
Sudden Infant Death Syndrome: Mothers' Experiences of Parenting

July 2012

Isis Cherie Davidson-Olsson

Student Number: 09212279

Word Count: 31,716 (Excluding abstract, contents, references and appendices)

Acknowledgements

I would like to thank all those who offered their support in making this project possible, including Jean Simmons from the Foundation for the Study of Sudden Infant Death Syndrome (FSIDS), who facilitated the recruitment process, and to the seven mothers who generously offered to share their stories with me. I would also like to express my gratitude to Dr. Barbara Mason, the research supervisor, who provided invaluable support and advice throughout the duration of this project. Lastly, I would also like to show my appreciation for Janice Cheeseman, who kindly sacrificed her time and energy in ensuring the quality of the write-up and to Tim Appleby, whose unwavering faith in my abilities has never failed to amaze me.

Table of Content

1. Abstract	78
2. Introduction	79
2.1 Background	79
2.2 Aetiology	81
2.3 Distinctive Features of SIDS Bereavements	86
2.4 Perinatal Bereavement	88
2.5 Parenting after Loss	95
2.6 Aims of the Research	101
3. Methodology	103
3.1. Overview	103
3.2 Qualitative Research	103
3.3 Interpretative Phenomenological Analysis	103
3.4 Participants	105
3.5 Ethics	108
3.6 Data Collection	112
3.7 Data Analysis	116
3.8 Quality and Validity	119
3.9 Self Reflexivity and Position in Research	120
4. Results	122
4.1 Pre-Interview Measures	122
4.2 Interpretative Phenomenological Analysis	122
4.3 Channelling the Parent Within	123
4.4 Parenting Outside of Yourself	128
4.5 Restoration Through You	133
4.6 The Bitter Restoration	137
4.7 A Disruptive Appreciation	140
5. Discussion	147
5.1 SIDS and Mothers' Experiences of Parenting	147
5.2 Implications for Clinical Practice	162
5.3 Methodological Considerations	163
5.4 Future Research	165
5.5 Conclusion	166
6. References	168
7. Appendices	183

List of Tables

Table 1: <i>Definition of Sudden Infant Death Syndrome (Beckwith, 2003)</i>	p. 80
Table 2: <i>Environmental Risk Factors for SIDS (Hunt & Hauck, 2006)</i>	p. 83
Table 3: <i>Demographic Profile of Participants</i>	p. 108
Table 4: <i>Total Scores and T-Scores for the IES-R and the SCL-90-R</i>	p. 122
Table 5: <i>Master Themes and Subthemes</i>	p. 123
Figure 1: <i>International Incidence Rates of SIDS (Hauck & Tanabe 2008)</i>	p. 84
Figure 2: <i>Infant Mortality Rates per 1000 Birth: 1900 - 2000 (Hicks & Allen, 1999)</i>	p. 95
Figure 3: <i>Parenting Typologies (Carr, 2006)</i>	p. 148
Figure 4: <i>Model of Parenting in the Aftermath of SIDS</i>	p. 156
Figure 5: <i>Attachment Style (Srivastava & Beer, 2005)</i>	p. 157
Figure 6: <i>Internal Working Models of Self and Others (Bartholomew, 1990)</i>	p. 159
Figure 7: <i>Input Output Model of Parenting</i>	p. 161
Figure 8: <i>Pyramid Model of Parenting</i>	p. 161

1. Abstract

Background: The death of a child has been found to have long term consequences for both individual and family functioning. This is particularly true for bereaved siblings who have been found to be at increased risk of developing mental health difficulties in later life. Literature on parental bereavement proposes that the parenting phenomenon, such as replacement child syndrome, subsequent child syndrome and the parenting paradox, which can emerge after the death of a child, may account for this. However, there is very little research on these labels of observed parenting phenomenon and, as a result, any hypothesis offered remains under elaborated. In addition, limited evidence suggests that, due to the sudden, unexpected and unexplained nature of the loss, SIDS parents are more likely to experience a greater degree of distress and adjustment difficulties than other perinatally bereaved populations. Given this, it could be hypothesised that SIDS parents may be likely to experience these parenting phenomena. Despite this, however, SIDS remains a neglected area of research.

Aims: As a consequence of this research gap, the study aims to explore mothers' experiences of parenting in their transition from being a parent unaffected by Sudden Infant Death Syndrome to a parent affected by Sudden Infant Death Syndrome.

Methodology: Semi-structured interviews were conducted with seven mothers who had experienced an incident of Sudden Infant Death Syndrome. The interviews were then transcribed and analysed using Interpretative Phenomenological Analysis (IPA).

Results: Five master themes emerged from the analysis: 'Channelling the Parent Within', a naturally developing and responsive parenting style that is facilitated by internal mechanisms, such as flexibility and confidence; 'Parenting Outside of Yourself', a parenting style that develops in the aftermath of a SIDS event, which is characterised by self doubt and a reliance on external mechanisms such as reassurance and restriction; 'Restoration Through You', the restorative effect of the subsequent and surviving children, which allows vindication and re-establishes happiness; 'The Bitter Restoration', a restoration that encompasses internal knowledge and external evidence of loss, including a disrupted family composition and a continued awareness of existential threat; 'A Disruptive Appreciation', the development of a greater appreciation for the subsequent and surviving children that impacts discipline and incorporates indulgence. These, along with the subthemes contributing to them, are presented as a narrative account.

Conclusion: The results imply that mothers who have experienced a SIDS event shift into a permissive and anxious style of parenting which is characterised by safety behaviours. A model of parenting in the aftermath of SIDS has been proposed in order to explain the underlying cognitions and processes which drive this behaviour and the factors which serve to maintain it. By doing this it is hoped that, when working with bereaved parents and siblings, clinicians will be better positioned to frame parenting practices and intervene at a cognitive level.

2. Introduction

**“Sometimes I will hug you far too tight
Check on you ten times a night
Sometimes I will kiss you a little too much
Cling to you, sing to you, tickle you and such**

**As you grow up I will kiss your nose
Touch your hair and feel your toes
I will cry when you walk, laugh when you talk
Worry as I sit and wait and scream when you come home late**

**I do not want you to have my fears
So I will often pull you close to hide my tears
Because you see I'm not just your mother
A long time ago, I lost another”**

(Saunders, 2012)

2.1 Background

The medical term Sudden Infant Death Syndrome (SIDS), also known as cot or crib death, refers to a Sudden and Unexpected Death in Infancy (SUDI). SIDS is one example of perinatal death (e.g. stillbirth, neonatal death, sudden infant death syndrome, acquired disease, death determined at birth and accidental death in infancy) and the number one cause of death in healthy infants aged between one and twelve months (FSID 2011; Hunt & Hauck, 2006; Lewis, 2003; Sullivan, & Barlow, 2001; Williams, 1990). The determining feature of SIDS is that the cause of death remains unexplained, despite a thorough post-mortem, police investigation and coroner's report (FSID 2011; Hunt & Hauck, 2006; Lewis, 2003; Sullivan, & Barlow, 2001; Williams, 1990). The identifying markers for SIDS include the age of the deceased (i.e., developmental stage allows other causes to be ruled out, such as trauma associated with a live birth), the gender of the deceased (i.e. males are 1.5 times more likely to be affected), time of death (i.e. death usually occurs during a period of sleep) and that in the preceding 24 hours there was no suggestion that death was imminent (Beckwith, 2003). For a comprehensive definition of SIDS, please see Table 1.

Table 1. Definition of Sudden infant Death Syndrome (Beckwith, 2003)

Proposed Definitional Approach of Sudden Infant Death Syndrome (SIDS)	
Generic Definition*	
The sudden and unexpected death of an infant younger than 1 year and usually beyond the immediate perinatal period, which remains unexplained after a thorough case investigation, including performance of a complete autopsy and review of the circumstances of death and of the clinical history. Onset of the lethal episode was presumably during sleep (ie, the infant was not known to be awake). Minor inflammatory infiltrates or other abnormalities insufficient to explain the death are acceptable.	
Subset Definitions†	
Category I SIDS	
An infant death that meets the generic criteria and also meets all of the following standards:	
Age between 3 weeks and 8 months	
No similar deaths in siblings, close genetic relatives, or other infants in custody of same caregiver‡	
No evidence indicative of significant trauma, abuse, neglect, or accident	
No evidence of unexplained moderate or severe stress in thymus, adrenals, or other organs and tissues§	
Intrathoracic petechial hemorrhages are a supportive but not an obligatory or diagnostic finding	
Category II SIDS	
An infant death that meets the criteria for Category I SIDS except for 1 or more of the following features:	
Age younger than 1 year but outside the 3-week to 8-month range	
Similar deaths in siblings or other close genetic relatives that are not considered suspicious for infanticide (genetic consultation indicated)	
Inflammatory changes or other abnormalities somewhat greater than usual for Category I but not sufficient to be an unequivocal cause of death	
Cases in which accidental asphyxia is considered possible but not certain:	
Depending on specific features of each case and the preference of the certifying pathologist, such cases can be designated as Category I or II SIDS, or as undetermined cause. A diagnosis of suffocation or asphyxia in a case that would otherwise fit Category I SIDS should be made only with strong supporting evidence. Sometimes infants may, during a death struggle, get into situations that falsely suggest mechanical asphyxia.	
Category III SIDS	
While performance of a complete autopsy is a mandatory prerequisite to a diagnosis of SIDS, in some developing nations, religious groups, or economic settings, the performance of autopsies is difficult or impossible. Category III SIDS is suggested solely for purposes of developing statistical data from such situations and is intended to apply to those cases that seem to fit the generic criteria for SIDS but in which no autopsy is performed. It should not be considered an acceptable alternative to autopsy in most developed societies.	

Statistics by the Foundation for the Study of Infant Death (FSID) report that in 2009 there were 0.4 incidences of SIDS per 1000 live births. This equates to 316 deaths per year, nationwide (FSID 2009). Although 78% of SIDS cases occur within the first three months, and 90% within the first six months, 6.5% will occur after the infant's first birthday. Statistics also suggest that incidences of SIDS have reduced by 70% since 1991 (FSID 2009). However, Sullivan & Barlow, (2001) suggest that advancements in pathology and autopsy techniques have improved the reliability and validity of more recent statistics. In addition, advancements in pathology and epidemiology, over the last 20 years, could have increased the sensitivity of post-mortem techniques and improved the probability of establishing a cause of death. As a consequence, a proportion of SUDI cases may now be classified other than SIDS. If correct, this implies that, along with providing a diagnostic label for unexplained instances of SUDI, the term SIDS also refers to a knowledge gap which currently makes it difficult to explain a large number of infant deaths. Lewis, (2003) and Cote et al, (1999) support this idea by pointing out that, in the past, rare inherited disorders had the potential to be mistakenly classified as SIDS.

2.2 Aetiology

Since SIDS was first proposed by Beckwith in 1969, a large body of research and literature has been contributed by the scientific community (Beckwith, 1969, as cited in Beckwith, 2003). However, due to the enormity of the evidence base, only established neuropathological, biobehavioural, pathogenic, genetic and environmental perspectives will be presented here. Efforts will also be made to consider the cultural, ethnic and socio-economic variations, along with debates on misdiagnosis and covert homicide.

2.2.1 Neuropathology

Contemporary research suggests that neurological abnormality, seen *in utero*, plays a significant role in SIDS and accounts for other types of perinatal death, such as stillbirth and neonatal death (Ottavianni, 2011; Sparks & Hunsaker, 2002). Ottavianni, (2011) and Sparks & Hunsaker, (2002) also propose that, rather than having a distinct aetiology, neonatal death, still birth and SIDS exist on a continuum of neurological abnormality which leaves infants, who survive gestation, vulnerable to a failure of their autonomic systems (e.g. cardiac conduction, respiratory system, neurological sleep mechanisms etc). Kinney et al, (1992), Kinney, (2009), and Sparks & Hunsaker, (2002) argue that this is why infants usually succumb to SIDS within the first three months of life and state that during this time neurological abnormality would disrupt neurodevelopment and make continued survival unfeasible.

However, neuroscientific enquiry is still in its infancy and is grappling with the challenges of identifying abnormality on a molecular and cellular level (Kinney et al, 2009). At present, diagnostic and research techniques rely on neuroimaging. This technology is well suited to researching the architecture and anatomical connectivity of the living brain but, after death, capturing molecular, cellular and neurochemical activity becomes more challenging (Kinney et al, 2009; Ottavianni, 2011). Therefore, it is difficult to establish the role molecular, cellular and neurochemical abnormality plays in SIDS, which is diagnosed post-mortally.

2.2.2 Biobehavioural

Lewis, (2003) proposes that under responsive neuromuscular reflexes could be a mediating factor in SIDS. Research by Lewis (2003) has found that, as the nervous system develops, respiratory occlusion reflexes (i.e., head movements, wiping motions or the vigorous expulsion of air in response to stimuli that impact oxygen uptake, such as

mucus and foreign objects), once governed by subcortical operations, become a cortically led learned response. As a result, Lewis (2003) suggests that, during neurodevelopmental transition, those who fail to develop an adequate occlusion defence will be vulnerable to smothering. This fits with the fact that most infants who die of SIDS die before the age of three months, which is when behavioural transitions related to the development of subcortical and cortical mechanism is thought to occur (Lewis 2003). In addition, research on neuromuscular maturation suggests that occlusion is challenging when resting in the prone position, especially for babies who have underdeveloped or under-responsive reflexes (Lewis 2003). This reconciles with the 'back to sleep' campaign, launched in the UK in 1991, which discouraged belly sleeping and saw a two thirds reduction in incidences of SIDS (Dwyer & Ponsonby, 1996; Lewis, 2003).

2.2.3 Pathogens

An overview by Ottaviani, (2011) has also established that Toxic Shock Syndrome, caused by Staphylococcus bacteria, plays a role in SIDS and can cause organ failure, inflammation of the nasal and respiratory membrane, airway obstruction and swelling of the neural membrane (Morris, 1999; Raza & Blackwell, 1999). Morris (1999), however, suggests that micro-organisms and infectious agents other than Staphylococcus are involved in SIDS, with 50% of autopsies finding larger than expected quantities of bacterium and virions in the nasopharyngeal passage. Support for pathogenic research comes from Harrison et al, (1999) who investigated the epidemiological features of SIDS, and found seasonal variations and increased rates during influenza outbreaks. In addition, Blackwell & Weir, (1999) and Raza & Blackwell, (1999) have highlighted the protective role of immunisation and immunity through breast feeding.

Pathogenic research does not dismiss evidence from genetic, neuropathological or biobehavioural domains. Nor does it suggest that pathogens, in isolation, result in a SIDS event. Instead, it aims to establish how pathogens interact with predisposition (Blackwell & Weir, 1999). For instance, underdeveloped occlusion reflexes leave infants vulnerable to respiratory tract infections (Lewis, 2003). The airways remain blocked, increasing the temperature in the nasopharyngeal region, resulting in further bacterial and viral maturation (Harrison et al, 1999). The challenge for pathogenic research is that it uses animal models which do not adequately represent developing human infants. In addition, because SIDS is a leading cause of death, the numbers of infants who die of other causes are not sufficient for statistical comparison (Blackwell & Weir, 1999).

2.2.4 Genetics

Research by Narita et al, (2001) found 5-HTT gene variants in cases of SIDS. This causes deficits in serotonin levels, changing the neurobiology of the brain. Narita et al, (2001) proposes that this accounts for the abnormality in the embryonic development of the central nervous systems, resulting in deregulation of autonomic operations such as thermal regulation (Hunt & Hauck, 2006; Narita et al, 2001; Weese-Mayer et al, 2007). As a result, the research by Narita et al, (2001) reconciles with research by Sullivan & Barlow, (2001) on the role of overheating in SIDS. Weese-Mayer et al, (2007) have also found mutations in the C4A and C4B genes, which mediate inflammation, and the IL-10 gene, which promotes the body's anti-inflammatory mechanism. This makes these infants particularly vulnerable to the inflammation seen in respiratory tract infections (Blackwell et al, 2005; Hunt & Hauck, 2006; Weese-Mayer et al, 2007). Research by Weese-Mayer et al, (2007) on genetics reconciles with the overview by Ottaviani, (2011) on pathogenic research which states that it is not the pathogen that creates a lethal event but the way in which an infant's physiology reacts (Blackwell & Weir, 1999). It is worth noting that genetic perspectives on SIDS are supported by increased incident rates in males and siblings, suggesting genetic inheritability and the involvement of genes located on the Y/male chromosome (Beal & Blundell, 1988; Oyen et al, 1996).

2.2.5 Environment

The environmental risk factors associated with SIDS are well established and substantial. As a result, a summary has been provided in Table 2.

Table 2. Environmental Risk Factors for SIDS (Hunt & Hauck, 2006)

Maternal and antenatal risk factors	Infant risk factors
<ul style="list-style-type: none">• Smoking• Alcohol use (especially periconceptionally and in first trimester)• Illegal drug use (especially opiates)• Inadequate prenatal care• Low socioeconomic status• Low age• Low level of education• Single marital status• Increased parity• Short interval between pregnancies• Intrauterine hypoxia• Fetal growth retardation	<ul style="list-style-type: none">• Age (peak 2-4 mo, but peak may be decreasing)• Male sex• Race/ethnic background (e.g., black, Native Indian, other indigenous group)• No pacifier ("dummy") used at bed time• Prematurity• Prone or side sleeping position• Recent febrile illness• Exposure to tobacco smoke• Soft sleeping surface, soft bedding• Thermal stress/overheating• Face covered by bedding• Sharing bed with parents or siblings• Sleeping in own room rather than in parents' room• Colder season. no central heating

2.2.6 Culture, Ethnicity and Socio-Economic Status

Since the early 1990's the international community have witnessed a decline in SIDS. However, due to limited medical provisions in the developing world, deaths are often misattributed to regional illnesses such as malaria (Lewis 2003). As a result, no figures exist on SIDS in low income countries (Bajanowski, 2007; Dwyer & Ponsonby, 1996; Hauck & Tanabe 2008; Hunt & Hauck 2006; Lewis, 2003; Sullivan & Barlow, 2001; WHO, 2010). Please see Figure 1 for the international SIDS rates.

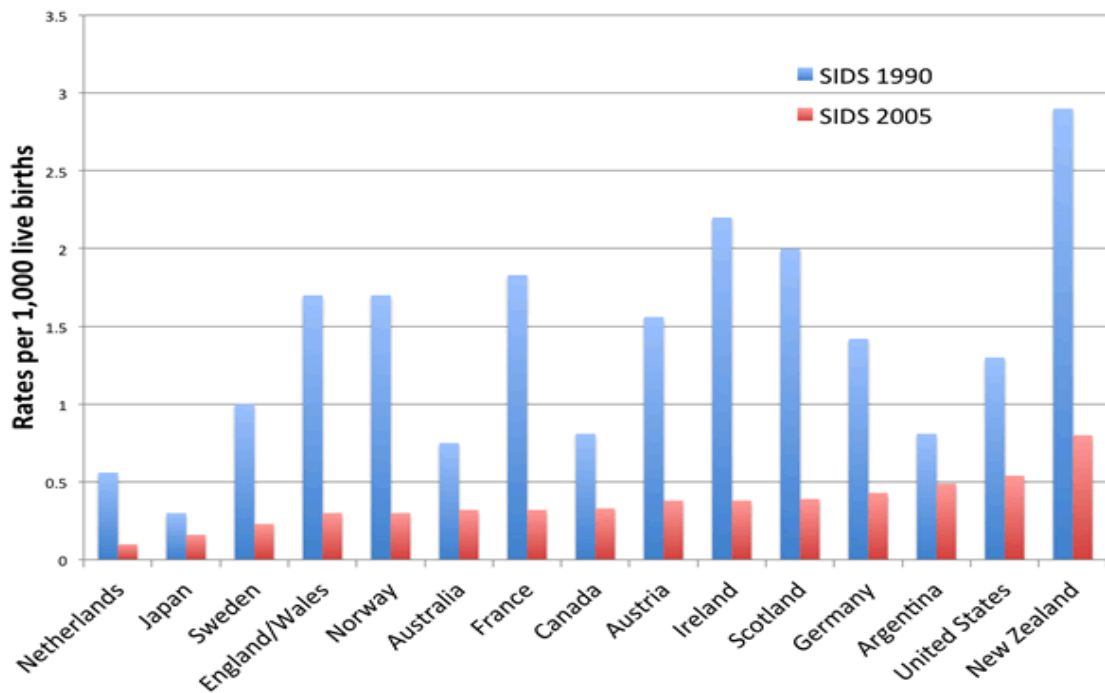


Figure 1. International Incidence Rates of SIDS (Hauck & Tanabe 2008)

Figure 1. shows the variation in international SIDS rates (Hauck & Tanabe 2008). Although the exact reasons for this are unknown, Beckwith, (2003) has proposed that the lack of an international and universally accepted definition is to blame. For example, Japan classifying unexplained incidences of SUDI as Postnatal Mortality (PNM). Further variability also exists within countries and is associated with ethnicity and socio economic status. An overview by Sullivan & Barlow, (2001) found that in the UK South Asian populations (e.g. Pakistani, Bengali, Indian etc) are less likely to experience a SIDS event, Caucasians are at moderate risk and Caribbean populations are at high risk (Hunt & Hauck, 2006; Bluglass, 1981). Sullivan & Barlow, (2001) report that these findings are

stable across the UK and America, with the addition of Hispanic populations who are, like Asian communities, less likely to experience a SIDS event. Ball et al, (2012), Farooqi et al, (2008) and Hunt & Hauck, (2006) have attributed these variations to cultural differences in child rearing practices. For instance, Ball et al (2012) and Farooqi et al, (2008) have found that the cultural preference for large extended families to commune within the same household, most commonly seen in Asian culture, is a protective factor in SIDS. The rationale they give for this finding relates to the idea that infants in busy households are held and observed more and will likely share a bedroom with other family members. Ball et al, (2012) and Farooqi et al, (2008) also found that cultural practices associated with sleeping arrangements, such as bed sharing and swaddling, can increase the risk of SIDS. It is, however, important to note that medical conditions associated with particular ethnic groups can also increase the risk of SIDS. One such condition is sickle cell anaemia which increases the risk of SIDS by up to 11% and is most commonly seen in Afro-Caribbean communities (Sullivan & Barlow, 2001).

Bluglass (1981), Leach, (1999) and Spencer & Logan, (2004) all report that SIDS rates can vary according to socio-economic status, with higher rates recorded in the presence of limited financial income, lone parent families, manual occupations, long term unemployment and limited educational opportunities. This may be reflective of difficulties accessing medical care. For instance, Sullivan and Barlow, (2001) found that limited pre and postnatal care is a risk factor for SIDS. Along with this, unhealthy behaviours which can result from a lack of education, such as smoking during pregnancy, are also risk factors for SIDS (Leach et al, 1999; Spencer & Logan, 2004). In addition, Li (2005) suggests that parents diagnosed with mental health difficulties are more likely to lose a child. However, mental health and low socio-economic status correlates and as a result the interaction is contentious.

2.2.7 Covert Homicide

At present, SIDS remains a diagnosis of exclusion (Beckwith, 2003; Brookman & Nolan 2006). This means that, when all other causes have been ruled out by autopsy and police investigation, the death will be classified as SIDS. This, along with the fact that SIDS is physically indistinguishable from suffocation, has led many to question what proportion of children are misdiagnosed and die as a result of abuse, maltreatment, neglect or non accidental injury (Bookman & Nolan, 2006; Cote et al, 1999; Levene & Bacon, 2004; Williams, 1990). Levene and Bacon (2003) report that 10-20% of SUDI cases are covert

homicide (i.e. a fatal injury that is unidentifiable due to the limitations of current autopsy and forensic techniques or an accidental injury inflicted during resuscitation). However, it could be argued, that misdiagnosis occurs due to the lack of research aimed at defining the characteristics of covert homicide and distinguishing it from SIDS, rather than from an operational deficit in the syndrome's definition. This assertion is supported by Levene and Bacon (2003) who highlight the inadequacy of autopsy techniques in identifying covert homicide.

2.3 Distinctive Features of SIDS Bereavements

The literature acknowledges that SIDS is distinctive and states that SIDS bereavements are different to other types of perinatal (i.e., the period of time prior to, during and after birth) loss (Boyle et al, 1996; Bluglass, 1981; Defrain, 1991; Dyregrov & Dyregrov, 1999; Dyregrov & Matthiesen, 1987; Hunt & Hauck, 2006; Kreuger, 2005; Lamb, 2009; Pantke & Slade, 2006; Vance et al, 1995). The reason for this relates to the traumatic circumstances of the death, which serves to heighten the grief reaction and increases the risk of psychological difficulties and parenting phenomenon such as over-protectiveness. (Dyregrov & Dyregrov, 1999; Dyregrov & Matthiesen, 1987; Pantke & Slade, 2006). In order to explore this suggestion further, the review will now consider SIDS bereavement in terms of a simultaneous traumatic life event, the legal procedures associated with SIDS and parental guilt. The review will then go on to consider the long-term outcomes for parents who experience a SIDS bereavement and provide a summary of the findings in this research area.

2.3.1 Bereavement and a Simultaneous Traumatic Event

The literature classifies SIDS as a traumatic bereavement and simultaneous major traumatic life event (Bluglass, 1981; Boyle et al, 1996; Dyregrov & Matthiesen, 1987; Handsley, 2001; Kreuger, 2005). This is due to the unanticipated nature of SIDS and the fact that a majority of these children die at home. As a result, parents usually discover the child and are left responsible for attempts at resuscitation until an ambulance arrives (Bluglass, 1981; Boyle et al, 1996; Dyregrov & Matthiesen, 1987; Handsley, 2001; Kreuger, 2005). On this basis, several academics have suggested that the level of trauma experienced in a SIDS event corresponds to the trauma one would expect to see in a homicide (Bluglass, 1981; Boyle et al, 1996; Dyregrov & Matthiesen, 1987)

2.3.2 Legal Proceedings

The law requires that all cases of Sudden and Unexplained Death be investigated by the police and the coroner's office. This makes SIDS distinct from other forms of perinatal death where a police investigation is not required. Kreuger, (2005) believes that the police investigations, which follow a SIDS event, are particularly difficult for parents and can leave them feeling overly scrutinised and blamed (i.e. removing furnishing and bedding from the home; forensic photography; removal and confiscation of clothing; a formal police interview, etc). In addition, Williams, (1990) and Kreuger, (2005) note that police investigations can cause stigma, with the lack of answers they provide having the potential to promote suspicion amongst family members, neighbours and health care professionals.

2.3.3 Guilt and the Unexplained Nature of SIDS

Beckwith, (2003) has reported that guilt and self blame are defining features in SIDS bereavements. Kreuger, (2005) supports this notion, stating parents continually question "what went wrong?", "what did I miss?". However, unlike other types of infant death, there are no answers and self blame is easily misattributed and rarely rescinded (Defrain, 1991). This is an unfortunate fact, given that, knowing the cause of death provides comfort and reduces the intensity of grief and self blame (Defrain, 1991; Lamb, 2009). In addition, medical uncertainty surrounding their child's death affects future parenting, with SIDS' parents often fearing they will be held responsible for the death of their child (Bluglass, 1981; Boyle et al, 1996).

2.3.4 The Long Term Impact of SIDS

A review of the literature suggests that coming to terms with the trauma of a SIDS event may take longer than would be expected in other perinatally bereaved populations (Boyle et al, 1996; Dyregrov & Dyregrov, 1999; Pantke & Slade, 2006; Vance et al, 1995; Williams, 1990). Kreuger, (2005) supports this suggestion, stating that SIDS is a significant trauma and, as a result of the circumstances surrounding the child's death, parents are more likely to experience difficulties associated with Post Traumatic Stress Disorder than other perinatally bereaved populations. In fact, a 12-15 year longitudinal study on the impact of SIDS, by Dyregrov & Dyregrov, (1999) found that two thirds of parents were still actively grieving for their children. In addition, Boyle et al, (1996) and Vance et al, (1995) both found that parents affected by SIDS were significantly more likely to experience anxiety and depression than those who had experienced other types

of perinatal bereavement. In terms of parenting after a SIDS event, Krueger, (2005) suggests that an incident of this nature shatters a parent's belief that they are able to nurture, cherish and keep their children alive. This is particularly true of SIDS as parents constantly question what went wrong (Pantke & Slade, 2006). Pantke & Slade, (2006) also report on a longitudinal study, which showed that 12-14 years after their initial losses, parents were still overprotective of the surviving and subsequent offspring.

2.3.5 Section Summary: Distinctive Features of SIDS Bereavements

Literature suggests that SIDS is distinctly different from other types of perinatal death due to the unanticipated nature of the death, the trauma associated with discovery, the unexplainable nature of SIDS and the police investigations which follow (Kreuger, 2005). In addition, limited evidence suggests that parents affected by SIDS experience a greater degree of emotional distress, depression, persistent grief and family disruption, which is akin to bereavement through homicide (Boyle et al, 1996; Bluglass, 1981; Dyregrov & Matthiesen, 1987; Vance et al, 1995; Williams, 1990). Despite these findings, there is still little research on parenting after a SIDS event (Lamb, 2002; Pantke & Slade, 2006; Warland, 2011a).

2.4 Perinatal Bereavement

The literature refers to the death of a child as the most distressing bereavement and life event one can expect to experience, which can have long term consequences for families (Boyle et al, 1996; Defraun, 1991; Dyregrov & Matthiesen, 1987; Dyregrov & Matthiesen, 1991; Harper et al, 2011; Laakso & Paunonen-Ilmonen, 2002; Lamb, 2002; Li et al, 2005; Vance et al, 1995; Wijngaards-de Meij et al, 2005; Wing et al, 2001). Boyle et al, (1996), Buckle & Fleming, (2011), and Wing et al, (2001) all state that, in addition to mourning the death of their child, parents may also grieve for intangible losses such as a changed sense of identity, a lost sense of safety in the world and altered social relationships. Much research has been conducted on parental bereavement, grief and mourning (Boyle et al, 1996; Defraun, 1991; Dyregrov & Dyregrov, 1999; Dyregrov & Matthiesen, 1987; Dyregrov & Matthiesen, 1991; Harper et al, 2011; Krueger, 2005; Laakso & Paunonen-Ilmonen, 2002; Li et al, 2005; O'Leary et al, 2011; Picard, 2002; Vance et al, 1995; Versalle & McDowell, 2004; Wijngaards-de Meij et al, 2005; Wing et al, 2001). As a result, only literature on grief and mourning in pre, peri and postnatal populations will be presented here. This will include an overview of the grieving process, how and why these losses differ from other types of bereavement, mediating factors, and the

trajectory of grief. The review will also consider complicated grief and trauma, the psychosocial impact of losing a child and individual differences associated with gender, culture and religious ideology. Before proceeding, it is important to note that the terms grief and mourning are used interchangeably in the literature and refer to one's personal response to a bereavement or loss.

2.4.1 Grief, Mourning and Loss

Vance et al, (1995) state that the defining features of grief, such as numbness, searching, yearning, disorganisation and depression, are symptomatically similar to a major depressive episode (Buckle & Fleming 2011; Pantke & Slade, 2006). Research by Vance et al, (1995) and Dyregrov & Matheson, (1991) have found that grief typically follows a thirteen month trajectory with peaks in grief, depressive symptoms and emotional distress, being evident between the first and eighth month. Vance et al, (1995) and Dyregrov & Matheson, (1991) also found that, after twenty-six months, symptoms of grief are unlikely to change. Studies on the long term impact of parental bereavement suggest that, although grief diminishes, the pain of losing a child is enduring and may not ever be fully resolved (Harper et al, 2011; Wing et al, 2001; Dyregrov & Matthiesen, 1991). Harper et al, (2011) support this idea, noting that 13, 35 and 62 year follow ups of bereaved parent have revealed ongoing functional impairment, high rates of depression, health problems and ongoing symptoms of grief. Boyle et al, (1996) and Defraun (1991) further bolster this argument, suggesting that those who do not develop psychological impairment will still experience intense and enduring sadness associated with the loss their child, and usually report that their lives will never be the same again.

But why does the loss of a child differ from other forms of bereavement? Boyle et al, (1996) believe that parental bereavement disrupts individual's expectations regarding the order, or sequence, their life will follow. O'Leary et al, (2011) are supportive of this idea and go further, stating that the loss of a child creates a noticeable gap in the present, infiltrates the future and spans every major life transition the family are destined to experience. Boyle et al, (1996) and O'Leary et al, (2011) are not alone in their views. Several have suggested that the death of a child is also the death of a hoped for future, a dream of a life the child might have led, the experience of raising that child and the family's representational composition/imagined family unit and family members (Grout & Romanoff, 2010; Laakso & Paunonen-Ilmonen, 2002; Lamb, 2002; Wing et al, 2001). In addition, academics and researchers have also commented on the guilt these parents

experience, stating that they often feel that they were supposed to protect their offspring and have failed to keep them alive (Buckle & Fleming, 2011; Dyregrov, et al 2003; Powell, 1995; Vance et al, 1995; Laakso & Paunonen-Ilmonen, 2002).

2.4.2 Mediating Factors

Research has established that one's adjustment to the loss of a child is not predetermined and that there are a number of factors that can mediate long term outcomes (Defraun, 1991; Dyregrov & Matthiesen, 1991; Harper et al, 2011; O'Leary et al, 2011). For instance, research by Harper et al, (2011) identified three major coping strategies, these being active, (i.e., seeking professional help, social support and information), soothing (i.e., utilising distraction and relaxation) and preoccupation (i.e., maintaining bonds with the deceased by thinking and talking about the loss). However, Harper et al, (2011) also found that outcomes were not dependent on the coping strategy, but the way in which it was implemented. For instance, preoccupation, where continued bonds with the deceased child are maintained by sitting at the graveside or through shrines, are likely to cause distress, whereas linking the child with an object or creating a representation is associated with high levels of comfort. In addition, researchers have highlighted the importance of homeostatic adjustment (i.e., an organisational and functional adjustment to transition that restores family stability) and family reorganisation (O'Leary et al, 2006; O'Leary et al, 2011; Patterson & Garwick, 1994; Carr, 2010; Valeriote & Fine, 1987). Valeriote & Fine, (1987) and O'Leary et al, (2011) states that failure to enter and complete the stages of adjustment leads to dysfunction, hinders the development of the deceased baby's personhood and prevents recognition of the family's loss.

Research has also identified risk factors, which can heighten the grief reaction (Defraun, 1991; Dyregrov & Matthiesen, 1987; O'Leary et al, 2011; Wijngaards-de Meij et al, 2005). Literature suggests that the greatest risk factor for long term negative outcomes is the manner in which the child died (Defraun, 1991; Dyregrov & Matthiesen, 1987; Laakso & Paunonen-Ilmonen, 2002; O'Leary et al, 2011; Wijngaards-de Meij et al, 2005). Dyregrov & Matthiesen, (1987) found that unanticipated death and deaths preceded by a long illness both correlated with negative outcomes. Further to this, Wijngaards-de Meij et al, (2005) found that those who experienced a postnatal death were at more risk than those who experienced a Neonatal Death (NND) or Stillbirth (SB). Conversely, the death

of an infant has been found to be more distressing than the death of an older child (Reid, 2007). Reid, (2007) believes this is due to parents of older children having memories of a child that grew, developed and lived, whereas parents of very young infants only have a 'snap shot' of a baby that died. In addition, Dyregrov et al, (2003) and Wijngaards-de Meij et al, (2005) report that the number of surviving children correlates with long term outcomes, with childless couples fairing worse. This could be the difference between losing one's identity as a parent, and maintaining one's identity through continued parenting of the surviving and subsequent children (Toller, 2008)

2.4.3 Complicated Grief and Trauma

Research on post traumatic stress has established that those who experience a stressful life event are more susceptible to psychological disturbance (Boyle et al, 1996; Dyregrov et al, 2003; Li et al, 2005). Due to this, and the fact that the death of a child is classified as the most distressing bereavement and life event one can expect to experience, it is sensible to assume that this could, in some circumstances, result in mental health difficulties. However, it is also important to note that stressful life events do not invariably lead to mental health difficulties, and that individual difference and contextual factors also have a role to play (Boyle et al, 1996).

The literature shows that 20-40% of bereaved parents develop social, relational, psychological and physical health difficulties such as marital breakdown and divorce, depression and anxiety and physical illness (Boyle et al, 1996; Defraun, 1991; Dyregrov & Dyregrov, 1999; Lamb, 2002; Li et al, 2005; Pantke & Slade, 2006; Vance et al, 1995; Wijngaards-de Meiji et al, 2005). Defraun, (1991) has also reported that the suicide rate amongst bereaved parents is higher than would be expected when compared to the general population. In addition, several research articles report that 25-50% of bereaved parents will experience pathological grief, post traumatic stress, anxiety and depression (Boyle et al, 1996; Dyregrov et al, 2003; Li et al, 2005; Vance et al, 1996; Wijngaards-de Meij et al, 2005). Again, when compared with the general population, these figures are higher than would be expected. Finally, research by Li et al, (2005) found that, in the five years following their child's death, bereaved parents are at significantly more risk of being hospitalised for a psychiatric illness. Li et al, (2005) also found that, given the rate within the general population, the loss of a child is over-represented amongst psychiatric patients. However, caution should be exercised when interpreting these

results. As mentioned in section 2.2.6 Culture, Ethnicity and Socio-Economic Status, mothers who experience mental health difficulties are at greater risk of losing a child. Therefore, it is possible that the mental health difficulties experienced by the bereaved existed prior to the loss.

2.4.4 Psychosocial Impact

Laakso & Paunonen-Ilmonen, (2002) believe that coping is a process of interaction and negotiation between the individual and his or her social environment. As a result, the ability to cope transcends the individual and will also depend on the resources possessed by the wider social network. Boyle et al, (1996) describe the death of an infant as “the loss of a unique bond of physical, psychological and social significance” (p. 1274). The fact that this is also a relatively rare event serves to heighten this experience by creating circumstantial isolation and limited support (Boyle et al, 1996; Lamb, 2002). This fits with the views expressed by Dyregrov et al, (2003) that limited support and isolation increases distress and decreases wellbeing in bereaved parents. However, Dyregrov et al, (2003) question whether isolation causes the distress seen in bereaved parents, or whether bereaved parents self isolate in response to their distress. Literature on this conundrum is supportive of both perspectives, with Laakso & Paunonen-Ilmonen, (2002) reporting that social networks can abandon grieving families, and Dyregrov et al, (2003) reporting that the bereaved parents may withdraw from a social network which cannot meet their emotional needs. Dyregrov et al, (2003) also report that social estrangement is typical in the presence of an experience differential (i.e. the person who experienced the trauma has very different thoughts and feelings to those who did not).

Buckle and Fleming, (2011) note that secondary losses, experienced in the psychosocial domain, can be perceived as rejection, isolation and a lack of societal support, which often results in the re-evaluation of social relationships. Buckle and Fleming, (2011) also report that bereaved parents feel less tolerant and patient in their social lives, especially when individuals complain or become fixated on trivial matters. However, this is not just an example of an experience differential. Buckle & Fleming, (2011), Hasting, (2000) and Troller, (2008) all cite instances on the reconstruction of identity, and how parental bereavement can change people’s ideas and values and, along with it, the relational positions they previously occupied. This fits with Klass, (1988) cited by Hasting (2000)

who regarded parental bereavement as an enduring change to the self. For instance, Buckle & Fleming, (2011) have identified a number of identity changes experienced by bereaved parents, including the reordering of priorities, approach to life and living in the present, loss of confidence, conforming less to social pressure and things that once held importance losing meaning. Changes to identity impacts one's 'way of being' and how they relate and interact with the world and those around them (Toller et al, 2008). Ultimately this has the potential to deepen already existing social relationships or destroy the commonality on which they may have once been based.

2.4.5 Individual Differences

Grief and grieving is largely determined by family, culture, personality, lifestyle, relationships, socialisation and societal expectation (Laakso & Paunonen-Ilmonen, 2002). Although much research has been conducted investigating these facets, the most common appear to be gender, culture and religion (Buckle & Fleming, 2011; Defraun, 1991; Dyregrov & Matthiesen, 1991; Dyregrov et al, 2003; & Paunonen-Ilmonen, 2002; Li et al, 2005; Vance, 1995; Wing, 2001; Wijngaards-de Meij et al, 2005).

2.4.5.1 Gender

Significant research has established that men and women experience parental bereavement differently (Buckle & Fleming, 2011; Defraun, 1991; Dyregrov & Matthiesen, 1991; Dyregrov & Dyregrov, 1999; Dyregrov et al, 2003; Lamb, 2002; Laakso & Paunonen-Ilmonen, 2002; Li et al, 2005; Pantke & Slade, 2006; Vance, 1995; Wing, 2001; Wijngaards-de Meij et al, 2005). Wing, (2001) has shown that bereaved mothers are likely to experience an intense and enduring grieving process, usually characterised by guilt. However, the research goes further with Vance et al, (1995) suggesting that mothers of the deceased are more likely to experience pathological grief, and Li et al, (2005) establishing that bereaved mothers are more likely to experience hospitalisation for a psychiatric disorder. In addition, Dyregrov et al, (2003) have established that women are more likely to experience psychosocial distress after the death of a child and turn inwardly toward their families for support.

Literature proposes that fathers struggle to express their emotions, turn outward toward their professional lives and experience anger toward inadequate psychosocial supports (Defraun, 2003; Dyregrov, 1991; Vance et al, 1995). Having said this, Dyregrov

& Matthiesen, (1991) found consistency amongst couples, with people tending to report similar distress levels as their partners. Researchers have suggested that gender differences are a result of evolution, with close mother-infant bonds being necessary for the offspring's continued survival (Wing, 2001; Wijngaards-de Meij et al, 2005). Feminist psychology, however, is critical of this suggestion, arguing that attachment and gender are socially constructed and a function of socialisation (Birns, 1999; Franzblau, 1999). It should also be highlighted that there is limited research on paternal grief and, as a result, none of the theories have robust empirical foundations (Vance et al, 1995).

2.4.5.2 Religion

Wijngaards-de Meij et al, (2005) state that religion is also an aspect of individual difference, with some experiencing religious support and others experiencing spiritual struggle. Wijngaards-de Meij et al, (2005) found that parental bereavement, like other forms of loss, can result in feelings of disenfranchisement and disillusionment. Research by Buckle & Fleming, (2011) supports this assertion, with parents reporting religious betrayal (e.g. punishment, despite faith and commitment to religious practice), defiance (e.g. unwilling to worship a deity that would take a child's life) or changed belief systems (e.g. the death of the child is proof that deity's do not exist, as they would not let this happen). As a result, Wijngaards-de Meij et al, (2005) believe that feeling betrayed, victimised or disillusioned by one's faith has the potential to cause negative outcomes. Wijngaards-de Meij et al, (2005) also believe that those who lack a well defined belief system fair better, due to the fact they attribute their losses to the law of averages, the 'it's got to happen to someone why not me' philosophy. However, Buckle & Fleming, (2011) note that for others the death of a child has the potential to instigate a religious belief or strengthen one that already exists.

2.4.5.3 Culture

Cultural expectations regarding the probability of losing a child, and anticipation of an infant's death, are also thought to impact how the parental bereavement is experienced. For instance, Boyle et al, (1996) state that medical advances in the developed world have reduced society's expectation that babies can, and do, die. See Table 2. For the declining rate of infant mortality between 1900 and 1990.

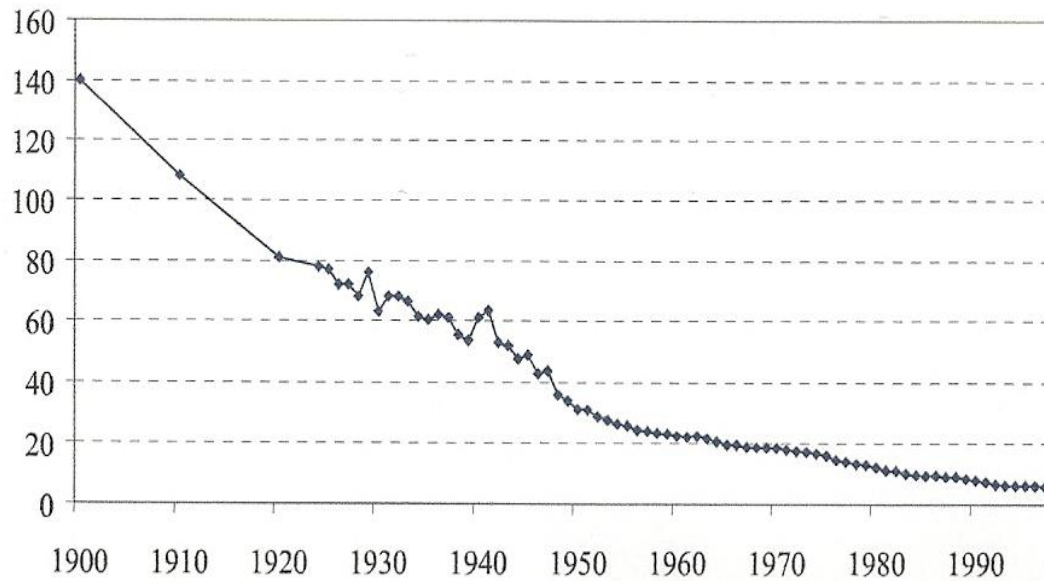


Figure 2. Infant Mortality Rates per 1000 Birth: 1900 - 2000 (Hicks & Allen, 1999)

2.5 Parenting after Loss

The existence of surviving and subsequent children means that those who experience a parental bereavement will be required to engage in the dual task of grieving and parenting. (Buckle & Fleming, 2011; Lamb, 2009). In addition, given the enduring nature of parental bereavement, surviving and subsequent children spend a large proportion of their childhood being parented in the presence of loss, and by mothers and fathers who have experienced a significant and stressful life event (Buckle & Fleming, 2011; Lamb, 2009). Valeriotte & Fine, (1987) state that changes to pre-existing parenting styles, caused by parental bereavement, can have secondary effects for children and alter what was once a well-defined parent-child interaction. Pantke & Slade, (2006) go further, stating that parenting styles, patterns and behaviours are related to the development of depression, anxiety, low self-esteem and interpersonal difficulties in later life. In fact, several researchers have established that the loss of a child can have consequences for surviving and subsequent children, increasing their risk of developing mental health difficulties (Ainslies & Solyom, 1986; Warland et al, 2011a; Warland et al, 2011b; Hutton & Bradley, 1995).

Despite these findings, Warland et al, (2011a) and Warland et al, (2011b) state that the process of parenting children after loss, and the effects of said loss on parenting

behaviours, are not completely understood or well documented (DiBartolo & Helt, 2007; Lamb, 2002; Warland et al, 2011a; Warland et al, 2011b). As a result, the review of the literature is compelled to focus on the theoretical ramifications of parenting through loss. This will include theories on replacement child syndrome, vulnerable child syndrome, the parenting paradox, positive parental impacts, associated with losing a child and intervention. The review will finish by providing a summary of this section.

2.5.1 Replacement Child Syndrome

The term 'replacement child syndrome' was first coined by Cain & Cain, (1964) and refers to a parental attempt to avoid painful emotions by consciously or unconsciously positioning a living child into the space left by the dead child (Ainslie & Solyom, 1986; Grout & Romanoff, 2010; Heller & Zeanah, 1999; Lamb, 2009; Powell, 1995; Poznanski, 1972; Reid, 2007). Originally, the term 'replacement child' only applied to children conceived after a parental bereavement (Poznanski, 1972). However, over the years it has been applied more flexibly and is now used by the literature when referring to surviving and subsequent children who have been affected by this phenomenon (Blechar, 1992; Powell, 1995). Much of the literature on this topic has been devoted to subsequent pregnancy (Defraun, 1991; Dyregrov & Matthiesen, 1987; Grout & Romanoff, 2010; Heller & Zeanah, 1999; Lamb, 2009; O'Leary et al, 2011; Pantke & Slade, 2006; Reid, 2007; Wijngaards-de Meij et al, 2005). This is largely due to the attachment issues and parental distress which is seen to arise alongside conception, prenatal development and the birth of subsequent children. As a result, this section has been divided into two parts, 2.5.1.1 Replacement Child Syndrome and Pregnancy and 2.5.1.2 Replacement Child Syndrome and Parenting.

2.5.1.1 Replacement Child Syndrome and Pregnancy

Pantke & Slade, (2006) report that, within six months of a parental bereavement, 76% of parents will have made the decision to have more children, with at least 24% having already conceived. Lamb, (2009) supports these figures in a twelve month follow up, which showed that 60% of parents had conceived another child within the first year of their bereavement. Bowlby, (1967) cited by Pantke & Slade, (2006) and Reid, (2007) would have attributed these findings to a need to 'recover the lost object' and alleviate the uncomfortable emotions associated with grief. Indeed, Pantke & Slade, (2006), Powell, (1995) and Wijngaards-de Meij et al, (2005) all report lower levels of grief in those who manage to conceive within the first year of their loss. Lamb, (2009) links

these findings to the expectation that the birth of a new child will bring an end to the emotional pain associated with mourning. Dregrov & Matthiesen, (1987), Lamb, (2009) and Reid (2007) suggest the opposite is true and that, in the long term, early conception is related to depression, anxiety and morbid rejections toward the child, either in late pregnancy or shortly after the birth. Pantke & Slade, (2006) note the gender differences in this process, with mothers usually feeling more anxious to conceive than fathers. Unlike fathers, however, mothers tend not to benefit from the arrival of a new child and report persistent anxiety in relation to their child's wellbeing (Pantke & Slade, 2006). In fact Lamb, (2009) reports that women are so affected they often resort to excessively benchmarking (i.e., comparing to a defined standard or reference point and measuring the rate of progress) their pregnancy and the development of their child, as a way of reassuring themselves at regular intervals and containing their anxiety.

Boyle et al, (1996) and Reid, (2007) suggest that the arrival of a new child brings complex emotional and cognitive experiences (e.g. the realisation that the birth of a new child does not negate their sense of loss and feeling guilt or disloyalty when parenting the new baby). Heller & Zeanah, (1999) and Pantke & Slade, (2006) believe that this is why attachment difficulties often arise in bereaved parents and their subsequent children. As a result, Grout & Romanoff, (2010) suggest that families should be supported in adjusting to the loss and completing the grieving process before going on to have more children. However, given the uncertain nature of grief and the time limited aspects of reproduction, this is not always a practical suggestion. It should also be noted that not all subsequent pregnancies will be experienced in this way, and some parents describe a salutary effect (Dyregrov & Matthiesen, 1987; Grout & Romanoff, 2010). In addition, Dyregrov & Matthiesen, (1987) report negative long term outcomes for parents who do not go on to have subsequent children, especially those who lost an 'only child'.

2.5.1.2 Replacement Child Syndrome and Parenting

Valeriotte & Fine, (1987) cite replacement child syndrome as the most frequent cause of unresolved grief and dysfunction in families, and consider it a barrier to adjustment. Lamb, (2009), Powell, (1995) and Reid, (2007) bolster this argument, suggesting that grief remains unprocessed in the presence of a replacement child. In essence, the birth of a replacement child signifies the parent's inability to tolerate the emotional pain associated with mourning and, as a result, they try and find ways to alleviate these

uncomfortable emotions rather than completing the grieving process (Patterson & Garwick, 1994; Carr, 2010; Oglethorpe, 1989). Lamb, (2009), Powell, (1995) and Reid, (2007) also state that this unresolved grief prompts parenting behaviours, styles and patterns, which are suggestive of replacement child syndrome. For instance, the literature describes the parenting of a replacement child as overprotective and avoidant, with parents being hypervigilant and quick to respond to perceived threats, being anxious regarding their child's continued survival and unable to emotionally invest (Heller & Zeanah, 1999; Lamb, 2009; Powell, 1995). The literature also suggests that these parents often experience difficulties separating or entrusting care to others and, as a result, can hinder individuation (Heller & Zeanah, 1999; Lamb, 2009; Pantke & Slade, 2006; Powell, 1995). Reid, (2007) believes that this results in the child becoming socialised into a role where they are responsible for relieving the parent's anxiety, and avoid separation and the emotions it elicits in the caregiver.

The literature shows that parental anxiety and limited emotional investment has consequences for the attachment relationship, with 45% of this group developing an insecure or disorganised attachment style (Heller & Zeanah, 1999; O'Leary, 2004; O'Leary, 2006; Pantke & Slade, 2006; Reid, 2007; Warland et al, 2011b). Reid, (2007), O'Leary, (2004) and O'Leary, (2006) attribute these difficulties to ongoing grief and the physical, psychological and social implications of losing a child. Lamb, (2009) however, notes that many bereaved parents discuss themes, usually associated with replacement child syndrome and, as a result, it is difficult to establish whether this is a normal response to parental bereavement or a maladaptive response to grief. In addition, retrospective research by Warland et al, (2011b) has found that replacement children provide positive accounts of their childhood and report feeling 'very wanted'.

Pantke & Slade, (2006) report that surviving and subsequent children experience the parenting they receive differently, with subsequent children seeing their parents as more controlling than surviving children. This fits with Blechar, (1992) and Powell, (1995) who suggest that parents struggle to modify their pre-existing approach to parenting with the surviving children but are able to establish a new approach with the subsequent children. However, it is also feasible that bereaved parents feel the need to redeem themselves. If this were the case, parents may feel more invested in the production and maintenance of subsequent children which would confirm that they are

able to successfully take a nurturing role and keep their children alive. Kreuger, (2005) supports this notion and believes this is why bereaved parents are so heavily invested in subsequent children.

2.5.2 Vulnerable Child Syndrome

The concept of 'vulnerable child syndrome' was first developed by Green & Solnit (1964). Vulnerable child syndrome occurs when parents, knowingly or unknowingly, become preoccupied with comparing the living child and the deceased child and finding actual or imagined resemblances and parallels (Green & Solnit, 1964). As a result of the resemblance and parallels, parents assume that the living child is also going to die (Blechar, 1992; Davis et al, 1989; Green & Solnit, 1964; Warland et al, 2011a; Pantke & Slade, 2006). The parents of vulnerable children are often described, in the literature, as overprotective and overly anxious about their child's physical health (Blechar, 1992; Green & Solnit, 1964; Warland et al, 2011a; Pantke & Slade, 2006). As a result, parents are reluctant to leave the child in case they become ill (Green & Solnit, 1964). Green & Solnit, (1964) also note increased checking of infants, especially during the night.

Another characteristic of vulnerable child syndrome is infantilization, with parents being overly attentive, overly indulgent and determined to maintain positive emotional states (Green & Solnit, 1964). As a consequence, these parents find it difficult to set limits and provide discipline (Green & Solnit, 1964). Finally, evidence suggests that vulnerable child syndrome is associated with developmental delay (Blechar, 1992; Green & Solnit, 1964). Blechar, (1992) and Green & Solnit, (1964) note that children who are expected to die prematurely are prevented from participating in activities that would facilitate their development. This is because such activities are perceived as being out of the child's competencies or unsuitable, given their fragility. Blechar, (1992) and Green & Solnit, (1964) believe that this inhibits development and is directly responsible for developmental disturbances. Vulnerable child syndrome has been linked to mental health difficulties in adulthood, including depression, anxiety and anorexia nervosa (Pantke & Slade, 2006; Warland et al, 2011a)

2.5.3 The Parenting Paradox

A recent article, by Warland et al, (2011a) considers the paradoxical parenting patterns that emerge after a parental bereavement. Parents often feel grateful for their surviving

and subsequent children, and want to protect them, but also fear that they may experience the loss of another child and establish an emotional distance in order to protect themselves (Warland et al, 2011a). In terms of their aims, these two parenting styles are in direct opposition of one another, one being a feared loss and attempts to prevent it, and the other being the acceptance of possible losses, and self preservation through emotional withdrawal (Warland et al, 2011a). Warland et al, (2011a) suggest that these parenting styles are connected to control and the prevention of a possible loss. For instance, Warland et al, (2011a) found that bereaved parents are particularly concerned with doing things properly, and exert control over the environment by refusing to leave their children in the care of others and by removing anything that could pose a risk (e.g. removing carpets that could attract dust mites and cause illness or even death). Parents could not tolerate the lost sense of control they experienced during normal childhood events (e.g. Illness or injury). In addition Warland et al, (2011a) noted reduced confidence, with parents reporting that they no longer trusted themselves and found it difficult to make decisions. Parents also reported that, in order to ensure wellbeing, they would constantly check on their offspring, even throughout the night. However, rather than subsiding overtime, Warland et al (2011a) found that these difficulties had the potential to remain stable in the long term.

2.5.4 Positive

Buckle & Fleming, (2011) report that bereaved parents feel more able to live in the present, have a greater appreciation for their surviving and subsequent children, and savour every moment of the parental role. In addition, Pantke & Slade, (2006) report that 58% of bereaved parents believe their relationship with their surviving and subsequent children has improved as a direct result of the loss they experienced. Finally, Handsley, (2001) reported that, after surviving what is considered to be the most difficult bereavement and life event, parents and families often feel increased confidence (i.e. self-confidence and self-efficacy that in the face of a catastrophic event they will be able to survive). This seems to suggest growth in which resilience is realised and appreciated.

2.5.5 Intervention

Research by Reids, (2007) has established that bereaved parents experience problems other than grief, such as difficulties in their continued role as parents. Despite this, no

guidance exists on what would be clinically helpful for parents experiencing replacement child syndrome, vulnerable child syndrome or difficulties around paradoxical parenting.

Intervention mainly focuses on grief and adjustment and advocates healing practices, such as the collection of mementos (Caoitulo, 2005; Gold, 2007; Price, 2007). Caoitulo, (2005), Gold, (2007) and Price, (2007) do provide literature on individual and group psychotherapy but state that this is aimed at reducing symptoms of grief. These approaches do not directly address parenting, which might be the main concern, and focus on the original cause of the dysfunction, parental bereavement or the resulting relational difficulties with subsequent and surviving children. As a result, the internal world of the bereaved parent is negated and the mechanisms, which drive particular approaches to parenting and reciprocal roles, are circumnavigated. Therefore, it is felt that the clinical field would benefit from a better understanding of the bereaved parent's internal world.

2.5.6 Section Summary: Parenting after Loss

A review of the literature suggests that parental bereavement can lead to parenting behaviour that is characterised by control and over-protection (Buckle & Fleming, 2011). The literature also suggests that the labels for observed phenomenon (i.e., replacement child syndrome, vulnerable child syndrome and the parenting paradox) have attempted to provide some hypotheses regarding the development of this type of parenting and the consequences for individual and family functioning. However, it seems that these hypotheses require further development and elaboration as the cognitive processes that underlie these phenomena have been left largely unexplored.

2.6 Aims of the Research

The research aimed to explore mothers' experiences of parenting after the loss of a child. The rationale for this was summarised in Section 2.5 and relates to limited research on parental bereavement, continued parenting and the mechanisms which drive it. More specifically, however, the research aimed to explore mothers' experiences of parenting after a SIDS event. Limited evidence presented in Section 2.3.5 suggests that, due to the sudden, unexpected and unexplained nature of the loss, SIDS parents may be more likely to experience a greater degree of emotional distress and adjustment difficulties than

other perinatally bereaved populations (Boyle et al, 1996; Bluglass, 1981; Dyregrov & Matthiesen, 1987; Vance et al, 1995; Williams, 1990). It could therefore be hypothesised that SIDS parents may be likely to experience the parenting phenomenon discussed in Section 2.5. Despite this, however, SIDS remains an under researched area and it is not unusual for SIDS populations to be merged with other types of perinatal death, such as stillbirth, neonatal death, acquired disease and death determined at birth. Therefore, it seemed sensible to consider a parenting group who may be likely to be affected by parenting phenomenon, associated with the death of a child, and for whom the research would be clinically relevant.

2.6.1 Research Questions

With the above in mind, four research questions were developed to explore mothers' experiences of parenting and capture their transition, from being a parent unaffected by SIDS to a parent affected by SIDS.

1. How do mothers affected by SIDS experience themselves as parents before, after and during their loss?
2. How do mothers affected by SIDS experience third party opinions, in regards to their parenting before, after and during their loss?
3. What are mothers', affected by SIDS, experiences of parenting their surviving children before, after and during their loss?
4. What are mothers', affected by SIDS, experiences of parenting their subsequent children?

3. Methodology

3.1 Overview

The study aimed to capture, understand and explore mothers' experiences of transitioning from a parent unaffected by SIDS to a parent affected by SIDS. The study was particularly interested in mothers' experiences of themselves as parents, their experiences of how others view them as parents, their experiences of parenting surviving and subsequent children and the perceived impact this may or may not have had on their experiences of parenting. In order to meet these research aims a qualitative methodology, Interpretive Phenomenological Analysis (IPA), was employed.

3.2 Qualitative Research

SIDS and mothers' experiences of parenting is a relatively neglected area of research (Warland et al, 2010a; Warland et al, 2010b). Therefore, a research methodology that focused on exploration of the topic, and 'gave a voice' to the research population, was considered appropriate (Smith & Osborne, 2008; Smith et al 2009). This is particularly important when considering complex phenomena, or mapping unknown psychological knowledge, as it allows for the generation of further hypothesis and the cultivation of a path that leads to possible explanation. (Smith et al, 2009; Sofaer, 1999).

3.3 Interpretative Phenomenological Analysis

IPA has its origins in existential phenomenology and is primarily concerned with the exploration of a persons' subjective lived experience, how they make sense of particular events and the relatedness and connectedness to aspects of their lives (Smith & Osborne, 2008; Smith et al 2009). However, as it is impossible to gain direct access to a person's internal world, the methodology is reliant on hermeneutics, also known as interpretation by the researcher (Smith & Osborne, 2008; Smith et al, 2009). In reality, this hermeneutic element is doubled by the fact that, as the participant is attempting to make sense of their lived experience, the researcher is attempting to makes sense of the participant's sense making. As a result, IPA is a process that can be either bolstered or undermined by the researcher's reflexivity. For example, for a researcher to interpret the participant's internal reality they must suspend their judgements, opinions or views that could influence the process, bias any derived understandings and provide information that is more reflective of the researcher's internal world. It is therefore important for the researcher to suspend critical judgement and consider themselves an interpretational conduit (Smith & Osborne, 2008; Smith et al, 2009).

The rationale for selecting IPA over other qualitative methodological approaches are as follows:

- IPA methodology is concerned with capturing an individual's lived experiences and was therefore considered the most suitable methodology for exploring SIDS and mothers' experiences of parenting.
- IPA methodology aims to consider individual subjective experience, or insider perspectives, rather than making objective claims regarding a large group of people. As a result, the methodology was well placed to say something specific about a small group of people and avoid generalisations usually seen in large scale quantitative methodology (Smith & Osborne, 2008; Smith et al 2009).
- IPA methodology is aimed at collecting phenomenological data and allowing themes to emerge in a process that is unrestrained by the researcher's expectations. Therefore, IPA is particularly well suited to under-researched topics, as unanticipated themes have the freedom to emerge. In essence the researcher does not have to know what is unknown in order to research it (Smith & Osborne, 2008).
- IPA methodology is designed to explore a person's lived experience, understand their relationship with these events and attempt to provide an accurate account or interpretation of the insider perspective (Smith & Osborne, 2008; Smith et al, 2009). Other methodological approaches such as discourse analysis (i.e., considering individuals as agents of discourse and focusing on the role language plays in constructing a social reality) and grounded theory (i.e. attempting to provide theoretical explanation of psychological phenomenon in social process) are concerned with other aspects of language, social processes and social constructions (Stark & Brown Trinidad, 2007).
- Despite being predominately concerned with subjective experience and meaning, IPA is also able to reveal shared aspects of experience across a group (Clarke, 2009).

3.4 Participants

IPA requires that the sample be a defined group that is able to offer insight into the experience and/or phenomena under investigation (Smith & Osborne, 2008; Smith et al, 2009). Therefore, sample homogeneity and definition is required in order to ensure the research question is significant and meaningful and able to elicit participants' perceptions, understanding and experiences (Smith & Osborne, 2008). Homogenous samples allow the researcher to identify theoretical variability by examining the convergence and divergence that exists within the group (Smith & Osborne, 2008). In line with this, the current study adopted a purposive sampling strategy, developed inclusion and exclusion criteria and aimed to target those for whom the research question would hold the most significance. Pre interview measures were also incorporated as a way of ensuring that the phenomenon under investigation was not compromised and to add another level of understanding to any instances of extreme convergence and/or divergence between participants. This will be discussed in more detail in Section 3.4 Data Collection, 3.4.1 Pre Interview Measures

3.4.1 Inclusion Criteria

In order to ensure homogeneity and appropriate convergence and divergence within the sample, participants were required to be mothers affected by SIDS. Participants were also required to have at least one surviving child and one subsequent child. The current study focused on mothers, rather than parents, as mothers are more often seen in the primary care giver role than fathers. It was also felt that primary care givers would be better placed to provide a well elaborated experience of parenting. In addition, the role of a mother and the role of a father have different societal and cultural implications and connotations. For example, mothers are often cast in the role of protectors and nurturers of very young children who are dependent on another for all their care needs (Pantke & Slade, 2006). Lastly, research has also established that men and women differ in their experience of parental bereavement. As a result, it was felt that mothers' and fathers' experiences of parenting may differ, and therefore disrupt the required homogeneity. Therefore, in order to achieve homogeneity, it was decided that gender should be a defining factor in the composition of the sample (Buckle & Fleming, 2011; Defraun, 1991; Dyregrov & Matthiesen, 1991; Dyregrov & Dyregrov, 1999; Dyregrov et al, 2003; Lamb, 2002; Laakso & Paunonen-Ilmonen, 2002; Li et al, 2005; Pantke & Slade, 2006; Vance, 1995; Wing, 2001; Wijngaards-de Meij et al, 2005).

The current study also required participants to have at least one surviving child and at least one subsequent child. The rationale for this was based on the aims of the current study, which required participants to provide information regarding the transition they had experienced. For instance, in order to capture, understand and explore mothers' experiences of transitioning from a parent unaffected by SIDS to a parent affected by SIDS, it was important that mothers had an experience of parenting in the absence of SIDS and an experience of parenting in the presence of SIDS. It was also important that mothers could reflect on their experience of parenting a child in the presence of SIDS and that this experience would not be influenced by a relationship established before the SIDS event, as would be expected with the surviving child.

3.4.2 Exclusion Criteria

An exclusion criterion was also developed, which required at least a twenty-six month period between the day of the SIDS bereavement and the day of participation in the study. The methodological reasoning for imposing this exclusion criterion was to ensure that the research was capturing the targeted phenomenon. As previously outlined, the current research aimed to understand and explore mothers' experiences of transitioning from a parent unaffected by SIDS to a parent affected by SIDS and more specifically their experience of themselves as parents, their experience of how others view them as parents, their experience of parenting both surviving and subsequent children and the perceived impact this may or may not have had on their experience of parenting. The research did not aim to capture, understand and explore grief reactions, the grieving process or grief trajectory. As a result, it was considered important to limit the impact of other phenomenon likely in the research population. A twenty-six month period between the day of the SIDS bereavement and the day of participation in the study was drawn from relevant literature which suggests that parental bereavement typically follows a thirteen month trajectory; with peaks in grief, depressive symptoms and emotional distress being experienced between the first and fifth month, a reduction in grief, depressive symptoms and emotional distress being experience during the fifth and thirteenth month and no significant change being witnessed after twenty-six months (Dyregrov & Matthiesen, 1991). It should be noted however that, exclusion criterion transcended purely methodological concerns and was also based on ethical considerations. This however, will be discussed in more detail in Section 3.3 Ethics, 3.3.3 Potential for Distress.

3.4.3 Recruitment

Recruitment was undertaken in collaboration with The Foundation for the Study of Infant Death (FSID), a charity working to increase public awareness, prevent SIDS and promote healthy and preventative parenting practices. The FSID Support and Education Manager and Communications Officer undertook the task of identifying mothers and families who met the inclusion and exclusion criterion and who had given their permission for FSID to contact them in relation to possible research participation. In addition to this, FSID also made efforts to advertise the current research in their newsletters (Appendix 1: Advertisement). After a number of potential participants had been identified, or made contact with FSID expressing their interest, an email was sent out by FSID enquiring whether they were happy to be included in further correspondence and contacted by the researcher regarding possible participation. Attached to the email was an information sheet which outlined the identity of the researcher, summarised the research, provided information on what participation would involve and emphasised the voluntary nature of participation (Appendix 2: Information).

3.4.4 Sample Size

It should be noted that, although SUDI and SIDS is the leading cause of death in infants aged between one and twelve months, it is still a relatively rare event with 0.4 incidences of SIDS per 1000 live births (FSID 2009). In addition, charitable organisations publicising SIDS and promoting awareness were only established within the last 40 years and did not receive patronage or become high profile until the 1980's. In addition, many families involved with FSID, in the aftermath of a SIDS event, do not remain active within the charity's database in the long-term. As a result, recruiting within the set inclusion and exclusion criterion was challenging.

The research aimed to recruit between six and eight participants and, after a nationwide recruitment, a sample size of seven participants was achieved. The rationale for the sample size was taken from literature on IPA research methodology which recommends six as the ideal but advises anywhere between four and ten participants (Smith & Osborne, 2008; Smith et al, 2009). Further guidance was sought from a research paper by Smith, (1990) which discusses purposive sample size in IPA, and the usefulness of personal construct theory, when considering participant numbers. Smith, (1990) and Fransella et al, (2004) both discuss the power of three and how it facilitates the identification of convergence and divergence between themes and elements (e.g.

considering the similarity between two and how they differ from the third). As a result, Smith, (1990) recommends that an IPA should not incorporate less than three participants, unless a case study is being considered, as this will limit the identification of thematic convergence and divergence. In contrast, an excessive sample size of more than fifteen can be overwhelming, increase the complexity of the analysis, leading to researcher fatigue, and decrease the chances of producing a penetrating analysis (Smith, 1990; Smith et al, 2004). Despite this, however, IPA is not prescriptive and ultimately the sample size will depend on the aims of the research, the richness of the data, research constraints and analysts' tolerance for the vast data generation associated with IPA (Smith et al, 2004).

3.4.5 Sample Demographic

Participants consisted of 7 mothers who had experienced the loss of an infant through SIDS. Ages ranged from 22 years-of-age to 46 years-of-age. Further demographic information was collected by the researcher in order to situate the data within its original context. Please see Table 3 Sample Demographic.

Table 3. Demographic Profile of Participants

*Participants	Age	Ethnicity	Marital Status	Number Surviving children	Number of Subsequent Children	Time Since Bereavement
1. Gale	33	White/British	Married	1	2	09 years
2. Corrine	22	White/British	Married	1	1	06 years
3. Bonnie	40	White/British	Married	1	1	12 years
4. Lydia	46	White/British	Married	2	1	14 years
5. Anita	38	White/British	Married	2	1	04 years
6. Nicole	33	White/British	Married	1	1	03 years
7. June	35	White/British	Married	1	1	03 years

* All identifying information has been changed in order to maintain anonymity

3.5 Ethics

Ethical approval was sought and granted by the Psychology Ethics Committee, under the delegated authority of the University of Hertfordshire's Research and Ethics Committee Board (Appendix 3: Ethics Approval Certificate). In addition to this, the National Research and Ethics Committee (NRES) were contacted in order to confirm that no additional ethical approval would be required (Appendix 4: NRES Correspondence). As a result, the research complies with the British Psychological Society's (BPS) Code of Human Research Ethics (BPS, 2010).

3.5.1 Informed Consent

In order to obtain informed consent, the researcher followed a stepped approach to recruitment. Participants were given an overview of the research aims, methodology and data collection, made aware of their role and rights as participants and informed of the researcher's responsibilities at every stage of the recruitment process.

Initially, information sheets were sent out via email to the identified interested parties (Appendix 2: Information Sheet). Those who expressed a continuing interest, after reading the information sheet, were then offered the opportunity to speak with the researcher directly regarding potential participation. If, following these telephone conversations, potential candidates decided they would like to participate, arrangements were made for a meeting. On meeting potential candidates the researcher spent 15 minutes reading through the information sheet with the participants, elaborating on key information and providing more detailed answers to any questions raised. The information sheets provided to participants and potential candidates explained who the researcher was, the organisations they were involved with (i.e., University of Hertfordshire) and the study aims and the rationale for conducting research of this nature. Information was also provided regarding what would be expected of participants if they agreed to participate, session protocols, including the completion of two questionnaires, and participation in an interview, the types of questions that would be asked and time required for participation.

Participants were also informed, verbally and in writing, that their decision to participate was entirely voluntary, that they were free to withdraw from the study at anytime without explanation and that in this event no data would be kept by the researcher. Participants were provided with information on data storage, including where their data would be kept, how long it would be kept for and assured that no identifiable information would be kept on record or used in the write up. The researcher acknowledged the potentially emotive nature of the subject matter and made potential candidates aware of the possible risks involved in participation. Participants were informed that, after participation, the researcher would be responsible for providing a full and thorough debrief, regarding the research, and that information outlining further support services would also be provided. Lastly, participants were informed that, once the research was complete, they would be provided with the opportunity to meet with

the researcher and discuss the results. After this process was complete, if candidates still wanted to participate in the research they were asked to sign a consent form (Appendix 5: Consent Form).

In addition to this, before commencement of the interview, participants were provided with information regarding the IPA interview and IPA interview Questions (Appendix 6: IPA Interview Information Sheet). This was done in order to meet the BPS's Code of Human Research Ethics, which stipulates that audio recordings, which capture sensitive data in methodologies that have the potential to increase the risk of exposing the participants' identity, requires separate consent and should provide separate information on how this data is collected, used and disposed of.

3.5.2 Confidentiality

Qualitative methodologies have the potential to elicit rich and personal data. As a result, it is of paramount importance to consider implications for confidentiality and methods under which researchers are best able to protect the identities of their participants (Silverstein et al, 2006). Due to the sensitive nature of the subject matter contained within the current study, these issues were of particular importance. As a result, participants were informed, from the offset, that all information would be private and confidential and that their anonymity would be maintained and protected throughout the duration of the research project and in any future publications. In order to achieve this, protocols for data collection, data handling and communication were devised. Firstly, all interviews were conducted at locations that could assure participants' privacy and confidentiality. No identifiable information was collected by the researcher and, for the purposes of data identification, a coded version of the participants' initials was amalgamated with the date of participation. Before conducting the interview session participants were provided with an IPA interview information sheet that assured them that the researcher did not know anything about them, or their histories (Appendix 6: IPA Interview Intervention). After collection, hard copies of demographic information was securely stored in a locked filing cabinet at the researcher's home address and digital copies were password protected, located on one computer securely stored at the researcher's home address. On the day of collection, audio recordings were uploaded onto the researcher's computer, password protected and deleted from the dictation device. Encrypted copies of audio recordings were sent to a transcribing service via a

secure and password protected data uploading site. In addition to this, the transcribing service recruited did not receive any identifiable information and were requested to sign a non-disclosure and confidentiality agreement (Appendix 7: Signed Copy of the Non-Disclosure and Confidentiality Agreement). Once complete, the transcribing service forwarded the transcripts via the secure and password protected data uploading site and destroyed their copy of the audio recording. On receiving the transcripts the researcher removed any information that had the potential to expose the participant's identity, password protected the documents, and securely stored the digital version on a computer located at the researcher's home address. Only one hard copy of each transcript was made for the purposes of analysis and this was destroyed after a digital copy had been developed, securely stored and password protected. Only anonymised transcripts were used by the researcher and research supervisors for peer review and data quality analysis.

In line with the University of Hertfordshire's (UH) good research practice guidelines, participants were informed that the data would be securely held for five years after which time it would be destroyed (UH, 2004). In addition to this, for the purposes of the write up, all participants were provided with aliases. Given that recruitment was done in collaboration with FSID, it is worth noting that the organisation was not provided with any follow up information after referring a potential participant and did not have access to information regarding who did and did not decide to participate.

The limits of confidentiality and the responsibilities of the researcher around issues of safety and welfare were also discussed with participants. This included information from the BPS Code of Ethics, when the code regarding confidentiality is not absolute and when it is appropriate to break confidentiality (BPS, 2009).

3.5.3 Potential for Distress

An ethical concern of the current study was the potential for distress. Ethical principles for conducting research with human participants dictates that it is the responsibility of the researcher to protect the psychological and physical wellbeing of participants and identify, legitimise and minimise the risks involved in participation (BPS, 2010). As a result, the exclusion criteria, designed to ensure homogeneity, was also imposed to limit the risk of participants experiencing psychological distress when disclosing their experience of SIDS. Participants who were likely to still be in the acute stages of grief

were excluded. This was done on the basis of research evidence regarding the typical trajectory of grief following the sudden and unexpected loss of a child (See Section 3.2 Participants, 3.2.2 Exclusion Criteria). However, it is acknowledged that there will be exceptions to the typical trajectory and, although the research suggests that acute grief will have subsided by this time, research also suggests that the distress, pain and grief of losing a child may never be truly resolved (Dyregrov & Matthiesen, 1991). Therefore, it was the aim of the exclusion criteria to access participants when they were more likely to be in a stable state and when depressive symptoms and emotional distress was likely to be lower.

Overall, participants commented that they had enjoyed talking about their experiences of SIDS and parenting because social uncomfortableness, associated with the death of a child, had limited their opportunity to discuss their children in other social settings. However, this did not deter acknowledgment of the difficult emotions that could accompany this subject matter and the potential for it to elicit participant distress. As a result, participants were assured that, if at any point they felt uncomfortable, unhappy or distressed by the interview, they were not obliged to continue and were entitled to withdraw at any time, without explanation, and that this decision would be supported by the researcher. Participants were also advised that, if at any point they felt distressed, they could stop the interview, take a break and continue when and if they felt it was appropriate. Guidance was also sought from Dyregrov's, (2004) research paper on bereaved parents as research participants. In line with this guidance, participants were given the opportunity to discuss their complete story, if they felt it would be helpful, and the researcher listened respectfully and followed the direction of the parent (Dyregrov, 2004). In addition, on completion of the session, participants were thoroughly debriefed regarding the nature of the research (Appendix 8: Debrief). Research participants were also provided with information regarding support services (Appendix 9: Information on Further Supports).

3.6 Data Collection

Data was collected using two pre interview measures and a semi structured interview schedule, developed by the researcher for use in the current study.

3.6.1 Pre Interview Measure

Pre interview measures were carried out in response to the methodological concerns raised in Section 3.2 Participants. As a result, the Impact of Events Scale – Revised (IES-R) by Weiss, (2004) and the Symptom Checklist 90 Revised (SCL-90-R) by Derogatis, (1975) were selected to assess participants’ psychological wellbeing and levels of general distress. The inclusion of the IES and the SCL-90-R was considered to be of particular importance as they allowed the researcher to identify whether the phenomenon under investigation, SIDS and parenting, had been impacted by other phenomenon, such as distress and trauma. This allowed the researcher further opportunity for situating the data within its original context. In addition, the inclusion of the IES and the SCL-90-R also provided valuable information regarding the homogeneity of the group/participants. IPA requires a comparatively homogeneous sample (Smith, 2008). The reasoning for this comes from limited participant numbers and, more importantly, the need for a closely defined group who will be responsive to the research question. Therefore, in order to reduce the limitations of the study and increase the validity of the research findings, it was important that the researcher could reflect and comment on group homogeneity and provide information on the characteristics of the community (e.g. along with demographic information, further community characteristics were assessed, such as distress and psychological wellbeing).

However, it should be noted that the current study made no attempt to exclude on the basis of psychological wellbeing or levels of general distress. The rationale for this came from literature which suggests that grief, associated with the loss of a child, is never fully resolved (Dyregrov & Matthiesen, 1991). Despite this, in line with ethical considerations and the studies potential for distress, measures were taken to exclude those who had lost a child in the previous 26 months and who were therefore more likely to be in the acute stages of grief (See section 3.4, Participants 3.4.2 Exclusion Criteria).

The IES-R and the SCL-90-R were selected for use after a rigorous review of psychometric tools designed to assess psychological wellbeing and general distress. The review took into account whether the measures had been used in previous research on perinatal death with bereaved parents, reliability, validity and standardisation issues and the length and accessibility of the psychometric tools (Appendix 10: Review of Psychometrics, including references; Appendix 11: IES-R; Appendix 12: SCL-90-R).

The IES-R is a 22 item self report questionnaire designed to measure subjective responses to a traumatic event, including intrusive thoughts, emotions and images, avoidance of feelings, situations and ideas and states of hyperarousal. The IES-R also provides an overall score of subjective stress. It can be used in both clinical and non clinical populations exposed to a specific traumatic event and correlates well with other measures of emotional distress, such as the General Health Questionnaire (GHQ). The IES-R is able to significantly discriminate between clinical and non-clinical populations with internal consistency sitting between .79 - .92 and reliability sitting between .93 - 1.00. In addition, the IES-R has been standardised for use with an array of clinical and non clinical populations and can be used for a range of traumatic events in different cultures and with different languages.

The SCL-90-R is a 90 item self report symptom inventory designed to assess psychological symptoms and psychological distress over nine dimensions, including Somatisation, Obsessive-Compulsive, Interpersonal Sensitivity, Depression, Anxiety, Hostility, Phobic Anxiety, Paranoid Ideation and Psychoticism. The measure also incorporates a Global Severity Index, which measures the overall level of distress, Positive Symptom Distress Index, which measures the intensity of symptoms, and Positive Symptom Total Index, which reports on the number of self reported symptoms. The SCL-90-R is revered as having superior sensitivity in comparison to competing scales, has good test-retest reliability and internal reliability ranging from .79 - .90. The measure is appropriate for use in clinical and non clinical populations, has been standardised across gender, age range and culture, and has been translated into 30 different languages.

These measures were incorporated to assess psychological wellbeing and general distress. Therefore, only the overall stress scores on the IES-R and the Global severity Index on the SCL-90-R will be reported in the results section.

3.6.2 Interview Schedule

A semi-structured interview schedule was developed, which focused on mothers' experiences of parenting in their transition from being a parent unaffected by SIDS to a parent affected by SIDS. The interview schedule was developed in line with the aims of the research and attempted to incorporate the personal, relational and practical aspects of parenting, before, after and during a SIDS event.

The interview schedule was designed to encourage participants to feel comfortable in adopting a conversational story telling style, positioning themselves as the expert on their account, and promote a thorough and rich account of their experiences (Smith et al, 2009; Smith & Osborne, 2008). However, the interview schedule was flexible and also attempted to create possibility for exploration of the participants' accounts. As a result, the interview schedule also incorporated prompts aimed at encouraging further elaboration. In addition, the interview questions were developed to be open and expansive and, in keeping with Smith et al, (2008) avoid over-empathic, manipulative, leading or closed questioning. Once the interview schedule had been devised, a copy was sent to the research supervisor for review and approval. As a result of this process the interview schedule underwent several revisions during its development. In addition, FSID were also invited to comment on the interview schedule (Appendix 13: Interview Schedule; Appendix 14: Interview Prompts).

3.6.3 Procedure

Participants were offered the opportunity to hold the session at their home address or at FSID head quarters in central London. Five participants opted to be interviewed at home and two participants opted to meet at FSID. Each participant was assigned a research pack. The research pack contained two research information sheets, two consent forms, one copy of the IES-R, one copy of the SCL-90-R, two interview information sheets, one interview schedule, two debrief sheets, and two information sheets on further supports. On commencement of the session the researcher and the participant reviewed the information sheet and discussed any questions or concerns. Participants were then asked if they still wished to participate and, if so, were requested to sign a consent form. After the consent form had been signed the IES-R and the SCL-90-R were completed. Before beginning the interview, participants were provided with further information such as the type of questions that would be asked, their continuing right to withdraw, and protocols regarding the recording and handling of audio data. After the participant had had the opportunity to have any questions answered, and had provided consent for the recording of the interview, the interview started and lasted approximately 75 minutes. Timing, however, was largely dependent on the length of participants' accounts and varied from person to person. On average, each session lasted approximately 90 minutes. After completion each participant was asked for their opinion on the interview schedule and procedure, thoroughly debriefed and provided further information on

support services. At the end of the session participants were provided with their own copy of the research information sheet, consent form, information sheets on the IPA Interview, debrief sheet and information sheets on further supports.

3.6.4 Post Interview Reflections

Post interview reflections were collected by the researcher. This was done in order to bring critical judgement, biases, emotional reactions and preference for a particular line of enquiring into the researcher's awareness, thus facilitating bracketing (i.e., suspending one's own assumptions) in the later stages of analysis and allowing the origins of interpretations to be considered (Biggerstaff, 2008; Smith et al, 2008).

3.6.5 Pilot

A pilot was conducted to identify any possible inadequacy in the design of the study, the procedure used during data collection, pre interview screening measures and the semi structured interview schedule. The pilot did not appear to reveal any inadequacies and after discussions with the research supervisor it was decided that the procedures, pre interview screening measure and interview schedule would remain unaltered. It was also decided that the data collected during the pilot could be incorporated into the study.

3.7 Data Analysis

Audio recordings were transcribed by a third party transcribing service (Appendix 15: Transcript Excerpt). Data analysis incorporated an idiographic approach to IPA, meaning each interview was analysed separately allowing detection of patterns and maintaining openness to the emergence of new themes. This process was informed by Smith & Osborn (2008) and Smith et al's (2009) work on IPA and methods of analysis. Each of the seven transcripts underwent the same process of analysis. For clarity the adopted procedure has been broken down into individual case analysis and cross-case analysis and the stages of analysis involved in both.

3.7.1 Individual Case Analysis

- **Stage 1: Data Immersion**

In order to develop an interpretative relationship with the transcripts, the analyst engaged in a process of sustained engagement with the text, allowing the person to become the focus of the analysis. This involved reading and re-reading of the text and

incorporated the analyst's personal preference of listening to the audio recording in a simultaneous fashion. Although, Smith & Osborn (2008) and Smith et al (2009) suggest this method is desirable in the initial stages of data immersion, it is worth noting that they also highlight the non-prescriptive nature when analysing IPA interviews and promote the importance of the personal process. A process of bracketing, or suspending one's initial assumptions, ideas and emotions continues throughout analysis as a way of facilitating entry into the participant's world and actively engaging without critical judgement, was also undertaken during the analysis. The initial phase of data immersion is focused on becoming familiar with the structure of the interview and narratives that bind certain sections of the transcript together. This was a particularly important task when analysing the current study, given the chronological nature of the questions and focus on transitioning. In addition, the researcher was considerate of the development of trust and rapport and how this provided richer data as the interview progressed, later contradictions and paradoxes, and funnelled the interview from a generic overview to specific and detailed accounts.

- Stage 2: Process of Exploration

The most labour intensive aspect of IPA analysis was the process of exploring semantic content and initial note making which involved mindful or metacognitive reading and not the unconscious, or closed, reading one usually engages in, as this can result in identifying expected information rather than novel ideas. This aspect of analysis required the analyst to identify descriptive core comments that explicitly communicate aspects of the individual's reality, such as places, people, events, etc. Once these had been identified the task moved on to considering what these descriptive core comments meant to the individual and what it was like for them. In this respect stage 2 and stage 1 converge. Another aspect of analysis at this stage was to consider the context and descriptive comments, use of language and linguistic content, and attempts to interpret the conceptual meaning of participants' comments. Deconstruction of the text was also incorporated into the analysis, and time was spent starting the analysis from different start points in the transcript.

- Stage 3: Development of Emergent Themes

Guidance suggested that analysis of explorative comments should be done in chunks. The exploratory process and initial note-making served to substantially increase and

expand the data set and, although the transcript remained central in the analysis, stage 3 was predominately occupied with capturing the essential quality of what was being communicated and condensing this into phrases whilst maintaining the complexity, patterns, connections, and interrelationships. Stage 3 of the analysis involved consideration of theoretical connections and, as a result, incorporated psychological terminology. However, it is important to note that the use of psychological terms and connections to theory remains grounded in what was being said by the participant. (Appendix 16: Excerpt of a Transcript that has undergone Step 2 and Step 3)

- **Stage 4: Thematic Grouping and Clustering**

Thematic grouping and clustering involved theoretical ordering. Up until this point the analysis had, for the most part, been conducted in a linear fashion. During stage 3 the analysis was considerate of the connections that existed between themes, mapping them into clusters that fit together, or were supportive of one another. These clusters or maps would then be allocated a name, which best described the multiple themes. This is known as a super-ordinate theme which forms an umbrella term for the subordinate themes. However, there were numerous ways of organising cluster including abstraction of related themes, subsumption, when a theme is considered to be a super-ordinate theme in itself, polarisation and the identification of oppositional relationships, contextualisation such as temporal moments, numeration and how many times a theme emerges, and the function of the theme. It is important to note that not all themes were incorporated and that this was done in consideration of the research aims. It is also important to note that this process of interpretation was constantly checked against the transcript and quotes were used to support the process (Appendix 17: Audit Trail for Stage 4)

3.7.2 Cross Case Analysis

- **Stage 5: Tabulating themes across the Group**

Once all of the interviews had undergone steps 1, 2, 3 and 4, required for individual case analysis, themes were considered across cases to identify convergence and divergence. In order to achieve this, super-ordinate and subordinate themes for each participant were organised into columns and cross-referenced for related and unrelated content

(Appendix 18: Tabulated Themes across the Group). As before, interview transcripts were continuously reviewed as a way of maintaining accuracy. After this process was complete the themes identified across the group were organised into a master table (Appendix 19: Master Table of Themes). The themes identified by the current analysis provided the basis for a narrative report and will be presented in Section 4.0 Results.

3.8 Quality and Validity

The quality and validity of qualitative methodology, and IPA in particular, can be hindered by one's own stance on the research, the aims of the research and the researcher's expectations. In order to meet these quality and validity issues, and to ensure the credibility and trustworthiness of the analysis and subsequent results, along with quality control procedures, a number of methods aimed at triangulation of multiple perspectives were incorporated into the analysis.

3.8.1 Supervision

In order to ensure theme credibility and trustworthiness, after step 2 and step 3 of the analysis, the transcript was reviewed by the research supervisor to assess the quality of the transcript and provide an opinion on the reliability of the theme elicited. In addition, the research supervisor also looked at patterns that had been identified across cases and provided an expert opinion and the management of this task. Finally, the analysis and associated themes were discussed in relation to the project aims throughout the duration of the analysis.

3.8.2 Thematic Review

In order to meet quality and validity issues, an IPA group was formed by a number of colleagues conducting IPA studies and led by an expert in IPA research. Throughout group meetings, colleagues would bring anonymised interview transcripts for consideration and each individual group member was tasked with identifying themes. On completion, those reviewing the transcript would compile the identified themes and discuss them with the contributor of the transcripts. The contributor would then compare the themes, identified by the group and group members, to the theme identified in the independent analysis. As a result, experience was gained in theme identification across transcripts and the transcripts from the current study were also the subject of review. In addition to this, a similar process was also completed with two colleagues

experienced in IPA. Overall, there was consistency amongst themes and identified themes corresponded to the themes identified in the independent analysis. It should be noted, however, that there were occasions when additional themes were identified by the group. This, however, was a welcome addition and served to provide multiple perspectives and a multifaceted account of the phenomenon and was consistent with the social constructionist origins of IPA (Smith et al, 2009).

3.8.3 Data Audit

In line with IPA recommendations, a colleague experienced in IPA was responsible for auditing two interviews and the related documentation created during each step of the IPA analysis. The audit established 100% adherence to analysis procedure.

3.9 Self Reflexivity and Position in Research

I would define myself as a 30 year old, White British female of Nordic decent. I was brought up in a socially deprived town in the North East of England and come from a predominately working class background. I have two brothers from my father's second marriage and one sister from my mother's second marriage. I have a large extended family, with over 250 family members on my maternal grandfather's side and over 150 family members on my maternal grandmother's side. My father's side of the family is small in comparison and is comprised of less than 15 family members. I am a married woman of heterosexual orientation and have no children. I am in my final year of training on a three year Doctoral training programme in Clinical Psychology.

Prior to clinical training, I worked for ten years in Mental Health settings, Learning Disability settings and Neuropsychological Assessment Centres. My experiences in these settings and on clinical training have led me to believe that the parent-child relationship is particularly influential in an individual's developmental trajectory over the life span. In addition, when I started my undergraduate degree in psychology, the Human Genome Project was dominant and teaching seemed to revolve around research on individual genetic difference and how this influenced brain structure, pathology and developmental trajectory. As a result of this, I became fascinated by psychological research which suggests that metacognition and thought also has a role to play in neural plasticity. I am particularly excited by what this might mean for clinical psychology and early intervention programmes as it could provide the foundation for a neurological evidence base for therapeutic intervention. Both these experiences led to a particular interest in

attachment and the parent-child relationship, the neurological components of attachment, parenting and developmental trajectory.

It was, however, working with a family that had had a perinatal bereavement and their experience of parenting since the event, during my second year Child and Adolescent Mental Health Service (CAMHS) placement, that led me to become interested in parental bereavement and the experience of continuing one's role as parents with surviving and subsequent children. This was due to a lack of literature and research addressing this topic when attempting to provide evidence based intervention and the personal belief that something significant was happening for these parents that had not been particularly well documented.

My specific interest in SIDS comes from a family experience of this type of loss and the lack of support and information available for parents after an event of this nature. Research and interventions related to SIDS are predominately concerned with identifying possible aetiology and associated risk factors and reducing the mortality rate. There seems to be little understanding of what this type of bereavement means for the individual and their role as a parent, other than to say it is a traumatic bereavement for the family. As a result, I was interested in considering this area in isolation and providing a study that was not inclusive of all types of infant mortality but that heard the voice of one particular subsection which has not been given much attention. I therefore approached this work believing that understanding the experiences of SIDS parents could be useful for those attempting to support this group. My main position was one of curiosity: if the transition from being a mother unaffected by SIDS to a mother affected by SIDS provided a new experience of parenting, why and in what ways.

4. Results

4.1 Pre Interview Measures

The results of the pre-interview measures indicated that none of the participants met the cut offs for clinical significance on the Impact of Events Scale – Revised, or exceeded the t-score expected in a normative population on the Symptoms Check List – 90 – Revised. This means that none of the participants reported feeling significantly distressed on the day of the interview. For the IES-R and the SCL-90-R general distress scores see Table 4.

Table 4. Total Scores and T-Scores for the IES-R and the SCL-90-R

*Participants	Impact of Events Scale – Revised Total Score	Symptom Check List–90- Revised t-score
1. Gale	0 *	79 **
2. Corrine	2 *	77 **
3. Bonnie	3 *	69 **
4. Lydia	4 *	70 **
5. Anita	18 *	79 **
6. Nicole	10 *	73 **
7. June	16 *	79 **

* Impact of Events Scale – Revised: Clinical Significance = Total Score < 25

** Symptom Check list- 90 – Revised: Cut off for normative population = t-score < 81

4.2 Interpretative Phenomenological Analysis

The remainder of this chapter will be devoted to presenting the results of an Interpretative Phenomenological Analysis of seven mothers', who had lost a child to SIDS, experiences of parenting. Five key themes emerged to form the basis of the analysis:

- Channelling the Parent Within
- Parenting Outside of Yourself
- Restoration Through You
- The Bitter Restoration
- A Disruptive Appreciation

For an overview of the master themes, and subthemes contributing to them, see Table 5. (Appendix 19: Table of Master Themes, Subthemes and Quotes)

Table 5. Master Themes and Subthemes

Channelling the Parent Within	<i>The flexible parent</i>
	<i>A mother's instinct</i>
	<i>The expert position</i>
Parenting Outside of Yourself	<i>The novice</i>
	<i>Safety through restriction</i>
	<i>Selfchecking</i>
	<i>Hands off parenting</i>
Restoration Through You	<i>Vindication and redemption</i>
	<i>They keep me going</i>
	<i>Taking away the pain</i>
The Bitter Restoration	<i>Bursting the protective bubble</i>
	<i>My heart's not in it</i>
	<i>Experience shapes expectation</i>
A Disruptive Appreciation	<i>I live for them</i>
	<i>The pressure of value</i>
	<i>Holding tight</i>
	<i>Too precious for tears</i>

In order to provide one possible account of mothers' experiences of parenting in their transition, from a parent unaffected by SIDS to a parent affected by SIDS, the master themes and subthemes will now be presented as a narrative. For ease of reading, the supporting quotes included in the result section omit utterances and repetitions. Identifiable information has also been removed and aliases have been provided for each participant, their children and their family members.

4.3 Channelling the Parent Within

All participants described feeling confident and relaxed prior to their experience of SIDS and indicated that their approach towards parenting had developed naturally, unfettered by persistent thoughts that their children could die. Participants also described the parenting approach they adopted as easy to undertake and the responsive parent-child relationship as effortless. All participants made reference to their reliance on internal mechanisms and states during this time. However, whereas some discussed flexibility, others referred to

instinct, and there was one who felt they were the expert on their child. Despite the differences, all participants expressed the idea that these internal states and mechanisms gave them the confidence to parent.

4.3.1 The Flexible Parent

Five of the participants experienced their parenting as adaptable to circumstances and flexible to the needs of the child.

My style must have been really in his routine, I kind of went by him, I mean it's more his routine I went with. I think it was my Nan that actually said, you know, if he needs something, he'll tell you, he'll know and you'll know, and that's the way I went about it. If you're baby's hungry you're going to feed your baby, you're not going to not feed it for another half an hour because it's not, say, due... and the same with sleeping, you know, Henry always slept on his back, James wanted to sleep on his front, I used to be, well, however your baby wants to sleep, go with how your baby does it (Corrine)

Corrine's experience prior to SIDS was one of feeling able to adapt herself to the needs of her child and follow his routines. She also alludes to the idea of accommodating the child's preferences and not feeling compelled to correct their behaviour on the basis of her views or ideas, regarding what she thought was best. Whilst Corrine discusses adapting to her child's routine, Gale discusses how she could easily deviate from the routines she had put in place and adapt herself to the situations she faced or the social circumstances she found herself in.

Even though I had a routine, I could easily break the routine if I had to. I could go out and... if I didn't bath him one night, it wouldn't matter, you know, if we were out and stayed late at friends, it wouldn't matter, he could go to bed later (Gale)

Unlike Gale and Corrine, Bonnie discusses how the happiness of her child influenced her decision not to impose routines and, instead, follow a child led approach to the parenting, which focused on adapting to her daughter's preferences. Bonnie also relates this approach and the absence of a routine to her relaxed attitude and believes this was a motivating factor in the parenting choices she made.

Before Annabel started school I didn't really have a bedtime routine, at mealtimes if she didn't want to eat something I'd give her what she did want to eat, probably poor parenting actually, but then I thought that when she actually did go to school I'd give her a bedtime routine. I've always been quite relaxed "oh I know that grandparents might have said that I should have got her into a routine by now" and I never felt that was important, it was more important for me to have a happy baby. (Bonnie)

Anita's statement corresponded with Bonnie's, stating that she enjoyed seeing her children happy and felt that imposing restrictions or routines may have impacted her ability to have fun with her children. However, Anita goes one step further adding that she did not feel there was a correct course of action that could be followed. This suggests that she felt free to improvise with what she felt was right at the time and there were no standards she had set for herself or ways of being she was trying to meet.

I didn't want there to be too much restriction with them, I used to enjoy seeing them happy really, enjoy having fun, freely with them. Quite relaxed compared to some of the friends I had around me, you know, if they didn't want food at certain times I was quite relaxed, I didn't have no routines and there was not real right or wrong with anything. I didn't... you know have a program that I had to work with, I just did what I thought was good, and trusted it. (Anita)

This was echoed in June's account, who reported feeling very able to do what she and her husband felt was right on a day to day basis. Rather than being flexible around routines, however, June felt that she was able to adapt her methods of parenting and explore different parenting techniques rather than pursuing one particular method.

If something didn't work we'd just try to change it so, if we tried a technique and it didn't work, we would have looked for other options, so I think, because we were quite flexible, it weren't set in stone, have any like rigid ideas of how we were going to bring him up, we just sort of took each day as it come with him. (June)

4.3.2 A Mother's Instinct

Prior to SIDS, four participants experienced their parenting as naturally occurring and not something they worked hard at developing but something they just knew how to do.

I think it's just in my nature, I know I keep saying the word "natural" but for me I didn't have to try hard to be a parent to her (Bonnie)

From Bonnie's previous account, that her parenting style was guided by her child's happiness, her description of her parenting style as naturally occurring tells us that the responsive relationship she held with her daughter was not something she felt she had to put conscious effort into. For some, doing what came naturally was what they relied upon to inform their parenting practice and was a way of parenting that they felt confident in.

You know it wasn't really something I had to kind of study, you know, try really hard at. It just kind of came naturally really and, you know, it's not really been an effort for me. You never feel like the perfect parent but on the whole I was confident, Amy was happy then I was happy and yeah I felt, as a young parent, It just kind of came naturally, I felt at home being a mum... I felt quite at home doing the job. (Nicole)

Nicole and Bonnie's accounts appear to correspond in this instance, with both feeling like the task of parenting was effortless. Nicole, however, also discusses how this intuitive style gave her self-belief and made her feel safe and capable of looking after her child, even in the absence of previous experience or specialist knowledge.

Being at home just means being warm and being safe , feeling safe, making sure that everyone's together, you know, happy, as much as you can do, just being able to protect your children and the whole family (Nicole)

Gale however, suggested that she had no choice in her approach to parenting and referred to the process as something that spontaneously develops between a mother and her child. This tells us that, for Gale, this way of being emerged with the birth of her own children and was not something that she felt she possessed before she became a mother. Gale's previous statement, that her approach could be flexible, suggests that, despite not choosing an approach, she was adaptable and when necessary able to suspend it.

I didn't choose anything. It's just the way it ... it's one of those things that just came ... it just comes to you as a parent doesn't it, how to bring them up. I'd never really had anything to do with babies and children until I had Philip, but as I say, it just came naturally. It's just a mother's instinct isn't it, you know, it's ... just a motherly instinct that you have with your children (Gale)

Lydia on the other hand, felt that her instincts were something she could fall back on, in the absence of experience, and something that she could trust in to guide her in looking after her children. Like Nicole, Lydia felt that these instincts and gut feelings made her feel capable and reassured that she was able to care for her children.

I just thought, God I've got a baby, what on earth am I going to do, and I think, to a certain extent, in some ways it was a gut instinct to start with, and you thought, well okay, if they're crying, they need something. I would say, for the first couple of months, I was a bit nervous because I'd never had children before, but I think over time you get more experienced and I think it was just a combination of experiences and a gut feeling, I don't know, where you think to yourself, yes, I am looking after them. (Lydia)

4.3.3 The Expert Position

Unlike participants who experienced their parenting as naturally occurring, instinctive and not something they had to work hard in developing, one participant differed and

described experiencing herself as the expert on her child and felt strongly that no-one could comment on her child's needs but her and her husband.

I used to get midwives coming round saying “well you shouldn't be weaning him yet, he's too young”, and I knew he was hungry and needed food, so I weaned him earlier than like the recommended guidelines, just from a feeling that I knew my own child, knew he needed solid food. I'd just go with what I felt was right and there were guidelines at the time, like there are now, about keeping baby in your room until they're six months old, but I found he settled better in his own room, own cot, so I did that. So probably a lot of things against guidelines, but just what I thought were right.. what me and my husband thought was right for Jacob and for us as a family. (June)

From June's previous account, that she felt able to be flexible and explore different parenting techniques, her description of herself as the expert on her child's needs and what was at that time best for her family, suggests that she felt better positioned than any professional in meeting her child's needs. It also suggests that her confidence was such that she felt able to go against guidelines and follow her own path.

4.4 Parenting Outside of Yourself

All participants experienced dramatic changes to their approach to parenting after their experience of SIDS. Prior to the bereavement, participants described themselves as flexible, adaptable and intuitive parents, who knew what was best for their children. After a SIDS event, however, participants reported losing the internal mechanisms which had previously aided their parenting. Participants reported new doubts in their ability to meet their child's needs or keep them safe and either looked outwards, towards professional and third party support, or began restricting their child's activities or checking their action as a way of protecting them. Although the experience of change was common across all participants, the ways in which it manifested differed.

4.4.1 The Novice

Four participants experienced a return to a novice status and no longer felt they had the necessary skills and knowledge to provide effective parenting.

So you go back to feeling like you're a brand new parent, because you've never dealt with it, you don't know the people that have dealt with it, so it's all ... you feel like a really crap parent because you just don't know what to do. (June)

June discusses how she went back to feeling like a brand new parent, due to the unknown nature of her experience, and therefore felt like a novice in its management. This was also echoed by Lydia who felt that everything she had learnt, or thought she knew about parenting, had lost its value. As a result, Lydia described feeling reliant on others for the answers.

Everything that I believed in was just thrown on the floor, as a mother you're supposed to look after your child and I felt as if I'd let him down, I wasn't there. Had I done something that could have changed? Was the way that I looked after him any different? It was absolutely everything, that I'd learned that I'd practically done, was completely changed. (Lydia)

I turned round and I said to the doctor, look, I said, I'm going to be in here every five minutes, and he turned round and he said to me, "that's fine, don't worry about it". I spoke to the midwife and the health visitor. I said I'm going to be paranoid. I said you know what's going to happen, I said I'm going to ask you a question that I know the answer to, I said, but I'm going to be asking you that question because I just want the guarantee that somebody else has said it, because my confidence level is so low (Lydia)

Unlike June and Lydia, Nicole felt that not only had everything she had learnt and experienced been erased but that it was worse than going back to being a first time mum because the experience of losing a child had left memories of what can go wrong.

It was like going back to Amy when she was first born but worse because I had, you know, all of the awful experience of Abby, you know, seeing Abby after she had died and it was really difficult. I mean, when Daisy was born, yeah, I don't really know how else to describe it, it kind of took all the good things that happened with Amy, at the time it felt that all of that was wiped out. (Nicole)

Whilst Nicole discusses how this time was similar to being a first time mum, Corrine's account states that parenting through loss was worse than this and that her experience with her subsequent child was the opposite of what she had experienced with the birth of her first son.

It's the complete opposite. I would never have say doubted myself, I was worried the first time because I was a first time Mum, so I hadn't really you know dealt with a new born baby, but it was completely different. I just felt I'd lost all confidence. (Corrine)

These accounts suggest that, for these participants, the process of parenting had moved from an internal and implicit sense of feeling able and being capable to meet their child's needs. This was replaced with the idea that everything they thought they knew about parenting had been removed or was useless in its application. It seems that whatever was underlying their confident and self assured approach had been altered.

4.4.2 Safety Through Restriction

For two participants, however, rather than feeling that they had returned back to novice status, they felt that their parenting behaviour had moved away from being flexible and non-restrictive to being heavily reliant on constant observation and experiencing separation as threat.

I didn't let them out of my sight basically. So if they did go to my Mum's, they'd be home at a certain time, they never stayed late overnight, I'd check on them every night. Two or three times a night to make sure they were still breathing. All the time they're under my eye, they were being closely watched, but as soon as they were out of sight.. If they went back to a friend's for tea, I would like somebody to text to say that they're okay, they're eating their dinner, they're not choking on anything (Anita)

Anita's account discusses how she began to restrict her children's movements and did not feel relaxed unless they were in her presence. Gale's account corresponds. Both Anita's and Gale's earlier accounts discuss not wanting to restrict their children and

feeling able to be flexible when needed. This suggests that both Anita and Gale began parenting in opposing ways and that they were no longer able to reassure themselves and had become reliant on external restriction, observation and behavioural evidence.

Just protecting him, you know, just... really protecting him... Tying to protect him from anything bad happening to him... I wouldn't let them out of my sight, or ear shot, and you know wherever I went they had to come. They'd say, oh, do you want me to watch him, no, no, no, its fine (Gale)

A lot of my friends are just leaving ... just saying, oh sod it, let's just you know stay out, we'll go home when we're ready, if the kids fall asleep in their clothes, well that's fine. I'm not very good at doing that. I like to make sure I'm back home. (Gale)

4.4.3 Self Checking

The two participants who had described experiencing a return to novice status also described how the self efficacy they felt before their experience of SIDS fell away and how they began to check their decisions by making comparisons to external sources. As before, these two participants differed from those who had described attempts to keep their children safe through restricting their activities and who described separation as threat. This suggests that, unlike those who attempted to control the environment, those returning to a novice status did not trust themselves, resulting in the described checking behaviour.

I always double check things, you know I always know what measurements of you know medicine or anything like that, but I always read them about four times now with Stephan, I would have a look at the medicine and it would say that amount, I'd give it to him. Now James I look at it, I'll look at it again, I tend to get Adrian to read it, and then I'll do it. (Corrine)

In her account, Lydia discusses how she began doubting herself and outlines her struggle to administer routine care, in case she makes a potentially life threatening mistake. Her account reveals that the relaxed child led approach she discussed prior to her experience

of SIDS has been replaced with something quite different, in which she needs reassurance from others that she is doing okay, rather than relying on the child's cues.

I used to constantly check on them to make sure that they were okay on absolutely everything, even like with my daughter walking down to school, crossing the road, something we'd done numerous times, I used to double check the road and everything. I used to say to myself, stop being so stupid, you know, what you're doing, and I used to get very angry with myself, where this other person kept coming in, and turning round and putting the doubts in there. (Lydia)

Unlike Corrine, Lydia's initial account, of being responsive to her child's needs and having a 'gut feeling' that she was doing the right thing, appears to have been replaced by what she refers to as the "other person". This implies that Lydia's view of her prior self as a parent has been so altered that she feels like a different person, who focuses on constant self doubt rather than an implicit knowledge that she was able to care for her child.

4.4.4 Hands off Parenting

Unlike the other participants, however, one participant did not experience a return to novice status, checking behaviour or the need to maintain safety through restriction. Instead she discussed her experience of deferred parenting and how she no longer felt able to tend to her children in times of sickness or injury and relied on others to meet this need.

I just couldn't, I knew I'd panic and that doesn't help anybody in an emergency or in a possible emergency. Mark spoke to me about, when there wasn't anything happening, he said "Bonnie, you've got to, you don't help any situation, try not to panic", and he knew it was hard for me so in the end the best thing is Mark's really calm, if Liam has an accident or I think he's ill, or Sally, let Mark because he's the calm one and I just used to say , because I didn't want to, so I just used to, sometimes I'd just literally, I'd give him to Liam and I'd put a cushion over my head, until I heard Mark say "he's fine". (Bonnie)

This was in direct opposition with her earlier account, and tells us that what Bonnie once faced without fear now inspired a sense of panic so strong she could not contain her emotions and relied on others to meet the children's needs and provide reassurance.

*When Sally was a baby she bumped her head she fell off the bench at the swimming pool once, when she used to sit up when she was 3 months old she was unstable and I'd sit her up on the bench and I went into my bag or something and she fell and hit her head but I didn't panic, I just calmly drove her to the hospital and she had her head stitched and it wasn't a big deal
(Bonnie)*

4.5 Restoration Through You

All participants reported feeling that their children had been a restorative influence in their lives. This had allowed them to bring back something that was lost such as proving their capabilities to themselves and third parties, re-establishing their happiness or simply giving them a reason to live. This meant that the children were positioned in different roles and, instead of being dependent on their parents, to some extent their parents had become dependent on them for restoration and the healing of wounds inflicted by their loss. Although restoration was a common theme across all participants, the ways in which it emerged differed. For some, restoration related to the continued survival of the subsequent child and how it proved their capability as a parent. For others, restoration was linked to the birth of the subsequent child and how it had aided their recovery. There were also those who felt their continued role of parenting the surviving child was restorative and gave them a reason to live.

4.5.1 Vindication and Redemption

Four of the participants reported how the birth and continued survival of their subsequent children proved that they were capable of parenting and brought back their confidence.

Having Daisy has been just wonderful really and it's kind of proved that, you know, actually we are good parents, we can be good parents, and even though something awful like that has happened I suppose that is important for me really you know, having gone through what we've gone through and still, you

know we're still able to function as parents and to show people that and you know to just show other people that you can (Nicole)

Nicole discusses how the birth of her child was significant because it proved that she and her husband could be good parents and showed third parties that they were able to function. Lydia's account is similar but alludes to the idea that the birth and survival of the subsequent child allowed her to prove something to herself.

It's like you've got to that stage, you've proved to yourself that you haven't done anything wrong, because your next child has gone beyond that stage. In some ways maybe that has proved to me that it wasn't me because I have had another child that's gone on to live longer than what Angus done, so in some ways, having Charles it was like it healed me probably in the fact that it proved that I was who I was (Lydia).

Corrine on the other hand felt that the growth and development of her subsequent child has allowed her to regain her confidence in her parenting abilities.

My confidence has come back, that bit more, obviously now he's like a year and a half, I'm starting to ... I'm a lot more open to things. I've not really got a ... I'm not so worried, so my confidence is I say coming back as he gets older, but I would say that ... so I'd say my confidence is coming back (Corrine).

These accounts reveal that, for these parents, the dynamics of their parent-child relationships changed and the continued survival of subsequent children became necessary for their restoration and continued recovery. Bonnie describes this best in her account.

so I say to him "you know Annabel" because he talks about Annabel - I'll say "do you know when Annabel died it made mummy and daddy very unhappy and we would never want another one of our children to die so please, if you're going to cross the road, look before you cross the road, please don't go and put yourself in dangerous situations" (Bonnie)

4.5.2 They Keep me Going

Rather than feeling that the birth of their subsequent children had proved their capability as parents, three participants discussed their surviving children and how their presence had provided salvation and given them a reason to continue with their lives after their loss.

... I kind of felt like I had to cope, so there was no not coping, I couldn't let them down, every day, had the children not been around I don't think I would have got up, got through it, because they were there I just thought well they've got no-one else to (Anita)

Anita's account discusses how her surviving children ensured her continued functioning in the aftermath of her bereavement and how this facilitated her ability to get through it. June's account corresponds suggesting that routine functioning and meeting the needs of her surviving child meant she did not give up. However, she goes further and suggests her surviving child saved her life.

Well I think, honestly, if Jacob hadn't have been there, with all the love he gave, I don't think I'd be alive today because I think it was Jacob ... I think it was Jacob that got us through it. I really feel for people that lose their first child, because I don't know how they get out of bed in the morning because he was the person that, "Mummy, I want my breakfast", and you've got to get up, you've got to function, you've got to take him to school, and it keeps some routine in your life, so I think that love really, really helped us because we had to function and you had to face going round the supermarket to buy food for him. I don't think we did ... I just don't think we'd have been here if it weren't for Jacob (June)

Gale also agrees that her surviving child got her through her losses but says something about feeling reliant on him. These accounts, again suggest a changing relationship with the surviving child and positions the child in a different role, where their presence is necessary for their parents continued functioning or survival.

Well Philip was just smothered then you know with ... I didn't want him out of my sight. I couldn't let him out my sight. I had to take him out of his own

bedroom and bring him into our bedroom because I needed him to be near me all the time. And I relied on him. He got me through it all (Gale).

4.5.3 Taking Away the Pain

Unlike the other participants, two participants suggested that the birth of their subsequent children had a salutary effect and allowed them to move forward with their lives. One of the participants, who had described her surviving child as the reason she continued living, also experienced her subsequent child as restorative. The second participant, who highlighted the continued survival of her subsequent child as necessary for her personal redemption, also felt that the birth of her subsequent child had restored her happiness by completing the family composition.

I think I've been very lucky to have another healthy baby. I think that has helped me get through things, give me something to focus on. Some people don't want to have more children after, but we decided that we wanted to because we wanted a sibling for Jacob, so we decided that we would have another baby, by no means a replacement for Robert, it was a way of moving on (June)

June's account focuses on how the birth of the subsequent child gave her something to focus on and helped the family attain their desired composition. Bonnie's account appears to be in agreement but adds that the birth of the subsequent child brought back her happiness.

She died and I needed another baby to complete my family and make me feel happy again and that's exactly what we did. But even if you go on to have another baby, or you've still got a child, there's still that person there, and you miss that person so I always think something is missing (Bonnie)

Both accounts emphasize that the deceased child could not be replaced. This suggests that, for these participants, their happiness and recovery is dependent on the success and prosperity of the subsequent child, not because they are replacements for the deceased but because they have restored contentedness.

4.6 The Bitter Restoration

Despite the restorative properties of the subsequent and surviving children, all participants reported feeling that something had remained permanently lost or altered by the death of their child. This was not just with respect to the family's composition, or as some participants put it "the missing piece", but was related to a lost sense of safety and a new found sense of seriousness. Although this knowledge brought the benefit of perspective, it also brought an awareness of a continued existential threat and loss. However, the ways in which it manifested itself differed across participants. For some this disrupted their enjoyment of the parenting process, for others it elicited dread and foreboding.

4.6.1 Bursting the Protective Bubble

Three participants reported that they felt that they had lost a sense of safety and that this ultimately affected their ability to continue with life unabated.

Before I just assumed, be it naively, that if you looked after your child, you fed it, you kept it warm everything would be fine... I think you do learn to accept something that's changed. I suppose, when you start off, everything's maybe you know you think is absolute flowers and things like that, but life, you know, things happen in life, and I suppose you just have to get through it, and thankfully, you know, we have got to a point where I think we have sort of moved on but, as I say, there is still a lot of things in life that could change this the other way, you don't know (Lydia).

Lydia's account discusses how she had been naive in her unquestioning belief that she could protect her children and keep them safe. Lydia also reflects on how life is not always positive and that it is something to be gotten through. However, Lydia also makes reference to never quite knowing whether you are at the other side of something because of how quickly it can all change. This implies that she might be feeling insecure in her position. Like Lydia, Bonnie discusses the carefree nature of naivety and suggests that she envies people who can continue to live their lives in this way. For Bonnie, Pandora's Box has been opened and she cannot erase what she has experienced.

You put things into perspective and I don't mean to say that in a patronising way or anything because I would rather people live their lives the way they live it, in a bit of a bubble... I've never been able to go back to being carefree like that and thinking and having that kind of, you know, the privilege of not knowing about sudden infant death and having a baby die so yeah that would never be the same and my conscience will probably never be the same (Bonnie).

Corrine's account corresponds with Lydia's and Bonnie's, in that she now knows that life can take unexpected turns, which seem unfair and unjust. However, Corrine goes further suggesting that this new knowledge strengthened the parent-child relationship she holds.

I feel it makes you more aware that, to be honest, the world is not ... you know it can be cruel, so ... so as a person I just feel it's made me stronger with my kids because you never know really what can happen and they're my children, you know, really strong with them (Corrine).

4.6.2 My Heart's Not in It

Unlike the three participants who felt that their experience of SIDS had resulted in a loss of innocents/naivety and a lost sense of safety in the world, three participants reported feeling that they no longer found joy in the routines of family life with their surviving and subsequent children.

Like Christmas, it's like ... yes, everyone's like oh its Christmas and its only five more sleeps, and you're so lucky to have two little kids at home for Christmas. I know however much I love seeing their faces on Christmas Day, in a way, your heart's not in it because you've got one missing and it's like holidays, you go on holiday, but even though you can see your family and your children enjoying it, and you do have a nice time, but then you'll see like a three year old round pool and think, hmm, that would have been Robert (June)

June discusses how the loss of her child has left a gap in the family and although she feels lucky to have her surviving and subsequent children she also feels that she cannot enjoy

her time with them as much. Rather than discussing absence, Anita discusses how she has lost her relaxed approach to parenting and the fun side of the parent child relationship.

... There was no relaxed fun side, that had all gone after losing her, so it's quite sad really, the boys probably, yes ... whether they noticed a change, but there was a definite change. I tried not to. I was very aware of it (Anita)

Rather than focusing on the loss of fun and enjoyment, Nicole discusses the emergence of anger and irritation and how she tries to hide it from her surviving and subsequent children. Despite this, however, there are times when it comes out and she feels overwhelmed.

I don't really try and let my serious side come out in front of the children but I think that stress sometimes builds up and I kind of get quite very irritable and angry so it comes out in kind of... I'll get cross, like really, really cross and just lose it and then have to take a few minutes and then it's OK again (Nicole)

These accounts suggest that the loss of a child altered these participants' ability to enjoy their time with their surviving and subsequent children and as a result may have impacted the relationships they hold.

4.6.3 Experience Shapes Expectation

Three participants discussed how their experiences had led to excessive worry and left them thinking that they would lose another child. Two of these participants had also experienced either a lost sense of safety in the world or no longer feeling joy in the routines of family life. However, unlike the other participants, one participant only described her experience of SIDS as shaping her expectation that her other children would die.

I think he'd fallen over, and he'd hit his head... I just thought he was going to have major brain trouble. I'd think that things were going to be a lot worse than what they were so I sort of went up ... the practical brain in me used to turn round and say, this is the reason why you're thinking this, because you've

had the worst case scenario happen to you, so of course, you feel that everything's going to go to that level (Lydia)

Lydia reflects this very well in her account, stating that since her loss she expects every negative event, potential injury or illness suffered by her children to go to that extreme. This suggests that the fear parameters have changed and expanded to accommodate what is now thought to be the worst case scenario. This is echoed by Nicole's account, which states that she continually experiences dread that something awful will happen, her experience of this reinforcing those beliefs.

I think the feeling that something awful can happen at any time, that's always in the back of my mind and also, you know, I'm not so bad when I'm here at home but sometimes, when I'm out and about, I'll get a terrible feeling of dread as if something awful is going to happen (Nicole).

Gale also discusses the idea that inconsequential childhood illness now holds dreadful possibilities for her. This says something about how vulnerable these participants now feel and their sensitivity and hypervigilance to a possible threat.

... I worry, I just worry, about them, the whole time. Now when they get a cold, or they tell me they've got a headache, I think, God, that's it, they've got a brain tumour, they're going to die, you know, whereas I never used to think that, you know, every little thing (Gale)

4.7 A Disruptive Appreciation

All participants reported permanent changes to how they viewed their children, as a result of their experience of SIDS, and felt that they had a greater appreciation for their lives. The way in which this was experienced differed. Some found that their lives revolved around the children and focused on maintaining a positive emotional state within them. Others found that they struggled to give their children independence and discussed the pressure of value. Despite the differences, all participants felt that this had permanently altered the parent-child relationship and how they approached parenting.

4.7.1 The Pressure of Value

Five of the participants discussed how an increased appreciation for their children had resulted in an increased pressure that they lived with on a daily basis.

You value them more so you could go either way and be, like, either really, really stressed and serious and all that, and there is a side to me that is stressed and serious. I don't want to lose it so easily and at the same time I think that's probably, it's a product of, you know, all the stresses that you carry with you all the time and sometimes you just, ordinarily being a parent is stressful but I do think these worries, these underlying worries and anxieties (Nicole)

Nicole discusses how increased value could result in someone becoming very serious and unable to relax around their children (i.e. when you are so grateful for their presence and very fearful that you will lose them). Gale's account corresponds with Nicole's, stating that she felt very grateful to have more children but that this is tainted by the feeling that she is tempting fate and that eventually something will go wrong.

I felt so fortunate to be having another child, and obviously I worried, I worried, I worried about him, and when I had Lloyd, in a way, I felt I was very lucky to have another child, but I also felt I was pushing my luck, thinking, you've got Philip, you've had Benjamin, he's healthy, he's fine, you're really pushing your luck now having another, so part of me felt ... I feel and did feel just ... yes, I worry more, because I felt like I shouldn't have been having another, when I'd got Benjamin, I should have thought, be grateful you've now got Benjamin, don't push your luck in having another (Gale).

In her account Anita alludes to the fact that there is no longer the time for fun or laughter in her household because she is preoccupied with other things, such as making sure the children are safe and secure.

I think ... there was so much fun and laughter in the house before, but now there's ... there is that a little bit, but there's just no time for it (Anita)

While Nicole, Anita and Gale discuss the serious nature of caring for someone so precious to them, June points out that the joy is overshadowed by the fear that something will happen to them.

Yes. Yes, you've still got all the love, and the happiness that a child brings you, and the fact that you want to do anything for them and protect them and look after them, but it's kind of overshadowed by fears and anxieties as well about what might happen to them (June)

Lydia discusses how the constant pressure of possible loss plays on her mind and increases her levels of affection. There is something in Lydia's account regarding the finality of every moment and how pressured one is to enjoy every moment and make every goodbye a final farewell.

I always turn round and make sure I kiss them and cuddle them and say look after yourself. My daughter goes out in her car, I turn round and say be careful, you're always going to worry about it, but I always make sure I make the time to say, goodbye, or be careful, and I'm always standing at the door when they go, at the back of my mind, I'm thinking, terrible thing, but that might be the last time I see them, do you know what I mean, so I think, yes, that is a crux (Lydia)

These accounts demonstrate how pressured these parents feel to focus on every moment with their children and gives the impression that they are metaphorically 'holding onto sand'. By feeling pressured to enjoy every moment, which ultimately they are unable to hold onto, they cannot enjoy the parenting journey.

4.7.2 I Live for Them

Three of the participants discussed self sacrifice and how, since their experience of SIDS, they would do anything for their children, even if it caused them difficulties. One participant experienced both the pressure of value and living for their children. Unlike the participants who had experienced the pressure of value, two participants described indulging their children because of the increased value they held.

Well let him, both of them, do what they want to do and I'll fulfil it as much as I possibly can and it might be a little bit of hard work for me, you know, cups to clear up and crumbs to pick up, so what, they've had their fun and their friends love coming round our house and staying and being so relaxed so I'm not going to change. If Liam wants to stay up a bit later I let him stay up and if he wants to have sleepovers with 10 friends I'll let them stay. He's never said to me ever, can someone stay or can I go over and I've said no (Bonnie)

Bonnie discusses how she indulges her child and willingly provides him with anything he might want. Bonnie goes on, adding that she would do anything for her child, that this is her role in life and even when she does impose boundaries she will usually rescind them. This tells us that, for this participant, there is a struggle between devoting herself to him and maintaining boundaries.

I would do anything in the world for him, he knows he can get on the phone to me and say "mum can I have £5 for my Playstation" and I might say "no", and he goes "mum please" and I say "all right darling" and cave in straight away. When his teeth fall out I give him £5 a tooth and someone will say "£5?" and I say yeah I know. I spoil him that way and so what if he tries it on with me and I say you're going in the bath he's say "I'm not running it" so I'll go and run it for him and I think to myself "do you know what, that's why I'm here on this earth" (Bonnie)

For Corrine, living for her children means doing everything for them and not missing a moment of their development. Corrine adds that this is how she feels close to the children and talks emotionally about how difficult it would be for her if she missed something.

Oh now I wouldn't want to miss anything of them. If he had a tooth coming through that I didn't know about and it came through at someone else's house, I'd be devastated, and just like the little things, like the smaller things, I wouldn't like ... I don't want to miss anything. And it makes me upset to think if I ever missed anything, school play, it's important to them and you know I'm here for them, so to me it's just really important that I do everything for them

and it does ... I just feel really close to them and I feel that's a good way you know of being close to your children anyway (Corrine)

Anita on the other hand, discusses how she devotes herself to her children and how difficult this has been for her and her husband. Despite this, Anita maintains they will continue with the new approach because ultimately they fear they will lose what they have if they do not. These accounts tell us that, for these participants, living for their children transpired with the loss of their child and is a way of making their children's lives as enjoyable as possible.

You neglect yourself really, as a husband and wife... everything's for the kids, they're most importantly, whereas before we used to do half and half, whereas now it's like 90% children and 10% of what we want to do. I think we both feel a little bit because my husband says well I could be going to golf, and I say well I could be going out with my friends, well, it's tough isn't it, at the end of the day we're both quite happy doing what we've got, but feel quite tied down, and we know deep down inside we can't have what we had back, because we know we're frightened that we might lose it again (Anita)

4.7.3 Holding Tight

Unlike the other participants, three participants discussed feeling unable and unwilling to give their children independence and imposed dependence as a way of ensuring their survival. One participant who experienced difficulties giving her children independence also experienced self sacrifice and the idea that she lived for her children. Two participants who had described the pressure of value also described being unable to give their children independence because they had become so valuable.

He wanted a BMX and he wants a scooter and he'll go out with his friends and I'll say to him, for me to let him out, Liam's teacher, my health visitor and my parents , my mum and everyone in the end and Mark will say "look you have to let him out", because all the kids, and I live on one of those new housing estates, and there'll be little kids knocking on the door saying "is Liam there, can he come out" and I'm like "no, no, he can't come out (Bonnie)

Bonnie and June both describe feeling unable to give their children independence and wanting them to be as safe as possible at all times. This tells us how difficult these parents find it to expose their children to any form of threat, even when it is an appropriately measured risk, necessary for individuation and autonomy.

Benjamin's never slept in his own room. He's nearly three. He has to sleep in our room because I have to keep my eye on him (June).

Lydia, on the other hand, discusses how difficult it was for her to see her child as an independent person and how she would position herself as his protector, even against her older children. These accounts suggest that the precious nature of these children's lives inhibits their parents from allowing freedoms necessary for development.

I don't know whether the kids would agree with me, I do find that sometimes I do tend to go on his side. If there's any arguments I maybe do tend to sort of go you know on his side, not deliberately, but I think over time it's getting a bit better in the fact that I've forced myself to say he's an independent person (Lydia)

4.7.4 Too Precious for Tears

Unlike the other participants, two participants described feeling unable to continue normal discipline procedures and boundary setting in the presence of a precious child and how difficult it was to cause them emotional discomfort. One participant, who experienced the pressure of value and difficulty giving her children independence, also found it difficult to discipline her children as she did not want to upset them. The other participant, who had experienced the pressure of value, also felt that she could not take the risk of disciplining her children as their behaviour could indicate their need for maternal support.

I probably have been very lenient on them. I let them get away with so much I suppose because I'm always worried ... I don't like upsetting them. I worry about upsetting them. I don't ... I know it sounds silly, but I just have this ... they're just so precious (Gale)

Gale described how she no longer feels able to be firm or boundaried with her children as she feels that this might impact them emotionally and that they are too precious to her for her to do this to them. June, however, feels slightly differently and talks about how she would rather be lenient and let her children push the boundaries than be disciplined and firm and fail to observe an emotional need. This tells us that these children have become so appreciated and precious that their parents no longer feel able to cause the emotional discomfort associated with boundaries and discipline.

If he got upset at school I'd go in and see a teacher, but maybe it was just something and nothing that I'd have just said before, you know, come on, it's just silliness at school, get on with it... probably a lot softer with him, he probably knew how he could get away with a bit more. Probably wasn't as strict with him... but you can't take that risk of saying, no, come on, bed, now, whereas before it would have been it's 8 o'clock, lights out, and go to bed, because you don't know whether they are playing on it, whether they do need you. If I don't get my act together I'm going to have a really naughty child on my hands (June).

5. Discussion

5.1 SIDS and Mothers' Experiences of Parenting

The discussion will attempt to place the findings within the wider context and frame the results within the already existing literature. Some of the literature discussed in the introduction will be revisited. However, due to the unanticipated territory IPA research can take, some literature will be being introduced for the first time (Smith et al, 2009). The key finding of the current study was that the parenting experience changed from being natural, flexible and internally guided to being restrictive, novel and reliant on checking behaviour and external validation. Other key findings included the restorative nature of the surviving and subsequent children, a new found appreciation that was disruptive to the parenting approach and a restoration tainted by existential knowledge and feeling unsafe in the world. These findings can be linked back to a body of theory relating to parenting styles, behaviours and patterns and the consequences of this on the parent-child relationship.

5.1.1 Parenting Typology

In her work on parenting, Baumrind (1966) developed four dimensions of parenting, these being discipline, warmth and nurturance, communication style, and expectations regarding maturity and control. Based on these four dimensions, Baumrind (1966) hypothesised that there were three parenting styles, authoritarian, authoritative and permissive. Authoritarian and authoritative parenting styles both refer to an approach which is boundaried and disciplined, with high expectations and behavioural limitations being set for the child (Baumrind, 1966; Baumrind, 1967; MacCoby & Martin, 1983). The authoritarian style is described as a more repressive and prescriptive approach, where the child is expected to follow instruction without question, and where self will and self directed behaviour is actively discouraged. Authoritative parenting is again seen as a firm, disciplined and boundaried approach to parenting but benefits from parents sharing their rationale, explaining the reasoning behind their actions and remaining open to alternative positions (Baumrind, 1966; Baumrind, 1967). Permissive parenting, however, differs substantially and avoids the high expectations and behavioural limits seen in authoritarian and authoritative styles, preferring instead to approach all the child's impulses, actions and desires with affirmation and acceptance (Baumrind, 1966).

MacCoby & Martin, (1983) made revisions to Baumrind's (1966) original parenting typologies by drawing on attachment theory and reducing the dimensions to warmth and control. They also separated permissive parenting into two distinct categories, the first being the indulgent permissive parent, who demonstrates high responsiveness towards the child and low demand regarding behavioural expectation and limits (MacCoby & Martin, 1983), and the second being the neglectful permissive parent, who shows low responsiveness and low demand and who is preoccupied with their own needs (MacCoby & Martin, 1983). See Figure 3 for the four parenting typologies across two dimensions.

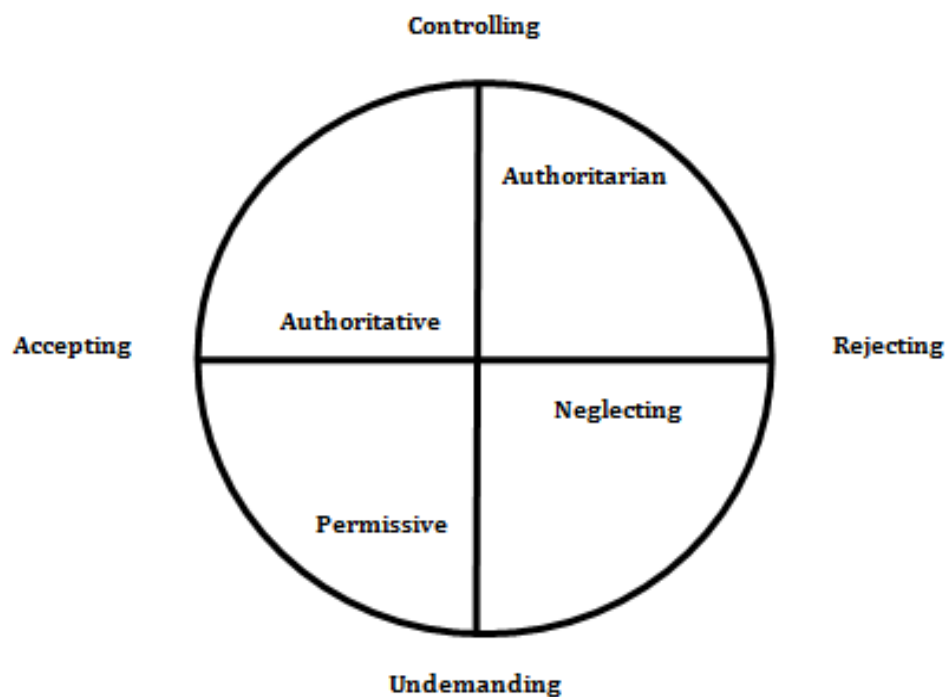


Figure 3: Parenting Typology (Carr, 2006)

Mothers in the current study all reported experiencing their approach to parenting as altered by the SIDS event. One aspect of this transformational experience was the new found appreciation all participants felt for their children. This appreciation, however, appeared to have a disruptive effect on parents' abilities to set boundaries and discipline their children appropriately, and motivated a parenting style characterised by permissiveness (i.e. a parenting style that lacks expectation and behavioural limits and is accepting of all the child's demands, desires and activities). As a result, participants reported themselves as being overly responsive to the needs of their children, eager to

promote positive states and avoidant of the emotional discomfort associated with demands, boundary setting and punitive measures. This can be seen in the 'Disruptive Appreciation' theme which encapsulated not only participants' heightened sense of appreciation for their children but also their difficulty in disciplining and setting boundaries. This suggests that the mothers in this study experienced a change in their parenting typography and that they entered what would be described by Baumrind, (1966) and MacCoby & Martin, (1983) as a permissive and indulgent style of parenting.

5.1.2 Parenting and Anxiety

Along with a parenting style characterised by high responsiveness and low demand, participants also reported an increased need for control. In the 'Parenting Outside of Yourself' theme, some participants reported reverting back to feeling like a novice, others found it necessary to consistently check their decision making and actions and there were those who restricted their children and the environment, in order to keep their offspring safe. This could be interpreted as anxious and protective parenting, which does not fit within Baumrind, (1966) and MacCoby & Martin's, (1983) parenting dimensions or typologies. However, a theoretical model which does house an amalgamation of permissive and indulgent parenting and anxious and protective parenting is affectionate versus affectionless control.

Affectionate control, affectionless control and affectionate constraint has its origins in attachment theory and is largely associated with the relationship between parenting and the development of childhood anxiety (DiBartolo & Helt, 2007). There are three components to the theory. Firstly, affectionate control refers to a parenting style that is more controlling than would normally be expected but which relies on indulgence and high affection to protect the child from the emotional distress caused by the care-giver's repressive behaviour (DiBartolo & Helt, 2007). If applied to research on parental bereavement, it could be suggested that affectionate control maps well onto vulnerable child syndrome. For instance, affectionate control and vulnerable child syndrome both emphasize overprotective parenting, resulting in attempts to control the environment and restrict the child's activities and decision making. In addition, affectionate control and vulnerable child syndrome both highlight infantilization, with parents attempting to maintain positive emotional states in their offspring by being overindulgent and over-attentive (Green & Solnit, 1964). The second component is affectionless control.

Affectionless control refers to a parenting style that is more controlling than would normally be expected but which is avoidant and lacks emotional warmth, such as acceptance, affection and responsiveness (DiBartolo & Helt, 2007). Again, if this were to be applied to research on parental bereavement, affectionless control maps onto replacement child syndrome and the parenting paradox, both of which highlight protective and controlling parenting styles and the attainment and maintenance of emotional distancing (Cain and Cain, 1963; Warland et al, 2011a). In this model, affectionate control and affectionless control are believed to be motivated by parental anxiety and promote childhood anxiety. The third component of this model is affectionate constraint, which is seen as the more appropriate approach to care-giving and a method which reduces the likelihood of childhood anxiety developing. Affectionate constraint is characterised by acceptance, affection, responsiveness and emotional and behavioural involvement. However, unlike affectionate control and affectionless control, parents feel more able to contain their anxieties and do not feel driven to emotionally regulate through control or avoidance of their children (DiBartolo & Helt, 2007). Mothers in the current study all described how their parenting had become controlling, anxious or restrictive and encouraging of dependence. This can be seen in the 'Parenting Outside of Yourself' theme. However, as seen in the 'Disruptive Appreciation' theme participants also discussed an increased responsiveness, attentiveness and emotional and behavioural over-involvement motivated by an increased appreciation. Therefore, it could be suggested that the shift in parenting, experienced by the participants, was also indicative of a transition into a parenting style characterised by permissiveness and affectionate control.

While Baumrind (1966) and MacCoby & Martin, (1983) define control as being characterised by behavioural expectations and discipline, Wood et al (2003) describe control as overprotective parenting which relies on excessive regulation of the child's routine and environment and encourages dependence. Control in this instance refers to a parent who cannot contain their anxieties and who regulates parent related anxiety by controlling their child. As a result, children are prevented from engaging in activities, situations or developmental tasks that the parent finds anxiety provoking. All participants in the current study described their parenting as changed and alluded to the presence of a new anxiety which prevented them from allowing independence. This can be seen in the 'Parenting Outside of Yourself' theme and the 'Disruptive Appreciation'

theme, both of which encapsulated experiences of restriction and difficulties facilitating independence. On this basis, it could be suggested that the mothers in the current study were engaged in a parenting style, motivated by anxiety and anxiety regulation and, given the traumatic nature of their losses, it seems entirely plausible that participants might feel apprehensive about their continuing role as parents. Ultimately however, affectionate versus affectionless control was designed to consider the transmission of anxiety from parent to child and highlights parenting patterns that increase the likelihood of the development of an anxiety disorder in childhood. If correct, it is possible that the participant's children were, as a result of their parenting, at greater risk of developing difficulties with anxiety either in childhood or in later life.

5.1.3 Expressed Emotion

The parenting shift discussed by participants is also reminiscent of the concept expressed emotion. The term expressed emotion refers to the quality and frequency of attitudes and feelings expressed in the communication styles of parents and key relatives. There are two components to expressed emotion, the first being criticism and hostility and the second being emotional over-involvement (Brown, 1985). The affective family climate or emotional atmosphere can be classified as either high in expressed emotion or low. This depends on whether high or low levels of criticism, hostility or emotional over-involvement (i.e. extreme protectiveness and/or self sacrificing behaviour) are identified within the communication style (Peris & Baker, 2000). High expressed emotion refers to a process in which parents and key family members direct criticism and hostility towards a particular family member and who are overly emotionally involved in their lives (Kuipers, 1994). Low expressed emotion refers to a process where there are low levels of criticism and hostility but high levels of emotional over-involvement (Kuipers, 1994). Parents and key relatives who demonstrate low levels of expressed emotion tend to view family members as dependent and not responsible for their actions and behaviour. This results in criticism, disapproval or hostility not being expressed and causes distress for parents and key relatives. However, low expressed emotion can also cause distress for the person it is directed at, including a sense of enforced dependence and family spotlighting (Kuipers, 1994). Mothers in the current study all described a parenting style that was over involved, overprotective or self sacrificing and avoided criticism, hostility and behavioural correction. For instance, the 'Disruptive Appreciation' theme encapsulated

experiences of self sacrifice, extended dependence and a parenting approach characterised by avoidance of the emotional discomfort caused by discipline. As a result, it could be suggested that participants were describing a parent-child relationship low in expressed emotion. Patterson & Birchwood, (2005) have correlated over emotional involvement to parents and care givers who are themselves experiencing anxiety and depression. Given the impact and long term consequences of a parental bereavement it seems plausible to propose that this could also impact the affective family climate and emotional atmosphere. Patterson & Birchwood, (2005) would agree, stating that losses can mediate the frequency and quality of expressed emotion within families.

Expressed emotion is known for its successful application as a reliable predictor of onset, relapses or poor outcomes in a variety of mental health difficulties (Kuipers, 1994; Hashemi & Cochrane, 1999; Hodes & Le Grange, 1993; Ivanovic et al, 1994; Kog & Vandereycken, 1985; Paley, 2000; Waller & Slade, 1989). However, a study by Peris & Baker, (2000) reported the increased use of expressed emotions in assessing the parent child relationship and its reliability as an indicator of psychopathology and disruptive behaviour in children. Further to this, Kwon et al (2006) have found maternal expressed emotion to be a reliable predictor of childhood anxiety, perceived competence and hyperactivity. As before, this suggests that the parenting styles, patterns and behaviours reported by participants in the current study may, in the long term, increase the likelihood of emotional and behavioural problems for their children.

5.1.4 Vulnerable Child versus Vulnerable Parent

Although participant accounts described some behaviours associated with vulnerable child syndrome such as protectiveness, restriction, overindulgence, over-attentiveness and infantilization, none of the participants made reference to experiencing their child as vulnerable to, or at heightened risk of death. Nor did participants over-identify and express the belief that their subsequent or surviving offspring shared characteristics with the deceased, which would increase the likelihood of them dying. This, in addition to the literature on parenting, suggests that, rather than seeing their children as vulnerable, it was parents who felt unsafe and defenceless against parenting related anxiety (Wood et al, 2003; DiBartolo & Helt, 2007; Patterson & Birchwood, 2005). This was prevalent in the 'Parenting Outside of Yourself' theme and the 'Bitter Restoration'

theme, which captured parental anxieties and new found existential knowledge which left participants feeling unsafe.

It is not within the scope, nor is it the intention, of the current research to imply pathology. However, it was notable from participants' accounts that they were actively engaging in safety behaviours and neutralising behaviours usually associated with Obsessive Compulsive Disorder. For instance, the 'Parenting Outside of Yourself' theme encompassed self checking, the need for outsider witnessing and deferred parenting. It was also notable that these behaviours were present in the participants' approach to parenting and in their attempt to behaviourally control the uncontrollable (e.g., must say "be careful" before the child leaves). Obsessive Compulsive Disorder is a diagnostic term used to describe a cluster of symptoms, including persistent thoughts, images or urges, regarding catastrophic events, one's own safety or the wellbeing of others. These thoughts, images and urges can cause significant distress and functional impairment and as a result attempts are made to ignore, suppress or neutralise said thoughts through thought or action (ICD-10, 1993; DSM-4, 2000). This can include repetitive behaviours such as checking, mental acts such as internal arguments, and action in response to the thoughts such as the application and the following of rigid rules and restrictive behaviours.

All participants in the current study described their parenting as altered by their experience of SIDS. This can be seen in the 'Parenting Outside of Yourself' theme and the 'Disruptive Appreciation' theme where this was discussed in terms of checking themselves, looking for reassurance from others, restriction and over protectiveness. However, unlike Obsessive Compulsive Disorder, which incorporates an element of irrationality and 'magical thinking', these parents have faced the worst case scenario, the death of their child. This resulted in participants reporting that they felt unsafe in the world, as seen in the 'Bitter Restoration' theme, and motivated to prevent reoccurrence and subsequent losses. Behavioural attempts to control the uncontrollable may be attributable to the unknown nature of SIDS. For instance, when the cause of death remains unknown parents may become hypervigilant towards any and all potential threat. In addition, with uncertainty regarding which behaviours will keep their child safe and which may cause their death, parents may become reliant on brief illusions of control to provide temporary relief from their anxiety.

5.1.5 Replacement Child versus Restored Parent

Although participants described some behaviours associated with replacement child syndrome and the parenting paradox, such as over-protectiveness and controlling parenting styles, participants did not report behaviours aimed at creating and maintaining emotional distance, as found by Warland et al (2011a) and Warland et al (2011b) and observed by Cain & Cain, (1964). Instead participants in the current study all reported an increased sense of appreciation for their children and the idea that their offspring were in some way responsible for their salvation, restoration or vindication. This was apparent in the 'Restoration Through You' theme and the 'Disruptive Appreciation' theme. One possible explanation for this comes from literature on SIDS and perinatal bereavement. Kreuger, (2005) suggests that parental bereavement shatters a parent's perception of themselves and leaves them feeling unable to successfully undertake a parenting role. Handsley, (2001) agrees but goes further suggesting that these shattered perceptions transcend self perception and challenge the parenting identity. One of the main drivers for these changes is thought to be guilt, with many parents reporting that their inability to protect their child from death left them feeling that they had failed in their primary role (Blechar, 1992).

Beckwith (2003) and Kreuger, (2005) have both discussed the self blame and guilt which can accompany a SIDS event. Unlike other forms of parental bereavement, however, this sense of guilt and self blame is not alleviated by autopsy results, explaining cause of death. Instead SIDS parents are left in a position where the only blame they can attribute is to themselves and the parenting actions and inaction carried out in the hours preceding the child's death (Beckwith, 2003; Kreuger, 2005). The continued survival of surviving and subsequent children, however, may provide disconfirming evidence for the belief that they were inadequate parents and that action or inaction caused their child's death. This would alleviate the guilt and self blame and provide vindication, allowing restoration of self and of the parenting identity. This may be the reason participants in the current study felt excessively invested in their children, as reoccurrence does not just result in the tangible loss of a child but also the loss of the vindication and restoration these parents have experienced. This may account for the experiences encapsulated in the 'Restoration Through You' theme.

5.1.6 Model of Parenting

In response to these findings, literature on permissive parenting, affectionate control and expressed emotion and ideas regarding the vulnerable parent and the restored parent, a model of parenting in the aftermath of a SIDS event is offered. The model draws on participants' accounts regarding restriction, self checking, avoidance and mental arguments and on cognitive models of anxiety and rumination and safety behaviour and neutralising behaviours (Westbrook et al, 2007; Salkovski et al, 1998; Butler et al, 2008). The model also draws on participants' accounts regarding increased appreciation, existential awareness, reprioritising and self restoration and from literature supporting the notion that significant bereavements can increase relational value and that restoration of the self is entwined with the survival of surviving and subsequent children (Beckwith, 2003; Blechar, 1992; Bowlby, 1967 cited by Pantke & Slade, 2006; Buckle & Fleming, 2011; Handsley, 2001; Kreuger, 2005; Reid, 2007; Wing et al, 2001).

The model does not imply pathology but attempts to further elaborate on the hypotheses provided by the labels of observed phenomenon (i.e., replacement child syndrome, vulnerable child syndrome and the parenting paradox) and develop some understanding of the underlying cognitive processes. The model hypothesises that a SIDS event can change beliefs, thoughts, cognitions and schema, regarding one's safety in the world. This has two consequences for parenting. Firstly, parents experience concerns regarding their child's safety and doubts about their parenting abilities. This leads to neutralising actions or thoughts and safety behaviours. Secondly, parents experience increased appreciation for their children and increased investment, leading to self sacrifice and emotional over-involvement. A combination of these two facets leads to permissive parenting, affectionate control and low expressed emotion in the parent-child relationship. The continued survival of the surviving and subsequent child serves to provide temporary relief from these anxieties and promotes self restoration, reinforcing this approach to parenting. As a result, parents avoid exposing and hence habituating to their anxiety. However, parents also experience secondary gains, as the continued survival of the surviving and subsequent child vindicates the parent and legitimises the loss. Anxiety avoidance and vindications both serve to fuel the continuation of the parenting cycle. See Figure 4 for an overview of the proposed model.

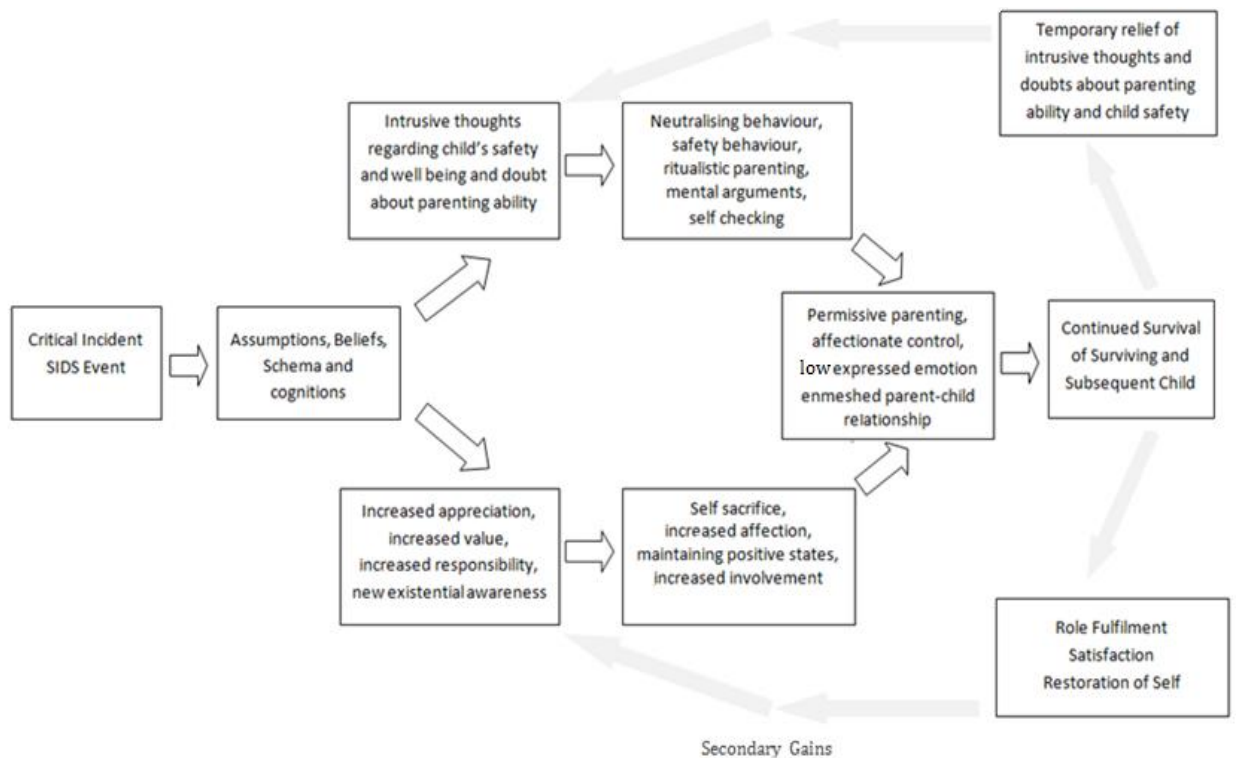


Figure 4. Model of Parenting in the Aftermath of a SIDS Event

It is worth noting that the rationale for proposing a model of parenting comes from: qualitative methodology, which aims to explore and describe phenomena; model/theory development, which aims to organise, summarise and explain complex observations, behaviours, events and relationships; and IPA, which emphasises the importance of theoretical generalizability and linking findings to professional experience and existing literature (Smith, 2008; Lefrancois, 1999; Graziano & Raulin, 2004). IPA was undertaken by the current study to explore mothers' experiences of transitioning from a parent unaffected by SIDS to a parent affected by SIDS. This exploration, however, led to the emergence and identification of five key themes, which reflected parenting behaviour, the processes which underlie it and the mechanisms which serve to maintain it. As a result, the proposed model makes attempts to organise, explain and summarise these themes. Therefore, this linear approach to the proposed models should not be confused with other qualitative methodologies which focus on theory development by intentionally identifying the research question within the data, building inductive theories and engaging in theoretical sampling (Smith, 2008).

5.1.7 Attachment

The proposed model, however, does not provide any insight into the relational implications of this parenting approach or the long term consequences this may have on the surviving and subsequent children's developmental trajectory. For this the findings of the current study will now be linked back to attachment theory.

Bowlby (1988) and Ainsworth, (1978) have long since established a connection between attachment style, parenting style and the developmental trajectory of children. Bowlby (1988) proposed that attachment style has the potential to define how we see the world, ourselves and others. He referred to these beliefs and expectations as working models and speculated that these could affect the way we respond to, and interpret, interpersonal relationships (Waters et al, 2000). Bowlby (1988) also proposed that working models could endure across the life span, affect one's self concept, influence how we regulate emotional experiences, and have long term consequences for the relationships held in adulthood (Cassidy & Mohr, 2001). Four attachment styles have been identified, these include secure, avoidant, resistant or ambivalent and disorganised or disorientated (Ainsworth et al, 1978; Main & Solomon, 1990).

Figure 5 shows the four attachment styles across the avoidance and anxiety dimensions.

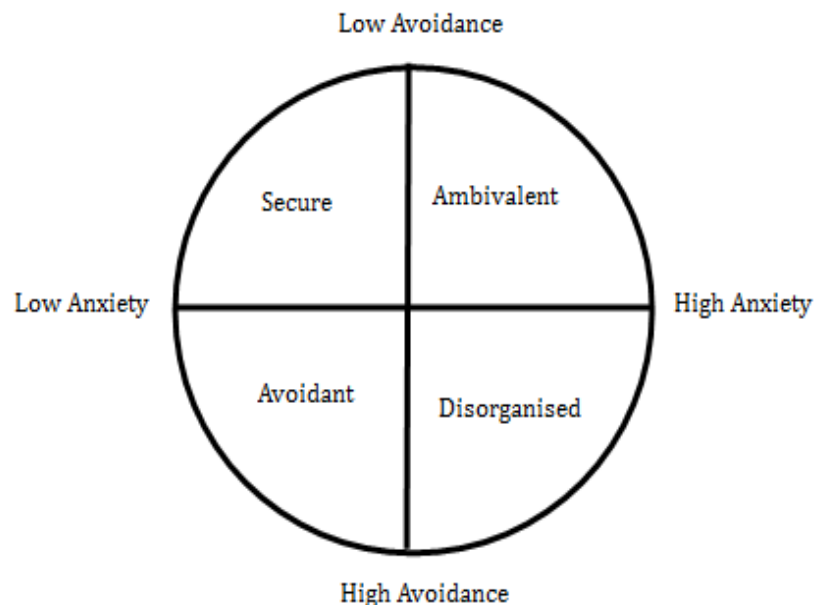


Figure 5. Attachment Styles (Srivastava & Beer, 2005)

As seen in Figure 3 Parenting Typologies and Figure 5 Attachment Styles there is a striking similarity between attachment theory and theories on parenting typology. Although attachment theory is a relational construct that refers to the affective bond between parent and child, and parenting theories are aimed at describing parenting behaviours and patterns, the two remain intrinsically linked. Cummings & Cummings (2002) agree, stating that attachment patterns are systemically related to parenting behaviour and that parenting is the foundation of attachment. Therefore, when considering parenting approach, one can also speculate on the types of attachment styles present and the resulting mental models. This is supported by Neal & Frisk-Horbury, (2001) who have mapped parenting approach onto attachment style and believe authoritative parenting, which is warm, boundaried and predictable, is indicative of secure attachment; authoritarian parenting, which is boundaried but dismissive and lacks warmth, is indicative of avoidant attachment; permissive indulgent parenting, which may be responsive and warm but fails to respond to attachment signals appropriately (e.g. kissing a child who does not want to be kissed or refusing to let a child partake in developmentally appropriate exploration) is indicative of an ambivalent attachment that is dependent and anxious; permissive neglectful parenting, which lacks warmth, predictability and boundaries is indicative of disorganised or disorientated attachment. This means that, when considering the developmental trajectory of children parented by permissive care-givers, we may consider insecure attachment under the same umbrella. The same can also be said for affectionate control which, as previously mentioned, also has its origins in attachment theory. This makes it possible to speculate on the long term trajectory of the participant's surviving and subsequent children. For instance, it could be suggested that the permissive parenting and affectionate control, described in the 'Parenting Outside of Yourself' theme and the 'Disruptive Appreciation' theme, can heighten the risk of developing an ambivalent attachment.

Permissive parenting and ambivalent attachment has long term consequences for developmental trajectory, with children being vulnerable to difficulties regulating their emotions, tolerating frustration or individuating from their care-giver (McKinney, 2004; Cairns, 2002; Baumrind, 1966). In addition, the children parented in this manner who do go on to exhibit ambivalent attachment are described as being immature and anxious, with low self reliance and low self control (Baumrind, 1966; MacCoby & Martin, 1983; Carr, 2006). Ultimately, permissive parenting and ambivalent attachment can result in a

child who cannot explore the world from a secure base but whom is restricted in their activities, anxious in their position and fully reliant on others for emotional containment (Carr, 2006). As a result, these children can go on to develop internal working models that incorporate anxiousness, low independence and high dependency. See Figure 6. for an example of the working models.

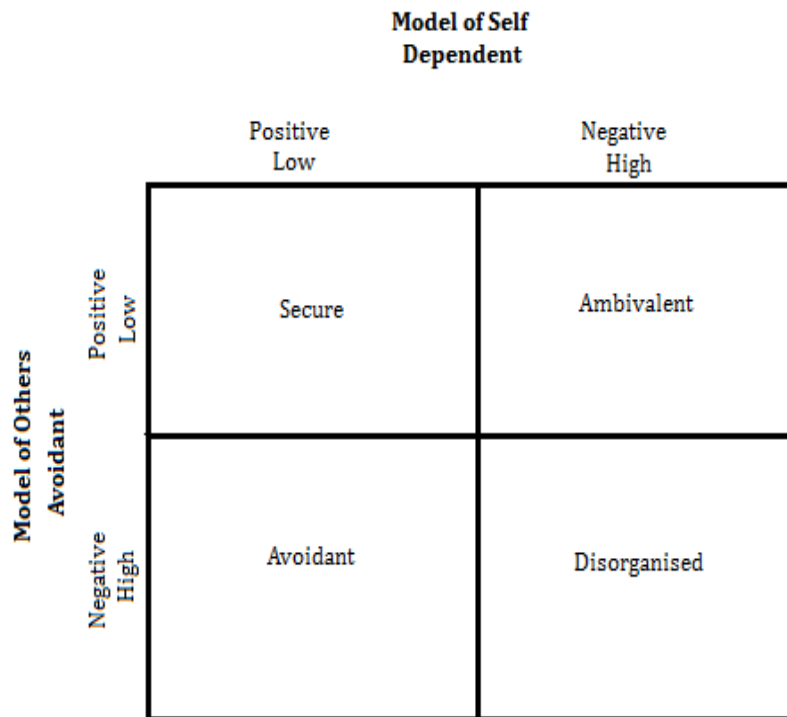


Figure 6. Working Models of Self and Others (Bartholomew, 1990)

Like parenting behaviour and attachment, working models also have implications for a child’s trajectory which can endure across the life span. This can be seen in the early parent child relationship, the development of emotional intelligence in adolescence, the intimate relationships held in adulthood, the attachment relationship held in parenthood and grief reactions in later life (Besser & Priel, 2008; Cairns, 2002; Green & Goldwyn, 2002; McKinney, 2004; Mehta et al, 2009; Rice, 1990; Van Ilzendoorn et al, 1995). Therefore, due to the permissive and anxious parenting seen in the ‘Parenting Outside of Yourself’ theme and the ‘Disruptive Appreciation’ theme, it also seems plausible to hypothesise that the participant’s surviving and subsequent children may go on to develop maladaptive mental models.

5.1.8 Attachment, Parenting and Long Term Trajectory

Parenting style and the attachment relationship can impact on the developmental tasks of childhood, such as individuation and identity development, self evaluation, emotional self regulation and emotional intelligence (Harter, 1999; Bandura, 1997; Cicchetti, 1991; Bar-On & Parker, 2000). A literature review by Carr (2006) has established that authoritative parenting, associated with secure attachment, is developmentally advantageous. Parenting conducted in this manner is associated with high achieving children who are not drawn to risky behaviour and who do not easily succumb to peer pressure (Steinberg, 1992; Carr, 2006). This is thought to largely coincide with the associated secure attachment, the modelling of emotional intelligence and skills such as emotional regulation and mentalization (Cummings & Cummings, 2002; Neal & Frisk-Horbury, 2001).

Indulgent permissive parenting, associated with ambivalent attachment, has been linked to disobedient children who have poor self control, difficulty tolerating frustration and who present as immature, developmentally delayed and dependent (Bandura, 1997; Baumrind, 1966; Carr 2006; MacCoby & Martin, 1983). In addition, permissive parenting and ambivalent attachment has been linked to psychopathology in later life and an increased risk of learning, behavioural and emotional difficulties (Cummings & Cummings, 2002; Carr 2006; Bandura, 1997). This may explain why surviving and subsequent children are more likely to experience mental health difficulties in adulthood (Warland, 2011a; Warland 2011b). On this basis, it is fair to hypothesise that the parenting described in the current study, in the 'Parenting Outside of Yourself' theme and the 'Disruptive Appreciation' theme, might, in the long term, also impact the psychological wellbeing of the surviving and subsequent children.

5.1.9 Section Summary: Parent and Child

If we accept the proposal that parenting behaviour and attachment style are linked then we can hypothesise that a shift in parenting, described in the 'Parenting Outside of Yourself' theme and the 'Disruptive Appreciation' theme, may result in an attachment style and mental models which are not developmentally advantageous. This may be attributable to the disruptive effect of infant bereavement. This is supported by Hughes et al (2001) who found that the children of bereaved parents are more likely to experience disturbance to the attachment relationship. Hughes et al (2001) also propose

that the bereaved parents' 'state of mind' is responsible for relational disturbances. Therefore, the underlying cognitive processes, described in the 'Bitter Restoration' theme, the 'Restoration Through You' theme and the 'Disruptive Appreciation' theme, may be indicative of this 'state of mind'. To some extent this may change how we view the parent child relationship.

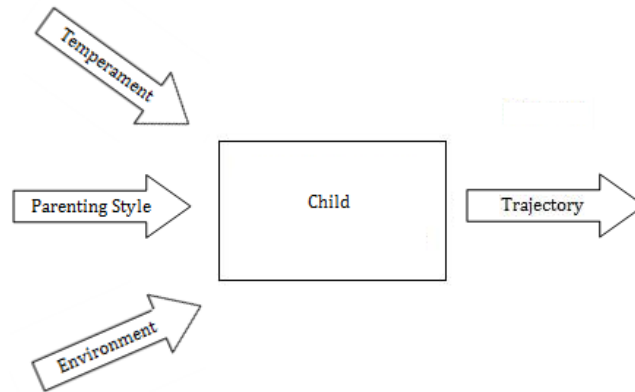


Figure 7. Input Output Model of Parenting

Instead of viewing parents as the providers of parenting and children as receivers (See Figure 7), we may start to consider the processes and cognitions which underlie parenting styles as the foundations for everything which comes after (See Figure 8).

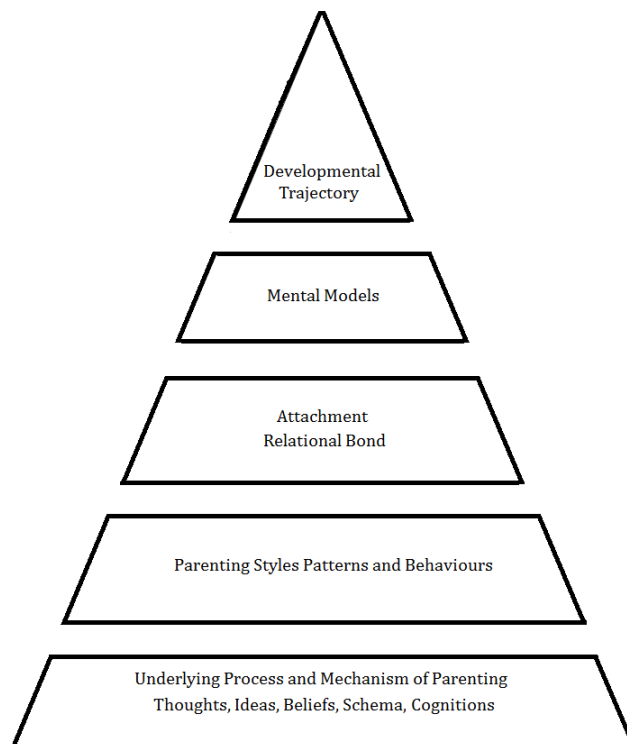


Figure 8. Pyramid Model of Parenting

5.2 Implications for Clinical Practice

Research has established that the death of an infant can have serious and long-term consequences for individual and family functioning (Boyle et al, 1996; Defraun, 1991; Dyregrov & Matthiesen, 1987; Dyregrov & Matthiesen, 1991; Harper et al, 2011; Laakso & Paunonen-Ilmonen, 2002; Lamb, 2002; Li et al, 2005; Vance et al, 1995; Wijngaards-de Meij et al, 2005; Wing et al, 2001). This can be seen in the parenting phenomenon which can develop after the death of a child (e.g., replacement child syndrome, vulnerable child syndrome and the parenting paradox). The current research, however, transcends the labelling of the parenting phenomena and attempts to provide a model aimed at describing the processes and cognitions which underlie disturbed parenting. This may have clinical implications for the intervention strategies used, with bereaved parents experiencing loss-related parenting phenomena. Caoitulo, (2005), Gold, (2007) and Price (2007) all discuss grief-focused individual and group psychotherapy for addressing the parenting dysfunction experienced by bereaved parents. However, the results of the current study imply that, for these participants, interventions which focus on the processes underlying parenting styles (e.g. anxiety and rumination and safety and neutralising behaviours) may also be helpful and improve the quality of their parenting life. It also seems that the relational aspects of parenting, such as attachment style, emotional over-involvement, enmeshment and imposed dependence, would also be improved by interventions which focused on these underlying processes. For instance, if parenting typologies are indicative of attachment style then it is fair to presume that intervening on parenting phenomenon, by targeting the underlying cognitions and processes, would indirectly impact on the parent child relationship.

Research has established that bereaved siblings are at increased risk of mental health difficulties in later life (Warland et al, 2011a; Warland et al, 2011b). However, input output models of parenting (see Figure 7) are limited and rely on parenting behaviour to explain a child's long term trajectory. Therefore, it might be more helpful to consider a five tiered approach (see Figure 8). The five tiered approach transcends parenting behaviours and considers the cognitions and processes which underlie it. It also conceptualises parenting as a pyramid, in which the underlying cognitions and processes are the foundations of parenting typology, attachment, the infant's developing mental models and the child's long term developmental trajectory. This might better support clinicians in developing hypotheses regarding why the surviving and subsequent

children of bereaved parents are at increased risk of developing mental health difficulties. For instance, rather than considering parenting behaviours in isolation, the clinician may also want to consider parenting cognitions and how these indirectly impact the child. This could have clinical implications for interventions undertaken with the surviving and subsequent children of bereaved parents, as it highlights the importance of the parents' parenting cognitions. As a result, the current study offers clinicians a modest evidence base for considering the parenting cognitions and for working through bereaved parents to change their child's long term trajectory.

5.3 Methodological Considerations

The aim of the current research was to explore mothers' experiences of parenting and their transition from being a parent unaffected by SIDS to a parent affected by SIDS. However, due to the bereavement and secondary losses these parents experienced, it was important to consider how the research could hone in on parenting and SIDS without being compromised by other phenomena such as grief. Significant efforts were made by the researcher to identify phenomena which could impact the research question and threaten the homogeneity of the group. Consequently, pre-interview measures were incorporated to provide information on the group's homogeneity, the presence or absence of secondary phenomena, and as a way of assessing the reliability and validity of the current research. However, despite these precautions, it should be acknowledged that self report measures are vulnerable to deception (Tomarken, 1995). It should also be acknowledged that temporal issues apply and, although the participants did not report feeling distressed on the day of the interview, they may have had a history of long-term intermittent distress (Tomarken, 1995). Research by Hunt et al (1997) and Winters, (2010) suggests that traumatic events can lead to avoidance and, as a result, difficulties processing the emotional content of the experience. As a consequence, those who are significantly distressed by events are often unable to develop narratives around their experiences (Hunt et al, 1997; Winters 2010). Therefore, one methodological consideration could have been the possibility of under elaborated stories within the transcripts.

Retrospective bias was another possible methodological concern and it is plausible that parenting before an experience of SIDS was seen in a more positive light because of the traumatic nature of the loss. For example, in comparison to parenting in the aftermath of

a SIDS event, the experience of parenting in the absence of loss could be considered effortless and uncomplicated. It would be interesting to follow this up further and consider these accounts in comparison to accounts provided by new mothers. One way to alleviate this would have been the incorporation of a prospective design. However, given that SIDS events are relatively uncommon, the sample size for a prospective IPA would be unfeasibly large, especially given the small numbers of participants usually required for qualitative methodology. In addition, the fact that pre-loss parenting was experienced as effortless and natural might emphasise how challenging and difficult things become in the aftermath of a SIDS event.

The hermeneutic nature of IPA, which requires the researcher to interpret the participant's interpretations, has been criticised for not adequately explaining how the researcher's position may impact the analysis (Willing, 2001). Willing (2001) suggests that the analysing of IPA is a journey of discovery rather than a process of construction, with results being influenced in unknown ways which may or may not be identifiable. In addition, social constructionists argue that IPA's focus on language, as a vehicle of description, is misplaced and that language is primarily involved in social processes and the construction of one's reality (Stark & Brown Trinidad, 2007; Willing, 2002). Therefore, it could be argued that IPA tells us more about how a person goes about constructing their reality than their experience of a specific event (Willing, 2002). It could also be argued that, if language is not a descriptive vehicle, humans lack the necessary apparatus to express their experiences to one another. One participant put this best when she said:

I think it's a really unique event and you can't really describe it to anyone, unless they've gone through that, you just can't, and even if people wanted to listen, to hear about it, they would not be able to envisage exactly what it meant, the feelings, the horror and the shock (Nicole)

Having said this, IPA is the only method that makes attempts at gaining direct access to an individual's subjective and internal world (Smith & Osborn, 2008). Given the aims of the current research, IPA remains the most fitting approach to undertake when focusing on mothers' subjective experiences of parenting. Therefore, as Smith & Osborn (2008) remark, it is the researcher's responsibility to bracket their belief systems, consider what the participant is and is not communicating, and on this basis attempt to make

interpretations on emotional states. Ultimately, however, interpreting an individual's interpretations means that the results of IPA cannot be generalised and will only provide an understanding of what the current participants experiences were.

5.4 Future Research

The current research findings and framing literature suggests that these participants experienced a parental shift into a permissive parenting style, characterised by affectionate control and low expressed emotion. The research findings and framing literature also propose that the participants' increased appreciation for their children may be disruptive to the parenting process. However, the research cannot be generalised to the wider population and it therefore remains unclear whether this is a common experience amongst bereaved parents or an experience exclusive to the current sample. In addition, the research cannot speculate on whether this shift in parenting is exclusive to SIDS populations or whether it is a common experience across various types of perinatal death and parental bereavements. Therefore, future research could focus on establishing whether permissive parenting styles are applicable to the wider population of bereaved parents and, if so, within which groups.

Previous research by Warland et al, (2011a), Warland et al, (2011b) and O'Leary (2011) has established that parental bereavement can result in emotional distancing and the replacement of the deceased with subsequent offspring. The current study, however, found that participants did not view their subsequent children as replacements. Instead participants felt that the continued survival of their surviving and subsequent children provided vindication and legitimised their losses, which allowed them to restore their identity and happiness and move forward with their lives. This resulted in emotional over-involvement rather than emotional distancing. This was a particularly interesting finding and, as the current study cannot generalise to SIDS populations, it would be interesting to follow this up. Further studies could focus on establishing whether the unexplainable nature of SIDS contributes to the need for vindication, leading to increased appreciation, or whether this is a common experience of all bereaved parents.

The current research also appeared to suggest that, for these participants, feeling unsafe in the world was a concern and led to attempts at behaviourally controlling the uncontrollable. It would be interesting to establish whether this non-pathological

'symptomatology', (e.g. rumination, safety behaviour, neutralising behaviour and avoidance) is common in bereaved populations or specific to SIDS populations. The current research hypothesises that this experience may be inherent in SIDS. This is due to the unknown nature of SIDS and the fact that parents cannot avoid a reoccurrence by identifying and circumventing causal factors. As a result, SIDS parents might become hypervigilant to threat and attempt to avoid anything that might pose a risk. This hypothesis, however, would need to be tested in further research.

Finally, in response to the master themes, subthemes and relevant literature, the current study proposed a model of parenting in the aftermath of a SIDS event (See Section 5.1.6 Model of Parenting). By reconciling the research findings with established theory, the model attempts to explain the underlying cognitions and processes which drove the parenting behaviour described by participants and the factors which served to maintain it. However, as the research findings cannot be generalised, it is unknown whether the model provides a robust map of the cognitions, processes and parenting behaviours experienced by parents bereaved through SIDS, or whether its usefulness is exclusive to the current sample. It is also unknown whether the model maps out the cognitions, processes and parenting behaviours experienced by SIDS parents or whether it could be applied more generally to other parentally bereaved populations. Therefore, in order to develop the proposed model further, research should be carried out to establish whether the research findings can be replicated within the wider SIDS population and with other parentally bereaved populations.

5.5 Conclusion

The current study has made a contribution to research and literature on mothers' experiences of parenting through SIDS. In many instances the results from the current study were consistent with previous research on parenting through parental bereavement. At times, however, the research was able to further elaborate on the hypotheses offered by labels used to describe the parenting phenomena seen in bereaved populations. This resulted in the development of a model focused on parenting in the aftermath of a SIDS event, which attempts to map what is already understood about anxiety and parenting styles onto parents' experiences and internal states. By doing this it is hoped that another level of understanding, regarding the cascading effect of parental bereavement, will be provided (e.g., parents' internal states, subsequent

parenting behaviour, the effect this has on the child's internal state and the child's developmental trajectory). The key finding of the study was that the transition, from being a parent unaffected by SIDS to a parent affected by SIDS, is characterised by a shift into permissive and anxious parenting that is motivated by a sense of unsafety and an increased appreciation for surviving and subsequent children. The study has also shown that, despite parenting disturbances, parents are keen to do their very best for their children and as a result may be open to hearing the effects of parental bereavement on parenting and how this can be considered in future parenting practices. To summarise, while the study tells us that a SIDS event can disturb parenting it also tells us that the increased appreciation felt for the surviving and subsequent children is also disruptive to the parenting process.

Even my husband will sometimes say “you love him more than you love me”, and I say “no it’s a different kind of love”, but I can’t explain, nobody in this world understands how I feel about Liam (Bonnie).

References

- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC
- Ainslie, R. C. & Solyom, A. E. (1986). The Replacement of the Fantasied Oedipal Child: A Disruptive effect of Sibling Loss on the Mother-Infant Relationship. *Psychoanalytic Psychology*. Vol. 3 No. 3 pp. 257-268
- Ainsworth, M. (1978). Bowlby-Ainsworth Attachment Theory. *Behavioural and Brain Science*, Vol. 1, No. 3, pp. 436-438.
- Bajanowski, T., Vege, A., Byard, R. W., Krous, h. F. & Arnestad, M. (2007). Sudden infant death syndrome (SIDS)—Standardised investigations and classification: Recommendations. *Forensic Science International*. Vol. 165, No. 2–3, pp. 129–143
- Ball, H. L., Moya, E., Fairley, L., Westman, J., Oddie, S. & J. Wright (2012). Infant care practices related to sudden infant death syndrome in South Asian and White British families in the UK. *Paediatric and Perinatal Epidemiology*. Vol. 26, No. 1, pp 3–12
- Bandura, A (1997). *Self Efficacy*. New York: Freeman
- Bartholomew, K. (1990). Avoidance of Intimacy: An Attachment Perspective. *Journal of Social and Personal Relationships*. Vol. 7 pp. 147-178
- Bar-On, R. & Parker, J. (2000). *The Handbook of Emotional Intelligence*. San Francisco: Presser
- Baumrind, D. (1966). Effects of Authoritative Parental Control on Child Behaviour. *Child Development*. Vol. 37 No. 4, pp 887-907
- Baumrind, D. (1967). Child care practices anteceding three patterns of preschool behaviour. *Genetic Psychology Monographs*, Vol. 75, No. 1, pp. 43-88.

-
- Beal, S. M. & H. K. Blundell (1988). Recurrence incidence of sudden infant death syndrome. *Archive of Disease in Childhood*. Vol. 63, pp. 924-930
- Beckwith, B. J. (2003). Defining Sudden Infant Death Syndrome. *Archive of Paediatric and Adolescent Medicine*. Vol. 157, pp. 286-290
- Birns, B. (1999). Attachment Theory Revisited: Challenging Conceptual and Methodological Sacred Cows. *Feminism & Psychology*. Vol. 9, No. 1, pp. 10-21.
- Blackwell, C. C. & Weir, D. M. (1999). The role of infection in sudden infant death syndrome. *FEMS Immunology & Medical Microbiology*. Vol. 25, No. 1-2, pp. 1-6
- Blackwell, C. C., Moscovis, S. M., Gordon, A. E., Al Madani, O. M, Hall, S. T., Gleeson, M., Scott, R. J., Roberts-Thompson, J., Weir, D. M. & Busuttill A. (2005). Cytokine responses and sudden infant death syndrome: genetic, developmental, and environmental risk factors. *Journal of Leukocyte Biology* Vol. 78, No. 6, pp. 1242-1254
- Blechar Gibbons, M. (1992) A Child Dies, A Child Survives: The Impact of Sibling Loss. *Journal of Paediatric Health Care*. Vol. 6, No. 2, pp. 65 - 72
- Biggerstaff, D. (2008). Interpretative Phenomenological Analysis (IPA): A Qualitative Methodology of Choice in Healthcare Research. *Qualitative Research in Psychology*. Vol. 5, pp. 173-183
- Bluglass, K. (1981). Psychosocial Aspects of the Sudden Infant Death Syndrome ("Cot Death"). *Child Psychology and Psychiatry*. Vol. 22, No. 4, pp. 411-421
- Bookman, F. & Nolan, J. (2006). The Dark Figure of Infanticide in England and Wales: Complexities of Diagnosis. *Journal of Interpersonal Violence*. Vol. 21, No. 7, pp. 869-889
- Bowlby, J. (1978). Attachment theory and its therapeutic implications. *Adolescent Psychiatry* Vol. 6, pp. 5-33.

Bowlby, J. (1988). *A Secure Base*. New York: Routledge.

Boyle, F. M., Vance, J. C., Jake, M. Najman, M. & Thearle, M. J. (1996). The Mental Health Impact of Stillbirth, Neonatal Death or SIDS: Prevalence and Patterns of Distress Among Mothers. *Social Science and Medicine*. Vol. 43, No. 8, pp. 1273 – 1282

British Psychological Society (2009). Code of Ethics and Conduct. Retrieved on the 5th of January 2011 from http://www.bps.org.uk/sites/default/files/documents/code_of_ethics_and_conduct.pdf

British Psychological Society (2010). Code of Human Research Ethics. Retrieved on the 5th of January 2011 from http://www.bps.org.uk/sites/default/files/documents/code_of_human_research_ethics.pdf

Brown, G. (1985). The discovery of EE: induction or deduction?. In Kuipers, L. (1994). The measure of expressed emotion: Its influence on research and clinical practice. *International Review of Psychiatry*. Vol. 6(3) pp. 187-200

Buckle, J. L. & Fleming, S. J. (2011). *Parenting After the Death of a Child*. Routledge: Hove Sussex

Butler, G., Fennell, M. & Hackmann, A. (2008). *Cognitive Behaviour Therapy for Anxiety Disorder: mastering clinical challenges*. London: Guilford Press.

Cain A.C. & Cain B.S. (1964). 'A Death in the Family – The Paediatrician's Role'. *Journal of the American Academy of Child Psychiatry*. Vol. 3, pp. 433-456

Cairns, K. (2002). *Attachment, Trauma and Resilience: Therapeutic Caring for Children*. London : British Agencies for Adoption and Fostering .

Caoitulo, K. L. (2005). Evidence for Healing Interventions with Perinatal Bereavement. *MCN*. Vol. 30. No. 6., pp. 389 - 396

-
- Carr, A. (2010). *The Handbook of Child and Adolescent Clinical Psychology: Second Edition*. London: Routledge
- Carter B, & McGoldrick M. (1989). Overview: the changing family life cycle: a framework for family therapy. In: Carter B, McGoldrick M, (Eds). *The Changing Family Life Cycle: a framework for family therapy*. Boston, MA: Allyn and Bacon. pp. 3-28.
- Cassidy, J. & Mohr, J. J. (2001). Unsolvability, Fear, Trauma, and Psychopathology: Theory, Research, and Clinical Considerations Related to Disorganized Attachment Across the Life Span. *Clinical Psychology: Science and Practice*. Vol. 8, No. 3.
- Cicchetti, D. (1991). Fractures in the Crystal: Development of Psychopathology and the Emergence of Self. *Developmental Review*. Vol. 9 pp. 395-401
- Clarke, C. (2009). An Introduction to Interpretative Phenomenological Analysis: a Useful Approach for Occupational Therapy Research *The British Journal of Occupational Therapy*. Vol. 72, No. 1, pp. 37-39
- Cote', A., Russo, P. & Michaud, J. (1999). Sudden Unexpected Death in Infancy: What are the Causes? *The Journal of Paediatrics*. Vol. 135, No. 4, pp. 437-443
- Cummings, M. E. & Cummings, J. (2002). Parenting and Attachment. In Bornstein, M. H. (eds). *Handbook of Parenting Volume 5 Practical Issues in Parenting* (pp. 36 -59). New Jersey: Lawrence Erlbaum Associates, Publishers.
- Darling, N & Steinberg L. (1993). Parenting Style as Context: An Integrative Model. *Psychology Bulletin*. Vol. 113, No 3. pp. 487-496
- Davis, D. L., Stewart, M. & Harmon, R.J. (1989). Postponing pregnancy after perinatal death: perspectives on doctor advice. *Journal of the American Academy of Child & Adolescent Psychiatry* No. 28, No. 4, pp. 481-487.
- Defraun, J. (1991). Learning about Grief from Normal Families: SIDS, Stillbirth and Miscarriage. *Journal of Marital and Family Therapy*. Vol 17, No. 3, pp. 215-232

-
- Derogatis, L. R. (1975). Symptom Checklist 90 Revised. United States of America: Person Assessments
- DiBartolo, P. M. & Helt, M. (2007). Theoretical Models of Affectionate Versus Affectionless Control in Anxious Families: A critical Examination Based on Observations of Parent Child Interactions. *Clinical Child and Family Psychology*. Vol. 10, No. 3, pp. 253-274
- Dwyer, T. & Ponsonby, A. L. (1996). Sudden infant death syndrome: after the “back to sleep” campaign. *British Medical Journal*. Vol. 313, No. 180
- Dyregrov, K. (2004). Bereaved Parent’s Experience of Research Participation. *Social Sciences and Medicine*. Vol. 58, pp. 391 - 400
- Dyregrov, A. & Dyregrov, K. (1999). Long- Term Impact of Sudden Infant Death: A 12- to 15- Year Follow Up. *Death Studies*. Vol. 23, No. 7, pp. 635-661
- Dyregrov, A. & Matthiesen, S. B (1987). Stillbirth, Neonatal Death and Sudden Infant Death (SIDS): Parental Reactions. *Scandinavian Journal of Psychology*. Vol. 28, pp. 104-114
- Dyregrov, A. & Matthiesen, S. B (1991). Parental Grief Following the Death of an Infant – A Follow Up over One Year. *Scandinavian Journal of Psychology*. Vol. 32, pp. 193-207
- Dyregrov, K., Nordanger, D. & Dyregrov, A. (2003). Predictors of Psychological Distress After Suicide, SIDS and Accidents. *Death Studies*. Vol. 27, No. 2, pp. 143-165
- Farooqi, S., Perry, I. J. & Beevers D.G. (2008) Ethnic differences in infant-rearing practices and their possible relationship to the incidence of sudden infant death syndrome (SIDS). *Paediatric and perinatal epidemiology* Vol.7, No. 3, pp. 245
- Fransella, F., Bell, R., & Bannister, D. (2004). *A Manual for Repertory Grid Technique (2nd ed)*. West Sussex: John Wiley & Son Ltd.

Franzblau, S. H. (1999). Historicizing Attachment Theory: Binding the Ties that Binds. *Feminism & Psychology* . Vol. 9, No. 1, pp. 22-31.

FSID Facts and Figures (2009). Retrieved on the 10th of September 2011 from <http://fsid.org.uk/document.doc?id=97>

FSID Giving Babies the Chance of a Life Time (2009). Retrieved on the 10th of September 2011 from <http://fsid.org.uk/page.aspx?pid=403>

Gold, K. J. (2007). Navigating Care After a Baby Dies: A systematic Review of Parent Experiences with Health Providers. *Journal of Perinatology*. Vol. 27, pp. 230-237

Graziano, A. M. & Raulin, M. L. (2004). *Research Methods: A Process of Inquiry (5th ed.)*. USA: Pearson Education Group Inc.

Green, J. & Goldwyn, R. (2002). Annotation: Attachment disorganisation and psychopathology: new findings in attachment research and their potential implications for developmental psychopathology in childhood. *Journal of Child Psychology and Psychiatry* . Vol. 43, No. 7, pp. 835-846.

Green, A. & Solnit, A. J. (1964). Reactions to the Threatened Loss of a Child: A Vulnerable Child Syndrome. *Paediatrics*. Vol. 34, pp. 58-66

Grout, L. A. & Romanoff, B. D. (2010). The Myth of the Replacement Child: Parents' Stories and Practice After Perinatal Death. *Death Studies*. Vol. 24, No. 2, pp. 93-113

Handsley, S (2001). "But what about us?" The residual effects of sudden death on self identity and family relationships. *Mortality*. Vol. 6, No.1, pp. 9-29

Harter, S. (1999). *The Cognitive and Social Construction of the Developing Self*. New York: Guilford Press.

Harper, M., O'Conner, R. Dickson, A. & O'Carroll (2011). Mothers Continuing Bounds and Ambivalence to Personal Mortality after the Death of their Child – An Interpretative

-
- Phenomenological Analysis. *Psychology, Health and Medicine*. Vol. 16, No. 2, pp. 203-214
- Harrison, L. M., Morris, J. A., Telford, D. R., Brown, S. M. & Jones, K (1999). The nasopharyngeal bacterial flora in infancy: effects of age, gender, season, viral upper respiratory tract infection and sleeping position. *FEMS Immunology & Medical Microbiology*. Vol. 25, No. 1-2, pp. 19-28
- Hashemi, A. H. and Cochrane, R. (1999). Expressed emotion and schizophrenia: A review of studies Across Culture. *International Review of Psychiatry*. Vol. 11(2) pp. 219-225
- Hastings, S. O. (2000). Self disclosure and identity management by bereaved parents. *Communication Studies* Vol. 51, No. 4, pp. 352-371
- Hauck, F. R. & Tanabe, K. O. (2008). International Trends in Sudden Infant Death Syndrome: Stabilization of Rates Requires Further Action. *Pediatrics* Vol. 122, No. 3, pp. 660 -666
- Heller, S. S. & Zeanah, C. H. (1999). Attachment Disturbances in Infants Born Subsequent to Perinatal Loss: A Pilot Study. *Infant Mental Health Journal*. Vol. 20, No. 2, pp. 188-199
- Hicks, J & Allen, G. (1999). A Century of Change: Trends in UK Statistic since 1990. Retrieved on the 20th of January 2012 from: <http://www.parliament.uk/documents/commons/lib/research/rp99/rp99-111.pdf>
- Hodes, M. and Le Grange, D. (1993). Expressed emotion in the investigation of eating disorders: A review. *International Journal of Eating Disorders*. Vol. 13(3) pp. 279-288
- Hunt, C. E. & Hauck, F. R. (2006). Sudden Infant Death Syndrome. *Canadian Medical Association Journal*. Vol. 174, No. 13, pp. 1861-1869

-
- Hunt, L., Marshall, M., & Rowlings, C. (1997). *Past Trauma in Late Life: European Perspectives on Therapeutic Work with Older People*. London: Jessica Kingsley Publishers
- Ivanovic, M., Vuletic, Z., and Bebbington, P. E. (1994). Expressed emotion in the families of patients with schizophrenia and its influence on the course of illness. *Social Psychiatry and Psychiatric Epidemiology*. Vol. 29 pp. 61-65
- Kinney H. C. (2009). Neuropathology provides new insight in the pathogenesis of the sudden infant death syndrome. *Acta Neuropathologica*. Vol. 117, No. 3, pp. 247-255
- Kinney, H. C., Filiano, J. J. & Harper, R. M. (1992). The Neuropathology of the Sudden Infant Death Syndrome. A Review. *Journal of Neuropathology & Experimental Neurology*. Vol. 51, No. 2, pp. 115-126
- Kog, E. and Vandereycken, W. (1985). Family characteristics of anorexia nervosa and bulimia: A review of the research literature. *Clinical Psychology Review*. Vol. 5 pp. 159-180
- Krueger, G. (2005). Meaning-Making in the Aftermath of Sudden Infant Death Syndrome. *Nursery Inquiry*. Vol. 13, No. 3, pp. 163-171
- Kuipers, L. (1994). The measure of expressed emotion: Its influences on research and clinical practice. *International Review of Psychiatry*. Vol. 6(2) pp.187-200
- Kwon, J., Delaney Black, V., Covington, C., Abell, S. C., Nordstrom-Bailey, B., Sokol, R. J. & Ager, J. (2006). The Relations Between Maternal Expressed Emotion and Children's Perceived Self- Competence, Behaviour and Intelligence in African American Families. *Early Child Development and Care*. Vol. 175, No. 2, pp.195-206
- Lamb, E. H. (2009). The Impact of Previous Perinatal Loss on Subsequent Pregnancy and Parenting. *The Journal of Perinatal Education*. Vol. 11, No. 2, pp. 33- 40

-
- Laakso, H. & Paunonen-Ilmonen, M. (2002). Mothers' Experience of Social Support Following the Death of a Child. *Journal of Clinical Nursing*. Vol. 11, pp. 176-185
- Leach, C. E. A., Blair, P. S. & Fleming, P. J. (1999). Epidemiology of SIDS and Explained Sudden Infant Deaths. *Pediatrics* Vol. 104 No. 4, pp. e43
- Lefancois, G. R. (1999). *Psychology for Teaching (10th ed.)*. Stanford: Thompson Learning
- Levene, S. & Bacon, C. J. (2004). Sudden Infant Death and Covert Homicide in Infancy. *Archive of Disease in Childhood*. Vol. 89, pp. 443-447
- Lewis, P. (2003). Crib Death: A Behavioural Phenomenon. *Current Directions in Psychological Science*. Vol. 12, pp. 164-170
- Li, J., Laursen, T. M., Precht, D. H., Olsen, J. & Mortensen, P. B. (2005). Hospitalisation for Mental Illness Among Parents after the Death of a child. *The New England Journal of Medicine*. Vol. 352, pp. 1190-1196
- Maccoby, S. & Martin, R. (1983). Chapter 2: Literature Review. In Damon, W & Eisenberg, N. (EDS.) *Handbook of Child Psychology* (pp. 85 – 120). Wiley & Sons: Texas
- McGrath, J. M., Records, K., & Rice, M. (2008). Maternal Depression and Infant Temperament Characteristics. *Infant Behavioural Development*. Vol., 31, No. 1, pp. 71 – 81
- McKinney, W. T. (2004). *Why Love Matters: How Affection Shapes a Baby's Brain* . New York : Brunner-Routledge .
- Mehta, N., Cowan, P. A. & Cowan, C. P. (2009). Working Models of Attachment too Parents and Partners: Implications for Emotional Behavior Between Partners. *Journal of Family Psychology* . Vol. 23, No. 6, pp. 895-899.
- Morris, J. A. (1999). The common bacterial toxins hypothesis of sudden infant death syndrome. *FEMS Immunology & Medical Microbiology*. Vol. 25, No. 1-2, pp. 11–17

-
- Narita, N., Narita, M., Takashima, S., Nakayama, M, Nagai, T & Okado, N. (2001). Serotonin Transporter Gene Variation Is a Risk Factor for Sudden Infant Death Syndrome in the Japanese Population *Pediatrics* Vol. 107 No. 4 pp. 690 -692
- Neal, J. & Frick-Horbury, D. (2001). The Effects of Parenting Style on Childhood Attachment Patterns on Intimate Relationships. *Journal of Instructional Psychology*. Vol. 28. No. 3 pp. 285 -312
- Oglethorpe, R. J. (1989). Parenting After Perinatal Bereavement – A Review of the Literature. *Journal of Reproductive and Infant Psychology*. Vol. 7 pp. 227-244
- O’Leary, J. (2004). Grief and its Impact on Prenatal Attachment in the Subsequent Pregnancy. *Archives of Women’s Mental Health*. Vol. 0, pp. 1-12
- O’Leary, J., Warland, J. & Parker, L. (2011). Bereaved Parents’ Perception of the Grandparents’ Reactions to Perinatal Loss and the Pregnancy that follow. *Journal of Family Nursing*. Vol. 17, pp. 330 – 356
- O’Leary, J., Gaziano, C. & Thorwick, C. (2011). Born After Loss: The Invisable Child in Adulthood. *Journal of Prenatal and Perinatal Psychology*. Vol. 21, No. 1 pp. 3 – 23
- Ottaviani, G. (2011). Sudden Infant and perinatal Unexplained Death: Are we Moving Forward Yet? *Cardiovascular Pathology*. Vol. 20, pp. 302-306
- Oyen, N., Skjaerven, R. & Irgens, L. M (1996). Population Based Recurrence Risk of Sudden Infant Death Syndrome Compared with Other Infant and Fetal Deaths. *American Journal of Epidemiology*. Vol. 144, No. 3, pp 300-306
- Page, L. A. & Percival, P. (2000). *The New Midwifery: Science and Sensitivity in Practice*. Churchill & Livingstone: Oxford
- Paley, G. (2000). Familial origins of expressed emotion in relatives of people with schizophrenia. *Journal of Mental Health*. Vol. 9(6) pp. 655- 659

-
- Pantke, R & Slade, P. (2006). Remembered Parenting Style and Psychological Well-Being in Young Adults whose Parents had Experienced Early Child Loss. *Psychology and Psychotherapy: Theory, Research and Practice*. Vol. 79, pp. 69 - 81
- Patterson, J. M. & Garwick, A. W. (1994). Levels of Meaning in Family Stress Theory. *Family Process*. Vol 33. No. 3 pp. 287 – 304
- Patterson, P. & Birchwood, M (2005). Expressed Emotion as an Adaption to Loss. *British Journal of Psychiatry*. Vol. 187, pp 48-59
- Picard, C. (2002). Family Reflections on Living Through Sudden Infant Death Syndrome. *Nursing Science Quarterly*. Vol. 15, No. 1, pp. 242-250
- Powell, M. (1995). Sudden Infant Death Syndrome: The Subsequent Child. *British Journal of Social Work*. Vol. 2, pp. 227-240
- Poznanski, E. O (1972). The "replacement child": a saga of unresolved parental grief. *Journal of Paediatrics*. Vol. 81, No. 6 pp. 1190-3.
- Price, S. K. (2007). Social Work, Siblings, and SIDS: Conceptual and Case-Based Guidance for Family System Interventions. *Journal of Social Work in End-of-Life & Palliative Care*. Vol. 3, No. 3, pp. 81-101
- Raza M. W. & C. C. Blackwell (1999). Sudden infant death syndrome, virus infections and cytokines. *FEMS Immunology & Medical Microbiology*. Vol. 25, No. 1-2, pp. 85–96
- Reid, M. (2007). The Loss of a Baby and the Birth of the Next Infant: The Mothers Experience. *Journal of Child Psychotherapy*. Vol. 33, No. 2, pp. 181-201
- Rice, K. G. (1990). Attachment in Adolescence: A Narrative and Meta-Analytic Review . *Journal of youth and Adolescence* . Vol. 19, No. 5, pp. 511-538.

-
- Salkovskis, P., Richards, H. & Forrester, E. (1995). The relationship between obsessional problems and intrusive thoughts. *Behavioural and Cognitive Psychotherapy*. Vol. 23, pp. 281-299.
- Salmon, C. A. & Shackelford, T. K. (2007). *Family Relationships: An Evolutionary Perspective*. Oxford University Press: New York
- Saunders, (2012). SIDS Poem. Retrieved on the 16th of April 2012 from <http://poetry.sidsfamilies.com/>
- Silverstein, L. B., Auerbach, C. F. & Levant, R. F. (2006). Using qualitative research to strengthen clinical practice. *Professional Psychology: Research and Practice*. Vol. 37, No. 4, pp. 351-358.
- Smith, J. A. (1990). *Self Construction: Longitudinal Studies in the Psychology of Personal Identity and Life Transitions*. D.Phil. dissertation, University of Oxford.
- Smith, J. & Osborn, M (2008). *Interpretative Phenomenological Analysis*. In J. Smith (Eds). *Qualitative Psychology: A Practical Guide to Research Methods* (2nd ed). London: Sage Publications Limited
- Smith, J., Flowers, P. & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage Publications Limited
- Sofaer, S. (1999). Qualitative methods: what are they and why use them? *Health Service Research*. Vol. 34, No. 5 (2) pp. 1101-1118.
- Sparks L. D. & Hunsaker, J. C. (2002). Neuropathology of sudden infant death (syndrome): literature review and evidence of a probable apoptotic degenerative cause. *Child's Nervous System*. Vol. 18, No. 11, pp. 568-592
- Spencer, N. & Logan S. (2004). Sudden unexpected death in infancy and socioeconomic status: a systematic review. *Journal of Epidemiology and Community Health* Vol. 58, pp. 366-373

-
- Srivastava, S. & Beer, J. S. (2005). How self-evaluations relate to being liked by others: Integrating sociometer and attachment perspectives. *Journal of Personality and Social Psychology*. Vol. 89, No. 6, pp. 966-977
- .
- Starks, H & Brown Trinidad, S (2007) Choose Your Method: A Comparison of Phenomenology, Discourse Analysis, and Grounded Theory. *Qualitative Health Research*. Vol. 17 pp. 1372- 1380
- Steinberg, L., Lamborn, S. D., Dornbusch, S. M. & Darlington, N. (1992). Impact of Parenting Practices on Adolescent Achievement: Authoritative Parenting, School Involvement and Encouragement to Succeed. *Child Development*. Vol. 63 pp. 1266 - 1281
- Sullivan, K. M. & Barlow, S. M. (2001). Review of Risk Factors for Sudden Infant Death Syndrome. *Paediatric and Perinatal Epidemiology*. Vol. 18, pp. 144-200
- Toller, P. W. (2008) Bereaved Parents' Negotiation of Identity Following the Death of a Child. *Communication Studies* Vol. 59, No. 4, pp. 306-321
- Tomarken A. (1995). A Psychometric Perspective on Psychophysiological Measures. *Psychological Assessment*. Vol. 7, No. 3, pp. 387-395
- University of Hertfordshire (2004). Guide to Good Practice in Research. Retrieved on the 17th of April 2011 from https://docs.google.com/viewer?a=v&q=cache:W3CMYTpG7BoJ:www.herts.ac.uk/fms/documents/other/university-ofhertfordshire-guide-to-good-practice-in-research.doc+university+of+hertfordshires+good+practice+research+guideleins&hl=en&gl=uk&pid=bl&srcid=ADGEEsGvqWfLN_orlaZ3V8Sc2FxSzNR1aiP9vtK9FwPJS0mMLsTXATPWR7nejr6uNuM1kEe41ct0i3tDkeNjMMdqLuktNwA2IL_2PvDhZXsgg2t1gAacx13asA5BZS-nzlm0PRnpzsA&sig=AHIEtbSyd_FkCmC1GXzDejmC1aHysVxWOg
- Valeriotte, S. & Fine, M. (1987). Bereavement Following the Death of a Child: Implications for Family Therapy. *Contemporary Family Therapy*. Vol.9 No 3 pp. 202 – 218

-
- Vance, J. C., Najman, J. M., Thearle, M. J., Embelton, G., Foster, W. J. & Boyle, F. M. (1995). Psychological Changes in Parents Eight Months after the Loss of an Infant from Stillbirth, Neonatal Death or Sudden Infant Death Syndrome – A Longitudinal Study. *Paediatrics*. Vol. 96, pp. 933-938
- Van IJzendoorn, M. H. (1995). Of the Way We Are: On Temperament, Attachment, and the Transmission Gap: A Rejoinder to Fox (1995). *Psychological Bulletin* . Vol. 117, No. 3, pp. 411-415.
- Van IJzendoorn, M. H., Juffer, F. & Duyvesteyn, M. G. (1995). Breaking the Intergenerational Cycle of Insecure Attachment: A review of the Effects of Attachment-Based Interventions on Maternal Sensitivity and Infant Security. *Journal of Child Psychology and Psychiatry* . Vol 36, No. 2, pp. 225-248.
- Versalle, S. & McDowell, E. (2004). The Attitudes of Men and Women Concerning Gender Differences in Grief. *Omega – Journal of Death and Dying*. Vol. 50, No. 1, pp. 53-67
- Waller, G., Calam, R. and Slade, P. (1989). Eating disorders and family interaction. *The British Psychological Society*. Vol. 28 pp. 285-286
- Warland, J., O’Leary, J., McCutcheon, H. & Williamson, V. (2011a) Parenting Paradox: Parenting After Infant Loss. *Journal of Midwifery*. Vol. 27 pp. e163 – e169
- Warland, J., O’Leary, J. & McCutcheon, H. (2011b) Born After Infant Loss: The Experiences of Subsequent Children.. *Journal of Midwifery*. Vol. 27 pp. 628 - 633
- Waters, E., Weinfield, N. S. & Hamilton, C. E. (2000). The Stability of Attachment Security from Infancy to Adolescence and Early Adulthood: General Discussion. *Child Development* . Vol. 71, No. 3, pp. 703-706.
- Weese-Mayer, D. E., Ackerman, M. J., Marazita, M. L. & Berry-Kravis E. M. (2007). Sudden Infant Death Syndrome: Review of implicated genetic factors. *American Journal of Medical Genetics Part A* Vol. 143A, No. 8, pp 771–788

-
- Weiss D. S. (2004). The Impact of Event Scale-Revised. In Wilson, J. P. & Keane, T.M. (Eds). *Assessing Psychological Trauma and PTSD: A Practitioners Handbook* (pp. 399-411). New York: Guilford Press
- Westbrook, D., Kennerley, H. & Kirk, J. (2007) *An Introduction to Cognitive Behaviour Therapy: Skills and Applications*. Sage, London
- Wijngaards-de Meij, L., Stroebe, M., Schut, H. Stroebe, W., Van Den Bout, J., Van Den Heijden, P. & Dijkstra, I. (2005). Couples at Risk Following the Death of Their Child : Predictors of Grief Versus Depression. *Journal of Consulting and Clinical Psychology*. Vol. 73, No. 4, pp. 617-623
- Williams, A. L. (1990). Sudden Infant Death Syndrome. *Australian and New Zealand Journal of Obstetrics and Gynaecology*. Vol. 30, No. 2, pp. 98 - 107
- Wing, D., Clance, P. R., Burge-Callaway, K. & Armistead, L. (2001). Understanding Gender Differences in Bereavement Following the Death of an Infant: Implications for Treatment. *Psychotherapy*. Vol. 38, No. 1, pp. 60-73
- Winter, D. (2010). Personal construct perspectives on Deliberate Self-Harm and Post-Traumatic Stress. *Therapeutic Models & Interventions: PCP 10*. University of Hertfordshire: Unpublished.
- WHO Information Data Base (2010)*. Retrieved on the 4th of January 2012 from: http://search.who.int/search?q=sids&ie=utf8&site=default_collection&client=en&proxystylesheet=en&output=xml_no_dtd&oe=utf8
- Wood, J., McLeod, B., Siman, M., Hwang, W., & Chu, B. (2003). Parenting and Childhood Anxiety: Theory, Empirical Findings and Future Directions. *Journal of Child Psychology and Psychiatry*. Vol. 44, pp. 134-151
- World Health Organisation. (1992). *ICD-10 Classifications of Mental and Behavioural Disorder: Clinical Descriptions and Diagnostic Guidelines*. Geneva. World Health Organisation.

Appendices

Appendix 1: Advertisement	184
Appendix 2: Information Sheet	185
Appendix 3: Ethics Approval Certificate	186
Appendix 4: NRES Correspondence	187
Appendix 5: Consent Form	188
Appendix 6: Interview Information	189
Appendix 7: Non Disclosure and Confidentiality Agreement	190
Appendix 8: Debrief	191
Appendix 9: Further Support	192
Appendix 10: Review of Psychological Wellbeing and General Distress Measures	194
Appendix 11: Impact of Events Scale Revised – IES-R (Weiss, 2004)	204
Appendix 12: Symptom Check List 90 Revised – SCL-90-R (Derogatis, 1975)	205
Appendix 13: Interview Schedule	207
Appendix 14: Interview Prompts	210
Appendix 15: Transcript Excerpt	211
Appendix 16: Analysis Excerpt – Stage 2. Exploration & Stage 3. Emergent Themes	214
Appendix 17: Audit Trail – Analysis Stage 4	221
Appendix 18: Tabulating Themes across the Group – Analysis Stage 5	229
Appendix 19: Table of Master Themes, Subthemes and Quotes	230

Appendix 1: Advertisement



University of Hertfordshire
Hatfield
AL10 9AB
UK

tel +44 (0)1707 284000
fax +44 (0)1707 284115
herts.ac.uk

Volunteers Wanted for a Research Study

My name is Isis Davidson-Olsson and I am a Trainee Clinical Psychologist undertaking Doctoral training in Clinical Psychology at the University of Hertfordshire. I am conducting a study which aims to explore mother's experiences of parenting prior to and after Sudden Infant Death Syndrome.

The study will involve participating in one session. The session will focus on your ideas thoughts and experience of parenting, both now and in the past.

Those wanting to participate are required to meet certain criteria. You will need to be a mother, affected by Sudden Infant Death Syndrome who has at least one surviving child born before your family's loss and at least one subsequent child born after your family's loss. In addition, those who have experienced a very recent bereavement (i.e. within 26 months) will not be eligible to participate. This might be upsetting for those who are not eligible who still want to contribute to the current research. However, these criteria have been developed in order to answer a particular research question and to protect participants from further psychological distress.

If you are interested in participating or you have any queries or concerns regarding the current research please contact either Isis Davidson-Olsson (Researcher) or Jean Simons (FSID Support & Education Manager) via the contact information provided below.

Researcher:

Isis Davidson-Olsson
isisdavidson@hotmail.com
07974147890

FSID Support & Education Manager:

Jean Simons
jean.simons@fsid.org.uk
020 7802 3200

NB: This study has been approved by the School of Psychology Ethics Committee Registration Protocol Number: PSY/06/11/ICD-0

Appendix 2: Information Sheet



University of Hertfordshire
Hatfield
AL10 9AB
UK
tel +44 (0)1707 284000
fax +44 (0)1707 284115
herts.ac.uk

INFORMATION SHEET

Title of Project: Sudden Infant Death Syndrome: Mothers' Experiences of Parenting

My name is Isis Davidson-Olsson and I am a Trainee Clinical Psychologist undertaking Doctoral training in Clinical Psychology at the University of Hertfordshire. As part of my training, I am conducting a study which aims to explore mothers' experiences of parenting prior to and after an experience of Sudden Infant Death Syndrome.

At present, there is very little research on whether Sudden Infant Death Syndrome influences mothers' experiences of parenting. The current research proposes that this could be important in understanding the impact of Sudden Infant Death Syndrome and in the development of interventions and after care services for those who feel they would benefit from further support.

If you agree to participate you will be asked to sign a consent form and take part in one session. The session will last for approximately 90 minutes, and will focus on questions regarding your ideas, thoughts and experience of parenting and how you believe others may view your parenting, both now and in the past. You will also be asked to complete two questionnaires, regarding your general wellbeing and current feelings regarding your loss. On completion of the study you will be offered the opportunity to discuss the research findings with the researcher. Any information you provide during the course of this study will remain both confidential and anonymous and will only be used for the purposes outlined here. No identifying information will be kept by the researcher and collected data will be securely stored for 5 years, after which time it will be destroyed.

It is important to note that your participation is entirely voluntary and should you wish to withdraw from the current study at any point you may do so without explanation. If you do decide to withdraw from the study no information will be kept by the researcher.

If you have any concerns, queries or questions regarding the research, either now or in the future, you are welcome to contact Isis Davidson-Olsson (Researcher) or Barbara Mason (Supervisor) via the contact information provided below. Should you decide to participate, you will also have the opportunity to have any questions answered both before and after participation.

The researcher acknowledges that this topic has the potential to elicit strong emotions and cause discomfort and distress. If this occurs you are entitled to ask for a break and/or stop the session at any time. You will also be provided with the name and contact details for support services.

Thank you for your time

Researcher:
Isis Davidson-Olsson
isisdavidson@hotmail.com
07974147890

Supervisor:
Barbara Mason
b.l.mason@herts.ac.uk
01707 285074

NB: This study has been approved by the School of Psychology Ethics Committee Registration Protocol Number: PSY/06/11/ICD-0

Appendix 3: Ethics Approval Certificate

Revised (September 2006)

SCHOOL OF PSYCHOLOGY ETHICS COMMITTEE APPROVAL

Student Investigator: Isis Cherie Davidson-Olsson

Title of project: Sudden Infant Death Syndrome: Mothers' Constructs and Experiences of Parenting


Supervisor: Barbara Mason

Registration Protocol Number: PSY/06/11/ICD-O

The approval for the above research project was granted on 20 June 2011 by the Psychology Ethics Committee under delegated authority from the Ethics Committee of the University of Hertfordshire.

The end date of your study is 1st July 2012

Signed:



Date: 20 June 2011

Professor Lia Kvavilashvili
Chair
Psychology Ethics Committee

STATEMENT OF THE SUPERVISOR:

From my discussions with the above student, as far as I can ascertain, s/he has followed the ethics protocol approved for this project.

Signed (supervisor):

Date:

Appendix 4: NRES Correspondence

RE: Confirmation

↓ ↑ | Full view

To see messages related to this one, [group messages by conversation](#).

□ NRES Queries Line [Add to contacts](#)
To 'Isis Davidson-Olsson'

20/07/2011

Reply

Thank you for your further email enquiry. As you are aware, our leaflet "*Defining Research*", explains how we differentiate research from other activities, and is published at:
<http://www.nres.npsa.nhs.uk/applications/is-your-project-research/>.

Based on the information you provided, our advice is that the project does not require ethical review by a NHS Research Ethics Committee.

If you are undertaking the project within the NHS, you should check with the relevant NHS care organisation(s) what other review arrangements or sources of advice apply to projects of this type. Guidance may also be available from the clinical governance office.

Although ethical review by an NHS REC is not necessary in this case, all types of study involving human participants should be conducted in accordance with basic ethical principles, such as informed consent and respect for the confidentiality of participants. Also, in processing identifiable data there are legal requirements under the Data Protection Act 2000. When undertaking an audit or service/therapy evaluation, the investigator and his/her team are responsible for considering the ethics of their project with advice from within their organisation. University projects may require approval by the university ethics committee. Please refer to our guidance on student research at:
http://www.nres.npsa.nhs.uk/applications/guidance/research-guidance/?esctl1654606_entryid62=83668.

This response should not be interpreted as giving a form of ethical approval or any endorsement to your project, but it may be provided to a journal or other body as evidence that ethical approval is not required under NHS research governance arrangements.

However, if you, your sponsor/funder or any NHS organisation feel that the project should be managed as research, and/or that ethical review by an NHS REC is essential, then please write setting out your reasons and we will be pleased to consider your request further.

Where NHS organisations have clarified that a project is not to be managed as research, the Research Governance Framework states that it should not be presented as research within the NHS.

If you have received advice on the same or a similar matter from a different source (for example directly from a Research Ethics Committee (REC) or from an NHS R&D department), it would be helpful if you could share the initial query and response received if then seeking additional advice through the NRES Queries service.

However, if you have been asked to follow a particular course of action by a REC as part of a provisional or conditional opinion, then the REC requirements are mandatory to the opinion, unless specifically revised by that REC. Should you wish to query the REC requirements, this should either be through contacting the REC direct or, alternatively, the relevant local operational manager.

Regards

Queries Line
National Research Ethics Service
National Patient Safety Agency
4-8 Maple Street
London
W1T 5HD

Appendix 5: Consent Form



University of Hertfordshire
Hatfield
AL10 9AB
UK
tel +44 (0)1707 284000
fax +44 (0)1707 284115
herts.ac.uk

CONSENT FORM

Title of Project: Sudden Infant Death Syndrome: Mothers' Experiences of Parenting

Statement by Participant

- I confirm that I have read and understand the information sheet for this study.
- I understand what my involvement will entail and any questions have been answered to my satisfaction.
- I understand that my participation is entirely voluntary, and that I can withdraw at any time without prejudice.
- I understand that all information obtained will be confidential.
- I agree that research data gathered for the study may be published provided that I cannot be identified as a subject.
- Contact information has been provided should I wish to seek further information from the investigator at any time for purposes of clarification.
- I agree to take part in the above study

Participant Name

Participant Signature Date

Statement by Investigator

- I have explained this project and the implications of participation in it to this participant without bias and I believe that the consent is informed and that she understands the implications of participation.

Investigator's Name

Investigator's Signature Date

NB: This study has been approved by the School of Psychology Ethics Committee Registration Protocol Number: PSY/06/11/ICD-0

Sudden Infant Death Syndrome: Mothers Experiences of Parenting
Candidate Number: 09212279

Appendix 6: Interview Information



University of Hertfordshire
Hatfield
AL10 9AB
UK
tel +44 (0)1707 284000
fax +44 (0)1707 284115
herts.ac.uk

IPA INTERVIEW QUESTIONS INFORMATION SHEET

Thank you for meeting with me today. As you know, I am doing research looking at what it is like to be a parent, before and after an experience of Sudden Infant Death Syndrome.

Although FSID's put us in contact, I do not know anything about you or your history – I just know that you have lost a child to Sudden Infant Death Syndrome, you have surviving child(ren) and have since gone on to parent another/other child(ren). I do not need you to tell me about the circumstances surrounding your child's death or your experience of that day, as I do not want you to find the interview upsetting, however if you chose to and feel these details are relevant to your experiences then please feel free to include this information.

What I would like to focus on today is your experiencing of parenting prior to and after your loss and your ideas about how you are viewed as a parent, both now and in the past. Please let me know if any of my questions are difficult to understand, as it might be that I have not worded them clearly.

I will be trying to get a good understanding of your experience, so I might ask you to explain things to me or provide more information about certain things. However, there are no right or wrong answers and I am only interested in your experiences.

For the purposes of this study, I would like to record the interview. The audio recording will be transcribed by an administrator, who will have signed a confidentiality agreement and who will not have any access to your identifiable information. The audio recording will also be listened to by me and destroyed once the study is complete – Is this OK? Upon request, a copy of today's interview can be provided to you

Please remember that your participation is entirely voluntary and that if you are unhappy or unsure about any aspect of the interview procedure, questions, recording and subsequent transcribing and handling of your information you are free to withdraw at any.

Before we begin, are you happy to continue? Do you have any questions you would like answering? If you decide to proceed, please remember that you can stop the interview or take a break at any time.

NB: This study has been approved by the School of Psychology Ethics Committee Registration Protocol Number: PSY/06/ 11/ICD-0

Appendix 7: Non Disclosure and Confidentiality Agreement



University of Hertfordshire
Hatfield
AL10 9AB
UK

tel +44 (0)1707 284000
fax +44 (0)1707 284115
herts.ac.uk

TRANSCRIPTION CONFIDENTIALITY/ NON-DISCLOSURE AGREEMENT

This non-disclosure agreement is in reference to the following parties:

The discloser: Isis Davidson-Olsson

The recipient: Helen Williams

The recipient agrees to not divulge any information to a third party with regards to the transcription of audio recordings, as recorded by the discloser. The information shared will therefore remain confidential.

The recipient also agrees to destroy the transcripts as soon as they have been provided to the discloser.

The recipient agrees to return and or destroy any copies of the recordings they were able to access provided by the discloser.

Signed: H Williams
Name: H WILLIAMS
Date: 23/2/12

NB: This study has been approved by the School of Psychology Ethics Committee Registration Protocol Number: PSY/06/11/ICD-0

Appendix 8: Debrief



University of Hertfordshire
Hatfield
AL10 9AB
UK
tel +44 (0)1707 284000
fax +44 (0)1707 284115
herts.ac.uk

DEBRIEF

Thank you for participating in the current study and making this research possible, your contribution is greatly appreciated.

The aim of this study was to explore how mothers, who have been affected by Sudden Infant Death Syndrome, view themselves as parents and experience parenting both before and after bereavement. I was particularly interested in exploring:

- How mothers viewed themselves as parents prior to bereavement.
- How mothers view themselves as parents after bereavement.
- How mothers believed others viewed them as parents prior to the bereavement
- How mothers believe others view them as parents after bereavement
- Mothers experience of parenting prior to bereavement
- Mothers experience of parenting after bereavements
- The perceived impact of Sudden Infant Death Syndrome on parenting

At present there is limit research on the parenting experience and Sudden Infant Death Syndrome. It is hoped that this research will contribute to our understanding of parenting and how it can be affected by this type of loss. Understanding the views, ideas and experiences of those affected by Sudden Infant Death Syndrome may inform the development of effective intervention and after care services.

If you have any further questions or you would like the opportunity to talk further about the study please do not hesitate to contact Isis Davidson-Olsson (Researcher) via the contact information provided below.

Regards

Researcher:

Isis Davidson-Olsson
isisdavidson@hotmail.com
07974147890

NB: This study has been approved by the School of Psychology Ethics Committee Registration Protocol Number: PSY/06/11/ICD-0

Appendix 9: Further Support



University of Hertfordshire
Hatfield
AL10 9AB
UK
tel +44 (0)1707 284000
fax +44 (0)1707 284115
herts.ac.uk

FURTHER SUPPORT

Talking about your experiences of Sudden Infant Death Syndrome may have been very difficult, elicited strong emotions and left you feeling some emotional discomfort and distress. This is a normal process and you may find that as the week progresses you feel better. However, if these feelings persist there are a number of support services that you might find helpful.

1. The Foundation for the Study of Infant Deaths

Freephone: 0808 802 6868
helpline@fsid.org.uk

The foundation for the Study of Infant Deaths provides a helpline which offers support to bereaved parents and their families. The helpline is open 10am to 6pm, Monday through Friday and 6pm to 10pm on Weekends and Bank Holidays.

2. The Compassionate Friends

Telephone: 0845 1232304
www.tcf.org.uk

Compassionate friends is a charitable organization for bereaved parents and their families. The helpline is manned by bereaved parents who offer support and further information regarding local support services. The helpline is open every day from 10am to 4pm and 7pm to 10pm.

3. The Samaritans

Telephone: 08457 909090
jo@samaritans.org

The Samaritans provides support for anyone experiencing emotional distress. The helpline is open 24 hours a day, every day of the year.

4. Cruse Bereavement Care

Telephone: 0844 4779400
helpline@cruse.org.uk

Cruse Bereavement Care offers support services for anybody who has experienced bereavement. The Cruse helpline is open from 9:30am to 5pm, Monday through Friday.

5. GP

If you feel that you need more support than the suggested support services are able to provide your GP may be able to refer you to more specialized local support services.

Alternatively, you may feel that the opportunity to discuss your experience of Sudden Infant Death Syndrome has left you with some thoughts and feelings that you would like to explore further with a trained professional. If this is the case then the following organization may be of some use.

1. British Association Of Counseling and Psychotherapy (BACP)

Telephone: 01455 88 33 00
bacp@bacp.co.uk

The British Association of Counseling and Psychotherapy is a registered charity which provides information on local counseling and psychotherapy services. The helpline and website is available for those who wish to discuss any queries or concerns they might have regarding therapy.

Regards

Isis Davidson-Olsson
isidavidson@hotmail.com
07974147890

NB: This study has been approved by the School of Psychology Ethics Committee Registration Protocol Number: PSY/06/11/ICD-0

Sudden Infant Death Syndrome: Mothers Experiences of Parenting
Candidate Number: 09212279

Appendix 10:

Review of Psychological Wellbeing and General Distress Measures

Google Search Term: Screening for Psychological Distress / Assessment Psychological Distress

- ❖ *K10:*
- ❖ *HADS: Hospital Anxiety and Depression Scale*
- ❖ *GHQ: General Health Question*
- ❖ *DT: Distress Thermometer*
- ❖ *OQ45*

SIDS and Bereavement Research

- ❖ *IES-15: Impact of Events Scale*
- ❖ *ICG: Inventory of Complicated Grief*
- ❖ *SCL-90: Symptoms Checklist – 90 – Revised*
- ❖ *BSI: Brief Symptom Inventory*

Measures of Distress: <http://www.psychotherapybrownbag.com>

- ❖ *DTS: Distress Tolerance Scale*
- ❖ *DASS21: Depression and Anxiety Scale*

Review of Screening, Assessment and Outcome Measures: Deadly, (2009)

- ❖ *The Recovery Assessment Scale*
- ❖ *Scales of Psychological Well-being (SPWB)*
- ❖ *Dispositional Hope Scale (DHS)*
- ❖ *The Traumatic Life Events Questionnaire (TLEQ)*
- ❖ *The PTSD Symptom Scale Self-Report (PSS-SR)*
- ❖ *Trauma Screening Questionnaire (TSQ)*

Summary Table

Measure	Diagnostic	Items	Perinatal Death Research	Reliability & Validity	Standardisation	Reference
K10	General Distress Mental Health Difficulties Sensitive to Anxiety & Depression - DSM-IV	10	No	Internal Reliability .92 - .93 Internal Reliability .83 Out performs GHQ predictive accuracy 76.7%	16 Languages Cultural groups Pregnant women Gender – No Bias Educational – No Bias	Kessler et al 2002 Andrews & Slade 2001
HADS	Hospital Anxiety and Depression scale: Inpatient and community settings Provides information regarding the symptom severity of depression and anxiety symptoms	14	No	Construct Validity Issues between the HADS and BDI – inter-rater reliability (Kappa .47) Does correlate to the GHQ No further information provided	60 languages Inpatients Community General populations	Golden et al, 2007 Bjelland et al 2001
GHQ	Detects Psychological Symptom: Somatic, anxiety, social, depressive	12-28	No	Adequate Reliability and Validity Test-retest reliability in clinical pop. .85 to .90 Lower in general population Internal Reliability .82-.86 Correlates .76 GHQ-28 and .70 GHQ-12 sensitivity of 89% - 80% GHQ-12 sensitivity of 84% - 82% GHQ-28 sensitivity of 78% - 85% GHQ-60 Correlates with to the SCL-90-R $r \geq 0.8$	50 languages diverse cultural groups cross-cultural relevance postnatal population are mixed	Goldberg & Williams, 1988; Politi, et al 1994 Chandrashekar et al 1989 Winefield et al, 1989 Dawe et al 2002 Vallejo et al 2008
DT	The distress thermometer, is a picture of a thermometer with numbers ranging from 0-10 0 = No Distress and 10 = Extreme Distress. The measure also includes a list of practical problems, family problems, emotional problems, spiritual and/or religious concerns and physical problems to give the administrator some idea regarding what might be cause the individuals distress.	5	No	Author reports Good reliability and Validity in clinical and end of life setting, however this measure has not been rigorously tested with non clinical population and/or the general population.	Standardised in a range of physical health problems and with men and women.	Roth et al, 1998 Holland & Bultz, 2007

OQ45	A measure used during a therapeutic process to outcome the result of therapy. The OQ45 assesses risk – suicidality, substance Abuse and Violence. The scale has three domains including Symptom Distress, Interpersonal Functioning and Social Role.	45	No	Originally developed to assess change in those who had had a short psychiatric admission Correlates with BDI/SCL-90-R/IIP/SAS at between .78- .84	Available in 17 languages Across a variety of patient populations Used in research and non-clinical population but has not be validated.	Leonard et al 2002
IES-R	The current degree of subjective stress experienced as a result of a specific event	15-20	Yes	High internal consistency .79 – .92 Demonstrating sensitivity in significantly discriminating between patient and non-patient validity with the GHQ-28 in measuring emotional distress sensitivity was found to range between 0.93 and 1.00 factor structure to be stable over different types of events, internal consistency .96) Correlation with the PCL (0.84). Internal consistency total score 0.95 subscales (re-experiencing/intrusion = .90, avoidance = .86 and hyperarousal = .85). Concurrent validity: scores correlate with earlier version of the IES and equivalent measures (Clinician-Administered PTSD Scale (CAPS), STAI, PSS-SR, BDI-II).	range of trauma Multiply languages range of cultural groups the most favoured tools for trauma exposure performed well has been validated on independent samples	Horowitz et al 1979 Zilberg et al 1982 Hodgkinson, et al 1995 Creamer et al 1995 Creamer et al 2003 Cassiday 1992 Deady 2009 Elhai et al, 2005 Brewin 2005
ICG	Inventory of Complicated Grief Assessing anger, disbelief, and hallucinations.	19	Yes	Internal consistency .94. The test-retest reliability .80. The scale has a clinical validated cut offs	Standardised for men and women Adults 18 + Available in a variety of languages Predominately used in the west	Prigerson, et al. (1995)

SCL-90 BSI Brief- SCL	Outcome measure: severity, intensity and extensiveness somatisation, obsessive compulsive interpersonal sensitivity depression anxiety hostility phobic anxiety paranoid ideation Psychoticism	90/ 53	Yes	More sensitive than equivalent scales Test-retest reliability .90 internal reliability .79. Correlations with the SCL-90-R range from .92 to .99. Adequate internal consistency ranging from .70 (phobic anxiety) to .89 (depression) and test- retest reliability ranging from .68 (somatisation) to .91 (phobic anxiety) over a two-week period	Across Gender adolescent populations Translated into a number of languages Validated in a range of ethnic minorities Non clinical populations Clinical populations Community Groups In patient Outpatients Non patients Adults Adolescence 13 years + Used in research	Deady 2009 Horowitz et al, 1988 Boulet & Boss, 1991
DTS	Ability to experience and endure negative states. Looks at regulation tolerance and absorption	15	No	Internal constancy .89 Retest reliability .61	No Information available Tolerance levels and cut offs differ for men and women	Simons & Gaher 2005
DASS	Measures dimensions of depression, anxiety and stress and more general dimension of psychological distress	21-42	No	Good internal consistency Good test-retest reliability Scales .92 - .9y, Subscales. 87 - .94 for Stress. Correlated with the BDI, BAI, and the STAI-T	Range of cultures Range of Languages Working Age Adults Adolescents	Lovibond & Lovibond, 1995 Henry & Crawford, 2005 Deady, 2009 Antony et al 1998
RAS	Test of empowerment, coping ability, and quality of life.	41	No	Test-retest reliability .88) Internal consistency .93 scale positively associated with self- esteem, empowerment, social support, and quality of life, Good concurrent validity. Internal reliability .73-.91	Outcome measure for recovery. Limited information Requires further study	Corrigan et al 1999 Corrigan et al 2004
SPWB	Assesses 6 areas of psychological well-being: autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self- acceptance	18-120	No	Recent studies question construct validity validity findings are limited correlations of equivalent measures are moderate	Elderly Working Age adolescents translated into a number of languages	Deady 2009 Clayman, 2005 Laukka, 2007 Ryff & Keyes, 1995

DHS	Measuring Agency and Pathways (i.e. goal-directed energy and planning to meet goals).	12	No	internally consistent.75-.85 Satisfactory construct and discriminate validity	Used in multiple countries Used with ethnic minorities some gender differences	Roesch & Vaughn, 2006 Kato & Snyder, 2005 Lee, Lee, & Choi, 2008 Snyder et al., 1991 Snyder et al., 1996
TLEQ	Evaluate the re-experiencing of symptoms associated with trauma and trauma symptoms including, intense fear, helplessness and horror	21	No	Good construct validity Adequate sensitivity test-retest reliability .83 low for some items. convergent validity with TLE-I- 80	adolescents prison populations ethnic groups	Oyefesco et al 2008 Adams 2004 Kubany et al 2000 Deady, 2009
PSS-SR	PTSD Symptom Scale	17	No	Internally consistent .91 Individual subscales .78 - .82 Test-retest reliability - 1 month -.74 Significantly correlate with equivalent instruments Sensitivity 62%, Sensitivity range .80 - .90 Specificity range .84 - .88	Trauma Population Research but not validated	Deady, 2009
TSQ	Trauma Screen Questionnaire	10	NO	sensitivity .86 Specificity .93 Efficiency .90	More Study's needed Predominately used in Australia	Brewin et al, 2002

References

- Adams, N. L. (2004). The relationship between childhood traumatic experiences and gang-involved delinquent behavior in adolescent boys. ProQuest Information & Learning: US.
- Andrews, G., Slade, T (2001). Interpreting scores on the Kessler Psychological Distress Scale (k10). *Australian and New Zealand Journal of Public Health*, 25, 494-497.
- Antony, M. M., Bieling, P. J., Cox, B. J., Enns, M. W., & Swinson, R. P. (1998). Psychometric properties of the 42-item and the 21-item versions of the Depression Anxiety Stress Scales in clinical groups and a community sample. *Psychological Assessment*, 10(2), 176-181.
- Bjelland, I., Dahl, A. A., Haug T. T. & Neckelmann D. (2002). The Validity of the Hospital Anxiety and Depression Scale. An Updated Literature Review. *Journal of Psychosomatic Research*. Vol. 52, NO. 2, pp. 69 – 77
- Boulet, J., & Boss, M. W. (1991). Reliability and validity of the Brief Symptom Inventory. *Psychological Assessment*, 3(3), 433-437.
- Brewin, C. R., Rose, S., Andrews, B., Green, J., Tata, P. & McEvedy, C. (2002). Brief screening instrument for post-traumatic stress disorder. *British Journal of Psychiatry*, 181, 158-162.
- Brewin, C. R. (2005). Systematic Review of Screening Instruments for Adults at Risk of PTSD. *Journal of Traumatic Stress*, 18(1), 53-62.
- Cassiday, K. L., McNally, R. J., VandeCreek, L., Knapp, S., & Jackson, T. L. (1992). The "Impact of Event Scale-Revised" for assessing rape victims with post-traumatic stress disorder. In *Innovations in clinical practice: A source book*, Vol.

-
- Clayman, S. L. (2005). *The relationship among disclosure, internalized homophobia, religiosity, and psychological well-being in a lesbian population*. ProQuest Information & Learning: US.
- Corrigan, P. W., Giffort, D., Rashid, E., Leary, M., & Okeke, I. (1999). Recovery as a psychological construct. *Community Mental Health Journal, 35*(3), 231-239.
- Corrigan, P. W., Salzer, M., Ralph, R. O., Sangster, Y., & Keck, L. (2004). Examining the factor structure of the recovery assessment scale. *Schizophrenia Bulletin, 30*(4), 1035-1041.
- Crawford, J. R., & Henry, J. D. (2003). The Depression Anxiety Stress Scales (DASS): Normative data and latent structure in a large non-clinical sample. *British Journal of Clinical Psychology, 42*(2), 111-131.
- Creamer, M., Bell, R., & Failla, S. (2003). Psychometric properties of the Impact of Event Scale-Revised. *Behaviour Research and Therapy, 41*(12), 1489-1496.
- Creamer, M., Foran, J., & Bell, R. (1995). The Beck Anxiety Inventory in a non-clinical sample. *Behaviour Research and Therapy, 33*(4), 477-485.
- Deady, M. (2009). A Review of Screening, Assessment and Outcome Measures for Drug and Alcohol Settings
- Doerfler, L. A., Addis, M. E. & Moran, P W. (2002). Evaluating Mental Health Outcomes in an Inpatient Setting: Convergent and Divergent Validity of the OQ-45 and BASIS-32. *Journal of Behavioural Health Service & Research*. Vol. 19, No. 6, pp. 394 –
- Elhai, J. D., Gray, M. J., Kashdan, T. B., & Franklin, C. L. (2005). Which instruments are most commonly used to assess traumatic event exposure and Posttraumatic effects?: A survey of traumatic stress professionals. *Journal of Traumatic Stress, 18*(5), 541-545.

-
- Goldberg, D., & Williams, P. (1988). *A user's guide to the General Health Questionnaire*. Windsor: NFER-NELSON Publishing Company.
- Golden, J., Conroy, R. M. & O'Dwyer, A. M. (2007). Reliability and Validity of the Hospital Anxiety and Depression Scale and the Beck Depression Inventory (Full and Fast Scen) in detecting depression in persons with hepatitis C. *Journal of Affective Disorders*. Vol. 100, No. 1, pp.265 -9
- Hodgkinson, P., & Joseph, S. A. (1995). Factor analysis of the Impact of Events Scale with female bank staff following an armed raid. *Personality and Individual Differences*, 19(5), 773-775.
- Holland, J. C. & Bultz, B. D. (2007). The NCCN Guidelines for Distress Management: A Case for Making Distress the Sixth Vital Sign. *Journal of the Nation Comprehensive Cancer Network* Vol. 5, No. 1, pp 3-7
- Horowitz, L. M., Rosenberg, S. E., Baer, B. A., Ureno, G., & Villasenor, V. S. (1988). Inventory of interpersonal problems: Psychometric properties and clinical applications. *Journal of Consulting and Clinical Psychology*, 56, 885-892.
- Horowitz, M., Wilner, N., & Alvarez, W. (1979). Impact of event scale: A measure of subjective stress. *Psychosomatic Medicine*, 41(3), 209-219.
- Kessler, R. C., Andrews, G., Colpe, N. (2002). Short Screening Scale to Motitor Population Prevalences and Trends in Non-Specific Psychological Distress. *Psychological Medicine*. Vol. 32, pp. 959 – 956
- Kato, T., & Snyder, C. R. (2005). [Relationship between hope and subjective well-being: reliability and validity of the dispositional Hope Scale, Japanese version]. *Shinrigaku Kenkyu - Japanese Journal of Psychology*, 76(3), 227-234.
- Kubany, E. S., Haynes, S. N., Leisen, M. B., Owens, J. A., Kaplan, A. S., Watson, S. B., et al. (2000). Development and preliminary validation of a brief broad-spectrum measure

-
- of trauma exposure: the Traumatic Life Events Questionnaire. *Psychological Assessment*, 12(2), 210-224.
- Lovibond, S. H., & Lovibond, P. F. (1995). *Manual for the Depression Anxiety Stress Scales* (2nd ed.). Sydney: Psychology Foundation.
- Laukka, P. (2007). Uses of music and psychological well-being among the elderly. *Journal of Happiness Studies*, 8, 215-241.
- Lee, D.-G., Lee, H.-K., & Choi, Y.-H. (2008). *Validation of Dispositional Hope Scale in Korea*. Paper presented at the American Psychological Association 2008 Convention Presentation.
- Oyefeso, A., Brown, S., Chiang, Y., & Clancy, C. (2008). Self-injurious behaviour, traumatic life events and alexithymia among treatment-seeking opiate addicts: Prevalence, pattern and correlates. *Drug and Alcohol Dependence*, 98(3), 227-234.
- Politi, P. L., Piccinelli, M., & Wilkinson, G. (1994). Reliability, validity and factor structure of the 12-item General Health Questionnaire among young males in Italy. *Acta Psychiatrica Scandinavica*, 90(6), 432-437.
- Roesch, S. C., & Vaughn, A. A. (2006). Evidence for the Factorial Validity of the Dispositional Hope Scale Cross-Ethnic and Cross-Gender Measurement Equivalence. *European Journal of Psychological Assessment*, 22(2), 78-84.
- Ryff, C. D., & Keyes, C. L. (1995). The structure of psychological well-being revisited. *Journal of Personality and Social Psychology*, 69, 719-727.
- Simons, J.S. & Gaher, R.M. (2005). The Distress Tolerance Scale: Development and Validation of a Self-Report Measure. Vol. 29, No. 2, pp. 83-102
- Snyder, C. R., Harris, C., Anderson, J. R., Holleran, S. A., Irving, L. M., Sigmon, S. T., et al. (1991). The will and the ways: Development and validation of an individual-

-
- differences measure of hope. *Journal of Personality and Social Psychology*, *60*, 570-588.
- Snyder, C. R., Sympson, S. C., Ybasco, F. C., Tyrone F. Borders, Babyak, M. A., & Higgins, R. L. (1996). Development and Validation of the State Hope Scale. *Journal of Personality and Social Psychology*, *70*(2), 321-335.
- Sriram, T. G., Chandrashekar, C. R., Isaac, M. K., & Shanmugham, V. (1989). The General Health Questionnaire (GHQ): Comparison of the English version and a translated Indian version. *Social Psychiatry and Psychiatric Epidemiology*, *24*(6), 317-320.
- Winefield, H. R., Goldney, R. D., Winefield, A. H., & Tiggemann, M. (1989). The General Health Questionnaire: Reliability and validity for Australian youth. *Australian and New Zealand Journal of Psychiatry*, *23*(1), 53-58.
- Vallejo, M. A., Mañanes, G., Comeche, M. I., & Díaz, M. I. (2008). Comparison between administration via internet and paper and pencil administration of two clinical instruments: SCL-90-R and GHQ-28. *Journal of Behavior Therapy and Experimental Psychiatry*, *39*(3), 201-208.
- Zilberg, N. J., Weiss, D. S., & Horowitz, M. J. (1982). Impact of Life Event Scale: A cross-validation study and some empirical evidence supporting a conceptual model of stress response syndromes. *Journal of Consulting and Clinical Psychology*, *50*(3), 407-414.

Appendix 11: Impact of Events Scale Revised – IES -R: Weiss (2004)

IMPACT OF EVENT SCALE - REVISED

INSTRUCTIONS: Below is a list of difficulties people sometimes have after stressful life events.

Please read each item, and then indicate how distressing each difficulty has been for you **DURING THE PAST SEVEN DAYS** with respect to _____, how much were you distressed or bothered by these difficulties?

	Not at All	A little Bit	Moderately	Quite a Bit	Extremely
1. Any reminder brought back feelings about it.	0	1	2	3	4
2. I had trouble staying asleep.	0	1	2	3	4
3. Other things kept making me think about it.	0	1	2	3	4
4. I felt irritable and angry.	0	1	2	3	4
5. I avoided letting myself get upset when I thought about it or was reminded of it.	0	1	2	3	4
6. I thought about it when I didn't mean to.	0	1	2	3	4
7. I felt as if it hadn't happened or wasn't real.	0	1	2	3	4
8. I stayed away from reminders about it.	0	1	2	3	4
9. Pictures about it popped into my mind.	0	1	2	3	4
10. I was jumpy and easily startled.	0	1	2	3	4
11. I tried not to think about it.	0	1	2	3	4
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them.	0	1	2	3	4
13. My feelings about it were kind of numb.	0	1	2	3	4
14. I found myself acting or feeling like I was back at that time.	0	1	2	3	4
15. I had trouble falling asleep.	0	1	2	3	4
16. I had waves of strong feelings about it.	0	1	2	3	4
17. I tried to remove it from my memory.	0	1	2	3	4
18. I had trouble concentrating.	0	1	2	3	4
19. Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.	0	1	2	3	4
20. I had dreams about it.	0	1	2	3	4
21. I felt watchful and on guard.	0	1	2	3	4
22. I tried not to talk about it.	0	1	2	3	4

Appendix 12: Symptom Checklist 90 Revised – SCL-90-R: (Derogatis, 1975)

INSTRUCTIONS:
 Below is a list of problems people sometimes have. Please read each one carefully, and blacken the circle that best describes HOW MUCH THAT PROBLEM HAS DISTRESSED OR BOTHERED YOU DURING THE PAST 7 DAYS INCLUDING TODAY. Blacken the circle for only one number for each problem and do not skip any items. If you change your mind, erase your first mark carefully. Read the example before beginning, and if you have any questions please ask them now.

	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY	
1	0	1	2	3	4	Bodyaches
2	0	1	2	3	4	Headaches
3	0	1	2	3	4	Nervousness or shakiness inside
4	0	1	2	3	4	Repeated unpleasant thoughts that won't leave your mind
5	0	1	2	3	4	Faintness or dizziness
6	0	1	2	3	4	Loss of sexual interest or pleasure
7	0	1	2	3	4	Feeling critical of others
8	0	1	2	3	4	The idea that someone else can control your thoughts
9	0	1	2	3	4	Feeling others are to blame for most of your troubles
10	0	1	2	3	4	Trouble remembering things
11	0	1	2	3	4	Worried about sloppiness or carelessness
12	0	1	2	3	4	Feeling easily annoyed or irritated
13	0	1	2	3	4	Pains in heart or chest
14	0	1	2	3	4	Feeling afraid in open spaces or on the streets
15	0	1	2	3	4	Feeling low in energy or slowed down
16	0	1	2	3	4	Thoughts of ending your life
17	0	1	2	3	4	Hearing voices that other people do not hear
18	0	1	2	3	4	Trembling
19	0	1	2	3	4	Feeling that most people cannot be trusted
20	0	1	2	3	4	Poor appetite
21	0	1	2	3	4	Crying easily
22	0	1	2	3	4	Feeling shy or uneasy with the opposite sex
23	0	1	2	3	4	Feelings of being trapped or caught
24	0	1	2	3	4	Suddenly scared for no reason
25	0	1	2	3	4	Temper outbursts that you could not control
26	0	1	2	3	4	Feeling afraid to go out of your house alone
27	0	1	2	3	4	Blaming yourself for things
28	0	1	2	3	4	Pains in lower back
29	0	1	2	3	4	Feeling blocked in getting things done
30	0	1	2	3	4	Feeling lonely
31	0	1	2	3	4	Feeling blue
32	0	1	2	3	4	Worrying too much about things
33	0	1	2	3	4	Feeling no interest in things
34	0	1	2	3	4	Feeling fearful
35	0	1	2	3	4	Your feelings being easily hurt
36	0	1	2	3	4	Other people being aware of your private thoughts
37	0	1	2	3	4	Feeling others do not understand you or are unsympathetic
38	0	1	2	3	4	Feeling that people are unfriendly or dislike you

	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY	HOW MUCH WERE YOU DISTRESSED BY:
38	0	1	2	3	4	Having to do things very slowly to insure correctness
39	0	1	2	3	4	Heart pounding or racing
40	0	1	2	3	4	Nausea or upset stomach
41	0	1	2	3	4	Feeling inferior to others
42	0	1	2	3	4	Soreness of your muscles
43	0	1	2	3	4	Feeling that you are watched or talked about by others
44	0	1	2	3	4	Trouble falling asleep
45	0	1	2	3	4	Having to check and double-check what you do
46	0	1	2	3	4	Difficulty making decisions
47	0	1	2	3	4	Feeling afraid to travel on buses, subways, or trains
48	0	1	2	3	4	Trouble getting your breath
49	0	1	2	3	4	Hot or cold spells
50	0	1	2	3	4	Having to avoid certain things, places, or activities because they frighten you
51	0	1	2	3	4	Your mind going blank
52	0	1	2	3	4	Numbness or tingling in parts of your body
53	0	1	2	3	4	A lump in your throat
54	0	1	2	3	4	Feeling hopeless about the future
55	0	1	2	3	4	Trouble concentrating
56	0	1	2	3	4	Feeling weak in parts of your body
57	0	1	2	3	4	Feeling tense or keyed up
58	0	1	2	3	4	Heavy feelings in your arms or legs
59	0	1	2	3	4	Thoughts of death or dying
60	0	1	2	3	4	Overeating
61	0	1	2	3	4	Feeling uneasy when people are watching or talking about you
62	0	1	2	3	4	Having thoughts that are not your own
63	0	1	2	3	4	Having urges to beat, injure, or harm someone
64	0	1	2	3	4	Awakening in the early morning
65	0	1	2	3	4	Having to repeat the same actions such as touching, counting, or washing
66	0	1	2	3	4	Sleep that is restless or disturbed
67	0	1	2	3	4	Having urges to break or smash things
68	0	1	2	3	4	Having ideas or beliefs that others do not share
69	0	1	2	3	4	Feeling very self-conscious with others
70	0	1	2	3	4	Feeling uneasy in crowds, such as shopping or at a movie
71	0	1	2	3	4	Feeling everything is an effort
72	0	1	2	3	4	Spells of terror or panic
73	0	1	2	3	4	Feeling uncomfortable about eating or drinking in public
74	0	1	2	3	4	Getting into frequent arguments
75	0	1	2	3	4	Feeling nervous when you are left alone
76	0	1	2	3	4	Others not giving you proper credit for your achievements
77	0	1	2	3	4	Feeling lonely even when you are with people
78	0	1	2	3	4	Feeling so restless you couldn't sit still
79	0	1	2	3	4	Feelings of worthlessness
80	0	1	2	3	4	The feeling that something bad is going to happen to you
81	0	1	2	3	4	Shouting or throwing things
82	0	1	2	3	4	Feeling afraid you will faint in public
83	0	1	2	3	4	Feeling that people will take advantage of you if you let them
84	0	1	2	3	4	Having thoughts about sex that bother you a lot
85	0	1	2	3	4	The idea that you should be punished for your sins
86	0	1	2	3	4	Thoughts and images of a frightening nature
87	0	1	2	3	4	The idea that something serious is wrong with your body
88	0	1	2	3	4	Never feeling close to another person
89	0	1	2	3	4	Feelings of guilt
90	0	1	2	3	4	The idea that something is wrong with your mind

Appendix 13: Interview Schedule

Experience of parenting prior to losing a child to SIDS

- *Please could you tell me how you would have described yourself as a parent prior to your experience of Sudden Infant Death Syndrome?*
 - How would you have described your approach to parenting?
 - What is your understanding of why you chose to adopt this type of parenting?
 - How would you have described your confidence in these methods?
 - Why? What do you think lead to this level of confidence?
- *What was your relationship with your child(ren) like prior to your experience of Sudden Infant Death Syndrome?*
 - How did you show your affection?
 - How close was your relationship with your children?
 - Why? What do you think led to this type of relationship developing?
 - What were your beliefs regarding your child's mortality/safety?
 - What do you think led to these beliefs?
- *Prior to your experience of Sudden Infant Death Syndrome how did you think and feel about your parenting abilities?*
 - What were the benefits/disadvantages of this approach/method of parenting?
 - What was enjoyable/ difficult about this approach/method of parenting?
 - What were your beliefs regarding your capability as a parenting?
- *How do you think other people saw you as a parent prior to your experience of Sudden Infant Death Syndrome? (Partner, Family, Friends, Society etc.)*
 - How confident do you think others were in your parenting abilities?
 - How do you think others would have described your approach/method of parenting?
 - How would others have described your relationship/closeness with your child(ren)?
 - Why? What do you think led others to view your parenting in these ways?

Experience of parenting in the aftermath of SIDS

- *What was your description of yourself, as a parent after your experience of Sudden Infant Death Syndrome? (Approach, Confidence, Style)*
 - How is this different/ similar to your previous description?
 - Why do you think this stayed the same/ changed?
 - What were the benefits/disadvantages of this changing on your parenting?
 - What were the benefits/disadvantages of these changes on you personally?
 - Do you think this change would have occurred if you had not experienced SIDS?

-
- ***What was your relationship with your child(ren) like after your experience of Sudden Infant Death Syndrome? (Affection, Closeness, View on Mortality/Safety)***
 - How is this different/similar to your previous description?
 - How? Can you give examples of how it has changed/stayed the same?
 - Why? What is your understanding of these changes (if change occurred?)
 - Do you think this would have changes/stayed the same if you had not experienced SIDS

 - ***How did you think and feel about yourself as a parent after your experience of Sudden Infant Death Syndrome (fulfilment, Capability, Advantages/Disadvantages)***
 - How? In what ways has this changed/stayed the same?
 - Why? What is your understanding of this?
 - What do you think led to these changes (if change occurred?)
 - Do you think this would have changes/stayed the same if you had not experienced SIDS

 - ***How do you think other people saw you as a parent after your experience of Sudden Infant Death Syndrome? (Partner, Family, Friends, Society etc.)***
 - Whose views changed? Whose view stayed the same?
 - Why? What do you think has lead to this changes / same view (if changed described)
 - What is your understanding of why this has happened/changed?
 - Do you think this would have changes/stayed the same if you had not experienced SIDS

Experience of parenting following an experience of SIDS

- ***What is your description of yourself, as a parent now?***
 - How has this description of yourself remained the same in the years since your loss?
 - How has this description of yourself changed in the years since your loss?
 - Why do you think it stayed the same/ changed/reverted back to how it was previously?
 - What led to it staying the same/changing/reverting back?
 - How do you think your parenting style would be if you had not had lost your child?

- ***What is your relationship with your child(ren) like now?***
 - In what ways has your relationship remained the same/changed since your loss?
 - Why do you think it stayed the same/ changed/reverted back to how it was previously?
 - What led to it staying the same/changing/reverting back
 - How do you think your relationship would be if you had not had lost your child?

- ***How did you think and feel about yourself as a parent now? (fulfilment, Capability)***
 - Has the way you think and feel about yourself as a parent remained the same?
 - Has the way you think and feel about yourself as a parent changed?
 - Why do you think it stayed the same/ changed/reverted back to how it was previously?
 - What led to it staying the same/changing/reverting back?
 - How would you think and feel about yourself as a parent if you had not lost your child?

- ***How do you think other people see you as a parent now? (Partner, Family, Friends, Society etc.)***

-
- Do you think people still view you in this way?
 - Has the way people view you changed in the years since you loss? How? Examples?
 - Why do you think it stayed the same/ changed/reverted back to how it was previously?
 - How do you think other people would see you, as a parent if you had not lost a child?

Ending

- ***How has it been for you talking with me today?***
 - Questions /Concerns? What were your thoughts on the interview?
- ***Is there anything I haven't asked about that you feel I should have asked about?***
 - If we were to do the interview again what would you suggest I include?
 - Is there anything that did not feel relevant to your experience of SIDS?
- ***Is there anything else that would help me understand your experience?***

Appendix 14: Interview Prompts

Exploratory Prompts

- Can I check I have understood correctly – do tell me if I am wrong
- What does that mean for you?
- I am very interested/curious about what you've just said.....
- Can you tell me a bit more about that?
- What was that like you?
- Everyone is different, so can you tell me what X means to you?

Appendix 15: Transcript Excerpt

Please can you tell me how you would have described yourself as a parent prior to your experience of sudden infant death syndrome?

I would say quite a confident parent and everyone was saying, well my mum would say, you know, "you are a good mum" and everything. You never feel like the perfect parent but on the whole I was confident, I was happy and XXXXX was happy and yeah I felt, as a young parent, I felt quite at home doing the job.

I am quite interested about what you just said and I'm wondering what "at home" means for you?

Erm, being at home just means being warm and being safe, feeling safe, making sure that everyone's together, you know, happy, as much as you can do, just being able to protect your children and the whole family really.

So just to make sure I've understood it correctly, and do tell me if I'm wrong, feeling at home for you means that it's almost being able to protect and look after .

Yes, yeah. yeah.

What is your understanding of why you tried to adopt this type of parenting, the protective type?

Well basically I think it just comes from my own experience, me growing up as a child, you know, the way my mum was towards us. You know it wasn't really something I had to kind of study , you know, try really hard at. It just kind of came naturally really and, you know, that's just what I've done with XXXXX and also with XXXX and they seem to be growing up quite well, they seem to be happy, you know, and obviously anything I need to get more information on I can get that information and take it on board and do whatever is necessary to help them as they're growing up. It's not really been an effort for me. I mean, things like the breastfeeding, you know doing all that and that obviously isn't easy and when they're little and they're crying that's hard but outweighing every thing they're wonderful to have really.

How would you have described your confidence in these methods?

Well with regard to what, in particular?

Well we've just been thinking of how you would describe yourself as a parent prior to your experience, it would probably be with XXXXX.

Yeah, I think I was fairly confident, confident that I could meet her needs, you know, I did enough before she started at nursery, you know, I took her out and played together and I was really, I felt at home being a mum and yeah, it was a joy really just to be with her, you know, bringing her up, which I still am doing (laughs) because she's only 5 .

I'm curious what you said at home again and I'm really interested in that because you say you feel at home being a mum. What does that mean for you.

Erm I think it just means that I always wanted to be a mum and I never really, I would say I had a happy childhood , it was something I always wanted to do, you know when she came along at first, obviously when it's your first baby and you're a bit scared and you think "what am I going to

do with this baby". I worked hard with the breastfeeding and that worked out, and that was a major thing for me and then the next stage is like weaning and you know teething and everything but all the way along I felt supported and felt quite confident really, it wasn't really a big effort in that I had to study what I needed to do next sort of thing, you know, it just felt quite natural really.

What do you think it was that led to this level of confidence?

I don't know really, I think support from my own mother and support from health professionals at the time, support from XXX as well, yeah, and just thinking from having, not really having worked and done like a, not had like a steady job and then having XXXXX was like it was something I was doing well at so I felt proud, you know, proud of being a mum and proud of bringing her up and, you know, she's always been a happy child so I just kind of think "as long as she's happy" (laughs) that's the main thing really.

I wonder if you can tell me a little bit more about the pride you felt?

I don't know really (laughs), well being proud of seeing every sort of step, you know, every time she developed like when she started talking, and she talked quite early on. She didn't really walk and that was one of the things I was concerned about that she wasn't walking by I think 18 months but she bum shuffled, like XXXX's doing at the moment, and just every sort of, every kind of milestone, you know every sort of achievement and because she talked early it meant that we could, it was a good thing because she would be, at least with her talking, she would be one of the ones doing well at school, you know, and it showed she was bright and happy, I was proud that I could take her out in public and she would be really content and happy and, you know, that other people could see that she was really chilled out and just a content little baby really and I think that's all you want really, I mean some people say "your babies are", like, XXXX, I took her to the hairdresser the other day and she was just really, really good and she just sat there in her pushchair and then she was out of the pushchair and she was really sociable you know and I was proud of that, that they are so good.

Everyone is different so I was wondering if you could tell me what it means to you that others would see your children as contented.

Well I think it is important because I am quite self conscious. I'm not self conscious of the fact that I won't, I'll avoid doing things because I'm afraid of what people think but out in public I am quite, if I have a baby crying I feel quite, I do feel that people, you know, that people are sort of judging me but then I've never really let them cry so that's never really happened. The only time people looked is when I've been breastfeeding in public which is quite funny because I do it anyway, I mean I don't stay indoors just to do it. I think my own reaction, if I hear a baby cry I don't think "oh shut that baby up" but feel more concerned really, I hope that woman's all right, does she need any help, but I think I am proud that I can take them to nice places and that they are really good.

How would you describe your approach to parenting.

Erm I would say fairly relaxed although there were times I had anxieties with XXXXX but certainly before XXXXXXXX died I found parenting quite, it was challenging but I didn't find it overwhelmingly scary or anything, it was just kind of, well I just went from step to step with XXXXX and, you know, it seemed to be quite natural my approach.

What was your relationship with XXXXX like prior to your experience of sudden infant death syndrome?

Erm I think I was really, she was quite independent so she would go off and, bear in mind how old was she when XXXXXXXX, 2, no she had just turned 2 when XXXXXXXX was born. It was always quite a close relationship and she was always happy, we've always had a close and good

relationship really and yeah she is happy, she's happy now. After XXXXXXXX died of course we were all quite sad and she did go through a period when she was a very sad little girl, that's when I looked at a nursery for her to go to and we found a really good one and we told them right from the start about XXXXXXXX and the fact that if XXXXX mentioned her it was OK because we talk about, you know we've always been open about it, you know we've always talked about it, she was there, she was in the other room and just saw everything, you know XXXXXXXX was lying on the bed, the ambulance people coming in, bringing her down here and trying to resuscitate her, you know, XXX did all of that but it's just a fact and it happened, so the nursery were brilliant because she lost a lot of confidence, I think we all, well I did in particular, so they helped to boost her confidence and the other children at the nursery, she socialised with them so I kind of felt she wasn't missing out, she was with other children and she really benefited from that. I'm probably jumping ahead a bit.

You mentioned that you felt that your relationship with XXXXX was close but that she was independent and I was just wondering what you felt led to this type of relationship developing?

Well I think, I never really wanted to be too over-protective of her so I've always let her when she, when she wants to be on her own I've let her be on her own and now it shows because she will play on her own, she doesn't always need to play with other children and her dad is an only child and I have a brother, it always goes back to family, but I have one brother very close in age and I was always conscious that I didn't really know what life was like without him. We were very close but I always think that maybe that's a bad thing because I used to be in tears when he wasn't around so when I started school I found it really difficult until he turned up so I sort of sub-consciously thought that XXXXX should be as independent as possible, just for her own sake really. Her dad, my husband XXX, is an only child and he's always been quite confident and yeah, on his own kind of thing, and I didn't want her to be on her own but I wanted her to be confident and have her own resources really and she, I mean she is an extremely confident child now and she was really, since she could speak, when she was just over the age of 1 really, and I see that as a very positive thing rather than wanting to stay around me all the time or, you know, I think that's a good thing really. I think that's largely because of my own experience and I wouldn't want to do it any differently so it depends really.

How did you show your affection to XXXXX?

Oh well, I'm always cuddling her and tell her I love her which I think is really important. If you don't tell them they don't just assume that you do but I've always told her, you know, she's clever, she's pretty, all of which is true, I'm biased but just being tactile, and she's the same towards me and towards other people as well, well mainly people in the family. Yeah, just encouraging her and praising her and, you know, giving her the opportunity to do what she wants to do. At nursery they used to take them out on nature walks and they were very hands on and we've been, we just saw that as an extension of what we did at home really, but at nursery they had the benefit of being with other children. She's a very affectionate little girl but she's always been hugged, well not always, when she's naughty she doesn't get hugged, but I think that's part of making her feel safe and for her to know that she's loved and safe as well.

What were your beliefs regarding XXXXX's mortality and safety?

Before I never really thought about her mortality in any way at all because to me she was a baby, and then she's growing up and you don't really think about that. You obviously think about their safety and their well-being and you are concerned about them when they're out and about or, you know, when they get ill but I would say that after XXXXXXXX died my feelings towards XXXXX's mortality and safety were very much, they were at the forefront. I mean whenever she got poorly I was so anxious and I just thought "it's going to happen again" or, you know, "what if something awful is going to happen" but before I never really, I didn't ever think about it because, you know, she's just young and she's growing up.

Appendix 16: Analysis Excerpt - Step 2. Process of Exploration and Step 3. Development of Emergent Themes

Emergent Themes	Original Transcript	Exploratory Comments
The use of intuitive parenting	<p>Please can you tell me how you would have described yourself as a parent prior to your experience of sudden infant death syndrome?</p>	<p><i>"I felt quite at home doing the job"</i> <u>Is home a safe place – predictable – familiar</u></p>
A child led approach to parenting	<p>I would say quite a confident parent and everyone was saying, well my mum would say, you know, "you are a good mum" and everything. You never feel like the perfect parent but on the whole I was confident, I was happy and XXXXX was happy and yeah I felt, as a young parent, I felt quite at home doing the job.</p>	<p><u>Confidence led by own and child's happiness</u></p> <p><u>Others important in confirming competency</u></p>
The importance of confirming voices	<p>I am quite interested about what you just said and I'm wondering what "at home" means for you?</p>	<p>Felt safe in her role as a parent</p>
The self as a guardian, protector	<p>Erm, being at home just means being warm and being safe, feeling safe, making sure that everyone's together, you know, happy, as much as you can do, just being able to protect your children and the whole family really.</p>	<p>Felt <i>"at home"</i> able to protect, keep everyone together and everyone safe.</p>
Confidence in this new role/new self	<p>So just to make sure I've understood it correctly, and do tell me if I'm wrong, feeling at home for you means that it's almost being able to protect and look after .</p>	
Self as a parent in relation to experienced parenting	<p>Yes, yeah. yeah.</p> <p>What is your understanding of why you tried to adopt this type of parenting, the protective type?</p>	<p>Parenting style has a transgenerational element (linked to parent)</p>
		<p><i>"It just kind of came naturally", "It's not really</i></p>

<p>Aware but comfortable with knowledge gaps</p> <p>Any hardships outweighed by the rewards of parenting</p> <p>Preparing offspring for increasing autonomy</p> <p>Building confidence and self belief with little victories</p>	<p>Well basically I think it just comes from my own experience, me growing up as a child, you know, the way my mum was towards us . You know it was n't really something I had to kind of study , you know, try really hard at. It just kind of came naturally really and, you know, that's just what I've done with XXXXX and also with XXXX and they seem to be growing up quite well, they seem to be happy, you know, and obviously anything I need to get more information on I can get that information and take it on board and do whatever is necessary to help them as they're growing up. It's not really been an effort for me . I mean, things like the breastfeeding, you know doing all that and that obviously isn't easy and when they're little and they're crying that's hard but outweighing everything they're wonderful to have really.</p> <p>How would you have described your confidence in these methods?</p> <p>Well with regard to what, in particular?</p> <p>Well we've just been thinking of how you would describe yourself as a parent prior to your experience, it would probably be with XXXXX.</p> <p>Yeah, I think I was fairly confident, confident that I could meet her needs, you know, I did enough before she started at nursery, you know, I took her out and played together and I was really, I felt at home being a mum and yeah, it was a joy really just to be with her , you know, bringing her up, which I still am doing (laughs) because she's only 5 .</p> <p>I'm curious what you said at home again and I'm really interested in that because you say you feel at home being a mum. What does that mean for you.</p>	<p><i>been an effort for me"</i> <u>intuitive element to parenting approach</u> led again by child's happiness <i>"they seem to be growing up quite well, they seem to be happy"</i></p> <p>Knowledge gaps recognised and filled "anything I need to get more information on I can get that information"</p> <p>The hard bits outweighed by <u>how wonderful it is</u></p> <p><u>Echoed how she "felt at home being a mum".</u></p> <p><u>Confident that she had done enough before starting nursery?</u> – For her to be OK without her?</p> <p><u>Echoed the joy of parenting</u></p> <p>Contradiction confidence vs. scared</p> <p><i>"what am I going to do with this baby"</i> <i>"I worked hard with the breastfeeding and that worked out, and that was a major thing for me"</i> <u>Something here about feeling scared but having</u></p>
--	--	--

<p>Importance of third party support for new mothers – related to confirming voices</p>	<p>Erm I think it just means that I always wanted to be a mum and I never really, I would say I had a happy childhood , it was something I always wanted to do, you know when she came along at first, obviously when it's your first baby and you're a bit scared and you think "what am I going to do with this baby". I worked hard with the breastfeeding and that worked out, and that was a major thing for me and then the next stage is like weaning and you know teething and everything but all the way along I felt supported and felt quite confident really, it wasn't really a big effort in that I had to study what I needed to do next sort of thing, you know, it just felt quite natural really.</p>	<p><u>little victories and being able to move on the next stage more confident</u></p> <p><u>Echoed intuitive parenting "it just felt quite natural"</u></p> <p><u>Support mentioned – played a role in confidence – similar to others confirming competency?</u></p>
<p>Pride in role originating from child's continued happiness</p>	<p>What do you think it was that led to this level of confidence?</p>	<p><u>Amplification of support and its importance.</u></p> <p><u>Pride in parental role originating from the child's happiness.</u> It seems to matter that her child is happy and that this is the cue/<u>behavioural confirmation that she is doing well.</u></p>
<p>Happiness is all that matters</p>	<p>I don't know really, I think support from my own mother and support from health professionals at the time, support from XXX as well, yeah, and just thinking from having, not really having worked and done like a, not had like a steady job and then having XXXXX was like it was something I was doing well at so I felt proud, you know, proud of being a mum and proud of bringing her up and, you know, she's always been a happy child so I just kind of think "as long as she's happy" (laughs) that's the main thing really.</p>	<p><u>Milestones, achievements and progress</u> seem to be important – early talking met with pride vs. late walking met with concern. <u>Another area on which to assess your performance as a parent?</u> Happiness being one and being "bright" and future performance/functioning being another?</p>
<p>Developmental stages a gage for parental performance Related to comment below</p>	<p>I wonder if you can tell me a little bit more about the pride you felt?</p>	<p><i>"because she talked early it meant that we could, it was a good thing because she would be, at least with her talking, she would be one of the ones doing well at school, you know, and it showed she was bright and happy"</i></p>
<p>Developmental stages a gage for predicting future success and functioning (Respondent used developmental stages</p>	<p>I don't know really (laughs), well being proud of seeing every sort of step, you know, every time she developed like when she started talking, and she talked quite early on. She didn't really walk and that was one of the things I was concerned about that she wasn't walking by I think 18</p>	

<p>to gage the child's progress and her image of the child's future)</p> <p>Public opinion important to developing identity as a parent (Related to comment below)</p> <p>Identity as a parent led by child's reactions (Happy contented child positively impacts view of self as a parent and mediates the public's view of the parent and visa versa)</p>	<p>months but she bum shuffled, like XXXX's doing at the moment, and just every sort of, every kind of milestone, you know every sort of achievement and because she talked early it meant that we could , it was a good thing because she would be, at least with her talking, she would be one of the ones doing well at school, you know, and it showed she was bright and happy, I was proud that I could take her out in public and she would be really content and happy and, you know, that other people could see that she was really chilled out and just a content little baby really and I think that's all you want really, I mean some people say "your babies are", like, XXXX, I took her to the hairdresser the other day and she was just really, really good and she just sat there in her pushchair and then she was out of the pushchair and she was really sociable you know and I was proud of that, that they are so good.</p> <p>Everyone is different so I was wondering if you could tell me what it means to you that others would see your children as contented.</p> <p>Well I think it is important because I am quite self conscious. I'm not self conscious of the fact that I won't, I'll avoid doing things because I'm afraid of what people think but out in public I am quite, if I have a baby crying I feel quite, I do feel that people, you know, that people are sort of judging me but then I've never really let them cry so that's never really happened . The only time people looked is when I've been breastfeeding in public which is quite funny because I do it anyway, I mean I don't stay indoors just to do it. I think my own reaction, if I hear a baby cry I don't think "oh shut that baby up" but feel more concerned really, I hope that woman's all right, does she need any help, but I think I am proud that I can take them to nice places and that they are really good.</p>	<p><u>The public view/perception of children also appear to be important</u> - Out in public content and happy could be <u>another marker for ones performance and could invite others to confirm competency.</u></p> <p><i>"I could take her out in public and she would be really content and happy and, you know, that other people could see that she was really chilled out and just a content little baby and I think that's all you want"</i></p> <p>Feeling concern for other mothers with crying babies <i>"is she OK" "Does she need help"</i>. Is the present of a <u>discontented child seen as a marker for a mother that is not managing, who is not OK.</u></p> <p><i>"if I have a baby crying I feel quite, I do feel that people, you know, that people are sort of judging me"</i> - Possibly thinking that she is not managing or that she is not OK.</p> <p><i>"Step to Step", "It seemed to be quite natural my approach"</i> <u>Repetition of step, stages, events.</u> Related to dealing with each events and feeling more confident?</p> <p><i>"Before Phoebe died I found parenting quite, it was challenging but I didn't find it"</i></p>
---	--	--

<p>Staged parenting – adapted to needs</p> <p>Challenging nature of parenting</p> <p>Balanced relationship: investment in autonomy and dependency (Close but independent)</p> <p>Failure in role as a guardian and protector (i.e. protect surviving child from being a living witness and failure to keep the dead child alive)</p>	<p>How would you describe your approach to parenting.</p> <p>Erm I would say fairly relaxed although there were times I had anxieties with XXXXX but certainly before XXXXXXXX died I found parenting quite, it was challenging but I didn't find it overwhelmingly scary or anything, it was just kind of, well I just went from step to step with XXXXX and, you know, it seemed to be quite natural my approach.</p> <p>What was your relationship with XXXXX like prior to your experience of sudden infant death syndrome?</p> <p>Erm I think I was really, she was quite independent so she would go off and, bear in mind how old was she when XXXXXXXX, 2, no she had just turned 2 when XXXXXXXX was born. It was always quite a close relationship and she was always happy, we've always had a close and good relationship really and yeah she is happy, she's happy now. After XXXXXXXX died of course we were all quite sad and she did go through a period when she was a very sad little girl, that's when I looked at a nursery for her to go to and we found a really good one and we told them right from the start about XXXXXXXX and the fact that if XXXXX mentioned her it was OK because we talk about, you know we've always been open about it, you know we've always talked about it, she was there, she was in the other room and just saw everything, you know XXXXXXXX was lying on the bed, the ambulance people coming in, bringing her down here and trying to resuscitate her, you know, XXX did all of that but it's just a fact and it happened, so the nursery were brilliant because she lost a lot of confidence, I think we all, well I did in particular, so they helped to boost her confidence and the other children at the nursery, she socialised with them so I kind of felt she wasn't missing out,</p>	<p>overwhelmingly scary” – As opposed to now? If it wasn't like that then is it like that now?</p> <p>Independent but happy and close – emphasises that she is happy now but after her siblings death she was a “very sad little girl”.</p> <p><u>Looked for nursery</u> – related to the idea that she had done all she could – she needed peer support</p> <p><u>Her daughter had seen/been exposed to everything - failure protect dead and living child?</u></p> <p>Lost confidence – “we all did” Child lost confidence but so did mother “I did in particular”</p> <p>A lot of information here – a story within a story or an IPA within an IPA. Concern for her surviving child and the impact it had had on her.</p> <p>Mother encouraged independence, confidence and resourcefulness</p>
--	--	---

<p>Mothers encourage self efficiency, self esteem and self efficacy (preparing child and teaching skills for the future self, the self they will become)</p> <p>Self as a parent related to experience of being parented (mentioned on first page)</p> <p>Affection as the development of self (i.e. child becomes who they want to be</p>	<p>she was with other children and she really benefited from that. I'm probably jumping ahead a bit.</p> <p>You mentioned that you felt that your relationship with XXXXX was close but that she was independent and I was just wondering what you felt led to this type of relationship developing?</p> <p>Well I think, I never really wanted to be too over-protective of her so I've always let her when she, when she wants to be on her own I've let her be on her own and now it shows because she will play on her own, she doesn't always need to play with other children and her dad is an only child and I have a brother, it always goes back to family, but I have one brother very close in age and I was always conscious that I didn't really know what life was like without him. We were very close but I always think that maybe that's a bad thing because I used to be in tears when he wasn't around so when I started school I found it really difficult until he turned up so I sort of sub-consciously thought that XXXXX should be as independent as possible, just for her own sake really. Her dad, my husband XXX, is an only child and he's always been quite confident and yeah, on his own kind of thing, and I didn't want her to be on her own but I wanted her to be confident and have her own resources really and she, I mean she is an extremely confident child now and she was really, since she could speak, when she was just over the age of 1 really, and I see that as a very positive thing rather than wanting to stay around me all the time or, you know, I think that's a good thing really. I think that's largely because of my own experience and I wouldn't want to do it any differently so it depends really.</p> <p>How did you show your affection to XXXXX?</p>	<p><i>"I wanted her to be confident and have her own resources", "I see that as a very positive thing rather than wanting to stay around me all the time", "I sort of sub-consciously thought that Grace should be as independent as possible".</i></p> <p><i>"I wouldn't want to do it any differently"</i></p> <p><u>Adapting parenting to one's own experiences - Wanted things to be better for her child</u></p> <p><i>"It always goes back to family"</i></p> <p>Describes the process of affection as physical and verbal with emphasis on making it explicit.</p> <p>Complimentary, tactile, encouragement, praise, esteem building</p> <p>The importance of having her "do what she wants to do" is described in the same body of text inferring that <u>affection comes under the same remit of putting her wants/needs first.</u></p> <p>Part of making her feel safe - <u>affection is more than expression it seems to be about having the other person made aware that they are valued and the</u></p>
--	--	---

<p>and parent give them the necessary resources' and space to become who they are) – Can you give your child space and autonomy to become who they are if your attempts to protect have increased</p> <p>Affection as containing fear and providing a sense of security (is this destroyed by the knowledge that you can't keep your child safe)</p> <p>A new awareness of death/an Awakening (existential topics)</p> <p>Self deception/denial (related to the death of a child)</p> <p>Cross that bridge when we come to it (don't think about things that are seeming non-applicable to current situation)</p>	<p>Oh well, I'm always cuddling her and tell her I love her which I think is really important. If you don't tell them they don't just assume that you do but I've always told her, you know, she's clever, she's pretty, all of which is true, I'm biased but just being tactile, and she's the same towards me and towards other people as well, well mainly people in the family. Yeah, just encouraging her and praising her and, you know, giving her the opportunity to do what she wants to do. At nursery they used to take them out on nature walks and they were very hands on and we've been, we just saw that as an extension of what we did at home really, but at nursery they had the benefit of being with other children. She's a very affectionate little girl but she's always been hugged, well not always, when she's naughty she doesn't get hugged, but I think that's part of making her feel safe and for her to know that she's loved and safe as well.</p> <p>What were your beliefs regarding XXXXX's mortality and safety?</p> <p>Before I never really thought about her mortality in any way at all because to me she was a baby, and then she's growing up and you don't really think about that. You obviously think about their safety and their well-being and you are concerned about them when they're out and about or, you know, when they get ill but I would say that after XXXXXXXX died my feelings towards XXXXX's mortality and safety were very much, they were at the forefront. I mean whenever she got poorly I was so anxious and I just thought "it's going to happen again" or, you know, "what if something awful is going to happen" but before I never really, I didn't ever think about it because, you know, she's just young and she's growing up.</p>	<p><u>feelings that may invoke for them is security</u> <i>"I think that's part of making her feel safe and for her to know that she's loved and safe as well"</i></p> <p>Safety and wellbeing appears to be paramount in identifying things that could interfere with the child's health statues but <u>there seems to be a gap between health statues and the consequences of its decline (i.e. death) which is not bridged. The death of a child seems to bridges this gap</u> <i>"after Phoebe died my feelings towards Grace's mortality and safety were very much, they were at the forefront"</i></p> <p><i>"she's just young and she's growing up"</i> synonymous with continued living but if this is the case why do parents worry at all? Contradictory. To overwhelming/unbelievable to considered or an unseen motivating factor</p> <p><i>"Something awful is going to happen"</i> <u>a transition brings the possibilities into the awareness. It's very real then.</u></p> <p><u>Respondent indicates that the persons outlook can defines ones beliefs about the world. "being an optimistic person".</u> But follows with <i>"not really allowing those thoughts to come in"</i> <i>"it's just something that you just don't want to think about"</i> and contradicts <i>"just doesn't come into your head"</i> – An unelaborated topic</p>
---	--	--

Appendix 17: Audit Trail - Stage 4

Emergent

Subordinate

Superordinate

Unwanted knowledge
Existential knowledge as a burden
Privilege of ignorance

Bursting of the protective bubble

have lost a child but some lose all
I used to think – poor me
peoples mundane problems
I could sit in traffic for hours
Unfazed by the little things
What was once important was lost

You get a reality check

Solidity of relationship
Unbreakable relationship
Naivety
Unawareness of threat
Unconcerned
Happens to other people
Death was not an option
Capability as keeping the child safe

It never entered my head

Living for the child
Enjoying while they can
Indulging while I still can
Their happiness as a priority
Anything for them to be happy
Children really living

If it means some extra crumbs so be it

Seeing the world anew

Emergent

Subordinate

Superordinate

Reclaiming the self
Subsequence child redeeming the self
Subsequent child brought an end to pain
Restorative effects subsequent child
Rebuilding family composition

Taking back what's yours

Surviving child as a different relationship
Relational difference with the surviving child
Forming of relationships in the presents of loss
Difference between surviving and subsequent
Different relationship subsequent & surviving

I love you the same it's just different

Child survival as defence
Fragility of the repaired self
A weak spot in the self
Fragility of self belief
Emotional fragility
Over protectiveness
Extended period of dependence
Extended period of overprotection
Dependence necessary for protection
The threat of Independence and separation
Reluctance to let go
A delay letting go of the reigns
The child as responsible for parental emotions

If anything happened to you it would make mummy cry

You made me whole again

Emergent

Subordinate

Superordinate

Affinity for role
Natural parenting
Enjoyable parenting a priority
Un-phased by new role
Breathing it in every moment
Parenting role fulfilling

It's in my nature

Prioritising a happy baby
Non imposing routines
Unstructured parenting
Flexible parented

Happy child happy mother

Deferred parenting
Avoidance of vulnerability
Diffusion of responsibility
Helplessness in protecting
Looming shadow of threat
Increased Susceptibility
Belief that child will die
Checking on child
Monitoring of the child
Obsessional Parenting

Give them to their dad and hide

**From hands on parenting to
hands off**

Participant 1: Main Themes

1. Seeing the World a New

Bursting of the protective bubble

You get a reality Check

It never entered my head

If it means some extra crumbs so be it

2. You made me whole again

Taking back what's yours

I love you just the same, it's just different

If anything happened to you it would make mummy cry

3. From hands on parenting to hands off

It's in my nature

Happy child happy mother

Give them to their dad and hide

Discarded Themes

Destruction of present and future life
Transgenerational Parenting
Transition into parenting
Monitoring of Child as Self Assessment
Mutual closes
Everything changes in an instance
Distress related to incomplete narratives
The living nightmare
Personhood of the deceased child.
The missing piece
Destruction of family's organisation
Taking a piece of you with me

Seeing the World Anew	
Bursting of the protective bubble	
<i>"I've never been able to go back to being carefree like that and thinking and having that kind of, you know, the privilege of not knowing about sudden infant death and having a baby die so yeah that would never be the same and my conscience will probably never be the same and my happiness, really my complete overall, I mean how could you say you were completely totally happy in every aspect when you've had like your baby die"</i>	35/25
<i>"you put things into perspective and I don't mean to say that in a patronising way or anything because I would rather people live their lives the way they live it, in a bit of a bubble"</i>	30/16
You get a reality Check	
<i>"whereas before, when I went shopping or to work and got caught up in a traffic jam and you sit there and go aargh and think that's stress and, when you have something like your daughter dying you think to yourself "how pathetic", you put things ... you get a reality check"</i>	31/11
<i>"a week after sally died and we just drove to this little, we just wanted to be on our own and get away from the house and the flowers and the cards and the constant letters and everything, we just went out and had a meal as this couple. There was only Mark and me and this other couple in the restaurant and this couple were just arguing, they were young and they were arguing "well, you didn't do this and that" and we just sat doing this and we just got up in the end and I said to them, I couldn't help it "do you know something, you two should just look at what you've got, do you love each other, and want to be together and what you don't understand is what you're arguing about is mundane"</i>	31/16
<i>"I've got no patience with people with self-inflicted problems" if you know what I'm saying and I've got no patience with it".</i>	32/3
It never entered my head	
<i>She was ill when she was 9 months old and had to go into hospital and that was traumatic but even then, she was quite ill with her kidney but I didn't think she'd die</i>	6/31
<i>Yeah, it didn't enter my head that I would ever have a baby that would die, or a child that would die, it just didn't enter my head at all.</i>	7/6
<i>I never questioned it. Never questioned that, you know, I never thought about it. I'd heard about cot deaths but it was something that would never happen to someone like me, that's what I used to think so, you know, I mean that I was once given a booklet at the hospital and, when you're going through it, it was just tossed to one side because to me it didn't feel relevant to me</i>	6/35
If it means some extra crumbs so be it	
<i>"If Liam wants to stay up a bit later I let him stay up and if he wants to have sleepovers with 10 friends I'll let them stay. He's never said to me ever, can someone stay or can I go over and I've said no"</i>	38/12
<i>"Well let him, both of them, do what they want to do and I'll fulfil it as much as I possibly can and it might be a little bit of hard work for me, you know, cups to clear up and crumbs to pick up, so what, they've had their fun and their friends love coming round our house and staying and being so relaxed so I'm not going to change".</i>	38/21
<i>"I had a thing where we were in a supermarket and Liam was a baby in a pushchair and he was a little bit restless so I was just standing there rocking the pushchair, in the queue, and this old lady kept saying to me, she tapped me on the shoulder and said "don't do that, you're going to make a rod for your own back" so I said yeah, so she said "no I mean it don't do it, you're just going to " and I said "you know what", I said, and I'm not normally rude to people, I said "I'll do what I want, my last baby died and if I want to stand and rock this pushchair that's what I'm going to do"</i>	37/25
<i>I'm trying to over compensate all the time I think, yeah, but I'm happy with what I do, so.</i>	36/30
<i>"because I had a baby die in the past I'm trying to constantly give them everything they want"</i>	36/34

You made me whole again	
Taking back what's yours	
<p><i>She died and I needed another baby to complete my family and make me feel happy again and that's exactly what we did</i></p> <p><i>Liam has been my only baby, literally, when I've said, right try for a baby, actually tried and planned for a baby even though when I was pregnant with Sally I was over the moon and with Sally, I hadn't planned her but I was over the moon but with Liam, I don't know, he's the one that made me feel happy again.</i></p> <p><i>it's a different way I feel about him and I think it's, and that's not Sally's fault and not my fault, it's not anyone's fault, but he happened to be the baby born after Sally, and quite quickly after Sally</i></p>	<p>30/35</p> <p>26/15</p> <p>25/33</p>
I love you just the same, it's just different	
<p><i>she'd say things to me in the past like "oh you're all for Liam, you know this and that" but I've always said to her "darling, I couldn't love you any differently, it's just different with Liam" and I openly admit and people frown upon me and I don't care one little bit</i></p> <p><i>I say to Sally, "it's not that I love Liam any more darling, I couldn't love him any more than you that, that's not possible", it's a different thing,</i></p> <p><i>I'm completely besotted with him and would do anything in the world for him, he knows he can (laughs) get on the phone to me and say "mum can I have £5 for my Play station" and I might say "no", and he goes "mum please" and I say "all right darling" and cave in straight away (laughs). When his teeth fall out I give him £5 a tooth, and someone will say "£5?" and I say yeah I know. I spoil him that way and so what if he tries it on with me and I say you're going in the bath he's say "I'm not running it" so I'll go and run it for him and I think to myself "do you know what, that's why I'm here on this earth".</i></p> <p><i>even my husband Mark will sometimes say "you love him more than you love me" (laughs) and I say "no Mark, it's a different kind of love obviously" but I can't explain, nobody, I feel nobody in this world understands how I feel about Liam</i></p>	<p>29/30</p> <p>25/29</p> <p>29/35</p> <p>30/14</p>
If anything happened to you it would make mummy cry	
<p><i>so I say to him "you know Sally" because he talks about Sally - I'll say "do you know when Sally died it made mummy and daddy very unhappy and we would never want another one of our children to die again so please, if you're going to cross the road, look before you cross the road (laughs), please don't go and put yourself in dangerous situations"</i></p> <p><i>he wanted a BMX and he wants a scooter and he'll go out with his friends and I'll say to him, for me to let him out, Liam's teacher, my health visitor and my parents, my mum and everyone in the end and Mark will say "look you have to let him out", because all the kids, and I live on one of those new housing estates, and there'll be little kids knocking on the door saying "is Liam there, can he come out" and I'm like "no, no, he can't come out"</i></p>	<p>34/15</p> <p>34/1</p>

From hands on parenting to hands off	
It's in my nature	
<i>I think it's just my nature, I just erm just don't really get myself distressed about anything - well probably more so now than then, but even more so now, but I've always been quite relaxed and I thought I just couldn't wait. I was quite good at school and quite intelligent but I never had any aspirations to be a career woman, I just always wanted to get married and have a family so I was just fulfilling my childhood dreams.</i>	2/30
Happy child happy mother	
<i>I always thought she was bathed, clean clothed, we were both happy, would go out and spend time together, we loved cuddling up together, and my parents and my friends used to say you're such a wonderful mum, and it was good to hear, you know, you're a lovely mum and I had a happy child and I just took that on board and it made me really confident as a mum.</i>	2/10
<i>I've always been quite relaxed and not one for thinking "oh I know that grandparents might have said that I should have got her into a routine by now" and I've never felt that was important, it was more important for me to have a happy baby.</i>	1/29
Give them to their dad and hide	
<i>I just couldn't, I knew I'd panic and that doesn't help anybody in an emergency or in a possible emergency. Mark spoke to me about, when there wasn't anything happening, he said "Soph, you've got to, you don't help any situation, try not to panic", and he knew it was hard for me so in the end the best thing is, Mark's really calm, if Liam has an accident or I think he's ill, or Sally, let Mark because he's the calm one and I just used to say, because I didn't want to</i>	28/7
<i>so I just used to, sometimes I'd just literally, I'd give him to Liam and I'd put a cushion over my, or until I heard Mark say "he's fine".</i>	28/14
<i>when Sally was a baby she bumped her head she fell off the bench at the swimming pool once, when she used to sit up when she was 3 months old she was unstable and I'd sit her up on the bench and I went into my bag or something and she fell and hit her head but I didn't panic, I just calmly drove her to the hospital and she had her head stitched and it wasn't a big deal but when Liam hit his head that would be it ... "don't let him sleep" it was always a big panic afterwards and Mark used to say (laughs) "stop panicking" and that was always bad I used to say "Mark you take him" and it was horrible, so I did change completely with him</i>	27/30
<i>you can deal with stitches, everything really, apart from them dying, which is what you can't deal with</i>	28/17

Appendix 18: Tabulating Themes across the Group – Analysis Stage 5

<p>1 Seeing the World a New</p> <p>1 Bursting of the protective bubble</p> <p>1 You get a reality Check</p> <p>1 It never entered my head</p> <p>1 If it means some extra crumbs so be it</p> <p>1 You made me whole again</p> <p>1 Taking back what's yours</p> <p>1 I love you the same, it's just different</p> <p>1 If anything happened I would cry</p> <p>1 From hands on parenting to hands off</p> <p>1 It's in my nature</p> <p>1 Happy child happy mother</p> <p>1 Give them to their dad and hid</p>	<p>3 A Demotion</p> <p>3 The Expert Position</p> <p>3 The Novice</p> <p>3 By the Book</p> <p>3 Devastated Gratefulness</p> <p>3 Thank my lucky stars</p> <p>3 My hearts not in it</p> <p>3 Breaching a necessary gap</p> <p>3 Children as saviours</p> <p>3 Disciplining the cherished</p>	<p>5 A tragic lesson</p> <p>5 Appreciate it, whilst you have it</p> <p>5 I don't want to miss a thing</p> <p>5 not the same person</p> <p>5 Changing Tactics</p> <p>5 They'll tell me what they want</p> <p>5 The opposite of me</p> <p>5 The best offence is a defence</p> <p>5 Getting back on the horse</p> <p>5 A ruined idea</p> <p>5 The Reliving</p> <p>5 The Return</p>	<p>7 from Field to Stable</p> <p>7 Out to pasture</p> <p>7 Fenced in</p> <p>7 Realisation of worth</p> <p>7 Taken them for granted</p> <p>7 Everything for them</p> <p>7 Parties Over</p> <p>7 Awesome fun</p> <p>7 Loss of laughter</p>
<p>2 And it all came tumbling down</p> <p>2 I feel right at home</p> <p>2 Back to the beginning</p> <p>2 huff and buff and blew my house down</p> <p>2 The bittersweet restoration</p> <p>2 See... We are good parents</p> <p>2 You are precious to me</p> <p>2 The pressure of value</p> <p>2 Out of the ashes</p> <p>2 It stays with me... still</p> <p>2 A privileged position</p>	<p>4 From light into darkness</p> <p>4 Locking out the night</p> <p>4 The loss of Innocents</p> <p>4 Walking in the Shadow of Death</p> <p>4 Have I missed something?</p> <p>4 Paranoid Mother Coming Through</p> <p>4 The Jekyll and Hyde Affect</p> <p>4 Failure in Child vs. Failure in Role</p> <p>4 Confirmation now reassurance</p> <p>4 You can't know everything</p> <p>4 Parenting through gut instinct</p> <p>4 I can't trust my own instincts</p>	<p>6 The Mooring</p> <p>6 Going with the flow</p> <p>6 Sailing to close to the shore</p> <p>6 Safety in the reservoir</p> <p>6 Two peas from two pods</p> <p>6 Born Survivor</p> <p>6 The fragility of the youth</p> <p>6 Play with it too much and it'll break</p> <p>6 Appreciating the gift</p> <p>6 Pushing your luck</p>	

Appendix 19: Table of Master Theme, Subthemes and Quotes

Channelling the Parent Within	<i>The Flexible Parent</i>
	<i>A Mothers Instinct</i>
	<i>The Expert Position</i>
Parenting Outside of Yourself	<i>The Novice</i>
	<i>Safety through Restriction</i>
	<i>Self checking</i>
	<i>Hands off Parenting</i>
Restoration through You	<i>Vindication and Redemption</i>
	<i>They keep me going</i>
	<i>Taking away the pain</i>
The Bitter Restoration	<i>Bursting the protective Bubble</i>
	<i>My heart's not in it</i>
	<i>Experience shapes expectation</i>
A Disruptive Appreciation	<i>I live for them</i>
	<i>The pressure of value</i>
	<i>Holding Tight</i>
	<i>Too precious for tears</i>

Channelling the Parent Within

The Flexible Parent

My style must have been really in his routine, I kind of went by him, I mean it's more his routine I went with. I think it was my Nan that actually said, you know, if he needs something, he'll tell you, he'll know and you'll know, and that's the way I went about it. If you baby's hungry you're going to feed your baby, you're not going to not feed it for another half an hour because it's not say due... and the same with sleeping, you know, Henry always slept on his back, James wanted to sleep on his front, I used to be, well, however your baby wants to sleep, you know, you go with how your baby does it (Corrine)

Even though I had a routine, I could easily break the routine if I had to, I could go out and... you know, if I didn't bath him one night, it wouldn't matter, you know, if we were out and stayed late at friends, it wouldn't matter, her could go to bed later (Gale)

Before Annabel started school I didn't really have a bedtime routine, at mealtime if she didn't want to eat something I'd give her what she did want to eat, probably poor parenting actually but then I thought that when she actually did go to school I'd give her a bedtime routine. I've always been quite relaxed and not one for thinking "oh I know that grandparents might have said that I should have got her into a routine by now" and I never felt that was important, it was more important for me to have a happy baby. (Bonnie)

I didn't want there to be too much restriction with them doing what they shouldn't have done, but yes, I used to enjoy seeing them happy really, enjoy having fun, freely with them. Quite relaxed compared to some of the friends I had around me, you know, if they didn't want food at certain times I was quite relaxed, I didn't have no routines and there was not real right or wrong with anything. I didn't... you know have a program that I had to work with, I just did what I thought was good, and trusted what I did was right. (Anita)

If something didn't work, we'd just try to change it, so if we tried a technique and it didn't work, we would have looked for other options, so I think, because we were quite flexible, it weren't set in stone, have any like rigid ideas of how we were going to bring him up, we just sort of took each day as it come with him. (June)

A Mothers Instinct

I think it's just in my nature, I know I keep saying the word "natural" but for me I didn't have to try hard to be a parent to her (Bonnie)

You know it wasn't really something I had to kind of study, you know, try really hard at. It just kind of came naturally really and, you know, it's not really been an effort for me. You never feel like the perfect parent but on the whole I was confident, Amy was happy then I was happy and yeah I felt, as a young parent, It just kind of came naturally, I felt at home being a mum... I felt quite at home doing the job. (Nicole)

being at home just means being warm and being safe, feeling safe, making sure that everyone's together, you know, happy, as much as you can do, just being able to protect your children and the whole family (Nicole)

I didn't choose anything. It's just the way it ... it's one of those things that just came ... it just comes to you as a parent doesn't it, how to bring them up. I'd never really had anything to do with babies and children until I had Philip, but as I say, it just came naturally. It's just a mother's instinct isn't it, you know, it's ... just a motherly instinct that you have with your children (Gale)

I just thought, God I've got a baby, what on earth am I going to do, and umm I think, to a certain extent, I think in some ways, it was a gut instinct to start with, and you thought, well okay, if they're crying, they need something. I would say, for the first couple of months. I was a bit nervous, because I'd never had children before, but I think over time you get more experienced and I think it was just a combination of experiences and a gut feeling, I don't know, where you think to yourself, yes, I am looking after them (Lydia)

The Expert Position

I used to get midwives coming round saying well you shouldn't be weaning him yet, he's too young, and I knew he was hungry and needed food, so I weaned him earlier than like the recommended guidelines, just from a feeling that I knew my own child, knew he needed solid food. I'd just go with what I felt was right and there were guidelines at the time, like there are now, about keeping baby in your room until they're six months old, but I found he settled better in his own room, own cot, so I did that. So probably a lot of things against guidelines, but just what I thought were right... what me and my husband thought was right for Jacob and for us as a family. (June)

Parenting Outside of Yourself

Safety Through Restriction

I didn't let them out of my sight basically. So if they did go to my Mum's, they'd be home at a certain time, umm, they never stayed late overnight, umm, I'd check on them every night. Umm... two or three times a night to make sure they were still breathing. All the time they're under my eye, they were being closely watched, but as soon as they were out of sight... If they went back to a friend's for tea, I would like somebody to text to say that they're okay, they're eating their dinner, they're not chocking on anything (Anita)

Just protecting him, you know, just... really protecting him... Tying to protect him from anything bad happening to him... I wouldn't let them out of my sight, or ear shot, and you know wherever I went they had to come. They'd say, oh, do you want me to watch him, no, no, no, its fine (Gale)

A lot of my friends are just leaving ... just saying, oh sod it, let's just you know stay out, we'll go home when we're ready, if the kids fall asleep in their clothes, well that's fine. I'm not very good at doing that. I like to make sure I'm back home. I like my children to be in their pyjamas, I don't know, I'm a bit weird, in the fact that I'll be like ... I'll be thinking, I can't let them sleep in their clothes because something might happen to them. (Gale)

Self Checking

I always double check things, you know I always know what measurements of you know medicine or anything like that, but I always read them about four times now With Stephan, I would have a look at the medicine and it would say that amount, I'd give it to him. Now James I look at it, I'll look at it again, I tend to get Adrian to read it, and then I'll do it. (Corrine)

I used to umm constantly check on them to make sure that they were okay on absolutely everything, even like with my daughter walking down to school, umm, crossing the road, something we'd done numerous times, umm, I used to double check the road and everything. I used to say to myself, stop being so stupid, you know, what you're doing, and I used to get very angry with myself, where this other person kept coming in, and turning round and putting the doubts in there. (Lydia)

The Novice

Absolutely dreadful. We just thought we were like terrible parents, so you go back to like feeling like you're a brand new parent, like, because you've never dealt with it, you don't know the people that have dealt with it, so it's all ... you feel like a really crap parent because you just don't know what to do. (June)

It was like going back to Amy when she was first born but worse because I had, you know, all of the awful experience of Abby, you know, seeing Abby after she had died and it was really difficult. I mean, when Daisy was born, yeah, I don't really know how else to describe it, it kind of took all the good things that happened with Amy, at the time it felt that all of that was wiped out. (Nicole)

It's the complete opposite. I would never have say doubted myself, umm, I was worried the first time because I was a first time Mum, so I hadn't really you know dealt with a new born baby, umm, but it was completely different. I just felt I'd lost all confidence, umm, because I think you just naturally do, because it's your child, who you've brought in, and brought up, umm, so I think just naturally I think you just ... you do. (Corrine)

Everything that I believed in, umm, was just thrown on the floor, as a mother, you're supposed to look after your child, umm, and I felt as if I'd let him down, I wasn't there, which now obviously I know is not right, but at the time, I felt as if I'd let him down. Had I done something that umm could have changed? Was there the way that I looked after him any different? It was absolutely everything, everything that I'd learned, umm, that I'd practically done, was completely changed. (Lydia)

I turned round and I said to the doctor, look, I said I'm going to be in here every five minutes, and he turned round and he said to me, that's fine, don't worry about it. I spoke to the umm midwife and the health visitor. I said I'm going to be paranoid. I said you know what's going to happen, I said I'm going to ask you a question that I know the answer to, I said, but I'm going to be asking you that question because I just want the guarantee that somebody else has said it, because my confidence level is so low (Lydia)

Hands off Parenting	<p><i>I just couldn't, I knew I'd panic and that doesn't help anybody in an emergency or in a possible emergency. Mark spoke to me about, when there wasn't anything happening, he said "Bonnie, you've got to, you don't help any situation, try not to panic", and he knew it was hard for me so in the end the best thing is, Mark's really calm, if Liam has an accident or I think he's ill, or Sally, let Mark because he's the calm one and I just used to say, because I didn't want to, so I just used to, sometimes I'd just literally, I'd give him to Liam and I'd put a cushion over my head, until I heard Mark say "he's fine". (Bonnie)</i></p>
----------------------------	---

Restoration through You

Vindication and Redemption

Having Daisy has been just wonderful really and it's kind of proved that, you know, actually we are good parents, we can be good parents, and even though something awful like that has happened I suppose that is important for me really you know, having gone through what we've gone through and still, you know we're still able to function as parents and to show people that and you know to just show other people that you can (Nicole)

It's like you've got to that stage, you've proved to yourself that you haven't done anything wrong, because your next child has gone beyond that stage. In some ways maybe that has proved to me that it wasn't me because I have had another child that's gone on to live longer than what Angus done, so in some ways, having Charles it was like it healed me probably in the fact that it proved that I was who I was (Lydia).

My confidence has come back, that bit more, obviously now he's like a year and a half, I'm starting to ... I'm a lot more open to things. I've not really got a ... I'm not so worried, so my confidence is I say coming back as he gets older, but I would say that ... so I'd say my confidence is coming back (Corrine).

so I say to him "you know Annabel" because he talks about Annabel - I'll say "do you know when Annabel died it made mummy and daddy very unhappy and we would never want another one of our children to die again so please, if you're going to cross the road, look before you cross the road, please don't go and put yourself in dangerous situations" (Bonnie)

They Keep Me Going

... I kind of felt like I had to cope, so there was no not coping, I couldn't let them down, every day, had the children not been around I don't think I would have got up, got through it, because they were there I just thought well they've got no-one else to (Anita)

Well I think, honestly, if Jacob hadn't have been there, with all the love he gave, I don't think I'd be alive today because I think it was Jacob ... I think it was Jacob that got us through it. I really feel for people that lose their first child, because I don't know how they get out of bed in the morning because he was the person that, Mummy, I want my breakfast, and you've got to get up, you've got to function, you've got to take him to school, and it keeps some routine in your life, so I think that love really, really helped us because we had to function and you had to face going round the supermarket to buy food for him. I don't think we did ... I just don't think we'd have been here if it weren't for Jacob (June)

Well Philip was just smothered then you know with ... I didn't want him out of my sight. I couldn't let him out my sight. I had to take him out of his own bedroom and bring him into our bedroom because I needed him to be near me all the time. And I relied on him. He got me through it all (Gale).

Taking Away the Pain

I think I've been very lucky to have another healthy baby. I think that has helped me get through things, give me something to focus on. Some people don't want to have more children after, but we decided that we wanted to because we wanted a sibling for Jacob, so we decided that we would have another baby, by no means a replacement for Robert, it was a way of moving on (June)

She died and I needed another baby to complete my family and make me feel happy again and that's exactly what we did. But even if you go on to have another baby, or you've still got a child, there's still that person there, and you miss that person so I always think something is missing (Bonnie)

The Bitter Restoration

Bursting the Protective Bubble

Before I just assumed, be it naively, that if you looked after your child, you fed it, you kept it warm everything would be fine... I think you do learn to accept something that's changed. I suppose, when you start off, everything's maybe you know you think is absolute flowers and things like that, but life, you know, things happen in life, and I suppose you just have to get through it, and thankfully, you know, we have got to a point where I think we have sort of moved on, but as I say, there is still a lot of things in life that could change this the other way, you don't know (Lydia).

You put things into perspective and I don't mean to say that in a patronising way or anything because I would rather people live their lives the way they live it, in a bit of a bubble... I've never been able to go back to being carefree like that and thinking and having that kind of, you know, the privilege of not knowing about sudden infant death and having a baby die so yeah that would never be the same and my conscience will probably never be the same (Bonnie).

I feel it makes you more aware that, to be honest, the world is not ... you know it can be cruel, so ... so as a person I just feel it's made me stronger with my kids because you never know really what can happen and they're my children, you know, really strong with them (Corrine).

My Hearts Not in It

Like Christmas, it's like ... yes, everyone's like oh its Christmas and its only five more sleeps, and you're so lucky to have two little kids at home for Christmas. I know however much I love seeing their faces on Christmas Day, in a way, your heart's not in it because you've got one missing and it's like holidays, you go on holiday, but even though you can see your family and your children enjoying it, and you do have a nice time, but then you'll see like a three year old round pool and think, hmm, that would have been Robert (June)

... There was no relaxed fun side that had all gone after losing her, so it's quite sad really, the boys probably, yes ... whether they noticed a change, but there was a definite change. I tried not to. I was very aware of it (Anita)

I don't really try and let my serious side come out in front of the children but I think that stress sometimes builds up and I kind of get quite very irritable and angry so it comes out in kind of... I'll get cross, like really, really cross and just lose it and then have to take a few minutes and then it's OK again (Nicole)

Experience Shapes Expectation

I think he'd fallen over, and he'd hit his head... I just thought he was going to have major brain trouble. I'd think that things were going to be a lot worse than what they were so I sort of went up ... the practical brain in me used to turn round and say, this is the reason why you're thinking this, because you've had the worst case scenario happen to you, so of course, you feel that everything's going to go to that level (Lydia)

I think the feeling that something awful can happen at any time, that's always in the back of my mind and also, you know, I'm not so bad when I'm here at home but sometimes, when I'm out and about, I'll get a terrible feeling of dread as if something awful is going to happen (Nicole).

... I worry, I just worry, about them, the whole time. Now when they get a cold, or they tell me they've got a headache, I think, God, that's it, they've got a brain tumour, they're going to die, you know, whereas I never used to think that, you know, every little thing (Gale)

A Disruptive Appreciation

I Live for Them

Well let him, both of them, do what they want to do and I'll fulfil it as much as I possibly can and it might be a little bit of hard work for me, you know, cups to clear up and crumbs to pick up, so what, they've had their fun and their friends love coming round our house and staying and being so relaxed so I'm not going to change". "If Liam wants to stay up a bit later I let him stay up and if he wants to have sleepovers with 10 friends I'll let them stay. He's never said to me ever, can someone stay or can I go over and I've said no (Bonnie)

would do anything in the world for him, he knows he can get on the phone to me and say "mum can I have £5 for my Playstation" and I might say "no", and he goes "mum please" and I say "all right darling" and cave in straight away. When his teeth fall out I give him £5 a tooth and someone will say "£5?" and I say yeah I know. I spoil him that way and so what if he tries it on with me and I say you're going in the bath he's say "I'm not running it" so I'll go and run it for him and I think to myself "do you know what, that's why I'm here on this earth (Bonnie)

Oh now I wouldn't want to miss anything of them. If he had a tooth coming through that I didn't know about and it came through at someone else's house, I'd be devastated, and just like the little things, like the smaller things, I wouldn't like ... I don't want to miss anything. And it makes me upset to think if I ever missed anything, school play. it's important to them and you know I'm here for them, so to me it's just really important that I do everything for them and it does ... I just feel really close to them and I feel that's a good way you know of being close to your children anyway (Corrine)

You neglect yourself really, as a husband and wife... everything's for the kids, they're most importantly, whereas before we used to do half and half, whereas now it's like 90% children and 10% of what we want to do. I think we both feel a little bit because my husband says well I could be going to golf, and I say well I could be going out with my friends, well, it's tough isn't it, at the end of the day we're both quite happy doing what we've got, but feel quite tied down, and we know deep down inside we can't have what we had back, because we know we're frightened that we might lose it again (Anita)

The Pressure of Value

You value them more so you could go either way and be, like, either really, really stressed and serious and all that, and there is a side to me that is stressed and serious. I don't want to lose it so easily and at the same time I think that's probably, it's a product of, you know, all the stresses that you carry with you all the time and sometimes you just, ordinarily being a parent is stressful but I do think these worries, these underlying worries and anxieties (Nicole)

I felt so fortunate to be having another child, and obviously I worried, I worried, I worried about him, and when I had Lloyd, in a way, I felt I was very lucky to have another child, but I also felt I was pushing my luck, thinking, you've got Philip, you've had Benjamin, he's healthy, he's fine, you're really pushing your luck now having another, so part of me felt ... I feel and did feel just ... yes, I worry more, because I felt like I shouldn't have been having another, when I'd got Benjamin, I should have thought, be grateful you've now got Benjamin, don't push your luck in having another (Gale).

I think ... there was so much fun and laughter in the house before, but now there's ... there is that a little bit, but there's just no time for it (Anita)

Yes. Yes, you've still got all the love, and the happiness that a child brings you, and the fact that you want to do anything for them and protect them and look after them, but it's kind of overshadowed by fears and anxieties as well about what might happen to them (June)

I always turn round and make sure I kiss them and cuddle them and say look after yourself. My daughter goes out in her car, I turn round and say be careful, you're always going to worry about it, but I always make sure I make the time to say, goodbye, or be careful, and I'm always standing at the door when they go, umm, at the back of my mind, I'm thinking, terrible thing, but that might be the last time I see them, do you know what I mean, so I think, yes, that is a crux (Lydia)

Holding Tight

He wanted a BMX and he wants a scooter and he'll go out with his friends and I'll say to him, for me to let him out, Liam's teacher, my health visitor and my parents, my mum and everyone in the end and Mark will say "look you have to let him out", because all the kids, and I live on one of those new housing estates, and there'll be little kids knocking on the door saying "is Liam there, can he come out" and I'm like "no, no, he can't come out (Bonnie)

Benjamin's never slept in his own room. He's nearly three. He has to sleep in our room because I have to keep my eye on him (June).

I don't know whether the kids would agree with me, I do find that sometimes I do tend to go on his side. If there's any arguments I may be do tend to sort of go you know on his side, not deliberately, but I think over time it's getting a bit better in the fact that I've forced myself to say he's an independent person (Lydia)

Too Precious for Tears

I probably have been very lenient on them. I let them get away with so much I suppose because I'm always worried ... I don't like upsetting them. I worry about upsetting them. I don't ... I know it sounds silly, but I just have this ... they're just so precious (Gale)

If he got upset at school I'd go in and see a teacher, but maybe it was just something and nothing that I'd have just said before, you know, come on, it's just silliness at school, get on with it... probably a lot softer with him, he probably knew how he could get away with a bit more. Probably wasn't as strict with him... but you can't take that risk of saying, no, come on, bed, now, whereas before it would have been it's 8 o'clock, lights out, and go to bed, because you don't know whether they are playing on it, whether they do need you. If I don't get my act together I'm going to have a really naughty child on my hands (June).