experience of parental bereavement is like, and generative evidence, where actions, cognitive processes and beliefs are reported as factors potentially affecting the bereavement outcome (Ritchie, 2003). The proposed study does not attempt to fulfil either an explanatory role, where the participant provides data on why they have chosen a particular coping strategy, nor does it attempt to fulfil an evaluative role by establishing the adaptiveness of any given behaviours or cognitions. The method chosen must therefore be one which is both contextual and generative.

3.2.2 Participant Population

The first consideration for the research design was the population under review. The research aimed to get as close as possible to the experience of parental bereavement, thus the participants themselves should be bereaved parents. Information from professionals or family members would not be sought in this particular project.

The results of the study were expected to inform a choice of factors for later quantitative testing in a broad range of participants whose child died at any age from birth to adulthood, and where the death occurred as a result of accident or illness, suddenly or following a lengthy period of decline. From this standpoint, it is clear that a number of participants must be involved, with a corresponding breadth of bereavement experiences. An individual case study approach would not be appropriate, since the research was intended to identify common factors across the different bereavement experiences. The research method should therefore highlight commonalities across the lived experience of parental bereavement.

3.2.3 Timing of Research

The course of parental grief over time is not clearly defined in the existing literature, however researchers have found continuing grief in bereaved parents over many years, even up to 62 years from the time of the loss (Arnold, Gemma & Cushman, 2005). This suggests that coping with parental bereavement may be a lifelong challenge, therefore the time since death for participants was not a criterion for participant recruitment.

Restrictions on the time available for data collection within the context of a PhD eliminated the option of longitudinal data collection, therefore each participant would be seen only once to gather the required information.

3.2.4 Participant Recruitment

The sensitive nature of this research was a key determining factor in participant recruitment and the researchers were keen not to unwittingly intrude on people who wished their experience to remain private. Participant recruitment would therefore be through an open invitation, allowing people who wished to take part to volunteer but without causing those who did not wish to take part any guilt.

3.2.5 Data Collection Method

The decision whether to use naturally occurring data or data generated for the purposes of the research project was made on the basis of practicality. Naturally occurring data could have been gathered by observation of bereaved parents or through conversation analysis, however both of these methods would have required multiple meetings over a period of time. Support groups would have provided an intense, concise set of data relating to parents actively discussing their experience, but may have resulted in a bias of results towards that of the culture of the organisations. Meeting bereaved parents outside of this type of situation, perhaps in a domestic or social setting, would probably give rise to rich naturally occurring data (Lewis, 2003), however the time to collect these results would not have been feasible within the constraints of the PhD process. As a result, the decision was made to arrange a single meeting with individual participants where the topic of parental bereavement would be explored in depth. Again, given the sensitive and highly personal nature of the experience, individual interviews were chosen in preference to focus groups, to provide participants with the highest level of privacy possible.

3.2.6 Protecting the Participants from Harm

The qualitative research was subject to the same ethical approval guidelines as the quantitative research. The research protocol, proposed interview schedule and participant recruitment method were evaluated and approved by the Department of Psychology Ethics Committee within the University of Stirling. At the time of the interview, the researcher made clear that withdrawal of consent to continue could take place at any time without explanation. Relevant local sources of support were provided to the participant in the form of an information sheet, and some time was set aside for an informal debrief with the researcher, once the data collection had been completed.

3.2.7 Protecting the Researcher from Harm

Since the interviews with participants would take place in their own homes, a security protocol was followed to ensure that the whereabouts of the participant was known at all times during the interview process. A named employee of the Department of Psychology was identified as the key point of contact. The researcher notified this named individual with the address of the interview, the house telephone number and the start time and likely finish time. If the interview continued past the estimated finish time, the researcher would send a text message to the named individual advising that an extension would take place. Once the interview was completed, the named individual would be sent a text informing them that the researcher was no longer at the participant's house. If any of these messages failed to be sent at the agreed time, the named individual would first attempt to contact the researcher on her mobile phone. If there was no response, the researcher was to call the home number of the participant and ask to speak to the researcher. If this did not happen or there was any doubt over the safety of the researcher, the police office local to the participant's home was to be

alerted. This security protocol was followed but no escalation was invoked throughout the data collection process.

As well as physical security, the emotional wellbeing of the researcher was considered and steps were put in place to minimise any distress which may have occurred when discussing these highly emotive experiences. The first supervisor, himself a qualified and experienced clinical psychologist, could be contacted immediately after the interview if distress occurred. Some of these meetings did take place and, where appropriate, debriefing was carried out. If the researcher experienced any ongoing concerns about the interview, both supervisors prioritised their availability for discussion, debrief and consultation at any time. Alternatively, the researcher had access to the counselling services offered by the university, should she feel that these would be beneficial.

3.2.8 Selection of Qualitative Method

A short list of three potential qualitative methods was considered for the study of the phenomenon of parental bereavement. This shortlist was derived from the research experience of the supervisors and within the wider Department of Psychology as a whole. The methods considered were discourse analysis, grounded theory and Interpretative Phenomenological Analysis (IPA). There is evidence of overlap between the techniques under consideration, however there were two key reasons why IPA was selected as the method to be used. The first is that the IPA method states clearly that its aim is to look beyond the actual words spoken in an attempt to interpret meaning from what is unsaid but implied by the research participant, thus generating deeper insight into the “lived experience” under analysis (Smith & Osborn, 2004). The degree of

interpretation that IPA recommends goes beyond what would be expected with, for example, grounded theory techniques. Secondly, the aim of the research is not to identify why the participant is voicing their experience in a particular way, but rather focuses on the phenomenological description of the experience (Smith & Osborn, 2004). This research focus therefore favours IPA over discourse analysis, since IPA's primary ontological premise is phenomenological. IPA was therefore selected as the method of choice for its combination of interpretation of participant accounts and phenomenological focus.

3.2.9 Limitations of IPA

IPA is a relatively new method for conducting research, having emerged in the last ten years and still meriting new publications clarifying the research method in detail (Smith, Flowers & Larkin, 2009). The evidence of its effectiveness has therefore had limited time to become established.

In addition, this study was carried out by an inexperienced researcher new to the process of depth interviewing. Achieving high quality data collection and relevant levels of probing and reflecting is a skill in itself and one which is likely to be perfected with practice. Although the researcher had prior experience of working with bereaved parents in a peer support situation, she had no prior experience of conducting professional research interviews. A training exercise took place with the first supervisor, where a mock interview was held and feedback given on interview technique. In addition, interview transcripts were reviewed by an independent IPA expert. This type of "rehearsal" training is seen as the best possible preparation for qualitative interviewing (Banner, 2010).

3.2.10 Conclusions for Choice of Qualitative Method

The IPA technique was chosen to elicit information about the lived experience of parental bereavement. The researcher would receive a high level of support for this study, both from an emotional and health perspective, as well as from a technical research perspective.

3.3 Quantitative self-report data

Self-report data is widely used in psychological research, relying on truthful responses to questions from which conclusions may be made. However, as a data collection technique, self-report questionnaires are not without their problems. Participants may answer questions in a particular way, which they feel presents them in the most socially desirable light (van de Mortel, 2008). It is possible to estimate the degree of this bias by using an additional measure, such as the 33-item Marlowe-Crowne Social Desirability Scale (Crowne & Marlowe, 1960). This questionnaire asks a number of questions whose answers are designed to be socially desirable but, in reality, are unlikely to be true. Scoring highly on this scale indicates that the participant is attempting to present themselves in an overly positive light, and this may skew the answers they have supplied in other areas of the questionnaire. Although this type of measure is certainly useful in identifying a social desirability bias, it was not included in the present project. Lengthy questionnaires are likely to increase the demand on participants and every attempt was made to keep the load on the participants to a minimum. The questionnaires used measures which have demonstrated high levels of reliability and validity in previous research. This, therefore, facilitated collecting reliable and valid data from large numbers of participants quickly, and cost effectively.

3.4 Cross-sectional Data Collection

As was the case in the qualitative research design, the quantitative research aims to identify common features of the phenomenon of parental bereavement across a range of bereavement experiences. The experience of parental bereavement is, thankfully, a rare one, and numbers of people who experience specific types of bereavement reduce the group sizes even more. To maximise responses and subsequent power of statistical comparisons, the participant group has been kept as wide as possible. Comparison of sub-groups will take place within the research to establish whether sub-groups of participants, for example those experiencing a sudden or violent death, have higher or lower scores on outcome variables. This will then be tested in multilevel regression analyses to establish whether certain types of parental experience significantly affect the outcomes being measured. In this way, testing of the phenomenon of parental bereavement as a single phenomenon can be carried out.

3.5 Analysis of Secondary National Data Sources

Data from Scotland, England and Wales captured from the census data collected every ten years will be used to identify the long-term impact of parental bereavement. This provides a readily available source of data which are made available free of charge to researchers. High levels of user support are offered by staff from the data service organisations. There are, however, a number of limitations of the data provided. The census has changed in format over the years, and the versions of the census data capture form ask questions differently or may omit certain questions altogether. This makes comparison of changes over time complex for some variables, and detailed methods for achieving comparative results must be negotiated with the staff involved in the data extraction process. This can be done by any researcher, however a background in

database management is extremely beneficial in this negotiation process. The data capture process takes place every ten years at a fixed date. Whilst this aids data analysis in that all results are captured simultaneously, it does leave a large window for changes which may take place and then recede. For example, a person may be fully employed on each census date but may spend most of the intervening time not in employment. Their status of “employed” will not then reflect their actual status over the period since the last data was captured. Finally, the data available are restricted to those which are components of the government’s census programme. The data items relate mainly to social factors such as employment, housing occupancy and marital status, which are augmented by life event information such as deaths and marriages. This limited information does not allow for more sophisticated analyses of factors associated with changes in social status, for example, the impact of medical treatment on levels of illness or time absent from work. This type of data source is only therefore appropriate for certain types of research where the data elements captured are sufficient for the researcher’s use.

3.6 Choice of Quantitative Self-Report Measures

3.6.1 Outcome Measures

3.6.1.1 Grief

Grief was assessed using the Inventory of Complicated Grief (Prigerson, Frank et al., 1995). The questions on this 19-item scale were adapted to suit the population by changing the term “this person” to “my child who died” (see Appendix II). Example questions are therefore, “I think about my child who died so much that it’s hard for me to do the things I normally do” and “I go out of my way to avoid reminders of my child

who died”. Each response is given a score ranging from 0 to 4. Unanswered or “don’t know” responses are given scores of -3 and -4 respectively. The total score on the Inventory of Complicated Grief indicates the severity of the participant’s grief symptoms. A score of 25 or over indicates that the participant meets the proposed diagnostic criteria for prolonged grief. Scores of 24 and under were identified as not having prolonged grief. The Inventory of Complicated Grief showed good test-retest reliability with a coefficient of 0.80 and is highly reliable with Cronbach’s $\alpha > 0.90$ and concurrent validity was established with the Texas Revised Inventory of Grief and the Grief Measurement Scale ($r = 0.87, p < .001$ and $r = 0.70, p < .001$ respectively). The Inventory of Complicated Grief was chosen as the preferred grief measure since it was developed specifically to match the proposed diagnostic criteria for DSM V, for the condition of Prolonged Grief (Prigerson et al., 2009).

3.6.1.2 Depression

Depression was measured using the Patient Health Questionnaire (PHQ-9) (Kroenke, Spitzer & Williams, 2001) . This short instrument of nine questions provides an indication of probable DSM IV “caseness” for moderate to severe depression (see Appendix III). The instrument measures the current state of depressive thinking, asking how often each of the problems has been experienced in the last two weeks. Examples of the problems are “little interest or pleasure in doing things” and “poor appetite or overeating”. A score between 0 and 3 is given for each problem, depending on the frequency experienced. There is a final question in the PHQ-9 which asks, “If you have been bothered by any of these problems in the last two weeks, how difficult have these problems made it for you to do your work, take care of things at home or get along with

other people?”. This question is used in clinical practice for diagnostic purposes and its response is not required for research purposes (Kroenke et al., 2001).

There are two methods of scoring depression using this instrument. These are either with a specified algorithm or by summing the total score (Kroenke et al., 2001). The algorithm requires that, for a probable DSM IV depressive disorder to be present, either question one or two in the PHQ-9 is given an answer of “more than half the days” or “nearly every day”. In addition, if five or more items are scored as “more than half the days”, the participant is likely to meet the diagnostic criteria for major depression. If question two, three or four was answered with at least “more than half the days” and question one or two is also answered in the same way, the participant is likely to meet the diagnostic criteria for minor depression. Using the total score method, a score of more than ten indicates moderate to severe depression, whereas a score of ten or less indicates mild or no depression. The total score method has been adopted in the present study, since this has been found to be consistent with algorithm scoring in previous research (Kroenke et al., 2001) and allows for comparison between total score for depression and other continuous variables.

The PHQ-9 was chosen over other self-report measures of depression for two reasons. Firstly, the number of questions was lower than, say, Beck Depression Inventory (Beck et al., 1961) (nine compared to twenty one, respectively). Secondly, the PHQ-9 has a higher level of validity and sensitivity to symptom severity than that reported by other screening and diagnostic instruments (Bjelland, Dahl, Haug & Neckelmann, 2002).

The PHQ-9 showed good test-retest reliability with a coefficient of 0.84 and is highly reliable with Cronbach's α between 0.86 and 0.89 and its validity, compared to the Mental Health Inventory, was $r = 0.93$, $p < .001$. (Spitzer, Kroenke & Williams, 1999).

3.6.2 Predictors

3.6.2.1 Trait Optimism/Pessimism

Optimism and pessimism were measured with the Life Orientation Test (Revised) LOT-R (Scheier, Carver & Bridges, 1994) (see Appendix IV). The LOT-R comprises ten questions, three are positively worded, e.g. "In uncertain times, I usually expect the best", three are negatively worded, e.g. "If something can go wrong for me, it will" and four are fillers. Each question is scored from 0 to 4 with 0 being strongly disagree and 4 being strongly agree. The total of the positively worded items gives an optimism score and the total of the negatively worded items gives a pessimism score. The LOT-R showed good test-retest reliability with coefficients of between .56 and 0.79 up to 28 months, and is highly reliable with Cronbach's $\alpha = 0.78$ (Scheier et al., 1994). The LOT-R was chosen as the preferred measure of optimism since it has been found to reliably measure trait optimism rather than state optimism, as is the case, for example, with the Optimism/Pessimism Scale (Burke, Joyner, Czech & Wilson, 2000).

3.6.2.2 Rumination

Two versions of the 10-item Response Styles Summary were used to assess rumination. The first version focussed on rumination traits associated with depression (Treyner, Gonzales & Nolen-Hoeksema, 2003) (see Appendix V). Ten questions measuring depression-focussed rumination are included in this scale, for example, "I think about how alone I feel" and "I think about how I don't feel up to doing anything". Participants

indicate what they generally do when they are feeling low, and responses are coded from 1 (never) to 4 (always). Higher scores indicate a greater tendency towards rumination.

The second version of the Response Styles Summary incorporates questions relating to brooding and reflection (Treyner et al., 2003) (see Appendix VI). Reflective rumination is described as a means of active problem solving by attending to a matter of concern and exploring problem-solving strategies in an attempt to alleviate stress. Brooding rumination, on the other hand, is considered to be a more passive behaviour, with no desire to achieve problem resolution. The Response Styles Questionnaire showed good high levels of construct validity ($r=0.47$, $p<.01$) and was therefore selected as a short but robust means of measuring rumination (Nolen-Hoeksema et al., 1994).

3.6.2.3 Coping Style

Coping style was measured using the Brief Cope (Carver, 1997), a 28-item instrument measuring 14 types of coping (see Appendix VII). The humour scale was removed from this study to avoid potential offence in participants. The remaining scales were aggregated into four summary sub-scales following O'Connor and O'Connor (2003). Problem Focussed Coping (subscale one) was derived from the total scores from the Active Coping and Planning scales, Avoidance Focussed Coping (subscale two) was calculated from Denial and Behavioural Disengagement. Social Support (subscale three) was derived from the Seeking Instrumental Social Support and Seeking Emotional Social Support. Cognitive Restructuring (subscale four) was calculated from Positive Reinterpretation and Growth Acceptance. Self-blame, Use of Religion, Focus and Venting of Emotions and Alcohol and Substance Use did not readily lend

themselves to any of these summary scales and were therefore retained as sub-scales in their own right. Test-retest reliability and validity of the scale have been shown to be acceptable (e.g. Cronbach's $\alpha=.81$, (O'Connor & O'Connor, 2003).

The Brief Cope was also chosen since it combined a relatively low number of questions with high levels of test-retest reliability over six and eight weeks (Carver et al., 1989).

3.6.2.4 Continuing Bonds

Continuing Bonds were measured using the Continuing Bonds Scale (Field, Gal-Oz & Bonanno, 2003) (see Appendix VIII). The wording of the questions in this scale was changed from "spouse" to "child", for example, "I seek out things to remind me of my child". There are 11 questions in the scale with the participants responding on a scale from 1 (not at all true) to 5 (very true). The total score indicates the level of continuing bonds that the bereaved has with the deceased. There is no published reliability or validity data for this scale.

A synopsis for each measure followed by a summary outline is presented in Table 3.1.

Table 3.1 Summary table of measures used in the research

<i>Construct</i>	<i>Name of Measure</i>	<i>Authors</i>	<i>Year</i>	<i>Number of Items</i>	<i>Rating Scale</i>
Grief	Inventory of Complicated Grief	(Prigerson, Maciejewski et al.)	1995	19	5-point scale ranging from 1=Never to 5=Always
Depression	Patient Health Questionnaire (PHQ-9)	(Kroenke et al.)	2001	9	4-point scale ranging from 1=Not at all to 4=Nearly every day
Trait Optimism/Pessimism	Life Orientation Test (revised) LOT-R	(Scheier et al., 1994)	1994	10	5-point scale ranging from 1=Strongly disagree to 5=Strongly agree
Rumination	Response Styles Summary			10	4-point scale ranging from 1=Never to 4=Always
Coping Style	Brief COPE	(Carver)	1997	28	4-point scale ranging from 1=Not at all to 4=A lot
Continuing Bonds	Continuing Bonds Scale	(Field et al.)	2003	11	5-point scale ranging from 1=Not at all true to 5=Very true

Chapter Four - Bereaved Mothers' Continuing Bonds and Ambivalence about their Own Mortality after the Death of Their Child – An Interpretative Phenomenological Analysis

4.0 Abstract

4.0.1 Background

The main objective of this study was to identify how bereaved mothers describe their coping strategies in their own words, to inform the design of the later quantitative studies reported in chapters four and five.

4.0.2 Method

The literature on parental bereavement is sparse, and the present study aims to add to existing knowledge by eliciting the mothers' experiences covering a wide range of child ages including infants, younger children and adults. Semi-structured interviews were carried out with 13 bereaved mothers in the United Kingdom. Causes of death include accident, illness and suicide. The methodological approach was Interpretative Phenomenological Analysis (IPA).

4.0.3 Results

The interview transcripts were analysed using IPA. This chapter reports three inter-related recurrent themes related to coping: (1) Continuing the bond with the deceased child, (2) Death and suicidal ideation and (3) Social changes following the death of their child. Participants reported that the relationship with their child was continued in a variety of ways, from tending to the grave and the child's remains, through linking objects, or by establishing a symbolic representation of the child within their daily lives.

Mothers continued the bond with children, regardless of the age of the child at time of death. All mothers talked openly about their own mortality, either demonstrating ambivalence about their own death, or expressing clear suicidal ideation. Death was seen as a release from living with the pain of loss. The presence of surviving siblings appeared to moderate suicidal ideation, but some mothers expressed concerns about their ability to care adequately for other family members during times of intense grief. Finally, participants indicated changes in the dynamics of their marital relationships and difficulties within their employment environment.

4.0.4 Conclusions

The level of suicidal ideation in bereaved parents requires urgent attention. Factors which mitigate suicidal ideation must be identified. The effect of different ways of continuing bonds with the lost child must be evaluated and their adaptiveness, or otherwise, established.

4.1 Introduction

According to Miller and Rahe (1997), the death of a child is the most significant stressor a woman can experience. The devastation that occurs for a mother when her child dies is said to leave her with “an oppressive sense of failure, a loss of power and ability, and a deep sense of being violated” (Rando, 1986), p.11). In order to come to terms with this devastating loss, according to the Dual Process Model of Coping with Bereavement (Stroebe & Schut, 1999), the bereaved must address both loss-oriented stressors and restoration-oriented stressors. Loss-oriented stressors relate to the loss itself and how the bereaved individual deals with the loved one no longer being physically present in their life. Restoration-oriented stressors relate to alterations to life which occur as a result of the death e.g. concerns over siblings, changes in domestic routines and future expectations. Coping with bereavement must therefore incorporate attendance to, and resolution of, both types of stressor.

The impact of a child’s death is believed to be long-lasting and in many cases perhaps even lifelong. Rubin (1993) found functional impairment and ongoing grief for 13 years post-death. Rogers, Floyd. Seltzer, Greenberg and Hong (2008) showed higher depression and health problems in bereaved parents up to 35 years following bereavement. (Arnold et al., 2005) found that grief continued for nearly two thirds of mothers up to 62 years post-death. The impact of surviving the death of a child may, therefore, endure for the parent’s whole lifetime.

4.1.1 Previous Studies of Bereaved Parents’ Coping

Little research exists to identify how parents actually cope with the death of a child. Hoekstra-Weebers, Littlewood, Boon, Postma and Humphrey (1991) assessed the

coping styles of bereaved parents using the Utrecht Coping List and compared those who had lost younger children (aged 3-9 years) with those who had lost older children (aged 13-19 years). The parents of younger children utilised a mainly active problem solving style of coping, such as finding ways of alleviating their distress, whereas the parents of older children were found to mainly use soothing coping styles for example, looking for diversions or relaxation.

Robinson and Marwit (2006) found bereaved parents used mainly task-oriented coping strategies, measured with the Coping Inventory for Stressful Situations, whereas Videka-Sherman (1982) found parents showed high levels of preoccupation with the child by talking about them and thinking about the loss, as well as evidence of turning to religion. Murphy et al. (2003a) demonstrated changes in coping strategies over time in bereaved parents using the COPE scale. At twelve months post-loss, mothers used repressive coping such as denial and disengaging behaviours to cope with their overwhelming sense of loss and events which may trigger intrusive memories. By sixty months post-loss, the mothers had begun to rely primarily on active coping styles such as problem solving through planning and management of activities.

It appears from these studies that parents demonstrated a wide variety of coping styles depending on time since bereavement, age of child and measure used. Lack of agreement between findings may indicate that different groups of parents do, in fact, cope differently with the death of a child, or alternatively, may reflect the use of different questionnaire measures of coping with bereavement.

4.1.2 Social Issues Following Bereavement

The quantitative studies reported in chapter five and six require the identification of appropriate predictors to determine which aspects of coping with the bereavement have better outcomes than others. The literature relating to bereaved parents' outcomes is sparse, however there have been some studies considering changes in health and social status in bereaved parents. As indicated in chapter one, bereaved parents are at higher risk of both mental and physical illness following the death of a child than matched non-bereaved controls (see Murphy et al., 1999; Li et al., 2004; Li et al., 2002; Kreicbergs et al., 2004 for examples). In terms of relationship difficulties, the picture is less clear with some researchers indicating that marital difficulties are no more common in bereaved parents than matched controls (Oliver, 1999), but others reporting that divorce was more common following bereavement (Lehman & Wortman, 1987). Financial changes may also be a feature of the parental bereavement experience, since Stebbins and Batrouney (2007) reported both financial and employment difficulties following the death of a child. It is likely, therefore, that bereaved parents will experience these, and perhaps other, as yet unreported, restoration stressors, as they come to terms with the loss of their child.

4.1.3 Phenomenological Research

A phenomenological approach to research is one in which the aim of the study is to identify the essence of the "lived experience" of a group of people (Langdrige, 2007). In the case of the present study, the "lived experience" under scrutiny is that of parental bereavement. Very little published qualitative research with bereaved parents has specifically adopted a phenomenological approach to investigate the core experiences of bereaved parents. One notable exception is Woodgate (2006) who investigated

parents' transitions following the death of their child, using thematic analysis. Four key themes were found, which were:

- (1) The need to keep memories of the child alive
- (2) Desire to reinforce the parent's belief in their own parenting ability
- (3) Recognition of the importance of being present when the child died
- (4) Importance of social support from friends, family and health care professionals (the latter if the child had received medical care prior to their death).

The Woodgate study investigated the experience of how parents cope following the death of their child due to illness, however the author recommends that a similar exploration of parental bereavement including accidental death should be carried out. The aim of this qualitative study is to explore how bereaved mothers describe coping with the death of their child in their own words, and to identify which coping behaviours, both adaptive and maladaptive, are common across a diverse range of bereavement experiences. The mothers' descriptions of their own experiences will be used to identify which coping behaviours they are using.

4.2 Method

4.2.1 Participants

Interviews were conducted with 13 bereaved mothers who were recruited from The Compassionate Friends charity (n=7) and from coverage of the study in a local newspaper (n=6). The Compassionate Friends (TCF) is an international charity which offers peer support for bereaved parents. An overview of the project, detailing the nature of the study and participant's involvement in it, was presented to the Scottish TCF Management Team after which the volunteers made contact and offered to

participate. The research project was also featured in a local newspaper as a human interest story. As a result of this, the remaining participants contacted us asking to take part. No effort was made to recruit participants beyond those who volunteered directly. The sample does not represent the full diversity of the bereaved parent population, and is described as purposive rather than representative.

Participants were aged between 32 and 64 years, with a mean age of 52 years. Time since death ranged from 1-40 years with a mean of 10 years. Child ages ranged from 2 weeks to 29 years. Further details of the research participants are provided in Table 4.1 below:

Table 4.1. Participant Characteristics

<i>Pseudonym</i>	<i>Years since death</i>	<i>Source</i>	<i>Gender of child</i>	<i>Child age at time of death</i>	<i>Cause of death</i>	<i>Participant age now</i>
Kay	1	TCF	Female	29	Long term illness	58
Donna	3	PRESS	Male	17	Accident	41
Francis	3	PRESS	Male	27	Long term illness	62
Gayle	3	PRESS	Male	2	Short term illness	32
				weeks		
Helen	4	PRESS	Male	29	Accident	60
Diane	5	PRESS	Female	5	Short term illness	36
Tracey	6	TCF	Female	19	Long term illness	55
Nancy	7	TCF	Male	9	Accident	50
Rita	7	TCF	Female	22	Unascertained/SADS	62
Katherine	8	TCF	Male	19	Suicide	46
Olivia	18	PRESS	Male	22	Accident	64
Susan	25	TCF	Male	2	Short term illness	51
Violet	40	TCF	Male	3	Cot death	61
				months		

Notes. TCF = Volunteer from The Compassionate Friends, PRESS = Volunteer from press coverage.

Due to the nature of the recruitment process, all participants knew that the researcher was also a bereaved mother. One of the participants ran the local branch of TCF which

the researcher had attended in the past. None of the others had any personal relationship with the researcher.

4.2.2 Data Collection

Ethical approval for the study was obtained from the University of Stirling Psychology Department. Interviews took place in the participants' own homes and lasted between one and four hours, with a mean time of one hour and 45 minutes. No financial incentive was offered for participation in the research.

An interview schedule was prepared prior to interviews taking place (see Appendix IX). This was created and piloted with a bereaved parent out with the participant group. The data collected in the pilot interview were not included in the current study. The questions in the schedule related to the circumstances of the death, what life was like now, and strategies and behaviours for coping with the bereavement. This approach was intended to elicit an account of the experience which was most pertinent to the participant and was designed to promote an "insider's perspective" of the phenomenon (see Conrad, 1990). The interview schedule was intended to act only as an aide memoir for the interviewer, to ensure the topics of interest were covered, however participants mainly engaged in free narrative about the circumstances of the death of their child, identifying the issues that were of particular relevance to them.

The interviews were recorded digitally, and were transcribed once all were completed. During transcription, pseudonyms were allocated for the participants and also for the child, and any other names mentioned were also changed to ensure confidentiality.

4.2.3 Data Analysis

The aim of this study was to explore the experiences of the bereaved mothers in their own words and from their own personal perspective. A phenomenological approach was chosen since it acknowledges the importance of focussing on how an experience, in this case parental bereavement, appears to those who undergo it (Langdrige, 2007).

The Interpretative Phenomenological Approach is widely used in psychology as a method for eliciting information about “the lives and experiences of others” (Brocki & Wearden, 2006). Smith and Osborn (2003) recommend the approach for areas where there is little published research or where the experience is considered to be particularly complex or novel. For these reasons, Interpretative Phenomenological Analysis (IPA) was the method deemed most suitable for this study.

All transcripts were subjected to IPA (for details, see Smith et al. (2009). The first phase of the analysis highlighted key words, phrases and idiosyncratic figures of speech in general. These statements explained how the participants coped with their bereavement. Each interview was read several times to increase familiarity with the participant’s narrative. The key phrases from each participant were identified, with a conscious effort to keep the coding emergent from each individual interview.

The next stage of analysis interrogated the transcript further by making comments and suggestions or asking questions in an attempt to generate “meaning” grounded in the participant’s own words. From here, initial themes were identified. Relationships and tensions between codes were sought out and those which appeared to refer to similar issues were grouped together as themes. From this analysis, recurrent themes emerged.

Recurrent themes are those which were prevalent in more than half of the accounts. The

coding that refers to these themes was then reviewed to ensure the themes remained relevant at the broader level, without compromising the meaning or significance of the participants' comments. Any individually coded items not relevant were removed from the broader themes.

The next phase of analysis required the whole dataset to be re-read. There were two reasons for doing this. Firstly, to ensure that the broad themes were an accurate reflection of the experiences of the participants and secondly, to check whether any additional comments should be coded to the broad themes.

Having ensured that all data relating to the broad themes were identified, the broad themes themselves were revised. Firstly, the quotations from participants were reviewed with reference to the themes, to ensure that the themes reflected what the participants were saying. Secondly, all of the transcripts were re-read to ensure that the themes were accurate in relation to the global experiences of the bereaved parents. If it was felt that a mismatch was evident, the terminology, specificity and focus of the themes were revisited until the descriptive titles and the overall testimonies were congruent. This cyclical process was continued until no further clarification or refinement was found. A separate analysis was carried out by an independent researcher, who is an IPA expert, using a random subset of the transcripts. The overall themes which emerged from this independent validity check matched those of the researcher's analysis. Once this validation check was carried out, the final interpretative thematic analysis of the transcripts was considered to be complete.

4.2.4. Impact of the Researcher on Participant Accounts

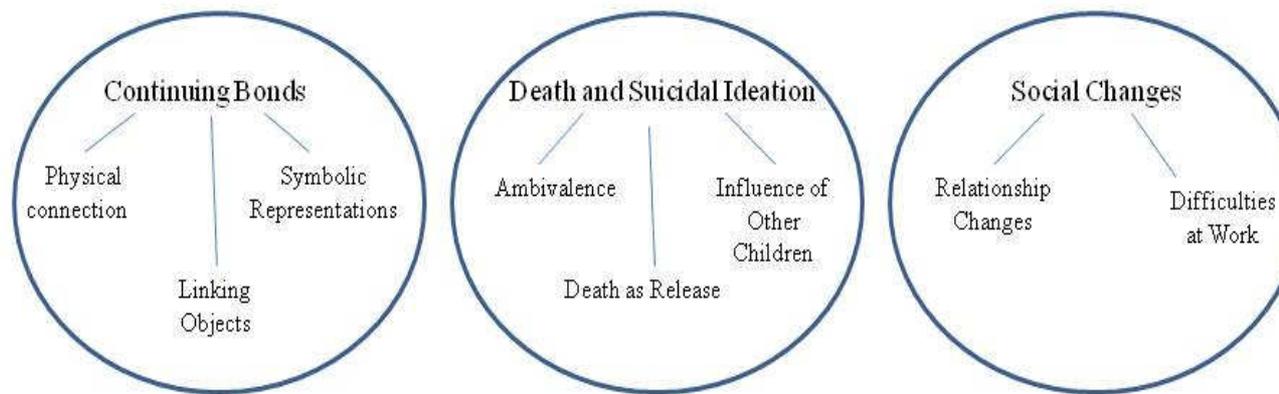
Consideration of the role of the researcher is a key component of any phenomenological research (Fry, Grogan, Gough & Connor, 2008). The participants in the present study all knew that the interviewer was herself a bereaved parent. At the conclusion of the interview, all participants spontaneously made reference to the fact that the researcher had experienced a similar experience and indicated that this was a key element in their decision to take part in the research. At this time and also during the interviews, the participants indicated their belief that the researcher would have a greater understanding of their experience, having also lived with the loss of a child. This meant that some interview content was initially given with the assumption of understanding on the part of the interviewer, at which point a deliberate attempt was made to clarify and encourage verbalisation of experience in the participant's own words.

Prior to carrying out both the interviews and the analysis, the researcher had no knowledge of the academic literature on coping and parental bereavement. This "tabula rasa" approach was a conscious decision on behalf of the researcher, to minimise preconceptions from findings published in previous studies. The researcher has personal experience of the loss of a child and had attended a local branch of TCF in the past. The participants in the current research had lost their children in a variety of situations, none of which was similar to that of the researcher. In addition, any previous contact that the researcher had with bereaved parents took place in the context of support seeking during early bereavement. The researcher therefore had no knowledge of longer term coping by bereaved parents in the situations reported in the current research.

4.3 Results

Once the analysis process was complete, it became clear that three main recurrent coping themes had been uncovered, as shown in Figure 4.1.

Figure 4.1. Key Recurrent Themes in Coping with the Loss of a Child



These were:

- a) Evidence of a continuing bond with the deceased child. This appeared to occur in three ways. Firstly, where a physical connection with the child was retained, secondly, where a linking object facilitated the bond and thirdly, where a symbolic representation of the child was adopted.
- b) High levels of death and suicide ideation. The level of ambivalence to the mothers' own mortality, which was seen as a release from the continuing pain of living with bereavement. There were indications that the presence of a surviving sibling moderated the mother's suicide ideation, however there were also concerns voiced over the ability to care for these siblings.
- c) Social changes attributed to the bereavement, manifested as relationship changes, either improving or worsening, and difficulties at work.

4.3.1 Theme 1a - Continuing the Bond with the Deceased Child – The Physical Connection

Most of the participants indicated that they felt a continuing bond with the child after the death. The only participant who did not refer to any kind of ongoing connection was Gayle, whose baby died aged two weeks. The concept of continuing bonds was offered spontaneously by all the other mothers, but did not feature in Gayle's account of her current situation.

For all other participants, the connection with the child appeared to take place on a number of different levels. Some participants chose to keep a physical connection with the child. Helen, whose adult son died as a result of a car accident, expressed the need to hold onto her son's physical remains. She told how she had carried her son's ashes around in a bag, taking them out with her when she left the house. She described this behaviour as "crazy" yet she went on to say that she believed it was "logical":

"I remember passing a house and it was like two or three in the morning and it was young Viv's house and eh they were having a party and I, I thought, I'll go in cos our Luke would like to go to that party. And my friend Hazel worked with Viv and she said "You had a party" and she said "yes" and she said "Helen went past, she was going to come in" she said "she should have just come in, she would have been most welcome" and then Hazel said "but she had Luke with her" and Viv went "how, what!" and she said "she had Luke" and she went "oh no, oh no!" so what to me at that time was quite logical to someone else was "oh no".

Helen referred to Luke as being physically present during this event. She contemplates the notion that Luke wants to join the party; not that he would have liked to have done such a thing when he was alive, but that he wants to attend the current event, now.

Helen reports her friend said she had Luke “with her”, not that she carried his ashes. At this stage, Helen has held on to her son’s remains so that she has physical contact with him. She acknowledges that others found the idea abhorrent, but she maintained this physical connection as a “logical” behaviour. Helen appears to have been unable to relinquish contact with her son, maintaining her relationship with what little she had left of his physical being. This may indicate a reluctance to believe that her son has permanently gone and an inability to adapt to life without his physical presence.

This need to continue contact with the child’s remains was also evident in other mothers’ accounts of grieving. Diane, whose daughter died from complications arising from chickenpox aged 5 years, said that she still visits the grave every day. She was aware that others felt this was not a positive use of her time, but she used the physical location of the graveside to continue her relationship with her daughter:

“I’m not going there to grieve. I go there because weather comes and it gets dirty and it gets untidy and she was a neat and tidy, clean little girl who liked to be just perfect going out and that’s her little bit of the world and I like her little bit of the world to be neat and tidy and clean and it’s somewhere I can focus on, something I can still do for her”.

Diane needed to continue to care for her daughter as she had done when her child was alive. She wanted to give her daughter’s “part of the world” as much care and attention

as she could, indicating an inability to give up the maternal role. This may have been further exacerbated for Diane since she had lost her only child. The only way she could continue to be a mother, she said, was by lavishing care and attention on the grave. It was as if the grave had become a symbol of the child, one which warranted devotion and tending, just as her child had. This appeared to help her cope by allowing her to retain a maternal role in the absence of any child to nurture. Diane had lost her only child and referred to herself as a “childless mother”. The grave was a focus for her and provided a physical symbol of her ongoing love for her child.

Whilst Diane saw caring for the grave as a positive activity, she also acknowledged that there were drawbacks to this strategy. She said several times during the interview that she visited the grave every day and had not missed a day since her daughter died five years earlier. This restricted her physical activity since she could not go too far from the grave in case it meant missing a day, and she could therefore not consider working away from home or going on holiday. She demonstrated no intention of changing her behaviour and saw attending the grave daily as a permanent situation for her, saying:

“You don’t move on from your child, you take your child with you, alive or dead your child will go with you for the rest of your life”.

Diane believes that her child is part of her own self and that leaving the child behind is not possible. There is an eternal bond which will never be broken, and the child will always be a part of her. She interprets this “moving on” as severing the relationship with the child in its physical form and is adamant that she will continue to tend the grave on a daily basis. Diane can see no other way to maintain a bond with her child,

other than to continue similar behaviours to those she carried out for her daughter when she was alive. Letting go of these tasks of keeping the grave area clean and tidy would be a betrayal of her child and her method of coping is to persevere with daily grave visits.

4.3.2 Theme 1b - Continuing the Bond with the Deceased Child – Linking Objects

For other mothers, a physical symbol was sought from items around the home connected with the child. Donna, whose son died in a road accident aged eighteen, chose a specific memento given to her by her lost child:

“Mark gave me a lovely wee em like a wee basset hound dog and that goes everywhere with me. I take it on holiday with me and I take it when I go away to work, I put it on the bedside cabinet and that’s just for me, that’s like me taking him with me”

For Donna, the physical proximity of the symbol was important as, by keeping the object near her, she felt as though she was keeping her son near her. The item had been chosen by her son as special and was given to Donna by him. It therefore represented an emotional response from her son, which Donna coveted as a symbol of her son’s love for her. The connection with her son was therefore on an emotional level, unlike Helen and Diane who sought an ongoing physical connection with their child. Keeping the object physically close to her meant that the child was also close on an emotional level.

Clearly, the significance of something that had a direct association with the child was meaningful for Donna. In Violet’s case however, the lost child was a baby of just three months. In his short life, her baby had not, in her words, established a role, therefore

could not have expressed preference for any items. Violet made many references during her interview to the fact that her baby's life was seen by others as insignificant, since he had not developed sufficient presence to be remembered. She felt cheated that others had not recognised the significance of his life, and it therefore meant a great deal to her when a neighbour offered something to place in the child's coffin:

“My neighbour said I've got a wee holy thing in the house, so she went next door and brought in an Infant of Prague and it was a nice thing, so we put it in his hand”

Violet went on to say that she had bought an identical duplicate item which she kept on display in her home. This statue appeared to unite them by providing a common bond, something that both of them could hold onto. Violet believed that, wherever her baby was now, he would be close to the statue, as she was close to it in her life. The statue served as a link between them, providing what was perceived as common experience. This allowed Violet and her baby to experience a shared connection, perhaps on a spiritual level, and meant that the baby would have something to link him to Violet. Wherever he was now, he would retain something to connect him with his mother, thus ensuring that the bond continued, even after death.

4.3.3 Theme 1c - Continuing the Bond with the Deceased Child – Symbolic

Representations

Although most of the participants indicated some kind of physical item played a part in their method of keeping connected with the child, many mothers adopted symbols for their child which they appeared to have little or no control over. Some participants

spoke of naturally occurring phenomena bringing them together with their child. Olivia described a beautiful view:

“we had just gone over this causeway onto Harris and you were just beginning to see the wee bits of the beaches in the distance and we went round this corner and suddenly this bay was revealed and it was the most gorgeous colour of water and the white sand and the beautiful hills behind and I just burst into tears then. I thought about Fraser right away, as I say, anything that’s beautiful like that, it seems to make a link to him somehow, strange, whether it’s a spiritual thing I don’t know”.

Olivia’s link to her son was with the beauty of nature; an unspoiled, pure and natural view. She also indicated that beautiful classical music had the same effect. The reason for this “link” and why it had an “overwhelming” effect on her may have been because it evoked a poignant reminder for Olivia of what her son had missed out on, since she said :

“Here am I here and he’s never going to get the chance”.

The link in Olivia’s case may have been driven by guilt and sadness that her son would not be able to experience the beautiful things in life that she had.

For Susan, a symbolic representation of her son came in the form of a ladybird. She recalled a memory of her son’s delight at seeing a flock of ladybirds not long before his death. Susan said that, throughout her life, ladybirds have appeared spontaneously and unexpectedly:

“we did see them in some very, very strange places really. It was on our towel on the beach in Cyprus, a ladybird, top of the World Trade Centre there was one on my back, we saw them, one in St. Andrews it was on the window of the car as we drove up to the caravan and never, never ever left the window of the car and it was quite windy and it just stuck there the whole time. Just little things but they mean a lot to us, so ladybirds became, that was our thing”

When asked what these incidents meant, Susan said:

“oh it just means he’s ok, he’s watching us, often it means that he’s watching George (her second son), George sees that as a symbol for him as well and we have seen ladybirds at times when it would mean that, you know, like George’s maybe done something or he’s, you know, struggling with something and suddenly there’s, you know, we’ll see a ladybird at that time so it means a lot of things. It kind of brings him into us, into the family you know. Whenever there’s a ladybird around we know that everything’s OK.”

The presence of the ladybirds reunited the family since they symbolically represented the lost child. The spontaneous nature of these visitations appeared to be particularly prized by the mothers, indicating to them that the communication worked both ways and the child was in some way able to send messages or signs to them. The signs appeared to reinforce the presence of the child, with the apparent reciprocity supporting the mother’s belief that the bond was current and ongoing.

In summary, for some mothers, the need to continue a parental role with their child was seen in the importance of spending time at the grave, in some cases with daily visits. Even though this caused restrictions to their daily functioning, these were considered to be acceptable by the mothers. It could be argued that the use of symbolic representations of the child may be a more adaptive way of continuing the bond, since many symbols chosen were portable and less restrictive than the grave or memorial site. The choice of symbols also appeared more subtle and tolerable by others than, for example, a shrine of photographs, candles and so on which some mothers kept at home. Symbols which had the ability to appear unexpectedly were taken to indicate that the child has actively chosen to make the contact, which many of the mothers found brought additional comfort.

There is some evidence of change in strategies over time, with some mothers reporting spending more time at the grave or memorial site in the earlier days of bereavement, reducing their commitment to the site over time. Some mothers returned to the site more often when they felt they were experiencing additional grief or at times of specific stress such as birthdays, Christmas and the death anniversary.

4.3.4 Theme 2a - Ambivalence to Personal Mortality

All of the mothers spoke about their own death openly and all appeared to have an ambivalent attitude to their own mortality. This was expressed in two key ways. The first theme was of seeing death as a way of being with their deceased child. Donna described her thoughts about other bereaved parents who took their own life following bereavement:

“Shortly after we lost Mark I saw the article about a young lad who was at uni who had taken his own life, he couldn’t cope. Three months later there was an article in the paper about his parents. He was an only child and they took their own life, and I actually felt jealous. I actually thought, Jesus you’re lucky [cries]. What a funny thing to think, how lucky are you? Because you’re actually together.”

Death was seen as desirable, since it would reunite the mother with her child. In addition, parents also reported that they saw death as a release from the emotional pain of grief. Diane described her consideration of plans for ending her life:

“I go to (the cemetery) all the time. There’s a really bad junction coming down out of there. I could just time it and get out of there in front of a lorry and I think, no I can’t do that because I’d leave my mum and dad. Right! We’ll all go to the cemetery together, we’ll all go in the one car then we’ll all go and there, we’re all wiped out and there’s nobody left and nobody’s got upset because we’re all dead and that’s perfect”

She then attempted to explain this comment:

“If you said to a sane person I want all my family to be killed outright in a car crash, they’re going to look at you and think you’re off your head you know, but if you talk to somebody else that’s lost a child, they’ll think, “I know what you’re talking about”. Because you can understand what it’s like to leave people behind, that’s why you can’t take your own life, because you’re stuck.”

Diane is indicating that she is experiencing inner turmoil in her choice of life or death. She wishes she was dead and with her child, but recognises that she would then be causing her own parents the same tragedy as she experienced herself. Knowing the trauma this would cause exacerbates feelings of guilt, and gives her a reason for living. She considers the idea of an “accident” where all of the family would die together as a potential way of addressing both desires and later spoke about the possibility of her own early natural death and that she saw this as a beneficial alternative:

“There was a lady who used to go (to a TCF meeting) and her son was 39 and I think, why are you here? Your son still had a life and that’s dreadful, she was devastated at losing her son at 39. And her way of looking at it was she had had her son longer so it was harder for her to say goodbye whereas I didn’t have mine for very long you know. And it’s true, it’s different perspectives isn’t it. And then that lady died and I was so glad for her, so pleased for her when she died and I thought that’s it, it’s over for you.”.

4.3.5 Theme 2b– Death as a Release

Diane saw death as a release from the pain of her grief and, if occurring naturally, would alleviate any guilt at having deliberately caused distress to her parents. Her decision to choose to live is unsatisfactory for her and causes ongoing distress, but this will inevitably be resolved once her own death occurs. This feeling that death is welcome was echoed by Helen who compared her own situation to that of the researcher:

“If there’s one thing that I, I, I have over you is that I’m old and you’re not”

The Researcher then asked – “and is that better do you think, is that easier?” to which Helen replied:

“I think I don’t have to live with it as long as you, that’s what I think.”

Helen sees her age as an advantage since death should happen sooner than someone who was bereaved at a younger age. Her grief and feelings of loss had not reduced greatly in the four years since her son’s death. She had tried many routes to alleviate her suffering including counselling, religion, spiritualist encounters and support groups. None of these had made a substantial improvement in her distress and she therefore felt that she would continue to suffer at this level of severity until she died. For Helen, it appears that death, when it comes, will mean the end of her suffering, bringing peace and ending this inner turmoil.

4.3.6 Theme 2c - Influence of Other Children

The mothers spontaneously added comments about why they didn’t choose to end their life after discussing their own deaths. All of these included consideration of the impact on other family members, especially the deceased child’s siblings. Donna said:

“My whole reason for living was them, to get them through, to make sure they’re ok, to make sure they’re functioning and they’re looking forward in their life and they’re not held back in any way”

“Norman (husband) and I said early on, if we didn’t have any children, I would not be here....The boys are here so we have no choice, it’s not a choice in my mind”

The parental duty to care for their living children was more powerful than the desire for death, but the presence of these other children meant that the choice of ending their life was not possible. Donna felt her duty was to offer the best parenting to her surviving children, at the expense of alleviating her own suffering.

Despite the moderating effect that surviving siblings had on death ideation, some mothers expressed the belief that preoccupation with the lost child was far more salient than the need to care for their other children. As Francis said:

“The first few months, the difficulty was all of the, sort of mundane things, looking after the kids or whatever, when I just wanted to go and curl up and cry”.

Francis felt obliged to fulfil her parenting role, at the expense of her own need to grieve. She put her emotions on hold in order to care for the younger children. Only when she had put them to bed and had discharged her caring responsibilities did she allow her own grief to surface. She was protecting the surviving children from exposure to her own suffering whilst endeavouring to provide them with the best care she could offer, putting her own needs secondary to those of the children.

Despite their best attempts, some mothers also reported emotional absence from surviving children. Olivia reported:

“The youngest one, Jimmy, he was 15 so he didn’t have anybody. But you know that never dawned on me for a long time and a long, long time afterwards I suddenly felt an enormous guilt that I hadn’t, maybe not been able to comfort him in the way he

needed because I was so distraught myself you know. Oh dear, it's just awful, but as you know, there's just nobody out there to help you. But I think at that time I, I felt I had to cope with this myself".

This extract suggests that Olivia's grief was so great that she was unable to offer compassion and support to her surviving son. Looking back, she is now aware that his emotional needs were unmet, but her own suffering limited her ability to offer help, even to her own son. She now feels guilty at this neglect, but recognises that she had done her best at the time.

Nancy also expressed guilt and sadness at her realisation of her surviving son's emotional distress, when she was unable to support him:

*"It really struck me at one time when I was just talking with Kieran (surviving son) we were just talking about Calum and I was saying, what's it like at school and he said "I miss him at playtimes. I don't see him" and I hadn't, you know, until he said that, it really hit me. God, the kind of the daily-ness of **his** loss".*

Nancy had been unaware of the suffering of her son, and had been unable to recognise his loss as a result of the incapacitation of her grief. She expressed anguish at her inability to care for her younger child and husband:

"I just couldn't cook, I just couldn't nurture, I couldn't feed us"

Nancy felt incapacitated by her grief, unable to perform basic tasks needed for survival. The grief had consumed her completely making even daily, mundane but essential tasks impossible. Nancy said that she felt herself fortunate that a local church stepped in to provide meals for the family, helping considerably with the domestic load. At the time, she could not bring herself to care for her family, a fact that worried her greatly with hindsight. Without the support of the local community, her surviving son's suffering could have been even greater. She needed external assistance to provide for the daily needs of her family, and worried that others without such strong support may not be so lucky, resulting in concerns for the protection of surviving siblings.

In summary, thoughts of their own mortality were expressed by all of the mothers.

Death was not seen as an undesirable event, but as a means of either ending the suffering and grief or reuniting them with their deceased child. Family, especially other children, appeared to moderate the desire for death. Conversely, especially in the early days of bereavement, other children were seen as a burden, and mothers reported a lack of ability to care for them either practically or emotionally.

4.3.7 Theme 3a - Social Changes Attributed to the Bereavement - Marital Situation

Of the thirteen mothers interviewed, two reported marriage breakdown subsequent to the bereavement. Both mothers believed that their separation was linked to the death of their child, but also noted that the marriage had not been strong prior to the event. In Helen's case, the marriage breakdown happened very soon after the death of her adult child;

“everything changes doesn’t it, everything changes, so I, I left. One day I thought, I can’t stay here any more, I’m not staying here any more and that was about maybe five months, four, five months and I just walked out and just left it all.....we had never been really happy”.

Helen decided to end the marriage and leave soon after the death of her son, but she went on to explain that she had been unhappy all her married life. Her husband was the son’s stepfather and she felt he had no real understanding of the depth of her grief. Being unable to communicate with him, and not receiving the support she felt she needed, she decided to move out, setting up a home for herself and her surviving children elsewhere.

Gayle, too, indicated there were problems in her marriage prior to the death of her son, and that she believed the trauma of the death was made the separation inevitable;

“We had really struggled from when Joshua (the previous child) was born really, we were having problems, but I think Kevin, I think just finished, finished it”.

Again, Gayle’s account is one of non- and mis-communication with her husband, with both parties grieving and expressing their emotions in separate ways. Gayle felt her husband was an additional burden that she could not cope with and left the family home with her young son.

Other mothers reported struggles in the marriage, but as at the time of the interview, these did not lead to marriage breakdown. Susan spoke of how she felt she had been the stronger partner during early bereavement and how her husband needed her support:

“it was before the funeral and he was, I think he’d been out organising that in fact and he was standing in the kitchen and he was sort of giving me a cuddle and he, he literally just leaned on me I mean his whole body just completely gave over to me and I, I almost couldn’t hold him. I mean he was so heavy anyway, but it was also like he was saying, I can’t do this you know, you’re going to have to do this, and that in itself was, was very difficult. But I also thought, I can’t, I can’t do this for you, you know, there was a bit of this in me thinking, I can only handle me you know, I can’t do this for both of us”.

Having her husband rely on her heavily was an additional burden for Susan, and one she felt she was unable to carry at that time. Her husband looked to her to guide him through his grief, but with a baby to care for as well, this was a great deal for Susan to attend to. She described a distance between the two for many years, with each following their own course of recovery. Now, some 25 years later, they have achieved a state of equilibrium, with shared memories and both becoming involved in supporting other bereaved parents.

Finally, some parents indicated that their marriage was actually stronger as a result of the suffering the pair had endured together. Katherine described the support she had received from her husband as crucial to her own ability to cope, and recalled many shared coping experiences, such as choosing a memorial site together and making decisions about where to live and what type of job she should seek to acquire. As a

result of this joint grieving, she said:

“I think Alex and I are probably closer than ever...we’ve always been really close but now we do everything together we’re really, really close and it has brought us closer”.

Katherine’s marriage had survived the suicide of her son, and she believed the way both partners had supported each other through the grief had made their marriage stronger with no reports of any tension between the pair.

Theme 3b – Social Changes Attributed to the Bereavement - Employment Status

Most of the mothers were employed at the time of their bereavement, and the employers in the main appeared to provide little support to those who needed it. Helen, for example, described returning to work despite being in a state of despair in the second year of bereavement;

“About 18 months later they said they couldn’t work with me. They said I was impossible to work with. They said I was moody some days, I didn’t speak to anyone, some days I just sat at the computer and didn’t even go for breaks. That was true.”

Helen’s behaviour was typical of someone living with grief and depression, however her employer interpreted this as “moodiness” and, as a result, she lost her job.

Katherine, too, described difficulty in returning to work and performing at pre-bereavement levels;

“ I actually lost my job through Eddie dying. I was a manager at a new nursery and at first they gave me, “oh stay off as long as you need” and then it got quite nasty and they took my manager’s job off me and said “you can come back as a nursery nurse” and I said “forget it”, so we lost the house.”

The initial support offered by Katherine’s employer did not last as long as she needed to return to her usual level of functioning at work. Rather than take a lower-paid job, essentially a demotion, Katherine took the decision to leave, but this caused the family income to be seriously depleted. With only her husband’s salary to live on, the family could not sustain their level of expenditure and sold their house, moving to a much cheaper alternative. Although this caused additional difficulties for the family, they felt this was the best option in the light of increasing financial hardship.

In Olivia’s case, she returned to work very quickly after her son’s death, and recalled her distress at how she was treated by her employer;

“It (the death of her son by electrocution) happened on the Thursday, so I was off that Thursday and then I was off the following week. Now at that time you were only allowed a week’s compassionate leave so that was a week and a day that I’d had. Do you know they took that extra day off me?”

Olivia took six days off work and was only entitled to five, according to the rules of her company. She therefore lost one day’s pay as a result of her absence from work.

Although the amount was paltry, this insensitivity on the part of her employer has

caused ongoing tension for Olivia, and she felt it was indicative of society's lack of understanding of the experience of parental bereavement.

Diane's employment situation was that she worked in a local shop with her husband, but the additional strain on the relationship following her daughter's death meant this situation was untenable. Although wishing to return to normal working patterns, her husband did not allow her to recommence working;

"After she died I thought I wanted to go back to work for a little while, just to get back in, and he asked me not to come back, he said "I think this is a good time for you just to move out of the business and not come back". So that was quite, quite difficult".

Diane's marriage had been in difficulty prior to her daughter's death, but again this event seemed to precipitate additional major changes in life, as her husband felt he could no longer run his business with his wife's involvement.

4.4 Discussion

4.4.1 Continuing Bonds

Whether adaptive or not, the mothers showed a strong desire to continue bonds with their deceased children. The more socially acceptable and portable symbolic representations of the child appeared to be more adaptive than persistent attendance at the graveside or domestic shrines. It is unclear why some mothers chose one method of continuing the bond over another. Some mothers expressed a strong desire to tend the grave or display a shrine to their child in the early days of bereavement. This focus

changed over time to caring for a symbolic representation of the child, and in some cases even moved to a connection with the child via a fleeting naturally occurring event, out with their control. The reason why this transition took place in some individuals and not others was unclear. Perhaps the parents who showed persistent adherence to care-giving behaviours around the grave or memorial site have been unable to fully accept the loss. They may have been unable to reorganise their life to accommodate the change precipitated by the loss, causing an ongoing inability to work through their grief (Bowlby, 1981). Alternatively, the mothers who retained a continuing bond with the grave may have been persistent ruminators, unable to face the reality of restoration orientation and all that accepting the loss might entail (Stroebe et al., 2007). The choice of method for continuing bonds and the association between the different forms and adaptation to bereavement are important considerations for future research, since the present data do not allow conclusions regarding the adaptiveness of continuing bonds to be made.

4.4.2 Coping Styles

Previous studies such as those by Hoekstra-Weebers et al. (1991), Robinson and Warwit (2006), Videka-Sherman (1982) and Murphy, Johnson and Lohan (2003) indicated that some parents may choose active, problem solving coping styles for their bereavement. Whilst this is an encouraging sign of potentially adaptive coping, it may only address part of the bereavement process, reflecting a focus on restoration-related stressors whilst not necessarily considering the role of loss-related stressors (Stroebe & Schut, 1999). The ability to address restoration-orientated stressors may come at the expense of dealing with loss-orientated stressors. Measurement of coping which includes consideration of loss-related stressors is needed to achieve a comprehensive

understanding of coping effectiveness. This will require bereavement-specific measures to be used such as the Dual Coping Inventory (Wijngaards-de Meij et al., 2008). The use of the Dual Coping Inventory allowed Wijngaards-de Meij et al. to identify levels of loss and/or restoration orientation in bereaved parents. The ability to make a transition in choice of method of continuing a bond with the deceased child may also be related to a change from a loss to a restoration orientation. Identifying whether such a link exists would be a crucial development in research with bereaved parents, since high restoration orientation was associated with lower levels of grief and depression not only in mothers, but also had an additional positive impact on the father's coping (Wijngaards-de Meij et al., 2008).

4.4.3 Phenomenology of Parental Bereavement – Impact of Cause of Death

The findings of the present study add to those of Woodgate (2006) by comparing the experience of bereaved mothers across a wide range of causes of death. The experiences were similar for all of the participants in the group, regardless of cause of death or age of the child at the time of their death, and the participants could therefore be treated as a homogenous group. Woodgate's first theme, keeping memories of the child alive, was found in the present study, but this was extended to a relationship rather than a more passive recollection of the child. This may be purely due to methodological differences in the analysis of data, since the present study follows IPA methodology, thereby incorporating an interpretative component within the presentation of the results, whereas Woodgate chose a purely thematic analysis with less interpretation.

Woodgate's second theme, that of the need for parents to believe they had been "good" parents, was not found in the current dataset. This may be an anomaly of the particular group of participants, or perhaps may be a further methodological issue. Woodgate's

study elicited data from interviews which, in most cases, included both parents simultaneously. Perhaps the discussion about good parenting was intended to alleviate guilt for the parent, either their own or their partners. Alternatively, the participants may have taken the opportunity to support their partner's parenting efforts to the researcher. There was no evidence in the present study of parents indicating the importance of being present when the child died. Again, this may be due to the idiosyncrasies of the particular group who volunteered for the research, or may be related to a lack of focus on this topic within the interview schedule. Alternatively, since many of the causes of death were sudden and accidental in the present study, being with the child at their time of death was, for some mothers, not an option. Parents who were present at the time of death in the previous study may have found benefit in this and sought to incorporate this as a coping strategy. A further explanation may be found in the demographics of the participants, since in the Woodgate study many participants were in the first three years of bereavement. At this relatively early stage, perhaps issues around the death itself may have been more salient to the participants. Finally, the issue of social support from friends, family and health care professionals was not found to be a key theme in the current research. Although mentioned in some accounts, this did not emerge as a key recurring theme in the analysis. This again may be due to different mean time since death in the current group of mothers, since the levels of social support obtained may have declined over time since the bereavement.

4.4.4 Ambivalence about Personal Mortality

All participants, without exception, reported a strongly held belief that their death would be welcome, either to end their current suffering or as a way of reuniting them with their lost child. If the mother had other surviving children, this appeared to

moderate their death ideation. The stress of bereavement and the all-encompassing grief that is associated with the loss of their child caused them to raise concerns about a reduction in levels of care for their surviving children.

The mothers in the present study demonstrated ambivalent feelings about their own death and all reported that it was not seen as threatening or fearful in any way. These findings conflict with those of (Barr & Cacciatore, 2008) who studied fear of death in bereaved mothers and found higher levels of fear of death in the bereaved mothers compared to the general population. The reason given by Barr and Cacciatore for their findings is that the mothers' primary concern is related to their "personal extinction" (p445). By losing a child, they have reduced their reproductive success. The authors suggest this fear of their own premature death may be adaptive, since it encourages the parents to fulfil their potential in other areas of their lives to compensate. The present study finds no evidence of such fear of death or extinction, and challenges the self-actualization theory cited by Barr and Cacciatore, since the basic ability to nurture surviving siblings was clearly compromised in this group of mothers. Participants in the Barr and Cacciatore study had a slightly different demographic to the present study, with approximately three quarters of their 400 participants experiencing miscarriage, stillbirth or neonatal death. The average time since death for these participants was eight months (median value). The focus on earlier deaths and the shorter time since bereavement may have had some impact on the results, since participants may not have time to fully accept the permanence of their loss. An alternative explanation may be that of the impact of the researcher's status of bereaved parent. Throughout the interviews, all of the mothers made reference to the fact that the interviewer would understand what they were saying since she, too, had experienced the loss of a child. Most mothers also

said that they had disclosed thoughts and feelings that they had never discussed before, again due to the perceived commonality of the experience of parental bereavement. Contemplating one's own mortality and expressing thoughts of suicide ideation are issues of a most personal nature. Perhaps the relationship with the interviewer in the present study facilitated this openness in a way that would be unlikely in the absence of the shared experience (Benoit, Jansson, Millar & Phillips, 2005).

The presence of other children in the family appeared to moderate the level of suicide ideation shown by the participants. (Agerbo, 2005) found bereaved parents to be twice as likely to complete suicide as a matched control group, but found that mother's risks decreased if there were other surviving children in the family. The present study elucidates this finding, as it shows that parents are conscious of the impact their suicide may have on their own children. They may be attempting to protect their surviving children from additional grief, and in turn the presence of other children protects them from suicidal behaviour. The approach taken by Agerbo was to look at the records of people who had completed suicide and analyse the risk factors from the statistics of this group. On this basis, it is not possible to compare the suicide rate in subsections of bereaved parents. The present study indicates that parents may delay suicide plans until their surviving children reach adult age. To identify whether this delay has an impact on subsequent suicidal behaviour, the suicide rates of bereaved parents must be scrutinized in both the short and long term.

4.4.4.1 Possible Sources of Support for Bereaved Parents

The present study also raises the question of whether there may be a need for enhanced social care following parental bereavement. Specialist palliative care social workers are

now being recognised as a valuable component to social services (Sheldon, 2000) but perhaps there is also a need for a social bereavement service to help parents who experience the death of a child. The mothers who were interviewed indicated that they had sometimes received help from friends, family and the local community to feed and care for their surviving children. In many cases, however, the mothers doubted whether the level of care given to the surviving siblings was adequate. In families where both parents care for the children, the nurturing of surviving siblings may be shared and may then be adequate during the periods of increased grief and mourning. The situation where a single parent is mainly responsible for child care may be more problematic, especially if additional social support is not forthcoming.

4.4.4.2 Suicide Risk

This study has highlighted a number of areas of concern over suicidality in this vulnerable population and the consequences for other family members. Excessive mortality following bereavement is a widely reported phenomenon (O'Connor & Sheehy, 2000), and, for bereaved parents, one possible explanation is that death has occurred by suicide, and this is a concern that requires further research efforts to resolve. Suicides may be misclassified as bereaved parents may take action, for example, to cause a road traffic accident, to take their own life without appearing to be directly responsible. Actual suicide rates and risk factors for bereaved parents must be established to enable clinicians to be more aware of the potential risk of suicide. The suicide risk may be higher in earlier months, but later suicides cannot be ruled out, and should be considered again as a risk factor when the surviving siblings reach adulthood. Based on the findings in the present study, it is essential that the needs of bereaved families are carefully considered. Further research is crucial to establish whether

additional social support is needed in families who experience the death of a child, to ensure surviving siblings are not at risk of neglect or abandonment.

4.4.5 Social Changes

The mothers did not provide a clear consensus on how their marriages were affected by the bereavement. Some mothers reported a strengthening of marital bonds whilst others indicated that their marriage situation had worsened following the death of their child. Those that did report problems suggested that these were a feature of the relationship prior to the bereavement, therefore may have been an underlying issue, possibly exacerbated by the additional stress. It appeared that there were differences in how the parents coped, but in the absence of corroboration from the fathers, taking the mothers' accounts of their husbands' behaviours does not permit a reliable comparison of coping strategies. The prevalence of changes in relationship status will therefore be measured in the later quantitative studies reported in chapters five and six.

Most of the mothers reported some difficulty in reintegrating to the work environment following their loss. The frequency of reported disruption in employment merits further investigation and will also be tested quantitatively in the larger population (see chapters five and six).

4.4.6 Methodological Considerations

There are some considerations to be made regarding the methodological approach chosen. The participants all knew in advance that the interviewer was also a bereaved parent. Many made reference to this within the interview process, often asking if the researcher had similar experiences or whether the story they were telling was typical. This happened more often in interviews where the participant was not a member of

TCF, perhaps suggesting the ongoing search for normality and referencing of the experience. When participants did ask about the researcher's experience, the fact that the interview situation was intended to elicit information about their own experience was reiterated, and the opportunity to ask questions about the researcher's experience was offered during the debriefing time.

After the interview, the researcher allowed time for debriefing with the participants where a general chat about the experience took place. It is important to note that, without exception, all of the participants said they were glad they had volunteered and found the interview to be a cathartic event. Most indicated that they would only have been able to divulge such intimate details of their experience to another bereaved parent, and many said that the interview was the first time they had been able to discuss their thoughts and feelings in such depth.

4.4.7 Limitations

We acknowledge that the reported results have been gathered from interviews with mothers only. No fathers took part in the interviews, although some had initially agreed to discuss their experiences. The views of fathers on their own coping and perhaps that of the family as a whole would add to the understanding of parental bereavement. Participants in the study were volunteers who wanted to tell their story. This is unlikely to be representative of the population of bereaved mothers as a whole. Those who chose not to volunteer may have had more negative outcomes, or alternatively may feel that they want to leave their experience in the past.

4.4.8 Conclusion

The findings from the present study are important for those interested in how bereaved parents cope with the death of their child. The suicidality of bereaved parents is a significant concern and merits prioritised further investigation. Protective factors and reasons for living must be established in this vulnerable group who appear to be at suicidal risk. In addition, the frequency and potential merits or disadvantages of continuing bonds should be assessed in large scale quantitative studies, in a wider population of bereaved parents. The predictive value of continuing bonds on symptoms of grief and depression, either positive or negative, should be evaluated and, if found helpful, considered as a factor worth incorporating into bereavement support for bereaved parents. The need for support for parents who are caring for surviving siblings should be urgently addressed, since some families may be struggling to cope with the demands of caring for children whilst enduring significant grief symptoms. The care package offered to bereaved parents should therefore consider whether childcare support and relationship management services may be appropriate, in addition to the counselling and peer support services which are currently available. Bereaved parents may require a more holistic support offering, which reflects the diversity of their emotional, social and welfare needs.

Chapter Five - Factors Affecting Outcomes in Parent's Early

Bereavement

5.0 Abstract

5.0.1 Background

Very little is known about the experience of parental early bereavement in the United Kingdom. The present study aims to provide information relating to the factors associated with differential grief and depression outcomes.

5.0.2 Method

Sixty-three participants were recruited from bereavement support organisations, between 2 and 59 months post-loss, mean 30 months (SD=15). A questionnaire was completed which comprised standard instruments measuring grief, depression, coping styles, rumination, continuing bonds and optimism/pessimism as well as a number of specific bereavement-related questions.

5.0.3 Results

Grief and depression were identified as clearly separate phenomena. Rumination was associated with both increased grief and depression scores. When controlling for depression, the key factors associated with higher grief were rumination and cognitive restructuring. Continuing bonds scores were not associated with bereavement outcomes.

5.0.4 Conclusions

Prolonged grief can be identified as a distinct psychological disorder, separately from clinical depression. Rumination is an important contribution factor to both grief and

depression. Cognitive restructuring may be associated with better outcomes and could form a beneficial component of bereavement interventions.

5.1 Introduction

5.1.1 Prolonged Grief as a Distinct Diagnostic Condition

The concept of prolonged or complicated grief as a credible psychiatric disorder has received increased attention in recent years, with a set of proposed diagnostic criteria for this condition now appearing to meet DSM criteria for the definition of a psychiatric disorder (Prigerson et al., 2009). The symptoms of prolonged grief as proposed for inclusion in DSM-V and ICD-11 are; separation distress with persistent or intense yearning for the deceased combined with cognitive, emotional or behavioural symptoms such as avoiding reminders of the loss, difficulty with accepting the loss and feeling incomplete without the loved one's presence (Prigerson et al., 2009). Whilst mindful of the need to avoid pathologising a naturally occurring phenomenon, where such symptoms would be expected to occur normally after a bereavement, many practitioners suggest that when symptoms persist beyond six months post-loss, or where they cause significant disturbance to normal functioning, therapeutic intervention may be indicated (Stroebe, Schut et al., 2007).

Individuals exhibiting symptoms of Prolonged Grief Disorder (PGD) may also demonstrate the potential for other psychiatric disorders such as major depression, anxiety disorder or post-traumatic stress disorder (Stroebe, Schut et al., 2007). Previous studies have indicated that a distinction exists between depression and grief symptoms in elderly bereaved spouses, bereaved psychiatric patients (Boelen, van den Bout & de Keijsers, 2003) and a cross-section of bereaved adults (Bonanno, Neria, Mancini, Coifman, Litz, et al., 2007). As yet, no studies were found which tested the

independence of grief from depression symptoms in a cross-sectional group of bereaved parents.

5.1.2 Rumination as an Avoidance Focussed Method of Coping

Rumination in bereavement is believed to be associated with negative outcomes such as depression (Nolen-Hoeksema et al., 1994). However, the “grief work” notion, where the individual must accept the loss and accommodate the changes needed into their life, has a conceptual overlap with many aspects of rumination (Stroebe, Boelen, van den Hout, Stroebe, Salemink, et al., 2007). The key difference identified by Stroebe et al. is that rumination may in fact be an avoidant strategy rather than an active processing one. By ruminating on matters around the loss, the individual is actually attempting to deny the reality of it and cannot, therefore, process their grief and accept the bereavement.

No published literature has been found relating to the role of rumination in the specific condition of parental bereavement, however there is a clear link between depressive rumination and psychological distress (Morrison & O'Connor, 2008). The current study aims to measure the association of depressive rumination, grief and depression in bereaved parents.

5.1.3 Identification of Risk Factors for Prolonged Grief in Bereaved Parents

The recent development of the Stroebe, Folkman, Hansson & Schut (2006) Integrated Risk Factor Framework has provided a means for identifying which are the key factors that predict bereavement outcome. A summary of this model is shown in Figure 5.1. The model is derived from earlier research which looked at specific risk factors and their impact on outcomes (e.g. the Cognitive Stress Theory, (Bonanno & Kaltman, 1999) and the Dual Process Model of Coping with Bereavement, (Stroebe & Schut,

1999)). The key feature of this new model is that it recognises the importance of multiple influencing factors on bereavement outcome, such as bereavement-related factors (e.g. whether the death was sudden or anticipated), interpersonal risk factors (e.g. social support, religious activity), appraisal and coping mechanisms and intrapersonal risk factors (e.g. gender, personality). This model is untested on any group of bereaved parents and Stroebe and colleagues have highlighted that not enough is known about the relative importance of individual factors in bereavement.

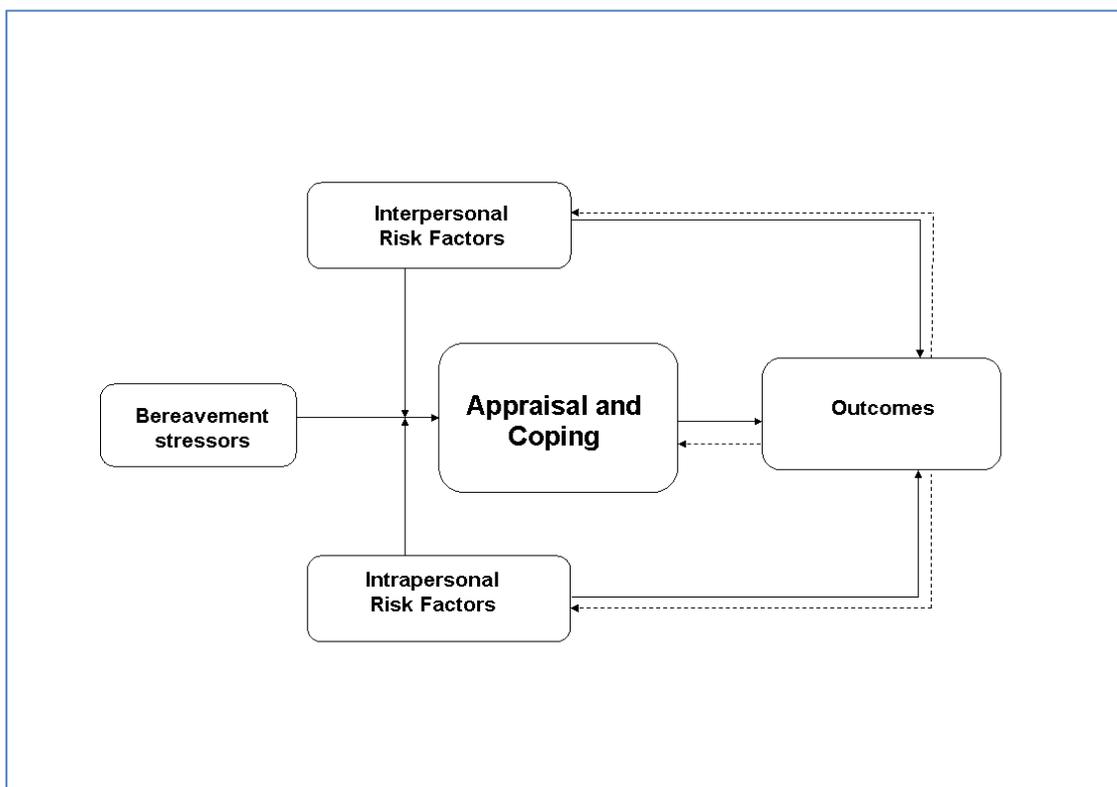


Figure 5.1 – Stroebe et al. Integrative Risk Factor Framework (2006)

A summary of the key risk factors for general bereavement indicates that the following factors are associated with poorer outcomes: greater age of the bereaved, sudden or violent deaths, lack of social support and additional domestic stressors (Sanders, 1993). The factors indicated as important by the parents interviewed for the qualitative study in chapter four were the level of continuing bonds, suicidal ideation and social changes.

These factors, and those highlighted by Sanders (1993), will be tested to establish which are most closely associated with prolonged grief and depression in a group of bereaved parents.

5.1.4 The Impact of Bereaved Parents Continuing Bonds with their Lost Child

Continuing bonds with their lost child emerged as a key theme for bereaved mothers in the qualitative investigation reported in chapter four. The mothers who were interviewed made repeated reference to the comfort they derived from their ability to maintain an ongoing relationship with the child, either through frequent grave visitation, by keeping mementoes of the child close to them or by establishing a symbolic representation of the child with which they could interact. From the general bereavement literature, however, the relative adaptiveness of continuing bonds in bereavement remains a contentious issue. An overall maladaptive association has been found between high levels of continuing bonds and prolonged grief (Field, Gao & Paderna, 2005). However, more detailed analysis suggests that continuing bonds have no association with increased grief when the individual is able to make sense of the loss and accept its ongoing permanence (Neimeyer, Baldwin & Gillies, 2006). The impact of continuing bonds in association with other factors of bereavement therefore merits more detailed investigation. The current study aims to establish the direction of any association between continuing bonds, grief and depression in bereaved parents.

The hypotheses for the current study were as follows;

- (i) Prolonged grief symptoms were present and were measurable independently from depression.

- (ii) Increased levels of rumination were associated with higher levels of grief and depression independently.

In addition, two exploratory analyses were carried out. These were

- (a) The factors most closely associated with grief and depression were identified.
- (b) The association between continuing bonds scores and grief and depression scores were examined.

5.2 Method

Ethical approval for this study was given by the ethics board of the Department of Psychology, University of Stirling.

5.2.1 Participants

Letters were sent to The Child Bereavement Charity, Child Death Helpline and The Compassionate Friends to request assistance with participant recruitment. These organisations are charities which provide support to bereaved parents within the United Kingdom. All three charities posted an invitation to participate on their web sites and The Compassionate Friends included the invitation in their quarterly newsletter, sent to people who pay an ongoing subscription to the charity.

People who expressed an interest in taking part in the study were sent information about what was involved and how the information supplied would be used. If they then agreed to take part, they could complete a questionnaire either in hard copy sent by post, or online. No reminder was sent to participants who agreed to take part but did not complete the questionnaire. Seventy two people requested a questionnaire of which, 64

were returned complete (89%). The participants were between 2 and 59 months post-loss, mean 30 months (standard deviation 15 months).

5.2.2 Measures

Data were collected using a combination of published psychological measures and questions specific to this study. Socio-demographic variables included sex and age of participant, relationship status now and at the time of bereavement, employment status now and at the time of bereavement, occupation now and at the time of bereavement, highest level of education, and age and sex of any other children in the family. Details related to the circumstances of the loss were age of child at time of death, sex of child, consideration of whether the death was sudden or anticipated, whether the child lived mostly at home at the time of their death, whether organ donation was considered and the impact of the donation decision. Information about how life has been affected post-bereavement including whether the participant has experienced problems at work, financial difficulties, difficulty caring for other children, house moves, concerns about other family members coping with the bereavement, access to grandchildren if the child was an adult with children of their own, knowledge of other bereaved parents, parent's experience of subsequent bereavements, whether the parent has a memorial site for their child and if so, how often they visit and whether the parent has a special item, object or living thing which reminds them of their child.

Published reliability and validity statistics for all measures are given in chapter three.

5.2.2.1 Grief

Grief was measured using the 19-item Inventory of Complicated Grief (Prigerson, Maciejewski et al., 1995) adapted for use by parents by referring to “my child” rather than “this person” in the question wording. The total score on the Inventory of Complicated Grief indicates the severity of the participant’s grief symptoms, with a score of 25 or over indicating that the participant meets the proposed diagnostic criteria for prolonged grief. The scale was internally consistent in the current study (Cronbach’s $\alpha = .86$).

5.2.2.2 Depression

Depression was measured using the 9-item Patient Health Questionnaire (PHQ-9) (Kroenke et al., 2001). The total score indicates the level of severity of depression, with a score of 10 or more indicating a potential diagnosis of moderate to severe depression. The scale was internally consistent in the current study (Cronbach’s $\alpha = .90$).

5.2.2.3 Trait Optimism/Pessimism

Optimism and pessimism were measured with the 10-item Life Orientation Test (Revised) LOT-R (Scheier et al., 1994) (see Appendix III). The total of the positively worded items gives an optimism score and the total of the negatively worded items gives a pessimism score. The scale was internally consistent in the current study for both optimism and pessimism (Cronbach’s $\alpha = .77$ and $.83$ respectively).

5.2.2.4 Rumination

The 10-item Response Styles Summary (Nolen-Hoeksema, 1991) was used to assess rumination where high scores indicate a greater tendency towards rumination. The scale was internally consistent in the current study (Cronbach’s $\alpha = .92$).

5.2.2.5 Coping Style

Coping style was measured using the 28-item Brief Cope (Carver, 1997), aggregating the scales into four summary sub-scales of Problem Focussed Coping, Avoidance Focussed Coping, Social Support and Cognitive Restructuring (O'Connor & O'Connor, 2003), along with the Self-blame, Use of Religion, Focus and Venting of Emotions and Alcohol and Substance Use scales. The internal consistency of the sub-scales was acceptable (Problem Focussed Coping – Cronbach's $\alpha = .75$, Avoidance Coping – Cronbach's $\alpha = .71$, Social Support – Cronbach's $\alpha = .82$ and Cognitive Reconstruction Coping – Cronbach's $\alpha = .75$). The individual scales were also internally consistent with Self-blame – Cronbach's $\alpha = .77$, Use of Religion – Cronbach's $\alpha = .79$, Focus and Venting of Emotions – Cronbach's $\alpha = .77$ and Alcohol and Substance Use – Cronbach's $\alpha = .96$.

5.2.2.6 Continuing Bonds

Continuing Bonds were measured using the 11-item Continuing Bonds Scale (Field et al., 2003), with the wording of items changed from “spouse” to “child”. The total score indicates the level of continuing bonds that the bereaved has with the deceased. The scale was internally consistent in the current study (Cronbach's $\alpha = .82$).

5.2.2.7 Suicidal Ideation

To identify suicidal ideation, participants were asked three questions. The first of these was an indication of whether or not they are thinking about suicide. The second asks, “Have you ever deliberately taken an overdose (e.g. of pills or other medication) or tried to harm yourself in some other way (such as cut yourself?)”, with permitted responses being “No”, “Yes – once” or “Yes – more than once”. The third question was,

“Have you ever seriously wanted to kill yourself when you have taken an overdose or tried to harm yourself in some other way?”. The possible answers to this question were “Yes”, “No” or “Not applicable”.

5.2.2.8 Education

Possible values for education level were secondary school only, college, undergraduate or postgraduate. These were collapsed into two categories – school or college and university (undergraduate or postgraduate).

5.2.2.9 Cause of Death

The cause of death was summarised as violent or non-violent. This was extrapolated from the cause of death which the parent supplied on the questionnaire. Violent deaths were those which occurred as a result of accident, murder or suicide in line with previous research (e.g. Neimeyer et al. (2006) (Neimeyer et al., 2006). All others were classed as non-violent deaths.

5.2.2.10 Death anticipation

Death anticipation was summarised into sudden or anticipated. Sudden deaths were described by participants as totally unexpected or expected in the hours before death. Anticipated deaths were expected for days or expected for some time.

5.2.2.11 Linking Objects/Symbolic Representations

Participants were asked if they had a special object, item or living thing that reminded them of their child. If they indicated they had such an object, they were asked whether this object helped them to cope with their loss. The options for response were “very helpful”, “usually helpful”, “neither helpful nor unhelpful”, “usually unhelpful” or “very unhelpful or upsetting”. These responses were collapsed with “very helpful” and

“usually helpful” indicating a positive effect of the symbol and other responses indicating a non-positive use of a symbol.

5.2.2.12 Relationship status

The relationship status at bereavement could be chosen from the following options – single, with partner, married, separated, divorced or widowed. These answers were summarised so that with partner or married was classified as “in a relationship.” The other answers were classified as “not in a relationship”.

5.2.2.13 Employment status

The employment status at bereavement was similarly classified. From the options, unemployed, caring for family, sick, permanently disabled, training/studying, retired, working full time and working part time, the final two were classified as “working”. All others were classified as “not working”.

5.2.2.14 Open-Ended Questions

Two questions were asked where the answer could prompt a response which required qualitative analysis. The first asked “Is there anything else you would like to tell us about your experience of coping with the loss of a child or of taking part in this research?”. This question was included for two reasons. Firstly, the questionnaire was designed with recognition of limiting the load on participants and keeping the survey as short as possible. Variables under test were chosen, but these may not have been what the participants believed to be important in their experience of coping. This question therefore acted as a means of establishing whether there were any other areas which may warrant further investigation in coping with the death of a child. The second reason for including this question was to acquire information about the experience of taking part, from the participants’ perspective. Although the consent form was completed at

the start of the study and participants were aware they could withdraw at any time, it was important to know if they had been caused distress when completing the form. This would again be useful in subsequent research projects. An additional question was asked which was intended to provide more information about the impact of the researcher's role as bereaved parent. This question was "This research project is being carried out by a researcher who has experienced the death of a child. Has this influenced your participation in this study and if so, how?" The answers to both of these questions would be subject to thematic analysis.

5.2.2.15 Participation Experience

The final question asked participants to rate the experience of taking part on a scale from 1 to 7, ranging from very negative to very positive. Again, this was intended to establish what the participant thought about their experience and would be valuable for further research.

Two versions of the final complete questionnaire were created, with the order of questions reversed for counterbalancing to minimise order effects.

5.2.3 Participant Demographics

Table 5.1 shows details of the demographics of the participants.

Table 5.1 – Demographics of participants who returned completed questionnaires

	<i>Participants (n=64)</i>
Mothers	59 (92%)
Fathers	5 (8%)
Deaths - female	23 (36%)
Deaths - male	41 (64%)
Mean parent age (SD)	48.8 years (11.7)
Mean child age (SD)	18.9 years (12.6)
Non-violent death	46 (72%)
Violent death	18 (28%)
Sudden death	50 (78%)
Death anticipated	14 (22%)
Relationship status at bereavement	52 (81%) in a relationship. 12 (19%) not in a relationship
Employment status at bereavement	43 (68%) employed, 20 (32%) not employed (n=63)
Education level	School 17 (27%), College or University 47 (73%)

The number of mothers agreeing to take part in the research far exceeded the number of fathers, which is consistent with previous research carried out with bereaved parents (e.g. (Murphy, Tapper, Johnson & Lohan, 2003; Woodgate, 2006).

5.2.4 Procedure

The University of Stirling Psychology Department ethics committee approved the project, following a pilot test of materials and processes, which also received ethical approval. The pilot exercise asked ten bereaved parents known to the researcher to review the materials which were to be sent to potential participants. Suggestions for improvements were incorporated into the final versions of the documents used in the study.

Three charities were approached for help with recruitment, who subsequently advertised the project on websites and in their newsletter. Respondents were offered the questionnaire in either a paper format or online. Participants who requested a paper

copy were sent the questionnaire along with a consent form, both of which were to be returned to the university in a reply paid envelope. Those who chose to complete the questionnaire electronically were sent a link to the online version. Prior to displaying the questionnaire, an initial screen was displayed containing a duplicate of the consent form. The questionnaire was only initiated if the participant answered positively to a question confirming they have read the consent information and were happy to proceed.

All participants were given a unique identification number. No details which would allow the participant to be identified were included in the collected data to ensure participant confidentiality.

5.2.5 Statistical Analyses

First, the number of participants who met diagnostic criteria for prolonged grief and those who met diagnostic criteria for depression were assessed using crosstabulation. A Chi-square test was not run since two of the cells contained a value of less than five (Field, 1999).

Second, the association between grief score and rumination score, then depression score and rumination score was analysed using simple linear regressions.

Third, the association between the outcome variables and the categorical predictors were considered. Univariate logistic regression analyses were carried out, testing each of the categorical outcome variables with each of the predictors. Only variables which were found to have a significant univariate association with the outcome variables were included in the next step of the analysis. Continuous variables were examined using

linear regression, to determine which were significantly associated with the measured outcomes variables. Again, only those which were found to be univariately significant were included in further analyses.

Those factors which remained were then included in multivariate regression analyses.

Depression is known to be a risk factor for prolonged grief (Stroebe, Schut & Finkenauer, 2001), therefore this was controlled for by entering depression into step one of the predictors in the grief analysis. Given the large number of potential variables, a forward entry regression method was chosen to examine the relative importance of all significant factors, as recommended by Field (2005).

5.3 Results

The means and standard deviations for all continuous variables are shown in Table 5.2.

Table 5.2 – Minimum, maximum, mean, standard deviation and number of responses for continuous variables.

	<i>Mean</i>	<i>Standard Deviation</i>	<i>Minimum</i>	<i>Maximum</i>	<i>Total n</i>
Grief score	41.6	11.5	16	66	64
Depression score	10.9	7.3	0	27	64
Optimism/pessimism score	13.5	6.1	5	49	64
Rumination score	25.5	6.4	14	40	64
Religion	4.2	1.9	2	8	63
Self-blame	4.8	1.9	2	8	62
Venting	4.5	1.9	2	8	62
Substance/Alcohol use	3.6	2.3	2	8	63
Problem focussed coping	10.2	3.3	4	16	63
Avoidance focussed coping	7.4	3.0	4	14	62
Social Support	10.0	3.0	4	16	63
Cognitive Reconstruction	9.8	3.4	4	16	62
Continuing Bonds Score	43.7	9.8	11	60	64
Time since death (months)	30	15	2	59	56
Experience of taking part	6.0	1.2	3	7	64

The frequencies of dichotomous categorical variables are shown in Table 5.3.

Table 5.3 – Frequencies of positive/negative responses in categorical variables.

	<i>Yes</i>	<i>%</i>	<i>No</i>	<i>%</i>	<i>Total n</i>
Prolonged Grief	59	92	5	8	64
Clinical Depression	30	47	34	53	64
Child lived at home at time of bereavement	34	53	27	42	61
Other children at time of bereavement	49	77	15	23	64
Know other bereaved parents	50	78	14	22	64
Problems at work	35	55	14	22	49
Financial difficulties	27	42	30	47	57
Relationship difficulties	41	64	20	31	61
Difficulty caring for other children	21	33	22	34	43
Moved house	12	19	41	64	53
Concerns about other family members coping	56	88	6	9	62
Experienced other bereavements since the death of their child	31	48	32	50	63
Visiting grave daily or weekly	28	44	32	50	60
Reported having a positive symbol	38	60	24	38	62
Reported positive impact of researcher as bereaved parent	18	33	36	67	54

There were only seven responses to the question about whether organ donation was helpful or unhelpful, therefore these data are excluded from further analysis.

5.3.1 Hypothesis One – Prolonged grief can be measured independently from depression.

The mean grief score for the group was 41.6, SD = 11.5 with a range of 16 - 66 (the maximum possible score being 76). The mean depression score was 10.9, SD = 7.3 with a range of 0-27. The maximum possible depression score is 27. Although 47 % of this group met diagnostic criteria for moderate or severe depression, 92% were likely to meet diagnostic criteria for prolonged grief.

An illustration of the number of participants meeting diagnostic criteria for prolonged grief and those likely to have moderate/severe depression is shown in figure 5.1.

Distribution of Grief and Depression Scores

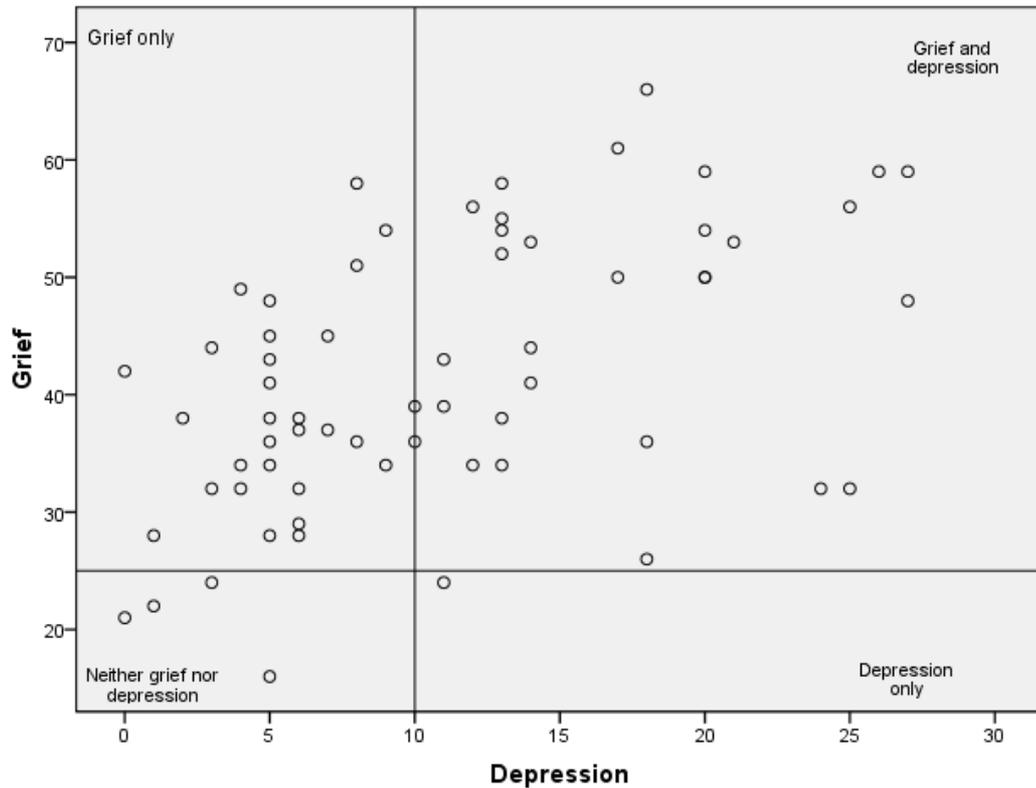


Figure 5.2 - Scattergram of participants' grief and depression status

Only one participant had depression without prolonged grief but 30 people (47%) had prolonged grief without depression. This indicates that depression and prolonged grief are separate constructs and that it is possible to meet diagnostic criteria for prolonged grief without having a likely diagnosis of depression. In this group of bereaved parents, having depression without prolonged grief was rare. The hypothesis, that bereaved parents could be diagnosed with prolonged grief independently from depression, was therefore supported.

5.3.2 Hypothesis Two – Increased levels of rumination will be associated with higher levels of grief or depression

Separate simple linear regressions were run to test the association of rumination separately with grief and depression scores. The association of rumination with grief was highly significant, $\beta = .73$, $t(63) = 8.34$, $p < .001$, and accounted for 53% of the variation in grief scores. The association of rumination with depression was also highly significant, $\beta = .75$, $t(63) = 8.82$, $p < .001$, and accounted for 56% of the variation in depression scores. The hypothesis that rumination scores are associated separately with both grief and depression was therefore supported.

5.3.3 Identification of the factors most closely associated with grief and depression

5.3.3.1 Factors Associated with Increased Grief

5.3.3.1.1 Categorical Variables Associated with Grief

Due to the large number of participants (92%) who met diagnostic criteria for prolonged grief in this sample, using grief diagnosis as a dichotomous categorical variable would be of little use. Instead, a median split was applied to the prolonged grief score. This was carried out at the median score of 43, with participants having a score of 43 or less being categorised as lower grief, and those scoring above 43 being categorised as having higher grief.

Univariate logistic regressions were carried out on all of the categorical variables, to determine which were associated with higher grief. Table 5.4 shows the categorical variables which showed a significant association.

Table 5.4 – Categorical variables univariately associated with higher grief

<i>Variable</i>	<i>B(SE)</i>	<i>Odds ratio</i>	<i>95% CI</i>	<i>p value</i>
Employment status of “working” at time of bereavement	1.50(.57)	4.46	1.46-13.65	<.01
Difficulty caring for other children	1.45(.65)	.23	.06-.84	<.05

The factors which were not significantly associated with higher grief were the participants’ own sex, relationship status at bereavement, change in relationship status, change in employment status, having other children, problems at work, financial problems, relationship problems, house move, concerns over other family members coping, other bereavements, knowing other bereaved parents, sex of child, violent death, sudden death, child living at home, frequency of grave visitation, having a helpful symbol and having considered suicide.

5.3.3.1.2 Continuous Variables Associated with Grief

Univariate linear regressions were then run to establish which continuous variables were associated with higher grief scores. Table 5.5 shows the variables which showed a significant association with grief scores.

Table 5.5 – Continuous variables univariately associated with higher grief

<i>Variable</i>	<i>t value</i>	<i>β</i>	<i>p-value</i>
Combined optimism/pessimism score	-3.58	-.41	<.001
Rumination	8.34	.73	<.001
Depression	4.72	.51	<.001
Problem-focussed coping	-2.22	-.27	<.05
Avoidance	4.84	.53	<.001
Cognitive restructuring	-4.17	-.44	<.001
Self-blame	2.39	-.47	<.001
Substance/alcohol use	2.16	.27	<.05

The following variables were not associated with higher grief – own age, number of restoration stressors, months since bereavement, child’s age, continuing bonds score, religious coping, venting and social support.

5.3.3.1.3 Relative Importance of Factors Associated with Increased Grief

Factors that were univariately significant in either the logistic regressions or the correlations were then analysed to ascertain which made the most significant contribution to explaining the variation in grief scores. The factors included in this analysis are shown in Figure 5.3.

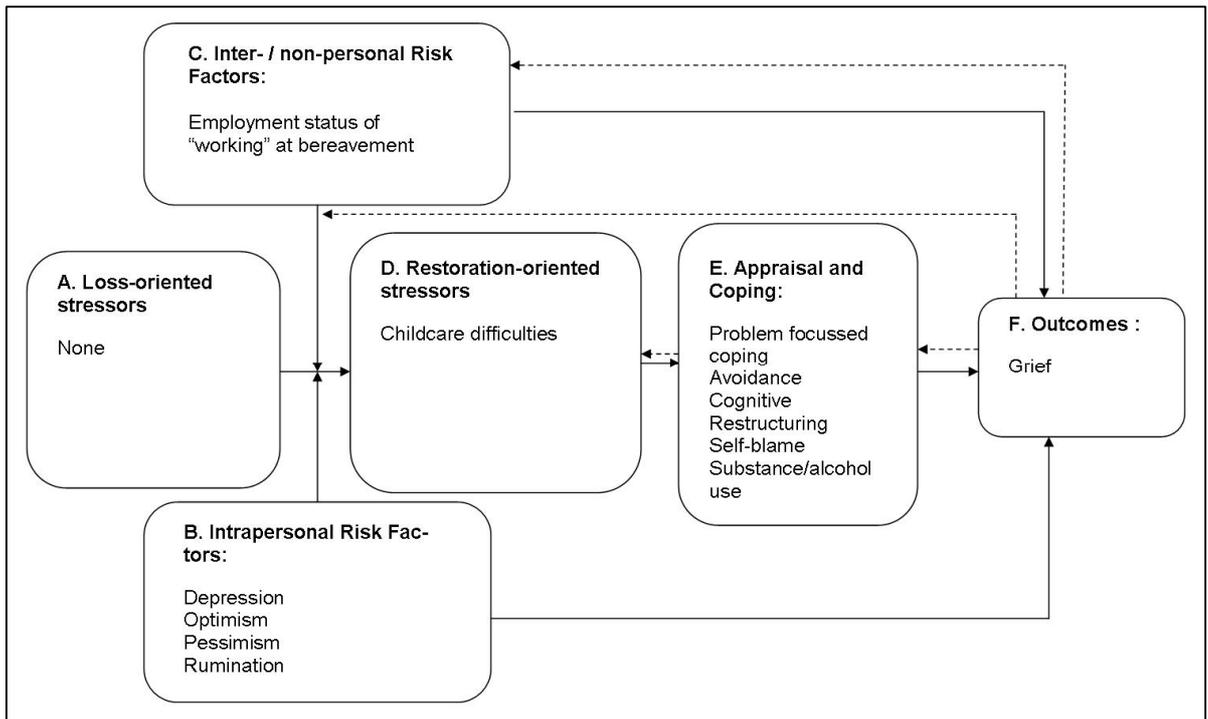


Figure 5.3 – Factors Univariately Associated with Grief

A forward-entry multiple regression analysis was conducted on the significant variables, controlling for the effect of depression by entering the depression score into step one. The analysis produced three models. The final model is shown below in table 5.6.

Table 5.6 –Multivariate Hierarchical regression analyses testing the relative contribution of factors to total grief score

	<i>Variable</i>	<i>R²</i>	<i>ΔR² for step</i>	<i>Final β</i>	<i>t</i>
Step1	Depression	.23	.23*	.78	3.51*
Step 2	Rumination	.57	.34***	1.52	5.55***
Step 3	Cognitive restructuring	.62	.05***	-.91	-2.47*

Note *p<.05, **p<.01, ***p<.001.

The model accounted for 62% of the overall variation in grief scores. Depression` accounted for 23% of the variance, rumination accounted for another 34% and cognitive restructuring accounted for another 5%.

5.3.3.2 Factors Associated with Depression

5.3.3.2.1 Categorical Variables associated with Clinical Depression

Univariate logistic regression analyses were carried out on the categorical variables, to determine which were associated with the classification of clinical levels of depression. Table 5.7 shows the categorical variables showed a significant association at $p < .05$.

Table 5.7 – Categorical variables univariately associated with depression

<i>Variable</i>	<i>B(SE)</i>	<i>Odds ratio</i>	<i>95% CI</i>	<i>p value</i>
Higher grief	1.69(.56)	5.40	1.82-16.03	<.01
Financial difficulties	1.84(.60)	.16	.05-.51	<.01

The factors which were not significantly associated with depression were own sex, relationship status at bereavement, change in relationship status, employment status at bereavement, change in employment status, having other children, problems at work, relationship problems, difficulty caring for other children, moving house, concerns over other family members coping, other bereavements, knowing other bereaved parents, sex of child, violent death, sudden death, child living at home, frequency of grave visitation, having a helpful symbol and suicidal attempts.

5.3.3.2.2 Continuous Variables Associated with Depression

A simple linear regression was run to establish which continuous variables were

univariately associated with higher depression scores. Table 5.8 shows the variables which showed a significant association at $p < .05$.

Table 5.8 – Continuous variables univariately associated with depression

<i>Variable</i>	<i>t value</i>	<i>β</i>	<i>p-value</i>
Grief	.33(.07)	.51	<.001
Time since bereavement	-.14(.06)	-.29	<.05
Combined optimism/pessimism score	-.30(.15)	-.25	<.05
Rumination	.85(.10)	.75	<.001
Alcohol/substance use	1.25(.39)	.38	<.01
Problem focussed coping	-.59(.27)	-.27	<.05
Avoidance	1.26(.28)	.51	<.001

The following variables were not associated with depression: own age, number of restoration stressors, child age, venting, religious coping, self-blame, social support and cognitive restructuring.

5.3.3.2.3 Relative Importance of Factors Associated with Increased Depression Scores

The significant factors were then analysed with a multivariate stepwise regression test to establish which made the greatest contribution to explaining the variation in depression scores. The factors included in this analysis are shown in Figure 5.4.

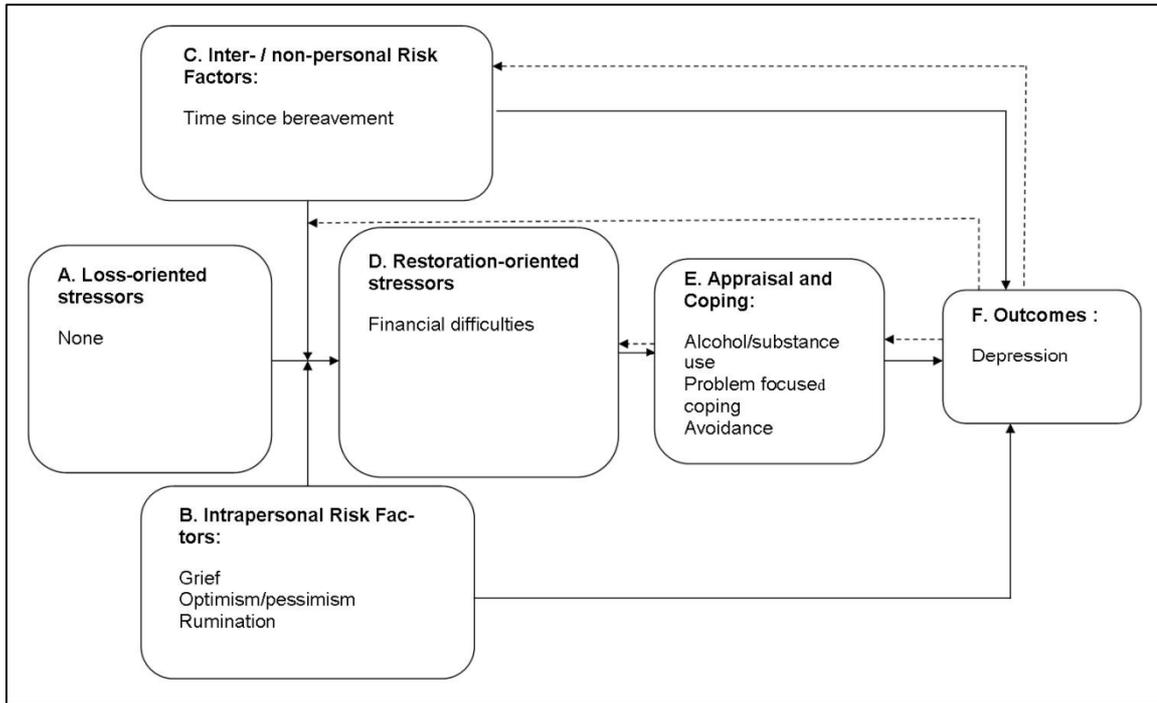


Figure 5.4 – Factors Univariately Associated with Depression

Again, the relatively large number of potential predictors indicated a forward entry regression method was appropriate (Field, 2005). The analysis produced only one model as shown in table 5.9.

Table 5.9 –Multivariate Hierarchical regression analyses testing the relative contribution of factors to total depression score

	<i>Variable</i>	<i>R²</i>	<i>ΔR² for step</i>	<i>Final β</i>	<i>t</i>
Step1	Rumination	.46	.46*	.68	6.24*

Note *p<.05, **p<.01, ***p<.001.

Rumination accounted for 46% of the variation in depression scores, $F(1,46) = 38.93$, $p < .001$, $\beta = .68$, $p < .001$.

5.3.4 Association with Continuing Bonds and either Grief or Depression

The univariate linear regressions indicated that there was no significant association between continuing bonds and either grief or depression scores.

5.3.5 Thematic Analysis of Other Relevant Information

Most of the comments made were reinforcing the answers to earlier questions, for example, indicating relationship problems or concerns over other family members coping. The most widely reported “other” concern was the impact of other people’s unhelpful reactions (n=9). In terms of comments about the actual questionnaire, one respondent found the forced choices frustrating, however another reported this was helpful as it made completing the answers easier. One participant suggested a “comments” box beside each question to enable personalised comments to be added. In addition, many positive comments were made about the experience of taking part and the feeling of doing something positive to help other bereaved parents.

5.4 Discussion

5.4.1 Prolonged Grief Independent of Depression

The results of the present study clearly indicate that depression and prolonged grief are separate constructs, with one not necessarily being a subset of the other. Almost half of the participants in the present study (47%) met diagnostic criteria for prolonged grief but not depression. Currently, in the absence of an accepted grief condition in medical terms, the suffering experienced by this group may not be recognised clinically. This may, in turn, have implications for the bereaved in terms of employment rights and insurance policies covering salaries whilst absent from work. To ensure that the distress of people experiencing prolonged grief in the absence of depression is recognised and

potentially treated, prolonged grief must be included as a recognised disorder in version five of the Diagnostic and Statistical Manual of Mental Disorders.

5.4.2 Rumination and Grief/Depression

Rumination was univariately associated with both grief and depression. Indeed, in the multivariate regression analysis, it was the only variable associated with depression and, when controlling for depression in the multivariate analysis of grief, held the strongest association with prolonged grief. This finding presents problems for those who offer therapeutic interventions with the bereaved since, as a potentially stable personality trait, the tendency to ruminate may not be easily altered. In this case, the additional risk factors univariately associated with complicated grief and bereavement, such as alcohol and substance use, a tendency for self-blame and childcare difficulties, must be addressed, if progress is to be made in alleviating symptoms of grief and depression in bereaved parents.

5.4.3 Risk Factors for Prolonged Grief and Depression

The additional factor associated with differential levels of prolonged grief, aside from depression and rumination, was cognitive restructuring. This construct refers to the individual reinterpreting the stressor in a positive light, for example, looking for something good that has come about as a result, or considering that the situation may not be as bad as it first seems. Benefit-finding, such as this, is an often unexpected finding in people who have experienced a traumatic event (Janoff-Bulman & Frantz, 1997). For the bereaved parent, this reinterpretation could mean carrying out some charity fundraising or helping other bereaved parents in a support group. Considering the experiences of others which may in some way be worse than their own

bereavement, for example, the cause of death, being able to say goodbye to the child or the child being able to end their life at home, may allow bereaved parents to re-evaluate their experience and find some positive, or perhaps more accurately less negative, aspects of their bereavement. This type of positive meaning making following bereavement has been associated with a better quality of life in parental discourses (Lichtenthal, Currier, Neimeyer & Keesee, 2010).

Engelkemeyer and Marwit (2008) (2008) found lower grief was associated with higher levels of post-traumatic growth in a group of parents bereaved up to 30 years (median time approximately 5 years) when time since death was controlled for. Posttraumatic growth increased in line with time since death in their participants. The concept of posttraumatic growth refers to the situation where an individual, when facing traumatic stress, experiences a profound change in their perception of life (Tedeschi & Calhoun, 2004). They may find a new direction for their life, spiritual strength or a changed sense of priorities as a result of their experience, thus developing a sense of recognising some good from the traumatic event which has occurred. Elgelkemeyer and Marwit found the presence of post-traumatic growth to be stronger in those who were tested at a later time since bereavement, but the present study indicates that this type of cognitive restructuring is both present and adaptive in early parental bereavement. This finding should be considered by bereavement therapists when developing interventions based on empirical evidence.

5.4.4 Continuing Bonds and Grief

The group of parents in the present study demonstrated no relationship between their level of continuing bonds and either grief or depression. An analysis of the interview

data in chapter four indicated that some forms of continuing bonds may be adaptive, such as a special linking object, whereas others, such as frequent grave visitation, may be maladaptive. The findings from the present study indicate that these behaviours were not the key determinants of differential grief or depression outcomes.

5.4.5 Research Experience

The participants in the present study rated it a positive experience, with a mean satisfaction score of 6 out of a maximum of 7. This indicates that research with bereaved parents should not be dismissed as potentially distressing and that recruiting potentially vulnerable participants may not necessarily be a barrier to future research. Indeed, other researchers have found that participating in qualitative bereavement research is seen as beneficial by those involved (Buckle, Dwyer & Jackson, 2010) and the present study suggests this finding extends to quantitative bereavement research also. Ethics committees must therefore be wary of paternalistically “protecting” bereaved people from participating in research, since, paradoxically, their informed consent to take part in studies such as the present project may actually be perceived by participants as highly valuable in their bereavement process.

Two thirds of the respondents in the present study indicated that the decision to take part was either wholly or in part influenced by the fact that the researcher was a fellow bereaved parent. Lack of prejudice when interpreting answers to questions, expertise in choosing relevant questions and level of understanding of the overall experience were cited as reasons for favouring a peer researcher. However, one third of participants said that the researcher being a bereaved parent had no impact on their decision to take part. The impact of the researcher on participant recruitment is therefore unclear.

5.4.6 Limitations of the Study

The recruitment process for this study involved support organisations advertising the study on web sites and in newsletters. The web sites, in particular, were likely to be visited by those actively seeking support. This may explain the large proportion of participants who were experiencing prolonged grief at the time. The newsletter is sent to people who had previously contacted the organisation and felt they would like to subscribe to the quarterly newsletter. These people may not actively be seeking bereavement support at the time of reading the invitation to participate. Although volunteers were asked where they saw the invitation to participate, very few indicated whether the response was due to the call on the web site or the notice in the newsletter. It is therefore not possible to identify any differences between the two recruitment methods. Replicating this research in a group of non-support seeking parents in early bereavement would identify how representative the current research is of the global population of bereaved parents.

Secondly, this group of participants was also comprised mainly of mothers. Previous research with bereaved parents has found that the majority of participants who agree to take part are mothers e.g. Murphy, Johnson and Weber, 2002; Lohan and Murphy, 2006. The perspective of fathers, and any sex differences, should be considered to establish a clear picture of parental bereavement for both parents.

Finally, the quantitative method of data collection may provide different responses to that of a qualitative approach. The questions relating to suicide in particular elicited different responses in respondents in the present study compared to that reported in chapter four. In the present study, suicidal ideation was present in less than one third of

participants (27%). In the study reported in chapter four, all of the mothers interviewed indicated that they had welcomed death or considered suicidal behaviours. One possible explanation for this could be that the impersonal nature of a questionnaire affected the likelihood of releasing such personal information. Alternatively, the participants in the interviews for the qualitative study may have been more likely to offer such information in a face to face encounter, where, by the time these issues were discussed, a relationship of trust with the researcher may have emerged. It is possible, however, that the parents who were interviewed felt obliged to say that they had wished for death when asked directly, as a means of indicating the level of the loss they have experienced. Finally, the difference in findings may be simply due to the fact that the interviewed group had a high level of death and suicide ideation, but the participants in the present study did not.

5.4.7 Conclusion

The group of bereaved parents in the present study were experiencing high levels of prolonged grief, but did not necessarily exhibit sufficient symptoms of depression to warrant a clinical diagnosis. The presence of prolonged grief as a diagnostic category condition separate to depression has been supported, and reinforces the need for a distinct new diagnostic condition to be added to DSMV. Rumination is a key factor in both prolonged grief and depression following bereavement. Due to the nature of such personality factors, therapeutic intervention for modification of ruminative behaviour may be difficult. Clinicians and therapists must be aware of the importance of this behaviour and any interventions must take cognisance of its presence. Cognitive restructuring and the ability to find benefits in the experience of parental bereavement, even in the early stages, must not be overlooked. Bereaved parents should be

encouraged to consider whether any facets of their experience did not occur in the worst possible form, and should also be assisted in their search to find any aspects of their life which have improved as a result of their living with the traumatic experience. Parents who have made attempts to find ways of coping may well find these efforts beneficial. The seeking and successful developing of strategies should be compared to the actual strategies chosen to identify whether it is the chosen activity which is important in grief processing, or the very act of considering and choosing a strategy. The role of continuing bonds in parental bereavement did not emerge from the present data. Their impact and association with grief and depression requires further analysis.

Parents in the early stage of bereavement provide an essential insight into the experience of grieving the loss of a child. The majority of participants in the current study (92%) indicated that taking part in the research was a positive experience, and researchers and ethics committees alike should not avoid including this group of people in research, for fear of distress being caused. It is imperative that bereaved parents are given a voice to allow their experiences to inform both medical and therapeutic practitioners and society as a whole, to allow this vulnerable group to receive optimum clinical and social care and support. More studies of this type with parents in early bereavement are required to establish how representative these findings are compared to the overall population of bereaved parents. Chapter six will examine if similar variables predict grief and depression later in the bereavement process.

Chapter Six - Factors Affecting Bereavement Outcome in Bereaved Parents Four Years Post-Loss

6.0 Abstract

6.0.1 Background

Grief in parental bereavement declines from the time of death until around three years, when a rise in symptoms is often experienced. Following this, bereaved parents are expected to steadily experience reduced symptoms. The experience of the loss of a child in this phase of mid-bereavement has received little attention from researchers, and requires investigation.

6.0.2 Method

A questionnaire was administered to a group of bereaved parents recruited from death records in Scotland. The questionnaire was completed by 106 participants at Time 1, mean 48 months post-loss (SD=10.9), and 81 participants completed the follow-up questionnaire at Time 2, three months later. The cause of the child's death included sudden and violent deaths as well as long term illness and stillbirths. The mean child's age at time of death was 8 years 8 months (SD=3.5 years).

6.0.3 Results

Prolonged grief and clinical depression were measured separately at Time 1. Depression-related rumination was associated with both grief and depression at Time 1. Reflective rumination was associated with grief and depression at Time 2. The factors significantly associated with grief at Time 1, in multivariate regression analyses, were depression, self-blame, the child normally living at home at the time of their death,

visiting the child's grave weekly or more frequently and the number of restoration stressors. Time 1 depression and self-blame predicted grief scores at Time 2. The factors multivariately associated with depression at Time 1 were rumination, problems at work and having a lower level of education. Time 1 rumination and level of education predicted depression at Time 2.

6.0.4 Conclusion

Those who offer support to bereaved parents must be aware that depression and grief may not necessarily co-exist in bereaved parents, and the presence or absence of each of these conditions must be evaluated and treated accordingly. In addition, the importance of social factors must not be underestimated. Bereaved parents require social and employment support through their grieving period. Therapeutic interventions must cover a variety of domains in order to address the factors which are associated with poorer outcomes in bereaved parents.

6.1 Introduction

The grief experienced by bereaved parents is thought to reduce from the time of bereavement until about three years, when an often unexpected increase in emotional distress is experienced (Rando, 1983). After this time, the parent is believed to experience an improvement in outcomes over time. By four years post-loss, the parent is therefore likely to have lived through the worst times of their loss and should be making a recovery in terms of negative symptoms. This period of mid-bereavement, from four years post-loss, is therefore of interest to researchers, since bereaved parents should then be moving towards resolution of their grief (Rando, 1983).

6.1.1 Factors Associated with Outcomes in Mid-bereavement

When measured in mid-bereavement, grief has been found to be associated with time since death (Anderson et al., 2005; Feigelman et al., 2009; Robinson & Marwit, 2006) emotional coping and avoidance coping (Anderson et al., 2005), sex of the parent, with mothers experiencing higher levels of grief than fathers (Bohannon, 1991; Littlefield & Silverman, 1991), social support and subsequent stressors (Hazzard et al., 1992). Losing a male child was linked with higher levels of depression (Hazzard et al., 1992) (Robinson & Marwit, 2006) as was the death being sudden (Hazzard et al., 1992) or the child being healthy prior to their death (Littlefield & Silverman, 1991).

Coping styles focussing on emotional expression, keeping busy and avoidance were associated with lower levels of grief (Robinson & Marwit, 2006). Finally, ruminative coping was found to be associated with higher levels of depression in a Japanese cohort (Ito et al., 2003). Although most of these factors were found to be associated with

different levels of depression or grief univariately, the relative importance of each when compared collectively in multivariate analyses has not yet been established.

6.1.2 Findings from Research in Early Bereavement

The results from chapter five indicated that grief and depression are distinct constructs in early bereavement, since prolonged grief was found independently from depression. These findings have, to date, not been tested in a group of parents in later bereavement, to establish whether the findings hold in respect of mid-bereavement.

Rumination was found to be associated with both grief and depression outcomes in early bereavement, however continuing bonds were not associated with grief or depression, despite their apparent importance highlighted in the phenomenological investigation of bereavement reported in chapter four. In the early bereavement study reported in chapter five, depressive-type rumination was found to be associated with higher levels of grief and depression. Other types of rumination, specifically reflective rumination, may not be maladaptive, and may even facilitate processing of grief and loss-related cognitions (Nolen-Hoeksema et al., 1994), however this claim has not yet been supported empirically with bereaved parents. The relationship between depressive and reflective rumination, separately, to grief and depression symptoms in mid-bereavement will be evaluated.

Continuing bonds was not found to be associated with grief or depression symptoms in early bereavement, despite its importance in the phenomenological study reported in chapter four. This may be due to factors associated with early bereavement, such as limited length of time to develop satisfactory strategies for continuing the bond with the

lost child. The relative adaptiveness of continuing bonds behaviour in mid-bereavement therefore requires investigation.

The hypotheses for the current study were as follows;

- (c) Prolonged grief is a construct independent of depression in parents in mid-bereavement at Time 1
- (d) Increased levels of depressive rumination would be associated with higher levels of grief and depression at Time 1
- (e) Increased levels of reflective rumination would be associated with higher levels of grief and depression at Time 2.

In addition, five exploratory analyses were carried out. These were :

- a) Analysis of the factors most closely associated with grief and depression at Time 1 were identified
- b) Examination of the relative importance of continuing bonds in explaining grief and depression scores at Time 1 was investigated
- c) Determination of whether grief and depression scores at Time 2, measured three months after the baseline at Time 1, could be predicted by those factors found to be most strongly associated with grief or depression at Time 1.
- d) Consideration of whether the researcher's status as bereaved parent had any bearing on the individual taking part in the research
- e) Analysis of whether participation in the research was viewed positively or negatively.

6.2 Method

Ethical approval for the study was granted by the ethics committee of the Psychology Department at the University of Stirling.

6.2.1 Participants

The General Register Office for Scotland (GROS) provided a list of death records for people who died in Scotland in 2005, aged from 0 to 30 years, and those who were stillborn. This yielded a total of 1351 records. The death registration process requires the informant to give the name of both parents of the deceased, if known. In the present sample, three deaths were recorded with no mother's name and 81 deaths were recorded with no father's name. Twenty-four parents had experienced more than one loss. From this, the number of registered bereaved parents of a child who died in Scotland in 2005 aged up to 30 years old was 2594.

Deaths recorded by a non-parent, for example, a grandparent, aunt/uncle or spouse, were excluded from the list of potential participants (parent n=444). If the registering parent supplied an address outside Scotland, they were also excluded from the list of potential participants (parent n=78). A mortality check was carried out to identify if any of the parents listed were subsequently present in the register of deaths. The name and address of each parent were used as search criteria in the death register. If a match was found, the parent had died and their records were removed from the list of potential participants. This step was intended to ensure that no letters were sent to families where the intended recipient is also deceased. Eighteen bereaved parents were found to have died following their child's death and were, therefore, removed from the database. Of these 18 deaths, 12 were from causes related to drug and alcohol use.

Finally, an address checking analysis was run on the database, using a commercial data cleansing organisation (www.data-8.co.uk). This was intended to check the database against records held of people who have moved away but left no forwarding address. This commercially-available service compares the given name and address combination against a register of “moved away” UK names and addresses. This register is generated mostly from electoral roll details, but is augmented by information from product warranty registrations, lifestyle questionnaires and magazine subscriptions. By comparing the mailing details presented against those held by commercial data cleansing organisations, it is possible to identify people who no longer live at the given address. The parent names and addresses were run through this data cleansing service and this step removed another 21 parents. The number of bereaved parents remaining in the potential participant list following all of these steps was 2033 (78% of all parents bereaved in Scotland in 2005).

Although both parents’ names may be given on the death certificate, only the address of the informant is recorded in UK death registration data. There is no indication whether the given address is correct for the non-registering parent. In the present sample, 64% of deaths following a live birth were registered by fathers and all of the stillbirths were registered by mothers. To minimise the impact of these biases of informant sex, an offer to take part was sent to both parents, at the registering parent’s address.

The letters were planned to be sent out over a two-week period and 1148 (56%) were posted as a first batch. We received 12 complaints from people we contacted, mostly relating to the use of their personal details which were not always understood to be in

the public domain. Although the number of complaints received was small (1% of the total letters sent) the level of distress that was experienced by these people was significant. Consequently, the research team took the decision not to send out any further invitations in order to avoid potentially causing distress to any other parents. Of the 1148 letters posted, 130 were returned undeliverable, therefore 1018 parents were assumed to have been contacted.

6.2.2 Measures

The study utilised the same approach as that of the early bereavement research presented in chapter five, namely a combination of published psychological measures, bereavement-specific questions and socio-demographic variables.

6.2.2.1 Grief

The 19-item Inventory of Complicated Grief was used to assess grief (Prigerson, Maciejewski et al., 1995). A score of 25 or over indicates that the participant meets the proposed diagnostic criteria for prolonged grief. The scale was internally consistent in the current study at Time 1 (Cronbach's $\alpha = .93$) and at Cronbach's $\alpha = .92$ at Time 2.

6.2.2.2 Depression

Depression was measured using the 9-item Patient Health Questionnaire (PHQ-9) (Kroenke et al., 2001) which assesses probable psychiatric caseness for moderate to severe depression. The total score is used to indicate probable caseness, with a score of 10 or above suggesting moderate to severe depression. The scale was internally consistent in the current study (Cronbach's $\alpha = .93$ at Time 1 and $.95$ at Time 2).

6.2.2.3 Trait Optimism/Pessimism

The Life Orientation Test (Revised) LOT-R measures trait optimism/pessimism (Scheier et al., 1994). The total score calculated from the 10-item measure indicates the relative strength of trait optimism or pessimism. The scale was internally consistent in the current study for both optimism and pessimism (Cronbach's $\alpha = .83$ and $.87$ respectively).

6.2.2.4 Rumination

Rumination was measured at Time 1 using the 10-item Response Styles Summary to measure depression-related rumination (Nolen-Hoeksema, 1991). Higher scores indicate a greater tendency towards the measured style of rumination. The scale was internally consistent, with Cronbach's $\alpha = .93$.

6.2.2.5 Coping Style

Coping style was measured using the Brief Cope (Carver et al., 1989), a 28-item questionnaire measuring 14 types of coping. The humour scale was removed from this study to avoid potential offence in participants. The remaining scales were aggregated into four summary sub-scales following O'Connor & O'Connor (2003). Problem Focussed Coping (subscale one) was derived from the total scores from the Active Coping and Planning scales, Avoidance Focussed Coping (subscale two) was calculated from Denial and Behavioural Disengagement. Social Support (subscale three) was derived from the Seeking Instrumental Social Support and Seeking Emotional Social Support. Cognitive Restructuring (subscale four) was calculated from Positive Reinterpretation and Growth Acceptance. Self-blame, Use of Religion, Focus and Venting of Emotions and Alcohol and Substance Use did not readily lend themselves to any of these summary scales and were therefore retained as sub-scales in their own

right. The internal consistency of the sub-scales was acceptable at Time 1 (Problem Focussed Coping – Cronbach’s $\alpha = .83$, Avoidance Coping – Cronbach’s $\alpha = .78$, Social Support – Cronbach’s $\alpha = .81$ and Cognitive Reconstruction Coping – Cronbach’s $\alpha = .74$) and at Time 2 (Problem Focussed Coping – Cronbach’s $\alpha = .69$, Avoidance Coping – Cronbach’s $\alpha = .80$, Social Support – Cronbach’s $\alpha = .70$ and Cognitive Reconstruction Coping – Cronbach’s $\alpha = .53$).

6.2.2.6 Continuing Bonds

Continuing Bonds were measured using the Continuing Bonds Scale (Field et al., 2003) (see Appendix VII). The wording of the questions in this scale was changed from “spouse” to “child”, for example, “I seek out things to remind me of my child”. There are 11 questions in the scale with the participants responding on a scale from 1 (not at all true) to 5 (very true). The total score indicates the level of continuing bonds that the bereaved has with the deceased. The scale was internally consistent in the current study (Time 1 Cronbach’s $\alpha = .83$, Time 2 Cronbach’s $\alpha = .87$).

6.2.2.7 Socioeconomic Status

Carstairs scores are used in research in Scotland to identify relative socioeconomic status (SES) as defined by a participant’s postcode (McLoone, 2004). The scores are constructed using indices of poverty including level of overcrowding in the home, male unemployment, and no car ownership, as recorded in the Census statistics published by GROS. The postcodes given by the participants were checked against the list of all postcode areas in Scotland and their corresponding Carstairs score as published by McLoone (2004). The scores were then collapsed into three categories to simplify comparisons, following Leyland, Dundas, McLoone & Boddy (2007). Those

participants with scores 1 or 2 were described as Affluent, those with scores 3, 4 or 5 were described as Intermediate, and those with score 6 or 7 were described as Deprived.

6.2.2.8 Suicidal Ideation

Participants were asked two questions to establish their level of suicidal ideation or previous self-harm attempts. The first question, “Have you ever deliberately taken an overdose (e.g. of pills or other medication) or tried to harm yourself in some other way (such as cut yourself?)”, allowed responses of No, Yes – once or Yes – more than once. The second question was, “Have you ever seriously wanted to kill yourself when you have taken an overdose or tried to harm yourself in some other way?” to which the participant could answer “Yes”, “No” or “Not applicable”.

6.2.2.9 Education

The options for education level were secondary school only, college, undergraduate or postgraduate. These were again collapsed into two categories – school or college and university (undergraduate or postgraduate), to simplify analysis.

6.2.2.10 Cause of Death

The cause of death being either violent or non-violent was derived from the underlying cause of death code supplied by GROS on the death records. Violent deaths were those which occurred as a result of accident, murder or suicide in line with previous research (e.g. Neimeter et al. (2006) and as carried out in chapter five. All others were classed as non-violent deaths.

6.2.2.11 Death anticipation

The anticipation of the death was summarised as either sudden or anticipated, where sudden deaths were totally unexpected or expected in the hours before death and anticipated deaths were expected for days or expected for some time.

6.2.2.12 Linking Objects/Symbolic Representations

If participants indicated that they had a special object, item or living thing that reminded them of their child, their response was summarised as either being a linking object, photograph, hospital memento, physical remains, symbols or other, with more than one category identified where this was indicated in the response.

6.2.2.13 Relationship status

The options for relationship status were single, with partner, married, separated, divorced or widowed. These answers were summarised so that with partner or married was classified as “in a relationship”, as in chapter five. The other answers were classified as “not in a relationship”.

6.2.2.14 Employment status

The options for employment status were unemployed, caring for family, sick, permanently disabled, training/studying, retired, working full time and working part time, the final two were classified as “working”. All others were classified as “not working”.

6.2.3 Time 2 Questionnaire

A second questionnaire was issued to participants at Time 2, three months later. This shorter questionnaire requested an update of the relationship and employment status at that time. It also included the same grief, depression, continuing bonds and coping

measures taken at Time 1, to establish which had changed over time. Rumination at Time 2 was measured using the 10-item Response Styles Summary for reflective rumination (Nolen-Hoeksema, 1991) . Higher scores again indicate a greater tendency towards the measured style of rumination. The scale was internally consistent with Cronbach's $\alpha = .72$. The data captured at Time 2 was important since this permitted the prediction of outcomes, rather than merely the association between predictors and outcomes, if sampling had taken place at only one time point.

6.2.4 Qualitative Data

At both Time 1 and Time 2, participants were asked whether they were experiencing any other stressors not listed in the questionnaire. At Time 1, they were asked if there was anything else they would like to say about the experience of parental bereavement. These questions were intended to establish whether there were any other relevant stressors which should be taken into account when considering the experience of parental bereavement. The answers to these questions were grouped into broad themes, to identify if there were any recurring themes being reported which had been missed in the quantitative measures. At Time 1, participants were asked if they had any views on taking part in the research. The reason for asking this question was to establish what the participants felt about completing the questionnaire. They were also asked whether the fact that the researcher was a bereaved parent influenced their decision to take part. At Time 2, parents were asked what the biggest challenge was that they had faced since their child died, what advice they would give to other bereaved parents and what support they feel should be offered to people in this situation. Again, answers to all of these questions were subject to thematic analysis to identify if there were any key factors which were not tested quantitatively.

Two versions of the final complete questionnaire were created, with the order of questions reversed for counterbalancing to minimise order effects.

6.2.5 Participant Demographics

Table 6.1 compares the demographics of the sample contacted and the sample completed to the total potential death registration sample supplied by GROS.

Table 6.1 – Comparison of demographics for all parents potentially contactable, those actually contacted and those who returned completed questionnaires

	<i>Potential Participants (n=2033)</i>	<i>Sample Contacted (n=1018)</i>	<i>Sample Completed (n=106)</i>
Mothers	1049 (51.6%)	524 (51.4%)	73 (68.9%)*
Fathers	984 (48.4%)	494 (48.6%)	33 (31.1%)
Affluent addresses	702 (34%)	344 (34%)	50 (48%)
Intermediate addresses	845 (42%)	409 (40%)	45 (43%)
Deprived addresses	486 (24%)	265 (26%)	9 (9%)**
Now live outside Scotland	n/a	n/a	2 (2%)
Deaths - female	516 (39.5%)	395 (41.1%)	43 (40.6%)
Deaths - male	789 (60.4%)	566 (58.9%)	63 (59.4%)
Deaths - unknown sex	2 (0.1%)	0	0
Mean child age (SD)	14.63 (11.15)	13.26 (10.98)	8.58 (10.85)
Non-violent death	978 (74.8%)	709 (73.8%)	81 (76.4%)
Violent death	329 (25.2%)	252 (26.2%)	25 (23.6%)

Note *p<.05, **p<.01

Comparisons between categorical variables in the group of potential participants, the sample who were contacted and the sample who completed questionnaires were made using Chi-square tests. There were no significant differences found in the comparison

of the potential participants and sample contacted groups. For the sample completed and sample contacted comparison, two differences were found. First, the percentage of mothers agreeing to take part in the research was higher than that of the potential population, $\chi^2(1) = 6.05$, $p=.014$. This is consistent with previous research carried out with bereaved parents (e.g. that reported in chapter five, Murphy, Tapper, Johnson & Lohan, 2003; Woodgate, 2006). Second, the number of participants in the deprived category was under-represented compared to the bereaved population, $\chi^2(2) = 10.76$, $p=.005$.

The mean age of the child at time of death was lower in the participants who completed the questionnaire compared to those who were contacted, $t(994) = 4.07$, $p < .001$. The mean age of parents who agreed to take part in the research was 42.8 years ($SD = 10.3$). Age is not available from the data supplied by GROS, therefore this cannot be compared to the potential participants or those contacted. Ninety-three participants (88%) were married or in a relationship at the time of the bereavement. Thirteen (12%) were single, separated, divorced or widowed. Within the sample, 29 (27%) were educated to high school level, 33 (31%) had attended college, 23 (22%) were university graduates and 19 (18%) had a postgraduate qualification. Two participants (2%) did not supply their level of education.

6.2.6 Procedure

GROS was approached to obtain a list of recorded deaths and their Privacy Advisory Committee considered the request. Since the records were already in the public domain, they approved the data for use in this research. The University of Stirling Psychology Department ethics committee approved the project, following a pilot test of materials

and processes, which also received ethical approval. The pilot exercise asked ten bereaved parents known to the researcher to review the materials which were to be sent to potential participants. Suggestions for improvements were incorporated into the final versions of the documents used in the study.

The first batch of participants were sent an information pack and an invitation to participate in the research. Those who agreed to take part indicated on the response form whether they would prefer to complete the questionnaire in paper format or online. Participants who requested a paper copy were sent the questionnaire along with a consent form, both of which were to be returned to the university in a reply paid envelope. Those who chose to complete the questionnaire electronically were sent a link to the online version. Prior to displaying the questionnaire, an initial screen was displayed containing a duplicate of the consent form. The questionnaire was only initiated if the participant answered positively to a question confirming they had read the consent information and were happy to proceed.

All participants were given a unique identification number which was cross-referenced to their details as supplied by GROS. No details which would allow the participant to be identified were included in the collected data to ensure participant confidentiality.

6.2.7 Statistical Analyses

First, the descriptive statistics were calculated for all variables. Any differences between Times 1 and 2 were compared using paired t-tests for continuous variables and repeated measures Chi-squares for categorical measures. Then, participants who met

diagnostic criteria for prolonged grief and those who met diagnostic criteria for depression were compared using a binomial test.

Second, the association between the rumination and grief and depression separately would be tested using univariate linear regressions.

For the exploratory analysis, logistic regression analyses were carried out, testing each of the categorical outcome variables with each of the predictors. Only variables which were found to have a significant univariate association with the dependent variable were included in the next step of the analysis. Continuous variables were examined using linear regression, to determine which were significantly associated with the outcome variables. Again, only those which were found to be significant were included in further analyses.

Those factors which remained were then included in multivariate regression analyses. Depression is known to be a risk factor for prolonged grief (Stroebe et al., 2001), therefore this was controlled for in the grief analysis by entering depression into step one of the predictive factors. Given the large number of potential predictors, a forward entry regression method was chosen to examine the relative importance of all significant factors, as recommended by Field (2005).

Finally, the factors found to be significantly associated with grief and depression at Time 1 were then tested using multivariate regression analyses to identify whether any variables predicted grief and depression scores at Time 2.

The level of significance will be set at $p < .01$ for the main analyses to include only the variables with the most highly significant associations, and $p < .05$ for post-hoc analyses throughout, to limit the number of variables included in the multivariate analyses to those likely to have the highest level of association with outcomes.

6.3 Results

Of the 1018 people contacted, 154 returned positive responses indicating they would like to take part in the research. Of these, 109 actually returned questionnaires. Three were only partly completed and were therefore excluded from analysis. Missing data were addressed using the method recommended from the WHOQOL Brief manual was used, i.e. “Where an item is missing, the mean of the other items in the domain is substituted” (p.7). Eighty one participants (76%) completed measures at both Time 1 and Time 2. There were no significant differences in participants’ sex, age, child’s sex, age, cause of death or suddenness of death between those who did/did not complete measures at Time 1 and Time 2.

For suicidal ideation, the first question asks, “Have you ever deliberately taken an overdose (e.g. of pills or other medication) or tried to harm yourself in some other way (such as cut yourself)?”. Seven people answered yes to this question. The second question for suicidal ideation is, “Have you ever seriously wanted to kill yourself when you have taken an overdose or tried to harm yourself in some other way?”. For this question, 19 people answered yes. There was clearly some confusion amongst participants on what was being asked, therefore the answers to these questions were excluded from analysis. Suicidal ideation as a dependent variable was therefore not included in the analysis.

There were only two responses to the question about whether organ donation was helpful or unhelpful with one reply to each, therefore these data are excluded from further analysis.

The means and standard deviations for all continuous variables at Time 1 are shown in Table 6.2. Time 2 results are shown in Table 6.3.

Table 6.2 – Minimum, maximum, mean, standard deviation and number of responses for continuous variables at Time 1

	<i>Mean</i>	<i>Standard Deviation</i>	<i>Minimum</i>	<i>Maximum</i>	<i>Total n</i>
Grief score	28.3	15.6	2	62	105
Depression score	6.13	6.4	0	26	104
Child age	8.6	10.8	0	30	105
Optimism/pessimism score	12.2	2.1	7	21	106
Rumination score	20.7	6.3	8	36	106
Age	42.8	10.4	22	66	101
Venting of emotions	3.6	1.5	2	8	104
Religion	3.3	1.9	2	8	104
Self-blame	4.4	2.1	2	8	106
Substance use	2.7	1.4	2	8	104
Problem focussed coping	8.4	3.4	4	16	105
Avoidance focussed coping	6.0	2.7	4	16	106
Social Support	8.1	3.0	4	16	106
Cognitive Reconstruction	10.2	3.1	4	16	106
Continuing Bonds Score	40.2	12.2	12	67	104
Time Since Death (months)	47.6	3.6	42	54	106
Perception of taking part	5.6	1.2	2	7	104

Table 6.3 – Minimum, maximum, mean, standard deviation and number of responses for continuous variables at Time 2

	<i>Mean</i>	<i>Standard Deviation</i>	<i>Minimum</i>	<i>Maximum</i>	<i>Total n</i>
Grief score	22.38	15.43	0	58	79
Depression score	5.27	6.67	0	26	81
Rumination score	19.35	7.9	10	55	78
Venting of emotions	3.56	1.87	2	8	80
Religion	2.88	1.27	2	8	80
Self-blame	4.46	2.18	2	8	80
Substance use	3.76	2.52	2	8	80
Problem focussed coping	8.54	3.89	4	18	80
Avoidance focussed coping	7.24	4.12	4	20	80
Social Support	8.07	3.05	4	18	80
Cognitive Reconstruction	9.41	3.21	4	14	80
Continuing Bonds Score	33.49	12.81	11	64	79

Depression scores did not differ between Time 1 and Time 2, however grief scores were lower at Time 2, $t(76)=3.47$, $p=.001$. The level of alcohol and substance use increased from Time 1 to Time 2, $t(79)=-4.12$, $p<.001$. Religious coping declined over time, $t(78)=3.02$, $p=.003$. Avoidance focussed coping was greater at Time 2 than Time 1, $t(79)=3.03$, $p=.003$. Cognitive reconstruction also declined over time, $t(79)=2.21$, $p=.030$. Self-blame, problem-focussed coping and social report remained stable between Times 1 and 2. Continuing bonds scores also decreased over time, $t(78)=4.77$, $p<.001$.

The frequencies of dichotomous positive/negative categorical variables at Time 1 are shown in Table 6.4.

Table 6.4 – Frequencies of positive/negative responses in categorical variables at**Time 1**

	<i>Yes</i>	<i>%</i>	<i>No</i>	<i>%</i>	<i>Total n</i>
Grief rating	57	54	48	46	105
Depression rating	28	27	77	73	105
Sudden death	86	82	19	19	105
Violent death	25	24	81	76	106
Child lived at home at time of bereavement	40	42	56	58	96
Only child at time of bereavement	39	37	66	63	105
In relationship at time of bereavement	93	88	13	12	106
Working at time of bereavement	83	78	23	22	106
Know other bereaved parents	66	63	39	37	105
Problems at work	29	33	60	67	89
Financial difficulties	22	23	73	77	95
Relationship difficulties	49	48	52	52	101
Difficulty caring for other children	23	25	70	75	93
Moved house	10	11	81	89	91
Concerns about other family members coping	71	70	30	30	101
Experienced other bereavements since the death of their child	50	47	56	53	106
Reported having a linking object with their child	66	63	39	37	105
Reported having a symbolic representation of their child	10	9	95	90	105

The frequencies of dichotomous positive/negative categorical variables at Time 2 are shown in Table 6.5.

Table 6.5 – Frequencies of positive/negative responses in categorical variables at Time 2

	<i>Yes</i>	<i>%</i>	<i>No</i>	<i>%</i>	<i>Total n</i>
Grief rating	42	52	39	48	81
Depression rating	16	20	65	80	81
Problems at work	22	32	46	68	68
Financial difficulties	17	23	57	77	74
Relationship difficulties	38	48	41	52	79
Difficulty caring for other children	15	21	57	79	72
Moved house	6	8	66	92	72
Concerns about other family members coping	52	66	27	34	79

The number of people who moved house did not change significantly between Time 1 and Time 2. All other categorical measures showed a significant decline between Times 1 and 2, as shown in Table 6.6.

Table 6.6 – Difference between measures at Time 1 versus Time 2

	χ^2	<i>p-value</i>
Grief rating	$\chi^2(1) = 19.87$	<.001
Depression rating	$\chi^2(1) = 42.29$	<.001
Problems at work	$\chi^2(3) = 21.02$	<.001
Financial difficulties	$\chi^2(3) = 33.68$	<.001
Relationship difficulties	$\chi^2(1) = 19.72$	<.001
Difficulty caring for other children	$\chi^2(2) = 16.52$	<.001
Concerns about other family members coping	$\chi^2(3) = 40.76$	<.001

Table 6.7 shows the responses to questions with categorical outcomes which were not yes/no answers, which were measured at Time 1.

Table 6.7 – Frequencies of sex of child and parent, education status, socioeconomic status and frequency of grave visitation reported at Time 1

		<i>n</i>	<i>%</i>			<i>n</i>	<i>%</i>	<i>Total n</i>
Sex of child	Male	63	59.4	Female	43	40.6		105
Sex of parent	Male	33	31.1	Female	73	68.9		106
Education status of parent	School/college	62	59.6	University	42	40.4		104
Frequency of grave visitation	Up to weekly	40	44.4	Monthly/few times per year	50	55.6		90
Socio-economic status of parent	Deprived	9	8.7					
	Intermediate	45	43.3					
	Affluent	50	48.1					

6.3.1 Qualitative Analysis

6.3.1.1 Additional Problems not Specified in Questionnaire

The answers to the “any other problems” questions which were reported by more than one participant are shown in Table 6.8.

Table 6.8 – Other problems reported at either Time 1 or Time 2

<i>Reported problem</i>	<i>n</i>
Depression	11
Problems with friends/social relationships	6
Guilt	4
Anger	4
Sleep problems	2
Anxiety	2
Legal problems	2

These low numbers suggest that there are not other problems being experienced by the group of bereaved parents which warrant further investigation. The answers to the question asking the participant if there was anything else they would like to say about their experience appeared to elicit narrative either about the lost child or about how the

parent coped. The question asking what was the biggest challenge at Time 2 elicited similar answers to the “other problems” questions answered at both time points. The analyses of these narratives did not appear to yield any examples of definite coping behaviours but were rather personal narratives indicating the individual’s feelings about their loss. Whilst potentially interesting as a source of information about the lived experience of parental bereavement, these answers did not indicate any other variables which should be included in the quantitative evaluation of the bereavement experience.

6.3.1.2 Impact of the Bereaved Parent Status of the Researcher

Thirty one participants (42%) said that the research being carried out by a fellow bereaved parent encouraged them to take part, or that they would only have taken part if this was the case. Twenty four (33%) said it made no difference. This indicates that response rates in the current study may have been higher than if participants had not been told the status of the researcher, or had believed the researcher to be a non-bereaved parent.

6.3.1.3 Advice for Other Bereaved Parents

When asked what advice they would give other bereaved parents, 37 participants (50%) said talking about the child, either to family, friends or counsellors, was helpful. The question about what help should be offered to bereaved parents reinforced this with eleven participants (15%) suggesting counselling should be offered, five (7%) suggesting talking generally and thirteen (18%) suggesting peer support groups. Two participants stated that more information would be useful for bereaved parents, one participant requested employment rights and financial support and one participant recommended altruistic charitable behaviour for bereaved parents. It appears from these

suggestions that talking to other people, either friends, family or professionals, was seen as potentially helpful for the parents questioned.

6.3.2 Hypothesis One – Prolonged grief can be measured independently from depression at Time 1

The mean depression score for the group was 6.1, SD = 6.4 with a range of 0 - 26 (the maximum possible score being 27). The mean grief score was 22.4, SD = 15.4, with a range of 2 - 62. The maximum possible grief score is 76. More than half (54%) of this group of bereaved parents probably met diagnostic criteria for prolonged grief and 27% demonstrate “caseness” for moderate or severe depression.

An illustration of the number of participants meeting diagnostic criteria for prolonged grief and those likely to have moderate/severe depression is shown in figure 6.1.

Distribution of Grief and Depression Scores – Time 1

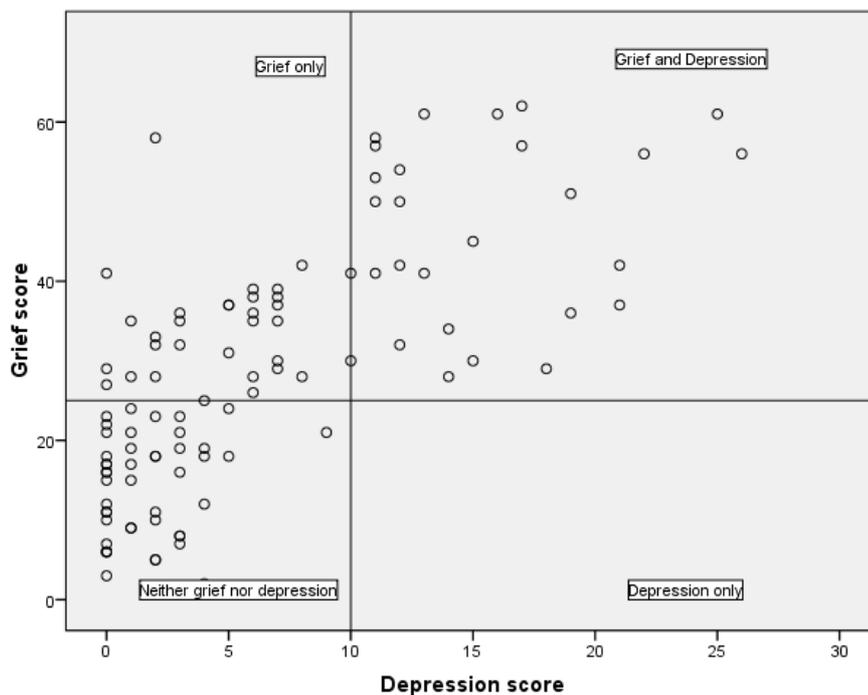


Figure 6.1 - Scattergram of participants' grief and depression status at Time 1

Over a quarter of the sample (27%) met diagnostic criteria for prolonged grief but not depression. No participants met diagnostic criteria for depression but not grief. This indicated that grief was found independent of depression, but depression was not found independent of grief. Those participants who demonstrated a likelihood of prolonged grief were not merely a subset of the depressed participants, but could be identified independently. A post-hoc binomial test confirmed the significance of the difference in depression diagnosis in the group without prolonged grief at $p < .001$. The hypothesis, that prolonged grief could be measured independently from depression, was therefore supported.

6.3.3 Hypothesis Two – Increased levels of depressive rumination will be associated with higher levels of grief and depression at Time 1

Separate simple linear regressions were run to test the association of depressive rumination with grief and depression at Time 1, univariately. The association of rumination with grief was highly significant, $\beta = .74$, $t(104) = 11.24$, $p < .001$. The association of rumination with depression was also highly significant, $\beta = .79$, $t(103) = 12.98$, $p < .001$. The hypothesis that depressive rumination scores associated with higher grief and depression scores at Time 1 was therefore supported.

6.3.3 Hypothesis Three – Levels of reflective rumination would be associated with higher levels of grief and depression at Time 2.

Separate simple linear regressions were again run to test the association of reflective rumination with grief and depression at Time 2, univariately. The association of rumination with grief was highly significant, $\beta = .46$, $t(75) = 4.46$, $p < .001$. The

association of rumination with depression was also highly significant, $\beta = .79$, $t(103) = 12.98$, $p < .001$. Post-hoc analyses considered whether this effect was related to the sex of the parent (Treyner et al., 2003). The data file was split by sex of parent and the linear regressions were run again. Both mothers and fathers demonstrated a strong association of reflective rumination with grief, fathers $\beta = .84$, $t(21) = 6.85$, $p < .001$, and for mothers, $\beta = .37$, $t(54) = 2.90$, $p = .005$. Both groups also showed a strong association of reflective rumination with depression, fathers returning $\beta = .76$, $t(22) = 5.30$, $p < .001$, and for mothers, $\beta = .40$, $t(53) = 3.11$, $p = .003$. The hypothesis that reflective rumination scores are associated with higher grief and depression scores was therefore supported.

6.3.4 Exploratory Analysis – Identification of the factors most closely associated with grief and depression.

6.3.4.1 Factors Associated with Increased Grief at Time 1

6.3.4.1.1 Categorical Variables

Univariate logistic regressions were carried out on all of the categorical variables, to determine which were associated with the likely diagnosis of prolonged grief. The factors which were associated are shown in Table 6.9.

Table 6.9 – Categorical variables univariately associated with likelihood of grief diagnosis at Time 1

<i>Variable</i>	<i>B(SE)</i>	<i>Odds ratio</i>	<i>95% CI</i>	<i>p value</i>
Financial difficulties – yes/no	2.15(.66)	.12	.03-.43	<.01
Violent or non-violent death	1.86(.59)	6.42	2.02-20.40	<.01
Relationship difficulties – yes/no	1.47(.43)	4.34	1.88-10.04	<.01
Grave visitation – up to weekly/more than weekly	1.56(.47)	.21	.08-.53	<.01
Sudden or anticipated death	1.78(.60)	.17	.05-.55	<.01
Concerns about family members coping – yes/no	1.30(.46)	3.68	1.49-9.07	<.01
Child lived mainly at home or not at home	1.22(.45)	3.40	1.42-8.17	<.01
Problems at work – yes/no	1.32(.49)	3.75	1.42-9.88	<.01

6.3.4.1.2 Continuous Variables

Univariate linear regressions were run to establish which continuous variables were associated with higher grief scores. Table 6.10 shows the factors significantly associated with higher grief scores.

Table 6.10 – Continuous variables univariately associated with higher grief at Time 1

<i>Variable</i>	<i>t</i>	<i>β</i>	<i>p-value</i>
Optimism score	-5.57	-.49	<.001
Pessimism score	6.92	.57	<.001
Rumination	11.73	.76	<.001
Depression	10.32	.72	<.001
Child age	4.69	.42	<.001
Number of restoration stressors	7.06	.58	<.001
Self-blame	10.48	.72	<.001
Venting	5.02	.45	<.001
Substance/alcohol use	2.71	.26	<.01
Avoidance	8.89	.66	<.001
Cognitive restructuring	-2.06	-.20	<.05

6.3.4.2 Relative Importance of Factors Associated with Increased Grief at Time 1

Factors that were important univariately were then analysed to ascertain which made the most significant contribution to explaining the variation in grief scores. The factors included in this analysis are shown in Figure 6.2.

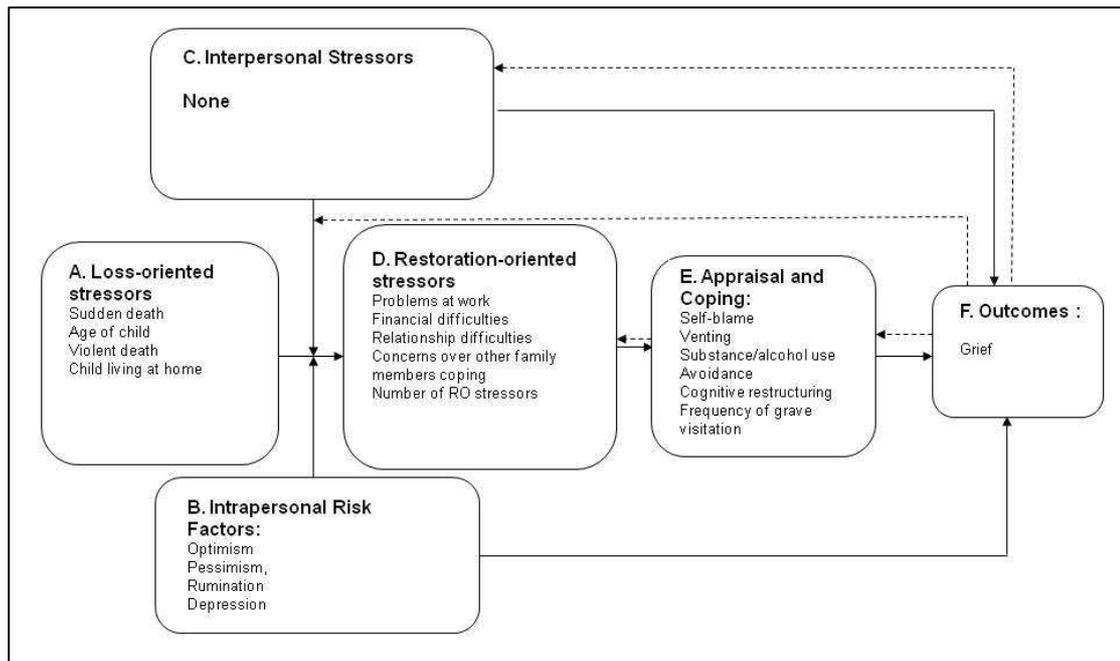


Figure 6.2 – Factors Univariately Associated with Grief at Time 1

A forward-entry multiple regression analysis was run on the significant variables, entering the depression score into step one. The analysis produced five models. The final model is shown in table 6.11.

Table 6.11 –Multivariate regression analysis testing the relative contribution of factors to grief score at Time 1

	<i>Variable</i>	<i>R²</i>	<i>ΔR² for step</i>	<i>Final β</i>	<i>t</i>
Step1	Depression	.50	.50***	.278	2.84**
Step 2	Self-blame	.65	.15***	.379	4.01***
Step 3	Child lived at home	.70	.05**	.180	2.40*
Step 4	Frequency of grave visits	.72	.02*	-.182	-2.45*
Step 5	Number of RO stressors	.74	.02*	.191	2.18*

Note *p<.05, **p<.01, ***p<.001.

The model accounted for 74% of the overall variation in grief scores, $F(5,57) = 30.34$, $p<.001$. Depression accounted for 50% of the variance in grief scores, self-blame accounted for a further 15%, the child normally living at home explained another 5%, the frequency of grave visits added another 2% to the explained variation, as did the number of restoration stressors.

6.3.4.2 Factors Associated with Increased Depression at Time 1

6.3.4.2.1 Continuous Variables

Again, linear regressions were run to identify those continuous variables which were univariately associated with higher depression scores. Table 6.12 shows the factors significantly associated with higher depression scores.

Table 6.12 – Continuous variables univariately associated with higher depression at Time 1

<i>Variable</i>	<i>t value</i>	<i>β</i>	<i>p-value</i>
Rumination	11.73	.451	<.001
Venting	5.02	-.243	<.01
Alcohol/substance use	2.71	.160	<.05
Problem focussed coping	1.79	.234	<.01

6.3.4.2.1 Categorical Variables

Logistic regressions were carried out on the categorical variables, to determine which were associated with the classification of depression. The factors which were significantly associated with depression are shown in table 6.13.

Table 6.13 – Categorical variables univariately associated with likelihood of depression diagnosis at Time 1

<i>Variable</i>	<i>B(SE)</i>	<i>Odds ratio</i>	<i>95% CI</i>	<i>p value</i>
Financial difficulties – yes/no	2.21(.55)	.11	.04-.32	<.001
Education – school/college or university	-1.63(.59)	.20	.06-.62	<.01
Grave visitation – up to weekly/more than weekly	-1.49(.52)	.22	.08-.62	<.01
Problems at work – yes/no	1.44(.54)	4.21	1.45-12.17	<.01

6.3.4.3 Relative Importance of Factors Associated with Increased Depression Scores at Time 1

The significant factors from the univariate analysis were then included in multivariate regressions test to establish which made the greatest contribution to explaining the variation in depression scores. The factors included in this analysis are shown in Figure 6.3.

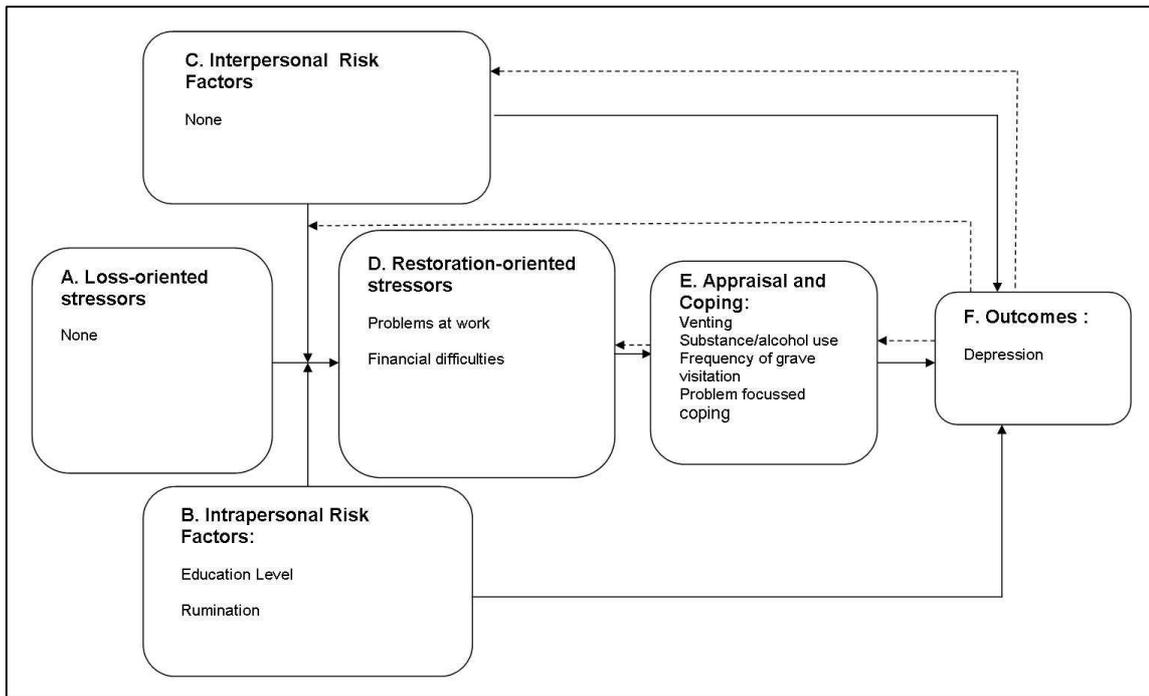


Figure 6.3 – Factors Univariately Associated with Depression at Time 1

Again, the large number of potential predictors indicated a forward entry regression method was appropriate (Field, 2005). The analysis produced three models, the final model being shown in Table 6.14.

Table 6.14 – Multivariate regression analyses testing the relative contribution of factors to depression score at Time 1

	<i>Variable</i>	<i>R²</i>	<i>ΔR² for step</i>	<i>Final β</i>	<i>t</i>
Step1	Rumination	.67	.67***	.733	10.70***
Step 2	Problems at work	.72	.05**	.230	3.43**
Step 3	Education level	.74	.02*	-.147	-2.22*

Note *p<.05, **p<.01, ***p<.001.

The final model consisted of rumination, problems at work and lower education level and explained 74% of the variation in depression scores, $F(3,66) = 58.95$, $p < .001$, $\beta = -.147$, $p = .030$.

6.3.5 Exploratory Analysis - Predicting Scores at Time 2 from Significant Time 1 Factors

6.3.5.1 Grief

The factors found to be significantly associated with higher grief scores at Time 1 were: depression score, self-blame, child living at home at the time of their death, frequency of grave visits and number of restoration oriented stressors. These were entered into a regression analysis, with Time 2 depression in step one, to control for its effects, and the remaining variables in step two, with a forward method of analysis. Grief score at Time 2 was entered as the dependent variable. The final model showed that only two variables would predict Time 2 grief; Time 2 depression and self-blame, as shown in table 6.15 below.

Table 6.15 – Multivariate regression analyses testing factors which predict Time 2 grief score

	<i>Variable</i>	<i>R²</i>	<i>ΔR² for step</i>	<i>Final β</i>	<i>t</i>
Step1	Time 2 Depression	.23	.23***	.244	1.74
Step 2	Self-blame	.34	.11**	.381	2.72**

Note * $p < .05$, ** $p < .01$, *** $p < .001$.

The final model of Time 2 depression and self-blame significantly predicted Time 2 grief, $F(2,59) = 13.54$, $p < .001$.

6.3.5.2 Depression

A similar analysis was run on the factors found to be significantly associated with higher Time 2 depression scores which were: rumination, problems at work and education level, with depression score at Time 2 as the dependent variable, using a forward entry method. The final model showed two factors predicting Time 2 depression; rumination and education level, as shown in table 6.16 below.

Table 6.16 – Multivariate regression analyses testing factors which predict Time 2 Depression score

	<i>Variable</i>	R^2	ΔR^2 for step	Final β	t
Step 1	Rumination	.36	.36***	.580	6.03***
Step 2	Education level	.41	.05*	-.224	-2.33*

Note * $p < .05$, ** $p < .01$, *** $p < .001$.

The final model was significant at $F(2,66) = 22.57, p < .001$.

6.4 Discussion

6.4.1 Prolonged Grief and Depression

The current study indicated that depression and prolonged grief are indeed separate constructs, since it was possible to meet diagnostic criteria for depression without grief and grief without depression, at Time 1. This result supported the findings reported in chapter five from early bereavement, and suggests that this is a finding that remains stable over time. Longitudinal studies following a cohort of bereaved parents over time would be required to further support this hypothesis, however it seems clear that the two conditions are indeed independent of each other. This finding supports the call for prolonged grief to be recognised as a distinct diagnostic condition in DSM-V (Prigerson et al., 2009).

6.4.2 Rumination and Depression

Both depressive and reflective rumination were found to be associated with grief and depression symptoms at Times 1 and 2, respectively. This finding suggests that reflective rumination may be just as maladaptive as depressive rumination. Reflective rumination was thought to be adaptive in bereavement, since it allowed the bereaved person to consider some of the issues causing them distress and either reappraise them in a less negative light or establish strategies for reduction in their symptoms by problem solving (Stroebe, Boelen et al., 2007). This did not appear to be the case in the current study, as reflective rumination was associated with both increased grief and depression scores, separately. Treynor et al. (2003) suggest that there may be a gender difference in the adaptiveness of reflective rumination in depression following bereavement. Again, this was not the case in the current study, with both mothers and fathers demonstrating an association between reflective rumination and both higher

grief and depression scores. The Stroebe et al. hypothesis about reflective rumination and grief is based mainly on the findings from Treynor et al., however the participants in that study were recruited from a random selection of households who were asked if they had experienced a significant stressor. Those participants did demonstrate that reflective rumination was not maladaptive in terms of depression symptoms, however this may not be the case when the stressor in question is bereavement generally, or perhaps parental bereavement in particular. The evidence from the current study does not support Stroebe et al.'s hypothesis that reflective rumination is adaptive in a group of bereaved people, either in terms of grief or depression symptoms.

6.4.3 Factors Associated with Prolonged Grief

The factors most strongly associated with Time 1 grief were depression, self-blame, the child normally living at home, the frequency of grave visits and the number of restoration stressors.

6.4.3.1 Depression

Depression is a widely-reported risk factor for grief (see Stroebe et al. 1996 for examples) however the present study is the first of its kind to demonstrate the importance of depression in the grief symptoms of bereaved parents. Depression was a key risk factors for grief accounting for 50% of the variation in grief scores at Time 1. This is important information for those involved in the treatment and care of bereaved parents, and treatment for depression symptoms should continue to form a key part of bereavement therapies. However, the finding that many people experiencing prolonged grief symptoms may not necessarily be depressed must not be overlooked. It is not enough to treat depression on its own – cognisance must also be given to alleviating the symptoms of grief.

6.4.3.2 Self-blame

The importance of self-blame in the prolonged grief symptoms of bereaved parents specifically has not previously been measured. Boelen, van den Bout and van den Hout (2006) reported self-blame as a key factor in depression and grief for a group of bereaved people, including bereaved parents, however the participant group also included others bereaved in different circumstance. Self-blame has been found to be associated with post-traumatic stress symptoms and depression in parents who had experienced late abortion, stillbirth or infant death (Jind, 2003), however grief was not measured. Hazzard et al.'s (1992) study demonstrated high levels of self-blame in bereaved parents although this symptom was not found to be statistically associated with higher grief scores. In the present study, self-blame accounted for 11% of grief symptoms at Time 1. The importance of self-blame was further demonstrated by these factors being the only variables which predicted levels of grief at the second point of measurement. Attending to cognitions about self-blame should therefore form an integral part of any therapeutic intervention for bereaved parents.

6.4.3.3 Child Living at Home

A further important factor in parental grief was the child normally living at home at the time of their death. This variable was originally designed to measure the significance of adult child leaving home and whether this had an impact on the parent's grief, however the situation also occurs in bereavements at other ages. Young babies who received continual care from birth may never have made the transition to leaving hospital, and many seriously ill children may have been living in hospice or hospital accommodation before the death. Additionally, babies who were stillborn would not normally have left the hospital environment. The sample therefore included children who did not normally

live at home across all age range. If the child did normally live at home prior to their death, the grief symptoms for the parent were higher. On first examination, it appears that this may be an important finding for those offering clinical care for seriously ill children or neonates since retaining the child in a hospital environment may appear to be linked to better bereavement outcomes. This assumption must be tempered, however, by the parent's desire to take the child home to die, which appears to have, mainly anecdotal, evidence of alleviating bereavement symptoms (Whittle & Cutts, 2002). The parent's and, where possible, the child's wishes about their place of death must be paramount in deciding on actions where the child's death is anticipated.

6.4.4.4 Frequency of Grave Visitation

Parents who visited their child's grave or memorial site weekly or more frequently had higher symptoms of grief at Time 1 than those who visited less frequently. A causal link was not established in the present study, therefore it is unclear whether people visit the grave frequently because they are grieving more strongly, or whether more frequent attendance to the grave exacerbates grief symptoms. No studies were found which investigated the impact of frequent grave attendance, nor were any found which unpicked the relationship between frequency of grave visitation and grief symptoms. From the phenomenological study reported in chapter four, mothers indicated that they used the graveside as a place to continue communication with their child and also as a means of maintaining their parental role of nurturing and caring for that child. Highly frequent grave visitation behaviour may therefore potentially indicate maladaptive attachment issues, or perhaps failure to accept the death.

6.4.4.5 Restoration-Oriented Stressors

Having a high number of reported stressors associated with the death of their child was found to be linked with poorer grief outcomes at Time 1. This is evidence which supports the dual processing model of bereavement, which states that outcomes for the bereaved are affected by loss-oriented stressors (features of the bereavement itself) but also restoration-oriented stressors which manifest themselves following the death. For bereaved parents, these appear to be highly significant. In particular, problems at work elicited a mean risk factor of 3.75 for grief and were also associated with higher levels of financial distress. In the UK, there are no employment rights for bereaved people and “compassionate leave” is at the discretion of the individual employer, leading to potentially highly variable support for bereaved people following their loss. Other restoration-oriented stressors which were important were financial difficulties, relationship difficulties, problems caring for other children and concerns about other family members coping. Perhaps support for bereaved parents should be extended from therapeutic intervention to the establishment of an advocacy role, similar to that carried out by palliative care social workers. An advocate working on behalf of bereaved parents could signpost potential sources of help for financial, relationship and childcare services, and may provide a valuable lifeline to parents in extreme distress. In addition, there are concerns about substance and alcohol use by parents as a coping strategy following their child’s death. In the parental mortality analysis carried out to avoid contacting bereaved parents who died following the death of their child, two-thirds of the parents who had died in the three years since their child’s death had causes of death linked to substance and alcohol use. This small sample may not be representative of the mortality of bereaved parents, and the link between child and parent mortality may have more direct causes, however the potential risk of death by substance or alcohol in

bereaved parents cannot be ignored. The issue of parental alcohol or substance use should therefore be a key consideration for anyone involved in the care and support of bereaved parents.

6.4.5 Factors Associated with Depression

The factors most closely associated with Time 1 depression were brooding rumination, problems at work and education level.

6.4.5.1 Rumination

Rumination appears to be a key factor in maladaptive coping by bereaved parents, since it is important for both grief and depression. The link between brooding rumination and depression has been strongly supported (see for example Nolen-Hoeksema et al. (1994) and its relevance in the specific experience of parental bereavement does not detract from this finding.

6.4.5.2 Problems at Work

As a specific restoration-oriented stressor, experiencing problems at work was strongly linked with higher levels of depression following the loss of a child. As stated previously, bereaved people have no specific employment rights and must rely on the generosity of their employer in being allowed leave from work to adjust to their loss. Further analysis of bereaved parents with specific reference to their experience in employment is therefore crucial to understanding and subsequently supporting people experiencing depression following bereavement. The exact nature of the problems being experienced and potential solutions for these merits detailed examination.

6.4.5.3 Education Level

The present study demonstrated a link between lower education levels and depression following bereavement. Brief literature searches found no studies reporting evidence of depression being linked to education levels, however intelligence is believed to be a protective factor for depression (Gale, Hatch, Batty & Deary, 2009). Education level was intended to provide a very crude approximation of intelligence in the current study, although inevitably there will be cases where the two are not linked. In considering the potential benefits of rumination as a type of “grief work” Stroebe et al. (2007) suggest that it may be helpful for an individual to attend to thoughts of their bereavement and loss as a means of carrying out their “grief work”. Problem-solving and cognitive reappraisal are essential, they say, in coming to terms with loss and reducing intrusive feelings of grief. The possibility that lower levels of intelligence/lower education levels impede this processing requires further investigation. This is especially true since, along with rumination, education level was one of the key factors which could predict depression scores at the second study measurement point.

6.4.5.4 Substance/Alcohol Use

Although significant only in the univariate analysis, substance and alcohol use was linked with higher levels of depression in the present study, at Time 1. This finding reiterates the importance of this coping style in bereaved parents, and further reinforces the need for advice and guidance in this area to be offered to bereaved parents.

6.4.6 Unexpected Findings

Factors which were assumed to be important in bereavement outcomes from the literature review reported in chapter four, but which were not supported in the current study, were the cause of death (violent or non-violent), the age of the child at their time

of death and whether the death was sudden or anticipated. All of these factors were important univariately which supports the findings found in the previously reported research, however when taken into account multivariately, these were not the key factors associated with either grief or depression. Only by conducting analyses where factors such as these and those from the other domains in the Integrated Risk Factor Framework are compared with each other, can the relative importance of key factors be determined.

6.4.7 The Research Experience for Participants

The participants in the current research reported the experience of taking part as mainly positive. Although there were problems with the recruitment process, these are likely to have been avoided if the invitation letter sent to the parents had explained that their information came from access to death records, which are publicly available data. The mean satisfaction scores given by participants (5.6 from a maximum of seven) showed that the experience was seen positively and this was supported by comments made which expressed comfort from doing something potentially useful for other bereaved parents.

6.4.8 Limitations of the Research

The current research, as is the case in any where volunteers are required to take part, is potentially at risk of bias due to only a subsection of those eligible to participate agreeing to proceed. This risk is tempered, however, by the coverage of participant demographics, since those who took part in the current study appeared to be representative of those in the bereaved parent population in Scotland as a whole. There was over-representation of mothers in the current study, however this is a feature of much research with bereaved parents. Additionally, those economically deprived were

also under-represented and the experience of people having low socio-economic status should be reviewed further. In the present study, there was no consideration of ethnic identity or the impact of personal cultures on the bereavement experience. This type of analysis should be carried out in an environment more culturally-diverse than that found within Scotland. Finally, the conflicting responses in the questions about suicidal ideation were disappointing, especially since the topic was covered so openly in the qualitative study reported in chapter four. Clearer and perhaps more sensitive wording of the question in future studies may elicit different results.

The present study recruited a very small sample size which, although mainly matching the spread of demographics in the population as a whole, would benefit from replication in a larger sample, to ensure that any small or moderate effect sizes were not overlooked.

6.4.9 Conclusions

High levels of depression and prolonged grief were found in this sample of parents bereaved four years previously. Grief and depression were identified separately, confirming that they are independent constructs. This supports the notion that bereaved parents are a group who require and deserve specific support to reduce their symptoms of distress following the death of their child. Within the analyses, the importance of social variables has been highlighted and in particular, the impact of problems at work on bereavement outcomes. Bereaved parents should therefore be able to access sources of support which may assist them in securing the help with employment, finance, relationships and limiting alcohol and substance use that they may need. These factors must be communicated clearly to those in bereavement support organisation to ensure

that the support offered to bereaved parents fits the precise requirements of this vulnerable group enduring the distress of the loss of their child.

Chapter Seven - Mortality, Marriage and Employment Changes in Bereaved Parents in Scotland

7.0 Abstract

7.0.1 Background

Bereaved parents are at risk of a number of negative outcomes following their loss. Suicidal ideation and alcohol/substance use are reported to be high, but it is unclear whether mortality rates are increased. The rate of marriage breakdown may be higher following the death of a child, and employment problems are likely to be found.

7.0.2 Method

A longitudinal retrospective cross-sectional design was employed comparing differences in the status of bereaved and non-bereaved parents of children born between 1991 and 2001. The data source was Scottish Census data linked to Vital Events Records up to 2006. Participants were Census sample parents and their spouses who experienced stillbirth or infant death (n=738) and those whose child lived (n=49,828).

7.0.3 Results

Up to ten years post-event (birth or death), bereaved parents had twice the mortality rate of non-bereaved parents. Divorce rates were not statistically different between the groups, however bereaved parents were significantly more likely to marry than non-bereaved parents and were significantly more likely to change employment status during the follow up period.

7.0.4 Discussion

Early childhood death is associated with highly significant mortality effects and important social changes in parents in the first ten years post-death.

7.1 Introduction

The Dual Process Model (Stroebe & Schut, 1999) suggests that the bereaved must cope with a number of restoration-oriented stressors following their loss. These stressors could be social, financial or health based, and their presence or severity may impact on the health or wellbeing outcomes for the bereaved person (Stroebe et al., 2006). The qualitative study described in chapter four indicated that the bereaved mothers had experienced a number of stressors following the death of their child. Employment problems, challenges within the marital relationship and suicidal ideation were identified as impacting on the daily experience of the parents. The potential impact of these problems indicates the need for a broader, large-scale quantitative investigation to establish the generalisability of these problems to a wider population of bereaved parents.

7.1.1 Marital Status

Marriage breakdown following the death of a child is not supported unequivocally in empirical research (Schwab, 1998), despite its prominence in the literature from support organisations such as the Child Bereavement Charity, the Stillbirth and Neonatal Death Society and The Compassionate Friends. The effect of the death of a child on the parents' marital status was reviewed and the findings were reported as inconclusive (Schwab, 1998). Indeed, a later study noted that several methodological issues such as lack of comparison groups, participant recruitment bias and low numbers of participants hindered a clear evaluation of the results (Oliver, 1999). A systematic review of over 100 studies concluded that there was insufficient unequivocal evidence to support the notion that divorce is more prevalent within bereaved parent couples than non-bereaved (Murphy et al., 2003). The Oliver review suggested that the opposite may in fact be

true, since it cites studies suggesting improvements in relationships following the death of a child. Evidence of changes in marital status following the death of a child, compared to an appropriate control group, is therefore required.

7.1.2 Employment Status

Given the literature which provides supporting evidence of multiple emotional and health issues in bereaved parents, it seems inevitable that bereaved parents who are in employment will experience some disruption in their ability to perform satisfactorily at work. Employment issues may arise due to problems with concentration and attention (Arbuckle & Devries, 1995). Comparison of bereaved parents with matched non-bereaved controls found the bereaved groups had a significantly higher level of unemployment (Lehman & Wortman, 1987). Furthermore, the bereaved parents were significantly more likely to have changed jobs in the period since their child died than the non-bereaved parents within the same time scale reflecting potential instability in employment. The number of bereaved participants was small (n=41) with a recruitment success rate of 45%. No information was available relating to the status of non-respondents so it is unclear how representative the sample under analysis might have been. The database searches carried out as described earlier did not reveal any other published research reporting on the employment status of bereaved parents. The effects of parental bereavement on employment are therefore unclear.

7.1.3 Mortality Risk

The most recent study found to evaluate mortality rates in bereaved parents was carried out in Denmark using data from national registers (Li, Precht et al., 2003). Some 21,000 bereaved parents were compared to 300,000 non-bereaved parents and the results

showed a highly significant hazards ratio of 1.43 for bereaved parents, with 95% confidence intervals between 1.24 – 1.64. Odds ratios were highest in bereaved parents whose children were aged between 10-18 years at time of death, and in deaths which occurred between 9-18 years previously. However, parents bereaved by the death of their adult children were identified and examined and no increased risk of mortality was found compared to rates from the general population in Israel (Levav, Friedlander, Kark & Peritz, 1988). The study of mortality following bereavement in a specific area of Wales showed an apparent increase in parental mortality in the first two years post-bereavement, but this was not statistically significant compared to mortality rates in the local non-bereaved population in general (Rees & Lutkins, 1967). The number of bereaved parents in the study was small at n=12. Comparisons in mortality rates of bereaved parents compared to non-bereaved parents are therefore inconsistent.

It is essential that bereaved parents and those who support them are given realistic expectations of changes they may expect to face in their lives based on methodologically sound evidence. This will enable them to enlist adequate resources to address their psychosocial transition through bereavement. To facilitate this, the present study aimed to establish what some of these expectations for life following the death of a child might be. Mortality statistics across a large scale population were compared, for the first time in Scotland, to the statistics related to bereaved parents. Divorce and marriage rates were compared across groups. Lastly, changes in employment status were examined and again, for the first time, comparisons were made of changes following either the birth or the death of a child.

The hypotheses under test are therefore that:

- a) bereaved parents will be at higher risk of mortality than non-bereaved parents
- b) divorce rates would be higher amongst bereaved than non-bereaved parents
- c) parents who have experienced the death of their child are less likely to be employed than those whose child lived.

7.2 Method

Ethical approval for the study was granted by the ethics committee of the Department of Psychology, University of Stirling.

The Longitudinal Studies Centre in Edinburgh, Scotland was contacted to obtain access to data in the Scottish Longitudinal Study database (SLS). In addition to Census data, the SLS contains linked data from Vital Events recorded at the General Register Office for Scotland, relating to births, deaths, marriages, stillbirths and divorces. The SLS contains Census data related to 5.5% of the Scottish population selected by date of birth falling on one of twenty dates spread throughout the year. This selection process is intended to provide a random sample of Census respondent data. Those Census respondents nominated for inclusion in the SLS database by virtue of their date of birth are known as SLS members. Spouses of SLS members were identified by date of birth on the child's birth certificate. The SLS members indicated their spouse's date of birth on the 2001 Census and if these matched exactly those on the birth certificate, the details given in the Census were included in the analysis as non-SLS members.

The participants' responses to the Census determine the change in marital and employment status with their status at event date taken as the "before" situation and the 2001 Census responses indicating the "after" situation. Census respondents were asked for their marital status however no options were provided on the Census to indicate cohabitation or non-marital partnerships. The available responses were (a) single (never married), (b) married (first marriage), (c) re-married, (d) divorced (decree absolute) or (e) widowed. For the 2001 Census, there was an additional option (f) separated but still legally married. Responses a, d, e and f were aggregated as not married; b and c were aggregated as married, to facilitate subsequent parsimonious analysis. The change in marriage status outcome was therefore coded as one of the following four options: continually married, continually unmarried, married to not married or not married to married.

For employment status, the available responses indicated whether the person was working (full time, part time or self employed), in training or education, about to start work, unemployed, sick or disabled and unable to work, retired, looking after home or family and other. Responses indicating full time, part time or self employed were aggregated as working; all other responses were taken to indicate not working, again to simplify results. The change in employment status outcome was therefore coded as one of the following four options: continually working, continually not working, working to not working or not working to working.

Mortality was measured using death and widowhood status of bereaved parents and their spouses. Death and widowhood status were obtained by checking the participants' details against the Vital Events death and widowhood records. These were available up

to 2006. No death or widowhood information was available for non-SLS members. The number of participants for the mortality analysis was therefore 28,928.

For 645 cases (1.3% of the total sample), marital status was not recorded or was unreliable at the time of the event. These records were excluded from the analysis, therefore the maximum number of participants in the marital status comparisons was 49,921.

A priori t-tests and Chi-square tests revealed no significant differences in employment, marital, mortality or widowhood status between the stillbirth parents and the infant mortality parents. Their data were therefore aggregated throughout the analysis process as bereaved parents. The numbers of parents experiencing infant death and stillbirth were supplied already aggregated for death and widowhood data, due to the small numbers involved in order to protect confidentiality. No individual analysis by type of bereavement was therefore possible for these measures.

7.2.1 Analysis

Chi-square tests were carried out on the data. The 2x2 analysis of mortality compares bereaved parents with non-bereaved, their status being alive or dead. The marital status comparison was initially conducted comparing the two groups of parents with a simple changed status/did not change status. Secondary Chi-squares examined the direction of the change separately. The analyses were therefore comparing the groups of parents for got married/did not get married and got divorced/did not get divorced. The same process was followed for employment data with an initial analysis of change/not change followed by an analysis of became employed and became unemployed. This facilitated

further examination of the data to establish the direction of any significant differences found for each measure.

7.3 Results

The characteristics of each participant group are shown in Table 7.1.

Table 7.1 – Group characteristics of individuals included in the analysis

	<i>Non-bereaved parents</i>	<i>Bereaved parents</i>
n (SLS members and spouses)	49,828	738
n (SLS members only)	28,928	435
Mother:father	26,208:23,620	387:351
Age in years at event date (birth/death) mean (SD)	30.6 (5.7)	29.5 (6.3)
Years since event mean (SD)	4.7 (3.0)	5.7 (2.9)

Ninety seven percent of the population reported an ethnicity status of “White”. One percent reported ethnicity as “Asian”. It was not possible to split these data by bereavement status since this would have been potentially disclosive.

Independent Chi-square tests showed the difference in sex of parent to be non-significant, The difference in age at event date as shown in table 7.1 was significant, $t(747) = 4.6, p < .001$ and the difference in number of years since event was also significant at $t(50,564) = 8.7, p < .001$. These differences are present due to the method of establishing event dates for the two groups of participants. If a parent experiences a stillbirth or infant death, this is taken as the event date, regardless of whether a subsequent birth to the parent took place. For live births, the date of the last birth was used as the event date.

7.3.1 Mortality Rates

Table 7.2 shows the mortality analysis for both groups. From event date to 2006, 482 (0.96%) of non-bereaved parents died or were widowed, compared to 15 (2.0%) of bereaved parents. A Chi-square test confirmed that the difference was significant, $\chi^2(1) = 8.62$, $p=.003$ with an odds ratio of 2.11, 95% confidence intervals between 1.27 – 3.52.

Table 7.2 – Comparison of Mortality Rates by Group

	<i>Mortality status</i>		
	Alive	Dead	Total
Bereaved	723 (97.97%)	15 (2.03%)	738
Non-Bereaved	49650 (9.04%)	482 (0.96%)	50132
Total	50373 (99.02%)	497 (0.98%)	50870

7.3.2 Change in Marital Status

The change in marital status for bereaved and non-bereaved parents is shown in Table 7.3.

Table 7.3 – Comparison of Changes in Marital Status by Group

	<i>Marital status</i>		
	Changed	Not Changed	Total
Bereaved	110 (15%)	611 (85%)	721
Non-Bereaved	5174 (10%)	44026 (90%)	49200
Total	5284 (11%)	44637 (89%)	49921

Bereaved parents were significantly more likely than non-bereaved parents to change their marital status, $\chi^2(1) = 16.87$, $p<.001$. The number of bereaved parents who got married was 52 (7.2%) and non-bereaved was 2027 (4.1%). This difference was highly significant, $\chi^2(1) = 17.02$, $p<.001$ with an odds ratio of 1.81; 95% confidence interval 1.36-2.41. The number of bereaved parents who got divorced was 58 (8%) and the

number of non-bereaved parents who got divorced was 3147 (6.4%). This difference was not statistically significant. A further Chi-square test for the bereaved group, looking at sex of parent and marital status was not significant.

7.3.3 Change in Employment

Table 7.4 shows the change in employment status for bereaved compared to non-bereaved parents.

Table 7.4 – Comparison of Changes in Employment by Group

	<i>Employment status</i>		<i>Total</i>
	<i>Changed</i>	<i>Not Changed</i>	
Bereaved	267 (37%)	471 (63%)	738
Non-Bereaved	13424 (27%)	36404 (73%)	49828
Total	13691 (27%)	36875 (73%)	50566

Bereaved parents were significantly more likely than non-bereaved parents to change their employment status, $\chi^2(1) = 31.43$, $p < .001$. The number of bereaved parents who changed employment status from not working to working was 238 (32%) and non-bereaved was 12,089 (24%). This difference was highly significant, $\chi^2(1) = 25.17$, $p < .001$ with an odds ratio of 1.49; 95% confidence interval 1.27-1.74. The number of bereaved parents who became unemployed was 29 (3.9%) and non-bereaved was 1335 (2.7%). This difference was also significant, $\chi^2(1) = 4.33$, $p = .037$ with an odds ratio of 1.49; 95% confidence interval 1.02-2.16. Comparing employment status in the bereaved group for mothers and fathers using a Chi-square test showed no significant difference for these groups.

7.4 Discussion

Following stillbirth or infant death, bereaved parents are significantly no more likely to divorce than non-bereaved parents, but are significantly more likely to become unemployed or start working. Bereaved parents are twice as likely to die as a non-bereaved control group. Clearly these additional stressors are likely to place extra strain on families who are already experiencing great psychosocial adjustments.

The higher levels of mortality in bereaved parents are of major concern. The number of deaths reported in this study is too small to permit more detailed analysis, however larger scale studies should be carried out to identify causes of death and whether there are any potential risk factors which may affect this outcome. Bereaved parents may be more likely to have completed suicide than matched non-bereaved comparisons (Li et al., 2003). Insufficient information was provided to rule out the contribution of death by suicide to the difference in mortality statistics. Alternatively, the stress of the bereavement may involve significant physiological effects, for example, suppressing the immune system (Kim & Jacobs, 1991) thereby increasing one's propensity to disease (Vedhara, Cox, Wilcock, Perks, Hunt, et al., 1999). Maladaptive coping strategies such as alcohol misuse have been reported as employed by parents experiencing stillbirth and infant death (Vance, Najman & Boyle, 1994) and this may in turn lead to higher incidence of alcohol-related illness or accidental death (Li, Smith & Baker, 1994). It is imperative that these options be further investigated in order to establish the factors leading to increased mortality in bereaved parents.

The marital status data quantify, for the first time, the changes experienced by bereaved parents compared to their non-bereaved counterparts. Although divorce rates appeared

higher in the bereaved group, this difference was non-significant suggesting that the divorce rate in parents bereaved at birth or in the child's first year of life is no higher than that of parents of living children. Although bereaved parents report struggles and challenges in their relationships (Schwab, 1998), (Oliver, 1999; Murphy et al., 2003), it appears that this may not inevitably lead to marriage breakdown in the longer term. The present study reports the actual marriage status of parents of a prospective representative sample of participants at a mean of four to five years post-event. In this particular group of bereaved parents, it appears that the divorce rate is no higher than the comparable population of non-bereaved parents, as was found in previous comparative studies (Schwab, 1998).

The statistics on marriage rates in bereaved parents have previously not been reported, but those in the present study support the notion that the death can have cohesive effects on a marriage as well as detrimental effects (Oliver, 1999). This is an important and, to date, overlooked change that may be important for bereaved parents to know about. Much of the literature around the area of parental bereavement reports only negative consequences. Only recently have issues such as posttraumatic growth begun to be assessed (Engelkemeyer & Marwit, 2008). The existence and measurement of potentially positive outcomes following parental bereavement, such as benefit finding (Holland, Currier & Neimeyer, 2006) should be considered by those involved in therapeutic interventions for bereaved parents.

The higher number of bereaved parents returning to work compared to non-bereaved parents could be explained in a number of ways. One simple explanation is that the parent returns to work since there is no childcare requirement for them to stay at home.

Alternatively, social support in the workplace may be beneficial to the bereaved parent (Kavanaugh, Trier & Korzec, 2004). Further analysis of the reasons for and consequences of returning to work after parental bereavement would provide greater insight into this finding. However, this information may again prove to be valuable to bereaved parents and those who care for them.

The higher rate of change to unemployment in bereaved parents is of concern. There appears to be no published literature which explains job loss after bereavement, however, in the phenomenological study reported in chapter four, twelve of the interviewees were employed at the time of the bereavement and eight of these reported losing their jobs soon after. Lack of understanding by employers and inability to perform at pre-bereavement levels were frequently reported. If this type of involuntary unemployment is common in bereaved parents, there may be cause for evaluation of employment rights following bereavement. There is a growing body of evidence which suggests that the concept of complicated bereavement should be acknowledged as a diagnosable and distinct medical condition (Bonanno, 2006). If the experience of bereaved parents suggests that job loss occurs as a result of their bereavement, perhaps the diagnosis of prolonged grief should be supported as a protective mechanism for bereaved people in the workplace. Further clarification of the reasons and factors associated with job loss following parental bereavement is required before such considerations can be made.

7.4.1 Limitations of the Study

The number of bereaved parents included in the study was small, but was consistent with the expected numbers within Scotland. More detailed examination of factors such

as causes of death, gender of bereaved parents and age of bereaved parents was not possible due to the restrictions placed upon the provision of potentially disclosive information supplied by the SLS. Data cannot be supplied where the numbers are small enough to potentially allow identification of individuals

The changes in relationship status were restricted to those officially married. No changes in permanent non-married relationships were measured, however this is a restriction necessitated by the questions provided in the Census data collection forms.

Finally, the sampling points in the study were restricted to the year of the event and the following Census year, 2001. No detailed analysis of changes by year was possible, due to the fixed nature of the Census sampling terms.

7.4.2 Conclusions

Retrospective sampling of participants by random cross section has shown that parents who experience stillbirth or infant death experience twice the rates of mortality and three times the unemployment rate of non-bereaved parents, but also experience higher marriage and employment rates. The negative consequences of the death of a child for parents are huge, however it is possible, in some cases, for positive changes to be experienced.

Further research examining the causes of death is necessary to allow practitioners to identify those at greatest risk of death or serious illness. Professionals involved in relationship counselling or providing information to bereaved parents should report the

positive as well as the negative outcomes. Employers must consider whether bereaved parents need additional support beyond basic compassionate leave arrangements.

Those who offer caring, supportive or therapeutic assistance to bereaved parents should take into account the needs for further adaptation beyond specifically child- or grief-related issues and should be aware of additional social needs in the first ten years following the death of the child. Most importantly, the information about potential consequences which might be anticipated by bereaved parents must be provided to assist this vulnerable group in their period of reconciliation and post-loss adjustment.

Chapter Eight – Long-Term Mortality, Employment and Relationship Changes in Bereaved Mothers in England and Wales

8.0 Abstract

8.0.1 Background

Up to ten years post-loss, mortality rates for bereaved parents were found to be double that of non-bereaved comparisons in Scotland, as were changes in employment status. No difference in divorce rates was found. In this study, the longer-term association of parental bereavement with mortality, employment and marriage changes up to 35 years post-loss was investigated.

8.0.2 Method

A longitudinal retrospective cross-sectional study was carried out using Census and Vital Event data from England and Wales from 1971 to 2006. The study reported differences between parents bereaved by stillbirth or in the child's first year of life (n=2761) compared to parents whose child was born and lived beyond the first year of life (n=120,874).

8.0.3 Results

Bereaved parents have four times the mortality risk of non-bereaved counterparts in the first ten years post-loss, reducing, but remaining statistically significant, up to thirty five years post-loss. Employment changes are more likely in the bereaved group in the first ten years only. There is no difference in divorce rates between bereaved and non-bereaved parents.

8.0.4 Conclusions

The increased mortality rate in bereaved parents requires urgent investigation as it exceeds even the risk of smoking on incidence of lung cancer. The changes in employment status suggest the impact of the death of a child on working patterns resolves after around ten years. Parental bereavement, in itself, is not associated with marriage breakdown.

8.1 Introduction

The study reported in chapter seven indicated that, at up to ten years post-loss, bereaved parents who have experienced the death of a child in the first year of life or stillbirth are more likely to become married or change their employment status, than non-bereaved counterparts. In addition, they are more likely to die themselves, or experience the death of their spouse. The data from the Scottish Centre for Longitudinal Studies reported earlier is restricted to a relatively recent time period, from 1991, therefore longer term comparisons are not possible using this dataset.

Within the limited published literature, very few researchers have attempted to consider the long-term implications for parents following the death of their child.

Some, such as Engelkemeyer and Marwit (2008), Hazzard et al. (1992) and Robinson and Marwit (2006) have considered the consequences for parents over a wide range of times since death, including longer terms of up to 31 years, but far fewer have considered outcomes for bereaved parents in a specifically longer term period.

The published papers that have reported the long-term effects of the death of a child have different definitions of what they consider to be “long term” parental bereavement. Lehman and Wortman (1987), for example, consider 4-7 years to be long term, and compared bereaved parents to bereaved spouses in this time frame. Their findings were that the levels of depression and impaired social functioning were higher in both bereaved groups compared to non-bereaved controls, and that bereaved spouses were experiencing more negative outcomes than bereaved parents. Schapp, Wolf, Bruinse, Barkhof-van de Lande and Treffers (1997) considered parents who had stillbirth and neonatal death 3-9 years previously and found that four of their 19 couples interviewed were experiencing both negative psychosocial impact and emotional consequences at

this time. Dyregrov and Dyregrov (1999) followed up parents who had experienced a sudden infant death, 12-15 years previously. Measures of psychological distress taken at this time indicated that the impact of their loss had diminished significantly over the term, and very few of the 26 parents assessed maintained a level of symptoms which indicated “caseness” for depression or anxiety at the time of assessment. Unfortunately, none of these studies considered a control group to identify whether the findings were bereavement-related and could be differentiated from the changes in a similar non-bereaved group. Lack of methodological rigour, small sample size and the absence of a control group make these findings of limited value when attempting to definitively establish the outcomes for bereaved parents in the longer term.

Earlier studies in this thesis indicate that the death of a child has a very significant impact on a parent up to six years post-loss. The SLS study reported in the previous chapter showed that employment difficulties remained up to ten years following a stillbirth or the death of an infant, and that mortality rates were also significantly higher in bereaved than non-bereaved parents. Marriage rates were higher, but divorce rates were no different to those of non-bereaved parents. Divorce rates were expected to be higher in bereaved parents than non-bereaved and perhaps the time since death being restricted to a maximum of ten years was not long enough for relationship problems to have manifested themselves in terms of legal divorce statistics.

The current study aims to consider the impact of the death of a child on bereaved parents’ mortality rates and social functioning, up to 35 years post-loss. Using a similar method to that described in the previous study, secondary analysis of census data will examine the experience of parents whose child is stillborn or dies in the first year of

life, compared to parents who have a live baby in the same time period. From this dataset, within a time frame of up to 35 years post-loss, based on the findings from the SLS study reported in the previous chapter, it was hypothesised that:

- a) Bereaved parents would have higher mortality rates than non-bereaved parents
- b) Divorce rates were higher in bereaved parents than non-bereaved parents
- c) Bereaved parents would be less likely to return to employment following the death of their child, than non-bereaved parents.

8.2 Method

Ethical approval for the study was granted by the ethics committee of the Department of Psychology, University of Stirling.

The Centre for Longitudinal Studies Information and User Support (CeLSIUS) contains census data from 1971, 1981, 1991 and 2001 censuses, for people resident in England and Wales, whose date of birth falls on one of four specified dates throughout the year. The database effectively contains data relating to around 1% of the population of England and Wales (currently around 950,000) study members. Members who were born after 1971 on one of the four dates, or who became resident in England or Wales and had a birthday on one of the key dates, joined the CeLSIUS dataset at the first available census, and members are removed from the data set on death or emigration from England and Wales.

The data available from CeLSIUS are similar to those provided by the SLS, with a few important caveats. Firstly, the data collection procedures have varied since 1971, and each census does not gather responses from individuals using the same questions and available responses over time. This makes direct comparisons over time problematic,

however CeLSIUS have developed a number of standard protocols for addressing this issue. For the purposes of the current study, the collection of marital or relationship data was particularly problematic, since each census considered different options relating to relationship status. The method adopted by the CeLSIUS technical teams amalgamates relationship status into either :

- 1) In a relationship – this covers cohabiting and married statuses
- 2) Not in a relationship – relating to single, widowed, separated or divorced
- 3) Not known – this situation would arise when the census record was completed incorrectly by the respondent.

Employment status, for the purposes of this study, was handled in the same way as the SLS dataset, with the options being:

- 1) Working – full or part time or self employed
- 2) Not working – unemployed, sick, disabled and unable to work, retired, looking after the home, family or other, in training or education
- 3) Not known – as above

Mortality and widowhood were measured by cross-referencing the CeLSIUS database with that of the Vital Events Record in the Office of National Statistics.

Employment and relationship status data are available up to the last census data collection point, in 2001. Mortality data were reviewed and added at 2006, therefore an additional five years of Vital Events is available for analysis.

Unlike the SLS dataset, records from CeLSIUS are only available for members of the cohorts, and not their spouses or partners. In addition, linking information for stillbirths

and infant deaths are only possible by cross-referencing to the Register of Births, which is available only for the child's mother. A limitation of these data is that they, therefore, relate only to the experience of the mother.

At each of the census time points, participants may return results which are incorrectly completed or unreadable. The CeLSIUS database marks these as missing data, and these records are therefore excluded for analysis at that particular census point. It is possible, therefore, that members of the CeLSIUS dataset may have their data included at one census, be excluded as missing data from the next and then reintroduced at a third time point. Taking this restriction and the methods used for data alignment over time into account, tracking individual members through each of the time points was not feasible within the restrictions of the present study. Data is therefore provided for members at their time of inception into the appropriate cohort, and at the most up to date data capture point i.e. 2001 for employment or relationship status and 2006 for mortality. No attempt has been made to track individual members over time, identifying changes that may have been recorded in the interim period.

To facilitate comparison with the SLS study reported earlier, data from parents experiencing stillbirth or infant death were aggregated, into one "bereaved parent" group for each census cohort. Again, restrictions on potentially disclosive information were adhered to, and no data were supplied which could be traced back to potentially identify individual census respondents.

8.2.1 Analysis

Chi-square tests were used to establish whether differences between groups were statistically significant. The mortality analysis was carried out using a 2x2 analysis comparing bereaved and non-bereaved parents with a status of either “alive” or “dead”. Relationship status was initially analysed using the two groups of parents and a “changed/not changed” comparison. Those cohorts who returned a statistically significant result were then subject to secondary analysis to identify in which direction the difference lay. Employment status was handled in the same manner, initially considering a “changed/not changed” comparison followed by detailed analysis of any which returned a significant association.

8.3 Results

The characteristics of each participant group are shown in Table 8.1. The table shows the maximum number of census records available. The actual number included in each individual analysis may be less than this total, due to missing data in subsequent censuses.

Table 8.1 – Group characteristics of members of each cohort

	<i>Cohort</i>	<i>Non-bereaved mothers</i>	<i>Bereaved mothers</i>
n	1971-81	36,062	1,120
n	1981-91	36,434	745
n	1991-01	30,956	481
Mean age at start of census period in years (SD)	1971-81	22.0 (5.7)	21.9 (9.0)
Mean age at start of census period in years (SD)	1981-91	22.4 (5.7)	22.5 (8.4)
Mean age at start of census period in years (SD)	1991-01	24.1 (5.2)	23.8 (8.3)

Independent t-tests showed no significant difference between the age of bereaved and non-bereaved participants in each cohort.

8.3.1 Mortality Rates

The members of each cohort were followed up at 2006, to identify how many had died or been widowed, between 1971 and 2006. Table 8.2 shows the results of this mortality analysis for the bereaved and non-bereaved mothers.

Table 8.2 – Mortality of cohort members or their spouses, followed up to 2006

<i>Cohort</i>	<i>Group</i>	<i>n alive or not widowed</i>	<i>%</i>	<i>n dead or widowed</i>	<i>%</i>	<i>Total n</i>
1971-81	Bereaved	1094	86.0	178	14.0	1272
1971-81	Non-Bereaved	35935	88.7	4589	11.3	40524
1981-91	Bereaved	777	94.0	50	6.0	827
1981-91	Non-Bereaved	38758	96.0	1623	4.0	40381
1991-01	Bereaved	622	94.0	40	6.0	662
1991-01	Non-Bereaved	39460	98.7	509	1.3	39969

For each cohort, the percentage of bereaved mothers who had died or were widowed as at 2006 was higher than the non-bereaved. A comparison was made between the bereaved and non-bereaved group for each individual cohort. These results were statistically significant for all three cohorts. For the 1971-81 cohort, the difference was $\chi^2(1) = 8.70$, $p=.003$, $n=41,796$; risk ratio = 1.24, confidence interval 1.08-1.42. For the 1981-91 cohort, the difference was $\chi^2(1) = 8.55$, $p=.003$, $n=41,208$; risk ratio = 1.50, confidence interval 1.14-1.98. and for the 1991-01 cohort, the difference was $\chi^2(1) = 11.1$, $p<.001$, $n=40,631$; risk ratio = 4.74, confidence interval 3.47-6.49.

The mean time between the event date and death was also calculated for each group in each cohort by subtracting the event (birth or death) date from the date of death. The results are show in Table 8.3.

Table 8.3 – Mean time between event and death for deceased in individual cohorts, by bereavement status

<i>Cohort</i>	<i>Status</i>	<i>Mean time between event and death in years (SD)</i>
1971-81	Bereaved	20.9 (8.7)
1971-81	Non-Bereaved	20.2 (9.7)
1981-91	Bereaved	13.6 (10.6)
1981-91	Non-Bereaved	12.7 (8.9)
1991-01	Bereaved	4.7 (5.9)
1991-01	Non-Bereaved	5.6 (1.4)

For the 1971-81 and 1981-91 cohorts, the mean time since death is longer in the bereaved group compared to the non-bereaved group, suggesting that the bereaved parents died earlier than the non-bereaved, on average. This situation was reversed in the 1991-01 cohorts. The difference was significant for all cohorts. For the 1971-81 cohort, this was $t(41,794) = 2.54, p=.011, n=41,799$. For the 1981-91 cohort, this was $t(41,206) = 2.87, p=.011, n=41,208$. Finally, for the 1991-01 cohort, the difference was $t(40,629) = 14.54, p<.001, n=40,631$.

8.3.2 Employment Status

The employment status of cohort members was followed up to 2001. The change in employment status of bereaved compared to non-bereaved parents between 1971 and 2001 is shown in Table 8.4.

Table 8.4 – Comparison of Changes in Employment by Group (71-01)

	<i>Employment Status</i>		Total
	Changed	Not Changed	
Bereaved	424 (44%)	535 (56%)	959
Non-Bereaved	14,924 (46%)	17,211 (54%)	32,135
Total	15,348	17,746	33,094

The difference in change of employment status between groups was not significant.

The change in employment status of bereaved compared to non-bereaved parents

between 1981 and 2001 is shown in Table 8.5.

Table 8.5 – Comparison of Changes in Employment by Group (81-01)

	<i>Employment Status</i>		Total
	Changed	Not Changed	
Bereaved	277 (45%)	340 (55%)	617
Non-Bereaved	13,601 (45%)	16,593 (55%)	30,194
Total	13,878	16,933	30,811

Bereaved parents in the 1981-91 cohort had the same rate of employment change as non-bereaved parents between 1981 and 2001 than non-bereaved parents.

The change in employment status of bereaved compared to non-bereaved parents

between 1991 and 2001 is shown in Table 8.6.

Table 8.6 – Comparison of Changes in Employment by Group (91-01)

	<i>Employment Status</i>		Total
	Changed	Not Changed	
Bereaved	150 (31%)	331 (69%)	481
Non-Bereaved	11,333 (37%)	19,623 (63%)	30,956
Total	13,878	16,933	31,437

Bereaved parents in the 1991-01 cohort were less likely to change employment status between 1991 and 2001 than non-bereaved parents, $\chi^2 (1) = 6.01, p=.01, n=31,437$; risk ratio = 1.09, confidence interval 1.02-1.15. Further analysis of the change in employment status in the 1991-01 cohort was carried out, to ascertain in which direction the difference in change rates occurred. The change in status from not working to working is shown in Table 8.7.

Table 8.7 – Comparison of Change in Employment Status from Not Working to Working by Group (91-01)

	<i>Employment Status</i>		Total
	Became employed	Became unemployed or unchanged	
Bereaved	70 (15%)	411 (85%)	481
Non-Bereaved	5,795 (19%)	25,161 (81%)	30,956
Total	5,865	25,572	31,437

More non-bereaved parents became employed than bereaved parents. This difference was significant at $\chi^2 (1) = 5.42, p=.02, n=31,437$; risk ratio = 1.05, confidence interval 1.01-1.09. There was no difference between groups becoming unemployed.

8.3.3 Relationship Status

The relationship status of cohort members was also followed up to 2001. The change in relationship status of bereaved compared to non-bereaved parents between 1971 and 2001 is shown in Table 8.8.

Table 8.8 – Comparison of Changes in Relationship Status by Group (71-01)

	<i>Relationship Status</i>		
	Changed	Not Changed	Total
Bereaved	472 (49%)	487 (51%)	959
Non-Bereaved	16,417 (51%)	15,750 (49%)	32,167
Total	16,904	16,222	33,126

Bereaved parents in the 1971-81 cohort were no more likely to change relationship status between 1971 and 2001 than non-bereaved parents.

The change in relationship status of bereaved compared to non-bereaved parents between 1981 and 2001 is shown in Table 8.9.

Table 8.9 – Comparison of Changes in Relationship Status by Group (81-01)

	<i>Relationship Status</i>		
	Changed	Not Changed	Total
Bereaved	357 (54%)	305 (46%)	662
Non-Bereaved	17,255 (52%)	16,220 (48%)	33,445
Total	17,582	16,525	34,107

Bereaved parents in the 1981-91 cohort were no more likely to change relationship status between 1981 and 2001 than non-bereaved parents.

The change in relationship status of bereaved compared to non-bereaved parents between 1991 and 2001 is shown in Table 8.10.

Table 8.10 – Comparison of Changes in Relationship Status by Group (91-01)

	<i>Relationship Status</i>		
	Changed	Not Changed	Total
Bereaved	351 (63%)	206 (37%)	557
Non-Bereaved	20,978 (60%)	14,021 (40%)	35,007
Total	14,235	21,329	35,564

Bereaved parents in the 1991-01 cohort were no more likely to change relationship status between 1991 and 2001 than non-bereaved parents.

8.4 Discussion

Bereaved parents are more than four times more likely to die or become widowed in the first ten years following the experience of stillbirth or the death of their child in the first ten years of life. Up to twenty years, this risk reduces to 1.5 times that of non-bereaved parents, and up to 35 years, bereaved parents still have a higher mortality rate than those non-bereaved (1.2 times). Non-bereaved parents were more likely to become employed in the first ten years following the birth of their child, than bereaved parents were following the death of their child. There was no statistically significant difference in relationship breakdown rates between bereaved parents and non-bereaved parents at any of the comparison time points.

8.4.1 Mortality

The mortality rates of the present study support the findings from the SLS database reported earlier. As before, detailed analysis of the cause of death was not possible within the restrictions set out by CeLSIUS, however it is imperative that future research considers which parents are at risk of increased mortality and whether any of these groups may be targeted with monitoring, support or interventions to alleviate this. It may be that stillbirths and infant deaths are more prevalent in people who, themselves, suffer serious poorer health (Fretts, 2010), thus leading this group to a lower life expectancy. However, the magnitude of the risk factor identified here indicates that analysis of parents bereaved by different circumstances is also urgently required to identify whether they are also at a similar risk of premature mortality to those who experience stillbirth or infant death.

8.4.2 Employment

Non-bereaved parents took up employment more often than bereaved parents, in the first ten years following their relevant vital event (birth or death). There is no published literature relating to employment following parental bereavement, making comparisons between this and other studies impossible. The results from the present study, however, appear to be counter-intuitive since, if anything, one would assume that a parent with a small child may be less likely to return to employment than one without a small child. This result may be explained by the bereaved parent having a subsequent live birth which may, in turn, have resulted in them taking longer to return to work than the initially non-bereaved. This scenario may explain why the difference is only seen in the first ten years following the birth or death of the child. Alternatively, the bereaved parent may be experiencing employment difficulties, similar to those reported by the participants in chapters four, five and six. Further analysis of employment following parental bereavement is required to explain this difference.

8.4.3 Relationships

The present study found no difference in relationship status between the bereaved and non-bereaved groups. The similarity in relationship breakdown rates provides support for the notion that claims of higher rates of marriage breakdown following parental bereavement are not valid (Schwab, 1998). The importance of the topic in bereaved parent support networks may therefore be due to marital conflict during bereavement, but this may not necessarily lead to higher levels of marriage breakdown. Bonanno (1991) suggests that grief is higher in bereaved parents reporting marital problems, however once grief symptoms have subsided, perhaps conflict does too. Klass (1986) carried out a qualitative analysis of bereaved parents in a self-help group and found that

their relationship problems were highly complex and were often affected by factors separate from the loss. Although there may be differences between parents as they grieve for their child, perhaps this, in itself, is not a key risk factor for relationship breakdown. Further analysis of parents who divorce could identify the relative importance of features of the relationship and other risk factors, including the experience of parental bereavement.

No difference in the rate of mothers entering a relationship was found in the present sample. This could be due to the different methods of measurement used by CeLSIUS compared to the SLS, or it may be a phenomenon linked to the sex of the parent. The SLS study represented both sexes, whereas the present study considers the situation for mothers only. Post-hoc analysis of the SLS data, however, found no sex difference in any of the mortality, marriage or employment results.

With the exception of the mortality issue, one positive finding from the present study was that the impact of the death of a child does appear to reduce over time. The layman's phrase "time is a great healer" does appear to hold, at least in terms of levels of employment and longevity of relationships. Beyond the time period of up to ten years, it appeared that the impact of the death of their child was no longer statistically significant in these areas. This may suggest that, although the trauma of losing a child stays with a parent throughout their whole life (Talbot, 2002), recovery and reintegration into a potentially fulfilling life is possible, but parents should perhaps expect this to take place over a longer time frame than that suggested for other types of bereavement (Prigerson & Maciejewski, 2005).

8.4.4 Limitations of the Study

The limitations of this study are similar to those of the Scottish study presented in chapter seven. The data supplied are restricted to avoid producing potentially disclosive results. In addition, the fixed sampling time points do not permit detailed year on year analysis of changes. This means that one can say, for example, that bereaved parents may have employment difficulties in the first ten years of bereavement, however these appear to be resolved by year twenty. No more detailed analysis of the second ten year period is possible, therefore the actual time to resolve employment issues may be somewhere between eleven and twenty years.

Finally, an important limitation of this and the previous study is the restriction of identification of bereaved parents whose child is less than one year old at their time of death. More detailed record linking work could potentially link census and vital events records for parents whose child died at a more advanced age. A comparison group, in this case, would have to be drawn from demographic matching. This would mean, for each bereaved parent, a comparison group of parents of a similar age, social background, education background, marital, employment and parental status would have be drawn from census data. If it were possible to conduct this further analysis, a rich source of case-controlled information, relating to a wide range of parental experiences, would provide a definitive mapping of the impact of parental bereavement over a lengthy time frame. This information would be invaluable to those offering therapeutic interventions to bereaved parents, or indeed to bereaved parents themselves, to allow adequate support to be provided over the long-term bereavement experience.

8.4.5 Conclusions

Increased mortality rates in bereaved parents, initially up to four times those of non-bereaved parents, merit further immediate investigation. This risk factor for premature death is greater than that of the risk of smoking on the incidence of lung cancer (Doll, Gray, Hafner & Peto, 1980). Investigations into the causes of death of these parents susceptible for decreased life expectancy following parental bereavement is required to establish whether specific high risk groups can be identified, and appropriate interventions delivered. Furthermore, evaluation of the needs of bereaved parents both in the workplace and in those seeking to return to work should be carried out to identify whether changes in employment practices are required to support this vulnerable group through their life-changing event. However, it has been noted that in the medium to long term (more than ten years post-bereavement) a return to levels of employment and relationship functioning may be achievable for those parents who experience stillbirth or infant death.

Chapter Nine – General Discussion

9.0 Abstract

9.0.1 Background

The current thesis offers a wealth of novel information about the experience of parental bereavement from multiple research methods.

9.0.2 Method

The findings from research carried out within the thesis are compiled and considered from a variety of perspectives. The key messages from the research carried out are then presented.

9.0.3 Results

Bereaved parents are coping with a variety of emotional and social problems. Levels of grief and depression were high up to four years post-loss. Grief and depression were shown to be independent constructs, and individuals with a prolonged grief reaction did not necessarily also exhibit clinical depression symptoms. Ruminative coping was associated with higher grief and depression in early and mid-bereavement. Cognitive restructuring was associated with lower grief symptoms in early bereavement. Depression and self-blame could predict higher grief in mid-bereavement, and rumination and education level predicted higher depression. Bereaved parents were no more likely to divorce than non-bereaved comparisons and were less likely to return to work following stillbirth or infant death, than mothers whose child lived, within the first ten years following the birth or death. High rates of mortality, up to 35 years post-loss remain an issue of significant concern.

9.0.4 Conclusions

Although the present PhD research was time-limited and focussed on a subset of factors which may affect the parental bereavement experience, important novel findings have emerged. Depression and grief are not necessarily co-morbid diagnoses and each should be assessed and treated independently. Factors which were associated with higher grief and depression emerged more clearly than those having an association with lower grief and depression. Therapeutic interventions should perhaps focus on reducing the impact of negative behaviours rather than seeking to promoting positive behaviours. Further research is necessary to identify whether other factors may be also be important.

9.1 Introduction

The results of the studies reported in the previous chapters have provided information about the experience of parental bereavement from a number of different sources. The phenomenological study in chapter four reported findings from a group of mothers, with a variety of bereavement experiences, from early bereavement (one year) up to late bereavement (forty years). Chapter five illuminated the experience of early parental bereavement, with a sample of parents recruited from support and self-help groups across the UK. Chapter six reported bereavement experiences from a cross-section of Scottish parents, around four years post-loss. The results from chapters six and seven came from a wide selection of parents who have experienced stillbirth or infant death, up to 35 years earlier. The research population for the current thesis is, therefore, demographically diverse and claims of providing a longitudinal perspective on parental bereavement are, accordingly, inappropriate. Despite this apparent limitation of the work carried out, a rich pool of data has been accumulated, in many cases, for the first time. It is therefore appropriate that overarching conclusions about the experience of parental bereavement be drawn from the project, with the caveat of population demographics and sampling variations in mind.

9.2 What are Bereaved Parents Coping With?

9.2.1 Prolonged grief

The standard measurement instruments used in chapters five and six indicate that bereaved parents are coping with high levels of grief. A comparison of parental grief with other types of grief, for example, spousal grief, is not warranted with the current data, as no comparison groups were recruited. The advantage of producing a type of “league table” of bereavement experiences may not necessarily be helpful, therefore the

key message about grief from chapters five and six is that a large percentage of bereaved parents are likely to be experiencing symptoms of prolonged grief in early to mid-bereavement (up to four years). This, then, poses a dilemma for the proposed diagnostic criteria for prolonged grief. Prigerson et al. (2009) suggests that grief becomes a disorder when symptoms are present for more than six months. The results presented in the current thesis seem to indicate that prolonged grief is the norm for many bereaved parents, however if this extended period of grief is “normal” for parental bereavement, how can this be classified as a disorder? However, if bereaved parents are expected to experience a severe and sometimes disabling grief reaction in early to mid-bereavement, the clinical significance of this must not be overlooked. Engel’s (1961) view of grief as a disease, discussed in chapter one, indicated that, even though grief may be natural and expected, when it impairs everyday functioning for an individual, its importance must be acknowledged. The experience of grief following parental bereavement must therefore be highlighted as potentially problematic for an extended period, although further research is needed to identify a “normal” trajectory for parental grief, and to indicate when problematic grief symptoms may routinely be expected to subside.

9.2.2 Depression

Although often a feature of the parental experiences reported in chapters five and six, depression is not necessarily a feature of grief, nor is grief universally associated with depression. The data presented in chapters five and six clearly show that depression and grief are dissociable constructs, with many bereaved parents meeting presumptive diagnostic criteria for prolonged grief, in the absence of major depression. Primary care practitioners must be aware of this distinction, since treating one condition may not

necessarily alleviate symptoms of the other. For example, pharmacological treatment of depression is now widespread (National Institute for Health and Clinical Excellence, 2010) but the effectiveness of antidepressants as a treatment for grief symptoms is inconclusive (Hensley, Slonimski, Uhlenhuth & Clayton, 2009). Treating one aspect of the bereavement experience is unlikely to result in the alleviation of all the distressing symptoms. The potential for inappropriate and/or ineffective mistreatment is likely to be higher in the absence of a grief diagnosis classification. DSM-V must therefore contain a description of a grief disorder to allow bereaved people to receive treatment specifically recommended for their condition.

9.2.3 Mortality

Increased mortality following the death of a child has been discussed in a number of studies, however these have often lacked methodological rigour or appropriate comparison groups (Hendrickson, 2009). The findings from studies seven and eight show conclusively, for the first time in the UK, that bereaved parents are at a significantly higher risk of premature death compared to non-bereaved counterparts. This important finding merits further urgent investigation. The mortality search in chapter six, where death records were searched to identify any bereaved parents who had died following the loss of their child, showed that causes of death were mainly alcohol or substance-related. Whilst the possibility of a familial link of unhealthy behaviours may be one explanation, the importance of alcohol and substance use as maladaptive coping strategies following the experience of parental bereavement must not be overlooked. This is an issue that those in a position to provide front-line support to bereaved parents need to be aware of. Again, assessment, and where appropriate,

treatment for alcohol and substance use may be part of the overall care package which should be offered, where appropriate, to bereaved parents.

9.2.4 Restoration-oriented stressors

9.2.4.1 Difficulty Caring for Other Children

In early bereavement, as reported in chapter four, difficulty caring for other children was associated with higher levels of grief. No studies were found reporting difficulties or need for assistance with childcare following the loss of a child and this appears, to date, to be an unreported phenomenon. From the phenomenological results reported in chapter four, it appears that many parents are aware that they are struggling, but perhaps find it difficult to ask for help. The reasons for this require further investigation, however a possible explanation may be the link between self-blame and grief, as reported in chapter six. If parents blame themselves for their child's death, then do they perhaps question their ability to nurture and protect other children? Help-seeking behaviour may further reinforce this belief and perhaps there is a reluctance to ask for help in an attempt to bolster their perceived level of nurturing self-efficacy. This proposed explanation lacks published empirical support, however the need for, and reticence to seek, assistance with childcare following bereavement requires urgent investigation, in order to avoid the risk of child neglect and the need to invoke child protection procedures.

9.2.4.2 Employment Difficulties

Higher levels of grief in early bereavement were associated with being employed at the time of the child's death. This directly contradicts findings from other studies into spousal bereavement, where employment status is seen as a buffer, notably by

providing enhanced levels of social support and perception of self-worth (Pai & Barrett, 2007). The reason why employment is a risk factor for grief in parental bereavement is unclear, however, from the results of the phenomenological study, it appears that support from employers may often be perceived as inadequate. When a baby is born, the new parents are offered time away from work, paid in the early stages and unpaid with job protection in the later stages. Financial support is available in the form of child tax credits and the childcare element of working tax credit, if the parents are employed. The death of a child appears to have a life-long impact on parents, and yet this vulnerable group are not currently offered any form of social or employment rights. It now falls upon our society to offer the same support to parents when a child leaves this world, as when it enters.

9.2.4.3 Financial Difficulties

In early bereavement, financial difficulties were associated with higher levels of depression. Loss of income in terms of state benefits has been reported as problematic for parents experiencing the death of a child with a long term condition (Corden, Sloper & Sainsbury, 2002). In these cases, parents often do not work or work part-time and rely on social security benefits as a key source of income for the family. These payments cease on the child's death and the financial impact is often devastating. The current research extends this finding to parents who have not previously relied on income related to their child's condition. Again, the issue of employment rights may be crucial here, since many parents in the qualitative study reported that they had left their jobs due to unacceptable pressures of work following their loss. If parents are unable to work due to prolonged grief, employers may pay only a percentage of salary in the longer term, therefore reducing overall earnings. In its most basic terms, the loss of a

child means a reduction in child benefit and child tax credit, which, particularly in low income families, may mean a significant drop in income. Financial difficulties are a risk factor for poorer outcomes in spousal bereavement (Martikainen & Valkonen, 1998) and, indeed, some studies indicate the moderating effect of higher income on grief symptoms (Stroebe et al., 2006). The mechanisms causing families to experience financial distress following the loss of a child therefore merits further investigation.

9.2.5 Continuing Bonds

The results of the qualitative study reported in chapter four indicated that the mothers found a high level of comfort in continuing bonds with their lost child. Whilst no attempt was made to measure grief symptoms in this group, the mothers indicated the importance they bestowed on the presence of linking objects or symbolic representations of the child. Findings from research in non-specific bereavement contradict this idea by indicating that both feeling that the deceased was still present or providing a guiding influence, or having a specific linking object with the deceased, were both associated with higher grief and depression (Boelen, Stroebe, Schut & Zijerveld, 2006). Furthermore, the results of the studies reported in chapters five and six show no association between continuing bonds and either grief or depression. The reason for this apparent contradiction in findings is unclear. Perhaps the nature of the relationship that is lost in parental bereavement has an influence on the need and adaptiveness of continuing bonds, compared to other losses, for example, spouses, other family members or close friends. Alternatively, perhaps the different methodological approaches used in the current thesis, qualitative versus quantitative methods, prompted different results. Asking questions to attempt to elicit whether a parent had a linking object or had constructed a symbolic representation of the child, without providing

potentially leading examples was problematic. The interview situation allowed answers to be probed and may have elicited clearer accounts of the details of such continuing bonds. Given the apparently high levels of continuing bonds behaviour exhibited by bereaved parents, more detailed investigation of the relative adaptiveness of different strategies for continuing bonds merits further investigation.

9.3 Cultural Considerations

The research reported within this thesis has been carried out in the context of the 21st century culture of the United Kingdom. The results reported must therefore be considered in the context of the cultural norms of Western society. Had the research been carried out elsewhere, the results may well have been different. Some cultures, such as the Achuar in eastern Ecuador, have a tradition of completely forgetting the deceased, therefore any notion of continuing bonds in this cultural context would be considered as a bizarre behaviour (Rosenblatt, 2008). For the Merina in Madagascar, however, consideration of the needs and wishes of deceased ancestors is as much a part of daily life as the requirements of the living (Walter, 199). The importance of the cultural norms in grieving is therefore significant in any understanding of grief reactions.

9.4 Social Models of Bereavement

In early 21st century Britain, the predominant model of cultural grief is influenced by the medical model, which in turn has been derived from observed reactions to grief responses in the late 19th century (Hagman, 1995). The notion of an introspective mourner continuing bonds with a lost loved one after their death is viewed as maladaptive, and the current position in thanatology research is that resolution of grief symptoms is achieved when the mourner has “moved on” and has severed emotional ties with the lost loved one (Field, 2003). Social theories of bereavement such as

Neimeyer's (2001) and Valentine's (2008) would dispute this belief, arguing that a continuing bond with the deceased is instead an adaptive and normal response to grief. Although this thesis provides limited evidence for the adaptiveness or otherwise of the continuing bond response, its prevalence in both the qualitative and quantitative studies suggests that it is a widely-occurring phenomenon. Different forms of continuing bonds may be relatively more or less adaptive and further research into this area is needed if the social models of bereavement are to receive increased support.

Building narratives and finding meaning following the loss of a loved one was not explicitly tested in this thesis, as the research undertaken was predominately quantitative in nature and the existence of a bereavement narrative would most be addressed most appropriately with qualitative research. An interesting finding, however, was that no particular positive coping style was associated with grief or depression. The current thesis does not, therefore, answer the question of how bereaved parents cope more positively with the death of a child. Perhaps the ability to build a narrative and find meaning in the lost loved one's life may be the behaviour that is associated with the resolution of grief symptoms, and may form the basis of a positive coping strategy, to come to terms with grief.

9.5 Limitations of the Thesis

The research reported in this thesis is, by nature of the PhD process, restricted to a three year time limit. A longitudinal study of the experience of parental bereavement was therefore not feasible, however mapping the experience of parental bereavement over time would prove invaluable in establishing norms for bereaved parents, and indicating adaptive and maladaptive coping mechanisms. All of the studies which required direct

input from participants elicited a clear desire from them to participate in research of this type which helped them to contemplated their own experiences, or alternatively, to help others who will encounter parental bereavement subsequently. Researchers must therefore be encouraged and facilitated in their search for knowledge about the experience, even in the early days of bereavement, following a cohort of bereaved parents from very early to long-term bereavement. Ethics committees should not be too paternalistic in their well-intentioned attempts to protect bereaved parents from the possible distress of participating in research of this kind. Bereaved parents are perfectly capable of giving their informed consent (or not) in relation to research participation, and the vast majority of participants in this programme of research reported that they had found it a positive experience. A comprehensive long-term evaluation of the bereavement experience is essential if knowledge, support and therapeutic interventions are to be improved for this deserving group of vulnerable people.

For chapters five and six which tested the Stroebe et al. (2006) model, a pragmatic view on variables under test had to be taken. The number of individual factors to be tested was restricted by the demand participants would feel when completing an over-long questionnaire. Other aspects not tested in these studies, such as attachment style, religiosity, family dynamics and cultural background warrant further investigation. More testing of a wider variety of factors would ensure that the key predictors associated with better outcomes for bereaved parents are found.

Within chapters five and six, no specific question related to therapies which the parent may have had access to, either psychological or pharmacological. Therapeutic and drug-based efficacy testing is beyond the scope of the current research, but the efficacy

of such interventions must be tested using stringent scientific protocols. Interventions found to be beneficial can then be included as factors in subsequent multivariate testing of factors thought to impact on the parental bereavement experience.

9.6 Recommendations for Future Research

There are a number of findings reported in this thesis which merit further investigation. The increased mortality of parents following the death of their child requires urgent investigation. Detailed analysis of health records is required, considering the experiences of fathers as well as mothers, across a wide range of causes of death and ages of the child at the time of their death. Causes of death and likely risk factors must be established, and comparison with a matched group of controls would indicate how important the bereavement experience is, compared to other factors associated with mortality.

A mapping of grief, depression and restoration stressors over the life course following the loss of a child, is also urgently required. Bereaved parents need to know what to expect, as the experience is, thankfully, rare in our society, and they are unlikely to have a perception of what the experience of life following the death of a child is likely to be.

The prevalence of substance and alcohol use in bereaved parents should be identified, as many parents may choose this as a means of self-medicating for grief and depression. Appropriate support and counselling, if warranted, could be offered routinely to bereaved parents as part of an overall care package, thus avoiding any ongoing healthcare costs as a result of maladaptive coping behaviours.

The requirement for support with childcare following the death of one's child should also be investigated. If required, the routine offering of childcare support would reduce any stigma the parents may associate with help-seeking and could reduce the risk of neglect of surviving siblings.

Employment and financial issues following the death of a child require more detailed examination. Comparing the experience of parents with employers who recognise and support their needs, compared to those employers who offer only routine short-term compassionate leave arrangements would identify the impact of employment practices on parental grief. Health economic research would complement these findings to illustrate the cost to society of the loss of contribution from bereaved parents who leave or reduce their activity in the employment market.

Finally, no satisfactory conclusions have yet been reached regarding the issue of continuing bonds and parental bereavement.

9.7 How do Bereaved Parents Cope with the Death of Their Child?

One of the aims of the thesis was to identify factors associated with grief and depression, hoping that there may be some behaviours, strategies or experiences that could in some way alleviate the distress of parents who experience the death of their child. Unfortunately, only one factor which was tested quantitatively was found to be positively associated with lower grief symptoms, namely cognitive restructuring. No factors were found to be associated with lower levels of depression following bereavement. It would appear from these findings that coping with parental bereavement appears to be more about reducing negatives (such as rumination, self-

blame and alcohol/substance use) than promoting more positive behaviours. This finding could represent a limitation of the choice of variables under test, however it could also mean that the experience is not one that is necessarily “coped with”, but, as one participant in the interviews pointed out “it’s just something you learn to live with”. If this is the case, feelings of grief for a lost child may never truly be resolved, but may lie dormant and hidden away by parents. This would explain the comment from a participant who said “I’ve had forty years to recover, but if I hear a certain piece of music, I can be back at day one in a heartbeat”. Whilst the day to day impact of the death of one’s child may recede over time, perhaps the grief of losing a child doesn’t get any less; it just gets further away.

9.8 Is Time the Great Healer?

The studies reported in chapters seven and eight indicate that social changes following bereavement are higher in the first ten year period following the death of a child.

Employment and relationship changes level out after this time, and match those of non-bereaved comparisons. If returning to similar levels of functioning as non-bereaved parents represents adjustment to the loss of a child, it therefore seems that somewhere around ten years might be a reasonable time frame for a bereaved parent to expect post-loss impairments to their lives to be present. At first sight, this seems to be a daunting prospect, as a ten year recovery time may seem hard to come to terms with for the bereaved parent. Compare this, though, with the common perception that “you never get over the death of a child”. Surely an adjustment period of up to ten years is more positive message to give to an individual than the prognosis of a lifetime of prolonged misery?

9.9 Conclusion – What this Thesis Adds to Knowledge about Parental Bereavement

The studies reported in the current thesis have added to knowledge in the following ways:

- The literature related to parental bereavement is sparse and provides limited information about the phenomenon
- Some bereaved parents see continuing a bond with their lost child as important.
- Bereaved parents often have high levels of suicidal ideation
- Coping with surviving siblings, particularly in early bereavement, may be problematic for many bereaved parents
- Employers do not necessarily offer the level of support that bereaved parents need to reintegrate into the workforce
- Grief and depression are dissociable and separate constructs, and can exist independently in parental bereavement
- Rumination, both depressive and reflective, is associated with poorer outcomes following the death of a child
- Social, employment and financial issues are a feature of bereavement up to four years post-loss
- Factors associated with the death such as age of child, cause of death, suddenness and level of violence are not as strongly associated with outcomes as coping strategies and ruminative traits
- Mortality is higher in bereaved parents than non-bereaved comparisons, up to thirty five years post-loss

- Marriage breakdown is no more frequent for bereaved parents than non-bereaved
- Employment issues return to similar levels as experienced by non-bereaved parents, after around ten years

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Appendix I – Proposed Diagnostic Criteria for Prolonged Grief

Disorder

(Prigerson et al., 2009)

Category Definition

A. Event: Bereavement (loss of a significant other)

B. Separation distress: The bereaved person experiences yearning (e.g., craving, pining, or longing for the deceased; physical or emotional suffering as a result of the desired, but unfulfilled, reunion with the deceased) daily or to a disabling degree.

C. Cognitive, emotional, and behavioural symptoms: The bereaved person must have five (or more) of the following symptoms experienced daily or to a disabling degree:

1. Confusion about one's role in life or diminished sense of self (i.e., feeling that a part of oneself has died)
2. Difficulty accepting the loss
3. Avoidance of reminders of the reality of the loss
4. Inability to trust others since the loss
5. Bitterness or anger related to the loss
6. Difficulty moving on with life (e.g., making new friends, pursuing interests)
7. Numbness (absence of emotion) since the loss
8. Feeling that life is unfulfilling, empty, or meaningless since the loss
9. Feeling stunned, dazed or shocked by the loss

D. Timing: Diagnosis should not be made until at least six months have elapsed since the death.

E. Impairment: The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning (e.g., domestic responsibilities).

F. Relation to other mental disorders: The disturbance is not better accounted for by major depressive disorder, generalized anxiety disorder, or posttraumatic stress disorder.

Appendix II – Inventory of Complicated Grief

Inventory of Complicated Grief

Please circle the answer which best describes how you feel right now:

1. I think about this person so much that it's hard for me to do the things I normally do...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

2. Memories of the person who died upset me...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

3. I feel I cannot accept the death of the person who died...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

4. I feel myself longing for the person who died...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

5. I feel drawn to places and things associated with the person who died...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

6. I can't help feeling angry about his/her death...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

7. I feel disbelief over what happened...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

8. I feel stunned or dazed over what happened...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

9. Ever since she/he died it is hard for me to trust people...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

10. Ever since she/he died I feel like I have lost the ability to care about other people or I feel distant from people I care about...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

11. I have pain in the same area of my body or have some of the same symptoms as the person who died...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

12. I go out of my way to avoid reminders of the person who died...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

13. I feel that life is empty without the person who died...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

14. I hear the voice of the person who died speak to me...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

15. I see the person who died stand before me...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

16. I feel that it is unfair that I should live when this person died...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

17. I feel bitter over this person's death...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

18. I feel envious of others who have not lost someone close...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

19. I feel lonely a great deal of the time ever since she/he died...

Never	Rarely	Sometimes	Often	Always	Unknown	Refused
0	1	2	3	4	-3	-4

Appendix III – Patient Health Questionnaire - 9 (PHQ-9)

Over the last two weeks, how often have you been bothered by any of the following problems?				
	Not at all	Several days	More than half the days	Nearly every day
Little interest or pleasure in doing things?				
Feeling down, depressed, or hopeless?				
Trouble falling or staying asleep, or sleeping too much?				
Feeling tired or having little energy?				
Poor appetite or overeating?				
Feeling bad about yourself - or that you are a failure or have let yourself or your family down?				
Trouble concentrating on things, such as reading the newspaper or watching television?				
Moving or speaking so slowly that other people could have noticed? OR the opposite - being so fidgety or restless that you have been moving around a lot more than usual?				
Thoughts that you would be better off dead, or of hurting yourself in some way?				
If you have been bothered by any of these problems in the last two weeks, how difficult have these problems made it for you to do your work, take care of things at home or get along with other people? Please tick one box	Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult

Appendix IV – Life Orientation Test – Revised (LOT-R)

Please be as honest and accurate as you can throughout. Try not to let your response to one statement influence your responses to other statements.

There are no ‘correct’ or ‘incorrect’ answers. Answer according to your own feelings, rather than how you think ‘most people’ would answer.

Using the scale below, write the appropriate number beside each statement.

0 = strongly disagree

1 = disagree

2 = neutral

3 = agree

4 = strongly agree

- 1) In uncertain times, I usually expect the best
- 2) It's easy for me to relax
- 3) If something can go wrong for me it will
- 4) I'm always optimistic about my future
- 5) I enjoy my friends a lot
- 6) It's important for me to keep busy
- 7) I hardly ever expect things to go my way
- 8) I don't get upset too easily
- 9) I rarely count on good things happening to me
- 10) Overall, I expect more good things to happen to me than bad

Appendix V – Ruminative Response Styles Questionnaire – Depressive

Rumination

Please tick the box that best describes you.	Never	Sometimes	Often	Always
I think about how alone I feel				
I think about my feelings of fatigue and achiness				
I think about how hard it is to concentrate				
I think about how passive and unmotivated I feel				
I think “Why can’t I get going?”				
I think about a recent situation, wishing it had gone better				
I think about how sad I feel				
I think about all my shortcomings, failings, faults and mistakes				
I think about how I don’t feel up to doing anything				
I think “Why can’t I handle things better?”				

Appendix VI – Ruminative Response Styles Questionnaire – Reflective and Brooding Rumination

Please tick the box that best describes you.	Never	Sometimes	Often	Always
I think “what have I done to deserve this?”				
I analyse recent events and try to understand why I am depressed				
I think “Why do I always react in this way?”				
I go away by myself and think about why I feel this way				
I write down what I am thinking and analyse it				
I think about a recent situation, wishing it had gone better				
I think “Why do I have problems that other people don’t have?”				
I think “Why can’t I handle things better?”				
I analyse my personality to find out why I am depressed				
I go some place alone to think about my feelings				

Appendix VII –Brief Cope (adapted)

Original wording: These items deal with ways you've been coping with the stress in your life since you're child died. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

- 1 = I haven't been doing this at all
- 2 = I've been doing this a little bit
- 3 = I've been doing this a medium amount
- 4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things.
2. I've been concentrating my efforts on doing something about the situation I'm in.
3. I've been saying to myself "this isn't real."
4. I've been using alcohol or other drugs to make myself feel better.
5. I've been getting emotional support from others.
6. I've been giving up trying to deal with it.
7. I've been taking action to try to make the situation better.
8. I've been refusing to believe that it has happened.
9. I've been saying things to let my unpleasant feelings escape.
10. I've been getting help and advice from other people.
11. I've been using alcohol or other drugs to help me get through it.
12. I've been trying to see it in a different light, to make it seem more positive.
13. I've been criticizing myself.
14. I've been trying to come up with a strategy about what to do.
15. I've been getting comfort and understanding from someone.
16. I've been giving up the attempt to cope.
17. I've been looking for something good in what is happening.
18. I've been making jokes about it.
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
20. I've been accepting the reality of the fact that it has happened.
21. I've been expressing my negative feelings.
22. I've been trying to find comfort in my religion or spiritual beliefs.
23. I've been trying to get advice or help from other people about what to do.
24. I've been learning to live with it.
25. I've been thinking hard about what steps to take.
26. I've been blaming myself for things that happened.
27. I've been praying or meditating.
28. I've been making fun of the situation.

Scales are computed as follows (with no reversals of coding):

Self-distraction, items 1 and 19

Active coping, items 2 and 7

Denial, items 3 and 8

Substance use, items 4 and 11

Use of emotional support, items 5 and 15

Use of instrumental support, items 10 and 23

Behavioural disengagement, items 6 and 16

Venting, items 9 and 21

Positive reframing, items 12 and 17

Planning, items 14 and 25

Humour, items 18 and 28

Acceptance, items 20 and 24

Religion, items 22 and 27

Self-blame, items 13 and 26

Appendix VIII - Continuing Bonds Scale

The following items may or may not be relevant to you. If the question is not appropriate for your situation, please tick Not Applicable. Otherwise, please tick one box on each line which describes how you feel.						
	Not applicable	Not at all true	A little true	Neither true nor untrue	Somewhat true	Very true
I seek out things to remind me of my child who died						
I keep items that belonged to or were closely associated with my child as a reminder of him or her						
I like to reminisce with others about my child who died						
I have inner conversations with my child who died when I turn to him or her for comfort or advice						
Even though no longer physically present, my child who died continues to be a loving presence in my life						
I am aware of having taken on many of my child's habits, values or interests						
My child has had a positive influence on who I am today						
I attempt to carry out my child's wishes						
I have many fond memories that bring joy to me						
When making decisions, I imagine my child's viewpoint and use this as a guide in deciding what to do						
I experience my child as living on through me						

Appendix IX – Interview Schedule

Interview Introduction

We've already had a look at the participant information sheet, but I just want to recap now on some of the key points.

I'm going to talk to you today about the circumstances surrounding the death of your child. I will ask you about life as a bereaved parent, how you have coped and are coping and how relationships with others/work/social life have changed.

I realise that we are going to touch on some very emotional events and if you want to stop the interview at any time we can. You don't need to give any explanation, just say that you want to stop and we will do so.

The information you give me is completely confidential – when I write up my notes I will change the names given to keep everything anonymous. No-one but me will hear this interview.

I'm recording to allow me to concentrate fully on what you say. If you don't mind, I'd also like to take brief written notes so I can refer back to some of the things you may say at different times in the interview.

Do you have any questions at this point?

(A) What is life like for you now?

-
1. Can you tell me about what happened when your child died?
 - i. *Prompt – age, name, gender, when was the death, cause, was it anticipated, other losses, how informed*
 2. Who else is in your family?
 - i. *Prompt – other children, partner, extended family support, other strong supporters*
 3. What impact has the death of your child had on your own health?
 - i. *Prompt - grief experienced, depression, other mental health issues*
 - ii. *Prompt - new physical illnesses*
 - iii. *Prompt - time off work*
 - iv. *Prompt – financial changes*
 4. In what way have your relationships with your partner or friends changed?
 - i. *Prompt – relationship problems or improvements*
 - ii. *Prompt - interactions with other people*
 - iii. *Prompt – social life, any new hobbies (creative especially)*
 5. How much of your life is affected now by the death of your child?
 - i. *Prompt – Christmas, anniversary, holidays*
 - ii. *Prompt – do you think about what age the child would be now – transitions e.g. school, work*
 - iii. *Prompt – if younger children, how did you feel when they reached the age of the lost child*
 - iv. *Prompt – are there any triggers that make them feel worse or bring back bad memories*
 6. What is the main emotion that describes how you feel about your child's death?
 - i. *Prompt – do they feel it was avoidable in any way*
 - ii. *Prompt – does anything make this emotion worse*
 - iii. *Prompt – have they ever considered suicide*
 7. Would you say these experiences have changed over time, since the death? If so, how?
 - i. *Prompt - worse then or now*
 - ii. *Prompt – how close is life now to before the death*
-

(B) Coping with bereavement – strategies and behaviours

8. Have you been offered any help with coming to terms with your grief? Was this helpful to you?
 - i. *Prompt – counselling, medication, support groups*
 - ii. *Prompt – employer, friends*
9. How often do you think about your situation now?
 - i. *Prompt – thinking about the child*
 - ii. *Prompt – thinking about current bereaved status*
10. Do you think you have been able to come to terms with the death?
 - i. *Prompt – intrusive thoughts, dealing with emotional events e.g. Christmas*
11. What things have helped you cope with the death?
 - i. *Prompt – religion, support from others, charity work, other family members (Children)*
 - ii. *Prompt – dealing with memories, photographs, memorials, symbols*
 - iii. *Prompt – alcohol*
12. What do you do to help you get through the bad days?
13. Do you have a grave or other memorial site to your child?
 - i. *Prompt – how often do you visit*
 - ii. *Prompt – how do you feel when you visit*
 - iii. *Prompt – are you happy with the arrangements you made*
14. What would you say is the biggest challenge for you as a BP?
 - i. *Prompt – everyday things, passage of time, special events, other people, finance*
15. What advice would you give other bereaved parents about how to cope with the death of their child?
16. What do you think would be a useful support for bereaved parents?
17. Are you able to see any positive changes in your life?
 - i. *Prompt – relationships, personal growth*
18. Can you tell me if you have met other BPs since the death of your child
 - i. *Prompt – better or worse off than you, how does looking into the future make you feel, can you identify with them*
19. What do you think other people think of your life and how you are dealing with it?
 - i. *Prompt – do non-BPs understand*
 - ii. *Prompt – able to be themselves, talk about the child or their feelings*
 - iii. *Prompt – do they think others appreciate their situation fully*

Is there anything that we haven't covered that you think is important for me to know about coping with life as a bereaved parent?